A STUDY OF BEREAVEMENT IN THE ABRAHAMIC FAITHS

by

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ABSTRACT

In the UK approximately 60% of deaths occur in acute hospital settings to people from different cultures and religions. This thesis explored the experiences of bereaved relatives from the Christian, Jewish and Muslim faiths, doctors, nurses, healthcare assistants and religious leaders to explore the essences of bereavement and implications for providing religiously appropriate end of life and bereavement care in an acute hospital setting. Phenomenology provided the philosophical and intellectual framework and van Manen's (1984) four existential dimensions of temporality, spatiality, corporeality, and communality the structure.

Chronological story telling allowed exploration of the 'lived' experience of bereavement and demonstrated that current bereavement theories and practice are not always reflective of the diverse needs of a multifaith and multicultural population. Similarities and differences in the requirements of the 3 Abrahamic faiths became apparent through the experiences of all participants and the importance and significance of doing the right thing, at the right time for the right person in a sensitive and caring way was demonstrated. The impact of end of life care on the bereavement experience was palpable throughout participant recollections.

The study highlighted education and training needs not only of hospital staff but of the general public and the need for a more holistic approach to bereavement theory, policy, practice and research.

This thesis is dedicated to my dear sister Helen,

always in my heart

The Heavy Stone

My grief was a heavy stone
rough and sharp.
Grasping to pick it up
my hands were cut

Afraid to let it go
I carried it.
While I had my grief
you were not lost

The rain of my tears
smoothed it.
The wind of my rage
weathered it,
making it round and small.

The cuts in my hand have healed.
Now in my palm it rests,
sometimes almost beautiful,
sometimes almost you.

Anon

FORWARD

Throughout my work experiences and, more recently, my position as Head of Bereavement Care in a large acute NHS teaching hospital trust, I have identified areas of need within end of life care, especially from a religious perspective which have caused concern, distress and have had a direct impact on the bereavement experience of those left behind. This has often been related to situations where staff were unfamiliar with the religious requirements of patients and their families at this final stage of mortal life.

In the course of my work, I have had discussions with thousands of bereaved people. I have gained anecdotal evidence about the experiences of these individuals and their needs as their loved ones were dying, and during their ensuing bereavement. As a nurse, I have had professional experience of end of life situations and have had many discussions with doctors, nurses and healthcare assistants about their experiences in this sensitive and often difficult area and its impact for them personally and professionally. I have also been privileged to work alongside faith leaders from the world's major religions and this has helped me to understand what is important to these different groups at such times and why.

Personally of much greater importance and significance, was the sudden death of my dear sister Helen during the writing up stage of this thesis. This has impacted upon my personal perspective of bereavement moving me from an objective position of providing care for others in their bereavement to a subjective position of being the cared for ''bereaved''. This has further heightened my sensitivity and reinforced my need to understand more about what the real essence of bereavement is to the individual and to understand what dying, death and bereavement means in differing religious contexts. It is hoped that my ongoing search for understanding can be of use to others seeking to understand what bereavement means to them following the death of a loved one; and to enlighten those involved in the provision of care at such times.

ACKNOWLEDGEMENTS

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CHAPTER 1

INTRODUCTION AND BACKGROUND

Bereavement is a darkness impenetrable to the imagination of the unbereaved.

Iris Murdoch

The loss by death of someone who was significant to us is commonly described as 'bereavement' and may be one of the most devastating and life changing events that we experience. The context of that experience and the way in which we respond to it will be varied and made up of many different factors and interconnections, including the behaviours of individuals that are encountered leading up to and immediately after the death of someone significant to us, our own and others' religious and cultural beliefs and the context in which the death occurred.

This thesis will explore the significance and influence of end of life requirements on the bereavement journey following death, within an acute hospital setting, in a multicultural multifaith population through the recollections of relatives, nurses, healthcare assistants, doctors and religious leaders.

1.1   Concept and theories of bereavement

The terms **bereavement, grief and mourning** are often used interchangeably to describe some of the emotional spiritual and clinical dimensions which are experienced by the bereaved. Stroebe *et al* (1999) suggest it is important to clarify and distinguish between these terms in order to use them appropriately and to avoid misinterpretation. They proposed the following definition:

> 'Bereavement is the objective situation of having lost someone significant; grief is the primary emotional (affective) reaction to the loss of a loved one through death…Mourning (is) the social expression or acts expressive of grief that are shaped by the practices of a given society or cultural group' (p.5)

Christ *et al* (2003) suggest that bereavement is:

> 'the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one' (p.554)

whilst grief is a more specific phenomenon:

> '…a complex set of cognitive, emotional and social difficulties that follow the death of a loved one. Individuals vary enormously in the type of grief they experience, its intensity, its duration, and their way of expressing it' (p.555)

This view suggests that the term bereavement includes the internal psychological processes associated with the death of a loved one, the adaptation by family members to their physical absence, and their subsequent expressions and experiences of grief. Kasterbaum (1998) offers the following succinct definitions:

- Bereavement: An objective fact

- Grief: A painful response

- Mourning: A signal of distress

The use of the term 'objective' with reference to the phenomenon of bereavement suggests that it is impartial and distanced from the more subjective components associated with a death, those of grief and mourning.

Parkes (2000) however, argues that there are universal components of grief which are common to all who experience it, irrespective of cultural or religious affiliation, and that these components are as a direct response to the psychological attachments of the individual. The layers of the bereavement experience however, will be moulded by the relation that the bereaved had with the deceased, coupled with the cultural and religious expectations and beliefs that the bereaved holds (Heyse-Moore 1996; Worden 1991). Religion, for some, will form an important part of such narratives and will include ways in which the bereaved person and their

community will make sense of the death (Klass and Goss 2002). This thesis sets out to explore these themes within the multi-cultural environment of the UK and specifically in the context of acute hospital care.

In the United Kingdom (UK) today, a mosaic of cultures, religions, spiritual traditions and interpretations exist. No single religious group is uniform and homogenous therefore a person's religion and associated culture provides many layers and dimensions to an already complex matrix of factors that may influence the bereavement experience and process. Despite this, there is little acknowledgement of religious diversity in bereavement literature and associated research. This may reflect the fact that many bereavement models and theories in use today were developed in the 19th and early parts of the 20th century. Whether these theories adequately reflect the experiences of the eclectic bereaved population of the UK in the 21st century warrants further study. This thesis will explore the importance that different religious paradigms play in the bereavement process, and it is anticipated that a deeper awareness of the experience and essence of bereavement will be achieved.

1.1.1 Death and bereavement: a historical perspective

Historically from the 15th to the 17th century, death was seen fatalistically as 'God's Will' and its inevitability and unpredictability were aspects of everyday life. In his seminal review of death, dying and bereavement, Walters (1994) makes the point that:

> 'For millennia, death has disrupted communities and the language of death has been the communal language of religion' (p.9)

With the onset of the 17th century and the emergence of theories on mathematical statistics and chance, Walters (1994) describes a shift in the perception of death from a fatalistic acceptance of death arriving at any time and a blind religious acceptance of it, to one of the reasoned probability of chance:

'The Age of Reason shifted death from the frame of religion into the frame of reason, from the frame of sin and fate to the frame of statistical probability' (p.9)

In the 18th and 19th centuries, developments within medicine and science allowed a shift in thinking and beliefs within the basic concepts of illness and death from a judgmental perspective for example, 'moral / immoral', 'deserved / undeserved', to a scientific perspective for example, normal / abnormal and healthy / unhealthy. In the 20th century, human emotion became associated with the rational medical field and Walters (1994) further suggests that the rationalisation and perceived control of death within secular Western society allowed a distancing from death and bereavement and the associated religious significances that were once linked to it. This can be seen by the increasing medicalisation of death, with dying now occurring predominantly in acute hospitals (Department of Health End of Life Care Strategy 2008) where the focus on treatment and cure contributes to feelings of guilt and failure when a death occurs.

The death of a loved one and the ensuing bereavement are potentially life changing events for a person. However, in modern Western secular society they are topics which are rarely discussed until illness and death manifests in someone close or significant to the person. Barriers to discussion on death and bereavement may include fears of one's own mortality or heightened awareness of

the loss of, or indeed causing the loss of, a significant other. Efforts to understand these fears have been addressed in a number of theories of bereavement.

1.1.2 Overview of bereavement theory

A number of theories of bereavement have developed over the last century. These have explored differing theoretical stances and have been valuable tools in attempting to create a framework for understanding human behaviour, providing possible explanations for individual and group responses to the phenomenon of bereavement. However, no one paradigm is universally dominant within bereavement research.

Much of the early work on models of bereavement stem from the perspectives of Western psychiatrists, psychologists and sociologists. Whilst this has presented a reasonably consistent view of bereavement, it has been one dominated by Western world ethos and therefore it may not, and indeed, is unlikely to, represent bereavement in other religions and cultures. One of the reasons for this may be that the frame of reference applied has focused on identifying risks to mental health as a result of bereavement and interventions designed to identify and prevent long term psychiatric problems as a consequence. This is demonstrated in the historical perspective whereby bereavement has been viewed as a condition or an illness to be cured.

Sigmund Freud pioneered the study of mourning with his psychodynamic or *'grief work'* model of bereavement, based on the premise of 'letting go' of the deceased

and moving on to reinvest in future relationships.   His paper 'Mourning and melancholia' (Freud 1917) set the stage in bereavement theory for many years and was key in reflecting the medical model of bereavement. This was followed by Lindemann's (1944) work with survivors of a nightclub fire in Boston which pioneered ways of identifying and categorising grief reactions in bereavement. These early works are credited with being the first to attempt to describe, in a sensitive way, the pain and reactions to bereavement.

The emotional attachment to the person and the associated pain of separation is pivotal to the bereavement experience. *Attachment theory* provides a framework for understanding the effects of bereavement in terms of the disruption of 'affectionate bonds' and in individual differences in response to loss. Bowlby (1969, 1973) developed 'attachment theory', building on the original work of Freud (1917).

Attachment behaviour is the development of strong affectionate bonds and is part of the healthy development in humans and other primates. It is an instinctive behaviour related to security and safety. When these attachments are threatened strong emotional protest and intense anxiety are provoked. The pattern of behavior Bowlby (1969) observed in young children traumatically taken away from their mothers was described as: Protest, Despair, Yearning, and Detachment. This can be seen in children if the parent disappears, when they react by clinging and crying in protest and anger. This behavior stops if it successfully results in the parent's return. If, however, the parent does not return then deep sorrow appears, often displayed by withdrawal, apathy and despair. These behaviors eventually

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fade over time and new attachments begin to be formed. These 'symptoms' of loss have subsequently been applied to the experience of bereavement and Bowlby's work on attachment theory is still extremely influential as recognised by Middleton and colleagues (1993) in their review of bereavement theory.

Parkes (1972) developed Bowlby's theory further with his work on a cognitive model of bereavement and suggested that bereavement was a programmed series of behaviors triggered by a specific 'environmental stimulus'. This model utilises the concept that each individual develops his or her own 'assumptive world', which involves past, present and anticipated experiences Therefore a loss can cause an individual to question their assumptions about their world and their existence within it and requires a period of adjustment in order to relinquish or readjust their connections with the deceased person. He suggests that antecedent, concurrent and subsequent factors related to the bereavement will influence the person's individual response to their loss (Parkes, 1972). It is recognised that grief reactions within the bereavement experience will have physical, emotional, cognitive, behavioral, and spiritual components which will vary in both duration and magnitude.

Later considerations of bereavement by Worden (1982, 1991) viewed it as a process, not a rigid state, and reasoned that people need to work through their reactions to bereavement in order to adjust to the loss. He proposed that the bereaved have four overlapping 'tasks' that facilitate working through the emotional pain of their loss and adaptation to a change in circumstances, role, status and identity. These include: i) acceptance of the loss, ii) working through

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the pain of grief, iii) adjusting to a changed environment, iv) emotionally relocating the deceased and moving on with life (Worden 1982). Importantly, the bereaved are seen as active participants in a self-determining process, rather than passive recipients.

A further consideration in Worden's work is that of the continuing presence of the deceased in the life of the bereaved. He suggests that although the relationship between the bereaved and the deceased has fundamentally altered, it is still a tangible relationship. This appears to be an early acknowledgement of a continuing bond with the deceased person, rather than an expectation of severing all connections with the deceased person.

Rando (1985) builds on Worden's bereavement theory and highlights six tasks which manifest throughout the bereavement journey: Recognise (the loss); React (to the separation); Recollect (through reviewing and remembering); Relinquish (the old attachments to the deceased and the old assumptive world); Readjust (to a new world without forgetting the old); Re-invest (in a meaningful life). He suggests that the memory of the deceased can be kept alive at the same time as new relationships and activities are evolving and that 'moving on' in the traditional sense is possible without 'letting go' of the memory of the deceased.

Kubler-Ross (1969) took a different stance in describing five stages that dying individuals may progress through: Denial, Anger, Bargaining, Depression and, Acceptance. As with Bowlby's work (1969,1973), Kubler Ross's original work was not initially intended to be applied to post bereavement situations but was

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originally aimed at identifying stages of loss relating to the emotions a person may experience having received 'catastrophic news', for example, a life threatening illness or terminal cancer. Kubler-Ross's work (1969) focussed on the dying person and their preparation and acceptance for death and not on the experiences of the recently bereaved.

Although early theories have provided the bedrock for much of the research that has been carried out in the field of bereavement several limitations should be noted. These early theories failed to explore individual ways of coping with the phenomenon of bereavement; focusing instead on the collective group of 'bereaved' and the processes they go through rather than the unique experience of bereavement as it impacts on the individual. Associated with this is an apparent lack of recognition that the impact of bereavement may depend on factors including the unique nature of the relationship, the nature of the loss and social, religious and culturally acceptable ways of demonstrating the loss. These theories are not readily generalised across different cultures since little recognition is given to the varying beliefs around death, dying and bereavement from cultural and religious perspectives and the impact that they will have on a bereavement experience and its processes. A central concept of all of these theories appears to be the assumption that objects of great love can be relinquished, or that their importance diminishes over time. As newer theories are explored in light of how inclusive they are of today's society, challenges to traditional approaches need to be considered.

A more recent and significant advance in understanding the phenomenon of bereavement is the *dual process* model of bereavement developed by Stroebe and Schut (1999). In contrast to previous work on bereavement as a series of stages leading to or progressing through the experience of loss, they suggest that part of the experience of bereavement is the oscillation between acceptance and denial of the death of a loved one. They suggest that both expressing and controlling feelings are important ways of coping and coming to terms with living a life without the person. In effect the person may 'take time off' from the bereavement process either because the reality is too painful to constantly bear or because they have to attend to more practical things related to everyday life.

For Stroebe and Schut (1999) the progression of the bereavement process is seen as active, fluctuating between focussing on the loss of the person who has died (loss orientation) and avoiding that focus (restoration orientation). The loss orientation acknowledges the primary loss and reflection on the loss of relationship with the bereaved and the associated grief, whilst the restoration orientation involves the active dealing with the secondary losses such as the social, physical, spiritual and emotional losses resulting from the death. They suggest that, earlier bereavement theories lack recognition of what has been lost and what has changed through bereavement. Stroebe and Schut (1999) state that**:**

> 'there has been a lack of recognition of the range of stressors, the multiplicity of losses, integral to the bereavement experience. Not only is there the loss of the person, but adjustments have to be made with respect to many aspects of life' (p.201)

They argue that both loss and restoration orientation are necessary for future adjustment to the loss, but the degree will depend on several factors such as the circumstances of the death, the relationship, gender, personality and cultural and

religious background. Importantly, they note that there are clear cultural differences in the extent to which the loss experience is dwelt upon and highlight the fact that grief is more often expressed as a physiological response in many non Western cultures (Stroebe and Schut (1999). Thus this dual process model identifies a need for flexibility which can be utilised within different contexts and environments.

A further important development in bereavement theory developed by Klass and Silverman (1996) promotes the concept of *continuing bonds.* They suggest that current understandings of bereavement and the grieving process need to be expanded and that healthy resolution of grief incorporates the maintenance of a continuing bond with the deceased. In particular they argue that maintaining an inner representation of the deceased person is normal rather than abnormal and can be described as an interactive and ongoing relationship, even though the other person is absent:

> 'people are changed by their experience; they do not get over it, and part of the change is a transformed but continuing relationship with the deceased' (p.19)

However, absent from this theory is any reference to the religious or spiritual context in relation to the continuing 'presence' of the deceased. To date, very little research has been carried out on religious beliefs and their impact on the bereavement experience and processes. There is therefore a risk that theories developed to inform knowledge of bereavement in one culture may not be applicable to another. Rosenblatt (1993) suggests that trying to adapt existing bereavement theories to a diversified society is pointless:

> 'realities differ so greatly from culture to culture that it is misleading and ethnocentric to assume that Western concepts apply generally…we will never understand people whose language or culture is different from ours if we translate what they say into our own terms

and assume the transcendent reality of those terms' (p.13-14)

Exploration of bereavement experiences from differing faith and cultural perspectives is therefore vital in gaining a deeper understanding of the experience and processes of bereavement and forms the basis of this thesis.

1.2   Religion and bereavement

1.2.1 Spirituality and religion

The terms religion and spirituality are often used interchangeably to mean one and the same. As intertwined as religion and spirituality can, at times, be, it is beyond the scope of this thesis to undertake an in depth exploration into the realms of spirituality. However, it is important to make the distinction between the two at the outset and clarify their different meanings.

The NICE guidance on Cancer services (2004) provides the following helpful clarification between the terms religion and spirituality:

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

Everyone has a spiritual aspect to their lives which may be either sacred (religious) or secular (non religious). It is important to note that whilst some people may perceive themselves to be both religious and spiritual, others will see themselves as spiritual without an associated religious affiliation (McClain – Jacobson 2004, Ironson *et al* 2002). Spirituality therefore can be seen in individualistic terms of a person's well-being or spirit, extending beyond a religious

framework, and not necessarily connecting to or acknowledging a collective higher being.

Emblem (1992) suggests that a religion is recognised by a set of rituals and beliefs which constitute a means of connecting with a higher being (God). In exploring the significance of religion in people's lives, Golsworthy *et al* (1999) divided this into two main strands, the integration of religion to such a degree that it becomes a way of life and thereby facilitates a social connectivity with others of a similar belief system and, the provision of a social position and recognition but only if there is a compliance with the rules of the society.

From this perspective the importance of religion as both a form of social cohesion and social control are valuable elements to its overall dimension. Ribner (1998) suggests that religion has long been recognised as a potentially beneficial mechanism for coping within bereavement, yet the religious aspect of dying, death and bereavement and its impact on the bereavement experience and processes is one that to date has been the attention of very little research.

1.2.2 Religious and cultural aspects of bereavement

There are obvious interconnections between death and bereavement and religious and cultural influences and beliefs. Within the UK population there is an expanding eclectic mix of individuals. The National Census conducted every 10 years, revealed in 2001 that the number of people who identified themselves from an ethnic group other than 'White' had grown from 3.0 million in 1991 to 4.6 million

(http://www.statistics.gov.uk/census/default.asp). Almost seventy per cent described their ethnicity as White and their religion as Christian. The remaining thirty per cent comprised of different cultural and religious groups including Sikhs, Hindus, and Buddhists; the largest of these being Pakistani and Bangladeshi Muslims.

This is reflected within the West Midlands, the location of the study described in this thesis, where, for example the Census indicated that the population of Birmingham consisted of Christian (59.1%), and Muslim (14.3%). The remaining 25% consisted of affiliations to the Sikh, Hindu, Buddhist faiths, those with no faith and 0.2% identifying themselves as Jewish.

Associated with all of these religions are differing belief systems and rituals many of which may only play a part at times of crises such as dying, death and bereavement. The importance and significance of these different rituals and beliefs can often be overlooked in a society where white Christianity predominates. However, the changing population in the UK means that we have to re evaluate not only the need for inclusivity but the evidence for a common approach and basis for concepts and theories including health care practice.

It is also important to acknowledge the merging of cultures in today's society where second, third and fourth generation descendants of immigrants and new immigrants merge on some levels with the indigenous society, whilst on other

levels still maintain 'traditional' cultural and religious values, often closely guided by elders within the family and community.

1.2.3   Religious perspectives of the Abrahamic faiths

The three Abrahamic faiths, Christianity, Islam and Judaism (the religious foci of this thesis) all share core common religious beliefs which can be traced back to the first prophet Abraham (Matthew 1.1-17 the great patriarch described in the Hebrew Bible (Torah), the Christian Bible and the Qu'ran. In Judaism the 12 tribes of Israel trace their lineage to Abraham through his son Isaac and grandson Jacob. In Christian scriptures Abraham is seen as a spiritual ancestor, "justified by faith." In the Qu'ran it is stated that he and another son, Ishmael, built the sacred site at Mecca, which by the word of Allah, through Mohammed, remains the holiest destination for Muslim pilgrims worldwide.

Each of the three religions has developed a separate interpretive belief system and associated rituals that allow identification with, affiliation to, and a perceived protection by, their respective faith. All three faiths encompass a belief in an after life that incorporates the concepts of Heaven and Hell and the associated concepts of judgment, redemption and salvation. Places of worship and specific Holy days are of significance to all three faiths as are the fundamental beliefs in an ultimate day of judgement and life after death. The differences and similarities are summarised in Table 1.

Table 1.   A comparison of differences between the Abrahamic faiths

	Judaism	Christianity	Islam
Birthplace	Middle East	Middle East	Middle East
Concept of God	One God	One God	One God
Central Figure	Abraham Moses	Jesus of Nazareth	Muhammad
Scripture	Torah, Prophets writings from the Talmud (oral tradition)	Bible - old Testament and New Testament	Qur'an – direct revelation from God. Hadith – sayings and teachings of Mohammed
Divisions	Modern movements include Reform, conservative, modern orthodox	Many theological divisions Roman Catholic, Eastern Orthodox, many Protestant Churches C/E, Baptist, Methodist..	Main division between Sunni and Shiite.
Holy state	Jerusalem	Jerusalem	Mecca, Medina, Jerusalem
Jesus	A historic figure. Not the Son of God	The Son of God	Highly respected as the second last Prophet. Mohammed regarded as the Last Prophet.
Hierarchy	No hierarchy. Rabbis seen as teachers	Roman Catholics and Orthodox have extensive hierarchy. Some Protestant branches have almost none.	No hierarchy. Prayers led by Imams – teachers who have studied the Qur'an.
Idols and Images	Images and statues are strictly forbidden	Images and statues are allowed in some divisions but not worshipped.	Images and statues are strictly forbidden
Charity	Tzedakah: 10% of income	Tithe: 10% of income	Zakat: 2.5% of income
Conversion	No active preaching to non Jews. Orthodox Jews must turn away a convert 3 times to ensure their commitment	Conversion considered important in most traditions. Missionaries are prominent among Protestants and Catholics.	Da'wa (invitation): Muslims should share their knowledge of Islam without trying to convert. Only God can bring someone to Islam.
Tolerance of other faiths	Jews tolerate other religions and do not seek to convert	Christians taught to 'love thy neighbour' and proclaim that Christianity is the only way to God.	Muslims taught to tolerate other faiths. Special respect for Jews and Christians as 'people of the Book'.
House of Worship	Synagogue	Church	Mosque (Masjid)
Main day of worship	Saturday (Shabat)	Sunday (Sabbath)	Friday (Jum'a)
Life after Death	No immediate life after death. Life in the 'world to come' after the coming of the Messiah.	Day of Judgment followed by Heaven or Hell.	Day of Judgment followed by Heaven or Hell.

Faith specific perspectives at end of life

Associated with the religious groups outlined in Table 1 are a number of faith specific requirements at the end of life which if not properly addressed have the potential to impact on the bereavement experience and process.

End of life considerations within Christianity

There appears to be a wide variation within the Christian religion regarding end of life requirements. A large percentage of the UK Christian population are secular rather than religiously observant. However, confession at end of life, anointing, and prayer may all be important considerations in the care of the dying person and their relatives. For the majority of Christians within the UK today, there is no immediate *religious* directive for a funeral to take place; although there is great cultural variation within this. Usually funeral arrangements take place five to ten days after the death. This 'delay' is, in part, due to the amount of time required to fulfil the bureaucratic requirements needed in order for a cremation to take place. There is personal preference over funeral arrangements with the majority (70%) choosing cremation (www.birmingham.gov.uk 30/3/8). There appears to be a common acceptance of, or resignation to, the amount of time for funeral preparation. Although this time creates the opportunity for the coordination of family and friends to attend the funeral service, those from the Islamic and Orthodox Jewish faith may argue that their funerals are well attended within a fraction of the time.

For many the emphasis of the funeral may focus on celebrating the life of the now deceased person rather than viewing death as a rite of passage to a religious afterlife. A differing perspective can be seen within Islam.

End of life considerations within Islam

Within the Islamic faith, respect and dignity are core elements that are of paramount importance at the time of death and beyond. Alongside this is an associated gender and religious affiliation specific significance of modesty that is an influential component in the care requirements for a deceased Muslim.

Procedures associated with the care of deceased and subsequent funeral planning are undertaken by family and friends. The requirement for funerals arrangements to take place rapidly and usually within 24 – 48 hours of death, necessitates the prompt completion of the appropriate documentation; an area where delays can occur in an acute hospital or if referral to the Coroner is required. Occasionally there may be a request for the deceased person to be repatriated to their country of origin. Documentation for this to happen must be provided by the Coroner and can lead to further delays

End of life considerations within Judaism

As with other religions there are varying degrees of observance within the Jewish faith. For those of the Orthodox Jewish faith, it is important that minimal physical contact should occur after death between the deceased person and 'gentiles' (non Jews). The post death care for the deceased will be taken over by the Jewish

Burial Society called the Chevera Keddisha. Family involvement with the deceased person is discouraged from this time on and an expectation is placed upon the Chevera Keddisha to make funeral arrangements with haste. Burial is the only acceptable form of funeral for Orthodox Jews however; progressive and reform Jews accept cremation. There are facilities within the UK for Orthodox Jewish funerals to take place at weekends and bank holidays, however, this is dependant upon the bureaucracy that surrounds death as well as the possible involvement of the Coroner.

The importance of specific prayers being recited at the very end of life is noted in all three faith groups; for those of the Islamic faith the concept of confession at end of life is of less important due to the daily ritual of asking for forgiveness in prayer before and after activities of daily living.

Being present at the time of death is an important consideration for relatives, carers and friends. For the Christian faith this may be determined by personal preference. For the Islamic faith this may be interwoven with a feeling of obligation. From the perspective of the Orthodox Jewish faith there may be a distancing from the immediately deceased person and a handing over of responsibility to the Chevera Keddisha, for 'appropriate' religious funeral preparation.

Care and dignity are of extreme importance to all faiths with the deceased person always treated with utmost respect. This, for the Islamic and Orthodox Jewish faiths, involves care after death only being provided by those of the same sex and

same religious affiliation as the deceased. Other issues around end of life and death that require consideration include, for example, tissue and organ donation (UK Transplant 2004) and the medical and coronial need for post mortem examinations. In all three faiths the saving of life is of paramount importance, but the taking of a life prematurely is tantamount to murder. Issues such as brainstem death have complex criteria, are difficult concepts to understand and may not fulfil the religious criteria for 'traditional' death. For the Jewish and Islamic faiths the belief that a body is on loan from God prohibits interference and mutilation with the body. Associated with this is the belief in the Day of Judgement where everybody will rise from their grave and be asked to give account for their actions in this life. Accompanying this is the belief that the person will be in a 'lifelike' state with all organs and limbs present to give account:

> They will say to their skins 'why bear ye witness against us?' They will say 'Allah hath given us speech to everything He created you for the first time, and unto Him were ye to return

وَقَالُواْ لِجُلُودِهِمْ لِمَ شَهِدتُّمْ عَلَيْنَا قَالُوٓاْ أَنطَقَنَا ٱللَّهُ ٱلَّذِىٓ أَنطَقَ كُلَّ شَىْءٍ وَهُوَ خَلَقَكُمْ أَوَّلَ مَرَّةٍ وَإِلَيْهِ تُرْجَعُونَ ﴿٢١﴾

Surah 41 Fussilat v 21 Qur'an

There is also a belief held by all Muslims that a person's organs will give account for their actions on the Day of Judgement:

> On the Day when their tongues, their hands and their feet will bear witness against them as to their actions

يَوْمَ تَشْهَدُ عَلَيْهِمْ أَلْسِنَتُهُمْ وَأَيْدِيهِمْ وَأَرْجُلُهُم بِمَا كَانُواْ يَعْمَلُونَ ﴿٢٤﴾

Surah 24: An-nur 24 Qur'an.

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The belief in the person being raised from the dead to give an account for their actions is part of the reason why, in the Orthodox Jewish and Islamic faiths, a person will always be buried and never cremated.

A further poignant reflection which reinforces the importance of burial for the Orthodox Jews today is the knowledge of the atrocities committed in the holocaust and the acknowledgement that millions of Jews were denied their religious funeral and gassed and burned en masse. Although this does not amount to a religious dictate, it does reflect the cultural history of the religion and reinforces the religious right for an appropriate funeral.

For many Muslims there is a superstitious / spiritual belief that, until the burial takes place, the soul is still present and has an awareness of all that is going on. For those of the Islamic and Orthodox Jewish faiths there is a requirement for burials to take place as soon as possible after the death has occurred. In both the Qur'an and the Torah, an immediate burial is advocated and this is part of the faith requirements. It has been suggested that this requirement may have evolved in response to the climate where the faiths originated from, for example, the Middle East, where temperatures are high and where cool storage areas are, or were, unavailable.

There have been anecdotal accusations of preferential treatment levelled at policies and procedures that facilitate 'fast track' funerals for some faiths whilst displaying a perceived indifference to the facilitation of others. However, the focus

of such policies and procedures are on the mode of funeral (burial or cremation) rather than the religious affiliation it serves.

In the UK, at certain cemeteries, burials can be arranged within hours of a death occurring; the approved mode of funeral and time span for Muslim and Orthodox Jewish burial services. Within the West Midlands, for example, it is possible to arrange a burial three hundred and sixty five days a year. Cremations require more time to organise as additional paperwork and checks on the deceased are legally required. For example, in the rare event of an accusation of foul play an interred body can be exhumed (www.dca.gov.uk 30/3/8); a cremated body is 'evidence' irreversibly lost. Cremation is acceptable to a vast majority of those of the Christian faith where a 'respectable' time between a death and a funeral is allowed.

These specific requirements at end of life are summarised in Table 2 and serve as a poignant reminder of the significant differences that exist between different religious requirements and how bereavement theories and practice that have evolved historically in a predominantly Western white Christian population may not be either reflective of, or inclusive of, the multicultural multifaith population that exists in the UK today.

Furthermore, given that approximately 60% of all deaths occur in an acute hospital setting (Department of Health End of Life Care Strategy 2008) they re emphasise the need for hospital policies and practice to embed these varied and diverse

religious requirements to ensure that they do not impact negatively on the bereavement process and journey of bereaved individuals.

1.2.4 Cultural and religious end of life perspectives

The cultural and religious requirements outlined earlier provide challenges for health care providers that have only relatively recently started to be addressed in health care policy and practice.

These differences take on deeper significance at times of dying, death and bereavement, where belief systems around dying and death may influence perceived requirements to support a peaceful end of life and to provide subsequent support and comfort to bereaved relatives and friends, as outlined in Table 2. End of life and bereavement care has generally been dominated by a western Christian ethos in societies where traditionally Christianity forms the majority religious affiliation. Golsworthy (1999) acknowledges the lack of research in the area of cultural and religious needs and requirements at end of life, and their significance with regards to the bereavement experience. Becker (2007) in a systematic review of religious and spiritual beliefs and their influence on bereavement states that more research is needed in this area for today's multi faith, multi cultural community.

The difference in the expression of grief across cultures and religions has been acknowledged by Parkes, Laugani and Young (1997) in their identification of the social versus private displays of grief. Importantly they state that there is no evidence to suggest that one approach, social or private, to bereavement is better

Table 2.   Specific requirements at end of life for the Christian, Jewish and Muslim faiths:

Considerations	Christian	Orthodox Jewish	Muslim
Confession	If requested	If requested	Confession part of every day prayer and process.
Anointing	If seen by religious leader	No	No
Prayers	Religious leader to recite if family wish, the Lord's Prayer , Sacrament of the Sick	23rd psalm and 90th psalm	Passages from the Qu'ran
Presence at time of death	Individual preference Religious leader if family wish	Family – Rabbi not necessary	Family / friend –
Organ donation	Personal preference	Personal preference usually no.	Personal preference usually no.
Last offices wash	Nurse and relatives	Chevera Keddisha	Family / community members
Gender issues	No specific religious /cultural requirements age and dignity considerations	Same sex care from Chevera Keddisha	Same sex care from family and community members
Post Mortem examination	Personal preference	No (unless Coroner's PM)	No (unless Coroner's PM)
Release of the deceased patient	No specific time line	As soon as possible	As soon as possible
Funeral requirements	Burial / cremation – no specific religious need for haste	Burial ASAP (variation with progressive Jews)	Burial ASAP no alternative
Place of funeral	UK unless visiting from abroad	UK (own cemetery)	Religiously UK but separate to other faiths. may be repatriated for burial in place of origin.

or more beneficial than the other in relation to the bereaved. However, their discussion falls short of why the different manifestations of grief may be significant and the impact that a perceived failure to 'do the right thing' religiously at the end of life may have on the bereavement experience. They concentrate more on the physical manifestation of bereavement than on its cultural and religious meaning and fail to address the impact on bereavement when the cultural and religious

processes of bereavement and grief, through public displays or quiet reflection, are inhibited or disrupted in any way.

However, Stroebe (2004) in a review of religious variables in bereavement, including cultural and religious beliefs, conclude that there is insufficient evidence to suggest that religious beliefs influence outcomes of bereavement. They stress that this is not to suggest that people who hold such beliefs do not find them helpful, but highlight the difficulty in research in this area where definitions and confounding variables are not concise or considered. This suggests that much of the bereavement research carried out to date has been within a quantitative paradigm. The utilisation of qualitative research, which values the lived experience of the individual and their view point, may be more adept at accurately capturing sensitive data of this type.

Raphael *et al* (1999) expand consideration of cultural diversity by suggesting that the differing patterns of cultural / religious reaction to loss require specific methodical study, concluding that

'there is a need to develop and test culturally specific programs.' (p.429)

Stroebe *et al* (1999) support this when they state:

> 'We need, then, further systematic, scientific studies of differing patterns of reaction to loss, research that goes beyond the charting of mourning rites and rituals by anthropologists and ethnographers, on which so much of our knowledge has had to rely so far.' (p.464)

Wortman, & Silver, (1987) suggest that, because the process of bereavement is so idiosyncratic, it is difficult to generalise about the course of bereavement across various groups of people. Therefore there is a need to look beyond the labels and assumptions, so easily attached to people, to the untapped wealth of experience

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and knowledge that each bereaved person carries in their heart. Indeed Lobar et al (2006) acknowledge that although cultural practices are described, there is limited research based evidence from key informants within cultures. It is suggested that it is the person's narrative that holds the key to the 'experience' of bereavement rather than generic guidelines drawn from 'experts' in the bereavement field. As Foskett (2003) states:

> 'Each individual has their own unique personal religious and/or spiritual experience. Common and predictable religious practices and beliefs are the stuff of creeds and scriptures and the authorities which enforce them, not of individual believers.' (p.16)

It is therefore suggested by these authors that research needs to be undertaken which focuses upon the individual lived experience of bereavement to see 'how it was for them' rather than relying on descriptions about how it should have been. Such work is necessary to bridge the gaps between theory and practice; experience and expectation of bereavement and forms the guiding principle on which this thesis is based**.**

In acknowledgement that bereavement is an emotive experience and one that will impact on people differently, Phenomenology was identified as both a philosophy and methodology in which to explore a person's 'lived experience' and the theories and concepts associated with this intellectual framework are outlined in Chapter 2. It was anticipated that its application would facilitate the exploration of the recollections of all those who had experienced bereavement; or had been involved with the care of the dying / deceased patient and therefore a participant, knowingly or not, in the bereavement pathway of another.

1.3   Influencing factors on the bereavement experience

1.3.1 Environment (Space) home versus hospital

Factors that may impact upon the bereavement experience include the location of a death, events leading up to the death, the cause of death, perceptions of care and its delivery and religious needs at the time and in the ensuing minutes, hours, days and months following the death. It is important to consider the potential impact of each of these influential factors on the bereavement experience, especially the impact of location. In the UK today, although most people state that they would prefer to die at home approximately 60% of deaths occur within an acute hospital setting (Department of Health End of Life Care Strategy 2008) However, the primary focus of acute hospitals is on treatment and cure, not on death, bereavement and religious requirements at end of life. To date, little research exists which specifically relates to the impact that the situation and environment in which a death occurs may have on all involved: patient, carers and relatives and healthcare professionals.

The Department of Health White paper *'Building on the best: choice, responsiveness and equity in the NHS '* (2003) mapped out a vision of healthcare provision from birth to death and stated that adults nearing end of life should be offered the choice to die at home. This is also reflected in the Gold Standard Framework (GSF) for end of life care which suggests that

> 'Patients are enabled to live well and die well in their preferred place of care'
> (www.goldstandardsframework.nhs.uk – last accessed 24/1/9)

and also in Lord Darzi's *Next Stage Review of the NHS* (2008) and the recently published Department of Health *'End of life care strategy'* (2008).

However, preferred place of death can change over the disease progression. Townsend's (1990) and Hinton's (1996) studies on terminal cancer patients and their relatives concluded that although home was the preferred place of death at diagnosis, this altered over time and with the onset of other aspects such as pain control. Other influencing factors have been shown to include the existence and involvement of a social network, carers' attitudes, and views and perceptions of care provided by alternative places of care such as hospices, hospitals, and nursing homes (Thomas *et al* 2001). Home can be seen to represent familiarity, the presence of loved ones and the possibility of enjoying a 'normal' life (Gomes & Higginson 2006). Indeed Higginson *et al* (2000) identified these among reasons why over half of participants with a progressive illness wished to die at home.

Gott *et al* (2004) examined the concept 'home' in relation to older people's perspectives of dying and death and reported that although initially home was seen as a 'good' place to die, this altered as the dying trajectory progressed. Research by Bond et al (2003), Ryan (1992) and Bass and Bowman (1990) all suggest that, for relatives, the relinquishing of care of a loved one over to a perceived safe environment of a hospital or care home had a positive effect upon their bereavement experience. Conversely, Grande *et al* (2004) suggests that death at home is associated with a better initial bereavement response, however importantly six months after bereavement there was no longer any significant difference in the bereavement progression.

Brazil *et al* (2002) found that death at home was associated with better mental health of the care giver, and Koop and Strang (2003) reported positive emotions in adult carers of people in the terminal stages of cancer, who felt a sense of positive achievement and accomplishment through allowing their relative to die at home. However, Addington - Hall and Karlsen (2000) suggest the opposite and purport that dying at home may actually increase psychological distress for relatives.

Gomes and Higginson (2006) undertook a systematic review of studies that looked at the place of death. They reviewed fifty eight studies with over 1.5 million patients from thirteen countries and uncovered 17 factors affecting the place of death and its effects. These included factors related to the illness (over 80% of the subjects had cancer), individual factors (although religion and culture were not identified in these) and environmental factors including social support. Interestingly they highlight that some deaths at home were not as a result of preference but because there was no other alternative for example, lack of hospice beds or not the right criteria for admission to hospice. However, the impact of death in hospital was not directly explored or addressed. This is disappointing when figures clearly show that the majority of deaths and therefore the majority of bereavement experiences are hospital based.

A death in hospital, by its very nature, cannot be described as 'homely' as it will occur in an unfamiliar environment and the person will be 'cared' for by strangers, especially at the end of life when specific requirements are important for some faith groups as illustrated in Table 2. Although the provision of such care may relieve the pressure from relatives, it may also reinforce the belief that 'proper

care' cannot be provided at home and reinforce feelings of guilt and failure for relatives and a sense of 'letting down' for the dying person which may influence the subsequent bereavement process and experience.

The majority of bereavement research has been undertaken on participants with cancer within a hospice or out patient setting. Although the term palliative care can be applied to a myriad of diseases and conditions, throughout the majority of literature reviewed it related solely to cancer (Higginson 1994; Higgs 1999; Lawton 2000; Lynn 1997; Ellershaw 1997; Quirt 1997; Parker 1992; Clark 2002, Patrick 2001). However, in an acute hospital setting, people not only die from cancer in palliative care units but also from a myriad of life limiting diseases and conditions, and from differing cultural and religious backgrounds.

1.3.2. Perception of death 'good' or 'bad' – The individual 'lived experience'

What defines a good or bad death is dependant upon a myriad of different factors individual to the person and the circumstances of the death. Field and Cassell (1997) cite the committee on end-of-life care of the Institute of Medicine (UK) definition of a 'good' death which acknowledges the absence of pain and suffering of both the patient and the family but also includes the cultural and religious needs of each individual. Finlay (2003) focussing on dying with dignity, states that hospices have been created to focus on the needs of dying patients and their relatives and are seen as areas of best practice for end of life and bereavement care. In acute hospital settings in the UK, Finlay (2003) notes end of life care is poor and cites mixed sex wards, limited facilities for relatives, bed pressures as

soon as a death has occurred, lack of continuity of care, doctors and nurses changing shift patterns all as factors which may contribute to a 'bad' or failed death.

The perception of a 'bad death' often translates into complaints about health care provision. The HealthCare Commission (2007) reported that 54% of all complaints received had a bereavement element to them. However research into what constitutes a 'good death' suggests that this is, at present, an unanswerable question given lack of evidence, especially from the patients and carers perspectives (Clark 2003; Bowling 2000) and is an area that warrants further attention.

The medical model of care, focusing on treatment and cure, has been universally accepted within acute hospital settings. However, its continuation and appropriateness for holistic end of life care should be questioned. Costello's (2001) research suggests that within a ward structure there is a delineation of roles when patients are dying with nurses focusing on the amelioration of physical pain but often failing to acknowledge or address the psychological and spiritual pain that may coexist.

The decision to stop active treatment and commence palliative care can be a difficult one to make as it demands recognition that a life is ending. Leonard-Jones (1999) highlights this subtle difference when stating that:

> 'The ethical situation is not that the patient is failing to drink and therefore will die, but that the patient is dying and therefore does not wish to drink.' (p.40)

Higgs (1999) in her paper on 'The Diagnosis of Dying' observes that:

'as clinicians we still find it difficult to make the diagnosis of dying.' (p.111)

and suggests that doctors fail to acknowledge that their patient may be dying. She offers the explanation that the majority of people avoid thinking about death and that medical staff are no different in this respect.

However Higgs (1999) suggests that ignoring impending death is a defense mechanism commonly utilised by doctors and nurses when faced with end of life and bereavement situations with patients and relatives. This, they propose, allows a detachment and denial of impending death that can result in an absolution of responsibility when death occurs. Statements such as 'we did everything we could' may be heard but may often be questioned in terms of the provision of a dignified and culturally / religiously appropriate death. As Higgs (1999) states:

'Explaining to patients that we do not know something is acceptable, failing to educate ourselves, or to contact the appropriate expertise in order to inform or help them, is no.' (p.111)

Costello (2001) and Cotter et al (2004) suggest that although there is an overall recognition of spiritual and emotional aspects of care there is, to date, little evidence of these needs being met at times of death and bereavement. Dowd *et al* (1998) state that there is a need for a more appropriate cultural model for training and education around dying, death and bereavement, which addresses varying aspects such as communication, time, space and social organisation.

1.3.3 Individual perspectives of bereavement

Relative's / significant other's perspective

The personal experiences of the impact of bereavement following the death of a

person form the basis of this study. The bereaved person's perspective should, rightly, have the most gravitas as the impact of bereavement will rest heavily with them. The experience of the death of a loved one (whether that be partner, other relative or friend) in an acute hospital setting, if inappropriately handled, has the potential to have a major impact on the ensuing bereavement experience and processes and make the experience of the death, as well as the loss, a painful memory for ever.

The death of a partner is acknowledged as being one of the most stressful events in a person's life (Zisook and Schucter 1991; Kaunonen *et al* 2000; Bonanno *et al* 2001; Parkes 1972). Several studies have looked at the experiences of bereaved relatives: (Main 2002; Hinton 1996; Golsworthy 1999; Stroebe & Stroebe 1998; Parkes 1972). Studies into spousal loss have looked closely at symptoms of stress during the bereavement journey and suggest a gradual decrease in the intensity of stress over time (Avis *et al* 1991; Liberman and Yalom 1992; Hyrkas *et al* 1997).

Further studies have highlighted gender specific considerations with findings that suggest that the death of a partner will have a more profound impact on widowers than widows with demonstrable results through associated illness and death (Bauer and Bonanno 2001; Martikainen and Valkonen 1998). However, other factors, including excessive dependency within the relationship and continuing bonds (Field *et al* 2004), are also influential factors within the bereavement experience. The availability of social support is seen to be a significant factor in the bereavement experience, whether from family and friends (Duke 1998) or

regular support group meetings (Tudiver *et al* 1995). However, the provision of support from a cultural or religious network was not explored within any of these studies.

The hospital environment is unfamiliar to many of the general public and many of the deaths within an acute hospital will be sudden or unexpected. Therefore most deaths in hospital will leave even the most robust person vulnerable and uncertain of immediate procedures and processes. This distressing event may be further compounded if the dying person has end of life requirements, derived from religious beliefs, which both they and their relatives fear may be questioned or left unmet.

Doctors / nurses and healthcare assistants experience

Little research to date has looked at the religious and cultural aspects of caring for dying patients and their relatives but even less has focused on the experiences of doctors, nurses and healthcare assistants trying to provide such care.

A lack of research is also apparent within the medical and nursing annals regarding the exploration and understanding of religious and cultural practices at end of life. Limited information does exist regarding generic faith requirements at end of life (Katz 1996; Gatrad 2002, 2003), however, there is a lack of explanation about why such requirements are needed and how they relate to religious beliefs. This is apparent in the striking difference between the care plan requirements for a specific clinical problem and the supporting rationale for the action to be taken compared to guidance issued for last offices at the end of life. For example, the

care plan for a patient with a chest infection will inevitably suggest that the patient is nursed in an upright position to facilitate full expansion of the lungs, avoid further consolidation and focus on airway clearance. A generic last offices guideline for a patient of the Islamic faith may state that a Muslim patient should be positioned to ensure that they are facing Mecca with no explanation or rationale. It is the 'why' that helps us understand, and care appropriately for the individual and gives meaning to requests that may appear alien and outside of 'normal' practice.

Gatrad (2003) in his work on palliative care for ethnic minorities states that we need to acknowledge the wealth of cultural diversity, not only in the patients and relatives that are cared for, but also in the staff that provide that care. He concludes that:

> 'we have a relatively untapped potential for penetrating insights into how to shape the future agenda for the provision of palliative care: the doctors, nurses and allied health care professionals who with their broad ranger of ethnic, religious and cultural backgrounds represent a most valuable learning source.' (p.176)

suggesting that although knowledge on cultural and religious diversity is already within the healthcare setting, how it is disseminated remains a concern. Bereavement care is not an 'add on' or an area of care exclusively within the domain of a particular group it is an integral part of the role of every doctor and nurse.

Religious leaders

The importance of religion as a form of social cohesion especially when a death is imminent or has occurred is a valuable element to its overall dimension. Ribner (1998) suggests that religion has long been recognised as a potentially beneficial

mechanism for coping with mourning, yet the religious aspect of dying, death and bereavement is one that, to date has been the attention of very little research.

The role of the hospital chaplain is pivotal, but not exclusive, in providing religious support and guidance in many areas of patient and staff support including end of life care. The Department of Health paper *NHS Chaplaincy* (2003) supports this and states:

> 'Chaplains spiritual care givers are the Trust experts on arranging and providing liturgies and ceremonies to meet the needs of the bereaved.' (p.20)

The appointment of hospital Chaplains from faiths other than Christianity is a relatively new occurrence within acute hospital settings (Ahsan 2002). With their arrival, the role of the Muslim and Jewish hospital Chaplain and their professional and personal experiences are, as yet, untapped research resources. As appointment to positions of non Christian Chaplains has been a recent event no documented research exists as yet which explores their role, their experiences and the expectations placed upon them. Indeed, to date no research has explored the multi religious / multi cultural experiences of bereavement from both relatives and staff perspectives within an acute hospital setting.

1.4 Healthcare provision and its relevance at end of life and bereavement care

Government led health care policy places increasing demands upon acute hospitals to meet targets that reflect key areas of work such as rapid case management, the delivery of national clinical priorities and reduction of waiting lists (Department of Health 'Building on the best' 2003, Department of Health NHS

Improvement Plan 2004). This often leaves little time for managing the needs of dying people and their families.

National inquiries following revelations regarding organ retention at Alder Hay, and Bristol (Royal Liverpool Children's Inquiry, Redfern 2001; the Report of the Bristol Royal Infirmary Inquiry: Kennedy 2001) along with Dame Janet Smith's Shipman Report (2005), the Isaac Report (2003) and more recently, the Department of Health advice '*When a Patient Dies'* (2005) have all been written in response to perceived failures in end of life and bereavement care.

There has also been recognition from the Department of Health ('When a Patient Dies' 2005) that the perceptions of end of life care provision can impact on the bereavement experience and on the health of the bereaved:

> 'the experience around the time of death and afterwards can influence grieving and the longer term health of bereaved people.'   (p.4)

and more recently in the Department of Health *'End of life care strategy'* (2008)

> 'How people die remains in the memory of those who live on' (p.1)

Currently there are no evidence based standards for bereavement care in the NHS. However, the National Institute for Health and Clinical Excellence guidance on improving supportive and palliative care for Adults with Cancer (N.I.C.E 2004) make reference to the availability of bereavement care following a death. These guidelines emphasise diagnosis, treatment and, for some, end of life care but there is scant mention of pre bereavement preparation, death management, or acute bereavement care and its ongoing management and no mention or recognition of religious and cultural diversity.

The importance of a coordinated response to bereavement and diverse needs is recognised by the Department of Health in 'When a Patient Dies' (2005) but not in a way that ensures the necessity for embracing, acknowledging and implementing a religious and culturally sensitive care package to improve care at the time of death and beyond:

> '…where a death occurs in hospital, it is essential that Trusts have in place systems, policies and practices that will ensure that a coordinated response to bereavement is taken by all staff to meet individual needs regardless of religious or cultural needs.' (p.2)

Recent national cancer care pathways and advice (National Institute for Health and Clinical Excellence, Liverpool Care Pathway, Gold Standard Framework) do briefly acknowledge care at time of death and beyond. However, the focus for end of life care in these documents is on the dying trajectory and the practical, often physical requirements. Little is documented relating to the psychological needs of the patient and specifically addressing their spiritual and religious needs or the final care for the deceased patient and the immediate and longer term needs of the bereaved family, who may have been long term carers.

This lack of consideration of needs at time of death and the importance of religious or spiritual dimensions at such times is a failing, but possibly reflects an historic perspective in which care at the end of life and the subsequent care of the bereaved, has not been an NHS priority even though it has been acknowledged in policy (Department of Health 'When a Patient Dies' 2005). The components of a good bereavement care service are recognised as providing the final care for patients and their relatives, ensuring that all documentation and explanation has been provided for relatives to facilitate the next step of their journey. It should also

provide support and training for staff on bereavement care matters to enable appropriate care for patients and relatives at times of bereavement (Chaplin 2003).

1.4.1 The Bereavement Care Service at a large hospital Trust in the West Midlands

In 1997 in response to complaints, and in acknowledgement to cultural and religious end of life care requirements, a large 2 site teaching trust in the West Midlands, established a Bereavement Care Service (Chaplin 2003) which won an NHS Silver Award in 2002 and provides the setting and context for the study reported in this thesis.

The Bereavement Care Service aimed to provide a hospital wide, centralised, culturally sensitive service, which caters for the individual needs of each patient and relative/ significant carer. The service can be described as a conduit between the organisation and the individuals, patients, relatives and staff that it cares for.

The Trust deals with approximately two and a half thousand deaths per year across diverse religious groups as shown in Table 3 with the Christian faith making up the majority. Whilst the number of Muslims deaths appears relatively constant and low it should be acknowledged that the Muslim population in the West Midlands is increasing and that first generation immigrants of the 1950's are now becoming elderly.

Table 3.   Number of deaths categorised by faith in 2003-06 in a large hospital
                Trust in the West Midlands

Year	2003	2004	2005	2006
Christian	1694	1573	1596	1422
Muslim	82	77	86	82
Jewish	24	19	9	13
Other	610	566	475	551
Total	2410	2235	2166	2068

Whilst the needs of the majority Christian group were acknowledged in models of care, the experience of offering a bereavement care service for all raised challenges for people identified from other groups, in particular the Orthodox Jewish and Islamic faiths. Although comparably small in numbers it was noted that these faith groups had specific requirements at end of life, which if not addressed, could cause distress and impact negatively upon both the patient and relatives. Some staff also felt uncomfortable or unhappy about pressure to provide care to religious groups that they were unfamiliar with, or when they did not totally understand their requirements.

In an initial effort to understand the impact of the death of a patient on relatives within this acute hospital, letters of complaint written to the Chief Executive following the death of a patient were examined as part of service evaluation (see Appendix A). Although it was recognised that these letters were not representative of all bereavement experiences, they provided insight into some areas of care that were important at times of dying, death and bereavement. They also provided the first glimpses of the 'other side' of bereavement care – the relative's experience. In

particular they showed a need for the relatives to make sense of the whole event, and the need to acknowledge the person as an individual and the impact that the loss had on them.

The stimulus to explore this issue grew as it became evident that, whilst it was assumed that those in bereavement care knew how to care for the bereaved, much of the knowledge base informing practice was rooted in a limited world view reflecting the dominant religious culture, a Christian perspective. Lack of local knowledge surrounding specific cultural and religious requirements at end of life became apparent as more information and views were gathered informally from people from faith groups other than Christianity.

As a result, the study reported here sought to explore experiences of bereavement in an acute hospital setting. The study focussed on people from the dominant faith groups in hospital who had experienced the loss of a loved one through death; the experiences of doctors nurses, healthcare assistants and builds upon policy and practice instituted within the Trust.

1.5   Conclusion

Research into dying, death and bereavement is fraught with difficulties that relate to the sensitive nature of the phenomenon and the many variables that influence the outcomes. Little research exists into the cultural and religious aspects of the phenomenon of bereavement and more inclusive research is required to establish

the personal experiences of those affected by bereavement especially in relation to the acute hospital setting where the majority of people die.

The models of bereavement theory explored provide valuable insight into understanding the bereavement experience, however, limitations are noted. It is important to acknowledge that, in general, individuals will never fit models exactly and that models provide the bare foundations on which to describe human activity. At present, there appears to be no model, which addresses and provides answers to all questions about the phenomenon of bereavement especially in a multicultural multifaith population. These existing theories provide a foundation upon which further research can be constructed.

Within acute hospitals the focus of care is on treatment and cure and doctors nurses and healthcare assistants are front stage in its delivery. However, at times of dying and death, other non-conventional 'treatments' such as spiritual and religious care may take precedence over medical treatment. This should be recognised as a continuation of care during the person's transition from life to death; just as other care will be provided in the transition from illness to health.

Although more recognition is being placed upon the importance of end of life and bereavement care in national policy this needs to be underpinned by a grass roots up approach to fully understand religious requirements at end of life and bereavement and ways of appropriately implementing them. This will help to ensure that situations and events that may impact negatively on the bereavement

experience (such as the inability to perform rituals and lack of control over funeral arrangements) are acknowledged and addressed in end of life and bereavement care management in acute hospitals.

In a multifaith, multicultural society, it is likely that staff caring for the dying person and their relatives will not be of the same faith / cultural group and therefore will lack an in depth understanding of specific faith requirements and their significance at end of life. Exploring doctors', nurses', healthcare assistants' and religious leaders' experiences of caring for dying and deceased patients from different faiths and their relatives will uncover where difficulties may exist, where gaps in knowledge base may impact on care and identify ways in which care provision may be enhanced for the benefit of the dying person and the bereaved.

1.5.1   Aims and objectives of the study

The aim of the study reported here was to identify and understand the significance of end of life care requirements within the bereavement care pathway in a multi cultural multi faith population and to uncover factors which may influence end of life / bereavement care for relatives and its impact on their bereavement journey when a death occurs within an acute hospital setting.

The objectives of the study were to:

1. Explore the Abrahamic faith perspectives of dying and death to gain an understanding of end of life requirements and their significance within the bereavement experience.

2. Uncover the 'lived experience' of bereavement following the death of a loved one in an acute hospital setting from the perspective of bereaved relatives, nurses, healthcare assistants, doctors and religious leaders using phenomenology as the intellectual framework.

3. Explore the impact and implications of the experiences on acute healthcare provision and practice.

CHAPTER 2

CONTEXT OF STUDY

This chapter aims to set out the intellectual context of this thesis within the framework of phenomenology as a philosophy for the exploration of the lived experience of bereavement.

2.1   Phenomenology

In acknowledgement that bereavement is an emotive experience and one that will impact on each individual differently, phenomenology was identified as a philosophy and intellectual framework in which to explore a person's 'lived experience' as well as providing the methodology. It was anticipated that its application would facilitate the exploration of the recollections of all those who had experienced bereavement, or had been involved with the care of the dying / deceased patient and therefore a participant, knowingly or not, in the bereavement pathway and experience of another. The purpose of this chapter is to provide an overview of phenomenology and its suitability as a research methodology for the exploration of the phenomenon of bereavement.

For years the quantitative approach to research has been justified by the success that researchers have experienced in measuring, analysing, replicating and applying knowledge gained from this method of enquiry (Streubert and Carpenter 1995). Quantitative research generally does not have the capability to uncover and explore what it is like to be a part of an experience, to actually 'live' it. It fails to provide an in depth explanation or understanding for some phenomena which are nebulous and defy tangible measurement, such as phenomena relating to human existence and experience, for example love, caring, being with and loss. These

are difficult concepts to quantify as there is no universal agreement or definition of the concepts or how they are comprised. Generally they are defined by an individual's belief systems and influenced by psychological, cultural and social experience.

Qualitative methods provide the ability to delve more deeply into exploring meaning by considering research questions that are not easily answered by experimental designs (Green and Britten 1998). Holloway (1997) suggests that qualitative methods allow the in depth exploration of human behaviour, experiences and perspectives of the participants being studied.

2.1.1 Bereavement as a phenomenon

The phenomenon of bereavement is a difficult concept to explore, due to the individual's unique relationships, history, culture and belief systems. If there is to be a deeper understanding of bereavement from, for example, a religious perspective, there is a need to uncover and explore personal experience; to ascertain whether there are indeed common threads for every bereaved person, as bereavement theories have suggested, or whether the phenomenon of bereavement is unique to the individual experiencing it.

The utilisation of phenomenology will assist in uncovering the beliefs and understandings of individuals and their frame of reference within the concept of bereavement. Many things are taken for granted in people's daily lives, however, at times of dying death and bereavement the assumptive world, with all that is held

near and safe can be thrown into chaos. In the struggle to make sense of the loss of a loved one and the inevitability of a changed set of circumstances people revisit all that was once 'known' from a newly created unique perspective; experiencing for the first time, a new world without their loved one physically present.

2.1.2 Origins of phenomenology

Spiegelberg (1981, 1994) is acknowledged as being the foremost historian of the phenomenological movement and, according to him, studies using phenomenology to explore subjective phenomena do so on the assumption that ultimate truths about reality are rooted in the 'lived experience'. Many differing phenomenological philosophies look at alternative ways of 'Being-in-the-world'. Heideggarian phenomenology provides a vehicle for such exploration allowing the researcher to bring in, without prejudice, their own experiences and interpretations into the analysing and interpreting process.

Walters (1995) defined phenomenology as:

> 'the name for a philosophical movement whose primary objective is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexamined preconceptions and presuppositions' (p.3)

This is supported by a later phenomenological researcher, Moran (2000), who suggests that phenomenology is:

> ' a radical, anti- traditional style of philosophising, which emphasises the attempt to get to the truth of matters, to describe phenomena in the broadest sense as what ever appears in the manner in which it appears, that is as it manifests itself to consciousness, to the experience…phenomenology's first step is to seek to avoid all misconstructions and impositions placed on experience in advance, whether these are drawn from religious or cultural traditions, from everyday commonsense, or, indeed, from science itself. (p.4)

These definitions and descriptions reflect the objective nature of the phenomenology of Husserl (1859-1938) the philosopher and mathematician credited with being the forefather of phenomenology, Husserl wrote of phenomenology as the first philosophy and the search for the foundations of all knowledge, (*Logical Investigations* 1900-1901) whereas Heidegger (1889-1976) focussed on capturing life as it is lived; studying phenomena as they appear through consciousness 'back to the things themselves' (*Being in Time* 1927). Other later philosophers (Hans-Georg Gadamer 1900-2002; Hannah Arendt 1906-1975; Emmanuel Levinas 1906-1995; Jean-Paul Sartre 1905-1980; Maurice Merleau-Ponty 1908-1961; Jacques Derrida 1930-) refer to phenomenology as a means of asking phenomenological questions, for example for the purposes of the study in this thesis: what is bereavement – what is it like to be bereaved?

However, Heidegger, Husserl's assistant and colleague for many years, built on Husserl's work and developed a branch of phenomenology which explored the subjective impact of the phenomenon on the individual, as opposed to the objective criteria of the constitution of the phenomenon itself which had formed the basis of Husserl's approach. Streubert and Carpenter (1995) refer to Heidegger's interpretations of phenomenology as a means of understanding the phenomenon as the person experiences it, the '*lived experience*':

> ' the lived experience that presents to the individual as to what is true or real in his or her life…..it is this lived experience that gives meaning to each individual's perception of a particular phenomenon and is influenced by everything internal and external to the individual.' (p.31)

These differences in emphasis demonstrate the challenges in the interpretation of what constitutes a phenomenological approach. To some this constitutes a

division that has its roots in history and is crucial to understanding phenomenology, as a philosophy as well as a research methodology. This division has led to phenomenologists following either Husserl and his belief in philosophy as a rigorous science with the primary emphasis on objectively and scientifically uncovering the essence of the phenomenon; or Heidegger with his belief in 'Daesin', Being-in-the-world and the individual 'lived experience' or how a phenomenon impacts on the individual.

The disparity in interpretations of the term phenomenology and its myriad of applications to research is acknowledged. However, it is important to develop a context for understanding phenomenology and the emergence of the phenomenological movement before using the approach to inform this research. The original aims are an important focus as there is always the potential risk in research of a qualitative nature for dilution or a discrete change in emphasis or for interpretation to take place. Therefore as a precursor to the phenomenological methodology chosen for this thesis, the pathway of phenomenology will be outlined from the 18th century to present day.

2.1.3 The History of phenomenology and key phenomenological philosophers.

Edmund Husserl (1859-1938) is credited with being the forefather of the phenomenological movement. Husserl's fundamental belief was that phenomenology would be able to provide description and clarity of all human experiences prior to the making of assumptions as to their cause. The term

phenomenology initially evolved as a response to the reductionist approach in science of the exploration of things in isolation, down to a single essence or description, which could then be proved or discounted. Husserl wished to rise above the mundane acceptance of everyday experiences and delve beneath their surfaces to discover their core structures. However, although Husserl's phenomenology was revolutionary in thought, he continued to conduct his work from a traditional scientific paradigm along with the assumptions of objectivity and neutrality as outlined by Flemming (2003).

Husserl believed that the task of phenomenology was to study or uncover essences. In its true sense phenomenology is purely descriptive and makes no attempt to explain or interpret phenomena as they manifest. Husserl applied an adapted mathematical approach of 'bracketing' or 'epoche' to the exploration of phenomena. He attempted to set aside existing thoughts about the phenomenon and view it free from prior knowledge and supposition. Thus bracketing is not a dismissal of previous knowledge about a phenomenon but an ability to identify such knowledge and set it to one side. Therefore bracketing can be seen as a way of defending the validity or objectivity of interpretation against the self-interest (set beliefs) of the researcher. However, whether bracketing is actually possible in practice is an ongoing debate as described by Crotty in 1996.

For Husserl, phenomenology was an attempt to use description to capture the pre conscious 'pure' phenomenon and glimpse back 'To the things themselves'. Although Husserl was ground breaking in his philosophical approach to the study

of phenomena, a criticism levelled at his work is that it failed to acknowledge the individual and the inevitable subjectivity of the experience of the phenomena. The myriad of unique experiences of a single phenomena and its impact upon an individual meant that further exploration was required in an attempt to uncover a deeper understanding, not only of the phenomenon under scrutiny, but also the impact it had on the individual.

Martin Heidegger was a student of Husserl's during the late 19th century. His main interests lay in ontology (how we live in the world) and issues regarding time and life experience. Heidegger questioned the Husserlian belief that meaning is neutral and can remain untainted by the interpreter's own views of the world (bracketing). He suggested that any researcher will carry with them background information, experiences and interpreted meaning of the phenomenon which cannot be ignored or bracketed; therefore it is impossible to view phenomena in isolation. Heidegger believed that past experience, which he referred to as 'forestructure' is critical to a person's perceptions as it immediately links the past, present and future; not in a linear way but more in a circle of understanding.

The term 'Heideggarian Hermeneutics' is used with reference to Heidegger's works and refers to the circular acts of interpretation reflection and further interpretation. Hermeneutics acknowledges that we are constantly influencing and being influenced by the 'world'. Therefore each person's experience of a phenomenon, such as bereavement, will be influenced by factors such as the environment (space), the involvement and intertwining of others (relationships),

the inevitability of occurrence (time) and its physical and emotional impact (body) as proposed by van Manen (1984,1990).

Heidegger also advocated the theory of co-constituting, which refers to the 'indissoluble unity' between a person and the world, the 'Being-in-the-world'. The *a priori* 'known' world is in existence therefore the person is within it and experiencing it from the very moment he/she is born. Therefore Heidegger's existential ontological view of the person is different from the epistemological Husserlian view based on Cartesian duality, a belief that the body and soul are separate entities.

Of relevance to the study described in this thesis, from a Heideggerian perspective, is that a person 'Dasein' (a human 'being' in the world) participates in the world within cultural, social and historical contexts. It therefore follows from a Heideggarian perspective that after a death and during the ensuing bereavement the whole aspect of 'Being-in-the-world' will require personal re-evaluation in light, not only of the loss of a significant other, but the associated 'in-the-world' losses of role, status, expectation. Not only will a person be assimilating the loss of someone close to them but also experiencing the realisation that their 'Being-in-the-world', their identity or essence, has altered as a direct consequence of their loved one's death.

The richness and depth of Heideggerian hermeneutic phenomenology has been explored by many academics that have devised varying inductive methods forging

paths of enquiry into the underlying 'essence' or 'being' of human experience. For example, Merleau-Ponty (1908-1961) supported Heidegger's view of 'Being-in-the-world' seeing embodiment as the essence by which a person can truly 'experience' a phenomenon. This argument is important when looking at research conducted within an acute hospital setting. If we look to medicine and its traditional emphasis upon treating the conditions of the 'body' the potential exists for other facets of the person to be overlooked. However, it is these other dimensions of the person that are of importance when exploring the 'whole' phenomenon and its impact upon a person's 'Being'. The whole person and their unique lived experiences are what Heideggarian phenomenology wishes to uncover.

2.2   Phenomenological application

Phenomenology is renowned for its difficulty in application and interpretation, with Crotty (1996) and Barkway (2001) considering its misuse by researchers. However, van Manen, (1990) an educational theorist, has applied phenomenology as a foundation for qualitative research in the area of educational enquiry, but its applicability to other forms of enquiry is acknowledged. His work offers clear and concise conceptual guidance on its application that can be adapted to explore other phenomena. He provides suggestions for organising and presenting text following phenomenological exploration and, as part of his analysis, advocates the use of four fundamental existential themes that are apparent in the 'lifeworlds' of every human being and argues that these are present regardless of the person's historical, cultural or social background (van Manen 1990).

The four existential dimensions of lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or communality) are used to provide meaning to the data collected in this study on the basis that all are integral to the bereavement experience as introduced in Chapter 1.

van Manen's work links in with the ideology of Heidegger relating to the researcher's interconnectedness with the phenomenon and 'being-in-the-world'. It provides a clear methodological framework that allows the researcher freedom to utilise initiatives within the dynamic process of hermeneutical phenomenological inquiry. van Manen states that phenomenological research 'aims to establish a renewed contact with original experience' (1984, p.40). In this sense he acknowledges Husserls' 'returning to the things themselves' but he places firm emphasis upon the 'lived experience' and the individual experience of the phenomenon in all its dimensions and aspects. The central aspect of van Manen's work is the attempt to understand 'what it is that makes this lived experience what it is' (1984, p.41)

The core aspects of van Manen's phenomenological methodology and philosophical approach are summarised in Table 4 that has been taken from van Manen (1984, p.42).

Table 4.   Aspects of van Manen's (1984) Phenomenological Methodology

A. Turning to the Nature of Lived Experience
1. Orienting to the phenomenon
2. Formulating the phenomenological question
3. Explicating assumptions and pre-understandings
B. Existential investigation
4. Exploring the phenomenon: generating 'data'
4.1 Using personal experience as a starting point
4.2 Tracing etymological sources
4.3 Searching idiomatic phrases
4.4 Obtaining experiential descriptions from subjects
4.5 Locating experiential descriptions in literature, art, etc
5. Consulting phenomenological literature
C. Phenomenological Reflection
6. Conducting thematic analysis
6.1 Uncovering thematic aspects in lifeworld descriptions
6.2 Isolating thematic statements
6.3 Composing linguistic transformations
6.4 Gleaning thematic descriptions from artistic sources
7. Determining essential themes
D. Phenomenological Writing
8. Attending to the speaking of language
9. Varying the examples
10. Writing
11. Rewriting (A) to (D) etc

He acknowledges that there has been little structure to phenomenological research in the past and that it can be seen to be more of a 'cultivated thoughtfulness' than a technique. van Manen (1984) argues that the procedures of his approach outlined in Table 4 allow for a rigorous interrogation of the identified phenomenon. This structure will be considered in detail specifically in relation to understanding the phenomenon of the experience of bereavement.

However, as recognised by van Manen himself, the exact approach is usually determined by the type of phenomenon under scrutiny which can emerge as part of the exploration. This framework provides a recognised methical approach to understanding the phenomenon of bereavement from a religious perspective, through the four existential dimensions of space, time, body and relationships.

2.2.1. A. Turning to the Nature of lived experience

1. Orienting to the phenomenon

The term 'essence' is utilised within phenomenological research, however, it is often used in a nebulous manner. For van Manen (1984), the essence of a phenomenon manifests through its description and an exhaustive description should enable the conceptualisation of the fundamental structure of a phenomenon. The language, for van Manen, is therefore the essential mode through which phenomenon can be unveiled:

> 'When I speak I discover what it is that I wished to say' (1984, p.41)

In the study reported in this thesis, interviews were seen to be a key way of obtaining relevant data. Only through their first hand experiences and unique perspectives could a deeper understanding of the phenomenon of bereavement be uncovered. However, acknowledging the complexity of phenomena, van Manen suggests that it is not enough to simply collect ones' own and others' experiences of a phenomenon but to see the phenomenon from a myriad of differing perspectives; to view and understand it in its entirety.

Although the focus in this thesis was on the bereavement experience of bereaved relatives, others involved in such experiences were also interviewed. Interviews

with doctors, nurses, healthcare assistants and religious leaders provide differing dimensions and layers to the overall phenomenon of bereavement through the eyes and experiences of all those involved. This '360 degree' focus should theoretically therefore, facilitate a more holistic interpretation of the phenomenon.

2. Formulating the Phenomenological Question

'What is something really like?' is the essential phenomenological question (van Manen 1984 pg 44). He advocates that any researcher undertaking research into a particular phenomenon must have a genuine interest in it in order to engage fully in the research process.

Chapter 1 outlined the underlying phenomenon in this thesis which arose from a work related observation of complaints raised by bereaved relatives following the death of a patient in hospital. The phenomenological question was therefore; how do differing perspectives, experiences and beliefs relating to dying, death and bereavement from a religious perspective, impact on the bereavement experience following the death of a person in an acute hospital setting.

3. Explicating Assumptions and Pre – Understandings

van Manen (1984) suggests the need to acknowledge ones' own thoughts and experiences of a phenomenon before exploring it phenomenologically, otherwise there is a risk of dismissively defining it without reflecting on the significance of the deeper phenomenological question:

> 'The problem of phenomenological enquiry is not always that we know too little about the phenomenon we wish to investigate but that we know too much'. (van Manen 1984, p.46)

He suggests the exploration of a phenomenon from all perspectives and asks the question whether a phenomenon can only be applied to certain people or whether the concept can equally be applied to others. For example, his work on parenting not only looks at the phenomenon through the eyes of parents – but also asks questions such as 'what makes a good parent' for anyone to consider, whether they have experienced being a parent or not.

To date the majority of research into bereavement has been undertaken in a few specialist areas, for example palliative care, cancer and spousal loss rather than in an acute hospital setting. The previous analysis of complaints following death in an acute hospital precipitated the study described in this thesis providing both the context and underlying assumptions (see Chapter 1). This has subsequently been supported by the finding reported in the Healthcare Commission report 'Spotlight on Complaints' (2007).

2.2.1 B. Existential Investigation

4. Exploring the Phenomenon: generating 'Data'

van Manen (1984) advocates the exploration of many kinds of data that may provide the researcher with a deeper understanding of the phenomenon under investigation. This may involve the researchers' own experiences, exploration of associated words and terms, art and literature, biographies or stories around the phenomenon and other people's lived experiences. It is important to note that van Manen advocates 'more than' interviewing others. He also explores the significance of the researcher within the whole process and talks of the researcher

needing to have practical wisdom regarding the phenomenon, which emerges from an interest in and experience of the phenomenon.

As Head of Bereavement Care the author was able to draw on thousands of conversations, scenarios, articles, films and scriptures to build on her vision and understanding of bereavement and in doing so inform the phenomenological investigation.

4.1. Using personal experience as a starting point

van Manen (1984) advocates a person's own personal experiences as a starting point for any research, in the assumption that others may have similar experiences. The aim is to provide a description of the phenomenon without adding any explanations or interpretations for it. The context of this work is explained in Chapter 1 and a personal account of the author's bereavement experience that occurred during the writing up stage of this study is outlined in Appendix B. At the onset of this study, the author's own personal experience was 'professional' and the investigation started from a place of dispassionate objectivity. However, as a result of the author's personal bereavement experience during the study, a more compassionate empathic stance became evident during the final stages of this thesis.

4.2. Tracing Etymological Sources

The use of words to explain a phenomenon is scrutinised by van Manen (1984). He advocates distillation down to the 'purest form' to re-establish the true

meanings of the words. Can words fully capture experience? This question had significance for some of the Muslim participants within this study when trying to capture and share extremely poignant and life changing experiences through the medium of a 'second' language. The offer of an interpreter to assist in this description was offered in this study in order to assist those subjects with capturing the right words with similar meaning in English. It may be argued that those who are more articulate in the language used are able to describe their experience more vividly. However the use of language is a skill and an art form often not developed to its full potential in every day life

4.3. Searching Idiomatic phrases

In an attempt to fully uncover the phenomenon, van Manen (1984) suggests close examination of common sayings relating to a phenomenon and tracking back to its original intended meaning. Examples of expressions or sayings relating to dying, death and bereavement may include the following:

- 'Only the good die young'
- 'Time is a great healer'
- 'God's will'
- ' Had a good innings
- 'When your time's up…'
- 'In a better place'

Exploring common phases can uncover their original meaning in relation to the phenomenon of bereavement. These sayings, when broken down may reveal much more about the phenomenon of bereavement than they may seem to contain at first glance.

'Only the good die' young suggests the purest achieving the 'reward' of death and a prized position in paradise sooner than those who may not have led such a good life. 'Time is a great healer' may have emerged in acknowledgement of the bereavement process whereby a progression takes people forward to a time of gradual acceptance of the loss of the person. However, it may also allude to the assumption of previous bereavement theories that advocate the 'letting go' of the deceased and the reinvesting in other relationships. Similarly 'God's will' and 'When your time's up…' and ' Had a good innings' all infer divine intervention, a fatalistic approach to death, and a pre determined finite time for a person to be alive.

Although well intentioned, phrases and sayings such as these may inhibit the bereavement journey as they instruct ways of behaving and conforming socially when a death occurs. They appear to act as dissuaders to people questioning 'why' and subconsciously imply a passive acceptance. Therefore a more detailed and thorough investigation and search for the meaning of non-obvious phrases is important to gain a deeper understanding of the phenomenon of bereavement from a faith perspective.

4.4. *Obtaining experiential descriptions from subjects*

van Manen (1984) suggests that the researcher becomes enriched by the experiences of others:

> 'other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or experience of an aspect of human experience' (p.55)

In order to optimise this enrichment, he advocates the use of taped interviews in acknowledgement that it may be easier to talk face to face about a situation rather than write it down alone. He suggests that the process of writing may force a person to reflect upon their experience more deeply than when engaged in conversation. This act may make it too painful to stay close to their emerging experience of the phenomenon.

This is an important consideration when dealing with emotive subjects such as bereavement and religious faith, as Stroebe (2004) and Stroebe and Schut (1999) acknowledge when they state that oscillation between acceptance and avoidance is already a daily occurrence in a person's bereavement experience. van Manen (1984) argues that using other people's experiences provides the researcher with a vicarious route to developing more experience about a phenomenon and thus becoming more aware of the extent of its significance. However, the focus of the study should always remain on the phenomenon in all its dimensions and not one person's, or one group of people's subjective experience and interpretation, hence the inclusion of a diverse set of participants within the study described in this thesis.

4.5. Locating Experiential Descriptions in Literature and Art

The exploration of art and literature can provide many differing perspectives around the phenomenon of bereavement. All literature includes phenomena such as love, hope, illness, death, grief and faith. Literature, drama and art can be catalysts to the exploration of life situations and their associated emotions from a 'safe' distance. This may be of added significance within modern secular society making visible what has become invisible and acknowledging what has previously been ignored. As a society, the UK today is, in general, death denying. Routines and rituals have changed since the 1900's when it was commonplace to put money aside for funeral arrangements and for people to pay their last respects to the dead in their own homes not in funeral parlours. There now appears to be a paradigm shift and an associated perception that death happens to others, not to us and our own. Today few people have seen a dead body in real life, only through the sanitised vision of a television screen. Therefore death on television, in theatre, on the radio and in literature is all relevant to people's expectations and form part of proxy experiences of bereavement.

5. Consulting phenomenological literature

The exploration of other phenomenological works can, van Manen (1984) suggests, identify where interpretative work in this, or similar areas, has already been undertaken. Alternatively, this can also highlight phenomena that have yet to be explored from a phenomenological perspective. Exploring phenomenological literature, for example, phenomenological research can provide valuable insight into the wealth of ways of analysis, interpretation and emphasis which can be

enriching when arriving at such stages in a person's own research. Only by exploring the differing approaches to phenomenological enquiry can one fully decide upon, and justify the approach most suited to their research. Finally, reading the literature about bereavement theory and personal experiences of bereavement provides a yet deeper understanding of the permutations that make up the phenomenon that is known as bereavement which has been outlined in Chapter 1.

2.2.1 C. Phenomenological Reflection

6. Conducting thematic analysis:

6.1. Uncovering thematic aspects in lifeworld descriptions

'Phenomenological themes are the structures of experience' (van Manen 1984 pg 59) therefore it is such themes that the researcher attempts to uncover. However, he suggests that it is impossible to capture 'lived experience' in conceptual abstracts alone. Such themes are gently but firmly interwoven throughout a person's whole being and therefore cannot be adequately captured by one statement. The use of descriptions of the phenomenon can, however, 'hint at' or 'alllude to' a particular aspect of the phenomenon. Therefore an overlaying of differing statements about one area of a phenomenon can build up layers of perspectives about its meaning.

For example, in reference to the study in this thesis, the dimension of time within the phenomenon of bereavement can reflect time spent with a person, time alive, time dead, time without the person present. All these differing perspectives will

gradually build up a picture of how the dimension of time threads through the bereavement experience. Similarly the dimension of space can refer to the place of care / place of death, perceptions of the environment and its perceived suitability, beliefs around final resting places; the existential dimension of body looks at the caring dimension within dying death and bereavement and the significance of that for the dying / deceased soul and the person providing that care and relationships explores the layers and intricacies of connections and expectations of roles and responsibilities within the relationships that form and overlap during death and bereavement in an acute hospital.

It is important to again acknowledge the limitations that some people may have with their use and depth of language, especially if the person's first language is not English. Therefore the whole 'picture' requires consideration through investigation in order to appreciate the full impact of bereavement on the person. In the context of this study this could, for example, include the relationship, nature and length of illness, acute hospital care, end of life care, religious and cultural requirements and support during the bereavement process in order to fully explore the four existential dimensions.

6.2. Isolating thermatic statements

van Manen (1984) advocates the use of two approaches to uncovering thematic statements, the 'highlighting' approach and the 'line by line' approach. By highlighting significant statements and reading and rereading the data, certain thematic commonalities should appear. The line-by-line approach involves reading

each interview and re writing to highlight emerging themes. Due to the vast amount of data collected and the focus on the four existential dimensions the highlighting approach was utilised in this study. Each transcript was read and themes relating to one of the four existential dimensions of *time, space, body, relationship* were highlighted.

6.3. Composing linguistic transformations

This, for van Manen, (1984) involves a rewording of sentences and statements about a phenomenon in an attempt to uncover further meaning and understanding. For example, 'He meant the world to me' could be linguistically transformed into 'He was my world' or 'without him my world is empty and meaningless'. The gentle transformation of words and sentence can highlight the subtle nuances in meaning and essence of the phenomenon being described. Although acknowledged in van Manen's framework, composing linguistic transformations in bereavement research and attempting to transform the verbal recollections of the bereaved and others, was not deemed to be appropriate for this study.

6.4. Gleaning thematic descriptions from artistic sources

Exploring artistic sources for thematic descriptions is another part of van Manen's framework (1984). For example descriptions of bereavement from Shakespeare though to modern day soaps, all add to an understanding of the 'lived experience' of the phenomenon of bereavement. For the purposes of the study in this thesis this section was seen to link in with, and add a further dimension to section 4.5 of the framework, *locating experiential descriptions in literature and art*.

7. Determining essential themes

Returning to the participant to check the analysis and agree or discard themes is an important component in the analysis process for van Manen (1984), along with the incorporation of the hermeneutic cycle of interpretation, clarification and correction by the participants, and further refined interpretation.

Although noted as an important aspect of data analysis, this aspect to van Manen's method was not utilised in this study primarily out of a concern that returning to participants to clarify the data, may cause unnecessary distress by 'questioning' their person recollections of a traumatic and very emotive event. Furthermore it was the essence of the first emerging thoughts of the phenomenological experience that was of interest to the study rather than the considered and measured response that revisiting the data may provide.

2.2.1   D. Phenomenological writing

Phenomenological description is only an image that points to the phenomenon being described. For example, if the description is powerful enough or close enough to the phenomenon then it can be seen to have a transparency about it which allows the researcher or reader to see or more accurately 'experience' the deeper meaning of the phenomenon. The appropriate use of exemplars or significant statements should allow the person reading the data to catch or feel a glimpse of the phenomenon. For example, when transcribing data following interviews with the bereaved, certain significant statements may unexpectedly trigger a surge of emotion in the researcher, almost a 'lived experience by proxy',

of the raw phenomenon of the person's bereavement experience. van Manen (1984) suggests that special attention should be focussed not only on the data but on the way that the data is presented, for example, the tone of voice and language used, body language and non verbal communication.

He also suggests varying examples of the phenomenon to obtain a holistic view of the phenomenon and all its potential manifestations which can be achieved for example, by the varying perspectives of bereaved relatives from each of the Abrahamic faiths, doctors, nurses, healthcare assistants and religious leaders. All may provide a wealth of data on bereavement from a faith perspective and each recollection provides another dimension to the phenomenon.

Writing and re writing are advocated as an essential process to truly uncover the essences and multi facets of the phenomenon under examination. Although laborious, this process can facilitate a rich awareness and understanding of the myriad of layers and levels of the phenomenon of bereavement from a faith perspective.

Table 5 uses van Manen's framework for phenomenological investigation and exploration and summarises the approach for the study described in this thesis related to the aims and objectives outlined in Chapter 1.

Table 5.   van Manen's framework applied to the study in this thesis

	Religious beliefs from scriptures	Bereaved 'relatives'	Healthcare professionals and religious leaders
Turning to the Nature of Lived Experience			
Orienting to the phenomenon	Identifying religious beliefs on life / death, bereavement ritual and its meaning	Exploring Bereavement theory	Exploring personal and professional aspects of bereavement
Existential investigation			
Exploring the phenomenon: generating 'data' using personal experience and obtaining experiential descriptions from subjects	Looking at the scriptures for guidance on meaning and ritual in bereavement	Listening to the bereavement experience to capture key essences of the experience	Listening to the experience to capture key essences of experience
Consulting phenomenological literature	Reading phenomological literature and studies relating to qualitative research	Identifying core components of bereavement reading personal acccounts	Identifying core components of bereavement
Phenomenological Reflection	Taking time to reflect on the meaning or essence of bereavement	Reflecting and exploring the significance of religion in bereavement	Reflecting on the impact and meaning of the death of a patient to healthcare professionals professionally and personally
Conducting thematic analysis			
Uncovering thematic aspects in lifeworld descriptions, and isolating thematic statements	Identifying themes in the data in relation to religion within van Manen's four existential dimensions of time, space, body and relationships	Identifying themes in the data in relation to bereavement within van Manen's four existential dimensions of time, space, body and relationships	Identifying themes in the data in relation to personal and professional experiences of bereavement and religion within van Manen's four existential dimensions of time, space, body and relationships
Writing and Rewriting	To uncover key components of the core phenomenon relating to previous knowledge and understanding and its ultimate impact	To uncover key components of the core phenomenon	To uncover key components of the core phenomenon

2.3   Conclusion

The historical development of phenomenology with its different interpretations and approaches provides an understanding of its overarching aims: to explore the essences of a given phenomenon and to explore the impact of a phenomenon on an individual. It has also identified the core concepts of the individuals who established phenomenology as a research methodology in the 19th century in an attempt to understand their main aims and processes.

Therefore a phenomenological approach was deemed to be the most appropriate and van Manen's framework (1984) the most applicable for capturing and analysing data from a relatively unexplored perspective of 'religion and bereavement'. It allows for the flexibility to incorporate fundamental aspects of Husserl's and Heidegger's phenomenology in order to fully explore both the phenomenon itself and its impact on the individuals it touches.

van Manen's approach allows for the acknowledgement of 'other' influences to be explored in a more systematic framework and within the elements of time space, body and relationships. This acknowledgement of interconnectedness and 'situation' facilitated the grounding of the phenomenon of bereavement in the setting of acute hospital and how that impacted on the bereavement experience from a faith perspective.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

This chapter will focus on the research design and methodology including data analysis employed in this thesis. It will begin with a review of the literature that provided the background to the eventual subject selection

3.1   Who participates in bereavement research?

With an emotive subject such as bereavement it is of relevance to the reliability and validity of bereavement research to understand who has participated in bereavement research, how they were selected and whether they were representative of the bereaved population as a whole in order to inform the study that was undertaken in this thesis.

Relatives

Stroebe & Stroebe (1989) looked at participants in bereavement research studies and questioned how representative they were of the 'bereaved population' in general. They offer the observation that if those that participate are the least distressed then we may be underestimating the impact of bereavement, and if they are the most distressed then the impact of bereavement in general may be overestimated. They state that, of the many studies carried out in the area of bereavement, little criticism has been directed to the way in which samples for these studies have been identified and recruited.

Parkes (1995) in his guidelines for conducting ethical bereavement research suggests that protective barriers are erected by self-appointed 'guardians' of the bereaved, who may be relatives, hospital staff or religious ministers. These

blockades prevent researchers accessing the whole of the bereaved population and force them to use non-random methods of sampling. These barriers are acknowledged by Sque (2000) in her reflections on researching the experiences of the bereaved. She suggests that recruitment rates to bereavement research can also be influenced by the following factors:

'Ethical considerations limit some research in view of the assumed distress that most bereaved people experience. Sample recruitment of the bereaved can be problematic. Samples are typically low, with response rates of 50%. It is likely that recruitment rates are affected by a number of factors that may include: the level of distress experienced by participants; the 'loss effect' or negative impact of bereavement on health and mortality, the need to talk, the willingness to discuss the loss (particularly with strangers); the general ease in communicating with other people, especially about such a profoundly and, probably, painful event; and the willingness to 'drag it all up again.' (p.24)

Sque (2000) addresses some important considerations for bereavement research but fails to acknowledge the diversity of the bereavement experience and the impact and influence that culture and religion may play at such times.

In bereavement research there appears to be an over simplified representation of the 'bereaved', reduced to a homogenous group. Whilst the outer 'obvious' layers are explored through the bereavement process and associated relationships and bonds with the deceased person, the core unique and individual religious/cultural essence of the experience is overlooked. There appears to have been a reluctance to explore a person's religious and cultural belief system at times of bereavement. However, it could be argued, such questioning is no more intrusive than the questions asked about the death of a loved one in existing bereavement research.

The majority of bereavement studies have involved participants from western society / culture where the predominant religion is Christianity. Although diversity

and equality are acknowledged as being important nationally in healthcare, a significant percentage of minority ethnic groups in the UK are excluded from bereavement research. However, as Chapter 1 has outlined, these minority ethnic groups will follow faiths such as Islam and Judaism where there are significant end of life religious requirements with the potential to impact on the bereavement journey which could bring a whole new perspective to bereavement research.

The Centre for Advancement of Health (2003) in their review of bereavement literature, suggest that:

> 'Research and conceptual work are needed to develop clearer frameworks for understanding the diversity and complexity of grief and bereavement research, both within a larger cultural context and with awareness that normal grief takes many forms' (p.75)

Inherent within this suggestion is that more research is required to expand on existing theories and concepts of bereavement in order to fully explore and understand the spectrum of 'normal' bereavement experience and grief reaction of people from all faiths and cultures.

Doctors / nurses and healthcare assistants

The views and experiences of doctors, nurses and healthcare assistants on bereavement or religious and cultural needs at end of life have not been widely researched in the area of bereavement but several studies have examined their perceptions of, and responses to, the death of a patient. However, the focus of the majority of the research undertaken to date, as the following examples will demonstrate, is not on the doctors, nurses and healthcare assistants as individuals but on certain aspects of their role and responsibilities

Boyatiz *et al* (2003) carried out a study in Australia with medical consultants and post graduate specialists in geriatric care. They found that the participants, although medically trained and with experience of a wide range of healthcare provision, expressed feelings of inadequacy when dealing with the bereaved and failed to acknowledge their responsibilities in the extension of their care to the acutely bereaved.

Ferris *et al* (1998) studied junior doctors' responses to the death of a patient and also found that the doctors perceived their care to cease immediately or soon after their patients' death. Research by Ellinson and Ptacek (2002) on doctors' interactions with relatives uncovered a distancing at death by doctors and a general lack of regard for the bereaved.

A major study conducted by Kuupppelomäki in 2000 included patients, relatives and healthcare professionals and examined attitudes toward death as well as opinions and beliefs after death and primarily focused on cancer in both acute and community settings. Semi structured interviews were recorded and content analysis performed.   The emphasis of the study was placed on relative, not patient, experiences and was seen to be retrospective not prospective. The data revealed that most interviewees were not afraid of death; the professionals interviewed appeared to be slightly more afraid of death than the patients and family members. Most subjects believed in God and life after death and the doctors in the study differed from the other groups as they appeared to read less literature on death, had less faith in God and in a life after death.

Kuuppelomäki (2000) concluded that the continuous presence of death in the work of health care professionals provides an important area of research surrounding perceptions of and reactions to, death and suggests that this should be the subject of further studies. She also suggests that research in this area may assist health care professionals' understanding of patients' perspectives through an increased self-awareness.

Fallowfield (1993) in a study of doctors' communication skills when breaking bad news explored the possibility of the detrimental effect on the bereavement journey for bereaved relatives if the bad news is not broken in a competent manner and recognised that it may be equally stressful for the person imparting the bad news. However despite this recognition the focus has been on improving communication skills in medical education and training rather than on more research to understand the experience and impact on the individual.

None of the research outlined has directly explored the experiences and responses of healthcare professionals to patients and relatives of different religions faiths and cultures.

Religious leaders

The role of the hospital Chaplain at times of death dying and bereavement within an acute hospital has not, to date, been researched in depth. Traditionally the role of the hospital Chaplain has been that of ministering to the sick, and to dying patients and their relatives (Finlay 2003). However, the impact that administering

such emotional care may have upon them as individuals has not been explored.

This summary of who participates in bereavement research has illustrated the paucity of information that exists in the literature with a focus more on responses to the circumstances surrounding a death rather than on experiences relating to the whole phenomenon of dying, death and bereavement. It indicates the need for more individualised research studies and a thorough examination of impact and how it can be addressed

3.2   Research design for the studies undertaken in this thesis

As outlined in Chapter 1, the aim of the study described in this thesis was threefold. Firstly, to explore the Abrahamic faith perspectives of dying and death in order to gain an understanding of end of life requirements and their significance within the bereavement experience. Secondly, to uncover the 'lived experience' of bereavement following the death of a loved one in an acute hospital setting from the perspective of the bereaved, and through the peripheral experiences of doctors, nurses, healthcare assistants and religious leaders and finally, to determine the impact of the phenomenological exploration on policy and practice.

The literature reviewed highlights a lack of research and, therefore, insight into faith considerations at end of life and during bereavement. Consequently, this study sought to focus on bereavement from a multi faith / multi cultural perspective

through the medium of the Abrahamic faiths. Seeking to understand the core essences of bereavement is a challenging task as the impact and emphasis of bereavement is different for all those involved and ultimately affected.

In aiming to explore the experience of bereavement this study sought the views of bereaved relatives with first hand experience of the loss of a relative within an acute care setting, the views and experiences of healthcare professionals (nurses and doctors) who care for the dying / deceased patient and their relatives, and religious leaders (including hospital Chaplains) who offer religious guidance to both the dying and the bereaved.

This study has been set within a phenomenological framework, the background and approach having been outlined in Chapter 2. Phenomenology aims to obtain an understanding of the 'lived experience' of the individual and / or a deeper understanding of the phenomenon itself (van Manen 1984). The primary aim of a phenomenological approach is to uncover the minutiae of the experience as it impacts upon the individual, not to conduct large research studies to be extrapolated to society as a whole. In seeking to identify the meaning attributed to the phenomenon of bereavement from the perspective of the 'lived' experience of individuals, van Manen's overarching philosophy of phenomenological enquiry was used as the framework for this study. This enabled the phenomenon to be considered in four existential dimensions: lived time, lived space, lived body, lived relationship to others, providing an overview and structure to the data collection and enabling comparisons to be made both within individuals and groups.

A full ethical submission was made to the South Birmingham Research Ethics Committee in 2003 outlining the purpose of the research and the proposed methodology. Approval was granted and the study given the following unique identification number LREC 0842 / RRK 2145.

3.2.1 Identifying participants

Sample sizes are usually small in most qualitative research including phenomenology. Sandelowski 1986 and Morse 1989 recommend that in phenomenological research, an optimum number of six participants should suffice. Utilising this guidance, at least six participants were recruited to the following three groups:

a) Recently bereaved relatives from the Jewish, Muslim and Christian faiths.

b) Hospital doctors, nurses, and healthcare assistants who had experienced caring for dying patients from the Abrahamic faiths within an acute hospital setting.

c) Religious leaders from each of the Abrahamic groups who were either hospital chaplains or community leaders who provided religious care for the dying and the bereaved within an acute hospital setting.

The bereaved

Participant inclusion / exclusion

Potential participants who were relatives of people who had died in the hospital were identified via the bereavement care database held in the hospital. Relatives

identified as next of kin for a deceased patient were highlighted as possible participants on the basis of the following criteria:

a)   Their deceased relative was identified as belonging to either the Christian, Jewish or Islamic faiths.

b)   That their relative's death had occurred in one of 2 hospital sites in the Trust in which the study was being undertaken.

It was anticipated that the bereaved relative would be of the same faith as the deceased person. This was found to be the case for all the bereaved relative participants in this study. As the study's primary focus was on the individuals 'lived experience' of bereavement it was not essential that the bereaved relatives were 'practicing' their faith, but that they had a generic understanding of their faith requirements at end of life and bereavement. Relatives who had been bereaved for less than six months were not invited to participate in the study. Although there are no defined time frames for participation in bereavement research, the focus of this study was on the bereavement experience and journey, therefore a degree of reflection over a period of time was required.

Exclusion criteria also included bereaved relatives who had submitted a formal complaint to the Trust following the death of a relative. Whilst acknowledging the potential wealth of experience this group could contribute, they were not invited to participate. This centred on the possibility that a letter of invitation to participate may add to their distress and that a profoundly negative experience may bias the data.

Recruitment process

Once potential participants had been identified from the database an information pack (Appendix C) containing a letter of introduction, an outline of the study; a letter of acceptance to consider participating in the study; a list of support agencies and their contact numbers and a pre paid envelope was sent out to identified relatives. The letters of invitation were translated into Urdu, Bengali and Gujarati in acknowledgement that some Muslim relatives may not be literate in written English. Whilst acknowledging that some participants may be able to speak, but not read their first language ('mother tongue') it was felt that the translation of transcripts would be seen to be an inclusive gesture that might assist people of the Islamic faith in their decision to participate in the study. The letters noted an offer of an interpreter and an open invitation for relatives to accompany the identified bereaved person should they wish.

The recruitment to the study for all groups of participants was time staged to ensure that all who expressed an interest in participating could be included, and also to allow for 'snowballing' to occur. The letters of invitation were sent out in batches of ten to gauge the response rate and ensure that adequate numbers were recruited and in recognition that the 'snowballing' technique can occur within purposeful sampling when people are recruited by word of mouth or by recommendation (Polit and Hungler 1991). To further facilitate recruitment to the study the research was highlighted in the Trust newsletter and at the yearly memorial services for bereaved families and friends.

Recruitment challenges and solutions

Parkes (2000) suggests that there will be self appointed bereavement 'guardians' who will attempt to protect the bereaved from further distress. Whilst this may cause difficulty in recruiting for such studies their altruistic motives should be acknowledged. In light of this the Parkes and Weiss (1983) checklist for ethical criteria that bereavement research was adopted to ensure that risk of distress to bereaved participants was minimised, as outlined in Table 6.

Table 6.   Ethical criteria checklist for bereavement research (taken from Parkes and Weiss (1983)

1		All research proposals will be approved by a properly constituted ethics committee
2		All bereaved people who are invited to take part in research will receive a document that:
	a	Explains the purpose and method of the research to them
	b	Reassures them of the qualifications and good faith of the researcher
	c	Informs them that the research has been approved by a particular ethics committee
	d	Identifies the organisation under whose auspices the research is conducted
	e	Introduces any person who will contacting them to arrange an interview
	f	Explains the precautions that will be taken to ensure their anonymity in any publication or reports
	g	Assures their right to withdraw from the research or to ask for recording equipment to be switched off at any time
	h	Invites them to sign one copy of the document (to ensure that the document has been read).
	i	The individual who is to interview bereaved people for the purposes of research will have received sufficient training in counselling to ensure that he or she will do no harm. The interviewer will receive regular supervision of his / her work from someone with advanced level training.
	J	Out of courtesy, the project officer will write a letter of appreciation and thanks to all respondents

It was acknowledged from the outset that one of the main challenges for this study would be the ability to recruit people from the Jewish and Muslim faiths both because of the small number of possible recruits given the relative number of deaths as indicated in Table 1 (Chapter 1) and a potential reticence to participate because of possible concerns about the nature of the study.

In the event this potential concern was realised in a lack of initial responses to the letters sent out to relatives within the Muslim community. In light of the non-response, discussions with Muslim colleagues from within the Trust and external religious leaders were undertaken to explore alternate ways of recruiting participants for the study. They agreed to act as advocates and approach potential participants to explain the reasons for the research and, as needed, to provide reassurance about the purpose and aims of the study. This approach succeeded in the recruitment of six Muslim participants.

Similarly, there was an initial poor response from the Orthodox Jewish community. The Administrator for the Birmingham Hebrew Congregation (who was also Head of the 'Chevera Keddisha', the Orthodox Jewish Burial Society responsible for the coordination of every orthodox Jewish funeral in the area) was contacted for advice. Similarly, he was able to act as advocate and explain the aims of the study to potential orthodox Jewish participants and as a result six individuals from the Jewish community agreed to participate.

It is acknowledged that this process exposed the subjective recruitment of participants and the presence of community group 'gate keepers'. However there was a need to recruit people who would be able to fully participate without undue risk and therefore guidance was taken from those who had both knowledge about the situation of the potential participants and who were able to act as intermediaries and outline the purpose of the study to prospective participants. This is not unusual when undertaking research work that extends beyond the researchers' cultural peer group.

Acceptance to participate

Relatives who wished to participate in the research sent back the 'agreement to consider participating in the research' slip in the pre paid envelope along with a contact telephone number. They were then telephoned, thanked for agreeing to consider taking part and provided with further information about the research. If, following this telephone conversation, they verbally agreed to take part in the study, a date and time for the interview to take place was agreed. Participants who after discussion declined to participate were thanked for their time and interest in the study. Once the first six in each faith groups had agreed to take part, recruitment stopped.

Recruitment of healthcare professionals (nurses, healthcare assistants and doctors)

The acute hospital in which the study was undertaken employs approximately 7,000 staff. Doctors were enlisted into the study via information placed in the

bereavement care offices, articles written in the hospital magazine and by word of mouth. A total of seven doctors expressed an interest in the research and were given an outline of the study and provided with an information pack for health care professionals (Appendix D).

A similar model of recruitment was adopted for nurses and healthcare assistants, but in addition to recruitment was also sought via bereavement link nurse meetings, which were attended by nurse and healthcare assistant representatives from every ward and department where issues pertaining to bereavement care were raised and discussed. A total of eight nurses and healthcare assistants expressed an interest in participating and were given the information pack for health care professionals (Appendix D).

In relation to the inclusion and exclusion criteria for the study the recruitment of doctors, nurses and healthcare assistants was not faith specific. This was because the impact of caring for a dying/ deceased patient and their relatives within a faith context was the primary focus of their involvement, not their own religious affiliation. However, the impact that the death of patients had on them personally and their personal beliefs were also important considerations. Although religious affiliation was not a direct question, within the interviews each healthcare professional freely offered their religious allegiance (or non adherence to religion). An exclusion criterion for staff was if they had experienced a personal bereavement within the past six months, however, none of the participants had

done so. Seven doctors and eight nurses / healthcare assistants were finally recruited to the study.

Recruitment of religious leaders

Religious leaders from the Abrahamic faiths were recruited to the study through the hospital's Chaplaincy department and from religious contacts with local minority ethnic groups. A total of nine religious leaders participated in the study, five from the Christian faith, two from the Islamic faith and two from the orthodox Jewish faith. Religious leaders from other faiths were not included in the study.

Summary of participants

Table 7 summarises the individuals who were recruited to the study and, for bereaved relatives, contains information relating to age, gender, relationship to the deceased and approximate time since death. Similar data is included as relevant for the nurses and healthcare assistants, doctors and religious leaders.

It was not felt appropriate to ask each participant their age but the age of each participant was approximated within a decade and noted here. The reason was to provide a guide to understanding of the breadth of ages of the participants and serves to highlight the potential variation in viewpoints which may be associated with age and experience.

3.2.2 Collecting the data

Utilising phenomenology as a research methodology facilitates the close examination of the 'lived experience' of a person in a particular situation or episode of time. Within this study participants were asked to recount very emotive episodes of their life. Relatives were requested to narrate the moment their mother, father, partner, child became ill and died. Doctors, nurses and healthcare assistants were asked to relive very difficult and emotionally charged episodes of time with patients and their relatives and, inevitably, to reflect on their management and care with associated feelings of responsibility and accountability. Religious leaders were given the opportunity to reflect upon their role at times of dying, death and bereavement and to share the impact that such situations may have on them as individuals.

Table 7.   Summary Table of Study Participants.

Christian relatives	Age	Sex	Deceased	Approximate time since death
C1	60's	M	Wife	9 months
C2	30's	F	Mother	9 months
	20's	F	Mother in law	9 months
C3	78	F	Husband	15 years
C4	40's	F	Mother	8 months
C5	40's	F	Father	7 months
C6	40's	M	Common law wife	10 months
Jewish relatives				
J1	70's	F	Mother	2 years
	40's	F	Grandmother	
J2	60's	M	Mother	1 year
J3	50's	M	Mother	2 years
J4	40's	F	Father	4 years
			Mother	2 years
J5	60's	F	Father	2 years
J6	60's	M	Father in law	18 months
Muslim relatives				
M1	50's	M	Mother	1 year
M2	60's	F	Mother	10 months
M3	40's	M	Organiser of funerals	N/A
M4	20's	F	Grandmother	2 years
M5	50's	M	Father	20 months
M6	40's	M	Mother	8 months
		F	Mother in law	
Doctors	**Age**	**Sex**	**Religion**	**Grade**
D1	30's	M	Hindu	Registrar (medicine)
D2	20's	F	Christian	Pre Registration House Officer
D3	30's	M	Muslim	Registrar (anaesthetics)
D4	20's	F	Jewish	Senior House Officer (medicine)
D5	30's	M	Muslim	Registrar
D6	20's	M	Christian	Senior House Officer
D7	40's	M	Muslim	Consultant
Nurses and healthcare assistants	**Age**	**Sex**	**Religion**	**Grade**
N1	30's	F	Christian R/C	R.G.N 'E' grade
N2	50's	F	Christian R/C (Irish)	Health care assistant
N3	30's	F	None	Modern Matron 'H' grade
N4	40's	F	Christian 'born again'	Sister 'G' grade
N5	20's	F	Christian C/E	Health Care assistant
N6	40's	F	None	Health care assistant
N7	40's	F	Christian	Sister 'G' grade
N8	50's	F	Christian	Health care assistant
Religious leaders	**Age**	**Sex**	**Religion**	
RL1	60's	M	Christian R/C	
RL2	50's	M	Christian Baptist	
RL3	60's	M	Christian Anglican	
RL4	40's	M	Muslim	
RL5	40's	F	Muslim	
RL6	50's	M	Christian R/C	
RL7	60's	M	Christian Franciscan	
RL8	60's	M	Orthodox Jewish	
RL9	60's	M	Orthodox Jewish	

The most fundamental ethical principles of research, beneficence and non maleficence (Eddie 1994), which encompass the saying 'do no harm' were uppermost at all times. It was recognised that in research of this kind the interview may trigger dormant or repressed feelings and emotions that may leave the participant swamped and powerless. As Coyle and Wright (1996) state:

> 'It is ethically questionable for researchers to address sensitive issues without being equipped to deal with resultant distress.' (p.431)

The potential anxieties that may be shared by the interviewees were an extremely important consideration as the study was exploring peoples' lived experience of very personal and emotive events. In acknowledgement of the potential distress that this study may evoke the services of local support agencies such as Cruse Bereavement Care and the Samaritans were secured to ensure that, if necessary, all participants would have access to their services.

In light of such a sensitive topic area, it was appropriate that the data collection was undertaken utilising counselling skills to elicit as much data as possible, but within a framework of mindfulness of the potential distress that such exploration could evoke. Sque (2000) reinforces the benefits of the interviewer utilising counselling skills in her article 'Researching the Bereaved: An Investigator's Experience' and reflects that:

> 'Counselling skills were important in the interview situation, such as the art of listening, paraphrasing, reflective summarising, and using open questions.' (p.27)

Coyle and Wright (1996) also suggest the use of counselling skills in in-depth interviews and state that utilising such skills allows the interviewer to 'create conditions in which the interviewee can derive therapeutic benefit' (p.434). However, it was important that the interview did not become a counselling session

but it was made clear that if the participant wished to receive counselling, details of appropriate organisations would be provided.

Specific considerations within each participant group will now be outlined.

Relatives

The use of bereaved relatives for research purposes poses difficulties. Parkes (1995) refers to 'gatekeepers' of the bereaved, who have the potential to over protect and erect barriers which prohibit the bereaved from participating research

> '..guardians (of the bereaved) are right to be cautious …but they often err on the side of being overzealous, depriving bereaved people of the opportunity to help with well founded research and forcing researchers to make use of non random methods of sampling….(p.172)

However, Parkes (1995) suggests that although the newly bereaved are vulnerable those who are not ready to talk will decline the invitation to take part, and those who do take part leave with an altruistic sense of purpose.

The experiences of relatives whether positive or negative, once heard, cannot fail to impact on others. This may be reassuring for others with the knowledge that they are not alone in their bereavement experiences, alternatively, this may influence change in those providing care at the end of life in such a way to help those facing the experience of bereavement.

Doctors, nurses and healthcare assistants

The research interview provided an opportunity for doctors, nurses and healthcare assistants to discuss difficult and emotional situations they had experienced, within a safe environment, without judgement or comment. Many of the nurses,

healthcare assistants and doctors became distressed whilst recounting their experiences of attempting to save a life or allowing a peaceful death. Re enactment of the situation was quite common with the staff 'acting out' resuscitation events and death scenes.

Religious leaders

The interview situation allowed the religious leaders' experiences to be voiced and their unique experiences to be told.

Researcher

One other view that is often overlooked is that of the researcher/ interviewer and the impact that undertaking research of a sensitive nature may have upon them. Rowling (1999) discusses the affect and role of the qualitative researcher in loss and grief research, within an academic setting, and suggests that the impact is overlooked, in a throwback to the positivist position of presumed detachment between researcher and participant apparent in the paradigm of traditional quantitative research. She suggests that the emergence of unanticipated emotive data in interviews of this nature can leave interviewers vulnerable. Detachment in these instances is impossible, due to the unpredictability of the emergent data and its significance within the researcher's frame of reference. Prior to undertaking this study the researcher had worked as a bereavement counsellor and been in very emotive situations with relatives on wards in a role as a nurse and ward sister, and with acutely bereaved relatives in the bereavement office. However, the support of

a counsellor / supervisor was enlisted who agreed to talk through, within the realms of confidentiality, any situations that were found to be overtly distressing.

3.2.3   Conducting the interviews

The study was conducted within an acute hospital setting. The hospital has a research facility that offered a location for undertaking research interviews. This venue was away from the main body of the hospital and had a neutrally decorated, private sitting room. Therefore for ease of access and neutrality, the majority of interviews with doctors, nurses, healthcare assistants and hospital chaplains took place in this facility However, early on in the data collection, it became apparent that researcher flexibility was of paramount importance to facilitate the collection of as much data as possible. As the research facility was closed at weekends the hospital bereavement care office was also used as a venue for a small number of interviews to take place, outside office working hours. The office was made 'presentable' to support a relaxed interview environment.

A number of bereaved relative participants did not wish to return to the hospital. This reluctance had both emotional and practical components which included a reluctance to return to the place where their relative had died; lack of transport; difficulty and cost of car parking and petrol; train or bus fares (although reimbursement for travel was offered); being in full time employment and therefore not available during the day and a preference to remain in the comfort of their own home. Therefore several of the interviews with relatives were conducted in their own home at a time convenient to them. The religious leaders external to the

hospital were interviewed at their place of choice that was commonly their place of worship.

In qualitative research, the use of interview is the most appropriate approach to explore the unique experiences of the participant. Although there are three main types of interview that can be employed in qualitative research, in general researchers use semi structured interviews in order to gain a detailed picture of participants' beliefs about or perceptions or accounts of a particular topic to allow them to recount their experiences freely and in their own words thus providing individualised and unique data. Smith (1995) suggests that the researcher may have a set of questions to ask but suggests that there should be flexibility in whether, and how, these are used in the interview. Indeed he states that the interviewer should be guided by the interview schedule rather than dictated by it:

> 'it is quite possible that the interview may enter an area that had not been predicted by the investigator but which is extremely pertinent to, and enlightening of the projects overall question. Indeed these novel areas are often the most valuable, precisely because they have come unprompted from the respondent and, therefore, are likely to be of especial importance for him or her'. (Smith 1995, p.233)

Both Sque (2000) and Jasper (1994) advocate the need for practicing interview and discussion techniques in order to avoid the researcher contaminating the data.

Smith (1995) acknowledges the need to capture as much relevant data as possible and states that the interviewer should have an idea of the area of interest and some initial focussed questions on the phenomenon to pursue as well as an understanding of the potential difficulties that may be encountered. This was an important consideration in relation to the phenomenon of bereavement and the possibility that participants may find it difficult to initially talk about their

experiences. A broad schedule was therefore drawn up for the interviews in this study which focussed on the aims of the study and the nuances in the anticipated experiences within the participant groups (Appendix F).

The majority of interviews took place as suggested by Smith (1995) in the presence of only myself (as the researcher) and the participant. However three did not for the following reasons:

- For participants of the Islamic faith, whose first language was not English, an opportunity was given to have a female interpreter present. One female Muslim participant utilised this service for her interview.

- A Christian participant suggested that the rest of his immediate family (5 members) would like to participate in an interview to provide their recollection of events. Therefore interview (C2) involved the identified participant with other data from family being noted to inform context.

- An elderly Jewish lady requested that her daughter be present for support.

All of the interviews began with an explanation of the research and discussion about confidentiality. An agreement was made that the interview could be stopped at any time without any future implications for the person. Once this had been clarified written consent was obtained.

As the interviewer, the effect of the interview on each of the participants was monitored both in terms of verbal and non-verbal responses, to check that the participants were not becoming unduly distressed.

Interviews with relatives

The interviews appeared, for the most part, to have a cathartic effect on the relative participants. Recounting times when the person was well through to the terminal events of their loved one enabled them to tell their story, without fear of judgement, comment or fear of upsetting people.

Relative participants were asked if they could share a little about what had brought their relative into hospital. This provided a background to the event and also helped to settle the person in to the interview situation. Each relative participant was then asked if they could recount what happened at the time of death and afterwards. This was in an attempt to ascertain their thoughts and feelings regarding their needs and those of their relative at that time. Although most relatives appeared hesitant and concerned that they were able to give the 'right' information to begin with, once they started to recount their experience they rarely needed prompting to continue. Occasionally there would be a need to gently guide them back to the area being explored.

Interviews with healthcare professionals: Doctors, nurses and healthcare assistants

The interviews also appeared to have a cathartic effect for doctors, nurses and healthcare assistants, but in a more 'objective' way. A tentative explanation for this may be in recognition that, whilst for relatives their experience was a once in a lifetime loss, doctors, nurses and healthcare assistants had an awareness that they would encounter other situations leading to bereavement in their daily work.

The professional experiences of caring for dying and deceased patients of differing faiths along with what they felt was important for patients and their relatives at this time, were subjects of discussion for the doctors, nurses and healthcare assistants. This was in addition to their personal experiences of caring for dying and deceased patients and relatives and how it impacted on them as individuals.

Interviews with religious leaders

The interviews with the religious leaders incorporated discussion around what their role was perceived to be, from their personal perspective and others' expectations of them. Their personal experiences and reflections upon being called to a situation involving the death of a patient and relatives' bereavement was also a key part of the interview. Their beliefs in an afterlife, Heaven and Hell and preparation in this life for the one beyond were also explored in relation to religion and the bereavement process.

3.2.4 Confidentiality

The concept of confidentiality is an important consideration in any study and implies that the sources of the data will only be known by the researcher (Behi and Nolan 1995). All participants in the study were informed that the data collected would be kept in a secure cabinet and would be analysed. It was noted that another nurse researcher would help with the process to inform the analysis and the research supervisor would see the transcripts. Reassurance was given that participant's details would be anonymised to ensure that only the researcher would

know the identity of each participant. All participants were informed that, following the completion of the research all data would be destroyed.

The fact that confidentially would be maintained was accepted without discussion by the relatives. Several stated that they did not mind who knew or read about their experience if, by doing so, it would help research into bereavement and others in a similar situation. Despite this, the standard of confidentially was maintained uniformly throughout.

Confidentiality was also a very important consideration for the doctors, nurses, healthcare assistants and religious leaders who participated in the study. It was important, to the majority of them, that the information they disclosed was kept secure and that any discussion surrounding the research was anonymised. The importance of this was expressed as a concern that other colleagues may hear their stories and pass judgement on them. Two healthcare professionals, for example, noted specific difficulties associated with their experience of caring for the dying. This included a need for counselling and expressions of concern about the behaviour of others at the time of the death of a patient. Both professional groups and clergy shared deep emotions and vulnerabilities which needed to be handled sensitively in the study and confidentiality was key to this.

Munhall (1989) suggests that the need to show accuracy of data must be balanced with the preservation of the privacy of the participant. Indeed qualitative research has a moral implication as outlined in the Declaration of Helsinki (1964). Cowles

(1996) looked at several concerns that may occur in qualitative research which included awkward or embarrassing behaviour by the participant such as silence, anger, excessive crying. Cowles also outlines concerns regarding the researcher which include an over identification with the subject's loss, a loss of composure, and an inability to control personal reactions to emotive disclosure. As indicated all of these were duly noted within the study.

3.2.5 Data recording and transcript

All interviews were recorded on a Mini disc. At the end of the interview participants were thanked sincerely for their valuable contribution. A short informal conversation with the interviewee at the end of the interview provided an opportunity to identify whether they were unduly distressed, had unresolved issues and/or they required access to the range of support mechanisms available. A hand written, personalised card was sent to each participant thanking them for taking part and reinforcing the importance and significance of their contribution to the study. Each participant was offered a summary of the study once the study had been completed.

Once the data had been captured and recorded from the participant interviews it was transcribed verbatim into a microsoft 'word' document. The transcription of each interview was time consuming, with a one hour interview taking between six to ten hours to transcribe, even longer if the participant's first language was not English as accents occasionally obscured words requiring careful listening and re listening to the tapes.

One third of the interviews were transcribed by myself and the remainder by an experienced (post doctoral) researcher, who agreed to be bound by the rules of confidentiality. The transcripts were then analysed to capture the individual 'lived experience' of each participant, similarities and differences between the groups of participants and the core 'essences' of the phenomenon of bereavement as described by all of the participants.

3.2.6 Data analysis

As outlined in Chapter 2, van Manen's (1984) phenomenological methodology and the existential dimensions of time, space, body and relationships in relation to the bereavement experience were utilised to both investigate and explore the phenomenon (Chapter 2, Table 4 and Table 5).

The transcripts were read and re-read with each reading uncovering new meanings so that essential themes were captured. In order to fully recapture each interview experience each taped recording several times, was re-listened to with notes made on the inflections, hesitations, and audible distress and on the tone and language utilised. Each interview was constantly reflected upon visualising the participant within the interview setting. Reflecting back over notes made immediately after each interview also provided a more rounded recollection of the interview. The transcript was treated as whole data at this stage therefore nothing was left out or highlighted as requiring special attention.

Emergent themes were identified and were tentatively organised into van Manen's four existential dimensions of time, space, body and relationships (van Manen 1984). These four existential dimensions appeared to capture the main universal essences of the phenomenon of the experience of bereavement within them. Within these broad categories sub categories emerged and these were interwoven into a narrative which gave a both a structure and 'flow' to the experiences of bereavement in relation to each of the main themes.

Due to the uniqueness of each individual experience, differing nuances within the four existential dimensions emerged throughout the interviews with the participants. van Manen (1984) suggests that a phenomenological description is always just one interpretation and that no single interpretation of human experience will ever exhaust the possibility of yet another complimentary or even potentially richer description. Therefore further interviews with more participants may have uncovered yet more aspects to the phenomenon of bereavement. It was not possible to explore this further as a larger, more diverse participant group was beyond the scope of this study.

Within phenomenological research, a very close relationship between the researcher and the data evolves as they attempt to uncover and understand what the person is expressing. There is also a need to utilise the researcher's interpretative resources to create some order and sense from the concepts and ideas extracted from the participant's responses (Smith 1996). van Manen (1984) also suggests that phenomenological research is the attentive practice of

'thoughtfulness', not just about the phenomenon itself, but about the experience of the phenomenon and its impact on the individual.

To address this as indicated, the data were categorised using van Manen's four existential dimensions of time, space, body and relationships. van Manen suggests that there are two approaches towards uncovering thematic aspects of a phenomenon in text, the highlighting approach and the line by line approach Here, the highlighting approach was deemed to be the most appropriate to draw out key issues pertaining to bereavement. Significant statements relating to one of the four existential dimensions of time, space, body and relationships were highlighted in all of the transcripts. These were then placed in four separate files relating to the four dimensions. Each of these file's contents was then read and re-read to gain an emerging sense of 'flow' to the data within the four dimensions, from the perspective of the lived experience of bereavement and are considered below.

Time

The dimension of time emerged through the concepts of times 'past', looking back to happier times when the person was well, times 'present' where the focus was on the person's illness and death; and 'future' where the focus was on a loss of dreams and a reorganisation of life without the physical presence of the person. Anticipation of the impending death along with associated planning and preparation for a life without the physical presence of the dying person were also emergent sub themes. Time in relation to a person's experiences of bereavement and time in relation to a 'time to live' and a 'time to die' were also explored.

Concepts of 'control over time', 'time of death' and the 'right time to die' were also important aspects to the overall dimension. Time with the dying person, time at death and time in relation to funeral requirements were categories that emerged in relation to differing religious perspectives. Time to remember the deceased through memorials, anniversaries and a time when the mourning should 'officially' end were the final subcategories in this Time section.

Space

The dimension of space incorporated the environment in which the dying/deceased person was; preferred place of death, social and isolated deaths, religiously 'safe' space after death and the importance of the final resting place for the deceased.

Body

The dimension of Body incorporated the emotions and feeling leading up to, at the time of, and following the death of a person. Being a physical presence for the dying person and caring for the body and soul at times of dying, death and beyond were areas of discussion. The last care of the deceased person and funeral and bereavement rituals were further areas identified as relevant to the bereavement experience.

Relationships

The fourth dimension, relationships, uncovered the interactions of the participants with others with whom the phenomenon of bereavement impacted. Relationships

between relatives and the dying person, doctors, nurses, healthcare assistants religious leaders, God and religion, death and the afterlife were all areas where thought provoking issues emerged. The dimension of relationality also appeared, for some, to relate to a sense of communal sharing and social interaction, or isolation, from others.

As the analysis progressed, the process of hermeneutics evolved and the data was explored and interpreted within the framework of the researchers' own identified, but unsuspended, beliefs. Although Bracketing 'or epoche, presuppositionlessness, or phenomenological reduction' (Beech 1999), is advocated by some researchers as a means of holding all preconceptions of a phenomenon in abeyance, in this study, recognition was given to the fact that the researcher's perspectives, values and experiences could not be fully suspended or bracketed. However, when identified and acknowledged, this perspective, from an ontological stance, brought a further perspective to the phenomenon of bereavement.

3.3   Results presentation

The following four chapters will present the themes that emerged from the data collected and analysed according to the methodology outlined in Chapter 3 and describe them corresponding to the 4 existential dimensions of Time, Space, Body and Relationships. It should be noted that the verbatim transcripts of the recorded

interviews provided vast amounts of data. A worked example of data analysis for each dimension is provided in Appendix G.

The main emergent themes will be described and illustrated with quotes from participants using their unique identification code as described in Table 7 in Chapter 3 and where C is Christian, J is Jewish, M is Muslim relatives, D is Doctor, N is Nurse / healthcare assistant and RL is Religious Leader.

It should be noted that some themes appear in more than one chapter of the results as they are discussed from the differing perspectives of the four existential dimensions.

3.4   Conclusion

The participants in bereavement research to date have often not been reflective of either the diversity of the multicultural multifaith population or of the myriad of conditions and events that result in death. However the studies performed to date provide useful insight into the way in which a study of the lived experience or the phenomenon of bereavement in different faith groups needs to be conducted in a qualitative research paradigm.

The methodological processes that were considered and instigated as part of the execution of the study are described which, for context, need to be read in conjunction with Chapter 2. The latter provides the intellectual framework for the

phenomenological investigation and the consideration of the 4 existential dimensions of time, space, body and relationships based on the work of van Manen (1984) as applied to bereavement in the Abrahamic faiths.

CHAPTER 4

RESULTS: THE EXISTENTIAL DIMENSION OF TIME

The indefinite continued progress of existence and events in the past, present and future, regarded as a whole…'

(Oxford English Dictionary pg 1352).

The phenomenon of time provides a framework through which we live our lives, from the moment we are born to the moment we die. Although intangible and, at times imperceptible, time provides a continuum on which we can measure our existence from birth through to death and beyond. Dimensions of time include the 'past', 'present' and future that appear to be key concepts in uncovering the impact that bereavement has within a time continuum. The past, present and future provide a time line on which a person's bereavement journey can be mapped.

For relatives in this study, the phenomenon of time was used to conceptualise the 'lived experience' of bereavement. Through this medium, recollections of the past were evoked where the (deceased) person emerged well and fully functioning within their family and societal roles. The 'present', for all participants in this study, was identified by the researcher as the time when the person was in hospital, the immediacy of rituals, and arrangements at the time of death and funeral preparations. The 'future' for relatives, referred to the changes imposed upon them, by the death of a loved one, and their experiences of adjusting to the loss of that individual through their bereavement journey.

The most poignant dimension of time, that of 'here and now', appeared to be absent from the conscious domain of the participants. It can be argued that 'now' is the only 'real' time a person experiences; yet we rarely, consciously, live in the 'here and now'. Reflecting back to the past and times gone by; or looking forward

to the future and anticipation of things yet to come, fill most people's daily thoughts. However, it must be acknowledged that 'now' is of paramount importance as it will define recollections of the past and provide an interlude to the future. This is especially so when the impact of bereavement on the individual is considered. The immediacy of the lived experience of witnessing and being involved in the dying and death of a person will influence the bereavement journey for relatives; and the way future end of life and death situations are managed by staff.

Five key themes emerged through the data analysis.

➤ *A time to live* encompassed the beginning of the bereavement journey through chronological story telling and descriptions of the person as an individual.

➤ *A time to die*, incorporated discussion on the 'right' time to die, the ellusiveness and unpredictability of death, the sanctity of life versus the time of death, quality versus quantity of life and the possibility of controlling death.

➤ *The time of death*, explored discussion around when exactly death occurs, perceptions of good and bad deaths, and the significance of time at end of life from the participant's perceptions. These ranged from a 'lack of time' through being present at time of death to a race against time with regards to funeral preparations.

➤ '*After death*' focussed on the significance of memorials and anniversaries.

➤ *Eternity* looked at time from an afterlife perspective and how this may be perceived after the death of a loved one.

A worked example of the data analysis for the dimension of Time is provided in Appendix G. The main emergent themes will be described and illustrated with quotes from the participants using their unique identification codes as described in Table 7 Chapter 3.

4.1 A time to live

Recounting their *bereavement journey* through *chronological story telling* allowed relatives to set the scene. The continuum of time enabled them to recollect and recount their loved ones illness and subsequent death. There appeared to be a need to ensure that these recollections were in a sequential order to provide an accurate and holistic overview of the whole unfolding events:

> 'Well basically my wife's illness started ….it's alright if I don't think it out it will make sense to me but it won't make no sense to you….. she was ill about eighteen months before, oh no, if you go back to her first illness……. I know, but if I miss the middle bit out…You're never going to get it.'(C1)

> 'I'll paint the whole picture myself' (J3)

> 'I clearly remember the dates when she got taken in, ill on the ** July'. (M1)

Within these recollections were the interwoven aspects of the *person as an individual*. These included an image of how they 'were' when they were young, healthy and full of life; how they 'are' reflecting the fall into illness and the decline into death; and how they would 'be forever ' remembered in a timeless 'ever present' yet 'forever gone' state. A sense of pride exuded from the bereaved relatives as they shared descriptions of the unique facets of their deceased loved ones:

> 'I left school at fifteen, which was the norm for me. Her said 'I'm not going out with you, you am too young'. I pursued her and pursued her, I worn her down to her knee caps (laughter) oh dear, even today I can't even think of anyone else, it's not possible, it's not possible. Wherever she went, I went…..' (C1)

'She was so extrovert, she loved like dancing' (J4)

'She was a very orthodox lady; she'd been a member of this one, synagogue ever since she got married and came to Birmingham – bout 70 years or so?'(J1)

'…... my mom was um, a very strong person, she didn't give in easily' (C4)

'…one of the oldest, not just in years but in length of time' (J1)

'She was a very active member of the community and used to go to the local mosque regular' (M6)

The importance of seeing the dying person within the wider context of their *time* on earth and their accumulated lifetime of significance was expressed from a Christian religious leader's perspective in his recollection of praying for an elderly dying patient:

'…..and I try and use phrases like, memories that are so painful today will become precious tomorrow, … but it's trying to say this person lived for eighty years not for eighty minutes, this person is not somebody sedated in ITU, this was somebody who worked as an engineer, who laughed and courted and married and, you know, did all those things, so I'm trying to bring those in to the prayers as well' (RL2)

showing that through the passage of a lifetime a person will impact on many others and that it is the journey through life which defines them rather than their last few moments on earth.

 In order to 'bring to life' their loved one once more, relatives recounted the antecedents of the person's illness as a means of pinpointing the time when their loved one shifted from well to unwell; from living to dying:

'I noticed that my mom ….. seemed to be quite tired all the time, and I thought it was because of her age……. I didn't actually notice that … she was ill, well we didn't know she was ill, she didn't know she was ill' (C4)

'She developed angina problems and um … well a long story short she had a series of um … heart problems which eventually culminated in her death, three years ago' (J3)

'She wasn't well but it wasn't a situation where she was really critically ill …... they threw us back out saying it's some sort of virus and she would recover from it' (M6)

These recollections appeared to be powerful evidence of the trajectory of the person's death; concrete confirmation of the beginning of the end of their loved one's life.

4.2   A time to die

The concept of an acceptable or *'right' time* for a person *to die* appeared to be an important consideration in relatives' understanding of, or making sense of, the death of a loved one. For some, there was a belief in predestination of life and death which was fixed in time and unchangeable:

> 'I'm a great believer, in when you are born you are given a date. You are born on that date, and when you die you are also given a date, and you die on that date. I don't care where you are it will find you, that is my belief'. (C1)

This view was mirrored by a Muslim relative as he explained the words of comfort that would be recited to the family by a Muslim Religious Leader:

> '……and he (the Imam)will tell us that we were all born but also born to return back as well, so death is imminent, it will happen at some stage', (M5)

A Christian religious leader also expressed the belief that everyone has a finite time on earth. He felt that people should be aware of the life they had lived and that, in doing so, should be aware that time on earth was running out for them:

> '…..because you've got more history than future in this world you know*' 'What do you mean by that' and I say 'well if you are 70 years old you'll be lucky if you live til you are 140 to double it……… to be kind you have also got to be realistic' (RL1)

This belief in a predestined time for death carried with it the assumption that 'God' ultimately held control over a person's death.

A Muslim relative explained an Islamic belief where every person is informed of the actual date of their death though a visitation from the Angel of Death. He

stated that although the visitation would provide the person with knowledge of his / her own time and date of death they would be rendered unable to share that information with another living soul:

> 'Some people are aware they are going to die, like sometimes the angel will come and visit people, may be forty days before they pass away and they may know that they are going to go. Sometimes some people can't tell anybody else' (M1)

The *unpredictability of death* materialised within many of the interviews.

The difficulty for healthcare staff to accurately predict the time of a patient's death caused distress for some of the relative participants:

> 'we had already said obviously how long can you go on like that. And the doctor said 'Well, how long's a piece of string.' (C2)

> 'I asked him (Dr) basically how long and he said look I can't tell you that but it could be hours or it could be a day but no more than a day' (M6).

Although understandable, this inability to pinpoint when death would occur caused different difficulties for one Muslim relative. His need to know centred on his obligation to inform his family, thus enabling them to perform their religious duties including being a visible, supportive presence when death occurred:

> 'so they told us it was a matter of hours but they wouldn't tell us yes/no because I wanted to get in touch with the relatives, his sisters who live in Peterborough …, yes so I wanted to know what was going on. They wouldn't give me a definite answer whether I should call the family or leave it for a while'. (M5)

The elusive 'time of death' also evoked feelings of unease and frustration for healthcare professionals. A nurse explained how being asked when a patient was going to die distressed her as she felt this question wrongly implied that nurses are privy to 'divine' knowledge:

> 'It is so cruel to ask the nurse and say "Do you think ……how many hours is he going stay?"…I cannot say….. .."You are a nurse you ought to know that when he is going to die?" My goodness – how would I know? I am not the holder of his life'. (N1)

In this study two doctors suggested that there was an inability, or unwillingness, by some of their colleagues to even acknowledge the imminence of death, let alone pinpoint a time for it to occur:

'I think we are very bad at recognising that people are dying ….. we don't want to admit it'.(D2)

'And I think we don't just recognise that people are dying' (D4)

The inability to predict when a death would occur was also raised by religious leaders:

'You can't tell someone is going to die, it can take days can't it; you know it is pretty soon, but it could be four or five days'. (RL6)

In light of this the last rites have now been re named as the sacrament of the sick and, within the Roman Catholic Church, consensus has been agreed to extend this ritual to all Roman Catholic patients admitted to hospital, regardless of the seriousness of their condition:

'Yes because we don't know when the last rites are actually going to be' (RL1)

The extension of this ritual to all Roman Catholic patients provides a protective religious cover should death occur unexpectedly, as this ritual is regarded by those who observe this particular Christian faith perspective, as facilitating their preparation to meet God.

The difficulties in identifying imminent death appeared to be a combination of a lack of awareness, whether deliberate or subconscious and an assumption of an overarching divine plan that was beyond any person's knowledge or control. Although a logical acknowledgement of impending death was present for many of the relatives, they described a feeling of shock and disbelief when the death occurred.

If the concept of bereavement in the context of time is considered, although, for most people there is an intellectual acceptance of the inevitability of death, for many there is a denial of the fact that it will affect us or our family and friends. There appears to be a head and heart conflict, battling with a covert knowledge of death being imminent against the hope that they will live a little longer. From a time context, it appeared to be difficult to accept both the inevitability and irreversibility of the loss and the fact that the dying person would no longer be a physical presence in the person's existence:

> 'I was in a bit of a daze 'coz all I was thinking was 'I wonder how I'm going …' I mean you know these things are going to happen but you don't expect it when they come'. (J4)

> 'I mean we knew it was going to happen, but quicker than we thought' (J5)

> '…..even though I was expecting it, it was still the biggest shock I've ever had in me life. I've got to admit it' (M6).

> 'So, even up to this day it is still a shock that she has gone because she was there one minute and she has gone in the other' (M6)

The perceived inability of western Christian society to accept the inevitability of death was outlined by one of the Christian religious leaders. He felt that, within western Christian society today, there is a reluctance to acknowledge death as a natural occurrence that will happen to everyone eventually:

> 'People don't expect you to die these days either, I was talking to a patient this morning who is ninety and her twin's just died and she was saying to me 'Why, why has God allowed this to happen?' She's ninety don't you think it was time for her to die, she's ninety, off you go dear' (RL1).

This reluctance to accept death was also expressed by a doctor who felt that with the development of new 'life support' machines and advances in medical technology there was an associated expectation that people could live indefinitely. However, she reinforced the reality that all human beings are designed to die:

> 'People just think that people are just going to go on forever and if there is something wrong then it is fixable and you almost have to remind people, he was 89, like my Nan's 89 now, she's designed to die at some point soon and that's okay, you know' (D4).

She reflected upon her professional experiences of this apparent denial that appeared to be more prevalent during her encounters with Muslim patients and their relatives:

> '….(with) Muslim families there is almost this element of kind of denial that it is never going to happen ….. almost until they take their last breath, you know, is there anything else I can do, it's as if they don't want it to happen'. (D4)

This, she felt, added another dimension to the already difficult task of informing relatives of the impending death of their relative. The perceived inability to acknowledge or accept the fact that the person was dying meant that such poignant information needed to be reiterated daily:

> 'But when you have told them quite clearly that nothing's going to make a difference, and you sometimes just have to tell them day in day out, , it's almost as if they have lost their memory … you just feel such a terrible person sitting down and upsetting them time and time again t, …it is almost as if they don't really want to hear that and then they will disregard it as soon as you have said it' (D4)

The dichotomy between *sanctity of life and time of death* was a concept explored by several participants from the Islamic and Jewish faiths. There appeared to be a firm belief in maintaining life at all costs, but alongside this was the acknowledgement that death was the inevitable outcome of life.

One Muslim son, whose mother had died, described his belief that life should be maintained at all costs and that it was God's will when someone died. Within this framework of belief he struggled with the concept of brainstem death and withdrawing 'life support'. These, he perceived, amounted to shortening someone's life and therefore hastening someone's death; both of which are forbidden in Islam.

> '…..Ending life prematurely untimely, life cannot be taken or shortened, and the religious point-of-view was basically, no you can't do that, because in actual thing what you are doing is taking a life away. You all know you are switching off the machine, you all know that she

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> has got no chance of surviving but the chance may be that, you know… miracles could happen and she could be there for 6 months on the ventilator and suddenly she could be alive' (M6)

The idea of 'hastening' death was likened to murder by a Jewish religious leader who believed, similarly to the previous participant, that God had given a finite amount of time on earth to each individual. He suggested, therefore, that the time of a person's death should be left to the will of God rather than the decision of doctors:

> '……for us life is infinite … therefore when somebody is close to a moment of death if we would do anything that could potentially hasten that moment it is an act of murder' (RL8)

The focus of end of life care appeared to be markedly different between healthcare professionals and relatives. *Quality versus quantity of life* appeared to be a strong concept for doctors but was only alluded to by other participants. One doctor discussed how the quality of a patient's life must be an important consideration which required careful management alongside the relatives' wish for life to be maintained for as long as possible. Although she acknowledged the relatives' desire for their loved one to be with them for as long as possible she personally felt that, for some patients, 'death is better than life':

> '…a lot of patients' relatives will tend to feel that quality of life is very important – and that keeping someone alive just to have a bit ….just to keep them alive - if the end result is that maybe they will be able to move one finger or blink an eyelid – is not really quality of life and, umm, it is probably in the patients' best interest that they do not live. In other words in that sense death is better than life'. (D1)

For several of the doctors, the timely change from treatment to palliative care was an important factor in the care they provided to the patient and their family. However, there was acknowledgement that this change in focus may be difficult for other members of staff to grasp:

> 'I don't know whether is because I'm at the beginning of things (PRHO) and when they're actually my own personal patients I may feel different, but I think there's a lot in the medical/nursing community that don't want to let go – its your job to keep people alive rather than its your job to improve the health and quality of life…..' (D2)

This theme was mirrored by another doctor who suggested that junior doctors may perceive death as a failure on their behalf, and therefore may continue with unnecessary treatment that will appease their guilt far more than it will assist the longevity of the patient:

> '……very junior doctors I think feel that they have failed if somebody is dying and therefore, they often don't sort of pursue a good death ….things like nebulisers…, it's uncomfortable, there's stuff blowing in your face, it makes a noise, it gets everyone agitated, there's really no need….. Are you doing it to make them feel better, are you doing it to try and cure them, are you doing it to make yourself feel better' (D4)

However, another doctor clearly demonstrated where the essence of palliative care should be:

> '…..there becomes that point where you know you are more trying to make sure they are comfortable and not suffering in any way' (D6)

Throughout the interviews the question of *who*, if anyone, *can control death,* arose. The ability to withhold or hasten death was significant to many of the participants and whether the patient, relatives, doctors or God or a higher being had overall control was frequently discussed.

One issue to emerge was that of *time* of death in relation to other significant dates. The perceived ability of a *patient* to stay alive until a certain significant date had passed was discussed in several instances. A daughter recounted her mother's determination to have one last Christmas with her family. Her power and strength of conviction were, in her daughter's eyes, contributing factors to the amount of time they were able to spend together:

> 'My mom shouldn't have been alive at Christmas last year, because they had only given her until mid October, but she'd said all along that she was going to eat her Christmas dinner, she said 'I don't care what you say', she said 'I'm having Christmas with my daughter and granddaughter'. And she did. And we had the most wonderful Christmas (gets upset)' (C4)

The importance of one last Christmas was also highlighted by one nurse participant. She recalled one patient who wanted to live long enough to have Christmas and New Year with her family:

> 'She was hanging on …she'd hold on to your hand and you know and she'd say I'm not going yet. She waited – they all come up the day after New Year's day, we dressed her beautiful – she was all smiles - and as soon as they left she died. And the daughter even said that she was waiting for that. She wanted us to all see her to say goodbye, all looking beautiful and then she went peacefully in her sleep, which was lovely….you could see it in her face – "please let me hang on" (N2)

The ability to 'hold on' to life and die on a significant date was also discussed by a Jewish participant. She described how she felt that her mother had waited to die on the Jewish date of the anniversary of her husband's death (Yahrzeit). The daughter believed that her mother had 'chosen' to die on that day, to be spiritually close to her husband and to enable her daughter to remember both parents on the same Remembrance Day:

> '… I think she was just waiting for … it was about … between twenty past, twenty five past two and exactly the same Hebrew date as my Dad. yeah, same date, it's just something very strange. Yeah, it's as if she … it was amazing how she waited all that time' (J4)

One doctor acknowledged the patient's apparent ability to hold death at bay until their relatives had left the bedside. She felt that this was perhaps their last effort to protect them from observing the visitation of death:

> 'Somebody's dying and the devoted spouse is sat by their bed and the patient is – it's almost like they're holding on because the other persons there (then) they go away for the evening and the patient dies and yet they've been by their bed solidly for 3 weeks……I think it's because they try and protect the other person really ….I always say to people – "sometimes they hold on when you're there and when you go they might go too"…."they might wait until you go and have a cup of tea because they're looking after you" (D2)

The perception of personal influence or control over the time of death was discussed by two relative participants. They recalled their involvement with 'Do not attempt resuscitation' orders and discussion around withdrawal of life support. One Christian relative, whilst acknowledging the inevitability of death also perceived

that he had been given the ability, or responsibility to control the eventual time of death of his wife:

> '… there was no rush, we were told that yeah, we could make that decision whenever, whether it be today, tomorrow or the next week, next month, you know, the decision was yours'.(C1)

For a Jewish relative, their involvement in the time of their relative's death focused firmly on the end of suffering. They placed emphasis upon the ability to not prolong a life unnecessarily; rather than to hasten death. In light of their relatives' suffering there appeared to be a muted desire for more control over the time and mode of death, and included ethical discussion about end of life care:

> '….while he hadn't signed a DNR we took that decision for him because his quality of life would have been um, unacceptable and he wouldn't have thanked us for it, so um … he died a distressing death because as my wife said 'You wouldn't do that to an animal', and I said 'No, you'd put an animal down but you can't put a human being down' (J6)

In contrast, one Muslim relative expressed a lack of understanding of the limitations of 'life support' and a belief that life could be maintained indefinitely. As a result he appeared to assume that doctors had the decision to maintain or terminate life and that these decisions were made without consultation with family:

> 'By switching the ventilator off…yes, just by switching it off you have said okay I have killed her basically, I have stopped that life and you cannot do that…. They didn't give us a choice….They didn't say its fine, its okay we will keep her alive on the ventilator as long as you want to'. (M6)

However, the term 'life support' can be misleading in these instances, especially when discussions follow such as needing to undertake 'brain stem death tests' and 'harvesting' for organ transplantation, all of which can leave confusion in the minds of most non-medical people.

From a medical perspective, one doctor felt that the ability to give permission for a person to die was important. She recounted an incident where such a discussion had taken place between herself and a patient and the patient had died that night:

> 'Oh I feel I've jinxed the patients – no one little old lady came in and she just said "oh I'm ever so tired – I just want to go, I just want somebody to say it's alright to go" and I said "well if it was up to me I think it's alright to go" and she died that night' (D2)

God was perceived by several participants to have overall control over life and death and had the ability to withdraw life at any time, as a Jewish participant stated:

> '…. you know, when your number's up your number's up, basically she'd just reached 'the' time' (J3)

In a similar vein, one doctor recounted an incident where the son of a Muslim patient, although deeply upset, accepted God's will that his father died at that time:

> 'I remember when he finally did pass away, and it was devastating for his young son, but he sort of said well it was God's decision and it's in his hands and it was his time.' (D6)

The Muslim submission to God's will is firmly entrenched within the five pillars of Islam. Therefore, within Islam, although life is sacrosanct there is a parallel acceptance of death as determined by Allah, as Yasien-Esmael & Rubin (2005) state:

> 'The Islamic world view of loss as a manifestation of God's will' (pg 508).

The concept of the time of death being 'God's will' was questioned by one doctor. He raised concerns that a fatalistic belief in God's decision at end of life could be detrimental to the ill person. He felt that such a belief would result in a resignation to death when appropriate treatment may still be usefully given:

> '…extreme cases where when actually health care can help them and they sometimes just say "Oh well, they are old, it is Gods will" when actually they could do something about it'. (D1)

Although the concept of God's overarching control of life and death was highlighted by a Christian religious leader, he stated that this belief was at the root of *all* religions and not just Christianity:

> ' I think that goes through all religions, not just merely Christianity but certainly would be in the Jewish and Islamic faith at the end of the day Allah or what ever you want to call God – he's the one that calls the shots….and its all written down for us you see.'(RL1)

The belief in a higher being that ultimately has control over life and death appeared to provide comfort to those of a religious persuasion. The power of the clergy however, should not be underestimated. Two Christian religious leaders discussed occasions where dying patients appeared to 'wait' to see a priest and, once having received confession and been anointed, then died a short while after:

> '…..there is the phenomenon of very devout Catholics almost keeping on until the priest comes and anoints them….. I'm sure there is a strength wherever that comes from, for people to be able to' (RL6)

> '….there are the odd occasions and we joke how powerful the anointing was that the patient died fifteen minutes later' (RL7)

There appeared to be the suggestion that the priest's presence and associated ritual facilitated, through comfort and religious affirmation, a 'relaxing' into death.

4.3   The Time of Death

A fundamental question which emerged from the interviews following on from who may 'allow' death to occur was *when does death occur?* What are the definitions of death and are they universal? The concept of brainstem death for a person on 'life support' was discussed separately by two religious leaders.

A Christian religious leader recounted a situation in which a brother was unable to accept his sister's 'death' on 'life support' in ITU. The difficulty appeared to arise

with the clinical definition of 'dead', although his sister appeared to be physically

'alive', breathing and perfused:

> 'I had to say to him 'Look, your sister, your sister is not dying, your sister is dead, you know…. And so I had to quietly convince him that a.) she was dead, b.) no matter what, she was not going to move from that unit as a live person, end of conversation. It was a profound experience' (RL7)

However, a more accepting and philosophical stance was adopted by another

Christian religious leader as he acknowledged advancements in medical science

and their accompanying ethical dilemmas and justifications:

> 'They may have been declared brain dead but the old chest is going up and down and it's all happening and they say 'That's not my husband, that's not…' And I say it is a very important shell, it was the shell that John… … it's difficult even when brainstem death, you can't say brainstem death equals (natural death), 'so again these are our ways of allowing to do transplants, we make up these definitions. You know, three hundred years ago when they couldn't feel your breath wasn't it that you were dead, it was heart, now we are into brainstem, no doubt there will be something else that sort of, but as I say they are more for our protection…Or vindicates what we are going to do' (RL2)

One doctor acknowledged the difficulties of relatives in understanding the concept

of brainstem death. He stated that careful and sensitive explanation was required

in order to ensure that they fully understood that their relative was dead:

> '…..you know if you explain that brain dead is dead and they are dead and that their heart is beating because you are supporting them and you are breathing for them but they are dead. I mean you don't die when your heart stops you die when you're brain dead and if you explain this to people then they don't feel like they are knocking off their relatives, they feel like they are just being given a chance to say goodbye or something and you know… if you explain things properly…' (D6)

However one Muslim relative found the concept of brainstem death almost

impossible to comprehend when signs of life were still present:

> '…at about two twenty he said to me, the nurse that was sitting there with us oh that's it she has passed away now and we need to started taking all the things out. To me she was still breathing and I said to him she is still breathing and he said no it's only the ventilator, I can understand what they were saying now but at that time to me she was still breathing…'(M6)

A more simplistic definition of the time of death was provided by a Jewish

religious leader who quoted from Jewish Law, that one must breathe to live and

therefore lives if they breathe:

'There is very beautiful thing in classic Jewish law, what is the way of testing when somebody has died, to place a feather under their nose. Why? … because it says that, it says in the bible that when God created Adam he breathed life into him, in other words the soul comes in through the nostrils …… and therefore when it leaves it leaves through the nostrils. So the act of breathing, is one of the fundamental signs of life, and the fact that there is a soul there in full force, um, therefore when the feather doesn't move under the nostrils that's one of the signs that somebody has ceased life, in other words the soul has left the body' (RL8)

The length of time death takes to occur was acknowledged by a Christian religious leader. The potential for flexibility when anointing, even after 'death', was explained in terms of acknowledgement that the soul may still be present immediately after death and allowing time for it to depart:

'So if a person has not been anointed before death – medical death* we are allowed to anoint up to 2 hours afterwards. So if a doctor comes along and says that person is dead I'm allowed, my church allows me to do it for 2 hours because we are not sure* we don't know how quickly it happens. The body could be dead but we don't know whether the soul is around obviously. So we really don't know.' (RL1)

However, for a Jewish religious leader, the actual confirmation of death was dependant upon the context in which the question was asked. He acknowledged that, as with so many aspects of life and death, definitions such as these will never be clear cut or universal:

'…so you are going to ask me when is somebody dead I am going to say it depends for what…. it is very important to understand that. It doesn't mean you make it up as you go along …… it mean that the corpus of law is such that it takes into consideration, in the final decision, all sorts of circumstances' (RL8)

Associated with the concept of the *right time* to die and its link with the bereavement experience, several of the participants focussed upon the perceptions of *good* and *bad deaths* from a time, or age, perspective. There appeared to be an unspoken 'score' for every bereavement experience and its perceived impact, dependant upon the nature of the relationship with the deceased person.

Every bereavement is unique and its impact will depend on a myriad of things including the relationship that the bereaved person had to the deceased person. Intertwined within this concept are subliminal societal beliefs that can be seen in everyday conversations which suggest that the death of an old person who has lived their life is more tolerable – no matter the cause of death, to the death of a younger person with their lives in front of them, for example 'he had a good innings/life', 'he lived for his five score years and ten', 'only the good die young', 'no one expects to outlive their children'. The loss of a child is such an emotive event and can be seen by many to be an intolerable situation to occur.

This was mirrored through the reflections of one Christian relative who stated that, in her opinion, the loss of a child was the 'worst' kind of loss a person could experience:

> '…you know, to create a child and lose it in your own lifetime must be horrendous, it really must, however you lose that child'. (C3)

However, for another Christian relative the impact of the loss of a child was tempered by a spiritual belief that it was not the right time for the child to be born; again suggesting that birth, as well as death, is under the control of God, or a higher being:

> ' I know it's bad when a woman loses a child but my estimation of it is it wasn't time for that child to be born' (C1)

The age of the person who had died was a consideration in the impact of the death for two relatives of the Jewish faith. Intertwined in these statements are three concepts; an acknowledgement of death as the end of a long life; death as a welcome end to suffering and the importance of celebrating the life lived rather than focussing on the end of it:

> '…it depends on, I suppose how old the person is that's gone' (J1)

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'I think sometimes it depends on the circumstances. If you lose..I mean my father died at 92 my mother in law who had sadly been ill for several years was 90 odd. That is no tragedy* I mean it's the end of a life we are very lucky to have had them for the time we did. So whilst we don't go out and celebrate it I don't really feel the need to do sack cloth and ashes' (J2)

However, one nurse felt that there could be no mitigating circumstances in death and bereavement and that all deaths were equally tragic:

… there is no such thing as a good death, if it's a 22 year old that has got run over and just dies, or if it is a 50 year old, or no, no there's no such thing as a good death (N4)

In a similar vein, a Jewish religious leader stated that within Judaism, life, old or young was valued equally and that life, at any stage or quality, was still to be held as sacred:

'…now during that stage, um, we don't do anything that could possibly hasten … death. The Jewish concept of life um, is … that it is of infinite value … and because it is of infinite value we don't balance one life against another life … and we don't balance lengths of life … so we would never build into one of our calculations, one of our bean balance jobs, that so-an-so can live for twenty years and this guy may only live for twenty minutes' (RL8)

One Christian relative, in her discussion on partner loss, stated that further factors to be considered in the impact of bereavement were the age of the person left behind and, if partners, the length of time they had been together. She suggested that there was a correlation between the length of time people had been together and the depth of grief experienced:

'But then again perhaps I was at a, you know, I'd just turned sixty and I was still young enough perhaps in my mind and perhaps to cope and do things, because obviously losing a partner happens at various stages in life and I feel obviously the older you are it's got to be more distressing, because you have been there longer close together' (C3)

The opportunity to *be present at the time of death* was an important dimension discussed by participants. The reasons for wishing to be with a person at the time of their death are many and varied but may include some of the following: to provide comfort and support; to be a familiar face, voice, touch and smell; to have time to say personal goodbyes, to ask forgiveness and to provide affirmation of that person's worth for them to hear one last time.

From a religious perspective there may also be an obligation to perform prayers and rituals to facilitate the closing of this life and a peaceful transition to a life beyond. For all participants there was the understanding of the need to be a 'presence' for the person at the time of their death. For one Jewish participant, the fact that he missed being present when his father died was distressing for him. However, he spoke with great integrity as he shared the fact that sitting watching his father die was just too painful for him to bear:

> 'I was very upset I wasn't with my father when he died – in a way it was my fault I knew the night before I said to the staff you know what's going to happen 'well he may go through the night he may not' you know.. sitting there all night, just waiting for someone to die is just awful*and they said we will call you if something happens and they did call ummm and you know I'm not very far away but by the time I got there it was too late. I'm not blaming them'. (J2)

Nurse participants talked of a perceived *lack of time to care* for dying patients and their relatives. The main reason consistently offered for this was *pressure of work.* One nurse highlighted how she felt that it was sometimes difficult for nurses to look after both the physical and spiritual needs of patients, due to other demands placed upon them:

> 'She is all alone on the ward and she is depressed and it is a (sic) 'pee pee' sometimes because nurses are too busy to cater to the spiritual needs and the physical needs of the patient' (N1)

This perceived 'lack of time' caused a conflict in demands for the nurses and appeared to induce feelings of inadequacy and associated guilt:

> '....time to care, time to comfort the relatives, …and the patient. .. When you know the relatives haven't been looked after, when you know the patient hasn't been looked after, …. There's a sort of taint to it. because it's a late shift and you are running round and the patient has died on their own, that's bad…', (N4)

> 'I was the only person out of all the nursing staff who went in and spoke to them on a regular basis because we were very busy we were short staffed, but the people just didn't go in and I felt dreadful that day', (N5)

Being present at the time of death and the timely interventions of religious leaders was discussed. There appeared to be a difference in expectation between the religious leaders and the bereaved about their roles and the rituals. The presence of clergy at the time of death and the ensuing minutes after seemed to be of comfort to relatives but, from a religious perspective, held little value for the deceased person's soul:

> 'I remember being called in once to a lady who was very ill, it was three o'clock in the morning and um, the daughter said 'I'd like you to say a prayer but don't make it too religious' (laughter), but at three o'clock in the morning you are getting the full gospel prayer believe me, nobody is having anything irreligious! That's an intriguing thing to say 'say a prayer but don't make it too religious'. (RL2)

> '.....and I have to say that if I am asked to bless a patient after death and there is no relatives there I wouldn't necessarily come out in the middle of the night because really there is no, there's no absolute need'. (RL6)

> '.....strictly speaking after death there is no urgency for a priest to come' (RL6)

The importance of being allowed *time with a loved one after death* was expressed by a daughter when she spoke of her experience with her mother's death. To be allowed time to sit with her mother after death had allowed her to start to absorb the enormity of what she had just witnessed and was a valuable gift for her:

> 'The nurse said 'take your time, in your own time, you don't have to leave yet', and that was so important' (C4)

This time spent with the deceased person appeared to be important on many differing levels for several of the Christian participants. It appeared to allow them to begin the process of accepting the reality of the loss. It provided a special 'end' time with the newly deceased person, whilst they were still perceived to be an individual, in the finite time between transition from 'person' to 'body'. However, the concept of spending time with the dying / deceased person was dismissed and actively discouraged within the orthodox Jewish faith. One Jewish religious leader

stated that end of life and death were activities that instantaneously severed contact with the person; and that these boundaries should not be blurred:

> '…quite often towards the last moments all the family will come and they will hug and hold hands and the whole business will be going on, this is something that we um, you know, we wouldn't want to encourage at all' (RL8)

The concepts of continuity of care, and their duty of care immediately after death including the timely completion of verification and certification of death, was discussed by several of the doctor participants. Whilst there was acknowledgement that a doctor's duty and care towards the relative does not cease after death, it was also acknowledged that some doctors fail to see the importance of this or the impact that delays will have on funeral arrangements and, therefore, upon bereaved relatives:

> '…you have still got to think about the relatives and everybody else and they don't want to be hanging around the hospital for a death certificate'. (D6)

> 'I don't know why with the junior staff, but especially with the House Officers they get bleeped from Bereavement Care to sort everything out and they kind of shrug it off. And I have seen them do it they kind of go, well they're dead, I've got 10 living people to sort out and you kind of think well they might be dead but they've got 10 relatives that are alive and waiting downstairs and you haven't completed your duties to this patient so get yourself down there and sort it out. And I've actually seen them do it they just kind of go "oh that is only paperwork that can wait" (D4)

4.4   After death

For relatives of the Muslim and Orthodox Jewish faiths the time immediately following their loved ones' death became a *race against time* to make arrangements for a burial to take place as soon as possible. The Islamic and Jewish participants appeared to display a subtle pride as they recollected the speed in which their faith community could arrange for a funeral could take place:

'I mean there was one, there was a funeral in the city, um, a few weeks ago when I think the person involved died … in the morning, fairly early in the morning and the funeral took place at seven o'clock that evening, so that was really quick' (J3)

'…we've had cases with people passing away in the morning and if it is a straightforward death and there are no complications then we have a funeral done in the evening or afternoon, that hasn't been a problem'. (M5)

'….well they do move because they know time Isn't on our side' (J2)

The main reasons for the requirement of an immediate burial for Muslims and Jews are presented in Chapter 1. However, this race against time for the funeral to take place was often hampered by bureaucratic and administrative barriers within an acute hospital setting beyond the control of the relatives / funeral arrangers, which often threatened to, or occasionally did, delay the funeral taking part:

'… the real problem is registering, is getting the death certificate um … avoiding a coroner's inquest, and getting, getting that death certificate translated into a um, a death registration………. if a death happens on a Saturday … bearing in mind the difficulty in terms of travelling and engaging in other activities there will still be a wish to have the burial on the Sunday'. (J6)

A lack of understanding of hospital processes and procedures, including rotas and shift patterns, and a failure to acknowledge the 'off duty time' of medical staff, was displayed by one Muslim relative:

'The only thing that aggravated us at the time was that mum died about mid day ish , just after 12 o clock and the hospital didn't release her body until, to us, until about one o'clock at night there were 4 doctors who had seen her. But at the end when she passed away on the Saturday none of them was around, none of them was available to sign off a certificate to say that, you know, yes I'd seen the patient and that's the cause of death'. (M1)

His comments also highlighted the perceived failure of medical staff to effectively hand over their patient's end of life care requirements in a timely manner.

A Muslim religious leader explained the Islamic beliefs around swift burials according to the prophet Mohammed emphasising that it is not a concrete time scale that should be the focus but the fact that funeral arrangements should take priority over every day events:

> 'The Prophet (pbuh), says three things must be done as quickly as possible. First of all praying the Zana Zat prayer and the organising the funeral is one of this. So when somebody dies, finish his funeral arrangements as quickly as possible is one of the sayings of our prophet….. So this is the one key issue, as quickly as possible – not 24 hours – because this is the word that somebody spread –not 24 hours OK' (RL4)

A further reason for ensuring that a speedy burial happened was explained from a spiritual dimension by a Muslim doctor who described the angst of the soul awaiting judgement:

> '… it shouldn't last more than twenty four hours, some people say um … your soul is still … apprehensive about the questioning and that apprehensive is like being tested and you don't know when the exam is, and you want to get on with it….. so until you actually go to the grave and then the angels of the grave will come and ask you, so the sooner they can get on with it you feel a bit more comfortable because 'Okay, I'm dead now, let's get on with it', and you know, putting in the fridge in three or four days this is something which is not acceptable. Yes, it's disrespectful'.(D5)

Therefore the sooner the burial, the sooner the 'soul' will be judged and hopefully be at peace.

Within the Jewish orthodox faith there is a requirement for a burial to take place as soon as possible after death and a Jewish Religious Leader gave a reason for this when he recounted a passage from the Torah:

> '…we know that you must bury the body as soon as possible, that's from where it says in the Torah the criminal is put to death, you do not leave the body overnight, the criminal is done that way so God says it should be done for everybody else'(RL9)

This states that if a criminal is afforded a quick burial, then so should every law abiding Jewish citizen. A further, more practical, reason for swift burials was offered in recognition of the deterioration of bodies in hot countries:

> 'The Jewish and the Muslim rites are the same in that respect, um … refrigerated morgue came in about sixty years ago? Um, we live in a temperate climate here but in the Holy land temperatures can rise to forty degrees um, and it ain't nice having dead bodies hanging around' (J6)

The *anniversary* of the person's death is significant within the Jewish faith (Ribner 1998) and appeared to be very significant for those participants of the Jewish faith in this study. It provided a formal time to remember and pray for the deceased person. Part of the ritual on the anniversary of a person's death is to light a candle

and allow it to burn for the twenty four hour period. However, when acknowledging this part of the Jewish ritual, two relatives stated that although a candle was lit to ritualistically symbolise the deceased's person's soul, they did not require such a formal ritual to assist with their memories of their loved one:

> 'It goes by the Hebrew day cos the Jewish calendar is different; we still light a candle on the date… (resigned). You know, the synagogue send you a reminder of what date it will be …to light the candle not that you need a candle to remind you' (J1)

> '… except for the anniversary of the death where you light the candle…. not that you need a candle to remind you' (J6)

The use of *memorials* appeared to hold a deep significance for the relative participants. This significance appeared as both a reminder of and a tribute to, the deceased person. The timing of the placing of the memorial also appeared to be an important factor and often signified the official end of mourning:

> 'Within the year, we have a stone setting, after the burial, um after the burial and then a lot of people do it twelve months later …I think it's a good idea…. I think it's a good idea, rather than doing it all at the same time, because you don't, everything is so muddled in your brain, you can't think what's going on, or, you're actually sometimes just travelling through it, being carried through this shady area and you think back, 'Did I or didn't I'. (J5)

> '…..so it is a mini funeral, where the stone is unveiled'. (J6)

'Everyone says how nice the stones are, they are granite, but they are very unusual granite, um

Very nice, I think so. There is only four in the cemetery like them, and I've got two (laughter), I've got two. I think they match anything you put on, no matter what flowers you put on'. (C1)

4.5 Eternity

An '*eternal*' dimension of time was captured through many of the participant's attempts to expand the concept of time to incorporate a life after death. Although this was not explicitly expressed by the relative participants, its discussion by healthcare professionals helped in the conceptualisation of time in relation to death and bereavement. An inability to fully understand time within the concept of

dying, death and the possibility of a dimension beyond death was expressed by one of the religious leaders.

> 'We don't have a full understanding of that fourth dimension. What does God mean in terms of time' (RL7)

In acknowledgement of the nebulous concept of time after death, an attempt to clarify the 'fourth dimension' from a Jewish perspective was provided by an orthodox Jewish Religious leader. He attempted to describe the difference between life and death in terms of the distinction between what is tangible, 'of this world' and in the 'here and now', with what is intangible, unseen, timeless and of a spiritual 'other world' dimension:

> 'What's spiritual and what's material …… this is something which quite often throws people …… we have a very simple definition of it, something which is material is something which is bound by time and space, in other words it is here and it's here now, in other words it has a beginning and it has an end. Um, that doesn't apply to spirituality, um, spirituality is godliness, god is not bound by time and by space, he always was and he always will be. There was never a moment he was born and there is never a moment he will die and there is no place that is absent from his presence, he is everywhere'. (RL8)

The analogy of time being one long unending day was explored by a nurse through her recollections of conversations that she had had with her grandmother. The disparity in 'time' appeared to intrigue her. She explained that although the bereaved will miss the deceased; grieve for them daily and may await the day of their own death so that they may join their loved one; for the deceased, the time elapsed from their date of death would always be 'one day'. There was a suggestion that time is only a tangible concept within life and that, after death, time has no purpose as eternity is fixed in an 'eternal day'.

> '…because eternity is one day when you're dead –but death it's one day – it's a never ending day –but (for) the person that's actually died it's only one day, but for the one that's left it's an eternity. Just waiting for that day to come – my grandmother always used to say I'll see you tomorrow and she meant that in death as well – "I'll see you tomorrow – your time on this world is one day to me when I'm asleep"(N2)

However, the concept of time after death has a different emphasis for those of the Islamic faith and the beliefs regarding the *journey of the soul* after death were shared by several of the participants. From an Islamic religious and spiritual perspective, one Muslim relative described what she believed happened to the deceased person's soul, depending upon the life a person lived:

> 'When the angel of death comes, it starts like, your soul can come out of the body from your feet, If they are a good person then, um, the soul is taken out gently, um, but if they were a bad person in their life, when the angel of death comes it won't be a peaceful, it won't be, you know, be more darkness than light'.(M4)

A Muslim doctor shared the Islamic belief of a visitation by angels in the grave. He illustrated a scenario of the soul being questioned and allocated to either Heaven or Hell, with privileges or punishments beginning immediately, dependent on their actions during life:

> 'Islamic philosophy when the last person leaves the grave yard and they came 20 yards away from the graveyard, angels comes and ask very basic few questions (to) the person. They make him sit and ask him few questions. If these few questions are passed they consider him as a good person they take him, I mean him in his soul*, in the place called 'Al Umere Wa' the place of rua, the place of souls*. Where, they enjoy the rest of the time until the day of judgement. Ok? And if somebody was bad and he failed the test, his punishment start from there. ….particular, particular special punishment going on … they will suffer' (M4)

Therefore, for the Islamic faith there appeared to be a clear procedure for the deceased person after death and an absolute belief regarding the journey of the soul after death and its intermediate resting places. A Muslim relative also explained the journey of the Muslim soul, transiently leaving the body but remaining in close proximity anxiously awaiting the burial to take place. The significance of the visitation by angels was again discussed and the weighing up of their good and bad deeds during the 'burial accounting'- *hisab al-qab:*

> '….at the time of death the soul does leave the body,. When you bury the body the soul comes back in a way, um, and that's when it's questioned.. 'Who is your God, what religion are you, who is your prophet?' those three questions are asked by two angels' (M6)

An explanation of the "after life" and a belief in al-Barzakh, the 'holding area', in both time and space, for souls awaiting the day of judgement was explored. It was suggested that al- Barzakh will either be a place of beauty and comfort or ugly and uncomfortable, depending on a person's behaviour in life:

> '…after the person has been questioned they are in this intermediary realm, um, they're not in heaven, they are not in earth, , the souls stay there until the day of judgement when all the souls will be gathered together to be questioned …… by Allah, so if that person were good in their life, this intermediary place will be um, a peaceful place,… big, wide, a place of peace and tranquillity, if they weren't then it won't be like that. it has been written that people can be tortured in the grave, they will stay there until the day of judgement' (M4)

From the *Jewish perspective* a Jewish religious leader attempted to describe the journey of the soul after death. In contrast to the clarity of description provided by the Muslim participants, he admitted difficulties in adequately describing a spiritual experience through confines of human understanding:

> '…after death, the soul goes, classically before the holy tribunal, … and, you re-analyse your life … from a spiritual perspective, and there are all sorts of discussions about what exactly happens and illustrations of how it happens, but the soul actually decides for itself what **…** it is very difficult to get away from using material descriptions to describe the spiritual process …'(RL8)

4.6   Summary

The phenomenon of time has had many facets attributed to it by man, but still remains chameleon like in essence with reference to the experience of bereavement. Table 8 provides a summary of the emergent themes for the existential dimension of Time.

Essences emerged related to the end of life experience in an acute hospital setting which appeared to have a lasting impact on the bereavement experience for relatives. As demonstrated participants clearly recalled their experiences and what they found helpful or otherwise. Similarly healthcare professionals had an

awareness of their role and responsibilities for the end of life care of a patient and the impact that this might have on the bereaved.

In order to attempt to define time within the context of bereavement, several participants compared time as we recognise it on earth with their vision of eternity, where they perceived time to be an obsolete concept.   An attempt to make sense of death and ameliorate the bereavement experience manifested through a faith perspective of eternity with beliefs in a life after death in the presence of God, or a higher being and an associated belief of reunification with loved ones, or as a collective essence with them.

Table 8.   Existential dimensions of Time

TIME

A time to live:
        chronological story telling
        the person as an individual

A time to die:
        the 'right' time to die,
        the unpredictability of death,
        the sanctity of live versus the time of death,
        quality versus quantity of life
        the possibility of controlling death: patient, relative, God,
        Religious Leaders, doctors

The time of death:
        when does death occur?
        good / bad death
        Present at time of death
        lack of time
        time with person after death
        race against time

After death:
        Anniversaries
        Memorials

Eternity: Eternal dimension of time

The ability of the bereaved participants to tell their story chronologically provided both context for, and propulsion through, their bereavement experience and clearly highlighted the magnitude of impact that admission to an acute hospital had. There was a degree of fatalism and an associated acknowledgement and acceptance of the finite time of a person's death; with for some, the belief that this was 'God's will'. However, this perspective was questioned through discussion regarding who, if anyone could withhold or allow death to occur. The inability to accurately predict when death would occur caused distress to both relatives and healthcare professionals alike and served to show how indiscriminate death can be and how unique each end of life death situation is, even within the rigid constraints of an acute hospital.

The sanctity of life was discussed from a faith perspective and concerns were raised regarding life support and brainstem death with new definitions of death seen to cause confusion, angst and blame. Fears were expressed by relatives regarding a doctor's potential to accelerate death or falsely diagnose death and their motives for this. However, conversely, doctors, felt strongly that quality of life superseded 'life at all costs'. Doctors, nurses and healthcare assistants both expressed concerns about extending life when death should naturally occur.

Concerns regarding a lack of time to care for dying patients and their relatives were expressed by nursing and healthcare assistant participants. However, whether this perceived lack of time was 'actual' or a defence against witnessing the potential distress of death has been brought into question.

Being with the person at the point of death was an important factor for all relative and nurse and healthcare assistant participants. Time spent with the person after death was of immense comfort to relatives of the Christian faith. However, for those of the Muslim and Orthodox Jewish faiths it became a race against time to bury the body as soon as possible. Anniversaries and memorials served both as powerful reminders of the person now gone, but also as facilitators of life moving gently on.

CHAPTER 5

RESULTS: THE EXISTENTIAL DIMENSION OF SPACE

'*The environment is everything that isn't me*'   Albert Einstein

The concept of 'space' for death in relationship to end of life care provision and requirements was explored from differing perspectives. These varied from the physical dimensions of 'space', looking at the environment in which the dying, death and bereavement took place, to the spiritual, emotional, religious and social connotations and expectations associated with the concept of 'space'

Five key themes in relation to space manifested from the data analysis covering:

➢ The hospital **environment** and whether it was perceived to be *adequate*, *appropriate* or *irrelevant* within end of life care. Issues pertaining to the *place of care* and whether it was spiritually and emotionally *safe or unsafe* emerged. The *reputation* and *ethos* of the place of care within the acute hospital were issues that either caused concern or provided reassurance for participants. Perceptions of whether the environment was *religiously and spiritually safe or unsafe* were explored and whether *live values* should be afforded to *dead people*. The possibility that the environment could be *damaging for staff* was also discussed.

➢ The physical **place of death** and its implications regarding the care of a person at the time of death and after was discussed in detail. *Home* versus *hospital* was explored in relation to preferred and actual place of death, including the avoidance of the *imprint of death* at home.

➢ The **space at the time of death** emerged as a key theme with thoughts on what constitutes a *social/ public* or an *isolated/ private* death and associated issues of *privacy and dignity* emerging as areas of concern. The need for a designated 'own' space in a very public environment appeared to be a very

important area of the bereavement journey along with the appropriate use of side rooms. Space as a selector of who would be present at end of life and during the bereavement journey uncovered concepts of *nurses and healthcare assistants as proxy family* and stereotypical assumptions of *family and community commitment*.

➢ The fourth aspect to the concept of space related to **the final resting place** and the possibility of *continuing bonds* with the deceased through the conceptual medium of space. The importance of perceived *Holy ground* and the *grave* gave rise to both *religious pride and separatist ideals*. Discussion surrounded whether the grave was a *second home* or a *holding* place for the soul. This final space acted as a statement of the death for the person but, from an Islamic perspective there was a fear of *desecration* by non-believers.

➢ Finally beliefs regarding **Heaven and Hell** were shared and discussion emerged on whether these are *concrete places or esoteric concepts.*

A worked example of the data analysis for the dimension of Space is provided in Appendix G. The main emergent themes will be described and illustrated with quotes from the participants using their unique identification codes as described in Table 7 Chapter 3.

5.1 Environment

Lived space, for the purpose of this study, referred to the *environment* in which the phenomena of dying, death and bereavement were experienced.

The hospital *environment* manifested as an important consideration for some of the bereaved relatives when recollecting their experiences. Perceptions of whether it was *adequate*, *appropriate* or indeed *irrelevant* were all expressed. One Christian relative clearly remembered the place where he was informed of the decline in his wife's condition; although, as he later recounted, he could not recall the content of the conversation:

> 'Him (Dr) and a Consultant had me in and they … we sat in a little office about this big really, it's on the ward here, on the side. The nurses have a meeting in there sometimes' (C1).

The suitability of the environment in which discussions about the patient's diagnosis / prognosis were held was discussed by a nurse. She recounted an incident in which relatives had been informed of the death of a loved one in a room adorned with Christmas decorations and Christmas party arrangements on display:

> '…it was Christmas, and the sister was talking about how this person had died and there were Christmas decorations in the room and notices up about Christmas parties and the person that was being broken the bad news cannot remember what the sister said but can remember all the decorations and the notices. It's about being sensitive'. (N4)

However, the environment appeared to be of little significance for one Christian relative. For him, a visit to the funeral directors where his wife now lay provided him with the opportunity to see her one last time. Therefore the surroundings were immaterial and significant only in their ability to facilitate one last meeting:

> 'The lad went to see her (in the funeral directors), he sad 'Dad would you mind being with me', I said 'No, I don't mind, I said I'd visit your mother anywhere, any time, any place, you name it I'm there' (C1)

The concept of the environment being *safe* or *unsafe* was explored by several relative participants. For one Christian relative, hospitals were perceived to be *safe* environments in which ill people received treatment and cure. Although the majority of deaths in the UK occur within an acute hospital setting (DH End of Life

Care Strategy 2008), hospitals did not appear to be seen as places where death 'naturally' occurs. The hospital where her mother had been admitted provided support and comfort to them both because of the expectation of care that she would receive there:

> 'And I desperately wanted her to come here (certain hospital) 'coz I knew that they knew here exactly what was wrong with her' (C4).

In a similar vein, this comfort and confidence was gained from the name of the ward or department where the person had been admitted and for one Christian relative it also clearly provided information regarding the seriousness of his wife's condition:

> 'Critical care says it all though doesn't it really., if you were hopeful of getting better, they wouldn't be in Critical Care. I think Critical Care says a lot more than ITU' (C1).

A Muslim relative expressed an underlying fear that the financial cost of keeping someone on such a highly technical unit may have been an influencing factor in the doctor's decision to take his mother off life support. He held a belief that she may have had more time alive if she had been placed in a less highly technical area:

> 'Then we thought is it the bed they are after because the NHS … pressure on the bed, on the NHS and especially the ICU which is the main costly area and we would have even suggested they put her somewhere else, in another room and we would have sat with her for days on end if we had had to' (M6)

Although there was a common consensus among all the participants that hospitals were an appropriate and safe place for patients to receive treatment, an underlying suspicion that they may be *unsafe* for dying / deceased patients emerged from participants of the Islamic faith.

A Muslim religious leader suggested that, from an Islamic perspective, hospitals, and in particular, hospital mortuaries, are spiritually improper places for dead

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Muslims to be 'stored'. This was intertwined with many other issues including a perceived lack of dignity for the deceased since in most if not all hospital mortuaries there is no separation between the sexes and the belief, or superstition, that because a Muslim's soul is still present and 'aware' of its body's surroundings it will be distressed by what it 'sees'. He firmly believed that the prompt removal of the deceased person to a Mosque would ensure that their soul was in a spiritually safe environment and would be bathed in the recitations of the Qu'ran, thus providing comfort to both the deceased person's soul and the bereaved until the burial could take place and the day of judgement came for the deceased:

> 'Somebody died in hospital. They want to remove the body as quickly as possible to an Islamic environment* Muslim environment. … Normally at homes in countries, people, surround the body and every body is reading the Qu'ran all the time. And in a mosque, if they can transfer a body in a mosque, every second somebody is reading Qu'ran, saying Qu'ran, the whole environment is like an Islamic environment, spiritually it feels good…..yes good angels always around there*….. Here, if you left it in a mortuary, there's nobody reading (the Qu'ran), compared to back home ….it (the mortuary) is honestly a non Islamic environment'. (RL4)

One nurse recounted how relatives had asked her about the mystical area of the hospital mortuary; what it was like and how their relative would be cared for 'down' there:

> "what's it like in the morgue" "are they going to be warm enough" "they didn't like the cold" "do you think they'll be able to put an extra blanket on them" – little things you know,… they're so inquisitive like a child – "why, what, when, where" (N2)

There appeared to be a naïve, or childlike wish for it to be 'another ward' where their loved one would still be provided with care, warmth and comfort, thus attempting to replicate *live values for dead people*. There appeared, in both the Muslim religious leader's and the nurse's discussion to be an inferred belief that death does not immediately mean dead and so the environment has the potential to impact on the deceased person after death and the journey of their soul.

The impact that the hospital environment and the constant exposure to dying and death might have on the well-being of healthcare professionals was discussed by one of the Christian religious leaders. In particular, he expressed concerns regarding the wellbeing of staff returning to work following a personal bereavement and how they coped with constant physical reminders of their own loss:

> 'I don't know whether there's research been done on how people who work in hospitals react when they return after a personal bereavement, but it seems to me a very brutal environment a hospital …you can't work in a hospital and avoid death…., there is no place in the hospital where you can say oh this is a death-free zone' (RL2)

The question of a potentially unrealistic expectation of the 'organisation' on staff emerges with an assumption that healthcare professionals have 'immunity' to the exposure to death on a regular basis and an ability to 'cope' with a personal bereavement whilst simultaneously dealing effectively with the bereavement of others.

5.2   Place of death

The importance of the actual *place of death* emerged during the interviews. One Christian relative recalled her husband's wish to die at home. Her ability to facilitate this had been a crucial part of the care that she provided for him and had empowered her in a seemingly powerless situation. She described how he 'relaxed into death' once back in familiar surroundings:

> 'He (Dr) said 'Now he wants to go home, he said he needs to be at home, can you manage?' C had passed away on the Wednesday as I had taken him home on the Monday, and he knew he was home so he let go in effect', (C3)

From a practical perspective, a Jewish relative suggested that a reason that many people die within a hospital setting is that their relatives are unable to cope at home with the physical and emotional demands of end of life care:

'I think most elderly people somehow manage to die in hospital don't they. Cause they are taken there in the end because nobody can cope' (J2)

A nurse recollected a patient who did not want her home, and her husband's memories of their home, to be 'tainted' with the imprint of her death. She made a conscious decision to die in hospital and in acknowledging this nursing staff tried to recreate a little of her home surroundings within the ward environment:

'…..the doctor said you can go home – but she said "no – I'd rather be here….. I think she didn't want to leave a memory of her being dead in that house – that she loved - she didn't want that. She wanted that house in perfect shape – I think she didn't want him to walk in to that house and think – "my wife died …..She was so proud of her house and her fireplace, so we had to make a makeshift fireplace for her to put a Christmas tree up and put her cards up for her (on the ward)' (*N2)*

This illustrates the need for awareness of the individual perspectives of the dying person and their family. What may be appropriate for one person may not be for another and taking time to uncover the reasons *why* will ensure that the most appropriate and sensitive care is provided in a timely manner.

5.3   Space at time of death

The concepts of *social v isolated or public v private death* within a space dimension are quite intricate concepts to unravel. The place in which a person dies may have differing meanings for all those involved. A side room can provide the comfort of a *private* and *dignified* death if relatives are present and staff are visible for comfort and support; however conversely, they can also create an isolated and lonely death, if family are not present and staff pass by knowing that death is imminent. Equally dying on a main ward may provide comfort being supported in the knowledge that people are around to care and support; or may provide torment in unending noise and business denying peace and tranquillity at end of life.

There is an expectation that imminent death will be acknowledged and noticed by staff within a hospital environment. However as the following recollections will reveal, there are many differing aspects to, and interpretations of these concepts. One Christian daughter described the last few hours that she spent with her dying mother. The use of a side room provided them with intimate time alone together allowing them the opportunity to say their last few words to each other, undisturbed by the hustle and bustle of a main ward:

> '….that was very important to me that I could actually be somewhere private with my mom um, for the time that she had left…… we could talk and the very first night we were in that room um, I, we didn't go to sleep, we talked all night long …… which was wonderful (getting upset) …… we just had time to say what we wanted to ……if we'd been on a general ward with a curtain around, and lots of noise and people in cubicles next door. That would have been a whole different experience, and I did feel sorry for people who have been in a similar situation and not had the privacy that I had, that was very important and I think other people um, would benefit from having the same facilities if they were able to' (C4)

The concept of a side room was an important consideration for Muslim relatives who reflected on the Islamic faith requirements at end of life. The availability of a side room provided them with the spiritual *space* to carry out Islamic rituals and behaviour away from the main ward. This semi private area provided a further dimension to the concept of safety as the relatives felt able to cry and recite prayers, safe in the knowledge that they were not disturbing others on the ward, or their actions witnessed and judged:

> 'I like that thing I really liked it.(being given a side room) …. because some people are crying although we know that we shouldn't do it – you know the other patient(s) they have, you know, disturb (that their crying may disturb others)'. (M2)

The impact that lack of ward space had upon people of the Muslim faith was commented on by a nurse. She described how Muslim relatives, trying to fulfil their religious duties for a dying person, were sometimes viewed by others in a scathing and judgemental manner:

> 'There's no relatives room for people to sit and for you to, people – they're always stood in the corridor or in the middle of the ward. No – nowhere for them to go…Especially with Asian people because there's always such a big family so many relatives and because there's nowhere, no room for them to go so people are quite ignorant about things like that. which I get very annoyed about obviously then (laughs)….you know they're huffing and puffing about relatives being there, but there's no room obviously for them to go'. (N5)

For several of the doctors, nurses and healthcare assistants interviewed, the concept of a side room had the added dimension of discreet control, when utilised for those of the Muslim faith. One nurse stated that she would offer a side room for a dying Muslim patient and their relatives in acknowledgment of their needs at times of death. However, there appeared to be an inferred 'other' dimension to this gesture. Whilst the provision of a side room facilitated the religious requirement for relatives to be present, it also created segregation from the main ward, therefore minimising the potential disruption that large numbers of distressed people may cause:

> 'I've never come across a Muslim family that has had a problem going into a private room… they are usually quite glad of it actually because then they can vocalise their grief if that's what they want to do or they can say their prayers… I've never seen it be a problem' (N4).

This 'dual effect' was expressed more openly by one female Christian doctor as she described the difficult task of trying to address the needs of *all* the patients in her care:

> 'If there's side room provision then that's a little more acceptable – especially if you can shut the door and keep some of the noise out ……its different if people are dying and we try and accommodate things – but everything can't be just for one patient when you have a ward of 30' (D2)

However, one nurse highlighted one crucial disadvantage of a side room, that of isolated or unnoticed death:

> '….because it must be horrible to die alone – or left in a side room' (N2)

making explicit the need to assess each patient's social 'space' needs even in their final days and hours on earth and a view that no one should die alone.

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The powerfully emotive concept that *no person should die alone* emerged through many of the participant's interviews. Underlying this consensus appeared to be the suggestion that death is an important rite of passage, and an assumption that the dying person would want physical and / or spiritual comfort from the presence of another person.   This concept of 'being with' the dying person was explored through the dimension of space as this appeared to be a determinant of whether a death was 'social' or 'isolated'. The possibility of a patient dying alone was a distressing thought for one nurse. She explained that, for her, part of a nurse's role encompassed 'being with' a dying person during their final moments:

> '…..for whatever reason it's a spiritual thing, the patient shouldn't die on their own…. because it's going to be a pretty lonely journey'. (N4)

One doctor shared his view that dying alone in an unfamiliar hospital environment was an awful one to contemplate:

> 'Nobody wants to die alone do they in a strange place with nobody there to hold your hand or whatever I don't think that anyone would want to die alone in hospital really. It must be awful'. (D6)

For one Christian religious leader, the concept of dying alone transcended the mere physical dimension to the spiritual domain. He felt that, whilst a person should not 'physically' be alone whilst going through the dying process they should also not have the feeling of emotional or spiritual aloneness either:

> 'Nobody should die alone or with a sense that they are alone' (RL3)

The nurse's role in caring for a dying person was acknowledged by a nurse who told of the care that she provided for dying patients. She felt that being a presence provided a sombre dignity to the event, especially in the absence of family; and that she undertook the role of a family member, or became *a relative by proxy*, in these instances:

'I think you can have a death with dignity can't you?...they sit there holding their hands and it's all very nice – that's how it should be, I've sat with people if they haven't had family and stuff' (N5)

This thought was also expressed by another nurse who felt that, in the absence of family members being present, a nurse's role naturally evolved to be a *relative by proxy.* She then felt able to "be" with the patient when they died, when the relative could not, or did not, wish to be present:

'The family ….you are there as a substitute carer in their absence'. (N4)

The simple act of being with a person at the end of their life was a serious duty that was willingly and soulfully undertaken by the nurse participants if relatives were unable to be present.

The concept that no person should die alone was poignantly explored by one nurse as she recounted an experience which had touched her deeply. She tearfully recollected an incident where an elderly lady had died unnoticed, unaccompanied, and with her belongings still in carrier bags by the side of the bed, in the middle of a busy nightingale style ward. The fact that a death may occur unnoticed in a side room is acknowledged, and to some extent expected, but the idea that a person could die and remain unnoticed for a period of time on a main ward was shocking to her. Her distress was further compounded by a senior nurse joking about the releasing of a bed; apparently placing more importance upon the environment than concern for the deceased lady or her relatives:

'This woman had obviously been dead, in the middle of the main ward in a bed – she must have been dead a good hour – nobody had noticed, not one person – everybody walking up and down, not one person….. they just assumed she was asleep …how awful – not, not one person… her bags still all packed on the chair –now I think that's awful….I think to lie there and die and not one person, one single person – even sitting with you or even actually acknowledging that you've – you're dead….I found that very…. and then you get the senior nurse who comes in and goes 'oh well at least we've got another bed now' – now that attitude – I just think 'well that could be your mother or your father lying there or any of your relatives,

why, how would you feel if you had a nurse turn round and say 'oh well at least we've got another bed now'. (N5)

The environment in which the death took place and the circumstances, dictated by the environment, were seen to impact on the experience of all participants and served as a powerful reminder of the importance of getting this right.

5.4   The final resting place (memories and reminders)

The final resting place for the deceased gave rise to an interesting discussion with all participants. Cremation as a way of disposal of the deceased person is forbidden in Islam. One reason given for this was the acknowledgement that a 'body' is only loaned by God and therefore should be respected and not damaged in any way. A second reason offered was the belief that the soul is still present and can still feel, hear and see everything. Therefore, it is assumed that it may experience the pain of burning in the cremator:

> '…one we feel we should go back to the earth as we, and not do anything to the body, the body should, sort of go into earth and almost …… go by itself, . I think there is a kind of belief that um, that the body of something, the soul or something feels pain still, it's difficult to understand but you shouldn't do anything, just respect the body and it will go back to earth itself' (M4)

Interwoven with these beliefs was the idea that cremation mimicked the punishment inflicted in Hell:

> 'Cremation… it's a torment of Hell' (M4)

This belief also manifested in one interview with a Muslim religious leader as he discussed the dissonance of cremation. He rationalised that humans do not naturally experience fire in our lives; therefore they should not succumb to it in death. He also alluded to the symbolism of the fire of cremation as a representation of Hell:

> 'Another point is Muslim body never burn in their life in any way, in any way never burn. Burning never comes for any reason, unless somebody burn in a fire. Otherwise no never… and burning is obviously like burning in Hell fire' (RL4)

Cremation was also acknowledged as a forbidden practice for those who followed the Orthodox Jewish faith. Similarities were noted with the Islamic faith belief that a body is only on loan from God, and overlayed with the atrocities of the Holocaust where thousands of Jews were indiscriminately gassed and burnt and denied a dignified burial:

> '…. basically the Jewish religion / Jewish Law does not allow cremation. …you go back into interpretation of the bible you are not supposed to in any way damage or deface the body …I have to say that following the tragedies of the Second World War I would have thought that cremation would have been something that would have been basically abhorrent to people because it's something that rings in peoples minds' (J2)

> '…and of course back in the war, there were thousands of millions of people who wanted a burial place but couldn't…' (RL9)

Funeral preferences were also discussed by the religious leaders. One Muslim religious leader recited a passage from the Qu'ran in which it states that man is created from the earth and therefore should return to the earth. This, he felt was guidance enough that burial was the only funeral option for Muslims:

> '…because the Muslim philosophy of life is we've been created from earth and we are going back to the earth. And this is the line of the Qu'ran (recites from the Qu'ran) these are the last verses we read when we put the soil on top of the body in the ground. So in God's word we are created from this soil and we return'. (RL4)

Graves and graveyards were significant 'spatial' areas, not only as dignified and respectful places for deceased people, but also because of the associated religious and spiritual connections to them.

The concept of the graveyard and the grave itself as a means of *continuing bonds* with the deceased person emerged through the interviews, as well as adding a deeper understanding of its significance and symbolism. One Muslim doctor discussed the perceived physical experience of being in the grave. He told how,

depending on how a Muslim responds to the Angels' questioning, they will either reside in a spacious and comfortable grave or one of immense discomfort:

> 'The other thing, burying a body in a coffin, we don't because you have to lay the body in his shroud, so that he can …have room to sit up or move …now the issue of having space for the body to be in is that the angels of death will come there and will somehow be able to sit you up and you can then be questioned and then whether you have been a good or a bad person, if you're a good person then your grave will be so big that it will be like a mansion and you will be able, given a window to see your place in paradise, …….(but if you have not been a good person) lonely and then the grave will come and squeeze on you, a squeeze, and it is one of the terrifying experiences because it's so bad and your grave will be so tight and you will not be comfortable in it until the day of resurrection'. (D5)

The continuing significance of space, in relation to the deceased person, was highlighted by a Jewish religious leader as he discussed the importance and exclusivity of an Orthodox Jewish graveyard:

> 'A Jewish cemetery is holy ground…and this goes from that bit of the bible where Abraham bought, his wife had died, and he bought a plot of land so that he could bury Sarah his wife and future generations of Jewish people, so it was important for a community, well used specifically for the Jewish…we are not inclusive, we are very separatist'. (RL9)

He went further and explained that a grave is a place where people physically visit to remember and acknowledge the dead, therefore keeping their memory alive:

> '…that (the grave) is a resting place for them, and when their children, grandchildren, great grandchildren come afterwards they will know that their great grandfather or great grandmother is there. It's got a Hebrew name; it's got a stone with 'here lies' with the Hebrew name, that is the Jewish way to do it'. (RL9)

The pride associated with final resting places was expressed by two Jewish relatives as they described the graveyard that their relatives now resided in:

'There's 2 (Jewish cemeteries). One actually is in B but the main one is W. It's beautifully kept' (J2)

> 'It's a beautiful cemetery, if you've been to the Jewish section, it is beautifully kept… gives rise to a nice vista' (J6)

In a similar vein, a Christian relative described in detail, his wife's grave and expressed his devotion to her through its maintenance:

> 'I've put her some crocus and some bulbs round the front (of her grave)….So her can't be without a flower. It'll take a while. Takes about a month but they'll come up no problem. Some blue hyacinths and some yellow crocus. …I mean I go down the cemetery now two days a week, but it's not anything morbid or anything like that. I go down of a Sunday to put flowers on, she must have flowers, got to have flowers… she's had flowers even when she

didn't have a headstone, she's got to have flowers. She only ever gets roses, don't get nothing else …..Everyone says how nice the stones are….Very nice, I think so. There is only four in the cemetery like them, and I've got two (laughter), I've got two. I think they match anything you put on, no matter what flowers you put on'. (C1)

In contrast to the adorning of graves and pride associated with their loved ones' final resting place expressed by the Christian and Jewish relatives, the grave was viewed in more practical terms from an Islamic perspective.

For Muslim relatives the grave was viewed as a '*holding place',* and as such should remain functional not fancy. The significance of the grave environment was further explored by two Muslim relatives as they talked about the reverence afforded to grave yards in Islamic countries and the wish for some Muslims to request to be taken 'home' for burial. They explained that in a Muslim country, not only would friends and family pray for the deceased person but people passing a cemetery would be obliged to say a prayer for all those resting there; thus providing bountiful blessings from strangers as well. Alongside this wish for repatriation was an associated *fear of desecration* of the grave in a non Islamic country:

'This is a non Muslim country, it is an English grave yard, they will destroy the grave yard all the neighbours of the graves, you know, they are not Muslim…. Back home, they will be in a Muslim country, and in general the grave yard in our country's by the side of the road. And there is a sign post so when ever any body pass they notice 'oh there is a grave yard – they read a particular prayer'.(RL4)

'It doesn't matter if it is in any graveyard, as long as it is a safe plot basically, where people, vandals cannot go there and dig things up…. they say if you are buried next to your family members in the same graveyard because of this issue with that your souls are there with you in the grave you are comforted having other people with you…' (D5)

However, a Muslim religious leader suggested that in Islam it is deemed wrong to do this, as transfer abroad delays the funeral:

'That's why some people do not like to take their body abroad, because they say it is going against our prophets teaching' (RL3)

Although acknowledged that this practice does not comply with Islamic rules for burial, bureaucratic delays in obtaining documentation, delays in funeral and accepting that the deceased person will need to be embalmed (a forbidden or *haram* procedure), all is durable with the knowledge that a loved one will be 'safe' in a Muslim country. Being attended to, and prayed for, by Muslims whether they be family, friends or Islamic brothers and sisters, may be an overriding consideration in the difficult decision made.

5.5   Heaven and Hell

Thoughts on the *afterlife* and what that may entail emerged within the interviews. The concepts of *Heaven, Purgatory* and *Hell* were discussed. Several of the Muslim participants discussed the concept of the afterlife existing as a tangible place, although this was not directly raised by the Jewish or Christian relatives. For the Muslim relatives there appeared to be an absolute acceptance of the existence of the afterlife with its associated dimensions of Heaven and Hell. For one Muslim relative this absolute belief in Heaven came from her knowledge of the Qu'ran which, for those of the Islamic faith, is believed to contain the exact words of God received by their Prophet Mohammed:

> '…..no doubt. If somebody think its doubt in Heaven, come to me and ask me this is guarantee I'm saying from my God word, not I'm saying, I'm saying with God's word and Mohammed (pbuh) word they said this is guaranteed. This is very true, very, very true'. (M2)

The hope that the deceased person's soul now resided in a 'better' place was seen to provide support to bereaved Muslims and assist them in their grief journey. This belief helped to mitigate and temper the feelings of grief that the bereaved were experiencing:

'But you think that other person would want you to be strong now, because they know what is to come …… they are in that place and they know, so they want the best for you, and I suppose you have to reassure other people in that way (laughter)' (M4)

'So if you know that that person was good then your hope is that they are in a better place now …… than before. So you have that feeling, you know, that you miss them and everything but, um, I suppose it is a little bit different' (M2)

A discussion with the religious leaders regarding the afterlife also unearthed interesting concepts regarding the existence and composition of Heaven and Hell. Many interpretations of an afterlife were offered by religious leaders; some from an overarching religious perspective and some from a personal perspective in relation to these two esoteric domains. One Roman Catholic priest discussed what he deemed to be an indisputable fact that an afterlife existed for all faiths:

'…..there is Heaven and Hell. And that equally applies in the Islamic faith and also the Jewish faith. You know, either you were good enough to join God in Heaven or not' (RL1)

For one Christian religious leader, the emphasis of an afterlife focussed on a person's relationship with God. For him, the emphasis was placed upon being closer to God rather than being in a place created by God; and of interpreting the scriptures rather than a verbatim acceptance of them, as he felt was the case with those observing the Islamic faith:

'I think the Islamic faith try and translate what they consider to be paradise on earth to Heaven multiplied by however times they want to multiply it by. At least that's the impression I get. Whereas we would say that Heaven is being with God', (RL1)

Another Christian religious leader's comments supported this concept of being closer to God and suggested that the concrete images of Heaven and Hell originated from man's interpretation of these through art rather than a static concrete place to be reached:

'But I also talk about moving in to the nearer or the further presence of god, but obviously I would also want to say that it is about not heaven as a place there and hell as a place somewhere else, I don't see them,…I think this is something that we have got from our art as …I appreciate you have concepts about Jesus saying you know in Matthew's gospel where he talks about going down and breaking down the gates of hell but this is all a question of do you take these things literally or do you see the metaphor then I don't see why heaven should

be static, 'coz I don't think God is static, if God is love then love isn't static, love is a dynamic property so I don't see any sense in it being a place, we've arrived, the Euston, the tour, 'The end of the line'(RL2)

Heaven as a spiritual domain rather than a static physical place was also discussed from the Orthodox Jewish perspective by a Jewish religious leader who described Heaven as being manifest all around us rather that an external separate place:

'When we talk about heaven for example, you ask someone about heaven and they all point upwards, that is a figurative expression, a heaven is as much in this room as it is in the synagogue, as it is in the office next door, as it is out in the garden, because it is spiritual, it is everywhere' (RL8)

He further explained a Jewish belief that Heaven was on many different levels. People were able to access these depending upon the good deeds that they had carried out throughout their life, and the length of time they had already spent in Heaven; essentially grading people on their lives lived, their evolving spiritual capacity and their length of time in Heaven:

'…once they are completely cleaned they then go to the Garden of Eden to the various stages whereby they are in a totally spiritual atmosphere, but spirituality, God has an ability to withhold spirituality, in other words he presents spirituality in different strengths … um, it's presented in a way the recipients can receive … um, there's no point in giving somebody a gallon of vodka if they have only got a little eggshell in which to put it … um, so God reveals, allows it to filter out, the essence of what is coming is totally spiritual but it is filtered and presented in such a way that they are able to take it and as the longer you spend in Heaven, the more, you are constantly going up in level …… and people will come in at different levels depending on how they have behaved down here, and how spiritual they have been down here'. (RL8)

The concept of *purgatory* was explored by a Roman Catholic priest. He explained the Catholic belief that this was a place for reflection and penitence to spiritually cleanse a person to allow them to be worthy to meet their God:

'I mean a catholic belief is that we're not, we're not ready immediately at death to meet God, and in a sense there is only one exit from purgatory'. (RL6)

Similarly, a Jewish religious leader explained the Jewish interpretation of purgatory as a place for self-realisation and cleansing before admission to Heaven:

'When you do a sin, for example, it's as if you take a piece of mud and pop it on top of the soul.. the soul decides for itself what needs to happen in order to cleanse it … and according to Jewish tradition there is a super launderette whereby the soul will go there to be cleansed … for anything up to a period of twelve months' (RL8)

However, one Christian religious leader, who was a Baptist, stated that the concept of purgatory was not recognised within his religious framework, thus demonstrating the similarities and differences of interpretations and beliefs, between and within religions:

'I mean purgatory is not a concept that either as a Protestant or as a Baptist that I would buy into' (RL2)

The existence of Hell as a tangible place was acknowledged by one Roman Catholic priest:

'I would believe in hell, really, I think, yeah. I think in this discussion you wouldn't want to major on this but I, on the other hand I think some beliefs are behind the things that people are doing'. (RL6)

Although he was reluctant to discuss this in any detail, his comments seemed to infer that the concept of Hell was a dissuader for people contemplating doing wrong acts.

The concrete presence of Hell and the physical punishments inflicted there were highlighted in discussion with a doctor of the Islamic faith. He compared the funeral method of cremation with the Qu'ran's description of the punishment of Hell. The apparent biological knowledge of the route of pain; described just under one and a half thousand years ago, he felt served as proof that the Qu'ran was the word of God; and therefore, ipso facto, Hell must exist:

'Cremation… it's a torment of hell, and it is only preserved for the sinners, um, actually the, the way it's the torment in hell is so physically is that um … the verse says that every time their skin matures and sloughs off we give them a new skin so that they can feel the pain of fire. Now this is one of the things that, look at it from a scientific point of view was, we acknowledged that the nerve sensation for um, heat are in the skin, therefore third degree burns do not, are not painful. First and second degree burns are okay but third degree burns when you actually lose the skin and the whole skin are not painful, bone will not hurt, muscle

don't hurt, just the skin, so that knowledge which was stated in the Qu'ran that fourteen hundred years ago saying that every time your skin sloughs off you are going to have new skin because your are going to feel the pain again and again and again, which, that gives you the concept that hell is a real physical place and as much as heaven is, and that's where we differ from the other sort of Abrahamic faiths that they think hell is a spiritual place rather than a physical one….It is a physical place, very much a physical place, it is, it is a different dimension basically'. (D4)

5.6   Summary

The dimension of space affected many aspects associated with end of life, death and the grief of the bereaved. Table 9 provides a summary of the emergent themes for the existential dimension of Space:

The environment in which end of life and death care was received was recounted by relatives, who displayed incredible attention to detail during their recollections. Discussion by nurses, healthcare assistants and doctors highlighted reasons for using side rooms for dying patients and their relatives, where possible.

The concept of safety arose in relation to the environment. Whilst the majority of relatives thought that hospital was the right place for the person to be dying in, once dead the environment became 'unsafe' from a religious perspective and relatives and religious leaders expressed a need to remove the deceased person to a place of religious purity.

Table 9.   Existential dimension of Space

SPACE
Environment: • adequate, appropriate or irrelevant, • safe v unsafe, • live values for dead people, • damaging for staff
Place of death: • Home v hospital, • imprint of death, • social v isolated or public v private death
Space at time of death: • privacy and dignity, • nurses as family by proxy • family and community commitment
Final resting place • continuing bonds, • Holy ground and the grave • religious pride and separatist ideals • holding place or second home
Heaven and Hell • Concrete places or esoteric concepts

The majority of the Muslim participants expressed concern about the spiritual safety of the dying and deceased person. The emotional safety of staff constantly exposed to death at work was a theme discussed by a Christian religious leader.

The journey of the soul, from both an Orthodox Jewish and Islamic perspective, was described. This provided a greater understanding and clarity to the rituals that are performed from the time of death until the burial has taken place. The reasons why burial is the only funeral permissible for orthodox Jews and Muslims were explored from both a societal and religious perspective and the reasons why cremation is forbidden for these two orthodox faiths were also discussed.

Christian and Jewish participants highlighted the importance of the grave highlighting the continuing need to 'look after' the essence of memory of the person after death in either very practical ways such as tending to the grave or in spiritual payers bestowed on all those in the graveyard.

Finally, the esoteric concepts of an afterlife with Heaven, Hell and Purgatory were discussed. No universal agreement was apparent and the interpretations varied from a belief in a tangible 'other' place where people existed in another dimension, to a belief that the afterlife merges in an imperceptible way with daily life. It therefore appeared that the place of dying, death and final resting place all had the potential to impact on memories and on the bereavement experience.

CHAPTER 6

RESULTS: THE EXISTENTIAL DIMENSION OF THE LIVED BODY

'All of us have mortal bodies, composed of perishable matter, but the soul lives forever; it is a portion of the deity housed in our bodies'

Flavius Josephus

The existential dimension of the 'lived body' was identified as a means of enabling participants to explore the physical and emotional aspects to dying, death and bereavement and the underlying importance of rituals and procedures at these times. This provided a framework to explore these rituals of mourning from a cultural, social and religious perspective for the three Abrahamic faiths. In exploring this phenomenon in common with the other two dimensions described five themes emerged:

➤ The first of these related to ***moving towards death****,* including *premonition* of, and *preparation* for impending death. *The care, respect and dignity afforded the dying / deceased* person and being a *presence* at the time of death were all important factors for consideration.

➤ The second theme related to the emotional impact of death and consideration was paid to the ***emotional manifestations of grief*** and associated feelings of *guilt* and *questioning.*

➤ A very emotive theme to emerge related to the ***last care*** afforded to the dying / deceased person ***and its implications.*** This included the *last offices* procedure that nurses and healthcare assistants performed for the patient; beliefs about the time immediately after death and the *journey of the soul* and an exploration of *cultural and religious requirements* at the time of death. *Community*

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support or isolation also appeared to be contributing factors within the overall bereavement experience.

➢ The fourth theme related to the bereavement journey and captured aspects of ***moving on, looking back*** and the ability to move the deceased person from '*outside in'. The universality of the phenomenon of bereavement* was questioned as was the *uniqueness of the loss. Talking about the loss* was perceived to be of help in the bereavement journey but there was discussion as to whether *cultural dictate* influenced the *bereavement response.*

➢ The final theme to emerge in this section related to the perceptions of, and core components of a ***good death*** and a ***bad death*** including *control* over the death, a *lack of suffering* and the *presence of others*.

A worked example of the data analysis for the dimension of Body is provided in Appendix G. The main emergent themes will be described and illustrated with quotes from the participants using their unique identification codes as described in Table 7 Chapter 3.

6.1 Moving towards death

The focus of bereavement care is primarily centred upon the bereaved person and their experience following the death of someone who was significant to them for example, partner, close family or friend. However, the deceased person's pathway

towards death is not always overtly acknowledged as an important factor in the bereavement experience of those left behind.

One of the first aspects to emerge through the relative's recollections of their loved one's *moving towards death* was an apparent *premonition of the impending death* of their loved one; a 'gut' feeling that the person was going to die soon:

> 'I know what you're going to say, she's not going to make it …'coz I know. We knew, I knew personally and the daughter knew personally, just by gut feeling that, the fortnight before, that she was not going to make it'.(C1)

> 'You know you could sense there was something not right, but you know in your mind you don't even think…' (M6)

This 'inner sense' of impending death was expressed by doctors, nurses and healthcare assistants too. One nurse recollected an incident where she instinctively knew that a patient was about to die and tried to arrange for relatives to be present during his final moments:

> '…do you think it might be best to call the wife at this moment in time as I have a feeling he may not be staying long?"(N1)

An awareness of impending death appeared to be present with patients too. A female doctor recounted how both she and a patient acknowledged that death was imminent although there were no obvious signs to indicate this. She tried to explain the difficulty in articulating or adequately explaining this 'feeling' to others:

> 'She'd said to me (whispers) "I'm dying" and I said to her "I know" ….and she said (whispers) "I think I'm about to go" and I said (whispers) "I think so too" and yet she looked very well – but you just got this overwhelming feeling that – that you can't explain to people' (D2)

The *preparation* for, and acceptance of, death was explored by one of the Christian religious leaders as he described a unity of grief which engulfed both the dying person and the bereaved relatives:

> 'There's a sort of reverse bereavement, i.e. the dying one being bereaved of you who are my beloved family or whoever going to go on living and I grieve for your grief that you will be feeling when I have died' (RL3)

Within the dimensions of physical and emotional preparation for death an important aspect to the role of the religious leader emerged. The perceived care they provided and its significance at such times was highlighted by several of the religious leaders and within this, the concept of being a *presence* was explored. One Christian religious leader explained the ability to accompany a person on their journey into death:

> 'Sometimes you can say very little but you can actually just hold somebody's hand and be a presence on the journey that they are taking…I always refer to (dying) as the 'loneliness of the long distance runner' um, the loneliness of someone who knows that they are terminally ill, particularly during the night, need somebody there because if they do happen to wake up then they often get frightened, and it's, it's a matter of just, of, of being a presence to actually accompany somebody on a journey of sickness, particularly towards a death'. (RL7)

One important component of their role appeared to be communication with the dying person. This intimate interaction was seen to be of extreme importance, even when it was unclear whether the dying person was conscious, or had an awareness of what was happening. Throughout this emotional transitional period, it was an imperative concern that the dying person's individuality and worth was maintained, irrespective of the closeness of death, or however moribund their appearance:

> 'Often of course the patient themselves are a bit in extremeness at this time but I always make a point, before I'll say a prayer I will talk directly to the patient, even if they are on ITU and they are sedated I will put my head very close to their ear basically and say 'Hello, my name is B I am the hospital Chaplain, your daughter's holding your hand, they have asked me to come in and say some prayers, don't be frightened, it's my hand that is holding your head', you don't know do you….'(RL2)

> 'It's not for me to judge what the conscious nature or other wise of the patient is because I have suspicions that patients are very much more conscious in um, you know, in the sedated ITU situation, for example, than we really suspect' (RL7)

These comments suggest a spiritual connection between people which both utilises known forms of communication such as touch and speech, but also incorporates an empathic spiritual connection of care and compassion.

Where the religious leader's focus should be at times of dying, and for whom the religious rituals are ultimately performed, was addressed by a Roman Catholic priest:

> 'It is important I think to realise that, particularly if you are not, if you don't share the faith, that people tend to see anything that we do for an unconscious patient as for the relatives, you have to remember that for a believing catholic, what you are doing is also for the person whether they are conscious or not'. (RL6)

The position and status of a dying person was explored by a Christian religious leader. Rather than viewing the dying person as disempowered and disappearing into death, he viewed them as pioneers, empowered with the experience of something which others have yet to endure:

> 'Look you are travelling this road before I am so in a sense in this discussion you are my teacher', because you're maybe discovering things that I will discover one day, but I am not in that position. And I think it seems to be helpful to people because the dying person is losing so much, losing control over so much, this is something special about them, they are dying but everyone has got to go through this and they are having this experience now so they can actually in that sense help those who are not dying and are still living'. (RL3)

A Roman Catholic priest recounted the end of life care provided by a nurse and was struck by the dignity afforded to the dying person:

> '… this guy was minutes away from death, ten, fifteen minutes away from death, and this nurse was working around this guy's bed and he was talking to him the entire time, and I thought that is so important isn't it?... And he was treating the guy with dignity' (RL6)

This observation highlights assumptions about the dying person's 'essence' and suggests that less care may be afforded to a dying person as they may be perceived to be 'less' of a person. It highlights perceptions associated with the transition from life to death and raises questions around terminology used; for example, when does a person become a body and when does end of life care transpose into body disposal.

The concepts of continuing *care including respect and dignity* towards the dying/ deceased patient appeared as core components in last care provision within the

Islamic faith. One Muslim relative recalled the dying moments of his Mother and was distressed by the care he felt that she received during the final few hours of her life. He explained how he believed that the status apportioned to her by the doctors and nurses changed from 'seriously ill patient' to 'research case' during her final hours and that this shift in perception resulted in a change in care which denied her a peaceful and dignified death:

> 'I think the other thing that I found sort of quite disturbing at the time was when she was dying was it almost became like a research case so they started bringing in training doctors and they started asking questions as to what her history was or what she was suffering from which was so uncomfortable because there she was you know … she was on the ventilator… as I said there wasn't any empathy there at all.   I think we were just overwhelmed by what was happening' (M6)

The importance of being a *presence* at the time of death was a very significant factor for relatives. The catalysts for this appeared to be a recognition of needs of the dying person and a self or community/ religion imposed obligation, to be present at the time of death; whilst there was simultaneous recognition that this was an intensely emotional experience for most people. One Christian daughter talked about her experience of being with her Mother as she died. Describing her emotions at that time she spoke of an incredible sadness which enveloped her as she realised that she would not have the physical presence of her Mother for much longer:

> 'So I wasn't scared at all, it wasn't that sort of feeling, it was more the feeling of she wasn't going to be with me for much longer (getting upset) … um, I knew the end had come' (C4)

Knowing this, she felt it was important not to "taint" her Mother's last moments with her own sadness and showed enormous strength and composure by focussing on reassuring her mother that things would be alright without her:

> '…. I didn't want my mom's dying memories to be of me being really traumatised and upset (very upset at this point) So, I didn't cry … I thought, I didn't know if she could still see me, but she could hear me and you can hear when people cry and you can tell by their voice so I was very in control …..I was holding her hand, stroking her hand and just talking very quietly to her and very soothingly you know, and saying 'It's alright, you don't need to worry about

anything at all I'll take care of everything, everything's going to be alright, and I'll be fine, don't you worry about me and I was glad I did that' (C4)

A Muslim relative explained the importance of being with a dying person, from an Islamic perspective. The presence of other Muslims would help the dying person to focus on Islam and Allah through readings from the Qu'ran and the recitation of the Shahada (the Islamic declaration of faith). Through this, it was hoped that the dying / deceased person would find comfort throughout their death and their journey to Heaven:

> 'See if you don't read the Shahada on dying then there is no room for you in Heaven…, the people around them – if they can actually say it (Shahada) loud so the person who is dying can actually hear it – and try to say it with them – then that's a good thing' .(M2)

Similarly, another Muslim relative espoused the comfort that listening to passages from the Q'uran would provide to the dying person. She suggested that being bathed in Qu'ranic verses both comforted and reassured the dying person, thus enabling them to relax into death with their final thoughts focussed upon Allah:

> 'The last words on the person leaving this life, they should be the testimony of faith ……..chapter thirty six in the Koran, this is a story that has been advised to read when the person have passed away or during that time. They say leaving this life can be a difficult time for the person, so they say that actually reading this helps, um, the person that's leaving. It also reminds, them, what is in it; it speaks about paradise and speaks kind of reassuring for the person' (M4)

The care provided for a deceased person was also discussed by religious leaders in relation to their role and responsibilities at times of dying, death and bereavement. The Christian religious leaders engaged in discussion around the secularisation of Christian society today. Two participants discussed how this impacted upon both societal and individual beliefs. One participant compared his role as hospital Chaplain to that of a parish priest:

> '……obviously the staff side of it has been very significant for me because I think a lot of people don't have, if people no longer go to their local church, and obviously I'm thinking particularly of Christians here, I'm in a sense the vicar, as far as they are concerned….., I see them as being my parish' (RL2)

Another saw himself as a spiritual guide for those who had not been observant within their given religion and therefore as an advocate for their religious needs:

> 'I can call to mind more readily are the people who are sort of apologetic, you know, who say 'Well actually he hardly went to church at all', or 'we're not really church-going people, but… but we do believe in God', and that sort of statement is much more common I think, 'and we would like some prayers now' (RL3)

In a similar vein, a Christian religious leader explained that for Catholics, even lapsed Catholics, religious ritual at the end of a life is very important. He therefore saw the role of the priest as assisting those who may be unfamiliar with religious proceedings at such times:

> '…acting as a Catholic priest we have got a much more structured set of things that we do, I mean, perform your sacramental, which is basically anointing those who are dying or in danger of death. And I would say that is still fairly important to people even in an age where people have dropped away from church and things. Even to um, even to people who aren't um…. who aren't going to mass it is important for them to know…. well I'm sure really that lapsed Catholics, Catholics who have some sense of faith maybe haven't got the confidence because they have not been praying themselves and so maybe they need someone… it sounds a bit patronising, but in a way they need someone to pray for them. To guide them' (RL6)

Another Christian religious leader discussed the religious formalities surrounding the care of a dying Catholic person:

> 'First of all they would expect, from a Chaplain that you would have met them in hospital, if it wasn't too sudden obviously. That you will have given them the 'last rites' in inverted commas. We call it the sacrament of the sick (RL1)

The Christian Religious leaders discussed the 'sacrament of the sick' or 'last rites' along with the religious ritual of anointing the sick. Although the sacrament was once seen as being performed exclusively on a dying person, more recently the sacrament has been given to sick patients in general and not exclusively to those in their terminal stages:

> 'To the older patients it was only done really around the time of death, this sacrament. Of course it is not just a sacrament of the dying…That's how it is envisaged, that's why we have tried to get away from it, and if you look at modern books you never say a phrase like 'last rites', in fact we never use the phrase 'last rites'…..(RL6)

> '…with any sacrament, strictly within the catholic faith…sacraments are for the living. The way that you could put that more positively would be to say that the dead don't need sacraments, they are in the presence of, they are in the presence of God already' (RL6)

The significance of confession and anointing were also discussed and their significance both for the journey of the deceased person and their preparation for being in God's presence, and the comfort that these rituals gave to the bereaved in the knowledge that all had been done to assist their loved one.

6.2   Emotional manifestations of bereavement

Three key issues relating to bereavement emerged: *grief, guilt and questioning*.

A Muslim relative poignantly described the diverse responses to grief. She subtly dismissed overt demonstrations of 'extreme' behaviour which some Muslims display, stating that this is non Islamic behaviour:

> '..it's fine to cry, whatever comes from the heart or the eye, and you know, there's nothing wrong with that but it's, you know, like sometimes people in the past they wail or hit themselves and things like this, and this, it's not really something you should do' (M4)

Overt displays of grief following bereavement were also discussed by a Jewish religious leader. Whilst he acknowledged that people experience sadness due to the loss of the physical presence of a significant person, he felt that this should be tempered by the knowledge that the person had now moved on to a spiritual plane, nearer to God:

> '…it's said on the Talmud one should never spare tears at the death of a good person … … in other words we don't look at gratuitous crying. But somebody has died, somebody has moved on, we no longer have the physical benefit of their presence, for that we cry, that's absolutely legitimate'. (RL8)

Although expressions of grief through displays of emotions were acknowledged by a Christian religious leader from the Roman Catholic perspective, he questioned the universality of the experience of grief, from a purest religious context. He felt

strongly that a person who had an absolute faith would not feel a sense of loss and therefore would not feel the emotions of bereavement:

> 'If a person has a strong faith they should not grieve If a person's faith, in Christianity certainly, was, in a sense, strong and perfect, if you like, then they would never see it as a loss. Therefore they would not grieve' (RL1)

Although a contentious statement, from a secular perspective this comment suggests that absolute faith can transcend the physical domain of the impact of death with a belief in a temporary separation ending with a collective spiritual reconnection occurring in Heaven.

One of the most powerful components of grief can be *guilt* and an associated *questioning* of circumstances and actions. These aspects of grief were apparent within a Christian wife's reflections upon whether she had done all that she could for her husband:

> '….and I was also very guilty with myself, did I do enough, did I care enough …… had I always put him first, um … and now of course on reflection I know that I was only human and none of us can do the impossible, but it's taken time to come to terms with that' (C3)

The experience of guilt and an associated questioning of care was discussed by a nurse when she recounted feelings of guilt following the sudden death of a patient under her care. She shared how she had promised the relatives she would look after him and expressed her feeling of guilt and 'if onlys' when he died without his family present:

> 'I felt terrible because the last thing his wife had said to me – she was a little old woman – and she grabbed a hold of my hand and said "you're going to look after him – you're going to sit with him', and I felt I was to blame then and it was terrible …… I had a lump here – I felt so guilty – if only I hadn't sent them home and they would've been there' (N2)

Guilt was also expressed by another nurse who felt personally responsible for being unable to make a patient's final hours more comfortable:

> 'I feel I neglected him because I cannot give any comfort to him'. (N1)

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A further dimension to the concept of guilt was discussed by a Muslim relative when he questioned whether he had done the right thing by "allowing" the doctors to switch off the life support for his mother:

> 'Yes, but to this day I sometimes do feel guilty that did I do the right thing. I know for a fact they said she won't survive, we've taken that but you still feel guilty that you have let them do even that gradual switching off the thing'.(M6).

This highlights the importance of communication and roles and responsibilities for end of life decisions. Unclear or ambiguous discussion, however well intended, may result in pain and anguish and recrimination for many months if not years, for the bereaved.

6.3   Last care and its implications

The *last care* given to the deceased person had *implications* and significance for many of the participants for many reasons and from many perspectives. The *last offices* procedure and preparation of the deceased person for burial was of paramount importance to all the Muslim participants. A significant proportion of the Muslim interviews contained careful explanation of what was required for the deceased person at the time of death and funeral and, very importantly, why:

> 'When a Muslim person dies …. we have to have the body facing towards Mecca ….. the body has got to be cleaned, ….the body has to be buried as soon as possible…there are various steps and various stages to this which have got to be followed very strictly'. (M1)

There appeared to be very clear instructions to follow and an absolute requirement to perform these correctly. The importance of participating in the last care of the deceased person and performing the Wudu (the ritualistic last wash accompanied by prayers and recitations from the Q'uran) in particular, was seen to be an honour by all the Muslim participants:

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'…it's quite amazing because you'd think that you would be very emotional, but um, you kind of feel it's an honour to be able to do part of that' (M4)

and led to a feeling of both moral and religious satisfaction once the procedure had been performed:

'…once she was dressed in the white cloth and everything, as if she was satisfied then, the look on her face, you know, it was quite touching'. (M4)

Although participation in this procedure was seen as an honour it was also seen as an obligation to be undertaken. There appeared to be a protective accompanying numbness and disbelief of the situation, similar to feelings associated with the immediacy of a death:

'You don't believe, um, at the time sort of, your mind's not thinking this is the person, um, you just feel like 'This is what I have to do', , I suppose it is afterwards that it, you know, sort of hits you then'.(M4)

Performing Wudu and being involved in the last offices of the person was not only perceived to provide benefits for the deceased person, by placing them on the right path for their journey into the next dimension, but also to provide rewards for the people involved in this last ritual:

'….you kind of feel closer to God …… you know, there's a big reward for the person who helped to prepare for the funeral, they say on the day of judgement he'll be dressed in silk, you know, he'll be honoured because what he does' (M4)

To be involved with the funeral arrangements was seen as a selfless act of kindness, in keeping with the words of Allah within the Qu'ran and the good deeds of his prophet Mohammed. It was thought that those who performed these selfless deeds would receive divine rewards for their actions which would benefit them on the Day of Judgement.

The importance of one's own religion and the significance of same religious orientation when dealing with a deceased person was discussed by one Jewish

relative. He appeared to be impressed that the staff had left his father in law undisturbed after death until the 'expert' Chevera Keddisha arrived. Interestingly, he referred to his father-in-law as 'the body' immediately after recounting his death and clearly showed the withdrawal of family at death and the relinquishing of responsibility to the Chevera Keddisha. This process appeared to signify the abrupt severing of life and death and the immediate transition from person to be cared for by family to 'body' to be appropriately disposed of by the burial society:

> '…as I recall they took the body into a private room … and left it there undisturbed without having being asked to do so which was good. They merely covered the body with a sheet and left it which was good. We were told it would be left in the room without being disturbed until the um, Chevera Keddisha, the burial society came to take it away' (J6)

This segregation of the deceased Jewish person after death impacted on the nurses providing the last care offices. One nurse stated that the fact that nurses were not 'allowed' to touch the body after death was upsetting for her and her colleagues. She explained that although they had provided intimate care to the person over the previous weeks and months, they were not allowed to perform their last duty of care for them:

> 'The families can be very cold and they give the feeling that you can't touch the body and you feel that you are restricted to – you know you've looked after the patients for months and months and months, you've been hands on with them and they've been hands on with you – and then to take that away…. I mean, you can hold them in your arms when they are actually dying and then that patient - the comfort they get out of it, I mean just stroking them is comforting isn't it and then like when they do finally pass away it's like closing the door dead quick and washing their hands of them, …, surely you want to give that care to …… it's very cold' (N2)

The inability to provide this last act of care left her feeling robbed and upset by the fact that she had not been able to say a final goodbye or pay her last respects to the patient:

> 'You just feel it and you haven't had time to say your goodbyes because usually when we do………. We say our goodbyes, that's taken away from you as a Nurse which is very – (distressing). It's like closing the door dead quick and washing their hands of them, and to me that's more for the family than the deceased because if they were like that in life, surely you want to give that care' (N2)

The majority of nurse participants recounted their experiences in providing the final care for their patients. The act of last offices was felt to be a duty that should be carried out with exemplary respect and dignity for the deceased patient. One nurse told how she often talked to the patient when washing them for the last time as, this made the task a little less difficult for her. Whether this could be considered to be a denial of death or a continuing respect for the person is open to discussion:

> 'I mean I feel talking to the patients who are still there with me until they have gone – I'll say "I'm just going to roll you" and some people will go "what are you doing", but to me it's for my sake and their respect and their dignity (N2)

Another nurse recounted a discussion with a colleague about the practices of last offices and suggested that their execution reflected the nurse's individual beliefs and customs:

> 'we were talking about just clinical practices, and we were talking about years ago when we were all students about people opening windows to let spirits out….Flowers on people…. customs and practices. … I guess those are our elements of personal, personal experience or personal beliefs aren't they and how you then transfer them'. (N3)

As an example of the potential differences in interpretation of care and respect at the time of death, one nurse discussed the 'traditional' placing of flowers on a deceased person. Although she acknowledged that some nurses and healthcare assistants perform this ritual as sign of respect, they were unaware that it may be seen as offensive in certain faiths. She concluded that nurses and healthcare assistants inadvertently risked imposing their beliefs and customs oblivious that these may not be in accordance with the deceased's:

> 'Like those people with the flowers, they get really offended when you say ' no don't put flowers on the shroud' What if that person never had flowers ….gently try and tell people that it's not acceptable they don't always like it… you can't make that assumption" I would rather leave plain,. (N4)

The time and care taken by a nursing colleague to open a window for the soul to leave impacted profoundly on one nurse participant. The fact that time had been

taken to respect the spiritual 'unseen' side to death as well as the immediate

'seen' physical care left a lasting impression:

> 'I always remember working with her (a colleague) and we'd laid a body out and she opened a window and …said 'because you have to let the soul go' ….and that's what she believes in and I thought that was lovely.   Yes and I thought 'God how… you know, what a nice way to think about things'. (N5)

However, another nurse felt that although the last offices procedure should be

undertaken properly and with respect she perceived that some of her colleagues

did not:

> 'But it is one of those things that people will get blasé about or joking about, you get inappropriate giggles, but the ultimate is that you don't do last offices to do it badly, you want to prepare somebody properly'….I think last offices is something that is horribly neglected. Not by everybody, and not out of malice. (N4)

From the relative's perspective, both Muslim and Jewish participants voiced

concerns about doctors, nurses and healthcare assistants understanding of

cultural and religious requirements in general but especially at end of life. A

Muslim relative expressed his concerns about doctors', nurses' and healthcare

assistants' competency in cultural and religious requirements at times of dying

death and bereavement and the fact that ignorance in these aspects may result in

needs not being met:

> 'And also the cultural and religious issues, I mean are they being followed or if the doctors and nurses aren't aware of what cultures they are, are they being asked as to what they need?' (M6)

However, one Jewish relative felt quite strongly that if special religious

requirements were needed, the responsibility for ensuring they were

communicated and carried out lay firmly with the relatives as advocates of the

dying / deceased person and not with nursing staff who may not understand or be

from the same faith:

> '….I think there is a little bit of an onus on the family to ask a question or two. I don't think it should be that the family stand back and say 'well it's up to them to get it right' * and complain if they get it wrong' (J2)

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Cultural and religious needs were concepts raised within the interviews with doctors, nurses and healthcare assistants. Several nurses and healthcare assistants suggested that a limited knowledge about other faith requirements was acceptable as long as time was taken to sensitively ask relatives what may be needed.

> '…with the Muslim faith and the Jewish faith, or whenever you are not sure it is best just to ask the family what they want….And that comes with a bit of maturity'(N4)

> '…..and why should it matter that you take five minutes out to go in and say 'what would you like us to do and what do you want us to do and what do you want to do, do you want to wash the body – do you want to stay in whilst we wash the body – you know – you tell us really' You know what's the harm in that'. (N5)

However, through discussion it was suggested that dismissive and flippant attitudes were displayed by some nurses and healthcare assistants in response to differing cultural and religious requirements at end of life:

> 'It's like banging your head against a brick wall sometimes……Mm, because they're not bothered really – they just think 'oh well it's done now' – they don't think about the next Asian person that will come in or say like the next Jewish person…..The family wanted to be in the room while we wrapped him – one member of the family wanted to stay – and people were huffing and puffing and 'oh they're looking at us' – 'well no, they're not looking at us they're praying over the body you know', oh – you can hear them chanting – they're not they're praying – you know'. I did have an argument - I said 'look you have to respect other peoples culture' I said, you can't just treat everybody the same and you know – we've got nowhere to put these people – if they're in the corridor if you ask them to move they'll move – it's not a problem…No, I mean they don't say 'oh what shall we do, we'll stand in the middle of the corridor and annoy them', you know they actually…… their Granddad is dying.' (N5)

Community support was also discussed in the contextual dimension of 'body'. The roles and responsibilities of the Jewish burial committee, the 'Chevera Keddisha' were explained by a Jewish religious leader. The Chevera Keddisha appeared to take over responsibility for the deceased person from the relatives and dealt with all the administrative aspects of the funeral. Relatives were required to take a step back and were dissuaded from taking an active role in the funeral preparations:

> '…before the burial, the Chevera Keddisha come in because they are involved with the preparation of the body, um, for …Family are not allowed to be part of that.. (RL8)

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He also shared how their role included the provision of comfort and a presence for

bereaved relatives immediately after the death of a loved one:

> '…so the Chevera Keddisha will go to the family, they will sit with them, um, , it says in the Talmud that the first three days of mourning are for crying… why? because the initial stage is the loss'. (RL8)

The Jewish relatives discussed some of the rituals of the mourning period

following the death of a relative and their significance. One Jewish man was at

pains to explain that 'Shiva' was a serious formal recognition of the death of a

person, not a social 'party' gathering in the same context as he perceived a

Christian wake to be:

> 'bereavement is taken very seriously in the Jewish religion…..we have the process of shiva which is sitting for seven days at which time, during which time, um, it's effectively open house, it's not a wake, it's not a party… as a visitor you are required to wait and be spoken to rather than have a party (J6)

Another Jewish relative appeared dismissive of the traditional Christian way of

dressing in black for a funeral. Her perception of a Christian funeral was that of

both a party and an occasion for indulging in self pity:

> '…and going around looking for black clothes …sorting out what is it the wake or whatever – because we have NONE of that. In fact the women there they don't dress up at all – no – sack cloth and ashes type of thing'. (J1)

Some of the rituals associated with the Jewish mourning period were described

although, for some relatives there was uncertainty as to their actual meaning:

> '…all the mirrors …had to be covered so you don't think about yourself. Somebody comes and cuts … (laughing) you usually wear something old. They cut it,on the left side (why) I don't know is it so everyone knows who the chief mourners are?....no I don't think so I think its, isn't there something in the bible about renting/ rendering well tearing clothes' (J1)

The essence of the 'Shiva' mourning period was alluded to by one relative as a

time of reflection where a person could take time to accept their loss. Therefore

external 'distractions' such as entertainment and thoughts of personal appearance

should be disregarded for a time:

> '…no music and then there's officially periods of mourning, – there's the initial 7 days – there's 30 days altogether of mourning where you shouldn't listen to music; you shouldn't … no dancing… I don't think men shave either cos you are not supposed to think of your appearance' (J1)

The spiritual significance of the ritual of Shiva was explained by a Jewish religious leader and the use of this protected time to begin the journey of acknowledgement and acceptance of the loss:

> '…bereavement is coming to terms … we try very much during the week of shiva to swap around physicality and swap that round to make a spiritual dimension ..it is to the spiritual aspect not the material aspect, the body that no longer functions.' and that's what we try and do during this week of shiva, and that's what all the practices are based around' .(RL8)

He suggested that the emphasis of a Jewish funeral is to assist the living to carry on without the physical presence of the deceased; for whom, there is the belief that they are now entering their second stage of life:

> 'Therefore everything that Judaism does, um, with regard to preparing for death, all the procedures dealing with the dead and what we do with regard to the dead once they have died, um, is all based on this concept of an ongoing life, um, and the relationship of those who are now alive in this physical world, how they relate to the soul of this person who is now on the second stage of life' (RL8)

The time frame of mourning allotted to mourners was explained by a Jewish relative. His explanation highlighted the hierarchical levels of mourning dependant on the person's relationship to the deceased person. A mourning period of one month would be expected for the death of a close relative (for example a brother, sister, wife, husband, child) but a period of one year should be undertaken for a parent, in recognition that, although one can in theory have more brother, sisters or children, parents are irreplaceable:.

> '30 days for if you lose a partner – a husband or a wife cos you can re marry; but if you lose a parent … but if its parents, you can't replace a parent* so it's a years mourning'. (J1)

> '..Seven days where they are in the house, for thirty days they can go back to work, then for parents only, in other words for father and mother, and we only have one father and one mother, that period extends to a year, well eleven months actually' (RL9)

A structured, *finite period of mourning* practice within the Islamic faith was described by both a Muslim religious leader and a Muslim relative:

> 'Normally it would be at least 40 days, but they should continue actually, they should lead their normal life, like the same way but Islam does not stop them going out going and doing necessary things. But in general people stay at least a month or 40 days at home. Some people more, some people less depending on their individuals' (RL4)

> 'Because I think we have this sort of 40 day thing whereby all the community members come along most of the days until 40 days' (M6)

It appeared therefore that, as with the structured approach to the start of the grieving process, there was a rigid finite end to its end. However, although an end to traditional mourning was stated there still appeared to be a flexibility to accommodate the individual's needs.

Although the relatives from the *Christian* faith did not mention specific cultural or religious rituals around support from family and friends; one participant discussed the compassionate leave that she was 'allowed' by her work. She tearfully recounted the days following her mother's death and how such a short period of time was insufficient for her to undertake funeral arrangements. Sadly, it appeared that she received little help or support from family or friends during this time:

> 'I only had two days bereavement leave. I think that's normal procedure, and it's not long enough. I had the day after she died and the day off for the funeral and in between I went to work. And to get the day off after her funeral I had to take it out of my holiday. Um, now people don't expect special treatment but I do think that when people are in my situation where I had no immediate extended family, I'm divorced I don't have a husband or a partner, I have no brothers or sisters, I'm an only child, I really could have done with a bit longer…...bereavement leave they just think of, you know, when it's a close relative you get two days, if it's a distant relative you don't get time off at all, perhaps have a few hours off for the funeral, and it's not enough' (C4)

Addressing the secularisation of some parts of Christian society and the associated lack of religious ritual, one female doctor stated that the prospect of caring for a Christian patient and their family was easier. This, she suggested was

because they usually had less immediate end of life and bereavement expectations than those of the Jewish and Muslim faiths:

> 'I just lump Christian into anything that isn't… "How terrible am I?" (Laughter). I lump Christian into anything that doesn't need anything doing about, you know, like anything special, isn't that awful …it tends to be a bit more relaxed because I don't, you don't have to do anything instantaneously. You don't have to predict, you know, are they going to die in the next hour, are they going to die tomorrow, can the early team sort this out or not. And so for doctors I guess they're slightly less involved' (D4)

6.4   Moving on, looking back

The concept of *moving on* within the bereavement process is often applied to bereaved relatives, although the concept and associated feelings of *letting go* have been questioned in bereavement research (Stroebe 1996). For one Christian relative the thought of reinvesting in new relationships was inconceivable and integral to his new life from now on would always be *looking back* to happier times. It appeared that his memories, although not as good as the 'real thing', were the next best thing as no one would ever be able to replace his late wife:

> 'Never go out with another one I'm afraid, 'I know, I know how I feel and I know exactly how I will react'. I could predict my reactions to anything or on anybody, it won't make no difference….never mind, never mind. Good old days, they won't come back' (C1)

For one Christian woman, reintegrating into a social scene without her husband was a daunting task to undertake. However, she discovered that being with others in a similar situation helped her to adjust to the new circumstances, reinforcing the healing power of social support:

> '… I remember the first Christmas, I was invited to go to a widow's lunch, and I remember going into this room, all alone … … my first reaction was I'd got to run out….., inside I wanted to cry and cry and scream. … And then of course I realised that I was in a room of four hundred ladies in the same situation as me, you know … without a partner. And basically from then I started to adjust and know, you know, that you have to go forward, um …' (C3)

For the Religious Leaders, part of their role appeared to involve facilitating relative's acknowledgement and acceptance of their loss and of the loss of the

physical presence of the person. Their aim was to help relatives reflect back to memories of times together with their loved one and to help them gently accept the reality, finality and new dimension of their life from now on; to move them from *outside* as a physical presence, *in* as an internal spiritual presence:

> '…in the preparation I said there is one thing you can't, you can do all of those things, you can reflect on your past lives, you can celebrate the love that you shared and so on and so forth but you can't sit together, lean over and do that, in other words you can't just touch somebody and so on, and, you know, I can't do anything about that. You can't do anything about that that is the one thing that you know loose, but it is the only thing you lose'. (RL7)

> '… We miss the physicality … and that's what we grieve … but are we unhappy for the individual? … of course not. Are we totally separated from them? … on the contrary, in the spiritual sense you are closer now than you were before, but you have to be able to move yourself over into that new reality, um, like the twin who felt it was all over, it is just the beginning So what one grieves is the physicality because we are physical people … and even the most spiritual person is a physical person. Um, the fact that you can't hug the person, the fact that you can't make them a cup of tea…somebody has moved on, we no longer have the physical benefit of their presence' (RL8)

> ' there is very little family fuss … because we want to move quickly the family on…And this is where a lot of people have difficulty with, generally with religious faith and especially with Judaism because we are not scared … to move people on'.(RL8)

Within the interviews there was discussion around *the universality of the phenomenon of bereavement* and whether the participants felt that it was a universal experience for all, or an experience that was unique to each individual. One Christian relative was very clear that bereavement was a unique experience:

> 'I think, you know, regards bereavement I don't think you can categorise it, and certainly it's different for each person' (C3)

The concept of the *uniqueness of the loss* was an important factor for another Christian relative. She recounted how people's well meant advice meant little to her as she perceived that they had no understanding of her unique frame of reference and the enormity of the impact of the loss on her personally:

> '…they have never experienced what I have, I don't think they quite understand how I feel'. (C4).

This sense of inability to capture, or truly appreciate, the dimensions of another person's grief was also expressed by a Christian relative, suggesting exclusivity within the inclusive phenomenon of bereavement:

'… Nobody can ever understand what goes on in your mind' (C1)

The importance of being able to *talk about the loss* and to express one's emotions was important to a Christian relative who suggested that a failure to do so may lead to an extension of the bereavement experience:

'… and I think as well people don't talk about it. You cannot do it. It's not possible, you bottle it up, it's three times as long'. (C1)

This was also an important aspect for his daughter in law. Although from a traditional family perspective the position of daughter in law may be perceived to be on the peripheries of the mourning hierarchy, she felt the need to talk about her mother in law's death and her feelings of loss with her husband. However, her husband found it difficult to verbally express his feelings of loss for his mother and he often became uncontrollably distressed when his mother was mentioned:

'It's hard to watch somebody though … 'coz I want to talk about it and… there are so many things happened this year that you know, it's all… I want to get it out but he won't… you know what I mean' (C2)

Similarly a Muslim reflected upon his inability to express and communicate his feelings about the loss of his mother. He felt that this may be connected with the fact that he was a man:

'Sometimes I am feeling something; I cannot explain what I am feeling into words. So it's difficult, hence you know, you just remain quiet…. I can't explain it. It's probably just men'. (M6)

A nurse stated that she felt that the experience of bereavement is different for everyone and that each person has their own individual way of dealing with their grief at their own pace:

'People say that bereavement is like in a scale – but a scale does not work for everybody,– ….you're going to start off like this – you're going to start off like that everybody is different – we've all got our own ways of coping' (N2)

Echoing a similar theme, another nurse stated that people deal with death differently and therefore responses are sometimes hard to predict. In light of this, she argued that it was easier to care for bereaved relatives if they were known to the nurse, as there would hopefully be more knowledge of the family relationships, personalities and personal reactions, therefore responses to grief would be easier to predict:

'Everybody responds differently to death and you can't always anticipate, you think some people are going to go over the top as in a huge emotional response and start screaming and they just sit there and they just … and you can see them calm down, just withdraw. And those are the people that you can't hug, so that's why it is easier sometimes to deal with relatives when you have known them for a while' (N4)

One doctor, who identified his religion as Hindu, felt that the bereavement experience was as individual as the person. He suggested that it was a person's life experience, regardless of *cultural dictate*, that influenced their *bereavement response*:

'It is as individual as a person is, I reckon…..life experiences relate to that (bereavement) massively and that is irrespective of culture'. (D1)

He also made a poignant differentiation between the culturally imposed external manifestations of bereavement and the individual emotional and physical responses to it:

'But I suggest from what little I have seen of people from other faiths and well within my own sort of culture that it does not actually vary – it is just the external manifestations vary.. –I think, yes, there are variations in how people manifest their bereavement process but fundamentally I do not think it actually differs as much as perhaps people may think it does. I think people go through similar stages they just – some stages may be more prominent and last longer with people of different cultural backgrounds. Umm, but the feelings and emotions are necessarily the same – the way they manifest them may be different, externally….But the hurt is all the same and it does not change – because people are not different – in that sense'.(D1)

Although acknowledging the uniqueness of the bereavement experience, one doctor highlighted the impact of a person's religious belief system and how this will influence a person's bereavement experience:

> 'I think that is very different, I think different cultures and different religions cope with bereavement in different ways. I mean some of their practices I guess are sort of outlined by their religion, they must do this and they must do that' (D3)

A Jewish doctor expressed her belief that although bereavement is different for everyone there were fundamental 'feelings' associated with loss that transcended religious beliefs. These were associated with the basic, primordial fact that the person was no longer a physical presence in their life:

> 'I think there are certain feelings, regardless of beliefs, however strong, people feel for the sheer, somebody was there and now they're not' (D4)

6.5   Good death / bad death

The concept of a *good death* or *bad death* and perceptions of what these may entail from a physical or 'body' perspective, were discussed in many of the interviews. These concepts looked at the differing aspects to death from physical, emotional, religious, spiritual and social perspectives.

The doctors, nurses and healthcare assistants recounted their experiences of both types of deaths that they had witnessed. One nurse recounted a 'good death' whereby a patient had died in her sleep from heart failure, rather than being asphyxiated by her neck tumour. She recalled the comfort that this mode of death had given to the family:

> 'It was the perfect death for her, it was absolutely perfect – you know she could have choked to death with the tumour, but she didn't – in the end it was her heart that had stopped – and the family there was not as much mourning as much as relief' (N2)

From a more altruistic perspective, one doctor suggested that a 'good death' was one which facilitated the end of suffering and, as such, was the best possible outcome for the patient:

> 'A good death …as in – it was good that the patient dies…..ending of suffering ….if a patient does die then you sometimes think " Well that was actually probably the best thing for them'. (D1)

Another doctor recounted two pieces of simple advice that she had received in Medical School. She felt that these were key to facilitating a good death; the first was to actually go and physically see the patient and the second was to ensure that they received adequate pain relief:

> 'Because to make somebody have a pleasant and comfortable death is – everybody says when you're a House Office – you can do 2 things for people, one is to see them (laughs) and secondly is you can prescribe Morphine (laughs). That's what we were told on our first day and I think that to a large extent is true – yes you can see them and yes you can prescribe Morphine to make things comfortable for them' (D2)

Ruminating on her grandmother's imminent death, one doctor felt that her grand mother would experience a 'good 'death if the following were in place:

'there was somebody there, that she could hear somebody and that she was comfy' (D4)

The concept of a good death from religious leader's perspective appeared to incorporate the elements of mental awareness, an acceptance of impending death and a peacefulness of mind:

> '…if we talk about a good death you are really saying that you want that person to be happy and peaceful, really. And if you can reassure the person that everything is going to be ok and they feel, not just hopeful but certain, 'yes, it is going to be ok' then they will not see it as a death'. (RL1)

> 'I think the good death would involve truthfulness about the situation in which the person dying is aware of what is happening, certainly has been fully informed… I think the good death would involve the … um truthfulness about the situation in which the person dying is aware of what is happening, certainly has been fully informed there is quiet awareness and acceptance' (RL3)

The presence of others was seen to be of comfort for the dying person, and, in turn, provided comfort for relatives:

'The presence of people, of loved ones um, hands being held, things being said, um even after consciousness has apparently gone still the words of gratitude, or appreciation, memories being shared' (RL3)

'I mean I can think of wonderful death beds that you go to where the patient is surrounded by their family, they're alert when you go there, they know what you are doing' (RL6)

'…but just that she wasn't on her own and that she was comfortable' (D4)

The concept of *being held in the arms of love*, physically and spiritually and metaphysically, was significant for a Christian religious leader:

'…where it's meaningful to the person yeah, prayers and assurance of God's presence and that God's love continues beyond death and that they have a hand holding them, hands holding them and that they are within the context of love, and love is not going to let them go, so all of that would be associated with a good death' (RL3)

A Christian Religious leader realistically acknowledged that even though a death may be perceived as good it would be naive to assume that it would therefore be pain free or without distress as, by its very nature, loss is painful:

'I'm not pretending that good death is pain free or distress free because it can't be I don't think, because there is loss there on both sides, and loss is painful'. (RL3)

For one nurse, the reality of seeing a person die fighting for life was in stark contrast to the fairy tale deaths of childhood tales or TV soaps:

'People cling on to life like………. or it's not all close your eyes and go to sleep………. and they're fighting and legs are kicking horrendous and you're looking - that's terrible' (N2)

She recounted the traumatic death of a patient who bled to death following a carotid 'blow out'. In the midst of this traumatic 'bad death' the importance of maintaining her composure and providing reassurance for the dying person right up to the very end was of paramount importance to her. Suggesting the ability, however limited, for medical and nursing staff to influence the experience of death:

'He just sat back because he knew his family was around him, he knew …– always had a smile … he did have a horrendous death, bless him – it was horrendous – was so long … the patient is aware of what's happening as he can see sprays of blood –you're there and you're trying to reassure these patients and they're looking directly at you in your eyes, and your holding their hand and you're saying "I'm just going to keep doing this" and you're trying to reassure them – and they're reading every expression on your face' (N2)

One of the doctors felt that a bad death was not solely about the experience but incorporated the mode of death too. He felt that deaths caused by trauma or violence were seen as 'bad' because they were potentially avoidable. The very nature of these 'unnecessary' deaths suggests that they will potentially have a negative upon the relative's bereavement experience:

> '…violent death or accident – I mean due to criminal or accidents – are seen as needless deaths and quite reasonably so – they are potentially avoidable'.(D1)

From a conciliatory perspective, one doctor felt that in an event of a 'bad' death, one consolation was that the 'memory of dying' would disappear immediately the person died and that this belief may provide slight comfort to the bereaved:

> 'The only way you kind of rationalise that is after they die there is no memory of events that precede it so that is one thing that you can perhaps comfort yourself about'(D1)

The concept of a 'Bad' death was also explored by the religious leaders. A feeling of being robbed of the experience of life was seen as a contributing factor to a bad death for one religious leader:

> '…if a person were kind of felt that his life was being taken away from him I suppose you could consider that to be not a good death'. (RL1)

Uncontrollable pain was seen as another contributing factor, not just because of its effect, but because its presence would hinder a person's ability to focus on preparing for death:

> 'If somebody is in dreadful pain, both of us have experienced this, in, in our work, and … you, there isn't that settling down to inevitability…. Trying to cope with, with the pain they can't cope with anything else. … that then produces, you know, that bad death scenario' (RL7)

Although the elements of a good or bad death were not explicitly discussed by the relative participants, the concept of a bad death through the presence of *suffering* was. Suffering was described as one of the main reasons for life not to continue.

One Christian relative intimated the degree of suffering that his wife had experienced:

> 'That woman suffered more than I would wish on any, ... even me worst enemy believe you and me…'(C1).

A nurse described how she felt relieved at the death of her father as she selflessly acknowledged that it was an end to his uncontrollable suffering:

> '…although it was a great release because it is terribly, terribly difficult watching…….
> Watching someone in the last throws and he would just rear up occasionally in great pain' (N3)

A possible explanation for suffering was given from a religious context by a Muslim relative. He proffered that the experience of pain in this life meant that they would suffer less in the next:

> 'They say that actually illness is like if you are ill in this life it is actually purifying you, so if you have difficulties in this life you won't have it in the next life so much'.(M4)

6.6   Summary

The personal experiences of the impact of end of life care through the existential concept of Body, and its importance and impact upon the bereavement experience was discussed by all participants. Table 10 provides a summary of the emergent themes for the existential dimension of Body:

Table 10.   Existential dimensions of Body

BODY
Moving towards death: • Premonition • preparation • Care, respect and dignity • presence
Emotional manifestations of grief: • Grief guilt and questioning
Last care and its implications: • Last offices • journey of the soul • Exploration of cultural and religious requirements • community support or isolation
Moving on, looking back: • outside in • Universality of the phenomenon of bereavement • Uniqueness of the loss • Cultural dictate
Good death v bad death • Control • Lack of suffering • Presence of others

Both relatives and healthcare professional participants recounted a 'gut' feeling that death was imminent. There was universal agreement that time for preparation and being present when death occurred were important physically, emotionally and spiritually.

The role of the religious leaders at time of death was discussed and differences emerged. For the Christians, there appeared to be both physical and emotional involvement before death. However, it appeared that the physical presence of the Jewish and Muslim leaders were not required immediately before death but that their roles became significant in the funeral preparations for the deceased and then with rituals and support for the bereaved.

The responses to the death of a loved one were described by relatives and nurse participants. It was acknowledged that these were highly emotionally charged and were often erratic and uncontrollable, but that full expression of these emotions was both normal and healthy.

Participants spoke with pride about the honour of being involved in the last care for the now deceased person. This was mirrored by disappointment and distress from nursing staff when denied the opportunity to fulfil their last care duties because of perceived religious incompatibility.

The mourning rituals of the Orthodox Jews and the Muslims were described in great detail. Although there was no discussion about formalised mourning rituals from the Christian participants they did discuss difficulties that may be rooted in the apparent lack of structured support in secular Christian society. The ability to 'move on' through the bereavement journey following the death of a loved one was discussed and it was apparent that for many of the bereaved, the concept of 'moving on' was incongruent to them.

The question of whether bereavement is the same or different for everyone raised much discussion. The majority consensus was that bereavement is a unique experience that may have some similarities in its core phenomenon that most people will recognise.

What core elements constitute a good death and bad death were explored and their influence on the bereavement experience of those left behind. Elements of a good death incorporated control, a lack of suffering, the presence of others, a peacefulness of mind and the feeling of being held in the arms of love. The elements of a bad death included an inability to control pain, or when a death was traumatic or could have been avoided,

Many participants recounted the suffering that they had witnessed and death was seen as a welcome visitor in these scenarios.

The existential and physical aspects of Body, as recounted in this chapter, all appeared to have significance with regards to the bereavement experience.

CHAPTER 7

RESULTS: THE EXISTENTIAL DIMENSION OF RELATIONSHIPS

We have to believe that even the briefest of human connections can heal. Otherwise life is unbearable.

Agate Nesaule

We humans are social beings. We come into the world as a result of others' actions. We survive here in dependence on others. Whether we like it or not there is hardly a moment of our lives when we do not benefit from others activities. For this reason it is hardly surprising that most of our happiness arises in the context of our relationships with others.

His Holiness the Dalai Lama

This section explored the data that emerged on the existential dimension of relationships and their significance within the phenomenon of bereavement. The interrelationships between all participants were explored and the perceptions and expectations that manifested in relationship to end of life and bereavement were explored and six key themes emerged.

➢ **Intertwining of relationships along the bereavement journey** emerged. This journey incorporated the experiences of relatives of their *continuing bonds* with the *deceased* and a *loss of dreams* for the future. The concept of continuing bonds also drew out the *power of prayer* during bereavement and the significance of *dreams* as ongoing channels of communication with the deceased person. Relatives' perceptions of the care they received from staff was also discussed.

➢ **Shades of truth** and **white lies** uncovered issues regarding *communication, trust, mistrust and white lies* were all addressed.

➢ The essence of **relationships across the divide** revealed participants thoughts and interactions with *God* and their *religion. Similarities and differences* both *between and within religions* were uncovered and within this both *pride of self* and *prejudice of others* manifested. *Beliefs in an afterlife* enabled participants to

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view their interpretation of their bereavement journey, from the perspective of their deceased loved one and in relation to themselves and the journey they were yet to take.

➢ The ***imprint of bereavement*** explored the impact of bereavement on participants. Views on whether an involvement with the final care for the deceased person carried *personal rewards* were expressed. The expectation of *support from friends and / or the religious community* emerged as a consideration for the bereaved person.

➢ The expectation and experience of ***bereavement counselling / support*** highlighted whether it was adequate *or inadequate*, and *culturally and religiously sensitive.*

➢ The importance of ***education and training*** for healthcare professionals on *end of life* and *bereavement care issues* were raised by participants as a means of enhancing the support that good relationships can offer.

A worked example of the data analysis for the dimension of Relationships is provided in Appendix G. The main emergent themes will be described and illustrated with quotes from the participants using their unique identification codes as described in Table 7 Chapter 3.

7.1   The intertwining of relationships along the bereavement journey

The existential dimension of relationships, within the phenomenon of bereavement, appeared to be significant for all participants. The *inter relationships* between all those exposed to the death of a patient were explored within the interviews. The pivotal relationship, discussed by all the relatives, was the one that they had experienced with their now deceased loved one. The feeling of a spiritual inter-connection with the person was shared by two Christian relatives:

> 'She was my soul mate, I think so….We're like two peas in a pod, well we was, … I knew what she was thinking and she would know exactly what I was thinking. It's unbelievable … yes, absolutely unbelievable' (C1)

> '… we were very much soul mates, you do feel part of you has gone, you know, you think your right arm has gone'. (C3)

The belief of a *continuing bond* or relationship with those who have died provided comfort and gave meaning and a continuing sense of purpose for some of the bereaved relatives. Oyebode *et al* in (2001) outlined manifestations of continuing bonds with the deceased including *A general sense of the deceased, Mental interaction and Symbolic representation.* Within this study, these aspects of a continuing attachment with the deceased person were a useful tool to explore the experience of the bereaved person with the altered relationship to their significant other. One aspect of continuing bonds Oyebode (2001) identifies is that of a continual inclusion of the deceased person in day to day activities and a general sense of the deceased. In this study a Christian relative recalled how her daughter had saved a seat for her recently deceased grandmother:

> 'We went to a pantomime a couple of weeks ago, now that's something Mom always ordered, organised, …and our babby said 'We better move up and leave Nan a seat' (daughter C2)

She also described how she herself had bought a present for her deceased mother. This action could be interpreted as a transient denial that her mother was no longer alive or a bargaining gift in the subliminal hope that she would return:

> 'I see things in shops and I say… you go to buy them sometimes…... I bought her a pin badge the other day, and thought 'What did I do that for?' (Daughter C2)

'Mental interaction', manifested as the bereaved talking to the deceased person as a way of continuing their relationship and involving them in family matters and appeared, for one relative, to be a way of keeping the absent person abreast of family matters through involvement by proxy:

> '….and I talk to her as well…especially having Elizabeth 'coz obviously she didn't see Elizabeth (baby daughter) So, (getting upset) that's hard'. (Daughter C2).

This one way conversation with the deceased person provided support for another Christian woman and she shared how she talked to her husband when things were difficult for her:

> '(I) talk to him when things are going wrong' (C3)

Symbolic representation, was demonstrated as a need to live life in a way that the deceased person would approve of with one Christian relative explaining how, for her, this involved doing things in a way that she hoped would please or be acceptable to her deceased husband:

> 'I try to do things that I think C would have wanted me to do. Rightly or wrongly I know he is motivating me…..No, you see so somewhere I am still wanting to please him'. (C3)

One strong theme which emerged throughout these recollections was that of someone from the 'afterlife' returning to 'collect' the dying person:

> 'I always say someone comes to fetch you. Someone of a late family will come and fetch you. I think so D always believed it. .Her always said 'when I go I hope mom comes to collect me… Silly but um … I believe it. Unless somebody can prove me different, and I don't think they can' (C1)

One Christian relative recounted the last time that he saw his late sister. He explained that she was seventy five and 'compos mentis' but that she had told him, on his last visit before her death, that she had been talking to her father. This unnerved him as their father had died fifteen years previously:

> 'Her said 'Dad come to see me… we was having a right old chat', her said 'Then he left'. I said 'Ah, that's very nice for you'. I've got to be honest I was a bit twitching towards that way, but it seems very strange. They rang me the next day, I was about an hour away from going up, and they notified me that she had passed away'. (C1).

The presence of a 'welcoming committee' after death was alluded to by one relative. She had been informed by a friend who was a faith healer that people in the afterlife were waiting to receive her husband:

> 'I had another colleague of my husband's who was a faith healer …… and he came over to visit and he said um, 'They are all ready for C' he said, 'and it will be peaceful'. He said … and I thought, well everybody is working to make it good for him …… there must be something in it, you know. We're not to know until it is our time of course' (C3)

A nurse shared her experiences of caring for patients at the end of life. She recalled that some held a belief that they were going to be reunited with their loved ones after death. She stated that she had witnessed on many occasions, the dying patient appearing to see or hear someone or 'something' shortly before their death:

> 'More often here somebody will say when they are dying "I'm going to see my mother now" or "I'm going to see my wife" and they say it …just coming to their last breath they'll sit up and they'll look and they're putting their hands out….somebody is coming' (N2)

Another nurse told of a side room in which dying patients would look to a certain corner, as if someone was there, waiting for them. This phenomenon occurred on more than one occasion and had been witnessed by more than one nurse:

> '…in the side room on (ward) when people used to look in the corner – there was the corner and a little shelf – and everybody used to look in that corner and point – it was so strange and that was why people would never go in on their own – they'd point and you'd be looking and people would go 'oh it's the drugs', but they always looked in that corner it was really strange and then after that it wouldn't be long and they'd die…. I do genuinely think that there was something in that room. I think… you know there were too many people for it to just be a coincidence – you don't just stare – it could have been somebody for them' (N5)

Several of the participants experienced a feeling of the deceased person's spirit being physically near to them. This feeling of presence or closeness to the deceased was a comforting factor for one Christian relative:

> 'On Sunday I laid on a hot and cold buffet and eighty seven people came in that day, signed a card and talked about C. And it was a good day …And I felt he was there every minute, I really did' (C3)

This ability to sense the deceased person was also expressed by a nurse recounting a patient's death. She vividly described how she could both see and smell the person she was recollecting. This clearly demonstrated the powerfulness of memory and the physical manifestations that it can evoke:

> ' I kept on seeing L – I can still see him – I can smell L now just talking about him – I can literally smell L. god bless his soul, just talking about him. I could see him and I could smell him – funny how you talk about somebody you can get that' (N2)

The loss of the physical presence of the person, and what that entailed, was described by one Christian relative, hinting at the many differing levels of interaction within a relationship:

> 'I wish he was here for that cuddle…I get frustrated and why isn't he here, and I have to ask someone to do something he would do, but that's all part of it and everybody has to cope with that'. (C3)

Associated with the theme of continuing bonds and absence of physical presence was the *loss of dreams* for an anticipated future with the deceased person:

> 'But I wish she was here I have to be honest.   … but we had such great plans for when we retire, and now they won't come to,… I'm not looking forward to retirement at all, I was, but I'm not anymore'. (C1)

The utilisation of continuing bonds appeared to provide a buffer from the experience of loneliness and abandonment that the death of a relative may bring.

The ability to 'do' something for the deceased person after death was seen to help ameliorate feelings of guilt and helplessness. One Muslim relative shared her Islamic belief that continued contact with the deceased could be maintained through prayers. She stated that prayers and good deeds in memory of the deceased person provided comfort and rewards for the person in al- Barzakh (the 'waiting area' for the Day of Judgement) and that they provide 'light' for them on the Day of Judgement to facilitate them being seen and accounted for:

> 'But people can pray for others who have passed away …… it can be … it's like light comes into their grave then, this was like relief for them in the grave, you should read aloud when you go to a grave so everybody can sort of share the blessings of it, . …..If someone has passed away going on Haj is like a big gift for them … there are certain ones (passages from the Qu'ran you can read and you make the intention to send it for that person's sake… if someone gives charity on behalf of the person it is like light for them, to ease the burden, and maybe they will have more light on the day of judgement'…(M4)

An ongoing 'awareness' after death and a continuing emotional two way connection between the deceased and the bereaved was described and explained by several of the religious leaders. The *power of prayer* in these circumstances was advocated as a means of communication across the world and otherworldly 'divide' from the bereaved to the deceased person:

> 'A life in which I think um they are aware of us on earth so there is still a linkage I say you pray for each other, validly pray for each other, the one who is living, the one who has died'. (RL3)

> 'It is mentioned in our Islamic traditions. That once somebody passed away anybody pray for them would get to them' (RL4)

> 'I think there's a deeper point that we also have more of a sense within the Catholic tradition of Christianity of praying for the dead. …..the Catholic faith teaches that we're a much more at communion with the dead and we have a tradition like in Catholic countries, you know and there are days of the dead in Mexico and we have a big tradition of all souls day, and of praying for the dead. We have a big tradition of praying for someone on the anniversary of their death …So there is that sort of structure. And there is that theology that we see ourselves maybe linked with the dead, that's a bit sort of …at a communion with the dead…That the dead pray for us and we pray for them' (RL6)

From a Jewish perspective, the significance of the Kaddish prayer, with regards to a protective continuing bond with the deceased, was explained:

> 'One of the reasons why we say, the Kaddish prayer, is that um, a Kaddish guards, um, the soul of the deceased from any of the more strenuous, perhaps from our perspective, more negative ways of being cleansed off, um, for an hour and a half. And that's why there are in fact sixteen Kaddish prayers said a day … which gives you twenty four hour protection. so, the family down here are still helping the soul on its journey … but in a very practical sense, albeit spiritual' (RL8)

A continuing connection to the deceased person through the medium of *Dreams* was discussed by a Muslim religious leader. He stated that a deceased Muslim was able to communicate with the living through dreams and could give reassurance that they were at peace, or in need of spiritual assistance through prayer or Zakat (donation to charity):

> 'People come to us in good dream, bad dream yes. People see their beloved one who died in good conditions, very happy, you know 'oh I saw him, he was praying', things like that. If anyone saw him in a bad situation obviously they feel bad and they try to do something good, giving money to the charity'. (RL4)

The experiences and perceptions of their relationship with doctors, nurses and healthcare assistants during the time their relative was dying and when they died was poignantly explored by many of the relatives. Discussion centred on the care that they and their relatives had received. In general the care was perceived to be good and was genuinely appreciated. Through their recollections they recounted, in minute detail, acts of kindness bestowed on them and their dying relative, by doctors, nurses and healthcare assistants:

> 'Well, um …they got her as well as they could possibly get her in my opinion…. this hospital and these doctors treated my wife like she was a queen' (C1),

> '….she was made comfortable, and she had um, well, from her diagnosis with leukaemia until she actually died I cannot fault any of her treatment at all' (C4).

One Christian relative tearfully recounted the kindness of the nurse involved in her mother's last care and the comfort that such physical contact had provided:

> 'I won't ever forget the nurse who was on duty because she was so lovely (getting rather upset)… I will never forget what the nurse did (getting upset) she actually put her arms around me, and hugged me, she said that it had been an experience for her, she said that she'd witnessed true love in that room between my mother and I' (C4).

An appreciation of the care their relatives received was also expressed by both Muslim and Jewish relatives:

> 'All the staff there (on unit) were very, very good, basically, and the nurse that was in charge of her she was very good' (M6).

> 'Really I couldn't fault it in any way. (J2)

The support and comfort that doctors, nurses and healthcare assistants gave to the relatives when their loved one was dying and after their death was recollected by two Christian relatives:

> '… (The nurse) comforted me … she was saying the right things at the right time. ….I knew she was sincere and … I felt that it was comforting', (C3)

> '(Doctor who certified her mum) he offered his condolences and actually hugged me and that was so nice, and then he left' (C4)

However, this kindness and compassion was not universally experienced and one Muslim relative expressed his disappointment with the staff providing care for his mother:

> 'They were very cold ….they need to be human about whoever they are talking to because I think it's all about the approach and the tone that you use. It's not even about knowing the language….they became very, very stroppy (when) we went to ask them any questions … they just wouldn't respond to us at all' (M6)

7.2   Shades of truth and white lies

Shades of truth and white lies were aspects of *communication* between staff, patients and their relatives. The way in which information was imparted, to whom, by whom and in what manner, were all important dimensions of the relationship that relatives experienced with doctors, nurses and healthcare assistants. One Christian relative stated that open and honest information was of paramount importance, no matter how dire the news was:

'I mean, truthfully I think it …. You'd have been… you can cope with things a lot better if people tell you the complete truth, not a half… the complete truth' (C4).

This concept was reinforced by a doctor who felt that honest communication was important. However, he was mindful that such information should be carefully delivered to allow a glimmer of hope to remain:

'You have to tell them the truth and if they ask you a straight question you have to give them a straight answer, but you tell them as much as they want to know really …..I think hope is probably the most important thing and keeps them going through the day and otherwise they would sink into a miserable depression and you know' (D6)

During the interview, a doctor explored his beliefs around 'good' communication which he felt was an essential aspect of a doctor's role. He went on to describe what he would expect if he was in the relative's position:

'I would imagine that if somebody is about to pass away, you know, good communication with the family is very important, to explain exactly what the problem is, what the prognosis is, the fact that the patient is very unwell and they are likely to pass away. I mean I would like to know that if I had a relative that was unwell' (D3)

A Christian relative recounted an incident where she felt that communication from medical staff had been sparse and described the associated anxiety that lack of information and fear of the unknown had generated for her:

'And it wasn't explained to us in anyway, and I think that would have helped, if it had been explained and I could have understood better … and I thought to myself are they doing this because they know she is not going to pull through, but they are not telling me, that did go through my mind' (C4).

How the 'bad news' relating to the imminent death of his mother was broken caused great distress to a Muslim son. The way it was imparted caused a rift in the relationship between the family and the doctor. The relative felt that that there was no longer any personal care for his Mother or his family and they had been reduced to the level of 'another statistic' at a time when they were in need of compassionate care:

'All night we though they are doing all they can and hopefully she will be fine and then suddenly at 6-7 o'clock in the morning the consultant comes…, "who is she?" and I said she is my mom and he said to me "do you know she is very, very sick?" and I said well I know

she's not well. In fact he said "I will go one further, in fact she is dying" and you just can't take that and it wasn't that he even sat next to me or told me in a nice polite way, he was just standing there as though he was just doing his job and that to me was quite blunt… Yes, okay I took it but obviously it takes you aback…. You become like a number really' (M6)

Doctor, nurse and healthcare assistant participants discussed whose role it was to impart bad news. There appeared to be differences of opinion about which profession was most appropriate and able to adequately undertake this task. One doctor explained that some of his colleagues found it difficult to break bad news and therefore tended to express it as quickly as possible:

'…and the doctors tend to say "oh yes she'll be alright" or "oh no, there's nothing we can do" and then scoot out the room as soon as they can'. (D4)

How badly a doctor had imparted the news of the death of a patient to relatives was recounted by one nurse. She recollected how upset she had felt by his manner, posture and that he had left her to comfort the family and answer questions on his behalf:

'The doctor that actually came round was very blunt and very to the point. He didn't even sit down.. He just came in and said 'well we did everything, '…and he just sort of said 'I'm sorry he's dead' well I just think he said 'I'm sorry' and that was it well obviously they were …and he just went 'mumble mumble' and walked out and you think 'well thanks for that then'. and answering their questions which really I shouldn't have to answer – when the Doctor comes in he should explain everything' (N5)

One doctor said that she had often been asked to give bad news to relatives by nurses who did not feel comfortable imparting the bad news themselves. Although she acknowledged that this was a part of a doctor's role, she concluded that it was often difficult if she had not met the patient or relatives before and was solely reliant on the information contained in the medical notes and the nurse's information:

'….you're often asked to come and speak to people or break the bad news – sometimes nurses do it and sometimes they don't want to and that's fine… you know at the end of the day that's our job, … but that's quite a difficult thing to break the bad news to people that you've never met before and all you've got is what the nurse tells you and what is written in the notes' (D2)

The concept of *trust* manifested as a very important component within the relationship between doctors / nurses and relatives / patient. Relatives found themselves in a vulnerable position and were heavily reliant upon the doctors, nurses and healthcare assistants being honest, open and caring towards their loved one and themselves. This dependant relationship occasionally became damaged as a result of poor communication or perceived lack of care. This breakdown of trust had the potential to lead to misunderstandings that may manifest into conspiracy theories. For one Christian daughter, her trust in hospital staff was put into question when she asked what time her mother had become terminally unwell during the night. The conflicting information that staff gave her drained the trust that she and her family had conferred upon them:

> 'The timings never matched did they? That's what got me and Dad …. the timings never matched…… she'd obviously got the time wrong But like…But that didn't add up … you still get an idea… who to trust and who not to trust'.(C2)

Inadequately explained causes of death left two relatives with confusion over how their loved ones had actually died and a longing for the last piece of knowledge about their deaths:

> 'Yes, even today if somebody explained to me I would be willing to sit down with somebody and say what did you find?... That, you know… on the death certificate you said renal failure but I knew that, so can you explain to me what was the cause of that you know… um… Even after a year I would love to know but' (M6)

> '…so, what sort of heart attack I've never been told….Or what caused it … nobody knows. (C1)

The concept of truth took on both cultural and gender dimensions for one doctor as she recounted her experience of a barrier in communication with a Muslim family. She felt that it had been fraught with difficulties due to a perceived unwillingness to face the inevitability of death. She also felt there

was another agenda for the family which involved a reluctance to acknowledge or listen to a young white female doctor:

> 'They don't trust you in a way…. 'The patients not going to die'… and you know they want to be with them all the time ….I don't think that they particularly trust……the medical profession and the nursing profession, they especially don't trust white women doctors……they certainly respond better to men… I think most of the Asian sub continent community respond better to men anyway. A lot of the elderly patients who are British respond better to men… um and they also have more respect and more acknowledgement for people who are older and who have obviously been in the job for a while – which you can understand,….. It's almost a complete disregard because in their culture you're (women) a second class citizen really –so the idea that some little white girl is coming to tell them what to do…' (D2)

Another doctor recounted a situation where she had been required to clarify the bureaucratic requirements associated with a death of a Muslim patient in hospital. She described how the family appeared to feel that she was being deliberately slow and unsympathetic to their needs. She felt trapped between the family's wishes and the legal procedures that she was obliged to undertake before the patient could be released from hospital care:

> 'But sometimes you get the impression that they think you are being deliberately obstructive, … well why aren't you sorting this out and you explain again why and they are just like, you know, we need to do this and you say I understand that, I am listening to you and I hear you but I still have to phone the consultant at home, if it is in the middle of the night to release the body etc', (D4)

She concluded that, in light of this experience, she now found it a daunting task when asked to speak with family of a dying Muslim:

> '…so it can be difficult when it is out of hours and you know there is going to be a huge distressed family and some of the young men are going to be aggressive and the women are going to be wailing and you are the wrong colour to understand them, for example, if you are Caucasian you kind of imagine that you are going to be in for a rough time whatever, even if you have a good grip of what is going on. And I think that is a shame' (D4)

The need for staff to use plain, uncomplicated language, rather than *euphemisms* and *medical jargon* was raised by a nurse. She recounted the difficulty that some relatives experienced when vague terms are used to explain the death of a person:

'I think when we say to relatives "they've gone" I hate that – I never use that terminology – they could be in the room for 10 minutes before they understand that…..   It   could   mean he's had treatment and he's gone home' (N2)

The use of medical jargon or 'medi speak' as a means of protection by doctors and nurses was also highlighted by a religious leader. He stated that often when this occurred, especially at times of death and dying, he was placed in the position of interpreter, attempting to explain to relatives what was being said in layman's terms:

'… Both our medics and our nursing staff do sometimes for their own protection use medi-speak don't they? And, I'm not saying that's wrong, I'm just saying that sometimes it's good to be an interpreter'. (RL7)

The 'embarrassment' of death was highlighted by a Christian religious leader who offered the explanation that euphemisms were used by staff in an attempt to cover up death's existence:

'Death is the last taboo in our society, it is different in other societies in the world where perhaps ...death is very visible;…we still sort of cover it over quite a bit in our society, so probably that's still lingers on, people don't talk about it, they talk about 'passing away' um, and we use these euphemisms in hospital, so we collude with that if you like um, which I think is unfortunate' (RL3)

Withholding information from relatives was discussed quite openly by several of the doctors, nurses and healthcare assistants. One nurse expressed a personal belief that not divulging the full information and the use of *white lies*, in some instances, was beneficial for the relatives:

'…I have lied, because that was kinder, I wasn't going to say "no actually he was in agony and he died at the end on his own because I was getting his morphine and I kept him waiting for twenty minutes" .It is better to say "no he was comfortable and I was there" or somebody else was holding their hand, because nobody else is going to turn round and do an incident report to say that J lied because… you're going to break somebody's heart…'(N4)

However, for another nurse, honesty was an integral part of her role. She expressed concern that doctor, nurses and healthcare assistants sometimes underestimated the intelligence of relatives:

'The other thing I find is that people aren't very honest with families…, this ringing them up and saying 'oh I don't think it's going to be very long' – when they've been dead for half an

hour. I find that appalling Yes, …… you know people aren't stupid and I think, I think nurses and doctors seem to think that relatives perhaps are sometimes' (N5)

From a doctor's perspective, one female doctor suggested that a degree of common sense, involving being slightly economical with the truth, was sometimes kinder than informing relatives of the harsh reality that they might have inadvertently contributed to their loved ones death:

> 'This woman in A&E had had a huge row with her husband that morning, he then had a heart attack and dropped dead, she's like "I killed him''. You just have to allay their fears, even if I mean having a row probably did contribute to, you can't tell them that, you know, you need to have common sense about what it is that you tell them……there's no need to be brutally honest all the time'(D4).

This concept of 'cushioning the blow' was supported by a religious leader who suggested that some information may be potentially damaging if imparted without consideration:

> 'I believe in telling the truth but I don't believe in telling the truth cruelly '(RL3)

7.3   Relationships across the divide

Relationships across the spiritual 'divide' were explored. Of significance was the participant's *relationship with God* with regards to the phenomenon of bereavement. It is an acknowledged fact that during times of great difficulty many people turn to religion for support and comfort. For others, there may be a rejection or denial of a God that could allow such a situation to happen to them.

One Christian relative spoke of her anger towards God, holding him responsible for her loss. However, she accepted that these intense feelings had gradually evolved into a realisation that 'God' was, in fact, looking after them both:

> '…you know, afterwards of course I was angry with God …… very angry with him,… but um, now I'm not angry with God anymore, I feel that he's taking care of C and that um, he's taking care of me' (C3)

A nurse explained how she could understand how people might turn away from religion and be angry with God following the death of a loved one:

'It's part of their bereavement – they turn away from God they turn away from the church – they're so angry – why has God took him – why has God took her – and the logic has gone out the window then' (N2)

A Muslim relative explained that those practicing the Islamic faith and possessing an overwhelming belief in God and his Prophet Mohammed, meant that their passage to Heaven would be assured:

'But this is a strong thing, if we believe Mohammed, this is not we say, this is Allah say (God who says this) – if you believe Mohammed you are mine, this is the big thing and you will be clean after that. If you read once in your life, once in your life li la illa la rusulla, Mohammed (pbuh) going to go on judgement day and ask you is there any people who said li la illa la rusulla Mohammed once in their life…. He ask it (Mohammed) as well – you know – you are the best friend of God' (M2)

The role of the religious leader in relationship to God was discussed. One Christian religious leader discussed the omnipotence of God and the associated role of the priest in the preparation of a person to meet God:

'It's putting the person basically in God's hands you see. And I try to explain to them that they are asking God's help to get better; but also if its not God's will for them to get better that they will trust in God to take care of them. In the next life. So every catholic, err, every catholic that knows about this, always, always, want the priest to be there for them at that moment in time…… When a person dies, in our faith, then God takes care of the whole situation. So depending on how God judges that person if you like, its in his hands anyway'. (RL1)

A Jewish religious leader explained that, for those of the Jewish faith, the soul is a part of God himself implanted within, therefore a person of the Orthodox Jewish faith would be constantly mindful of this, in all of their words and actions and in their preparation for death:

'On this earth is the time when the body and soul should be acting in consonance and that's why there is a whole code of how a Jewish person should act … and the reason why we act the way we act is that makes us in concert with the spiritual soul which is imbued within us which we see as a portion of god himself'. (RL8)

An individual's *relationship with religion* was raised by several of the participants. A Jewish relative explained that although a Jew may not have been religiously

observant during their lives, they may feel a spiritual need to return to their birth

religion at times of dying and death:

> '…even the people who are not orthodox will be buried. They want to die the right way' (J2)

This concept of primordial comfort derived from birth religion was explored by

several of the participants:

> 'You see a lot of people who turn away from religion and yet when they're ill – it's like at points, at crucial points – people that haven't been interested – they suddenly want that reassurance in religion, in a God… if it makes people feel better and it doesn't do any harm' (D2)

> 'People often sort of go back to these cultural faiths when they are forced to face the reality of death' (D6)

> 'Even if they have been away from the church, physically for 20 / 30 years they still want us there …… they return to their roots. And they remember what they were told when they were young. They may have put it on one side for long periods of their lives but they still remember' (RL1)

A religious belief, in the absence of proof, was the most fundamental aspect of any

religion for one Christian religious leader. The acceptance of a concept that was

not tangible and could not be proved was a basic requisite for such a belief:

> 'Faith, that's the essence, faith is the assurance of things unseen, and always will be and, you know, at the end of the day we don't know, we can't prove It' (RL2)

Similarities in beliefs around death and bereavement within the Abrahamic faiths

were acknowledged by some of the participants. A nurse made comparison

between all three faiths:

> 'coz looking at the actual faith the laws for high Church of England and Catholicism and Judaism and Muslim, they're not that different'.(N4)

The interfaith relationships within the Abrahamic faiths were highlighted by some

of the participants. One Muslim relative highlighted the similarities between Islam

and Christianity which manifested in the belief in one God and acknowledgement

of Jesus as a prophet. She stated that a person could not call themselves a

Muslim if they did not accept these fundamental beliefs:

> 'Our Islam says if you read Muhammed is Prophet, Jesus is Prophet … One God this is important…– Mohammed is (God's)best friend. This is good you are Christian because you believe in Jesus…. This is good, we believe in Jesus as well. We believe Jesus as a prophet he is prophet – we believe strongly. If we don't believe, we are not Muslim' (M2)

However, *differences* in which Christian and Muslim funerals are arranged were highlighted by a young Muslim woman who had converted from Christianity to Islam. She described how, in Islam, there was a significant role for relatives at the time of death and with funeral preparation. She suggested that there was more acknowledgement, awareness and acceptance of death in general from a Muslim perspective in comparison to a western secular Christian perspective. This acceptance and involvement, she felt, allowed Muslims to be more prepared for, and able to deal with, bereavement:

> 'I mean this is the first funeral, Islamic funeral I have ever been to. …I felt a part of it, I felt I could do something, …because we look at death in a different way maybe, a society where death is seen as so sad, I mean it is something that is difficult for the people that are left behind but your sort of purpose in life is really to go back to, you know, your Lord, so in a way people, you are sort of preparing for that as a Muslim' (M4)

There appeared to be a muted feeling of religious superiority from some of the relatives and religious leaders. This manifested within two interviews with Jewish relatives in reflected criticism at the length of time a Christian funeral took place after a death. For them this perceived 'delay' resulted in the bereaved experiencing the acuteness of their grief twice – once at the time of death and again at the funeral:

> 'Somebody dies and you've got over the worst shock and then two weeks later you have the funeral*. And it starts all over again' (J1)

> 'It's not go away and come back for a funeral in a week's time,…there is no need to have the body hanging around, the Christian tradition of leaving the body for a week just in case he comes back to life is, causes double bereavement, you can't get back to your normal life, but a week later you relive the death…… whereas we, we have the death and burial in the same day and the healing can start straight away'.(J6)

Conversely, a Jewish relative also acknowledged that the speed in which the Orthodox Jewish community bury their dead may appear, to other faiths, as hasty and uncaring:

> '…yes because I would imaging that people think 'oh how callous quick get rid of them quick' (J1)

A Jewish religious leader explained one of the differences in the provision of bereavement care between Judaism and other faiths. He suggested that the bereavement ritual is directed towards the person moving on, which may be perceived as being very prescriptive. He felt that other religions were not as directive in their ways but inferred that the orthodox Jewish way was the right way:

> 'And a lot of other systems (religions) tend to say what do the people need … um, we are sort of looking at it from the, not that we are a load of bullies, but we, you know, we understand what needs to be done and how to bring people forward and so in that sense we are quite upfront and we actually take over because the bereaved need time just to come to terms with what's going on, with things that need to happen' (RL8)

From the Christian religious leaders' perspective there appeared to be a need to demonstrate their universal role as spiritual care givers for all faiths. This may have been in recognition of the historical Christian focus of hospital Chaplaincy and the requirement, in the absence of other faith representatives, to minister for all:

> 'I get called all over the place. I actually pray with Sikhs; we talk to Muslims as if they were just one of the crowd' (RL1)

> '…..will have very good conversations with Muslims, with Hindus with Sikhs, with Buddhists, very friendly, they will view us as a spiritual figure very often. I mean I have never, some Muslims with a particularity of that religion as Christian is a particular religion who really don't want me to come, you know, it would be quite risky, I might try to convert them or something ……. but that is a rarity, more often than not there is a friendliness, there's a recognition as you say of one's being a spiritual representative' (RL3)

> 'We would act as gatekeepers (for people of other faiths)' (RL3)

There appeared to be a muted acknowledgement that ministering for other religions would not necessarily be acceptable at times of crisis and that, at such times as bereavement, most comfort would be found in their 'known' 'own' religion:

> 'Say you were on ITU, say it was me, and my Dad was dying and all of a sudden a Muslim turns up and says 'I'm the Chaplain on call', how would I react to that? Id' be thinking 'Well hang on a minute', or the Sikh, or B turned up, and said 'As it happens I'm the Chaplain on call, I happen to be Jewish, you're Christian, but there we are, does it matter?' (RL2)

Interestingly, the *differences* of interpretation and observance that are present *within the same religion* was discussed by some relatives

> 'What you need to know though is that there are many levels of orthodoxy in the Jewish religion as there are families, and I um … I am both a fundamentalist and a heathen depending on who is looking at me' (J6)

One nurse felt that it was not just different religious beliefs within a religion but the overlaying of different cultural interpretations as well, which were influencing factors in a person's response to bereavement:

> '… so how the culture perceives death, what happens after death, there's going to be…, it can be a difference between cultural and religious… just because somebody has got a religion it doesn't mean they follow that religion, and then there is the culture because as you have said, the culture of somebody who is Muslim is going to be different if their culture is English than if it was Pakistani or Indian' …and you've got some Christians that veer towards recycling as in incarnation…and Christians that believe in heaven and hell and an absolute' (N3)

This was mirrored in the reflections of a doctor who also acknowledged the differences within faith groups:

> 'They're not one homogenous entity, you see some differences there' (D3)

A nurse discussed the clear divide between religion and its cultural interpretation within secular Christianity today:

> 'I think our white Christian Catholic, Church of England culture, not so much the faith because if you look at the faith it's actually quite positive dying, but culturally it's not something you talk about, it's not something you celebrate, it's closed casket, it's very dour, you dress in black. You go to other Christian faiths, because of their culture they dress up and have a great big party. Irish people have a wake'. (N4)

Further support for this concept materialised from a religious leader as he acknowledged both diversity and discord between differing sectors of the same religion:

> 'The group actually who are a bit, keep away, are the Jehovah's Witnesses….Yes, they are, because I have a feeling they're instructed not to mix. In their own Kingdom Halls, meeting places, there is a clear instruction 'Don't mix with other, with Christian denominations and so on', so they obey that by and large by asking us to keep our distance, which is a bit sad, humanly because one wants to be at least friendly'. (RL3)

Concepts of *pride and prejudice* emerged from the participants as they described and explored their religious perspectives and the perspectives of others. Two Christian religious leaders from the Roman Catholic perspective expressed their religious pride regarding their 'Orthodox' perspective which accompanied a subtle dismissal of other sections of the Christian faith:

> 'What we do sometimes, far more than other Christian traditions is we involve the family far more in the funeral than others do…… the Anglicans may well do that but we do it on a regular basis' (RL1)

> 'Some of the things are cultural, things like large numbers of people coming around the death bed is cultural for instance. You wouldn't expect that from an English Catholic (but) within a traditional Irish family everybody would come'.(RL1)

This separatist approach of the Roman Catholic branch of Christianity was also acknowledged by a Christian religious leader from the Anglican perspective. He alluded to the fact that this inter religious divide was driven by the clergy not the lay person:

> 'Sacramentally, there is still this division so um you know a catholic will want to receive communion from his own church and not another church, and similarly what is seen with the sacrament of anointing and commending to God in death he will also want that to happen very much within his own church rather than from someone else. Um, not something I personally feel happy about but it is the state of the church at the moment….And you certainly don't want to tread on people's toes and say 'Well, never mind, I'm a hospital chaplain' tough you know….(Catholics) will certainly talk to me perfectly happily and invite me to pray and say we believe in the same God and we broadly believe the same things anyway don't we so I think sometimes the people on the ground as it were are more united than the clergy are, or the churches are' (RL3)

A part of the exploration of the phenomenon of bereavement nurses, healthcare assistants and doctors were asked for their thoughts on the concept of an *afterlife*. One nurse held the belief that people would meet up again in the afterlife. She felt that although it may seem a long time for those still alive it would only seem like a day until they were reunited for those who had died:

> 'Well I totally believe in the afterlife being a Catholic. I totally believe in that– there's not just us here, there's got to be a meaning for it "I don't mind if I pass away I will be with my husband – I will be with my children – they will come to me" – because eternity is one day when you're dead …my grandmother always used to say I'll see you tomorrow and she meant that in death as well – "I'll see you tomorrow – your time on this world is one day to me when I'm asleep"…"so I'll see you tomorrow" – that's the way I always look at it – I mean – even though it's been years, it's been one day before I go to see her (N2)

Another nurse shared her vision of the afterlife. She felt that the afterlife was an unknown entity but, following the death of her husband and the fact that she had had no contact from him since, was comforted by the thought that it must be so lovely on the 'other side' that people did not look or think back to their life before:

> 'Umm – sort of like the "big mystery" isn't it...I have been expecting at least somebody you know, can come and give me something in a dream. The way I see it, it is too quiet and they do not want to look back to the past life'. (N1)

One senior nurse described how she was brought up in a religious family but defined herself as an atheist. She shared her fear of death as a child, emanating from when she had tried to imagine being dead and not existing any more. She believed that an afterlife did not exist and that people only believed in the concept because they were death denying and frightened of 'nothingness':

> '….and that's why I guess I, you know, I fear death because I don't have that belief, … I fear death as well because I can remember as a young child thinking, …I can remember distinctly trying to imagine nothing…. trying to imagine dying and, or being dead and not existing any longer in any shape of form…. he (Father) used to talk to me about, the dead or the next-life spirits being all around you everyday in a kind of different um, not timeframe but in a different ……. existence, or dimension and I don't get that…. I don't believe in an afterlife and I think that, I think a lot of people are afraid to acknowledge that, that's my take on it'. (N3)

Although unsure about the concrete existence of an afterlife, another nurse felt that there must be something after death and not just a void of non-existence:

> 'I'd like to think there is something there and an afterlife – you have to have some sort of belief that you don't just die and that's it – there's got to be something'. (N5)

With reference to the bereavement experience, one doctor felt that, although people who had faith and believed in an afterlife and may be comforted by this thought initially, this belief would not make a difference to the bereavement process in the mid to long term:

> 'People who believe in an after life, and have an active faith regardless of which one of these three, or others, it may make it slightly easier for them to deal with in the short to medium term, in the long term outcome of the bereavement process with or without faith is unlikely to be much different'.(D1)

However, conversely, another doctor felt that faith and a belief in God would support people throughout the bereavement period and beyond into a new life without the deceased:

> 'In my opinion I think if you have a faith and a belief I think that would really help you get over bereavement because then you would have someone, or a being to turn to, i.e. God, and I think that would really help you get over the bereavement process'. (D3)

In a similar vein another doctor felt that, for people of the Christian faith, a belief in an after life would be very comforting and that people would feel relaxed at the end of their life, safe in their belief of a life hereafter:

> '…certainly for the Christian people I think that's a very comforting thought because if they've – if they have a relationship with God and they know God anyway and they have a proper Christian belief, not just "I believe in God" – you know they believe in the whole Jesus came down, he died for your sins you recognise him so you are going to heaven – it's a sure thing as long as you repent, you go to heaven so for Christians I think it's a very positive thing …. But Christians on a whole I think the afterlife is a very positive thing and I think that makes them very relaxed ….. Christians believe on the whole that life is just a bit of a rehearsal, but true wonderfulness – everything that was great here is going to be 3000 times better there' (D2)

However, it was acknowledged that no religion has categorically given concrete proof of a life after death, therefore questions and a feeling of uncertainty will, for some, always remain:

> '…and I don't I think that any religion has really been able to give a good enough explanation of what happens for people to say it's alright because they are going to heaven or they're doing this or they have became somebody else or. ….there is always a uncomfortable

uncertainness, and you're left without someone which is always going to be difficult regardless of what explanation you give it'. (D4)

For a Christian religious leader, the concept of an afterlife was one that he honestly admitted he could not explain as he had yet to experience it. However, he acknowledged that other Christians may have a more fundamental belief in the afterlife than he had. He felt that the body was redundant but the soul retained its own identity. However, he questioned whether there was indeed another dimension which we call Heaven or whether people remained only within the memories of those left behind:

> 'I have to say I have faith but I don't have foresight where, and I mean actually some Christians seem more sure than I have ever been able to find I could be so this is what I share with other people… the Christian faith is that you will retain your identity obviously lose this present body.. You will retain your own identity as one who is loved and valued, and unique' (RL3)

The inability to give absolute assurance in the existence of a life after death, or a definite explanation as to what happens to the essence, or soul, of a person was a concern raised by one Christian religious leader:

> 'But what happens to, that mysterious thing that attracts us to one another in terms of the , you can call it soul, you can call it personality, you can all it all sorts of things, but the spiritual dimension, for want of a better word, and that's a difficult one to explain, …..Will I see Uncle Fred again?' Well … I can't answer that anymore than you can' (RL7)

Lay people's thoughts about life after death were discussed and the need to balance 'simplistic' interpretations with possible alternatives:

> 'For many people um, there is this simplistic Sunday school vision of Heaven and so on, and um, you know they'll arrive and there will be Uncle Fred and so on and so forth. No, you know, I'm not going to argue against that, what they need is some sort of reassurance to how that, you know, is that going to happen, is that likely to happen, what happens after death'. (RL7)

This concept matured through discussion to the idea of a corporate soul rather than a collection of individuals:

> 'Now people find that very painful, they find the idea that they won't be reunited with their loved one, 'coz there is a school of theology that talks about the corporate soul and you become part of this corporate soul ..You don't, you no longer exist as D, or as B' (RL2)

Whether this corporate soul was multi denominational was not explored. This concept was explored by another religious leader from the perspective of an equal love where although there would still be a recognition of others there would be a universal love for all:

> 'There is a sort of equal love, yes okay you may see your loved ones again and they will be incredibly special but everyone else will be very special as well' (RL3)

A Christian religious leader attempted to explain the possibility that the afterlife may not be a tangible entity where the deceased person is replicated in spirit form. He suggested that people's memories can be reflected in the ongoing joy that we have for the people we come into contact with and the emotional situations that we experience. Inferring that human emotions are a reflection of Heaven:

> 'But what I can do is think, certain people in my life have made an impact, whose personalities have touched, again poetically, I can only express in terms 'have touched my soul', and it's those personalities who touched my soul, yes perhaps because they touched my soul some element of them will also always be with me regardless. (We) walk down the corridor and then all of a sudden our face lights up because we see so and so, and we have a love for and we recognise them, you know. And it is, taking that sort of delight. Now if that's a continuum in the time space calculation well again…, I say to people 'let it touch you', and it is on those occasions where you know …great events it doesn't matter what they are you know, always cry at weddings, funerals or something, it's this, it's, it's being there and I think part of that is part of, part of our understanding of, of um, our life in heaven' (RL7)

7.4   Imprint of bereavement

The *imprint of bereavement* explored the impact that the death of a person had on those emotionally and physically close to the person at the time of death and beyond. The *impact on self* of the loss of a loved one was discussed by two Christian relatives. For one, there appeared to be a selfless pity and a feeling of abandonment in the loss of all who had been significant to her. There appeared also to be a childlike questioning of her life experiences:

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> '....why can God be so cruel and take the one person, having lost my parents and my brother, you know, how can you be so cruel to take the one person I have got left' (C3)

However, for a Christian daughter, the knowledge of her mother's impending death enabled her to compose herself to support her mother through her last hours. Although incredibly difficult to do, she felt able to deflect her own feelings of grief to ensure that her mother's last moments were significant:

> 'I thought she was dying and I …. I thought 'I mustn't panic, I'll be no good to her' (C4).

This ability to remain self composed at such an emotive time provided her with comfort that she had 'been there' for her mother during her dying moments and this in turn appeared to provide her with continuing strength in her bereavement journey.

The emotional impact of caring for a dying patient, and their subsequent death, were important aspects to the care that the nurse participants provided. van Manen (2002) suggests that there can be a spiralling of emotions and this can be transposed onto the relationship between a nurse and a dying / deceased patient:

> 'The more I care for this person, the more I worry, and the more I worry the stronger my desire to care' (pg 272)

One nurse described the actions she took when a patient she was caring for died. She felt that a patient's death should always affect nurses emotionally. She appeared to feel that this personal impact was an aspect of a nurse's role as carer and inferred that if this were to be absent, the role of nurse was no longer right for that person:

> 'Go off and have a cigarette or go somewhere quite, have a coffee and just have 5 minutes for us, and then I always go and ask everybody how they feel, and are they feeling ok – it is a shock to people – people say you get used to it – you never get used to it – the day I get used to it is the day I will leave nursing – I'll be gone, I think if somebody says you'll get used it – no way – you never ever get used to this' (N2)

The ability to talk about and revisit her professional experiences of death in the interview appeared to be both cathartic and upsetting for one nurse:

> 'of all the deaths that I've experienced – that hit you deeper, but I'm – I'm so glad that I've talked to you about it now – you know –….(breaks down into tears)' (N2)

During the interview one nurse shared how she had been deeply affected by the death of a patient. She shared how expressing her raw emotions actually demonstrated how much she cared for that person and felt that such expressions were not 'wrong':

> 'I've been reduced to tears – I've seen other nursing staff cry with relatives – that just shows the relatives that you actually think of that patient as an individual – not as 'just another patient'. You know that you've actually taken the time to get to know them and it has upset you – and I think – I don't think it's anything bad in showing an emotion like that'. (N5)

A doctor suggested that the impact of a patient's death on health care professionals was not something that was openly discussed and that he personally felt saddened over the death of some of his patients. However, he felt that, contrary to the nurse's roles and responsibilities, doctors detach themselves emotionally from their patients in an act of self protection. He suggested that a failure to do this would result in a mini bereavement after the death of every patient and would therefore, in his opinion, not allow medical staff to perform their work adequately:

> 'Yes you feel sort of – sometimes a bit lower but ….And the reality is – and this is not often talked about – doctors and nurses, ……if it is only for a few minutes you feel "Oh how sad"….But the reality is that, as a medic, you do tend to disassociate your emotion from the patients otherwise if you had a bereavement process for every time a patient dies you just would not be able to do the job' (D1)

Similarly one female doctor acknowledged that there were occasions when she became emotionally attached to a patient, however, she responded to this thought with the suggestion that she needed to 'toughen up':

> 'Some deaths whether you know, it's because you got to know that patient a bit better or because it was very unexpected or whatever, they do touch you sometimes and certainly when you first start out in the job its quite a shock really. I tend to chat to people quite a lot

> on the ward and you get to know somebody and then you are there in the middle of the night trying to keep them breathing and then they die. Its awful, but you sort of toughen up to it a bit' (D6)

Mirroring some of the comments made by the doctor participants, the difficulty associated with walking into a very stressful situation without prior knowledge of the patient, or their relatives, was discussed by several of the religious leaders. The pressure of being in the spotlight at such an emotive time was seen as a cause of great anxiety:

> 'Some one has just passed on in which case one's needing to walk in there and relate to them very quickly and very sympathetically and sometimes it is quite difficult, people you've never met before, you don't really know the situation, I would just offer a few words of exchange just to establish trust really then go in to prayer. But not stay with them very long' (RL3)

> 'I have walked in to a single bed room, you know there are double bed rooms where the patients have been the only patient absolutely crowded with all ages of family, the wake almost if you like, sitting round the bed, and so that can feel quite difficult because you've got an expectant audience, it's like you are coming from behind a curtain to perform something' (RL3)

An important concept discussed by a Christian religious leader who was a Roman Catholic priest was that of 'over' exposure to death experienced by people working in an acute hospital. He suggested that whilst hospital staff may have seen the 'scene' many times before, there was a need to acknowledge that others (relatives) may be experiencing death, and, more importantly death of a significant other, for the first time:

> 'I think we have to realise as people who deal with death a lot that we um, we're in touch with bodies a lot, I mean I don't do things that nurses would do but I mean I do see people after death a lot, whereas to some people that can be their first experience of um, death' (RL6)

The sheer number of dying patients a religious leader was involved with over the years meant that, sometimes, they disappeared from memory. This was discussed with honesty by one religious leader:

> '…the other side is those deaths that you do get involved in. I think like most professions, most of them you can't remember, which sounds terrible but I think that is how you cope isn't it as a professional'? (RL2)

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The vulnerability of the role of religious leader was discussed on a very personal level by one Religious leader who was a Roman Catholic priest as he spoke of his isolation and the abhorrent bleakness of being alone with a deceased person:

> 'But I think one of the loneliest things, and I'm just talking about myself and maybe, you talk about the ideal death, the absolutely horrid thing is there, the patient is unconscious, there is no relatives, I find that very, very lonely and desolate……I have to say sometimes you are called in and you find the relatives have gone (laughter). And it is just you …… and it's even worse when it is a patient who has died, and that's just such a terribly desolate type of thing ... awful. ….. I have to pay tribute to staff, sometimes staff who are, probably haven't got a faith at all are aware of how isolated you are and they just stay with you in the room when you say that little prayer. And that is very supportive' (RL6)

The fact that exposure to death had a detrimental effect on those caring for patients was honestly discussed by another Christian religious leader. The importance of acknowledging this and developing strategies to deal with it effectively were explored:

> 'It is damaging, um, it damages all of us, and if we are caring for somebody we have got to actually come to terms with the element of, of grief and sadness of someone dying, one of our patients, and the reflected grief and so on of the relatives around them. Um … and we've got to know how we deal with that ourselves' (RL7)

The concept of *personal rewards* for selfless acts was discussed. This materialised as a 'dual effect' whereby a person carrying out good actions for the deceased would receive spiritual rewards, but that these good actions would also be felt by, and add to the deceased person's 'list' of good actions to be accounted for on the Day of Judgement. A Muslim religious leader explained the Islamic belief that any sustainable good actions or deeds a person carried out before death would continue to reap *personal rewards* for him/her after death:

> 'All the things that come to you, if somebody pray for them if they left something they made in their life good; they built a Mosque for example; or bridge or road or hospital or somebody is getting benefit, their heart (those who benefit) will pray for them – if you were a teacher you probably gave good teaching and from your teaching people are getting benefit so these things' (RL4)

However, although a moral and religious obligation exists for Muslims to provide support and comfort to the relatives and assist the departing spirit, it also became apparent that by doing so the person would receive rewards themselves:

> 'I feel that dealing with these difficult issues I will get reward and I feel that at least my time is valued. I thank God that I am doing something that is helping people. I wanted to do something which, any service I can offer, directly for the people – so I can immediately feed back….but some situations touch it was really touch. And doing good mean you will get forgiven from God for your bad things' (RL4)

The importance of caring for a deceased person and the personal rewards that a person would receive for this was also acknowledged within the orthodox Jewish faith. It was explained that helping a 'helpless' person would reap a mitzvah or 'personal reward' that would take the person performing it closer to God:

> 'A mitzvah is actually a commandment but nowadays we look at it as a good deed…..so we do a good deed for this person who is dead and that person will never be able to say thank you' (RL9)

A person's *relationship with others* at times of bereavement and the concept of *support* were themes that manifested throughout the interviews. What support the bereaved may need, who was most appropriate to provide it, when it was required and for how long, were all important and significant considerations within the existential dimension of relationships relating to the phenomenon of bereavement. Who provided the most appropriate support appeared to be a very subjective concept. One Jewish relative, although Orthodox in her views, felt that the support she had received from family and friends was more comforting than that which a religious leader could provide. There also appeared to be an underlying disappointment and an unmet expectation that the Jewish religious leader would take a more active role in supporting the family during their bereavement:

> 'I personally found I had more support from family and friends than the ones who were supposed to be supporting (synagogue)' (J1)

From a slightly different perspective, a Christian relative stated that the most significant support she received was from friends, rather than family. Although the support she received was of comfort, her family's distance and perceived disinterest lead to a sense of desertion and neglect:

'It was actually friends who helped us far more than family…. And since my mom's death I haven't seen my family at all since the day of her funeral in January have been very upset because I feel as if I've been abandoned by my relatives…… I didn't see the family, nobody came round, I was there entirely on my own and I cried all day. Um, and I don't know whether that was a good thing or a bad thing' (C4).

However, another Christian relative took a more pragmatic approach and was mindful of the limitations and boundaries of friendships:

'It doesn't matter how good friends and family are, you can't become a burden to them' (C5)

The theme of social isolation or avoidance was expressed by a Christian relative when talking about the immediate and long term reactions of his neighbours. This links in with the concept of a finite end to bereavement and how that can vary in perception. It also highlights people's discomfort with the phenomenon of bereavement and associated ways of avoiding awkward situations:

'Oh no, they kept away, they were like, neighbours were brilliant up until … about a week after the funeral. I don't see many of them these days …I think they are frightened of upsetting me, I don't know why' (C1).

This perceived 'avoidance' and associated 'embarrassment of the bereaved was dismissively acknowledged by one Jewish relative as an 'other' religious failing. He proudly stated that it was *not* something that would occur within the Jewish faith community where death and the associated bereavement were acknowledged and included rather than denied and avoided:

'Jews have no fear of talking to people who have suffered a loss … and therefore about talking about it, whereas non-Jews quite often, I've heard um, I've heard it said that non-Jews will avoid seeing people who have had a bereavement because they don't know how to deal with it' (J6)

A supportive and cohesive picture of Muslim community was painted by two Muslim relatives. The support provided by friends and community members was accepted without question and viewed by all as an obligation to be carried out. It was discussed as an absolute requirement for all and there appeared to be a muted assumption that this was normal procedure for everyone regardless of religious affiliation:

> 'And then all the nearest and dearest relatives who have experienced this, the community members are expected to embrace them and expect to say some words of condolences and some kind words to them and try and get them to get to terms with the loss' (M1)

> 'After that what happens is for the next ten days people will visit the family at their own home and they come and pay their respects on a daily basis. They will also offer any advice or help that the family may require' (M5)

A similar expectation of community support was expressed by two Jewish relatives. They described the significance of Shiva and the roles and expectations associated with it:

> 'Family come from around, friends come every night for the prayers and it's actually a great comfort cause your mind is…I know you have to grieve and mourn but you're not left by yourself to do it' (J2)

Even when there appeared to be a questioning of faith, the practical aspects of the Jewish bereavement ritual were still condoned:

> '…my wife's view was there is only one good thing to come out of the Jewish religion and it is the process of shiva….' (J6)

The positive power of Shiva was vividly expressed. The initial fear of being the focus of attention dissipated into a feeling of being immersed within a collective essence of known religious support. The expectation associated with the community involvement with funeral arrangements and support was described by one Jewish woman. Initially, the thought of seeing people in the aftermath of her bereavement was daunting; however, she found the experience to be immensely beneficial:

'When my father died I thought 'God, the thought of having people round, coming in and looking at you and talking to you. But by golly it's fantastic. I never believed it could be so powerful it sort of sort of brings you back to normality' (J1)

However, whilst a Muslim relative acknowledged that the social support at times of bereavement could be a positive thing, he experienced a feeling of claustrophobia and expressed a concern that this constant 'being with' the bereaved did not allow people time to themselves for reflection and private grief:

'In the community they all rush to your house, basically, to give you support and comfort. So as soon as that happened in the morning we had a whole houseful basically, of people trying to support us…it's a good thing and a bad thing as well. It's a good thing, yes you have got the community to help you and everything, but again you haven't got that breathing space for you to breathe in peace. You have got everybody surrounding you' (M6)

Honest and open communication about the death and the continuation of life were central components of the Jewish mourning ritual. Jewish participants recounted how, even in death, people celebrated life. This appeared through many mediums, both verbal in the statements expressed, but most importantly in the cohesive 'being' together at such times:

'Everybody who has come to the funeral is … obliged, by tradition…, greets the mourners with the greeting 'I wish you long life' because that person is dead, you wish the mourners a long life, and then at the, shiva, you enter the shiva house and you leave it, again with exactly the same greeting so you could say it to someone two dozen times in a week. It is a public activity, and therefore there is no mystery about it' (J6),

However, one Christian relative expressed incredulity at what she perceived to be a disrespectful haste of healthcare professionals in visiting the bereaved at such an early stage:

'C had passed away on the Wednesday as I had taken him home on the Monday, but the community nurse came in on the Friday to see how I felt. …Well, at that stage how did I know how I felt, less than forty eight hours? If she had come three weeks down the line then I would have appreciated that' (C3)

For participants from the Muslim and Jewish faiths, the role of, and relationship with, the religious committees who organised the funeral arrangements was invaluable. They explained that these committees took over funeral arrangements,

relieving relatives of the responsibility and leaving them reassured that everything would be done in a religiously correct way for their deceased loved one:

> 'Yes, the pressure is off to a certain degree in that the team then lead everything, they know exactly what to do at each stage' (M1)

> '…so you don't have to worry about anything' (M5)

> 'We had this burial team that came from the mosque and they were quite helpful and they tried to organise all the things for us so you know… … something nice to have in the community' (M6)

> 'The body will be dealt with by the Jewish burial society, called the Chevera Keddisha, the holy brethren who are performing the service to and for someone who will not be able to repay them in any way at all and therefore it's considered to be one of the greatest um, services you can provide' (J6).

> 'We don't do anything – we don't do a thing – you don't even have to think about the cars, the grave diggers, the anything! It's all automatically done' (J1)

7.5   Bereavement counselling / support

With the move away from traditional religion and its associated social cohesiveness bereavement support and counselling can be seen as the new religion of the 21st century providing comfort and meaning at times of loss. The difference between, and need for, counselling and support was highlighted by one religious leader:

> '…perhaps one in a hundred may actually need counselling. But all of the rest of them need support' (RL1)

Recent work undertaken by Schut *et al* (2006) has questioned the impact and effect of bereavement counselling. The relationship with support agencies and bereavement counselling, and their perceived benefit or otherwise, was discussed in the course of several of the interviews.

A Christian relative felt disappointed with the person allocated to provide bereavement counselling for her. Their perceived inflexibility in understanding her bereavement process and their lack of experience left her feeling that they would be of little help to her:

> 'I did go to C once but was very distressed with their attitude. I didn't like, it was a very young person, they sort of categorised it, they hadn't had experience of a bereavement in any form, and you know, I just, I was not going to get anywhere' (C3)

For one Muslim relative the lack of culturally and religiously appropriate bereavement support were all confounding factors in their bereavement journey:

> '… No we have had nothing not even maybe a couple of sessions or something like that to demonstrate your feelings… … but then you see we have realised that there is a need for something like that (culturally / religiously specific counselling)….The waiting lists are horrendous …there was nothing about cultural awareness or the language it was a white Irish lady that I was talking to and in fact she though that I could probably counsel her (laughter), that I was doing all the things she could tell me' (M6)

This suggests a deficit in traditional bereavement counselling and support, where the needs of an increasingly significant percentage of the UK population may not be appropriately met.

Bereavement counselling within the Orthodox Jewish community was discussed by a Jewish participant. He felt that external bereavement support was not required due to the robustness of Shiva and the support and structure that it provided from the Jewish community:

> '….as far as the bereavement counselling is concerned, because it's not allowed to, to fester and because the mourning is done in the first week um, the need for bereavement counselling is probably significantly reduced'(J6)

However, a feeling of being 'missed out' by not being offered bereavement support was expressed by another Jewish participant:

> 'I know that when J's mum died during the week that they were sitting somebody came round and offered them some sort of bereavement counselling. Because I remember when dad died nothing – nobody came –nobody offered us anything' (J1)

The inappropriateness of 'western' counselling in terms of religious diversity was highlighted by a Jewish Religious leader. He acknowledged the necessity for a secular bereavement service for a secular community; however, he stated that the emphasis of bereavement counselling was totally opposite to that of the doctrine of the Orthodox Jewish faith:

> 'I went bananas … a lady had lost a baby and the bereavement counsellor suggested they took the dead body home with them … as part of the grieving process, because they had set the room or something, they had bought and cot and whatever. So she said take the dead child and put it in its cot and then come back … and I just went ballistic … I just, you know, come on … (laughter). It's just not from where we come … a purely secular bereavement counselling system **…** um, will not interface with any of that (religious side). It will be 'What does the person need?', 'How can we help them grieve?' hold the baby, cry, we'll have a special ceremony, de de de, de, de, de, you know, and that's antithetical to what (we do)…'(RL8)

This belief in 'self help' within the community was also expressed by a Christian religious leader from the Roman Catholic perspective. He suggested that the person best placed to provide bereavement support / counselling in the community was the priest. This he felt was because they would usually already have knowledge of the person who had died and the bereaved relatives, and be aware of where ongoing support could be obtained and / or provided:

> 'Bereavement counselling should be – is in their local communities. Very often,well hopefully done by the priest because he, by the very nature of things – coz if he is going to carry out the funeral, spend time with the family, so leading up to the funeral and probably, if he knows them well, probably there the following Sunday. So there is a community support'. (RL1)

7.6   Education and training

The issue of *education and training* around end of life issues was raised by several participants. The content and appropriateness of training for medical students on dying and death was discussed.

Although it is acknowledged that training and education in this area has improved

(Field and Wee 2002) there were concerns that this education was still one

dimensional and that certain areas of bereavement care were not addressed:

> 'I do not think there is a lot in any Medical School curriculum about the bereavement process - it is probably a day or less in behavioural sciences or psychiatry or something, it will be there. It may be more in a medicalised context…And I think doctors should be shown how to diagnose dying people and what is sensible and what isn't' (D4)

> (Medical School)… they certainly do 'breaking bad news', but I don't think we touch too much on different cultural requirements. We certainly had communication skills type sessions and role playing sessions but there wasn't any particular emphasis on different cultures….. (D6)

> 'It isn't unusual for medical students not to see a dead body for several years. The possibility of people getting almost to their final year of medical school… and haven't seen a dead body. And I'm thinking 'Gosh, are these really the people that are going to have to certify', 'coz that's a physiological thing, they will be taught physiologically about … how on earth are they meant to be equipped in the psychological sense, in the social sense, in the cultural sense, teaching people of different faith communities, or rather telling people of different faith communities about somebody is dying, or has died' (RL2)

One doctor (Muslim) explained how his cultural upbringing had provided him with

the grounding to deal with dying and death in his current role:

> (In a Muslim country) …over there, even when you are little you know about death in the family, you are allowed to see the dead person, you're not 'Oh he's too little he doesn't need to see that' you know about it because it is a big process, and everybody participates in it and you go to the Mosque and attend the service, so you are actually trained into how to cope with death (.D5)

A junior doctor talked about the expectation that nurses had that doctors could be

called upon to deal with distressed relatives as they were perceived to have a

greater authority than the nurses, even though they had little training in handling

difficult situations such as end of life care:

> (when doctors are called if family are upset) when its got to a point when the nurse on the ward can't really cope, its not because you've had any training, but its because they think that you've got the authority ….. (D2)

Two of the nurse participants discussed the need for training for nurses on end of

life and bereavement care including cultural and religious requirements. The

importance of the appropriate information being provided was highlighted but both

acknowledged a lack of awareness of cultural needs by nursing staff and a

perceived indifference to the importance of these requirements:

> 'But it is one of those things (performing last offices) that people will get blasé about or joking about, you get inappropriate giggles, but the ultimate is that you don't do last offices to do it badly, you want to prepare somebody properly and I was mortified to… did some training and then went on to be a trainer for last offices and I am going down to the mortuary and seeing the state that people go down in, I was just like "why", it's basic common sense. But it's not, because I made mistakes based on common sense and inappropriate training; we can make assumptions about Jewish or Muslim patients but you still have to find out' (N4)

> 'I think they (nurses) need a lot of educating about bereavement. staff seem to come along and say 'no no you do this and you do that' and they seem to think that that (process) is across the board – for everybody, they don't understand about different faiths you just think 'ohh it's like banging your head against a brick wall sometimes' because they're not bothered really – they just think 'oh well it's done now' – they don't think about the next Asian person that will come in or the next Jewish person. I think you're always going to get these people who are just – who are ignorant and who aren't really willing – who aren't interested really – you know. It's just another person – so it doesn't matter whether they don't know' (N5).

These quotes appeared to highlight the importance of not only ensuring the right

information is provided in training, but that explanation and exploration of the

information is also undertaken to ensure that there is understanding of its

significance.

7.7   Summary

The dimension of relationships was interwoven throughout the bereavement

journey and the myriad of interactions within an acute hospital setting manifested.

Table 11 summarises the emergent themes for the existential dimension of

Relationships.

For the relatives, the most significant relationship explored was the one that they

had experienced with their now deceased loved one. A continuing bond with the

person was acknowledged and this manifested through feelings that the person

was still close by; having mental conversations with the deceased person, contact

through dreams and acting in a way that would please them; still including them in daily activities; and a belief that those who had died 'came back' to collect or guide those who were in the dying process through to the life beyond.

Table 11.   The existential dimensions of relationships

RELATIONSHIPS
Intertwining of relationships along the bereavement journey:
• continuing bonds
• loss of dreams
• power of prayer
• dreams as channels of ongoing communication
Shades of truth and white lies:
• communication
• trust, mistrust
• white lies
Relationships across the divide:
• God
• religion
• similarities and differences between and within religions
• pride of self v prejudice of others
• Beliefs in an afterlife
Imprint of bereavement:
• Impact on self
• personal rewards
• support from friends and family or a religious community
Bereavement counselling/ support
• adequate v inadequate
• Culturally . religiously sensitive?
Education and training of health care professionals
• End of life and bereavement care issues

From an Islamic and Jewish perspective a connection was also apparent through prayers and good deeds carried out in the name of the deceased. This continued connection with the deceased person(s) was seen as natural and normal. The

support and care provided by the hospital staff was remembered vividly and appeared to be a significant part of the relative's bereavement experience.

Communication within the context of dying and death was explored and it emerged that this was a pivotal component of the bereavement experience. The impact of how bad news was broken was shared by relatives and an associated anxiety about imparting the bad news was expressed by doctors, nurses and healthcare assistants. Descriptive scenarios were recounted about good and bad experiences of this.

The difficulty of adequate preparation for breaking bad news was acknowledged and honesty and integrity were perceived to be integral requirements for staff. Absence of these resulted in a loss of trust by relatives and the emergence of doubt and conspiracy theories. The concept of truth and honesty was discussed by staff. There appeared to be a consensus that being economical with the truth was acceptable if it spared relatives further pain.

There appeared to be an inherent fear in Muslim relative's interviews that their views would not be heard and their needs would not be met. This resulted in accusations levelled at doctors, nurses and healthcare assistants of a lack of understanding of religious and cultural requirements at end of life.

Anger directed towards God or a higher being was discussed by some of the participants. However, from an Islamic perspective, the focus of the dying person

and the soon to be bereaved appeared to be on the final destination of Heaven and being closer to God rather than on the pain and suffering that a person may go through on their journey into death. In a similar vein, relinquishing, or acknowledging their lack of control over death, was a pathway that several of the Christian participants discussed. The concept that God was an integral part of each individual rather than an external separate entity was explored by the religious leaders.

The generic 'core' beliefs of the Abrahamic faiths and the layers of differing interpretations were discussed. One interpretation of this cultural difference manifested in perceived superiority of each religious group and a dismissal of 'other'. Thinly disguised prejudice and intolerance seeped out in some interviews. This 'battle for supremacy' was also apparent within same generic faith groups.

Participants explored their beliefs on the feasibility of an afterlife. These beliefs shaped their approach and reaction to, bereavement and a life without the physical presence of a loved one. Discussions also centred around whether a person's individuality continued after death, or whether there was an amalgamation 'body of souls'.

The emotional impact of caring for a dying person was a theme that emerged in the majority of interviews with relatives. Caring for a dying patient also impacted upon nurses and healthcare assistants. There appeared to be an assumption held by staff that the death of a patient should always impact on nurses and healthcare

assistants and that this should be part of the defining essence of being a nurse, within this was an acknowledgement that this caring was potentially damaging for staff.

The impact of administering to dying patients was also discussed by religious leaders. The concept of religious leaders as conduits between the dying person and God, through which communication and preparation of forgiveness could be channelled, was explored.

From all three Abrahamic faith perspectives, the relatives' relationship with the deceased was seen to continue through prayer and good deeds that would not only benefit the deceased but also the person performing such deeds.

The need for support and who would provide it were very important aspects to the bereavement experience that the relatives recounted. Four sources of support were identified, family, friends, community members and religious leaders.

Formal bereavement counselling and support was discussed by several of the participants. There appeared to be a perception from the three faith perspectives that current bereavement counselling provision was not adequate; from a faith specific perspective but also from a relationship/ connection between counsellor and client perspective.

Although there appears to be an improvement in the provision of generic teaching on end of life and bereavement for doctors and nurses; there still seems to be a gap relating to cultural and religious requirements in these instances. Areas of training such as pre bereavement support were acknowledged as important care requirements. The ongoing difficulty of providing adequate, individualised education and training in such an emotive area was highlighted.

CHAPTER 8

DISCUSSION

The purpose of this thesis was to gain a greater understanding of bereavement through exploration of the experiences of the bereaved and of those healthcare professionals in an acute hospital setting providing end of life care from a religious faith perspective.

The study undertaken was prompted by three main observations. Firstly, that analysis of complaints received by an acute Trust following the death of a patient often reflected apparent deficiencies in end of life care and provided insight into areas of care that were important at times of dying, death and bereavement within this setting, not only for relatives but for others involved in the care pathway for example, nurses, healthcare assistants doctors and religious leaders (as outlined in Appendix A).

Secondly, that many theories of bereavement have been formulated from within a Western Christian centric paradigm which may not be fully inclusive of a multicultural, multi-faith society.

Thirdly, that to truly uncover the 'lived experience of bereavement' requires a different approach than the usual quantitative studies that have been undertaken which have focused on the collective group of the bereaved and the processes they are going through rather than the unique experience of bereavement as it impacts on the individual.

A large teaching hospital in the West Midlands `was the setting for the study described, where over 2000 deaths per year occur (Table 3, p.41) and a culturally sensitive Bereavement Care Service has been in place since 1997 (Chaplin 2003). Through this service it was recognised that while the needs of the majority faith of Christians were acknowledged in end of life care, differences existed in the delivery of equitable care for people of other faiths and in particular for those from the Orthodox Jewish and Islamic faiths. Their specific end of life care religious needs were not addressed in policy. The study therefore focused on these three Abrahamic faiths and explored the experience of bereavement from the perspective of relatives, doctors, nurses, healthcare assistants and religious leaders.

The need for research into the bereavement experience which encompasses a cultural and religious dimension has been acknowledged (Stroebe *et al* 1999). To date the majority of research undertaken in this field has focussed on the symptoms of grief, its short and longer term impact and bereavement management (Vargas 1989; Parkes 1997; Goldsworth 1999; Stroebe 1999; Sque 2000; Seamark 2000) with reference to the significance and implications of the culture or religion of the patient and carers.

The religious dimension of bereavement and its impact on the bereavement experience has significance when a death occurs within an acute hospital setting. National discussion and debate about end of life care encompassing preferred place of care/preferred place of death is ongoing. To date the majority of deaths

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occur within an acute hospital setting. This figure will not change dramatically over time until there is a paradigm shift in society's understanding and acceptance of death.

The use of phenomenology

Phenomenology was used as the philosophical and intellectual framework in order to provide the capability to uncover and explore what it is like to be part of an experience, to actually 'live' it. The subjective nature of qualitative research such as phenomenology has often been criticised. Phenomenology is a qualitative research method, which operates, in a very different model to the traditional scientific experimental methods. The phenomenological methodology is an individualistic approach, which focuses on a person's subjective unique experiences, which can provide the foundations for further research. Therefore it should not be which research methodology is 'best' but which research methodology is best suited to the ethos of the research being undertaken. The phenomenon of bereavement is a difficult concept to capture due to influences and meanings associated with an individual's relationships, history, culture, and belief systems. However, these fundamental and, for some, instrumental beliefs and influences are largely overlooked within the field of bereavement theory and research.

The presence of belief systems and the reverberating ripples of an experience through our physical, social, psychological, cultural, religious pools of experience and reference are important considerations. If we were looking at phenomenology as a philosophy and a methodology to study human experience, it would seem

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appropriate, indeed essential, to have an awareness of the beliefs and understandings of the participant, their frame of reference, the nearness of 'other'.

Whilst researchers have recognised the difficulty in applying and interpreting phenomenology in general (Spielberg 1994) and specifically within a healthcare setting (Crotty 1996), this study adopted the more structured approach proposed by van Manen (1984) as outlined in Table 4 (p.57). This decision was made because of the number of dimensions associated with the experience of bereavement in relation to religious faith and cultural requirements, the differing perspectives of relatives, healthcare professionals and religious leaders and the acute hospital setting in this study and the overall desire to elucidate the 'essence'.

van Manen's (1984) approach builds upon Heidegger's (1889–1976) work surrounding ontology, how we live in the world, and issues relating to time and life experience. Heidegger believed that past experience ('forestructure') is critical to a persons' perceptions as it immediately links the past, present and future; not in a linear way but more in a circle of understanding (hermeneutic circle). Therefore there is no end point only a deeper understanding of the phenomenon under exploration. van Manen (1984) uses four fundamental existential themes that are apparent in the 'life worlds' of every human being irrespective of a person's historical, cultural or social background.

Through van Manen's four existential dimensions of time, space, body and relationships it has been possible to explore how the phenomenon of bereavement

and people's experience of it, are influenced through the lens of religion. This can be magnified when a death occurs in an acute hospital setting where control over self and others can be lost.

The themes of lived Time (temporality), lived Space (spatiality), lived Body (corporeality), and lived Human Relation (relationality or communality) facilitated in this study a holistic interpretation of the phenomenon from the perspective of the three main groups of participants and also gave a much needed structure to the:

➢ methodology employed, based on what was already known

➢ questions to be explored

➢ interviews with participants, how they were conducted and the type of after support offered.

➢ data analysis and the identification and grouping of emergent themes. from the 41 taped interviews from relatives, healthcare professionals and religious leaders

➢ writing of the results and the conclusions inferred

The themes that emerged have been summarised in Tables 8, 9, 10 and 11 and serve to illustrate how informative this approach to the lived experience of bereavement has been. In comparison to the bereavement theories and research outlined in Chapter 1 it also serves to highlight how little of these previously published theories of bereavement and bereavement research have really explored the needs of a diverse population with specific faith requirements and how there is still much work to be done in acute hospitals and with healthcare

professionals to ensure that they and the setting are truly responsive and equitable in the care and support that is delivered.

The exploration of lived Time

The dimension of time provides a framework through which we live our lives, from the moment we are born to the moment we die. Although intangible and, at times imperceptible, time provides a continuum on which we can measure our existence from birth through to death and beyond. The dimensions of time have fascinated people throughout time from early writers to modern day poets.

> To everything there is a season, and a time for every matter or purpose under heaven:
> A time to be born and a time to die, a time to plant and a time to pluck up what is planted,
> A time to kill and a time to heal, a time to break down and a time to build up,
> A time to weep and a time to laugh, a time to mourn and a time to dance,
> A time to cast away stones and a time to gather stones together, a time to embrace and a time to refrain from embracing,
> A time to get and a time to lose, a time to keep and a time to cast away,
> A time to rend and a time to sew, a time to keep silence and a time to speak,
> A time to love and a time to hate, a time for war and a time for peace.
> *Ecclesiastes 3:1-8*

> Stop all the clocks, cut off the telephone
> Prevent the dog from barking with a juicy bone
> Silence the pianos and with a muffled drum
> Bring out the coffin, let the mourners come
>
> Let aeroplanes circle moaning overhead
> Scribbling on the sky the message He Is Dead
> Put crêpe bows round the white necks of the public doves
> Let the traffic policemen wear black cotton gloves
>
> He was my North, my South, my East and West
> My working week and my Sunday rest
> My noon, my midnight, my talk, my song
> I thought that love would last forever: I was wrong
>
> The stars are not wanted now, put out every one;
> Pack up the moon and dismantle the sun;
> Pour away the ocean and sweep up the wood
> For nothing now can ever come to any good
> *W H Auden*

Time can be seen to be an abstract structure measured through the twenty four hour clock and the three hundred and sixty five days of a year. However, this Western method of conceptualising time, through the Gregorian calendar, is not its finite measurement. Indeed, the Islamic and Jewish faiths have calendars which provide parallel time lines with differing measurements. For example, immovable dates in the Christian calendar such as Christmas and New Year are alien concepts within the Islamic calendar where the commencement and completion of Ramadan and the celebrations of Eid, are decided upon by the visibility and presentation of the moon. Similarly, the anniversary of a Jewish person's death 'Yartheit' appears to 'vary' as it is recorded against the Jewish, not the Gregorian, calendar. These differences however can potentially be important at times when emotions and awareness are heightened such as at times of bereavement.

Recounting the bereavement journey through chronological story telling allowed both relatives and some religious leaders to set the scene in the exploration of the lived experience of bereavement to them as individuals. The passage of a *lifetime* provided a context for the death and the relationship with the study participant as well as a fixing of a point in time when the death actually occurred. It also allowed the bereaved to talk about the now deceased person as an individual not a one dimensional façade that patients in a hospital bed can often be only seen as.

The concept of the right time for a person to die appeared to be an important theme, allowing all participants the opportunity to make sense of why and when the death occurred. Some participants spoke of a belief in a predetermined, finite

time on earth, others, whilst acknowledging this, displayed a denial of the imminence of death and a belief that life could be sustained or at least prolonged. The difficulty that doctors, nurses and healthcare assistants have with accurately anticipating or diagnosing impending death was one that caused distress to relative participants.

This has been previously identified by Rogers (2000) in a study of end of life care where a theme of disappointment emerged from questionnaires of bereaved relatives associated with the fact that doctors were unable to predict the exact time of their loved one's imminent death. This difficulty in accurately pin pointing when death will occur has been recognised in several other studies, for example Finlay (2003) who acknowledged that

' even the last days can remain an elusive time to predict with complete accuracy' (p.398)

and Christakis (2000) who studied over 300 doctors who provided estimates of approximately how long terminally ill patients would live for, at the time of hospice referral, and found that:

'Although doctors commonly have to prognosticate, most feel uncomfortable doing so. Neither medical training, nor published literature, treat prognostication as important and prognostic error is widespread' (p.469).

A further finding from this published study was that the better the doctor knew the patient the more likely they were to err on the side of caution with the diagnostic estimate. This suggests that, even with healthcare professionals, human emotions can come into play, especially when dealing with such difficult and emotive situations. However, as the results of the study in this thesis show, there may be unwillingness on the part of doctors to acknowledge the imminence of death driven

by the need to focus on treatment and this is an area that warrants further exploration.

For relatives this final timeline of impending death was important for many reasons but primarily to ensure that certain religious / cultural and purely secular requirements are enabled to make sure that the right thing is done at the right time. For those of the Islamic faith for example, it allowed time to prepare the dying person for their death through recitations of the Qu'ran and visits from friends and family; for those of the Christian faith it allowed them to say their goodbyes and be with the person when death occurred. From the healthcare professional participants in this study it was obvious that these specific requirements can be overlooked or not seen as important, especially for example when there are competing pressures for single occupancy rooms in an acute hospital setting and the study suggests the need for inclusion in both the underpinning education and training of healthcare professionals and in hospital policy and procedure.

Nurses, healthcare assistants doctors and religious leaders all recalled how there appeared to be some perceived control over death with individuals either 'holding on' until special occasions had been experienced, or 'letting go' and slipping into death after they felt they had been given permission. A US study (Lobar 2006) interviewed nurses on cultural requirements at end of life and highlighted deliberation about calling in a priest for 'last rites' or sacrament of the sick which appeared to evolve from an assumption that performing these last rites invoked

death to occur. In this study, the Christian religious leaders appeared to support this observation through their stories of people relaxing into death once the 'last rites' or anointing had been received.

The sanctity of life within acute hospitals appears to have evolved into a different dimension. Although traditionally, acute hospitals have purported an ethos of 'life at all costs'; life, or more accurately death, appears to be, if not under the control of doctors then certainly under their influence and was demonstrated clearly in this study. The 'time' of death and who, if any, has control over this, are valid poignant questions on Intensive Care Units where definitions and timings of death are associated with the mechanics of death, for example multi-organ failure and brain stem death. These can lead to controlled or clinical definitions of death but which, by default, result in 'natural' death occurring unnoticed.

Concerns were raised in this study by Muslim relatives that they perceived doctors had hastened their relative's death on an intensive care unit:

> 'And the religious point-of-view was basically no you can't do that because in actual thing what you are doing is taking a life away.' (M6)

Finlay (2003), in her paper on end of life care, discusses the medical decision to take a person off life support and the associated perception of prematurely ending life. She discusses the interaction between man, disease progression and technology and suggests that rather than the perception that the person's life has been shortened by withdrawal of life support they have actually had their natural life extended through being placed upon it in the first place.

> 'For it is the disease that kills the patient and when attempts to ward off death fail, the patient who has been kept alive by our technology is not killed by the doctor' (p.400)

Some of the concern is associated with either a misunderstanding of, or misbelief in, the prolongation of life by mechanical ventilation and its relationship to brain stem death, and when death had actually occurred. Even the author of the study in this thesis, a senior nurse and bereavement care manager had personal concerns regarding these issues following the collapse and subsequent death of her sister (see Appendix B).

In a specific paper on the Islamic faith, Sarhill (2001) suggests that death is defined as the departure of the soul from the body. However, it would appear that neither the Qu'ran nor the Haddith give clear signs as to how death is identified. Therefore the concept of brainstem death as a definition of death may be unacceptable within traditional Islam. Most Muslims consider death to be the cessation of all bodily functions therefore a person who is brain stem dead would be seen, by some, to be in the dying process but not actually dead. Ross (2001), in her paper on Islamic tradition at the end of life suggests that 'contemporary' Islamic authorities acknowledge:

> 'total brain death; including brainstem and that any physiological functions retained by mechanical equipment would be considered 'movement of the slain'. (p.84)

This difference in opinion highlights the varying interpretation within religious acceptance and understanding and the potential for disagreement within one faith which can be difficult to embrace in overarching policies and/or procedures.

The dichotomy between natural and mechanical death was explored by O'Gorman (1998) who suggested that mechanical intervention may cause further disempowerment for a person who is no longer in control of his / her own death:

> 'protected against dying and defeated by the victory of medicalisation over society the patient is no longer able to set the scene for his own death; nor can the professionals who have taken control of life and death, agree amongst themselves what actually constitutes death' (p.1130)

Such patients are potentially denied a 'good death' and some will be denied a 'natural death' as doctors determine death's final components. The dichotomy of technical 'life support' versus 'natural death' was also highlighted in Beckstrand's (2006) research in critical care nurses. One participant suggested that life support technology, although centred on the patient, may not be patient centred in the caring sense of the term.

> 'we are trapped between technology and reality' *(p.42)*

There can therefore be a take over of the body by healthcare professionals who may have developed their own 'rituals' for end of life, as demonstrated in this study.

The impact of all of these issues is evident in this thesis which showed that these final memories stay etched on the bereaved person's mind forever. It indicates the need for such complex and emotive situations to be communicated effectively by staff with withdrawal of intervention taking place without inferred responsibility for relatives. The requirements at such time for all participants should be the subject of further study.

There appeared to be a divide between healthcare professionals and relatives regarding quality versus quantity of life. Relatives, understandably, wanted their relatives to live for as long as possible, unaware of the complications and implications of this, whereas healthcare professionals had awareness of the futility

of further treatment set within the context of poor quality of life. This sometimes translated into perceptions of either a good death or bad death.

What defines a good death or bad death was explored in this thesis. The absence of suffering was seen as being paramount to all. However, if present, it was seen by those of the Islamic faiths to mean that the person was experiencing their 'punishment' earlier than others and would therefore have less to answer for on the day of judgement.

> 'if you are ill in this life it is actually purifying you, so if you have difficulties in this life you won't have it in the next life so much' (M4)

The importance of someone being present when a person was dying was universally agreed by all participants. Those relatives who were not present at the death described being 'robbed' of the experience and when they had not been able to be present, expressed feelings of deep regret and associated guilt in what they saw to be a dereliction of duty.

Several of the Christian relative participants spoke of their time with the person after death as a time of comforting reflective thought and the realisation of the finality of the situation 'presence to absence'. This need to spend time with the person after death supports Costello's research (1995) which suggested that bereaved relatives felt that one of the least helpful responses from nurses was that of removing them from the bedside soon after the death of their loved one.

For those of the Christian faith in this study there appeared to be a lack of structured religious support and ritual which may be reflective of the largely

secular society within the UK today. However, the orthodox Jewish participants described how they immediately stepped back following the death of their relative in acknowledgement of the race to get the burial done as soon as possible and hand over to the Chevera Keddisha who step in to oversee funeral arrangements within the Jewish community. The period immediately after death focuses on the dead person and the need to facilitate their burial as soon as possible (Deuteronomy Chapter 21 v 23). This focus shifts to support for the family once the burial has taken place as one Jewish religious leader explained:

> 'Prior to burial … the mourners are in a special state, which changes from the moment of burial. So whilst a mourner in Hebrew is called an 'Ovel' which is the classic mourning state, before the, before the burial, prior to burial they are called an 'Onen' , and an onen is a special state of pre-burial, pre-burial shock if you like, mourning but needing to do things. And in this state they are not required to do any of the positive commandments …… which are encumbered upon a Jewish person, so normally if you like before we drink we'd make a blessing, we pray three times a day, don't do any of that, a man wouldn't put his phylacteries on. Why? … because you are in the middle of a mitzvah, you've got somebody to bury. So, there is a whole suspension of many, many things, it's almost a limbo time, it's a very intermediate stage but it is very clearly defined in Jewish law … what you can and what you can't….. classically until the moment of, um, of burial they are considered an 'Onen', and only become the 'Ovel', the mourner once the burial once the mound of earth has been rounded on top of the grave.' (RL8)

As Lamm (1969) states, the recessional (departure) from the graveyard by the mourners signifies the redirection of sympathies and concerns from the deceased, to the mourners. The collective emphasis for the 'community' therefore changes from honouring the dead '*kavod hamet*' to an obligation to comfort the bereaved '*nichum avelim'*. The Muslim participants also discussed the absolute importance of facilitating a burial as soon as possible to ensure the departed soul's next steps:

> 'the deceased is in the process of experiencing the whole stages of death but his body doesn't show any signs of it, and that's why a lot of the process which comes after death, you know, why you have to bury, what you say to the dead person, what you read to him, he's aware of all this happening around him, he's aware that the angel of death is coming to him, he's aware that he's dead and they are carrying him over their shoulders and   they   are putting him in the grave and they are raising him after in the grave when they are asking him for what he's done in this life so he's actually aware but his body does not show it ' (D5)

Further influencing factors for those facilitating the last care for the deceased person was the belief that acts of care provided to the deceased would accumulate rewards for him / her and for the person providing that care which would all be noted on the Day of Judgement.

> 'so Allah says, God says in Islam if you do something for somebody (good deed) then you get 10 good deeds here and 70 after death.' (M2)

Medical staff appeared to step back at the time of death but recalled occasions when they were called to see bereaved relatives and mediate in difficult situations. There appeared to be a disassociation by some doctors once the patient had died which manifested in a failure to complete all documentation in a timely manner. This was seen as disrespectful to the deceased by some of the participants and the main reason for delays to funeral arrangements which caused frustration and resentment by the Jewish and Muslim relatives. This is obviously an area where specific education and training for doctors is required to enable a greater understanding of cultural and religious requirements is required and their final role in a patients' care.

For nursing staff there appeared to be a conflict in the time that they wished to spend with the dying / deceased patient with the time required to look after the ongoing needs of other patients and relatives in their care.

> 'I feel I, I neglected him because I cannot sort out his …..I cannot give any comfort to him.......... sometimes nurses are too busy to cater to the spiritual needs and the physical needs of the patient' (N1)

'sometimes it's time – they haven't got the time to sit and get to know this patient' (N2)

These two quotations serve to illustrate the many influencing factors in an acute hospital setting and the potential impact of lack of time on both the bereaved and on those caring for the soon to be deceased. This dichotomy is one that requires to be addressed if equitable care is to provided to all from birth through to death and beyond.

The passage of time served to highlight the bereavement journey for relative participants of all the Abrahamic faiths, which appeared to start when the person first became unwell and continued through treatment, hospital admission, dying through to death and the subsequent funeral arrangements and eventually to adjustment to life without the person being physically present. It also invoked contrasting feelings of mortality and immortality, a time to live, a time to die, whilst overlaying beliefs or wishes in an afterlife to give hope of a time everlasting. This highlights that the phenomenon of bereavement cannot be seen in isolation as an experience that occurs after the death of someone close but rather that it is a culmination of memories, feelings and experiences that are gathered along the end of life and bereavement journey, whether the death is expected or sudden. Each step of the bereavement journey and the experiences the relative faced along the way appeared to impact on and influence their bereavement experience after the death of a loved one.

For nurses and healthcare assistants, time created conflict for them which impacted on the care they provided for dying and deceased patients and their relatives. This arose out of a conflict of priorities and an associated demand on

their time between caring for a dying patient and the needs of other patients. Time is a priceless commodity but one which is invaluable and precious when death is approaching. Nurses and healthcare assistants described feelings of guilt and frustration if they were unable to give enough of this valuable commodity to patients and relatives. However, lack of time was also seen as a reason / excuse for not being able to provide adequate end of life care. This aspect needs further exploration to uncover perceived and actual time lines for ward nurses and healthcare assistants.

For doctors, the concept of time appeared to create a forum of control which has been recognised previously (Higgs 1999) with an expectation from family members that they could predict or prolong the actual time of the person's death. This also applied to the timeline of issuing documentation to allow the release of the deceased person thus displaying control over funeral arrangements. Within an acute hospital setting the timeliness of procedures is controlled by bureaucratic legal and medical processes which can cause conflict for those involved in end of life/death situations. Whilst some can be circumnavigated others cannot and create conflict between expectation, religious requirements and care provision for end of life and bereavement.

The concept of time for religious leaders incorporated the fourth dimension of eternity and life after death and allowed them to assist in the preparation of the dying person's soul for death and beyond. The significance of this important role

for the bereavement experience is another area worthy of further discussion and exploration.

The exploration of Space

From an historical perspective, a marked shift in the environment in which end of life care is provided has emerged over the past century. Costello (1995) acknowledges that modern secular society in the West does not encounter death in same way as it did at the turn of the last century and goes further to suggest that the West is now a death denying culture with the act of death hidden away in hospitals, hospices and nursing homes rather than at home. Whilst this may be accurate for a vast part of the secular Christian society of the UK, Costello fails to acknowledge the diversity of other cultures and religions which co-exist within UK society and, for whom, death is very much a part of life, openly discussed and acknowledged. Costello's work however, does highlight the need to look more closely and openly at end of life and death care to explore the appropriateness of the environment where death takes place.

Indeed the environment in which end of life and bereavement care was provided was seen as a gauge of the care and respect afforded to the dying, deceased person and their relatives. Whilst for some, this was seen as supportive and

cocooning for example, the use of side rooms, for others the environment was seen as hostile, oppressive and restrictive.

The place of death and the change in accepted rituals and secularisation within Christianity at times of death were highlighted by a Christian religious leader within this study:

> *'People died at home a hundred years ago. Front room, close the curtains…death was a ritual that we all took part in, with our dress, um, it was all very ritualised, , and we have lost that of course no, I mean it is all Celine Dion and my love will go on now course isn't it' (RL2)*

The majority of deaths do (Department of Health End of Life care Strategy 2008), and will continue to, occur in acute hospital settings and therefore the potential impact of place of death on the experience of the bereaved needs to be incorporated within national strategy, guidance and research. This will ensure that, instead of deaths in hospital being experienced as an unexpected surprise by staff and relatives, there will be appropriate planning and care in place to ensure that it is the right environment and the right circumstances for every death in hospital.

It has been suggested that deaths in hospital, where the emphasis is on acute care and cure may be an inappropriate setting for those in the terminal stages of their life (Main 2002) and in this study the environment in which death occurred emerged as a key component in the bereavement experience for relatives and healthcare professionals. Relatives and staff talked about the significance of space at time of dying and death and of the importance of side rooms to provide privacy for final words of comfort and rituals. Their recollections reflected where this had and had not been possible. Although their experiences were mixed, hospital was, and will be, the most appropriate place for some people to die. Therefore,

adequate attention to the environment must be provided in acute hospitals. Memories are pictorial and the space and environment in which end of life and bereavement care is provided will remain imprinted on the bereaved person's memory for ever.

Staff discussed the use of side rooms to facilitate privacy for the family and dying person, but also acknowledged that they had utilised them to control unruly and highly emotional situations such as a Muslim death separating the distressed relatives from the ward environment. Beckstrand (2006), in her US study of critical care nurses and their suggestions for improving end of life care, found that space was an important consideration for them. Among their suggestions for improvements to the environment at end of life for relatives were quiet places for meditation, reflection and prayer and the use of private / side rooms, concepts that were endorsed in this study.

Muslim relative participants viewed side rooms as an appropriate environment for a dying Muslim as they provided a safe environment in which rituals and recitals could be performed without disruption to them, disruption to others and without judgement and condemnation from others. Jewish relative participants again viewed side rooms as most appropriate for the dying / deceased person as it allowed a discreet separation between them and gentiles. For the Christian participants a side room was seen to facilitate privacy for the dying person and their family and allowed them to have their final moments quietly together, away from the hustle and bustle of the main ward environment.

However, the side room also evoked concerns about isolated deaths and the need to ensure that the dying person was not placed in there to die alone or out of view. This fear of an isolated death transcended the actual environment and was alluded to by one nurse participant (N5) who told of an elderly lady who had an isolated death, alone and unnoticed in the middle of a busy nightingale ward and is linked with a later discussion around the role of the nurse to be with a person when death occurs.

The Department of Health End of life care strategy (2008) reminds us that:

> 'How people die remains in the memory of those who live on.' Dame Cecily Saunders, End of life care strategy (2008, p.1)

The environment must therefore be fit for purpose and tailored to the needs of dying/deceased patients along the bereavement journey from diagnosis through prognosis to end of life care, death and bereavement support in an acute hospital setting. This aspect transcends space as merely the physical environment but explores the impact that the environment where the end of a life and death occur, has on the bereaved individual.

An alternative perspective is provided by Searle (1995) who suggests that encouraging or promoting hospitals as the place to die for the majority of people is a response to the threat of disorder that a death elsewhere may pose. By allowing or normalising deaths in hospital there is an associated collusion of the denial of death by hiding its occurrence away in the sanitised, impersonal surrounds of a hospital ward. However, Searle's argument fails to acknowledge the impact of

bereavement and the influence that an appropriate environment can have on that. It could be postulated that ill people will gravitate to hospitals for appropriate care and treatment and although the outcome for some will be death. The intention therefore is not that they are sent there to die 'discreetly' away from the public eye, but that some do and will continue to die in acute hospitals.

In the study described in this thesis, only one participant took their relative home to die, for the rest, the hospital was, in principle and eventually in practice, seen as the right place for them to die However, improvements to the environment both before and after death were felt to be needed by many participants and this is an area that to date has received little attention particularly in acute hospital policy and procedure.

Further exploration is required around the significance and impact of the environment in which end of life and bereavement care is provided, from single room, to ward, mortuary to final resting place as proposed by the Kings Fund in their work on the healing environment.
(www.enhancingthehealingenvironment.org.uk).

There has been much debate regarding preferred versus actual place of death. In the Department of Health White Paper '*Building on the best: choice, responsiveness and equity in the NHS' (2003),* the choice in care that should be provided was clearly   defined and for end of life care and preferred place of death proposed as :

'To offer all adult patients nearing the end of life, regardless of their diagnosis, the same access to high quality palliative care so that they can choose if they wish to die at home'

Much research has been written about preferred place of death, but the majority of these have focussed on patients with cancer (Beccaro *et al* 2006; Munday *et al* 2007; Townsend *et al* 1990; Gomes and Higginson 2006; Lock and Higginson, 2005; Gilbar and Steiner 1996). However, although the subject matter may be narrow, some interesting comparative data can be found within these studies relating to preferred and actual place of death that has resonance with the study undertaken in this thesis.

Lock and Higginson (2005) performed a large cross sectional analysis of all people aged 75 and over, dying of cancer in England and Wales (*n = 315,462)* and their findings supported previous research suggesting that there is an apparent gender bias to place of death, with the majority of older women dying in care homes (Hunt, 1993) and the majority of men dying at home (Higginson, 1999). This may reflect the traditional roles of women as carers, caring for their husbands at home or the fact that, women, in general live longer than men. Their findings showed that most deaths occur in hospitals (50%) and that fewest occur in hospices (13%) with home deaths accounting for 19% of the participants. The cause of death was also a significant contributing factor to the place of death although they were all cancer related. Gomes and Higginson (2006) looked at place of death for cancer patients in 58 studies from 17 countries including 1.5 million patients and suggest that

'for many people, home is more than a physical space; it represents familiarity, the presence of loved ones, and the possibility of enjoying 'normal' life' (p.515)

Therefore, they contend, that over half of people with a progressive illness express a preference to die at home and, at present, these wishes are not or cannot be fulfilled. Although the study admits to several limitations including lack of heterogeneity between the studies and the subjectivity in grading the strength of evidence within the studies, it was still an impressive undertaking, although narrowly focussed on Cancer patients. These studies and their limitations support the need for further research into end of life care and its impact on bereavement to ensure the environment in which death occurs is appropriate and fit for all.

Although not explicitly discussed by Muslim participants in this study, research in the US has stated that '*Muslims prefer to die at home'* (Sarhill, 2001 p.252), although no expansion on the reasoning behind the statement is offered. One possible explanation is provided by ALKhawari *et al* (2005) in a paper on UK Muslims attitudes to organ donation, in which he states :

> 'level of anxiety about potential 'desecration' or 'mutilation' of cadavers, many some participants preferred to die at home to avoid health care staff touching their deceased body.' (p.1329)

suggesting that there appears to be both myth and misunderstanding about hospital process and procedure in some communities. However, this may be compounded by certain incidents that have come to light in recent years ('Muslim families trauma over body defiled at mortuary', The Independent UK on Line 19th April 2003 ; 'Mortuary crisis' – scandal of bodies stored on floor of chapel of rest', The Independent on line 19th February 2001; Alder Hay 2001).

Concerns raised in this study focussed on the safety of the environment for the deceased person after death and the perceived delays in obtaining documentation

to release the deceased person from the hospital, especially from the Jewish and Muslim participants. The absence of reassurance of culturally sensitive care for deceased patients in the mortuary caused concern and distress for bereaved relatives. The immediate pressure from bereaved relatives from the Jewish and Muslim communities for early release to complete religious rituals, coupled with lack of knowledge and understanding of cultural and religious requirements, caused distress to staff as well.

It could be suggested that because to date the needs of dying and deceased patients have not been adequately acknowledged or addressed in general within acute hospital settings, and not from specific faith and cultural perspectives, people worry about the care their loved one will receive especially during the dying process and after death. This needs to be an important consideration in end of life and bereavement care provision and addressed both locally and nationally.

Several of the nurse participants in this study expressed concern about patients dying alone and how at times it was difficult to balance this with the needs of other patients in an acute hospital ward and the views of other colleagues. Beckstrand (2006) in a US study on Critical care nurses revealed that a common theme expressed by the participants was that no patient should face death alone and suggests that:

> 'every patient needs to have someone present with them at the moment of death – to touch them, speak to them, to let them know its ok to go' (p.41)

Camargo (2006) in her reflections on experiencing the death of a patient, talks about the loneliness of the experience of death for the dying person and that no

one can share the 'lived experience' of death. She further states that, although we cannot share death, we can share life and emphasises the importance of nurses being a physical presence for patients in their final hours or minutes. However, Searle's (1995) sociological paper entitled 'Dying alone' found that some lay people interpreted 'dying alone' in a hospital setting to incorporate those deaths that occurred without relatives present; even if staff were present. Therefore it could be argued that the nurse as a 'meaningful presence' in lieu of relatives or 'relative by proxy' at times of dying and death may not be appropriately acknowledged or recognised by the public and is an area that should be highlighted and further explored when the role of the nurse in care is being considered in national projects and commissions.

The impact of the environment for staff dealing with end of life situations on a frequent basis is an issue that has generally been overlooked. Whether that be staff who have dealt with the traumatic death of a patient on their ward and the associated feelings of guilt or staff returning to work following a personal bereavement where they may have constant reminders of their recently deceased relative. The health and well being of healthcare professionals must be a factor in future workforce development and staff support.

The importance of the final resting place was found to be of significance in this study and the themes and concepts that emerged echoed those expressed in research into environment and its significance after death (Hockey 2001). These include the continuation of close bonds between the living and the deceased

person and the persistence of normal grief, following the death of a loved one, throughout a lifetime. There appeared to be a close interwoven relationship between the process of memorialisation of the deceased and the reformulation of the personal identity of the bereaved person and this was mirrored in the oscillation between letting go and continued attachment to the deceased person throughout the grieving process.

Many relative participants in this study expressed the importance of a space in which to remember the deceased and to express their ongoing relationship with the now deceased individual. This supports the study of Francis, Kellaher, and Neophytou (2005) who recorded conversations with 15,000 bereaved people visiting six London cemeteries with a spread of cultural and ethnic diversity:

> 'show how people act in and on the burial landscape as a public theatre for the creation and continued expression of relationships with the deceased' (p.227)

Although the study left a lot questions unanswered it did demonstrate that the graveyard appeared to be a half way 'house' whereby the person was gone yet present and which provided a suitable space to openly acknowledge the deceased person. This materialised with the graveyard / grave appearing to take on the persona of a second home for the deceased person. These were then adorned with flowers / stones as a status symbol of how much the deceased person had meant to the bereaved and also as a gift to be received by the environment on the deceased's behalf. This behaviour was also poignantly described by one Christian relative participant in this study.

> 'I mean I go down the cemetery now two days a week, but it's not anything morbid or anything like that. I go down of a Sunday to put flowers on, she must have flowers, got to have flowers, …. she's had flowers even when she didn't have a headstone, she's got to have flowers. She only ever gets roses, don't get nothing else' (C1)

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The Jewish perspective that emerged from this study inferred a collective pride in the provision of a dignified and religiously appropriate final resting place for orthodox Jews. From the Islamic perspective the grave appeared to have a more concrete role as a holding place for the deceased until the day of judgement. This holding area also performed a rewarding or punishing task on behalf of God (providing comfort or discomfort) until the day of judgement which has also been reported by Ross (2001) in a paper on Islamic tradition at end of life:

> 'for believers the grave expands as far as the eye can reach and contains all the comforts of a heavenly garden. For unbelievers the grave contracts and a door is opened to allow smoke and heat from Hell 'Gehanna' to come into the grave' (p.84)

Yasien-Esmael & Rubin (2005) also clarify the 'true' Islamic meaning of the grave, and its symbolism of irreversible separation between deceased person and the bereaved. In stark contrast to the Christian recollections in this study, they state that the grave should not be treated as 'a *second home'* for the dead person:

> 'Burial symbolises that the deceased has severed the relationship to life on earth so the grave site is to be treated appropriately….the grave is not to be seen as the deceased's second home' (p.504)

They explain the Islamic belief that the grave should deteriorate over time signifying the disintegration of the 'shell' of the person and the subsequent lack of need for corporeal comforts and suggest that the slow 'disappearance' of the 'unattended' grave mirrors a gradual resignation to the disappearance of the person from the bereaved person's life. The significance of the grave and the time spent there before the Day of Judgement has been likened to the time spent in the womb according to Chittick (1992), a cocooned environment but with the added dimension of reflection on the life lived.

The significance of the environment at end of life appeared to impact on the bereavement experience for all the relative participants. The place and surroundings in which the person died where the person now was, physically and spiritually, all influenced the person's bereavement experience. However this significance was different for each faith group.

For those of the Christian faith the environment allowed privacy, dignity and time for memories to be made which became part of the bereavement experience. For example, private time alone with the person after death or visiting a grave with flowers. For the Muslim participants, the perception of the environment changed from safe to unsafe once the person had died and there was a need to remove the deceased to a place of religious safety as soon as possible. This appeared to be a similar belief for the Jewish participants.

The concept of environment for doctors, nurses and healthcare assistants manifested through private versus public deaths and there appeared to be a dual purpose to the use of side rooms, providing privacy and dignity, but also discretely separating 'overt displays of grief' from the public gaze.

However, it must also be acknowledged that with the focus of hospitals on infection control, many side rooms are taken over for barrier nursing, which strategically appears to take precedence over end of life care requirements which will need to be addressed in hospital policy and practice.

The exploration of body

The existential dimension of 'Body' manifested through the physical and emotional care, and religious rituals afforded to the dying / deceased person and their relatives and their meaning and impact. The respect and dignity that was afforded to the dying and deceased person and the bereaved relatives was of paramount importance, as was the ability to be with the person and provide the last care for them. This appeared to be a universal human need irrespective of culture, religion or relationship to the person.

Some of the nurse and healthcare assistant participants described the last care they provided and the importance they assigned to providing this. If the provision of this last care was denied, for example for cultural / religious reasons, they described feelings of being robbed of part of their role and their parting gift to their patient. This was particularly significant when caring for patients of the Jewish and Muslim faiths:

> ' you haven't had time to say your goodbye's because usually we do ……. We say our goodbye's, that's taken away from you as a Nurse ….. The families can be very cold and they give the feeling that you can't touch the body and you feel you are restricted to – you know you've looked after the patients for months and months and months, you've been hands on with them and then to take that away. I mean, you can hold them in your arms when they are actually the comfort they get out of it, and then like when they do finally pass away it's like closing the door dead quick and washing their hands of them, and to me that's more for the family than the deceased because if they were like that in life, surely you want to give that care to – you know – give them a bath you know to get them on the way, it just seems like that when they come, especially the Rabbi you know, ……..it's very cold' (N2)

However they also recounted tales of their colleagues being dismissive of this last care which they perceived to be disrespectful to the deceased person. The belief in the journey of the soul and transition from body to spirit gave rise to the need for rituals to be performed by the appropriate people at the appropriate time to

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facilitate the optimum commencement of the journey. Therefore, the significance attributed to the provision of this last care by the nurse participants was juxtaposed with the discussion from Muslim and Jewish relatives who commended nursing staff for not intervening further after death and respecting the religious requirement for the provision of faith specific last care.

Both of these observations highlight once again, the need for more systematic embedding of the religious and cultural requirements of the multicultural population that is being served by the acute hospital in the education and training of healthcare professionals. This needs to be coupled with a greater understanding of the potential impact of actions both on the bereaved and on other colleagues who may themselves for example, hold strong religious beliefs. There would also be a major benefit from making the public more aware of death, dying and bereavement, to assist them in understanding the process, what to expect and the variations in religious and cultural requirements. This is crucial as the meaning associated with end of life and the bereavement ritual is further explored.

Several papers have been written on end of life care for those of the Muslim faith (Gastrad 1994, 2002; Riad 2005; Sarhill 2001; Ross 2001) but, although informative they fail to provide a reason why certain funeral practices are required. As there is no specific mention of funeral practices in the Qu'ran burial practices have been established by religious jurisprudence as described by Ross (2001) and Islamic religious instructions regarding funeral arrangements can be found in the Haddith. The Haddith are traditions relating to the words and deeds of the Prophet

Mohammed (pbuh). These collections are regarded as important tools for determining the *Sunnah* or Muslim way of life, by all traditional schools of jurisprudence as Muslims aim to mirror the ways of being of the Prophet Mohammad in all of their daily thoughts and deeds.

A Muslim doctor, stated that, within Islam, there was a finite time for overt displays of grief, three days known as *hidad (*mourning)*, and that bereavement from then on, should not interfere with daily activity:

> 'I know Muslims are not supposed to overtly express their grief for more than 72 hours, 3 days, I don't know if you knew that, but that's a fact. I mean if you are upset, you're upset, you shouldn't make it, you shouldn't stay away from work and make a big issue of it for that long' (D3)

This is supported by a Haddith quote which shows that Mohammed suffered grief at the loss of his son, but that there was a gentle re-engaging with society after a period of three day intense grief:

> To grieve for a person is not in one's control. In fact, it is so natural that the Prophet himself wept over the death of his son, Ibrahim......The Prophet while weeping remarked: The eyes shed tears and the heart is aggrieved but we shall only say that with which the Lord is pleased and we are sad at being separated from you O Ibrahim! ..... **The thing which is desirable is that a person should come back to his or her normal life routine by not later than three days. They should not just sit and sob after this period, but should try to adjust to the new situation and follow their general routine.**
>
> http://www.salaam.co.uk/counselling/archive/bereavement.html (19/6/7)

Therefore highlighting the importance of religious ritual to provide guidance and elements of control in a highly emotional situation.

Within Islam there is a strong belief in the afterlife. Gatrad (2002) and Ross (2001) suggest that prolonged periods of mourning should be discouraged as a person's sense of loss and mourning should be, mediated by the belief that any separation

is temporary and that a continuing bond with the deceased person is still present until they re-join them at death. This was supported by a Muslim relative in the study who described the interconnectiveness between the living and the dead:

> 'The belief is that after the person has been questioned then they are kind of in this intermediary realm, they're not in heaven, they are not in earth, it's this intermediary place where they will stay the souls stay there until the day of judgement when all the souls will be gathered together to be questioned by Allah, …But people can pray for others who have passed away …it can be … it's like light comes into their grave' (M2)

Respect for the dying / deceased person and the care that should be afforded to them was discussed by several of the participants in relation to the concept of communication with the recently departed soul through prayers. Although it was acknowledged that most faiths incorporated prayers for the dead it was acknowledged that these were faith specific as one Muslim relative explained:

> 'If you hear that someone has passed away you say like um, 'From earth we were created to him we return', you say it like in English or in Arabic or whatever you like, but normally, say if a funeral car comes past you and it's a Muslim then people should make fatihum, which is like a prayer, it's like an opening chapter of the Koran, in a way it's similar to, it would be similar to the lord's prayer say' (M4)

A Muslim participant felt strongly that a person's 'essence' still remained and therefore the body should be treated with utmost respect:

> 'And the body has got to be handled very carefully because, at the end of the day, it is a body, you know, its 'somebody' (M1)

A fear of inadvertently doing the 'wrong thing' religiously or culturally for the deceased person and, therefore being unwittingly disrespectful caused concern for one nurse. This saddened her as this added 'mindfulness' removed the spontaneity of providing the last care to a patient:

> 'The fear factor sets in you and I think that's really, really sad (because you are) frightened of doing the wrong thing religiously for them' (N2)

This served to illustrate that much more needs to be done to support healthcare professionals and especially nurses and healthcare assistants in their role as the

main carer and advocate for dying and deceased patients and their relatives within acute hospital care.

Within this study, Christian participants did not discuss specific faith requirements at times of death, dying and bereavement. A possible reason for this is suggested by O'Gorman (1998) when she contends that in the first half of the 20th century the indigenous society appeared to lose sight of the importance of rituals relating to death and dying and for the associated need for appropriate death education. In modern western society the hospital or institution appears to take over the care of the individual prior to death.

Funeral directors arrange the preparation of the body, utilising modern technology to enable the deceased person to look as natural as possible. It could be suggested that this shift away from religious ritual for those persons in the secular Christian society may add to the sense of loss experienced by relatives as there is no collectively acceptable way of expressing their grief. This therefore manifests in a highbrid post religion response to the death, as one Christian religious leader stated:

> 'Its all Celion Dion – our love will go on' (RL2)

A further explanation for this is expressed in a paper by Holloway (2005) who suggests that the emphasis in Western societies is on the 'here and now' rather than preparation for the 'here after'

> '…in Western societies, whose rituals celebrate the life lived rather than commending the soul of the departed (p.835)

suggesting a lack of forethought about death and its ensuing bereavement which leaves people ill equipped without an infrastructure (previously provided by religious rituals) to deal effectively with the last care, funeral arrangements and the impact of bereavement.

It was evident in this study that where there were more ritualistic approaches to death, such as for those from the Jewish and Muslim faiths, this was associated with a more structured response to bereavement. In common with the suggestion of Ikeda (1988) it was apparent in this study that the, long revered, Christian ethic has disappeared, leaving Western society without a strong religious base. This has led to confusion of ideas about healthy life and death and as Ikeda (1998) suggests that, in order for more structured support at times of death for people of the Christian faith, traditional values need to be revisited, or new sets of values need to be developed which are better suited to our times.

The importance of providing the last care for the deceased person impacted on the bereavement experience for both relatives and staff. This was explored through the description of feelings of being satisfied that they had provided appropriate care or feelings of being robbed if they had not been able to be present or not allowed to provide such care. This final care provision gave rewards both emotionally and spiritually. For staff these manifested as feelings of completion and satisfaction and care to the end, whilst relatives felt that through the last care and continuing prayers and good deeds in memory of the deceased person they were still caring for the now deceased person and, in doing so they would also be rewarded by God for these acts of kindness.

The exploration of Relationships

Contemporary bereavement theory suggests that continuing bonds with the deceased are a normal aspect of bereavement (Attig 1996, Klass, Silverman & Nickman 1996; Walter 1996; Oyebode 2001). These more recent perspectives conflict with traditional bereavement theory which suggests the purpose of grief is to sever ties with the deceased and 'move on'. However, an integral part of the continuing bonds theory, is the understanding and acceptance of the deceased person as a continuing presence in a bereaved person's life, and that this phenomenon does not automatically indicate abnormal or complicated grief.

Oyebode *et al* (2001) in her series of research undertakings in the UK looked at bereaved spouse's experience of continuing bonds with their deceased partner. Established bereavement research suggests that attachment to the deceased after a 'protracted' period of time is complex grief and therefore deemed to be unhealthy or abnormal. The work carried out by Oyebode (2001) and her three colleagues; and similar work carried out in Utrecht by Klass, Silverman and Nickman (1996) suggests that the relationship with the deceased person is often still central to the bereaved partner's life, and that, for the majority of people this phenomenon is not dysfunctional. This is indeed the overwhelming view held by the author as a result of conducting the study described in this thesis. The dichotomy of the concept of absence being presence is one that is difficult to grasp and yet one that makes perfect sense to those who have lost, yet still retain, the essence of their loved one.

This continuing relationship with the deceased was very much evident within this study from all faith groups through discussion about prayers, good deeds and rewards, ongoing inclusion of the person in thought processes and decision making and, in the caring for and adornment of, graves.

From an Islamic perspective, Yasien-Esmael & Rubin (2005) suggest that although the physical presence of the person has gone, and will be missed, comfort can be found in memories and thoughts about them that remain:

> 'Death is understood to be the loss of the physical relationship with one's loved one, but tradition does not mandate severing involvement with the mental imagery and memories of the deceased' (p.505)

They suggest that specific actions from the bereaved, such as offering prayers and greetings, charity, fasting, performing Hajj (pilgrimage to the holy city of Mecca) and reciting the Qu'ran in the name of the deceased will all provide rewards for the departed soul and for the person undertaking these actions:

> 'the funeral is a time when people send blessings to the deceased, which will help him, or her, later on the way to Heaven.' (p.502) …..'Attending a funeral is believed to enlarge the mercy accorded to the deceased and this serves to minimise punishment in the grave (p.504)

A previous study on the experiences of South Asian patients being in hospital in England found that the participants (whose religious affiliation consisted of Hindu, Sikh and Muslim) did not hold an expectation that staff would have an in depth understanding of their religion (Vydelingum 2000). Several studies have highlighted that nurses feel inadequately prepared for their role in the provision of end of life care (Beckstrand 2006; Lobar 2006; Costello 1995), especially when dealing with cultural and religious requirements (Lobar 2006) and that they often

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have had to learn 'the hard way', by experience. However, in an increasingly multi cultural / multi religious society this Vydelingum's conciliatory response is unlikely to be so acceptable and there is therefore a need to acknowledge, and be inclusive of and responsive to, the diverse needs of society today.

A cross cutting theme running through all of the four existential dimensions was that of the difficulty that healthcare professionals have in communicating effectively and sensitively with relatives during the dying and death of their loved one and their ensuing bereavement stages. This can lead to frustration, anger and resentment from relatives in some instances.

Previous research (Main 2002) highlighted the fact that staff were uncomfortable talking explicitly to relatives about their dying relative and often resorted to the use of euphemisms. This was apparent in this study from the experiences of relative participants. Individuals in Main's study stated that the reason for this was that they had a lack of training and support for dealing with dying patients and their relatives. A question then arises; is it possible to ever fully equip doctors, nurses and healthcare assistants with the right amount of training to allow them to deal appropriately and effectively with emotive, individualised episodes of loss? This is further compounded with the added perceived 'difficulty' of attending to the needs of a person who's cultural and religious frames of reference may be very different to our own.

Many concerns have been levelled at the amount of training in communication skills that healthcare professionals receive. Fallowfield (2003) states that little time in medical schools is allocated to the area of communication and breaking bad news and that incompetence, whether perceived or actual, in this area is a major source of concern for doctors. Field and Wee (2002) examined the teaching provided on dying, death and bereavement in all medical schools in the UK via a postal questionnaire. Their findings suggested that education on death dying and bereavement, through the medium of the palliative care pathway was much improved. However, although a lot of time and money has been invested in palliative care and cancer in particular it must be noted that most people do not die from cancer or receive palliative care. Although Field and Wee (2002) note that religious and cultural aspects of dying were on the curriculum for medical students, unfortunately they provided no details about what this actually entailed, how it was assessed and whether it was adequate and fit for purpose.

Rogers (2000) in his work with bereaved relatives looking retrospectively on the care their deceased relative received found that a small minority of respondents (5 out of 138) poignantly requested that:

> '…medical students and junior doctors should not be allowed access to terminally ill patients because they seemed so inept in these circumstances' (p.54)

Such a statement, although shocking, powerfully highlights the need for appropriate training and, more importantly, supervision for junior members of the medical profession.

How much information is imparted, when, and to whom, has always been a difficult aspect of care to gauge, and balance appropriately, within the area of dying and death. It is acknowledged that there has been a significant shift away from the paternalistic unilateral decision making by doctors of days gone by and today's emphasis within the NHS is placed firmly upon open and honest communication and information sharing.

However, Main (2002) suggests that, health care professionals can act as gatekeepers of information, especially if the information to be divulged is 'bad'. She states that they can, and do, withhold information when they are faced with situations in which they are unsure, uncomfortable or if they feel the need to protect the relatives in a paternalistic way which has been confirmed through the comments of healthcare professionals within the study in this thesis.

The concept of *trust* manifested as a very important component within the relationship between doctors / nurses and relatives / patient. Relatives found themselves in a vulnerable position and were heavily reliant upon the doctors, nurses and healthcare assistants being honest and open and caring towards their loved one and themselves. This heavily dependant relationship occasionally became damaged as a result of poor communication or perceived lack of care. This breakdown of trust had the potential to lead to misunderstandings that may manifest into conspiracy theories and shattered trust.

The use of 'white lies' (withholding the full truth as a means of protecting someone) by healthcare professionals, although essentially well meaning, highlights the continuing existence of a paternalistic 'doctor / nurse know best' attitude. There needs to be a breaking down of such barriers and the 'them and us' attitude and a realisation that the title 'bereaved' will be held by each and every one of us at some time during our lives.

A further observation in the retrospective study of end of life care in bereaved people by Rogers (2000) was of poor communication between medical staff and relatives and that relatives had high and often unrealistic expectations of medical interventions interwoven with cultural, religious and societal beliefs that deny the imminence of death, viewing all deaths as sudden and unavoidable rather than natural and inevitable, which were left unchallenged by medical staff. This was mirrored in this study as illustrated in the following quote:

> 'You get this feeling that okay she was sixty-seven. Sixty-seven is nothing but to them they might have thought she is a pensioner and there is nothing much we can do for her and you know… you hear stories and…she is just a number and they just want to move on basically…..Remember they had pressurised us into switching off the machine.'(M6)

The difference in the experiences of witnessing death was also highlighted in this study. Whilst the death of a person could be the most significant and devastating event in a relative's life; it could also be a 'routine' event within the work experiences of doctors, nurses and healthcare assistants. This imbalance could leave relatives with feelings that staff were uncaring, when the reality may be, at times, they care too much.

Wright (2000) and Spall (1997) suggest that exposure to other people's bereavement will inevitably make people aware of their own mortality and that of those closest to them. It was inferred by healthcare professionals that by giving a part of themselves through empathic understanding meant that a part of themselves became damaged; whether via guilty thoughts that they could have 'done more' or via painful and traumatic recollections of the distress of others.

Doctors, in this study, recounted being saddened by the death of a patient, but described how they tried to distance themselves from the emotional distress of the situation. Whether such an approach is institutionally orchestrated, whether this perceived detachment constitutes denial, and the 'healthiness' of such an approach are all questions which warrant further exploration but are beyond the remit of this study.

Redinbaugh's (2003) research on doctor's responses to the death of a patient found that, on average the doctors reported experiencing two out of the fourteen symptoms of grief scale; those being a feeling of distress and an associated numbness. Redinbaugh's study concurs with the data gathered from this study which suggests that the feelings of professional isolation and the personal emotional impact of the death of a patient are not openly discussed. Sadly these feelings of isolation were expressed in Redinbaugh's study by junior doctors who did not feel comfortable to approach their attending physician (Consultant equivalent) for support:

> 'the culture of medicine, through its emphasis on biomedical issues and its lack of emotional support, may also contribute to trainees' reluctance to report needs for emotional support' (p.7)

Interestingly nearly half of the attending physicians in Redinbaugh's study felt that they would find *no one* 'helpful' to them following the death of a patient, clearly illustrating the isolation and helplessness residing in some doctors. A salient question for further research is raised in Redbaugh's study:

> ' what may be the cumulative impact of emotionally draining deaths on attending physicians (consultants) who 'do not need' emotional support' (p.8)

It is suggested that if the strong emotional responses to death, that are undeniably experienced by doctors, are not discussed or openly acknowledged by senior doctors to junior doctors, this may convey a subliminal message of how death should be handled. A potential conspiracy of silence regarding emotional responses may lead to isolation, maladaptive behaviour and burnout among medical staff.

The emotional impact of caring for a dying patient, and their subsequent death, were important aspects to the care that the nurse participants provided. van Manen (2002) suggests that there is a spiralling of emotions within the relationship between a nurse and a dying / deceased patient:

> ' the more I care for this person, the more I worry, and the more I worry the stronger my desire to care' (p.272)

The ability to talk about and revisit her professional experiences of death in the interview appeared to be cathartic for one nurse:

> 'of all the deaths that I've experienced –that hit you deeper, but I'm – I'm so glad that I've talked to you about it now – you know –….(breaks down into tears)' (N2)

One nurse commented how emotionally draining caring for a dying patient could be. This was due, in part, to the emotionally charged engagement with the dying

person and their relatives and recognition of the enormity of what they were experiencing:

> ' it is too heavy emotionally really. So the way I see it, it is quite a hard ..um ..when somebody - you have to deal with patients emotionally - because you have to have lot of understanding of how they feel' (N1)

Personal and professional experiences of grief may, for example, only emerge or manifest when nursing staff are 'off duty'. A uniform, plastic apron and gloves may protect against infection, a professional demeanour may present a façade of empathy and understanding but neither will protect the staff from the ravages of their own personal emotions following professional and / or personal experience of death and bereavement.

The potential for hospital staff to be damaged personally and professionally when returning to work following a personal bereavement has been highlighted by Costello (1995). She suggested that a nurse's personal experience could be a hindrance when trying to help bereaved relatives due to the rawness of their own feelings and an inability to protect or separate their grief from that of the relatives which without help or intervention could be potentially damaging for the staff involved.

From the author's personal experience an offer of objective support and an opportunity to discuss the personal situation and its impact personally and professionally would have been valued. However, local, national and research based work made this a difficult request to fulfil and one that would have actively had to have been pursued rather than readily available.

However, professional support for staff following a traumatic or poignant death or following multiple deaths or if returning to work following a personal bereavement is a fundamental requirement that all acute hospitals should provide but in reality rarely do, a situation that requires concerted action to achieve against an undeniable backdrop of evidence base.

The impact of caring for a dying person and their relatives, and the associated impact that this may have on the religious leaders, emerged through their interviews. In this study religious leaders acknowledged the difficulty of their role at times of dying, death and bereavement including feelings of being under the gaze of relatives whilst performing rituals and a fear of being alone with recently deceased patients. To date this is an area in which very little research has been undertaken, especially from a multi faith / multi cultural perspective at times of dying, death and bereavement. A Christian religious leader was very clear about his role and boundaries in this area and felt that he passed on all the associated emotional 'burden' of this part of his role to God. Not to do so, in his opinion, would be out of selfish pride and beliefs of self importance:

> 'Well I haven't got any strain because he, God takes all the strain. Why should I worry because some would say I pass all my worries on to him ….you know what I mean. If I didn't then I'd take on burdens from somebody else and me carrying them and I can't do that I've got enough problems of my own without carrying everybody else's as well because that, that would be pride if I tried to do that … so I pass it over and say Lord its up to you now I can't do any more than that….. yes you get tired but there's not any particular tension caused by death and dying and bereavement. I don't take that on board at all* tired because there is such a lot to do* but no more than that because if I did then I am retaining – almost saying to God 'look I'm carrying this person's burden and he'd say I didn't ask you to do that…. Help yes, but not carry the burden… that's why you can be involved without getting stressed out with it'. (RL1)

This suggested that although he may be present and performing rituals, he was doing 'God's work' and so no responsibility or burden could fall upon him to carry.

Yasien-Esmael and Rubin (2005) discuss the roles and responsibilities of a religious leader of the Islamic faith. They suggest that such a role is to remind people of the spiritual meanings of loss and death and the importance of patience:

> 'it is a religious duty to offer condolences, and those who fulfil it are awarded ajr (immediate religious recompense for deeds performed).' (p.508)

In the study described in this thesis, a female Muslim religious leader alluded to the infancy of a multi faith Chaplaincy within an acute hospital Trust and the difficulty in identifying the roles and responsibilities of a Muslim 'Chaplain'; as the term 'Chaplain' has very Christian connotations which will need to be addressed in national and local policies:

> 'I have found that because Muslim chaplaincy is still very much in its developmental stages …I must admit when I first saw that title ' female Muslim Chaplain' (laughs) it seemed to me to be a contradiction of terms of the role here. Because we don't have any clergy as such and to my understanding a Chaplain was a member of the clergy. …So it seemed to contradict, because we don't have any ranking in Islam as such. Even an Imam from a Mosque, it's not his ranking, it's a responsibility that he has, that he takes. …but trying to understand what a chaplain, a hospital chaplain does do – there was nothing that contradicted the way that a Muslim should behave in terms of meeting those needs of people. So I thought well chaplain certainly fits the bill thought it has Christian connotations to it. And then when I was asked what I would like to be called, when I was offered the job after coming to the interviews, I wasn't sure but I could not find a more… a word which could replace chaplain that would mean the same thing' (RL5)

From a Jewish and Muslim relatives' perspective, the support from friends and their community was seen to be invaluable. It appeared to be provided within a religious framework, and gave a structured format for the bereavement to be experienced and for the bereavement experience to receive formal recognition. It was suggested that such intervention and support alleviated the need for specialist intervention and counselling. This support was seen as an obligation for all and facilitated a cohesive 'group' approach to the death of a part of the collective

community. However, both a Jewish and Muslim participant felt that an open offer of traditional bereavement counselling support would have been welcomed.

Support appeared to be lacking within the Christian participants' accounts. There appeared to be a communal lack of acknowledgement of the impact of the loss; a lack of a formalised structure for acknowledging the loss and a distancing of family, friends and community members; although, for one Christian participant this distancing was self imposed.

A question then arises: in a secular society where do those of no faith find support and comfort following the death of a loved one? Is the emergence of models of grief and counselling within secular societies a replacement for the family support of yesterday and a part of a new religion for tomorrow? However, there appeared to be an agreement that at times of stress and uncertainty such as end of life situations some people will return to the comfort of their birth religion, even if they have lived quite secular lives

This suggests that a return to religion at times of crisis will in some way realign the person with their God and thus allow consideration for a place in Heaven. This belief pattern appeared to give comfort to bereaved relatives and provide a structure and 'context' to their bereavement, in the absence of absolute belief.

One Christian religious leader suggested that within an increasingly secular society, if a person did not have a religious belief, at times of dying and death, they would take comfort from being in the presence of someone who had:

> '…if everyone doesn't believe themselves they like to think someone does on their behalf almost, it's almost like vicarious belief, you know, 'I can't believe it but I'm glad you do B……I suspect that many funerals I have taken I've been the only one who has actually believed what I have said (laughter). I suspect they have wanted to believe what I have been saying, especially in that context of being at the crem' (RL2)

This belief in returning to the 'nurturing mother religion' is supported by Yasien-Esmael *et al* (2005) when they state that:

> ' For the relatively secular person, generally there is comfort and structure in following the precepts of the religion immediately upon experiencing the death of a loved one' (p.515)

A 'prodigal son' concept appeared to emerge whereby Christian religious leader participants shared a belief that even though people may 'leave' or not adhere to their birth religion doctrine throughout the majority of their lives, people returned to its bosom at times of great distress such as dying, death and bereavement. This they described as religion by proxy.

Costello (1995) in particular suggested that nurses receive little education or training in formal bereavement counselling. Although an interesting point, it raises the issue not of whether nurses should have knowledge of bereavement counselling but, having acquired the expertise, whether a ward environment would be the appropriate place in which to use it. As Stroebe and Schut (2005) states in regards to the potential damage that bereavement counselling may cause:

> 'The worst case scenario is of unsolicited, routine referral shortly after bereavement for no other reason than the person has been bereaved' Stroebe and Schut (2005)

From a health and wellbeing perspective, the need for formalised bereavement counselling only exists within a small percentage of the bereaved population. This is stated clearly within the NICE guidelines (2004) which emphasis that only a small percentage of people will need formal *bereavement counselling* a few more

may have need of *support* and befriending, but, for the majority of bereaved relatives appropriate information and advice is all that they will require.

However, nurses, healthcare assistants and doctors require up to date education on normal and complicated grief and influencing factors in end of life and bereavement care but it would appear that this is lacking from current education and training and mainstream healthcare literature. This lack of knowledge and understanding will be reflected in the delivery of appropriate and sensitive end of life care for dying / deceased patients and their relatives and should be addressed. The focus on high quality care for all as set out in the NHS Next Stage Review (2008) and the Department of Health End of Life Care Strategy (2008) provides a unique opportunity to put quality at the heart of end of life and bereavement care such that frontline staff can lead change that improves the quality of this care and patients can be empowered to ensure that it is fit for the needs of the local population.

The interrelationships and communication during the pre death bereavement journey all impact on bereaved relatives' post death bereavement. What was said and how it was said all contribute to the phenomenon of bereavement and shape a person's experience of it. Whilst relatives recounted how they had wanted to hear the truth, doctors, nurses, healthcare assistants and religious leaders recollected how they had delivered bad news and how information had at times been 'diluted' out of acts of perceived kindness.

'I believe in telling the truth I don't believe in telling the truth cruelly' (RL3).

However, if discovered these 'acts of kindness' led to immediate mistrust.

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Whilst the Jewish and Muslim relatives talked about the support, mostly welcome, from relatives and friends during their bereavement journey, Christian relatives talked of their isolation and difficulties re integrating into a changed situation.

Support for staff following a traumatic death on the ward or a personal bereavement was also discussed and found to be needed, not as an add on or as a 'treatment' but as part of normal integrated care for staff. This was also noted through the reflections of the religious leaders and highlights the importance of recognising that, regardless of title we are all human and all affected by death and bereavement.

The importance of support training and education for staff cannot be emphasised enough. If we do not adequately educate, train and support the staff providing end of life and bereavement care then this will translate into poor bereavement experiences for relatives, some of whom will inevitably be staff.

Such training and education should highlight the importance of doctors, nurses and healthcare assistants relationships with relatives and enhance the delivery of good communication and appropriate end of life care which should impact positively on the bereavement experience and ultimately reduce the number of complaints following the death of a person in hospital (Appendix A).

Relationship of the emergent themes to the objectives of the study

This thesis set out to explore some fundamental questions about dying, death, and bereavement in the context of, and in relation to the Abrahamic faiths. To understand the significance of religious and cultural requirements at times of dying, and death and their impact and significance on the lived bereavement experience.

Although theories of bereavement (Kubler-Ross (1969), Bowlby (1969,1973), Parkes (1972)) have provided the bedrock for much of the research that has been carried out in the field of bereavement, many of these have failed to explore the individual experiences and facets of dying, death and bereavement within a faith context. There has been more of a focus on collective groups of 'selected' bereaved rather than on the unique experience as it impacts on the individual. This makes it difficult to compare the outcomes of this study with published bereavement theories. However in this study all the relative participants irrespective of religious faith, who were between eight months and four years after the bereavement experience, displayed movement through the six tasks of mourning as highlighted by Rando (1985) including recognition of the loss, reacting to the separation, recollection through reviewing and remembering and were beginning to readjust to their new circumstances without the physical presence of their loved one.

Although the relationship to bereavement theory was not a central component of this thesis, due to the nature of attempting to ascertain the 'lived' experience it was noted that there was also some manifestation of the dual process model of

bereavement identified by Stroebe and Schut (1999) which appeared through descriptions of oscillation between loss and restorative orientation. The former being displayed through the vivid recollections of the end of life and bereavement journey and the latter expressed through the consideration of new secondary relationships and continuing relationships and religious rewards, particularly for those of the Muslim faith. The most significant theme however was the demonstration of continuing bonds as described by Klass and Sliverman (1996) and Oyebode (2001).

This emerged in all participants and manifested as an interactive and ongoing relationship with the deceased but its expression was different across the three faith groups. Those of the Muslim faith displayed this through prayers, good deeds in the name/honour of the deceased and a knowledge of reunion after the day of judgment. There were similarities with those of the Jewish faith in terms of prayers and beliefs in an after life but also included remembrance of the deceased on the Jewish anniversary of their death and through significance of the grave. Those of the Christian faith displayed this through prayers, internal conversations with the deceased and gifts to the grave.

As stated previously, to date very little research has been carried out on religious beliefs and their impact on the bereavement experience which led Rosenblatt (1993) to suggest that trying to adapt bereavement theories to a diversified society is pointless. Since then various authors (Ribner (1998), Golsworthy (1999), Becker (2007)) have suggested that religion is a potentially beneficial mechanism for

coping with bereavement and have all called for further research on its impact on the bereavement experience and journey. The study in this thesis has shown the importance that religious belief and rituals play as part of the overall experience of bereaved relatives from the Muslim and Jewish faiths and how this can be different for those of the Christian faith.

Table 12 summarises the end of life care and lived experience themes that emerged for the bereaved relative groups divided according to faith and illustrates both areas of commonality and differences as well as the potential implications for providing culturally sensitive end of life and bereavement care. The study serves as a powerful account of the issues that can impact on and influence the bereavement experience and is an approach that should be used in further studies to gain a greater insight. In this study it has demonstrated the impact that the situation and the environment may have had on all involved.

For Muslim relative participants life is sacrosanct and to be maintained at all costs, however, when death occurs this is accepted as 'God's will'. It is a religious obligation for Muslims to visit the sick and dying to show support and assist in prayers for recovery or preparation for death and adequate provision for this to occur is required. An understanding of end of life requirements by staff including the end of life and bereavement care provision by family, friends, and funeral arrangements is an essential part of end of life care and its delivery as has been demonstrated in this study will impact, positively or negatively on the bereavement experience of relatives and friends.

The individual experiences of the Muslim participants highlighted concerns about the shortening of life though withdrawal of life support and a mismatch between the medical definition of brain stem death and Islamic teaching which illustrated the need to ensure that there is a greater public understanding of such dilemmas.

Table 12.   End of Life care and lived experience themes

Participant group	End of Life Care requirements	Lived experience
Muslim Relatives	➢ Treatment to continue for as long as possible ➢ Information recognises belief in life at all costs ➢ Visitors able to pay last respects and recite Quran / prayers in preparation for dying and to assist the person into death ➢ Space and privacy for 'religious' requirements of being present at death and ability for people to express grief ➢ Staff awareness and understanding of needs including the importance of 'Islamic' requirements ➢ Ability to facilitate rapid release for funeral preparation and for family and community involvement ➢ Respect and gender specific care after death, belief that soul is present and can still experience	➢ Concerns that lives have been shortened ➢ Brainstem death not acknowledged in Islam ➢ Feelings of being dismissed and judged for overt expressions of grief and need for people to visit dying/deceased ➢ Poor communication by doctors; no explanation, little compassion ➢ Delays in documentation perceived as deliberate and unnecessary whereas for relatives there is a race against time to arrange funeral ➢ Acting as dying/ deceased guardians due to both perceived lack of understanding and worries about care of deceased after death ➢ Comforting belief in rewards and continuing bonds with deceased ➢ Set mourning period with family involvement ➢ Graves seen as waiting area until day of judgement ; unpretentious ➢ Perceived community support but not always appropriate
Jewish Relatives	➢ Honesty and openness valued and recognition that trust lost if poor communication from staff ➢ Death not to be hastened in any way ➢ Difficulty with withdrawal of treatment (focus on life) ➢ After death importance of involvement of Chevra Keddisha and withdrawal of family to grieve ➢ Where possible after death minimal contact by gentiles and of disturbance of body respect for dead ➢ Body seen to be loaned by God and need to be returned to earth as quickly as possible, requires speedy completion of documentation and formalities	➢ Life at all costs but inevitability as God's will ➢ Importance of presence when dying but not after death ➢ Acceptance of hospital as right place until death ➢ Lack of understanding by staff of significance of care by Chevra Keddisha and need for rapid release to enable return to earth ➢ Feeling of being judged and of being treated with contempt ➢ Belief that there are deliberate delays in issuing certificates ➢ Set mourning period, family and community involvement but would also have liked offer of bereavement support ➢ Own Jewish days for remembering and collective community pride in looking after dead in memorials
Christian Relatives	➢ Honesty and openness valued and recognition that trust lost if poor communication from staff ➢ Death pain free, surrounded by relatives and loved ones, importance of saying final last words and not on own going into death ➢ Ability to say goodbye after death and not to be rushed ➢ Recognition that nursing staff will take over care after death and will do the right thing	➢ Inevitability of death and of 'knowing' death was going to occur ➢ Perceived collection of the dead from the 'other' side ➢ Acceptance/trust in role of hospital/staff throughout pathway including care after death ➢ Presence at death to experience reality of the loss and for individual not to be seen as any less of a person ➢ Vunerability, helplessness and lack of connectivity with religion ➢ No recognised mourning period, with feelings of void in days/weeks and months after loss ➢ Isolation and ad hoc community/bereavement support ➢ Continuing bonds with deceased through graves/memorials and pride in adornment

Whilst religiously and morally obliged to visit the dying, relatives expressed feelings of being judged and of staff being dismissive of their needs at such an emotive time. Poor communication coupled with a perceived lack of compassion led to perceptions of unnecessary delays by doctors with the issuing of necessary documentation after death. This perceived indifference and at times judgmental attitude from staff caused concerns about the care that the person would receive after death. Therefore there was a desire to remove the deceased person to a religiously appropriate place for final care to be given and burial to take place as soon as possible.

For the Jewish relatives honest and open communication by medical staff was important and trust was lost if communication was poor. Similarities were evident between end of life care requirements for Jews and Muslims with similar views on life as sacrosanct and the importance of burial as soon as possible. After death, family stepped back into mourning and funeral preparation and arrangements were undertaken by the Chevera Keddisha to ease the burden for the bereaved and to ensure that religious requirements for the final care of the person were carried out appropriately.

Jewish relatives recounted their experiences and discussed their belief in life as sacrosanct but also acknowledging that there was a designated time for everyone to die. They expressed concern that staff did not fully understand their religious requirements at end of life and that some were judgmental, but felt comforted when staff stepped back and allowed the Chevera Keddisha to take over the care

of the deceased person. The period of Shiva was described as a structured time of community support, reflection and readjustment to an altered life, which all, irrespective of level of orthodoxy, felt highly beneficial.

Christian relatives again valued open and honest communication from staff which, if found to be inaccurate, caused mistrust and concern. The importance of being present during the dying period, at and after death appeared to be very important to participants. The here and now rather than preparation for the here after appeared to be most important. This time allowed relatives to say their goodbyes and affirm their love for the dying person. The recitation of prayers and preparation for after death was not a significant consideration for relatives to undertake at this time, and if required, would be undertaken by a religious leader on their behalf. Time with the deceased person after death allowed the reality of the loss to commence and there was an acceptance that care of the deceased from now on would be undertaken by others in a timely manner.

The Christian relatives talked of the person before their illness and their relationship with them. There appeared to be a trust in healthcare staff that they would provide appropriate care before and after death which therefore did not manifest adversely on the bereavement journey. Although overt religious process and belief was not discussed there was reference to life after death through stories of long deceased relatives coming to collect the dying person.

Some displayed a vulnerability and associated helplessness by virtue of a lack of connectivity with religious support and ritual at death and through the bereavement journey. No mourning period was discussed or recognised with relatives recounting feelings of isolation and loss of meaning resulting in seeking bereavement counseling for several participants. Connection with the deceased appeared through ongoing mental conversations with the deceased person and gifts placed at their grave.

The situational impact of the death in hospital meant, for the Muslim and Jewish participants that added concerns related to appropriateness and timeliness of last care and funeral arrangements influenced their bereavement experience – mostly in a negative way. This must be an area for further work to ensure that bereavement care is fit for all in acknowledgement of the multifaith multicultural society.

Most of the themes that emerged can be addressed via education and training and public awareness but require a systematic long term approach rather than a one off to ensure that good practice becomes embedded within daily care and is regularly evaluated and reviewed. It is a powerful account of the individual experiences of loss.

Table 13 summarises the experiences of nurses, healthcare assistants doctors and religious leaders and provides an insight into their 'lived' experience both as Individual

Table 13.   Experiences of nurses, doctors and religious leaders

Participant group	End of Life Care requirements/role	Lived experience
Nurses and healthcare assistants	➢ Open and honest communication (not white lies) ➢ Clear understanding of all religious requirements and reasons why and when they are needed during the dying and death trajectory ➢ Recognition of nurses and healthcare assistants role in closer involvement in caring for patient, knowing more about them and their families ➢ Awareness of potential impact on bereavement experience for relatives ➢ Self protection from grieving for every patient ➢ Requirements of nursing staff in last care procedures and what can and cannot be done	➢ Difficulty in communicating with some relatives and tell them honestly what was/had happened ➢ Role of relative by proxy in absence of relatives during dying/death ➢ Feeling of being robbed if deprived of last offices / religious requirements especially if cared for patient for long time ➢ Doctors not always equipped or feel confident in breaking bad news and task falls to nurses to provide support ➢ Emotional impact of caring and experiencing death of a patient ➢ Associated guilt of wanting to do more for patients as well as not always seeing the person as an individual ➢ Balance between wanting to spend time with dying person and needs of other patients ➢ Attempts to understand other religious and cultural requirements but limitations/fear of getting it wrong recognised as well as prejudices of other staff members even during last offices
Doctors	➢ Distancing when patient in dying phase and contrast with active treatment phase but focus on pain free death ➢ Focus on patient as one dimensional and a 'condition' rather than on the person as an individual ➢ Communication skills in breaking bad news and impact of environment ➢ Not viewed as nurturing and caring role – still paternalistic ➢ Awareness of potential impact on bereavement experience ➢ Importance of death certification and relationship to appropriate religious care and mourning of the deceased	➢ Maintaining objectivity at all times and seeing quality of life rather than quantity ➢ Pressure put on them by relatives in certain situations and particularly related to when death is going to occur ➢ Process and outcome focused and see their role as failing in death ➢ Put in difficult situations at times and not always supported by senior colleagues ➢ Caught between relatives and bureaucracy at times ➢ Irritated, dismissive of pressure from faith groups requiring documentation ➢ Detached as a way of protecting and getting too involved
Religious Leaders	➢ Primarily present to look after soul and to prepare for eternity ➢ Facilitation of religious ritual and preparation to move from one life to next which needs to be both recognised and embedded in care pathway to ensure enough time ➢ Christian – seen as expert within a secular community ➢ Islam/Jewish – seen as leaders, teachers and source of knowledge in community ➢ Broader knowledge and acceptance/inclusivity of other faiths and need to look beyond the Christian ethic	➢ Vulnerability – seen as God like but still very much human and feel out of depth at times ➢ Act as conduits for Gods will and work ➢ Expectations of them are usually high especially in preparation for death and sometimes at death (e.g. Muslim) ➢ New definitions of death can be confusing and used to justify actions of staff ➢ Provision of comfort and reassurance and sometimes a relaxing into death and a calmness for the bereaved ➢ Judgemental and dismissive of other religions

Individual healthcare professional and unique person areas which other studies have generally not attempted to explore.

Nurses, healthcare assistants and doctors reflected on their communication with relatives and shared how and why they had sometimes withheld or altered information they gave in the belief that they were protecting relatives. This appeared on occasion, to be related to not knowing how to approach highly emotive situations in general or in a sensitive culturally acceptable way. This is an area that requires further study to clearly ascertain education and training needs and provision. Nurses and healthcare assistants were generally seen as being the delivers of care whereas the perception of doctors was often one of holding the key to treatment or the withdrawal of life. The failure to address or understand the implications of this for those of the Muslim faith concurs with the observations of Higgs (1999).

End of life care and concerns about being perceived to be culturally/ religiously insensitive were discussed by nurses, healthcare assistants and doctors. They acknowledged that they were unsure of cultural and religious requirements at end of life, its significance and impact on the bereavement care which was echoed in the relatives experiences. Dowd *et al* (1998) stated that there was a need for a more appropriate cultural model for training and education around dying, death and bereavement which addresses aspects such as communication, time and space which is supported by the experiences of staff reported in this thesis. The impact of lack of support for staff constantly exposed to bereavement emerged

and is an area of concern which needs to be urgently addressed to ensure that individuals are protected emotionally and can function in an environment where death is relatively commonplace.

The experiences of religious leaders, which has received little research attention, illustrated the fundamental differences between those of the Christian faith who are seen as an expert within a largely secular society compared to those of the Muslim and Jewish faiths who are seen as leaders, teachers and scholars within the community and upholders of the religious rites and rituals. The experiences have highlighted their key role in providing support and reassurance and the need for inclusivity and tolerance within the hospital 'chaplaincy' team. It is also worthy to note that they too are vulnerable and need to be supported in what is a hostile and difficult environment at times.

Finally, the impact and implications of these experiences for education and training and for healthcare policy and practice are outlined in Table 14.

A High Quality Workforce (Department of Health 2008) published alongside the NHS Next Stage Review (2008) recognised that clinicians need to be supported and developed to be practitioners, partners and leaders in care through education and training that is fit for the future challenges of healthcare provision and for an NHS where high quality care for all is the organising principle. It also outlined initiatives to ensure that modernised career pathways for doctors and nurses and other professional groups are introduced and where local education and training

Table 14.   Impact of study findings for health policy and practice

Implications for healthcare policy and practice	Implications for education and training
• Acute hospital policy and practice inclusive of differing end of life care requirements for all faiths and cultural needs • Clear end of life care and bereavement pathways with roles, responsibilities and provision clearly outlined • Reaffirmation locally and nationally of role of staff in end of life care and in bereavement including nurse as carer • National policy reflective of cultural and religious needs for example in death certification • Recognition of and support for staff in difficult and emotional situations including debrief and counselling • Regular audit of practice and outcomes including on the experience of the bereaved • Recognition of the role of the religious leader	• Communication and breaking bad news training for doctors, **nurses and healthcare assistants** in simulation settings • Training and education for all staff on differing religious and cultural requirements and their significance in end of life care; bereavement theory, care and practice; grief reactions together with appropriate assessments of competence • Process and procedure relating to legal and coronial requirements for the deceased • Education for the general public on hospital procedures, end of life care and what to expect and planning ahead

needs can be commissioned through partnerships between the NHS, Higher

Education Institutions and others . A recurrent theme throughout the study in this

thesis related to training and education for doctors, nurses and healthcare

assistants on end of life and bereavement care incorporating religious

requirements and their significance and is an area that needs to be addressed

both in national and local education and training and modernising career

initiatives.

Similar to Main's study (2002) this study found that nursing staff felt uncomfortable

and ill-equipped to communicate effectively with bereaved relatives. At times they

resorted to 'white lies' on the premise that these were to protect the relatives, but,

in truth, may have been initiated to protect staff from witnessing and having to deal

with the impact and aftermath of breaking bad news. Medical staff also expressed similar difficulties although often hid behind the façade of needing to keep a distance to protect themselves as well as a perception that their work had been done as active treatment was no longer possible and/or needed. Other workers (Field and Wee 2002; Fallowfield 2003) have highlighted the need for training and education in end of life and bereavement care to be available for all medical staff – not just for those with an interest in palliative care.

Effective communication is a vital component in any situation but especially at times of emotional distress such as bereavement. It is clear from this study that people recounted with absolute clarity how and what the doctor / nurse had said when their relative was dying or had died and that these words were etched in their memories forever. Education and training in this area needs to be a part of undergraduate and postgraduate education and available for all staff involved in patient and relative contact, from health care assistant to consultant

Public awareness on dying death and bereavement is also an area that needs to be addressed. The work of Allan Kellehear (2005) on Compassionate Cities in Australia gives an excellent example of how a public awareness campaign can educate and inform people on grief and bereavement, especially in a death denying culture. Such a programme could be adapted to include cultural and religious requirements and medical and legal requirements with clear explanation as to their meaning thus dispelling myth and misunderstanding.

The possibility of facilitating public debate and discussion on dying death and bereavement can only enhance end of life care and thus improve the bereavement experience through realistic expectation, open and honest discussion and the ability to seek help if required without embarrassment or stigma.

The Department of Health sets the strategic health care policy for providers of NHS care in England. The recent Next Stage Review of the NHS (2008) led by Lord Darzi has set a 10 year strategic direction which has incorporated clinical visions for future care provision outlined by the 10 strategic health authorities in England across 8 clinical pathway groupings including end of life care. The latter being informed by, and reflective of, the Department of Health End of Life Care Strategy (2008). Both of these publications have given a further prominence and a platform for end of life and bereavement care in future NHS service provision to meet the needs of local populations building upon the 2005 publication *'When a patient dies'*. In most national policy documents there is greater focus on inclusivity and embracing equality and diversity in all of its different guises and in being responsive to the needs of individuals. However, the consultation document on improving medical certification does not yet address the needs of religious groups clearly showing that these considerations are not always recognised and acknowledged in national policy.

Although NHS Chaplaincy policy (2003) embraces spiritual and multifaith care there is at present a gap between end of life religious requirement and end of life practical care. This gap needs to be bridged to facilitate holistic end of life care

that incorporates both elements. The appointment of chaplaincy members from faiths other than Christianity if utilised properly should assist in, and provide guidance on, religiously appropriate end of life care.

This study has demonstrated that the provision of equitable end of life and bereavement care will require local hospital policy and procedure to be inclusive of differing end of life care requirements for all faiths and cultural needs. Although care for the dying, deceased and bereaved person is clearly set out within the faith groups, the ability to meet individual needs can be challenged when a person dies within an acute hospital setting as demonstrated in this study. Care pathways which outline the patient and carers journey and set out an integrated approach to care have been developed. For example, the Liverpool care pathway (www.lcp-mariecurie.org.uk/publications) states that it is an:

> 'evidence based framework for the delivery of appropriate care … for patients and relatives …… it encourages a multiprofessional approach to the delivery of care that focuses on the physical, psychological and spiritual comfort of patients and their relatives that has also been shown to empower generic staff in the delivery of care.'

This care pathway together with the Gold standards framework (www.goldstandardsframework.nhs.uk/24/0/09) and the End of Life Care Strategy (DH 2008), whilst excellent in raising the profile of what is required based on available evidence, primarily focus on palliation of symptoms and very targeted support for example psychological and spiritual rather than on concrete religious considerations. The National Care of the Dying Audit – Hospitals (NCDAH, 2006) highlighted that bereavement care needs do not appear to be addressed within hospitals and that the religious needs of the dying relatives are not universally acknowledged. Thus illustrating that the holistic needs including religious care of

the dying person and their families must be embedded within end of life and bereavement care and within the very fabric of the acute hospital and the roles and responsibilities of staff. Performance and accountability for outcomes should be regularly audited and practice evaluated and reviewed. To not do so, will not only fail to fully acknowledge the person as a whole, but will remain a life long memory for the bereaved, as has been illustrated by many of the participants in this study.

There will however be a need to bridge the gap between primary, secondary, tertiary and voluntary sector to ensure the needs of the dying, deceased and bereaved are met by all involved along the bereavement journey. It will be important to develop and introduce national quality standards for care wherever it is delivered which is both measured and utilised and that best practice is continually spread and adopted so that NHS provider organisations become exemplars in delivering high quality end of life and bereavement care.

To ensure end of life and bereavement care is truly reflective of local populations, initiatives should be encouraged to bring research, educational and academic credibility to the field and evidence based challenge to old models and theories.

CHAPTER 9

CONCLUSION AND FURTHER CONSIDERATIONS

This study has explored the phenomenon of bereavement from a faith perspective through the experiences of bereaved relatives from the Christian, Jewish and Muslim faiths, religious leaders and healthcare professionals providing end of life and bereavement care in an acute hospital setting.

The use of van Manen's (1984) structured phenomenological approach compartmentalised the bereavement experience into four existential dimensions of 'time', 'space', 'body' and 'relationships'. This allowed the 'essence' of bereavement to be determined in a way that caused no undue harm or distress to any of participants but rather enabled them to tell their story. Its use facilitated the construction of themes from the raw material of individual stories and provided a richness of information that many of the published studies on the collective experiences of groups have not been able to capture.

Specifically related to the acute hospital setting, it demonstrated an interconnectedness between end of life experiences and their subsequent moulding and impact on the bereavement experience. The two being inextricably interwoven with bereavement not being a stand alone objective phenomenon. Furthermore, it illustrated how current theories of bereavement need to be more inclusive of the secular society of the 21st century in the UK and the myriad of differing faiths. They also need to be inclusive of individual experiences rather than assumed generalised principles from selective groups of individuals most often cancer related. There is much that can built upon especially from a comparative

perspective with the potential to explore the temporal bereavement experience and understand how the 'lived' experience evolves with time.

It does however remain a study performed in one acute hospital Trust with a relatively small number of participants and in only 3 religious groups. Although in the context of qualitative research, it was a representative sample size and reflected issues that had been observed within the particular hospital and through the analysis of letters of complaint about end of life and bereavement care.

Many implications have emerged relating to the appropriateness, relevance and inclusivity of existing bereavement research; on the training, education and support for healthcare professionals on religious and cultural requirements at end of life as well as on behaviours and attitudes to care; and the importance of making environment, process and procedures fit for purpose in an acute hospital setting. It has illustrated the need for staff and others caring for those who may be bereaved to understand that the memories of the last days of life and of the actual death itself will stay with them forever and thus impact on the bereavement experience. This is so much more challenging in an organisation that is so often associated with the 'saving' of lives and in which the environment reflects that ethos through its policies, procedures and practice.

The current focus on high quality care for all as outlined in the Next Stage Review of the NHS (2008) and the integral components of safe and effective care to improve the patient experience need to be embraced and implemented in a

culturally sensitive way for dying, death and bereavement. This will ensure that it is reflective of both individual need and of the multifaith multicultural local population that is being served. It needs to span the whole quality framework from standards through to clear measurable outcomes for both end of life and bereavement care, such that individuals are supported through an experience and impacts are minimised efficiently and effectively.

Central to implementing the findings of this study is, as a minimum, the existence within acute hospital settings of a culturally sensitive bereavement care service as previously described elsewhere (Chaplin 2003) and proposed in the 2005 DH document *'When a patient dies'*. In addition, an explicit end of life care pathway is required that includes religiously appropriate bereavement care as well as clarity on the roles and responsibilities of staff and the delivery models. This together with an active local research network would enable the findings of the studies in this thesis to be built upon and developed to provide an evidence base for future practice in bereavement care in the NHS.

Further studies

To date most bereavement related research studies have been conducted within a white Christian population. Although the potential impact of differing religious beliefs has been acknowledged, none have actively sought the experiences of bereaved relatives from other faiths or religious leaders as in this study which has illustrated the importance of acknowledging religious components as part of the

end of life and bereavement experience. Therefore further research is required to explore the influence and impact of faith (or no faith) on the bereavement experience

Further research, like the study undertaken in this thesis, is needed to look at the bereavement experiences of people including those from differing cultural and religious persuasions to fully understand and be able to provide for all needs at end of life and into bereavement care. Although the sample size in the study in this thesis is relatively small this is in keeping with the research design and does illustrate the differing individual needs and expectations at end of life which, if not facilitated, can impact negatively on the bereaved and on those delivering care. A broader understanding of the essence and impact of bereavement on the individual needs to be considered, both from a faith and van Manen's four existential dimensions perspective and should be an important component of other future studies in this area.

The thesis has indicated that in addition to the above the following should be the subject of further studies.

1.   Wider insights into the phenomenon of bereavement

1.1   The study undertaken in this thesis was limited to the views and perceptions of the three Abrahamic faiths. To further understand and appreciate the experiences of bereavement it is suggested that a similar study, gathering the

experiences of relatives from other religious denominations and those with no faith, would provide a rich picture of end of life and bereavement care from a religious perspective.

1.2   The recently published DH End of Life Care Strategy (2008) suggests that a large percentage of people in the UK would like to die at home. A more in depth study is required to capture the reasons and influences behind 'preferred place of care / death' and to explore the experiences of bereaved relatives who have lost relatives / friends in differing settings for example in acute hospitals, hospice, home.

1.3   This thesis has highlighted the lack of understanding of the general public on hospital policy and procedures that surround dying and death as well as legal and other requirements. The specific requirements need further exploration to inform the development of pilot material for a public awareness campaign to heighten awareness of the need for end of life and bereavement care planning.

2.   **Greater understanding of the impact of caring for the dying on staff and the support they can offer in the bereavement process**

2.1   The study in this thesis noted that healthcare professionals may be at risk by their exposure to dying and death on a regular basis, and at times of personal bereavement. A study of the support mechanisms available for healthcare

professionals and ways of coping at times of professional and personal loss would provide further insight into the bereavement experiences and coping mechanisms of healthcare professionals.

2.2   A questionnaire based survey of current education, training and competency based assessment and perceived need in areas of communication and culturally sensitive end of life and bereavement care could be undertaken in nurses and doctors to highlight both deficiencies in provision and where good practice exists. This could inform the more in depth needs analysis and recommendations for inclusion in undergraduate and postgraduate education and training proposed in 3 below.

3.   Respond to staff needs for education and support by provision of appropriate education and support programmes

3.1   A review of end of life and bereavement care in training and education currently provided to pre and post graduate healthcare professionals would provide insight into current levels of training and inform future training needs in relation to bereavement as the last step in end of life care

3.2   Existing *ad hoc* training programmes should be assessed and evaluated to ensure that there is uniformity and consistency in its delivery and that it is up to date, relevant and fit for purpose or where there are opportunities for embedding in formalised education and training programmes

4.   Theoretical base of bereavement

4.1   Research into the essence of definitions of death and their meaning should be undertaken to establish where myth and misunderstanding may exist and to look more deeply into the phenomenon of death to inform and enable improved appropriate communication about death and dying with relatives.

4.2   An analysis of communication used to describe a person needing artificial assistance to maintain life should be undertaken. Including a concept analysis of terms such as 'Life support' and 'brain stem death', and how these concepts are communicated to lay people.

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APPENDIX A

**ANALYSIS OF FIRST LETTERS OF COMPLAINT FOLLOWING
THE DEATH OF A PATIENT**

Introduction

Approximately 60% of all deaths in England and Wales occur within an acute hospital setting (National Statistics 2003). Many families write to express their gratitude to staff for the care and consideration provided to the deceased and themselves during the last few days of their relatives life. However, formal letters of complaint are also received following the death of a patient. These are usually addressed to the Trust Chief Executive and are acknowledged and responded to within nationally agreed set periods of time.

Box 1 highlights the importance and scope of complaints

<div style="border:1px solid">

- ❖ Complaints matter to patients and relatives
- ❖ Complaints are extremely diverse
- ❖ Complaints come from a range of people
- ❖ Complaints can be seen as threatening by staff
- ❖ Complaints are more often about organisational problems or failure of systems
- ❖ Complaints are difficult to make
- ❖ Complaints do not sit in isolation

</div>

Complaints are an important measure of the quality of services provided and are valuable aids to highlight where deficits in care occur and where improvements can be made. Complaints are also an important part of the clinical governance process.

As a prelude to the studies described in this PhD thesis an audit was conducted of the first letters of complaint that were written to the Chief Executive of University Birmingham Hospital NHS Foundation Trust following the death of a patient

between January 2002 and December 2003. This was undertaken partly in an attempt to firstly explore fully the motives for writing the letters from the relative's perspective and secondly to try and identify and capture some of the first reactions and responses to bereavement that were expressed by relatives.

It should be noted that, by their very nature, letters of complaint are not indicative of the care that most patients receive in their final days and hours. However, they provide significant insights into unique individual experiences of bereavement.

Methodological Approach

University Hospital Birmingham NHS Foundation Trust deals with approximately 2,500 deaths a year and the Complaints section of the Patient Services Department gave their permission for the letters to be analysed.

The total number of deaths in the Trust for the 2 year period (January 2002 until December 2003) was 4769 with 51 formal written complaints received relating to the death of a patient, representing 1.07% of the total.

Of the 51 complaints identified, 37 were deemed suitable for analysis. Of the fourteen excluded

> ➢ 2 were written by solicitors on behalf of the family therefore, whilst the factual content was accurate the letters were written from a legal stance and devoid of the emotional recollections of first hand accounts

- ➤ 5 were verbal complaints which were forwarded on to the Patient Services department by the managers who had received them and only a summary of the complaint was available

- ➤ 5 were responses to complaints that had been made at meetings that had been attended by relatives and staff representatives, with the original letters unavailable to be analysed

- ➤ 2 letters contained very little information and requested a meeting to discuss concerns rather than documenting them on paper.

Of the 37 letters that were used in the study the complainants consisted of the following in relation to the deceased

Spouses:	Husband n= 3	Wife n=10
Children:	Daughter n= 14	Son n= 5
Grandchildren :	Granddaughter n=1	
Parents:	Mother n= 1	
Sibling:	Sister n= 2	
Other:	Partner of niece n= 1	

A phenomenological approach was undertaken for this study. Two of the most referenced researchers in the field of phenomenology,, within the nursing literature, are Edmund Husserl and Martin Heidegger. Husserl is credited as the founder of Phenomenology and Heidegger was one of his students, although their ideologies on phenomenology differed over time.

Husserlain phenomenology is often referred to as descriptive or transcendental and focuses on understanding the core elements of a phenomenon 'essences' – what makes it what it is.

Martin Heidegger developed his own interpretation and methodological approach to phenomenology. For Heidegger the emphasis was placed firmly on interpretation and understanding of the phenomenon rather than just the description of it. Heidegger's phenomenology is also referred to as existential, interpretive or hermeneutic.

> 'Descriptive phenomenology presents the 'essential' features of phenomena. Interpretive phenomenology uncovers concealed meanings embedded in the words of participant narrative'.   Maggs-Rapport 2001

To understand the use of phenomenology in the context of this analysis, Husserl places emphasis upon the phenomenon of bereavement itself for example, 'what *is bereavement, what makes it what it is?'*. Whereas Heidegger is concerned with how the phenomenon impacted upon the individual for example, 'how *did it feel? What was the 'lived experience' of bereavement'?*

Hermeneutics (interpretation) is one of the processes that we use to make sense of our everyday lives. Through it there is an acknowledgement that a person cannot be seen in isolation and that they exist and are an integral part of a social-psycho-cultural-religious-spiritual world. Hermeneutics provides an opportunity to uncover and give meaning to human experiences as they impact upon individuals:

> *'(an attempt to) understand life as humans live it, find meaning in it as we struggle to understand things that can seem to be beyond human comprehension'*
> Lawler 1998

Therefore this method of enquiry was undertaken to facilitate the exploration of the meanings that bereaved relatives had for writing first letters of complaint.

It may seem, at first glance, obvious why letters of complaint are written. It can be presumed that they are written because people are unhappy with the care; situation or outcome of events which resulted with the death of their relative. These are important aspects of the letters and this fact should neither be dismissed nor negated. However, phenomenological exploration of these letters can uncover further significant meanings within them.

Analysis of data

The letters were analysed using a combination of Colaizzi (1978) and Van Kaam's (1966) methodologies.

- ❖ This involved reading each letter to get an understanding 'to make sense' of the whole event.
- ❖ Then each letter was read again and *significant statements* were extracted.
- ❖ The meanings that these statements represented were then formulated (going from what people say to what they mean).

- ❖ This was repeated for each letter and the meanings uncovered were placed into *clusters of themes*.
- ❖ Once the themes had been identified the letters were read once again to ensure, that the meanings are apparent or implied within them.
- ❖ Hopefully what is then obtained is what Colaizzi refers to as an *exhaustive description* of the phenomenon under examination.

❖ Finally the *exhaustive description* is used to create a clear statement of the fundamental structure of the phenomenon as possible.

Colaizzi (1978) suggests that a final validating step can be asking the participant (in this case the person who wrote the letter) whether the *exhaustive description* appears to encapsulate their feelings at that time.

This was not deemed to be appropriate for this study as there was the potential to distress relatives further or become embroiled in an ongoing complaint. Therefore in order to provide validity Van Kamm's (1966) process of the use of an expert judge was utilised. The letters were independently analysed by another phenomenological researcher. Only those themes which were deemed by both researchers to be significant and applicable were included in the final data.

Seven core themes emerged from the data. These will now be discussed and their discovery shown through 'significant statements' drawn from the letters.

Emergent Themes

1. A need to 'make sense' of the whole event.

This manifested through perceived breakdowns in communication which left relatives without the vital information that they felt they needed to understand what was or had happened. This is illustrated by the following significant statements extracted from the letters:

a) Concerns that relatives were not informed about diagnosis and prognosis

'even at this late stage we have not been informed of the circumstances surrounding her last moments'.

'no one confirmed that he had had a stroke yet this was put on the death certificate'

'At no time was death mentioned

'why did things turn to death point so quick….. no one contacted us that night as she was slipping away' '

'what could be causing that shocking weight loss – he loved his food and his diet was good'.

'only a few months ago we thought cancer wouldn't affect us but here we are having lost our mum to something we never fully realised'.

'if we had known we would have been able to at least prepare ourselves in some way'

b) Poor communication and using medical jargon

'A simple 'that is how it is sometimes' does not help us come to terms with our loss………for 10 days my mom was in hospital and not once did we see Dr. F so we were still in the dark as to what was going on in my mom's body'

'I know some diseases cannot be taken away by magic by doctors but I also know that there are ways of dealing with matters which can make it more comfortable for the people involved.

'no one came to see if we needed any assistance or to inform us he was in the process of dying'

c) Desperation to have more information to create a whole picture of events

'answers to the questions raised here are essential if we are to be at peace instead of forever tormenting ourselves with the 'whys' and 'what ifs'.

'would it be possible for you to supply us with a copy of my mothers notes, I doubt they will convey much to us, but psychologically maybe it will help to ease the extreme feeling of guilt we have for not insisting on having more information from the very beginning'.

'Any information that would help us understand how it came to happen so quickly would be received with the upmost gratitude'.

This lack of communication and information resulted in the loss of anticipation, and therefore preparation, for the death by the relatives. It is this that appears to be

instrumental in loss. Not just the loss of the physical presence of the person but of a 'known' and anticipated future; a 'loss of dreams'

2) Loss of dreams

> 'we are a very close family and feel very bitter about the fact that we were robbed of the opportunity to spend the last hours of our mothers life at her bedside'

> 'I didn't get to say goodbye, I missed that one day'.

> '…having been assured that all was well and having made future plans on the morning of the 21st..' (day he died) I have been in shock

This also links in to the importance and significance of 'being there' at the time of death. As nurses there is an awareness that people may wish to be present at the death of a loved one and may aim to facilitate this. However, there are very many reasons for why this may hold special significance. These may be

- ❖ To provide comfort and support for the person who is dying; to be a familiar face, voice, touch.
- ❖ To say personal, intimate goodbyes, to ask forgiveness; to provide affirmation of that person's worth for them to hear one last time.
- ❖ To be able to perform prayers and rituals to facilitate a closing of this life and a peaceful transition to a life beyond.
- ❖ To have or be a 'presence' at that time

> 'we were very disappointed that no one warned us that the treatment she was being given would lead to this as naturally we would like to have had the opportunity for a final goodbye'

'The nurse stated that there was no need to rush which we thought was a strange thing to say but became clear when we arrived.

3) Primordial cries / spiritual disease

In several of the letters the anguish expressed in the letters was almost palpable. These first letters of complaint seemed to encapsulate some of the immediate raw emotions following the loss of a loved one

'I felt that everyone knew that my mothers cause was lost but that no one was telling us so …….I did not feel it was my job as a grieving daughter to tell my family that my mother was dying'.

'What does 'being stable' mean?

'why did no-one help him…..he bled to death – I am devastated'.

'life in whatever form, is still life..'

4) Guardian and protector

No one can know a person as well or care for them as well or as deeply as partner, relative or close friend can. They are special and precious and vulnerable when they are 'broken'. It is therefore painful when others treat them as unimportant or stupid or simply don't listen to, or pick up on their needs or pleas.

Therefore, it appeared from the letters that relatives felt that there was a need to highlight where their intervention had been necessary and why. There was also a need to state the distress felt by other family members emphasising how far the impact of bereavement can extend.

'having watched hourly his deterioration we had a better view than many…. even if the iv fluid would have been a short lived result, for something so important as time alive it should have been carried out'

'He told us he had been requesting for many hours to be cleaned (being doubly incontinent). He was not attended to until I enquired why he had been left in such a state'
'my last memory of my mother is of her in a frightened and anxious state'

towards the end she hardly had the strength to eat food….(the doctors) seemed to attach little importance to her general condition which seemed to me to be paramount if she was to recover'

His pain killers were put on the table out of his reach and no one checked that he had taken them'

'I explained …..that the role of a doctor is not to play God with patient's lives'

5) 'Perception and Uniqueness', the person as a whole

This emerging theme appeared to be about the love and pride that the relatives had for their loved ones and an attempt to make known how special and unique they were. It appeared that there was an attempt to show their deceased relative as a 'whole' multi- faceted, multi- dimensional person rather than the one dimensional façade that a person, at first glance, can appear to be.

The letters appeared to suggest that there had been a lack of acknowledgement of their relative as an individual in his / her own right. The authors of the letters implicitly expressed a need to show how important and significant that person was, and to whom. It almost felt, on reading them that they were bringing a picture of the person out of their wallet to show us.

' To us we have lost something that can never be replaced; a son, husband, brother and a dad'.

'He too was a lovely person, a soldier who fought for US to have a free country, a beloved father and grandfather whose elder grand daughter had just become engaged. I could go on but he is missed in so many walks of life'.

'I have lost a wonderful husband having been married for 51 years and his children have lost a wonderful dad.'

'what do I tell her son, who has lost his mum, friend, companion and home

'but people forget that she was someone's mother, grandmother, and great grandmother and was loved by many more'.

'3rd October 2002 our Daughter, my Wife, our Sister, our aunt and our beloved Mummy passed away at your hospital at the age of 34 years'.

6) Selflessness

Selflessness was a further theme running through the letters in the study. It became apparent that one of the primary reasons for the people writing in was in the hope that by doing so others would not have to experience what they had. Several of the letters exhibited altruistic and 'saviour' like qualities. Even in the depths of their anguish they selflessly took action to try and prevent others suffering.

'I want some indication that no one else will have to go through what we have'

' and hope by writing this letter someone else will benefit'

'nothing can return C to her children and her family….. but If lessons are not learnt, then other children will continue to lose parents needlessly'

'I therefore have made these comments so that if there are any procedural changes that might prevent another death in the future, then I cannot let this opportunity go by'.

'Please think of the families watching their loved ones die'

7) Ability to acknowledge good aspects of the situation at such a difficult time

Following on with the theme of selflessness, many of the letters contained words of thanks and gratitude for wards or staff that had provided support or care for them and their relative.

'Finally we would like to thank 3 nurses……these nurses were angels and had BA interests at heart…..they are worthy of your profession

'I thank you for the opportunity to express my thoughts – which I acknowledge are made as a lay person'.

Conclusion

The letters and the phenomenological approach taken to explore them provided a rich source of information which can be summarised as :

- ❖ unique information which can be utilised to improve patient and relative care.
- ❖ a reflective tool to mirror the care provided ; to transiently place healthcare professionals on the receiving end of the experience to allow a glimpse of the provision of our care through patients and relatives eyes.
- ❖ a valuable tool in understanding how we can improve end of life care for both patients and their relatives; but also for the staff who provide that care.
- ❖ a cathartic vehicle for relatives which has facilitated the expression of their loss and, very importantly, in receiving acknowledgement of this.

It would appear from the personal accounts of the complainants that there were concerns about the loss of identity and individuality at times of bereavement. Relatives appeared to feel it necessary – or perhaps even their duty, to be guardians of the dying. This appeared in some, to transcend the individual and become a selfless crusade, or mission in an attempt to other who may be in a similar position. A presence of altruism and a surprising absence of anger pervaded the letters.

The importance of being able to tell their experiences also appeared to be a cathartic experience in itself and one third of the letters ended with the fact that no further action, other than the guarantee that it would not happen to anyone else, was requested.

It should again be acknowledged that these results have arisen from data that is not typical of the bereavement experiences of most relatives within an acute hospital trust. They only reflected a relatively small proportion of the total deaths that had occurred within the Trust.

However, although these conclusions are not generalisable, the essences of the data can help in gaining a greater understanding of relative's distress at times of bereavement and identify areas where improvements can be made and further research can be undertaken.

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APPENDIX B

HELEN - A PERSONAL STORY

This Appendix is not available
in the digital version of this thesis

APPENDIX C

INFORMATION PACK FOR RELATIVE PARTICIPANTS

Information sheet
For Relatives

<div style="border: 1px solid black">

Information regarding this study:-
'Bereavement in the Christian, Jewish and Muslim Faiths'.

</div>

May I firstly take the opportunity to thank you for taking the time to read this information sheet.

About the researcher

My name is Dawn Chaplin and I am the Bereavement Care Manager for University Hospital Birmingham NHS Trust (Queen Elizabeth and Selly Oak Hospitals) My background is nursing and I became the Bereavement Care Manager in 1997.

About the research study

As part of my role in Bereavement care I am interested in listening to the experiences of people from different faith groups about their bereavement. The loss of a relative can be one of the most difficult events we experience. Every one of us will have a very personal and unique experience of loss. I am interested in the experiences of people from the Christian, Muslim and Jewish faiths. To find out what you found helped you, where you received comfort and support from and whether you feel that all of your requirements and those of your relative were met. Each person will have certain thoughts and beliefs regarding death, dying and bereavement. It is hoped that this study will provide valuable insight into the experiences of bereaved relatives.

Benefits to others due to your participate in the research

- Your experiences will be invaluable in helping to understand bereavement from an individual and personal view point.
- This study will help to identify certain cultural and religious requirements which are important to patients and relatives at the time of death and beyond.
- It is hoped that it will help in identifying and providing appropriate, sensitive care for all patients and relatives.

Difficulties with the research

- By taking part in this research you will be asked to recount your experiences relating to your bereavement. I do appreciate that this may be distressing for you. I have attached a

list of support agencies which you and your family may find useful. These organisations will be able to provide ongoing bereavement support and counselling should you feel that you or a member of your family may require this.

 I am also available if you would like to talk through any issues that you may have relating to your bereavement. This offer is extended even if you feel that you would not like to participate in the research study.

What exactly will you have to do?

Step 1
In order for you to participate in this study the following details should apply:-

- You have experienced the loss of a relative at either the Queen Elizabeth or Selly Oak Hospital between 1998 - 2001.
- That your relative was from the Christian, Jewish or Muslim faith.

Step 2
If you would like to take part in this research then I would be grateful if you could sign the agreement slip (enclosed) and return it to me as soon as possible in the pre paid envelope.
If you do not wish to participate please disregard this letter.

Step 3
If you do decide to participate in this study I will arrange for a time which is convenient for you to meet with me at the Queen Elizabeth hospital where we can talk through your experiences. The interviews will last approximately one hour (your travelling expenses to and from the hospital will be reimbursed). In order for all the information to be captured, the interview, with your permission, will be tape recorded. You are more than welcome to bring along another family member or friend for support. If your first language is not English and you feel that you may require the assistance of an interpreter then please inform me and I will gladly make these arrangements. I will go through the information sheet with you and address any questions that you have regarding this research study. I will then ask you to sign a consent form, stating that you are happy to participate in the study, before we proceed with the interview.

What happens at the end of the research?

- If you would like to discuss the results of the study with me then this will be arranged following completion of the study.
- If you would like a written summary of this study then I will arrange for one to be sent to you following the completion of the paper.
- The research will be presented in a thesis and shared with colleagues. The research findings will be used in publications and at conferences to help other colleagues and improve services.

What happens if you change your mind during the research?

If you choose to participate in this study you still have the right to withdraw at anytime.
If you do decide that you no longer wish to take part in the research then please simply telephone or write to me to let me know.
If you withdraw from the study then all the information that you have provided will be destroyed.

What happens to the information?

All of the information that is obtained from the interview (which, with your consent will be collected via a tape recorder for accuracy) will remain strictly confidential. Each interview will be given a code number to protect your identity, no names will be used for any information given or recorded in this study.
 I will keep your details and the information I obtain from you safely locked away during the whole duration of the research and only I shall have access to them. If the results of this research are to be published then I will ensure that no one who participates in this research is identifiable.
 Once I have finished with the audio tapes they will be destroyed.

Who else is taking part?

I will be inviting next of kin of patients who have died within the University Hospital Birmingham NHS Trust between 1998 - 2001. The next of kin will be selected by the documented religion of their relative. I will be asking doctors and nurses about their experiences of caring for patients and relatives from the Christian, Jewish and Muslim faiths. I will also be asking religious leaders what requirements they feel are needed at the time of a patients death.

What if you have questions or there is something that you do not understand?

Please contact me on the telephone number provided at the end of this letter. I will be happy to answer any questions that you may have or organise for you to speak to other Trust staff if you so wish.

Ethical Approval

In order to make sure that this study is acceptable and appropriate, I have obtained the approval of an independent ethics committee to enable this study to proceed.

What happens if you decide to take part in this study?

If you feel that you would like to take part in this study please fill in the agreement slip and return it to me in the pre paid envelope provided. I will then contact you to arrange a mutually convenient time for us to meet.

What if you feel that you do not wish to take part in this study?

If you do not wish to proceed further then please kindly disregard this letter.

I hope that, after careful consideration, you may accept my invitation to participate in this research. May I take this opportunity to thank you in advance if you do choose to take part. I also thank you for taking time to read through this letter if you decide not to proceed further.

If you require any further information please contact me on the number below

Dawn Chaplin
Bereavement Care Manager

Support Agencies

Cruse Bereavement Care

Provides bereavement counselling and support.

National   0845 758 55 65
Birmingham   0121 687 8010

The Samaritans

Provides 24 hour telephone support service.

National   0845 790 9090
Birmingham   0121 666 6644

The British Association of Cancer United Patients (BACUP)

Provides a cancer information and support service.

Information   020 7613 2121
Counselling   0141 553 1553

The Compassionate Friends

Offers support & friendship to bereaved parents and their families

Helpline   0117 953 0630

The National Association of Widows

Offers information and support through local branches.

Tel. 024 7663 4848

APPENDIX D

INFORMATION PACK FOR HEALTHCARE PROFESSIONALS

Information sheet
for Doctors and Nurses

Information regarding this study:-
'Bereavement in the Christian, Jewish and Muslim Religions'.

May I firstly take the opportunity to thank you for taking the time to read this information sheet.

About the researcher

My name is Dawn Chaplin and I am the Bereavement Care Manager for University Hospital Birmingham NHS Trust (Queen Elizabeth and Selly Oak Hospitals) My background is nursing and I became the bereavement care manager in 1997.

About the research study

The focus of this study is the bereavement experiences of relatives of deceased patients from the Christian, Jewish and Muslim faiths. The study will involve interviews with bereaved relatives to fully obtain their recollections.

I am also interested in interviewing nurses and doctors to obtain their experiences of caring for dying and deceased patients from these faiths and their relatives. I wish to explore your experiences of dealing with the death of a patient from the Jewish, Muslim and Christian faiths. Also your perceptions of what you feel was of importance to them from a cultural and religious perspective.

I am interviewing relatives of deceased patients of the Christian, Jewish and Muslim faiths to obtain their experiences of their bereavement. I am also interviewing religious and cultural leaders to discover what is a cultural and what is a religious necessity when a death occurs.

It is hoped that this study will provide valuable insight into the bereavement care required for patients from the Christian, Jewish and Muslim religions and their relatives.

Benefits to others due to your participate in the research

- Your experiences will be invaluable in helping to understand bereavement care and requirements from an individual professional perspective.
- This study will help to identify certain cultural and religious requirements which are important to patients and relatives at the time of death and beyond.
- It is hoped that it will help in identifying and providing appropriate, sensitive care for all patients and relatives.

Difficulties with the research

If you have experienced a personal bereavement in the last six months I would advise that you not to participate in this study.

If you do take part in the study you may find that it is distressing for you. I have attached a list of support agencies which you may find useful. I am also available if you would like to talk through any issues that you have relating to bereavement. This offer is extended to you even if you feel that you would not like to participate in the research study.

What exactly will you have to do?

Step 1

In order for you to participate in this study the following details should apply:-

- That you have cared for a dying / deceased patient of the Jewish, Muslim or Christian faith.

Step 2

If you would like to take part in this research then I would be grateful if you could sign the agreement slip (enclosed) and return it to me as soon as possible in the pre paid envelope.

If you do not wish to participate please disregard this letter.

Step 3

If you do decide to participate in this study I will arrange for a time which is convenient for you to meet with me at the Queen Elizabeth hospital where we can talk through your experiences. In order for all the information to be captured, the interview, with your permission, will be tape recorded. I will go through the information sheet with you and address any outstanding questions that you may have regarding the research study. I will then ask you to sign a consent form, stating that you are happy to participate in the study, before we proceed with the interview.

What happens at the end of the research?

- If you would like to discuss the results of the study with me then this will be arranged following completion of the study.
- If you would like a written summary of this study then I will arrange for one to be sent to you following the completion of the paper.
- The research will be presented in a thesis and shared with colleagues. The research findings will be used in publications and at conferences to help other colleagues and improve services.

What happens if you change your mind during the research?

If you choose to participate in this study you still have the right to withdraw at anytime.

If you do decide that you no longer wish to take part in the research then please simply telephone or write to me to let me know.

If you withdraw from the study then all of the information that you have provided will be destroyed.

What happens to the information?

All of the information that is obtained from the interview (which, with your consent will be collected via a tape recorder for accuracy) will remain strictly confidential. Each interview will be given a code number to protect your identity, no names will be used for any information given or recorded in this study.

I will keep your details and the information I obtain from you safely locked away during the whole duration of the research and only I shall have access to them . If the results of this research are to be published then I will ensure that no one who participates in this research is identifiable.

Once I have finished with the audio tapes they will be destroyed.

Who else is taking part?

I will be inviting next of kin of patients who have died within the University Hospital Birmingham NHS Trust between 1998 - 2001. The next of kin will be selected by the documented religion of their relative. I will be asking doctors and nurses about their experiences of caring for patients and relatives from the Christian, Jewish and Muslim faiths. I will also be asking religious leaders what requirements they feel are needed at the time of a patients death.

What if you have questions or there is something that you do not understand?

Please contact me on the number provided at the end of this letter. I will be happy to answer any questions that you may have or organise for you to speak to other Trust staff if you so wish.

Ethical Approval

In order to make sure that this study is acceptable and appropriate, I have obtained the approval of an independent ethics committee to enable this study to proceed.

What happens if you decide to take part in this study?

If you feel that you would like to take part in this study please fill in the agreement slip and return it to me in the pre paid envelope provided. I will then contact you to arrange a mutually convenient time for us to meet.

What if you feel that you do not wish to take part in this study?

 If you do not wish to proceed further then please kindly disregard this letter.

I hope that, after careful consideration, you may accept my invitation to participate in this research. May I take this opportunity to thank you in advance if you do choose to take part. I also thank you for taking time to read through this letter if you decide not to proceed further.

If you require any further information please contact me on the number below

Dawn Chaplin
Bereavement Care Manager

APPENDIX E

INFORMATION PACK FOR RELIGIOUS LEADERS

Information sheet
for religious / cultural leaders

Information regarding this study:-
'Bereavement in the Christian, Jewish and Muslim Religions'.

May I firstly take the opportunity to thank you for taking the time to read this information sheet.

About the researcher

My name is Dawn Chaplin and I am the Bereavement Care Manager for University Hospital Birmingham NHS Trust (Queen Elizabeth and Selly Oak Hospitals) My background is nursing and I became the bereavement care manager in 1997.

About the research study

The focus of this study is the bereavement experiences of relatives of deceased patients from the Christian, Jewish and Muslim religions. The study will involve interviews with bereaved relatives to fully obtain their recollections.

I am also interviewing doctors and nurses to obtain their knowledge and experience of caring for dying and deceased patients from these faiths. I would then like to meet with religious and cultural leaders from these faiths in an attempt to understand the significance of certain requirements at and around the time of death. Also to discover what may be a religious necessity and what may be a cultural requirement when a death occurs.

It is hoped that this study will provide valuable insight into the bereavement care required for patients from these faiths and their relatives.

Benefits to others due to your participate in the research

- Your experience and expertise will be invaluable in helping to understand bereavement care and requirements from a religious and cultural perspective.
- This study will help to identify certain cultural and religious requirements which are important to patients and relatives at the time of death and beyond.
- It is hoped that it will help in identifying and providing appropriate, sensitive care for all patients and relatives.

Difficulties with the research

I appreciate that it may be difficult for you to attend the hospital due to your work commitments.

Alternative arrangements can be made with the researcher to obtain your valuable input.

What exactly will you have to do?

Step 1
In order for you to participate in this study the following details should apply:-

- That you have religious / cultural knowledge regarding the requirements and expectations for the care of dying / deceased patients of the Jewish, Muslim or Christian faith and their relatives.

Step 2

If you would like to take part in this research then I would be grateful if you could sign the agreement slip (enclosed) and return it to me as soon as possible in the pre paid envelope.
If you do not wish to participate please disregard this letter.

Step 3
If you do decide to participate in this study I will arrange for a time which is convenient for you to meet with me at the Queen Elizabeth hospital where we can talk through your experiences. If you are unable to attend the hospital then I can arrange for a convenient time for myself to visit you.
In order for all the information to be captured, the interview, with your permission, will be tape recorded. I will go through the information sheet with you and address any outstanding questions that you may have regarding the research study. I will then ask you to sign a consent form, stating that you are happy to participate in the study, before we proceed with the interview.

What happens at the end of the research?

- If you would like to discuss the results of the study with me then this will be arranged following completion of the study.
- If you would like a written summary of this study then I will arrange for one to be sent to you following the completion of the paper.
- The research will be presented in a thesis and shared with colleagues. The research findings will be used in publications and at conferences to help other colleagues and improve services.

What happens if you change your mind during the research?

If you choose to participate in this study you still have the right to withdraw at anytime.
If you do decide that you no longer wish to take part in the research then please simply telephone or write to me to let me know.

If you withdraw from the study then all of the information that you have provided will be destroyed.

What happens to the information?

All of the information that is obtained from the interview (which, with your consent will be collected via a tape recorder for accuracy) will remain strictly confidential. Each interview will be given a code number to protect your identity, no names will be used for any information given or recorded in this study.
 I will keep your details and the information I obtain from you safely locked away during the whole duration of the research and only I shall have access to them . If the results of this research are to be published then I will ensure that no one who participates in this research is identifiable.
 Once I have finished with the audio tapes they will be destroyed.

Who else is taking part?

I will be inviting next of kin of patients who have died within the University Hospital Birmingham NHS Trust between 1998 - 2001. The next of kin will be selected by the documented religion of their relative. I will be asking doctors and nurses about their experiences of caring for patients and relatives from the Christian, Jewish and Muslim faiths. I will also be asking religious leaders what requirements they feel are needed at the time of a patients death.

What if you have questions or there is something that you do not understand?

Please contact me on the number provided at the end of this letter. I will be happy to answer any questions that you may have or organise for you to speak to other Trust staff if you so wish.

Ethical Approval

In order to make sure that this study is acceptable and appropriate, I have obtained the approval of an independent ethics committee to enable this study to proceed.

What happens if you decide to take part in this study?

If you feel that you would like to take part in this study please fill in the agreement slip and return it to me in the pre paid envelope provided. I will then contact you to arrange a mutually convenient time for us to meet.

What if you feel that you do not wish to take part in this study?

 If you do not wish to proceed further then please kindly disregard this letter.

I hope that, after careful consideration, you may accept my invitation to participate in this research. May I take this opportunity to thank you in advance if you do choose to take part. I also thank you for taking time to read through this letter if you decide not to proceed further.

If you require any further information please contact me on the number below

Dawn Chaplin
Bereavement Care Manager

APPENDIX F

INTERVIEW SCHEDULE

INTERVIEW SCHEDULE

An interview schedule was created to ensure that the interview was carried out in a consistent and coherent way for all participants.

All participants were welcomed on arrival. An outline of the research was explained to them and they were thanked in advance for their contribution to the study. Confidentiality was addressed with all participants and reassurance given that all data would be anonymised. All participants were informed that they could stop the interview at any time if they felt uncomfortable or distressed. The use of a mini disc to capture the interview was explained to participants and written consent was then obtained.

• Welcome
• Introduction
• Explanation of research
• Thanks
• Discussion on Confidentiality
• Agreement that interview can stop at any time.
• Interview duration approximately one hour
• Written consent obtained
• Check mini disc recording

Prompts / questions for relatives

The relatives were asked if they could start the interview by recounting what brought their relative into hospital. Prompts, as outlined below, were then utilised as appropriate during the interview. These helped to enable relatives to tell their

bereavement story and discuss any factors that might have impacted on their experience.

• Can you tell me a little about what brought your relative into hospital?
• Can you tell me a little about what happened at the time of your relatives death
• Did you find your religion a support at that time and if so in what way
• Can you tell me a little about what happened after your relatives death
• Was the care that you and your relative received religiously appropriate?
• What was good or could have been improved about your experience?

Prompts / questions for doctors / nurses

Doctors and nurses were asked to recollect experiences of caring for dying, deceased patients and their relatives from the Christian, Jewish and Muslim faiths and how those experiences may have impacted on them personally and professionally. They were asked what they thought constituted a good death or a bad death and whether a belief in an afterlife may make a difference to the dying person and their relatives. They were then asked to consider whether bereavement is the same for all or different.

• Could you tell me about your professional experiences of caring for dying and deceased patients, and their relatives, from the Christian, Jewish and Muslim faiths?
• How did dealing with those dying and deceased people and their relatives' impact on you personally and professionally?
• Is there such a thing as a good death or a bad death and can you describe the components of each?
• Do you feel that a belief in an afterlife and may make a difference to the dying patient and their relatives?
• Do you have a belief in an afterlife?
• Do you feel that the core elements of bereavement are the same for everyone?

Prompts / questions for Religious leaders

The questions for religious leaders were similar to those for doctors and nurses. A prompt around the esoteric concepts of Heaven and Hell and whether a belief in these impacted on the bereaved person's bereavement experience was added for the religious leaders.

• Could you tell me about your professional experiences of caring for dying and deceased patients, and their relatives, from the Christian, Jewish and Muslim faiths?
• How did dealing with those dying and deceased people and their relatives' impact on you personally and professionally?
• Is there such a thing as a good death or a bad death and can you describe the components of each?
• Do you feel that a belief in an afterlife may make a difference to the dying patient and their relatives?
• Do you feel that the core elements of bereavement are the same for everyone?
• Do you think that a belief in Heaven / Hell impacts on a person's bereavement experience?

End of Interviews

At the end of each interview the participant was thanked for their contribution and their time. A list of support agencies was provided to ensure that longer term bereavement support was made available to them should they wish.

As part of the finishing conversation there was a gentle re focussing of the individual with discussion around what plans they had for later on that evening.

• Thank the participant once again
• Provide list of support agencies
• As debrief / step down from interview focus, ask what participant will be doing later

APPENDIX G

**A WORKED EXAMPLE OF DATA ANALYSIS FOR EACH OF
THE FOUR EXISTENTIAL DIMENSIONS (TIME, SPACE, BODY
AND RELATIONSHIPS)**

The following example shows the process of data analysis. Significant statements relating to each of the four existential dimensions were highlighted (green for Time, red for Space, blue for Body and purple for Relationships). These were then further analysed and placed in the emerging sub sections of each existential dimension.

Interview C1

Preamble with Mr F talking about keeping birds, putting a summerhouse up and not wanting to move into a bungalow as he's been in his house for thirty eight years etc.

D: So, just sort of as an introduction perhaps, could you tell me a little bit about what put your wife into hospital and just a little bit around it?

F: As long as you don't want the medical jargon.

D: No, none of that because we can't spell it anyway so that's fine.

F: No, no, no… Well basically my wife's illness started ….it's alright if I don't think it out it will make sense to me but it won't make no sense to you.

D: That's alright.

F: That's alright, she was ill about eighteen months before, oh no, if you go back to her first illness which was um, … what do they call it, on the head, when you get the head?

D: Um, water on the…

F: No, no, no, no nothing like that, um, can't think of the damn word.

D: No, don't worry, that's okay. But something with a…

F: Basically, you get that bad you have to walk around holding walls.

D: Oh, it's not like tinnitus is it?

F: No, worse than tinnitus, it's in the head, it's a terrible thing. It's like migraine only ten times worse.

D: Oh, gosh.

F: There is a word for it, a simple word, can't think of it, it'll come back.

D: It'll come. Yeah, it'll come back.

F: Anyway, she stopped work because of it. She didn't want to retire, she had the option because she was a school cleaner, so therefore she could have gone on to sixty-five if she wanted, but unfortunately it wasn't safe. I think she very much regretted packing it in because like me she liked something to do. It's one of those things, probably got fed up of seeing me, I don't know (laughter). We're like two peas in a pod, well we was, re-phrase that, was. And that went on for the best part of four years, and then one, I had an appointment here in… in June to have a stent put in my main heart valve.

D: Oh gosh, so you were here under…

F: This was the same morning it all started, I was going home and when I got home, before I went home the lad come to pick me up and he said, he had a phone call and said 'Dad we got to go to Sandwell', I said 'Why we got to go to Sandwell?' He said 'They've just admitted Mother'. I said, 'Alright then we'll go to Sandwell, I don't mind' (laughter) and then when I got there the daughter explained it to me. Her said, 'coz her normally calls in every morning regular as clockwork, she doesn't do it now, I've stopped her doing it 'coz I think it is dragging her out of her way.

D: Ah, was she the one I met at the…

F: Yes, the rattle-box, like me (laughter), like me. Anyway, to cut a long story short as they say, and her said 'Well Mother rang me this morning, her said Jeanette can you pop up, I don't feel very well'. Her said 'When you say you don't feel very well mother what do you mean?' And her said 'Well, I feel sick, and me heads going round and I don't feel right at all'. And her said, 'I'll pop in, no problem'. And when her popped in there was Dor leaning over the bed, the whole carpet was plastered of blood and there was a bowl full of blood at the bottom as well, she'd fetched the lot up.

D: Oh, gosh.

F: There is another medical term for it, I can't think of. What basically what it is, when you liver is shutting down, which we didn't know at the time, but it was, they reckon it could have been shutting down for over twenty years slowly.

D: Yeah, yeah.

F: What it does, when you get like you get fast flowing blood out your main veins, because it couldn't go into the liver vein it was spreading itself and going everywhere, all up the short veins, and just busting them wide open. It busted the lot wide open.

D: And that all happened on that morning?

F: On that morning yeah. They took her in and they tried to stem it. She had um, they reckon she had roughly about six pints of blood on the floor, yeah it took some cleaning up I tell you, but that's beside the point.

D: I bet. And frightening too to see that.

F: I didn't see it I just sort of went home and cleared it up. But um, the granddaughter seen it, her didn't take no notice, surprising, she's a tough little nut that one.

D: How old is she?

F   She's only eleven. Her's a tough little nut, her's mommy's, her's granddad's girl that one I'm afraid.

D: Is she?

F: Yeah, the lad's nanny's boy, you always get it.

D: You do, you do.

F: She spent, … she was admitted there and they kept her on a ward, and they couldn't stop it, no matter what they did they pumped six bags of blood in one day and before you visit the next day it would be out somewhere else, it'd just pop out. She'd got an orifice she would bleed from it literally, she was terrible, in a terrible state. In the end they tried to stem it in a theatre and they couldn't do it. The same doctor actually works here now, Mr C.

D: Oh, yes I know.

F: He was D's doctor when her was down there, he's a very nice lad. You may as well call him a lad, he is a lad to me (laughter). But he said, yeah it was a pitiful sight to see in the theatre 'coz they lost her twice on the table, and they got her back. He said all you could see was doctors just squeezing blood bags trying to push it in, as fast as it was going in it was flowing out somewhere else. And that's when they got in touch with the liver unit here. They knew what was causing it but they couldn't treat it. She had about three big bleeds while she was here before she had a liver transplant. Her was in a shocking state, I tell you, … unbelievable. They put her in your intensive care which used to be down the bottom at one time

before they moved over to the new one, and they did her a small operation on her, put in a what do you call 'em, a stent, they put a stent in to open the valve back up again so it allowed the blood to flow, but they said if her hadn't have had a liver transplant she would have only lasted a couple of months anyway.

D: So it got that….

F: It was poisoning the whole of her, all her systems being poisoned, literally. So they did that, and we didn't wait that long actually, I think um…

D: That's good. From when they decided they needed to do a transplant to when…

F: They have you in for a week, for full tests, they make sure you are fit. Her only just passed the fitness, only just, but…

D: Is that because she was so weak by that stage?

F: Very weak. That woman suffered more than I would wish on any, ... even me worst enemy believe you me, no way. In fact I'm glad she is where she is to be honest, 'coz they wouldn't have done anything else for her. They did tell me this but you don't want to hear the end bit you want to hear the middle bit.

D: Well no no, I want to hear all of it.

F: No not yet, I know, but if I miss the middle bit out…

D: No that's true.

F: You're never going to get it.

D: Let me just check that this is…. No that's fine I was just a bit… that's doing very well.

F: So she came in, she was sitting at home one night and about quarter to six he phone went and it was the, … the liver coordinator, said 'Can you come in tonight as you are scheduled for a liver transplant tomorrow'. We hadn't waited that long really.

D: Really?

F: No, she was deteriorating badly, you could tell. Her actual colour was yellower than this.

D: Was it, and her eyes and everything?

F: Oh yes, oh yes, her eyes shot back in her head, like somebody had pushed 'em. I think it showed, I actually I've got a photo I've just had done at home, the last photo we ever had took of her was when her was at the lad's wedding 'coz her couldn't stand to have her photo took once her was bad. i don't think women do.

D: No, I think you are right. I think that's …

F: They shy from it, I don't know why.

D: Um, it's difficult.

F: you look terrible, we know you look terrible but that doesn't matter to we, as long as you are with us it don't make no difference whatsoever. But. It's on our wall now and we've got one, I've got two photos up at the moment, I've just put up, one when her was fourteen and one when her was sixty four, just sixty years between them but she does, she looks real bad on it, I think so. Anyway, we got her here, frightened her to death, she didn't want to go. I sat all night on the bed with her talking about it. 'coz you have to, you don't have a choice. I wouldn't have just popped her off and left her like some of 'em would have done, I couldn't do it, impossible. Anyway she had her liver op and then we're, she was fine for the first three days, I wouldn't say any longer.

D: Yeah, this is after the transplant?

F: And then she started to get different, … her body started to reject different things, 'coz they did tell we that part of your body could shut down while it is adjusting to take the liver. I didn't realise it was possible but it is, oh yes.

D: And what was that?

F: Your kidneys will shut down, your liver, … your lungs will go at half capacity, anything could happen, you could lose the use of your legs, it's amazing. It's not the sort of thing you rush into believe you me.

D: No, it's a major, major thing.

F: Terrible, absolutely terrible. And then um, … we had her home. We've only ever had her home about, … over a span of about two and half years, we've only ever had her home for a week, that's it, we haven't had no more. After that, the first time her come to the clinic I said 'Don't go' 'coz I could see she wasn't right, she wasn't right at all. She couldn't stand let alone anything else. Her said 'I've got to go it's an appointment'. I tried talking her out of it but her wouldn't have it. And she got in the clinic and … in the house over the back, I don't know what you call it.

D: Um, Nuffield House is it?

F: Nuffield House.

D: Yeah, I know the one, yeah.

F: Well she collapsed there, and they put her back on the ward again. Next thing I knew we were back on a ventilator again.

D: Oh gosh, … she must have been very poorly.

F: Her was, she could hardly stand, but her's a determined woman or was, you couldn't tell her nothing, forget it. Her's like me, I'm very stubborn when it comes to health wise. I mean I had heart attack and I cancelled the ambulance, I told them to go

D: (laughter) Did you?

F: Yeah, I cancelled it personally (laughter) I said, 'I'm not going, cancel it' (laughter). Silly things you do, it is silly. Anyway, they bought her back in and they said 'I'm sorry but it will be a long time before she is allowed out again'. I said 'I know this, tell me something new'. And from there on in she had no output off her kidneys for six weeks, which made her quite bad.

D: Was she on dialysis then?

F: Yes, permanent, she was never took her off it. The machine would shut down, they would bring another one in and wire it back up and start again because the machine only run so much and it will shut, close it down. Her lungs kept filing of water, and her couldn't eat, that was the worst part of it, the eating, from the time she had a liver transplant she never ate a thing. And she had her liver transplant nearly… nearly five and half months, … she didn't eat.

D: Did she have supplements then, was it just drips that she…

F: It doesn't do the job though really. The doctor said it will keep your organs going but that is about it. It won't put meat on your bones.

D: No, and did she just feel that she couldn't eat? Did she…

F: She didn't want to. I actually asked the doctor, and I think, I don't know but I think I'm right, is it possible that when somebody donates a liver you pick up certain things off that person, from that liver. It might have been an anorexic that give the liver up, I don't know. But she was terrible from the time that she had it, she was not the same person. We bought her down, when her was on the ward at the top her, we bought her down and we sat her in the canteen and everywhere, … she wouldn't eat.

D: No, and had she got a good appetite before she…

F: Yeah, she's have, … if the lad had something like pizza or anything like that of something from, delivered from the door, her'd have a piece, no matter what it was, but after that no, she didn't want one little iota. And actually, she was never weighed, they gave up weighing her in the end, I think it was down to me because it was upsetting me so much, I reckon she went down to about six stone, from about thirteen. 'Coz I mean, If you don't eat it don't take much to fetch it off you. She was down to the bones. Anyway, how far … in three parts (laughter). If I'd got J here it would be easier, her remembers all the, … you know the big long terminated, big long words for it.

D: Does she?

F: I'm still trying to think what she suffered in her head, … the more I think about it the further away it will go.

D: Yeah, it'll just pop up.

F   I think it will eventually (laughter). It's such a simple, … when I say it I'll say, of course, thousands of people suffer from, and I can't think.

D: No and I can't either, I can't from a….. it'll….

F: It's one simple word, just one simple word and I can't think of it.   No, no.

D: No, no.

F: Well, um …they got her as well as they could possibly get her in my opinion, she spent another week, … she was due to go home for a while, to try it out, she was on um, … West 3 for …. three nights, only three nights, and they rang me at quarter past six on Saturday morning and said could I bring the family up. I said 'Why?' and they said 'Well, I'm afraid your wife had a massive heart attack during the night, and we don't envisage her, she surviving it'. But her did, she survived it little beggar. They had to give her eight pints of blood before they could move her.

D: Gosh.

F: So, what sort of heart attack I've never been told.

D: No, no.

F: Or what caused it, … nobody knows.

D: Did the doctor sit down with you afterwards and go through or…?

F: Not really. Staff nurse did, but not,… I didn't talk to any doctors about it. There was none forthcoming when I, can I put it that way, but I was more concerned about the wife.

D: Yes, yes.

F: So, it took 'em, … she had, … they wasn't even sure when she had it, because she didn't press her buzzer, and as you know they don't, they don't bother them on a ward unless you press your buther, buzzer not buther (laughter).   And they couldn't honestly tell me what caused it or what time she had it, or how long she had stopped breathing even. Um, Mr B? …Consultant on Critical Care, usually got a dickie-bow, you've probably seen him about.

D: Oh, B

F: B…. (laughter) He told me something actually, … but I'll get to that eventually, he told me he was the one who was fetched to her because he was on, and it was his decision not to revive her, he said but I was overruled, I was overruled by four doctors, they had six round her at one time. He said, 'Coz I could she what the damage had done' and he was perfectly right 'coz she only lasted a week after.

D   Did she?

F: Yeah, they put her back on the um, … back on the vent. The worst part about this is she was always on a ventilator, even at Sandwell, we couldn't even talk to her, we had to have sign language, 'coz her couldn't talk.

D: Yeah.

F: Obviously. If you have got the tube down your throat you can't talk, you're stuck. Yeah and he, he … didn't tell me this until we had to call a family meeting on the Wednesday night. I knew, I knew what was coming 'coz the nurse said 'He'd like a word' and it went, …. I'm always here, well I was, re-phrase that, I was always here from one until eight o'clock at night, guaranteed, and I'd sit by the bed until the nurse said 'Can I change her, or can I do whatever' and I'd move off, but apart from that I never went far, only went in the waiting room, that's as far as I went. But he come on the Wednesday and her said Dr B, I call him, B and I don't know whether she is right now, I don't know.

F: I'm reasonable on names but not much good on anything else (laughter). No, he, um… him and a Consultant had me in and they, … we sat in a little office about this big really, it's on the ward here, on the side. The nurses have a meeting in there sometimes.

D:	I know yeah, I know.

F:	He said, he'd got to have a word with me and he said 'But I don't think I need to tell you'. I know what you're going to say, she's not going to make it, …'coz I know. We knew, I knew personally and the daughter knew personally, just by gut feeling that, .. the fortnight before that she was not going to make it. You could see the stats they were going down badly. And every time we come on the nurse would say her's had a bad night, she's very weak, weak and frail was the only way she would ever describe to me.

D:	Really? Yeah.

F:	When you don't eat.

D:	Yeah, that's sort of part and parcel of it.

F:	But the little beggar would do her physio, her'd sit on the bed and raise her legs. I don't know where the hell her got her strength from I do not know. I tell you, and he said, that was when he told me that he, that … that morning when her had her heart attack it was his decision to let her go, … I think it would have been kinder to let her go, but he said 'I was overruled, I'm not allowed to, if I got a majority doctors….that's fine'. He said 'But the most we could give you is a fortnight, we can't give you no longer, if she goes that long. She's a very very weak and frail lady'. And I said 'I know this, we all know this'. Bar one, the son, he was still to this day will not have it.

D:	No?

F:	No, he won't have it.

D:	I can remember right at the time you saying that he wasn't….

F:	Yeah, it really cut him up. The other lad, we had, prior to this we had a little meeting, I called a meeting, well if I call a family meeting they all have to come (laughter).

D:	Quite right too.

F:	Not necessarily that I'm like that, but if I say, … if it's possible can we get together, say Saturday, they're there, there is no argument. They are there, even if I called them now, at this present moment in time, the lad at Devon would drive all the way over just to be there, 'coz that's what we are, we're a family like that. Nothing is ever made in our family unless it is discussed, and it has to be a unanimous decision otherwise it don't get done. If we have a slight dis-doubt we don't do it. We're like that.

D:	It sounds lovely.

F: A good many come to our house that say 'F I wish I was in your family'. I say 'Why? they say 'Ours we can't do nothing with 'em, yours are totally the opposite, even your grandkids'. My grandkids are golden. The daughter only said to me the other day, her said 'Dad, I know you are strict when you bought we up'. She was seventeen before she was allowed to wear make-up.

D: Was she?

F: She was, she was not going to get away with a thing. Her mother used to sneak it upstairs, and I'd say 'Pack that in' (laughter). No, and he said 'I'm sorry to say it, but a fortnight is the maximum'. He said, 'Her lungs keep filling up with water, we're really having to, in fact her hearts not working at all really it's the ventilator that's doing all the work, and can you get in touch with your family and we will have a meeting with them'. He even stopped over, … he stopped over for them. They all got there about eight o'clock. Three on 'em already said they knew what they were coming for, but the big lad, no, he was positive they could get a, I nearly said a solicitor then, I don't know what the hell was I thinking (laughter), … get a specialist in and they could cure her. I said 'There's no way S, your mom, it's her time, and that's it'. I'm a great believer, in when you are born you are given a date. You are born on that date, and when you die you are also given a date, and you die on that date. I don't care where you are it will find you, that is my belief. I reckon what, I know it's bad when a woman loses a child but my estimation of it is it wasn't time for that child to be born. Whether I'm right, wrong or indifferent. I know the Muslim religion believe it.

D: Yes, that's true.

F: And they do, I've believed it all my life, all my life. Anyway, we got them all up, all of them came up and … I had a little conflab with them and the what's-a-name told 'em what he told me.

D: Yeah, that must have been really hard to do that though knowing

F: There's nothing you can do really is there. I can only pass on what I am told.

D: Yes, yes.

F: We knew, three of us knew that….

D: You got that…

F: Oh yeah, definitely. J said 'Is it time', and I said 'I think so' that's all J says over the phone. I said 'Once I say I'm up the hospital her'll say 'Is it time?' And I said 'Yes, it's time'. And that's it, but the other one, no, no, … the other one wouldn't have it no road, he still won't today. We had a

christening, um … two months ago and he took we, … he tried to make a toast to mother, well I call her mother, I've never called her anything else really, you don't, … if you've got children you don't, your mother, your father, that's it, mom and dad that's it, we've always noted as mom and dad, I think most people do in my era, I don't know. I hate children that call their parents by their first name, oh, that's terrible. Shows a lack of respect for a start off, but never mind.

D: Um yeah, at any age, you still…

F: Oh yes, yes, it doesn't matter. We still call her mother, I always do, if I discuss anything, If I'm talking to anybody about her I always say mother, it's perfectly normal. Anyway, we got them there, S wasn't, … not very happy. I hate calling him on the phone because he's a bit, … his mind goes blank when it comes to things like his mother, he does it now, as I was saying he couldn't make the speech. i said 'let her go s, let it go'. and he cried most of the whats-a-name after, he still won't accept it.

D: Was it, .. it wasn't his child getting christened was it?

F: Yeah.

D: It was?

F: Yeah, my new granddaughter, yeah. She's only four months, so it's only been a couple of months ago.

D: And it's still…

F: Anyway, we got in there, we got talking and he explained to them exactly the same as me, and as he told me, … and the only question, the only question that came, he asked me if I'd got any questions and I said 'No' I hadn't got none. You can only do what you do that's it, you can't work miracles. And the only question that came out of it was 'She won't be revived', he said 'no, can't revive her. No reviving. What we'll do we'll give her a pain killer and she'll drift off'. That's fine. But he wouldn't even except that, … he said 'but what happens if her goes now and a little bit later on they find a cure'. And I said 'S, they are not going to find a cure, you have to except it, it's life, except it'. And we sat there and her, …. nearly quarter to nine, we went in the meeting at half past, half past eight, and then we went there and we watched her go.

D: Oh, you were all there.

F: Nothing we could do. But he wouldn't come near her.

D: S wouldn't?

F: No, stayed right at the bottom of the bed, wouldn't come by her. I don't think today he even excepts it, I don't think so. Deep down inside, no, he doesn't except it. That's fine, he'll have to come to terms with it some other way, …. it's up to him. It's individual.

D: Yes, it is, it is.

F: We said, and we said ta ra to her and we went down and had a cup of tea and I said ' We'll have one last look at her before you take her away' And he still wouldn't come by her. I think the colour frightened him, … because I don't know whether you are familiar with ventilator patients.

D: Yes, yes.

F   Are you familiar with them?

D: Yes, I have sort of looked after a few.

F: No, I mean death-wise.

D: Oh yes, yeah. People sort of change ….

F: How quickly they go black.

D: That's right, yeah.

F: I think that is what put him off. I said, you have to, it's all the oxygen the machine has pumped into the body and it can't get out, … so it changes colour. I was very surprised. Anyway, we had a, … we left, we were here about an hour roughly. A couple of friends popped up, but um, we were here about an hour then we went home. And I made arrangements to have her picked up and took to our local undertakers. And I'm very surprised, he went to see her there to be honest.

D: He did, did he?

F: I stood by him, I think it's fright, I think it's fright.

D: Yeah.

F: I've got to be honest, he's never seen a dead body.

D: No, and when it is your own, it's very….

F: Oh yeah, I've seen many, too bloody many.

D: Have you?

F: Oh yes, lots.

D: Family and ….

F: Lots, fifteen years ago I buried all, … I buried four In three months. I didn't know what time of year it was let alone anything else.

D: No, gosh.

F: I buried a mom, step-mom, aunty and an granny, … in less than three months. I thought the F's had got a plague, literally. The old fashioned saying, 'somebody up there has dropped a clobber 'em' It nearly come true, Jesus I've never had so many funerals. I think, …. I've got to be honest, I know I like to laugh about it but you have to in my case I make a joke of anything, it doesn't matter what it is that's me, there is no pun intended or anything, but I was one of his best customers that funeral parlour (laughter)

D: Gosh, but how draining, with you know, and it makes you wonder then, how is it going to stop I suppose.

F: I've buried a couple more since then, but. I buried a sister three years ago. She, actually, … this might have some bearing on what you're after really, the last, … the day before she died I went to visit her, she was in Sandwell, and she was seventy five at the time, and I know the nurse well because her mother lives two doors from me, and her said 'F I hate to tell you this' I said 'Why, what's the matter?' Her said ' I think A's', her name was A, her said ' I think she's going … senile'. I said ' what do you mean her's going senile? She's as sane as I am, saner than me', in fact, she'd got a brilliant head for seventy five. Her said 'Well I popped in the other day, just to give her an injection and her said her was there talking to somebody, rattling away to somebody that wasn't there. There was nobody there. According to her there was nobody there, not according to A there wasn't, ah, it's silly

D: And who was A talking to, did she say?

F: Dad, he'd died fifteen years earlier. Her said dad come to see her. And I take her word on anything, anything whatsoever. She may be seventy five but she was all there with her marbles. She had got a better head than me, or did have. Her said 'Dad come to see me,… we was having a right old chat', her said ' Then he left'. I said 'Ah, that's very nice for you'. I've got to be honest I was a bit twitching towards that way, but it seems very strange. They rang me the next day, I was due to go up, at the time, I was about an hour away from going up, and they notified me that she had passed away.

D: Gosh

F: That's another belief of mine, whether it's true or not, I always say someone comes to fetch you. Someone of a late family will come and fetch you. I think so.

D: Yeah, and there's…..

F: D always believed it.

D: Did she?

F: Her always said 'when I go I hope mom comes to collect me' 'Coz her lost her mom um, just, … a fortnight before we got married. Her wanted to cancel the wedding, her said 'No'. They cancelled the church wedding, we were due to have a church wedding, we ended up with a what's-a-name one.

D: A registrar, a registry one.

F: A registrar, yeah. Silly but um, … I believe it. Unless somebody can prove me different, and I don't think they can.

D: I don't think so.

F: I don't think so (laughter) I don't think so. As I was saying, the lad went to see her, he said 'Dad would you mind being with me', I said 'No, I don't mind, I said I'd visit your mother anywhere, any time, any place, you name it I'm there'. And um, … it was only me and him went, 'coz he said the moment he walked in, 'coz I don't know if you've been to many undertakers but it has a smell all of its own, that's neither here nor there, you can't ? a smell.

D: Yeah, but it has …

F: It brings it home to you that's where you are.

D: You're very aware, yeah.

F: Yeah, and he said I could only ask one thing and I said 'Why, what's the matter, what do you want to ask?' he said, ' Don't be upset' he said ' if I walk out'. I said 'It's fine, I'll leave the door open for you'. I said 'There's a chair there if you want to take it in with you', he said 'No, I'll stand a while and see how it goes'. And he did, he stopped, I've got to give him his due, he stopped.

D: Yeah, but he had given himself that little, … just in case.

F: Oh yeah, just leave the door open just in case. That's fair enough, you can't argue with it. I have to say that she looked lovely, apart from the colour.

D: Was her colour still…?

F: Black. When I first went to visit her in the chapel of rest they said ' Mr F I'm sorry but the body is not in good condition'. I said ' What do you mean by not in good condition?' Because as you remember she fell off the trolley. I mean I hadn't seen her then. As far, …. all I knew was what the nurse told me which was correct, she had got a piece of sticky tape across her nose, you could see where her nose has flipped over and they had pulled it back and stuck it back down again.

D: Right.

F: He said, 'Because she's got some very bad bruising on her neck', I said 'Don't worry about that love, that's where they used to put the lines in for the…'

D: Yeah, for the dialysis.

F: Dialysis. And I said 'When they take them out obviously the skin is that weak it just goes black, solid black'. And she said 'Oh thank goodness for that I thought it was something our lot had done'. I said, 'Don't be silly' (laughter). 'Coz it was noted when I picked her up that her had fell off the trolley, which is alright, wheels go, there is nothing you can do about it, it is not worth making a fuss about. If it had been the other way round it wouldn't have got made a fuss about either. That's one of them things, I would have probably hit the floor with me head 'coz I'm a bit heavier (laughter).   No, we had a beautiful coffin for her, mahogany.

F: And we dressed her in silk. We had a silk gown and …

D: Oh, beautiful.

F: And a silk, I don't know what they call them, shroud thing, like a shroud.

D: Yeah, It's sort of.

F: And her's got a hood, got a hood job. Her's got a beautiful coffin. I think that's what made him stop really, 'coz it didn't show up the colour so badly as white does. I think black on white is terrible.

D: Yeah, yeah.

F: We had a beautiful day actually, … surprised me very much. 'coz we only went to our local church down the road, there was no room, … they was

standing outside. they, …. I didn't get the vicar I wanted, I've got to be honest, but that's fair enough she was away.

D: Oh, was that your local, your normal vicar?

F: Yeah, normal vicar. She done As, she's a Jamaican but she's a lovely woman. She talks your sort of language, her's like um, …. oh fiddle (laughter) the vicar, … that came to the ..

D: Oh is it F?

F: F, very much like F, talks plain English. Her talks plain English. I would have loved to have had her because she's a lovely woman, but it doesn't matter, we had the other vicar. I don't reckon he was half as good but I'm biased (laughter), he's not the greatest vicar in the world. I don't know what it is but he ain't, he just hasn't got it. He might be brilliant in services but when it comes to funerals he has not got it, he has not got it. He hasn't got it at all, never mind. It would have been nice though, but it doesn't make no difference. Yeah, we had horse-drawn one. because her always wanted, … her said if ever I, I… 'll rephrase that, when it comes to me funeral I would love a horse-drawn one. I said, 'yes, if that's what you want, that's what you shall have'

D: Oh, beautiful.

F: They all say I'm a, um,... how can you put it, …. not exactly weird but, the plot that I own down the cemetery, I've got one there and one next to it. I've got D in one and A in the other. And I bought them believe it or not, twenty odd years before. And they always thought I was weird. I said I don't care. Dad done exactly the same, he bought his plot long before he needed it. I said fine.

D: You have security there, that it's there.

F: Oh yeah, as well as you could chose where you want to go. That is, that was the most important thing as far as I'm concerned. 'Coz it will take six people, I don't know where we are going to get the others from but never mind (laughter) we'll have to drag a few in off the streets (laughter), no, it's true, it's true. The daughter-in-law asked me 'F, don't take this the wrong way'. I said 'No go on, what do you want' her said, 'You know when you bought your plots', I said 'Yes', her said 'Where did you get the six from?' I said, 'I didn't particularly go for six, but they were two, three body plots'. And they were the only, three, two together so I had them (laughter). Oh yes, it surprised me.

D: Well sometimes people don't think, …. people don't sort of want to think about it.

F: It's always been done in our family, I don't know why, dad did it, dad did it exactly the same. Mind you, mom did die when her was thirty four so, oh yes, it was a baddy one that was. She did of what is, what they used to term then as Bright's disease, the better known for it now is cancer. It never used to be called cancer then.

D: I didn't realise that.

F: Yes, I was only eight. We lost quite a few actually, but there was thirteen of us. Two died of um,…. (whistling), um,… anyway it's the things you have the needles for now.

D: Oh right, would it be TB, or….

F: No not TB.

D: … measles?

F: Measles, and the other one…, there's another one.

D: There is, mumps, measles, rubella?

F: Anyway, we lost two of those, one got drowned, one got run over, um, ….and one died of what they term natural causes, a bit young but they couldn't find nothing else for it.

D: Yeah, yeah, sort of the sudden infant, what they term it, different terminology now.

F: I remember the day A died actually. He'd just had a bright new pair of wellies, red ones, and in that day a pair of wellies was really something, oh my god, with thirteen in the family we were lucky if we got an orange for Christmas, but we didn't bother, we didn't care, I'm still not a Christmassy person, I still don't, I still don't. Anyway, he ran out and he slipped, and he went right underneath the lorry as it went by, … tore him to bloody pieces, and he lasted two hours in hospital. I don't think he even with today's technology they could have done much for him. He was in a terrible state. I even remember the firm, G & F.

D: Really, the lorry …

F: They used to make flour, at one time, MD took them over (laughter). Oh yeah. But we haven't had what we call an easy life by any means.

D: No, no.

F: But it doesn't matter. And, I don't know whether you know this but the young lad is disabled anyway. He was born disabled. He only had one leg,

one inch shorter than the other, when he was born. And when he reached fourteen it was ten and half inches shorter.

D: Really?

F: It's been a long time. This is getting off the subject (laughter). If I waffle on please tell me. I won't take offence in anyway whatsoever. No, she had a beautiful funeral. Apart from the flowers. I've never seen so many, I've got to be honest, beside what the family did, … which was a large cross, a big heart, the open and shut gates, all this we done, we done this one. And there was at least, … we counted fifty four bunches of flowers on the front garden. We didn't know what to do with them. The undertaker said 'I've never seen so many'. He said, we'll have to open the boots and if we can't get them all in our boot ask some of the people who followed the hearse to put them in theirs. But we did get them on eventually, the grave was up there (laughter). You could spot it the moment you went through the gate, … but I wish she was here I have to be honest. Not from a morbid point of view, no, … but we had such great plans for when we retire, and now they won't fall through, well they won't come to, not fall through. Still, we'll get there. I'm not looking forward to retirement at all, I was, but I'm not anymore. Her wanted me to retire when I had my heart attack I said 'No thank you, I don't want to retire it's too early'. I don't think we would have got on so well, …. no, because I don't care who you are, if you've got somebody who wants to go to work but can't go to work it's got to have an effect on the marriage, I don't care.

D: I think you're right.

F: Anybody who knows me or anybody in our family will tell you exactly the same, we have never had a cross word in forty three years, … and that is how long we were married, forty three years. We have never had a cross word. I think we are two, what I used to term as two peas in a pod. I knew what she was thinking and she would know exactly what I was thinking. It's unbelievable, … yes, absolutely unbelievable. I tell people at work, I say 'Well', you know because they do ask, I don't mind, and some people they won't speak to you, and are frightened to death, I don't get upset, I don't get upset in that way. There would have to be something very serious to upset me. I'm not that way inclined.

D: So, people didn't always sort of approach you afterwards?

F: Oh no, they kept away, they were like, neighbours were brilliant up until … about a week after the funeral. I don't see many of them these days (laughter). It's one of them things, and yet I am in and out all the while, I'm never still, I'm never still. I'm always, in, out, all over the place. But, I don't know what it does to them. Now, if that was me I'd have to ask them, see how they were doing, anything I can do for them. Mind you I am very

independent me, I do all me own cooking, cleaning, everything, I don't, we don't have the neighbour pop in with the duster, no.

D: No (laughter). But as you say, just a word every now and then.

F: I think they are frightened of upsetting me, I don't know why.

D: And quite often, … but what they say isn't going to make you anymore upset….

F: Actually … stopping you talking, I did, when we went to this memorial service, I don't know if you noticed her, there was lady with a stick, walks with a stick, big, fairly biggish woman, I have seen her many times in the waiting room, I don't know if it was her husband her lost, I don't know, and I only said hello and she looked at me and she started to cry, and I thought ' Better leave that one alone', I was going to ask 'How are you keeping', but I'm glad I didn't, Jesus, I don't know. You never get over things like that, I don't care. You have to put your best foot forward and keep going. You stop and I think you are stuck, I really do, really stuck. Absolutely.

D: And sometimes people think, you know, that moving forward means …

F: Forgetting.

D: But you never, ever.

F: I never forget. No, in actual fact in our wardrobe this present moment in time is her last two presents. There is a Christmas present, which is still in the wrapper, I haven't unwrapped it, I know what it is so there is no point (laughter), Oh no, I do beg your pardon, I did unwrap it, I took it to the hospital and I showed it her, not that we could talk, we couldn't talk. Her couldn't talk anyway.

D: Could she write down things, could she, was she ?

F: No, she was that weak she couldn't hold a pen. It's just pitiful, I stopped asking her because she was like that, like an eighty year old trying to write. It was terrible. I stopped the kids doing it as well. I said ' It's upsetting her too much, don't do it' Do the sign language, that's better. We used to get on fine with sign language. The nurses come on day and said 'Fred, can you find out what her wants' we've tried. I said ' What do you want?' And her wants her teeth cleaned, …. because we think alike, it's always the same.

D: That's it.

F: You are on the same wavelength, basically.

D: Yeah, and that's what you get when you know somebody, … you just know that person.

F: Oh yes, even though I was expecting it, it was still the biggest shock I've ever had in me life. I've got to admit it.

D: Was it still holding on to that little bit of, you know, she's in ITU, she's …

F: Critical care says it all though doesn't it really. If you're were good, if you were even remotely, fairly, … how can you put it, … hopeful. Hopeful's a better word, if you were hopeful of getting better, they wouldn't be in Critical Care. I think Critical Care says a lot more than ITU.

D: It does, doesn't it?

F: I think so, 'coz West Bromwich, Sandwell has only got an ITU, it is only a very small one, it is nothing like the one you've got here. It's only a very, it's only like a, what's the other, you come out the ITU and you go into the little side ward.

D: HDU isn't it, the high dependency ….

F: It's a bit like that there's is. Basically the same thing, it's got monitors and everything all over but it is nothing like the size of this one at all.

F: Yeah, I don't mind going back in there, it doesn't bother me, doesn't bother me. The doctor, as far as I'm concerned this hospital and these doctors treated my wife like she was a queen, and I don't care who says any different, they are talking through their backside, I'll put it politely (laughter). I don't swear, I don't swear, you're safe, you're quite safe. Anything else I can tell you?

D: No, I think that's.

F: I did ask you if you ever wanted a word with the rest of the family.
D: Yeah, yeah.

F: Is that on or?

D: That would be lovely, that would be really lovely.

F: Now, to get 'em, this will be a problem.

D: On a Saturday. Or in an evening perhaps?

F: Now, I'm going to suggest something to you, it may not make much sense to you but it makes sense to me. Would it be possible for you pop at our house and see them.

D: That would be lovely.

F: That's fine. That's no problem. I can get them there at a click of a finger but to get 'em here is another matter.

D: It's difficult, yeah. No, that would be lovely. If that's alright with you.

F: You find me a date and I'll work on it.

D: Okay, well perhaps if we pop back down I'll get my diary and we'll have a look at that.

F: Yes, you're more than welcome, you are absolutely more than welcome. You can do it that way.

F: I left school at fifteen, which was the norm for me. Everybody left school at fifteen, we hadn't used to stop on like they do now. The first job I ever had was at Palethorpes. Do you remember Palethorpes?

D: I've heard of Palethorpes yeah.

F: We both, the wife already worked there, 'coz she's four years older than me. I'm a toy boy (laughter). Actually, it makes a lot of difference, used to make a lot of difference to Dor, not to me. Anyway, I started, I left school on Friday and I started work on the Monday, and I'd only been there …. about two hours before I clapped eyes on her, and I've never been out with anyone else since, that's it. Her said 'I'm not going our with you, you am too young'. I pursued her and pursued her, I worn her down to her knee caps (laughter). At the end I wore her down to her knee caps. Her said 'I can't go out with someone as young as you'. I'm only four years for god sake, what's that? It took me ages to get her to come out with me, ages, yes, bloody ages, it's weird.

D: Be nice to see the picture, you know the one you said that you've got.

F: Oh yes, the difference, yes.

D: Be nice to see.

F: Yes, so weird. I can see it now, today, walking round in her little white smock and her little white turbie (laughter). I said 'You look more like Hilda Ogden' (laughter), oh dear. No, I would, …. even today I can't even think of anyone else, it's not possible, it's not possible. Wherever she went, I went. The only time we were ever apart was when I was at work. Most husbands would rather go out than shopping with their wives, I don't know why. A load of 'em at our place, oh no, they go to the pub, no problem at all that ain't, but to go shopping, forget it.

D: No, no.

F: I don't know why. I used to love shopping, I still do. I can spend hours walking round Birmingham, it's no problem to me. But some won't do it, some won't do it.

D: Do you think that is a man thing or is it just, you know, they don't, .. the pubs more enticing?

F: I wouldn't call it a man thing, no, I think it is interfering with the drinking time, that's my basic. I mean, I don't, I personally don't drink, I've never drank in my life. Never, there's nobody in our family, apart from the daughter, her's the alkie of the family, as we call her (laughter), her likes a vodka, her likes one glass of vodka a day, that's it. I said 'you am an alcoholic' (laughter). It gives you something to buy her anyway when it's her birthday. I don't encourage her though, her knows I don't. Her's the alkie of the family. Her's a weirdo. No, it took we ages to, ages and ages. I can't remember exactly, um … I'll get at it, …. we were married forty three, …. I courted her for two, that's forty five, … yeah, be about two years, nearly coming up to two years before I could get her to go out, yeah, weird woman.

D: You were very persistent then.

F: Yeah, I know, and my mother said I was. I said ' That's mine, take you hands off, that's mine'. Don't get me wrong, I mean D's been out with several boyfriends before, but not me, I've only ever been out with one. Never go out with another one I'm afraid, … sorry to say it but, I've got a couple in our family that don't agree, but that's neither here nor there. The daughter said 'I know you won't', but the other two aren't so sure. They say 'you can't say that dad, three or four years down the line, moving on, you don't know'. I said, 'I know, I know how I feel and I know exactly how I will react'. I could predict my reactions to anything or on anybody, it won't make no difference. I am a weirdo like that (laughter), you have to say weirdo, some people are.

D: Yeah, but, it sounds like she meant, she was your other half.

F: She was more, she was my soul mate, I think so. Very much so. Not very often, … don't get me wrong I mean I go down the cemetery now two days a week, but it's not anything morbid or anything like that. I go down of a Sunday to put flowers on, she must have flowers, got to have flowers, …. she's had flowers even when she didn't have a headstone, she's got to have flowers. She only ever gets roses, don't get nothing else.

D: Does she? Red roses or a mixture?

F: It doesn't mater what colour, as long as it is a rose, doesn't matter. And, to be honest she'd curse me blind if her was, …. more for the fact that she can't do it (laughter), she don't like them she don't like fresh flowers, couldn't stand them, likes plastic, plastic! God, you can't have a flower in the house that's plastic, …you might if it is a table decoration, that I can understand but I don't know, terrible. I've just had her grave re- …. start again. I've just had her grave re-turfed, 'coz it never sinks properly.

D: No, no.

F: In some, because it is a open plan sort of thing, all you have got is the upright stones, and a big wide gap and then you have got another lot of upright stone, sort of one there, one there, one there and one there, and it,… they are lovely if they have been buried say about three or four years because then the ground sinks as low as it is going and that's it, then they usually level it off, but. It's not my cup of tea anyway so it don't really matter, I don't have say in that one, that's normal policy for the, for the cemetery, 'coz it's an open plan. I hate graves that you've got to climb over somebody else's to get at. We got, …. I attend six of them when I go down there on a Sunday, we spend nearly three and a half hours down there, me and the granddaughter. I do one, she does one, I do another one, she does another one (laughter).

D: That's lovely, so everybody is together there then in that …

F: Oh no, they've all separated, that's the trouble.

D: They are all over the, still in the same cemetery?

F: I've got two there, two over there, one right over the back and I've got another two over the end (laughter). I put flowers on D's mom and mom's grave as well, always have done, we've always done it. Every, … every Saturday, when we've finished shopping you always used to pick up a bunch of flowers, take them down. Do it every Saturday. I do it on a Sunday 'coz it's easier, I think it's easier on a Sunday. I've put some um….because they can't put roses on, … this will probably be the last week, for the simple reason that the frost kills them so fast, just and they've gone. I've put her some crocus and some bulbs round the front.

D: Oh, how lovely.

F: So her can't be without a flower. It'll take a while. Takes about a month but they'll come up no problem. Some blue hyacinths and some yellow crocus.

D: Oh beautiful.

F: Everyone says how nice the stones are, 'coz we have had a,… what do they call them? ……

D: What type, is it granite or…?

F: They are a granite, but they are very unusual granite, um…. um … Kensington stone, they are nice.

D: Oh, lovely.

F: Very nice, I think so. There is only four in the cemetery like them, and I've got two (laughter), I've got two. I think they match anything you put on, no matter what flowers you put on. We even had a meeting over that, 'coz I gave them the book, passed the book round the family. I said ' Let's have your verdict, on what sort of stone you'd like for mother'. You don't need me to tell you what Shaun said. 'Whatever you want dad is fine by me'. I knew he'd say it, but the other one liked the grey, don't get me wrong, grey was nice but this is sort of a um…. Sort of browny mottle, that's the best description of it, like a goldie colour really. Yeah.

D: Quite stunning really.

F: But, I couldn't have done with the grey one sorry. Actually, she's the only one in our family that has got a stone, the other two did not want one so I've never put one up. Dad never wanted a stone. Granny never wanted a stone. Weird isn't it. Step-mother never wanted a stone.

D: Did they ever say why, or was it was just like don't?

F: No, they don't want no fuss. When aunty and granny died in that three months, the last words,… I buried them both so, the last words to me was 'I don't want no marker'. Her'd go mad at me if she found out I put a cross on it (laughter). It's awkward to find graves though I tell you. At one time down there every grave had a number, it's the simplest thing in the world, just follow the numbers. Then they started complaining they couldn't cut the grass, so they took all the numbers down and threw them away. Now there isn't a grave down there with a number on, unless you don't know exactly where it is forget it.

D: Is it a big cemetery?

F: It's quite big yes, They are extending down the bottom I see, oh yes. We've been dealing with it now for the best part of, got to be over fifty years, easily. I've got great great granddads in there from the first world war, so (laughter), it's been going a bit, just a little bit. No it's silly, I don't understand why they did it, you don't push a lawn mower down there, it's only just a skimmer, just skims the top.

D: Is it, not one that's going to get damaged if it hits against something?

F: No, I think it used to break the cords in them so often. And then you used to get used to a pathway, pathway was easy, follow the path, it's the fourth on the left. What did they do, take the pathway out and bury people on it. So you don't get no pathway now, it's just one load of stones top to bottom (laughter). I can't understand it.

D: No, no.

F: It's the worst thing they ever done. The only good thing about having a stone now is 'coz you can have the actual grave number engraved on the back of it. They do that automatic, before it goes in. Once they get your deeds, your papers, they take your number off that and they have it engraved on the stone itself. So anybody looking for it know where to find it. Mind you, I know them all, there's only me goes down actually, the rest of our family in my opinion are a perishing disgrace. I've got two brothers, three brothers still alive, and there hasn't one been down to dad's grave since he was buried, that's over fifteen years. I don't think they know where to find it. Still, their loss.

F: Anyway, I'm holding you up.

D: No, that's lovely.

INTERVIEW END

Interview C1 – Existential Themes

TIME

Setting the scene

'Well basically my wife's illness started ….it's alright if I don't think it out it will make sense to me but it won't make no sense to you…..'

'she was ill about eighteen months before, oh no, if you go back to her first illness……. '

'I know, but if I miss the middle bit out…You're never going to get it.'

Person as a whole

I left school at fifteen, which was the norm for me. Everybody left school at fifteen…We both, the wife already worked there, 'coz she's four years older than me. I'm a toy boy (laughter). Actually, it makes a lot of difference, used to make a lot of difference to D, not to me. I'd only been there …about two hours before I clapped eyes on her, and I've never been out with anyone else since, that's it. Her said 'I'm not going our with you, you am too young'. I pursued her and pursued her, I worn her down to her knee caps (laughter). At the end I wore her down to her knee caps. Her said 'I can't go out with someone as young as you'. I'm only four years for god sake, what's that? It took me ages to get her to come out with me, ages, yes, bloody ages, it's weird. Yes, so weird. I can see it now, today, walking round in her little white smock and her little white turbie (laughter). I said 'You look more like Hilda Ogden' (laughter), oh dear. No, I would, …. even today I can't even think of anyone else, it's not possible, it's not possible. Wherever she went, I went…..'

Time to die

 'But the big lad, no, he was positive they could get a specialist in and they could cure her. I said 'There's no way S, your mom, it's her time, and that's it'… But he wouldn't even except that,'

'he said 'but what happens if her goes now and a little bit later on they find a cure'. And I said 'S, they are not going to find a cure, you have to except it, it's life, except it'

 I'm a great believer, in when you are born you are given a date. You are born on that date, and when you die you are also given a date, and you die on that date. I don't care where you are it will find you, that is my belief'.

 'I know it's bad when a woman loses a child but my estimation of it is it wasn't time for that child to be born. Whether I'm right, wrong or indifferent.

'And the only question that came out of it was 'she won't be revived', he said 'No, can't revive her. No reviving. What we'll do we'll give her a pain killer and she'll drift off'. That's fine'

Good / bad death

'I know it's bad when a woman loses a child but my estimation of it is it wasn't time for that child to be born'

Time of death

'J said is it time and I said I think so'

'we went into the meeting at half past, half past eight, and then we went there and we watched her go'

SPACE

Environment

'Critical care says it all though doesn't it really. If you're were good, if you were even remotely, fairly, … how can you put it, … hopeful. Hopeful's a better word, if you were hopeful of getting better, they wouldn't be in Critical Care. I think Critical Care says a lot more than ITU'.

Adequate / appropriate

'him and a Consultant had me in and they, … we sat in a little office about this big really, it's on the ward here, on the side. The nurses have a meeting in there sometimes'

Irrelevant

'As I was saying, the lad went to see her(in the funeral directors), he sad 'Dad would you mind being with me', I said 'No, I don't mind, I said I'd visit your mother anywhere, any time, any place, you name it I'm there'

'don't know if you have been to many undertakers but it has a smell of its own, that's neither here nor there.. it brings it home to you that's where you are'.

Home v hospital

'we had her home. We've only ever had her home about, … over a span of about two and half years, we've only ever had her home for a week, that's it, we haven't had no more'

Final resting place

'Everyone says how nice the stones are'

'There is only four in the cemetery like them, and I've got two (laughter), I've got two. I think they match anything you put on, no matter what flowers you put on'.

BODY

Premonition

'coz her couldn't stand to have her photo took once her was bad. I don't think women do'

Gut instinct

'and then she started to get different'

'He said he'd got to have a word with me and he said ' but I don't think I need to tell you'..I know what you're going to say, she's not going to make it, …'coz I know. We knew, I knew personally and the daughter knew personally, just by gut feeling that,.. the fortnight before that she was not going to make it.'

Preparation

'You look terrible, we know you look terrible but that doesn't matter to we, as long as you are with us it don't make no difference whatsoever'

'it was still the biggest shock I have ever had in my life, I've got to admit it'.

Suffering

'That woman suffered more than I would wish on any, ... even me worst enemy believe you me, no way'

'In fact I'm glad she is where she is to be honest'

Presence at time of death

'and then we went there and we watched her go'

Guilt

'you still get to a point where you do sit and think….. well some people do sit and think 'Did we do the right thing?'. But we'd already worked that out at Christmas….It's …. Well, as I say, at the end… towards the end it was just a case of…let's go with the flow. Really there's nothing you could have done'.

Grief

' had a christening, um … two months ago and he took we, … he tried to make a toast to mother…. his mind goes blank when it comes to things like his mother, he does it now, as I was saying he couldn't make the speech. I said 'Let her go S, let it go'. And he cried most of the whats-a-name after, he still won't accept it'

RELATIONSHIPS

Family / support

'but if I say, … if it's possible can we get together, say Saturday, they're there, there is no argument. They are there, even if I called them now, at this present moment in time, the lad at Devon would drive all the way over just to be there, 'coz that's what we are, we're a family like that. Nothing is ever made in our family unless it is discussed, and it has to be a unanimous decision otherwise it don't get done. If we have a slight dis-doubt we don't do it. We're like that.'

Relationship with doctors and nurses

'Well, um …they got her as well as they could possibly get her in my opinion'

'he asked me if I'd got any questions and I said 'No' I hadn't got none'.

'You can only do what you do that's it, you can't work miracles'

'The doctor, as far as I'm concerned this hospital and these doctors treated my wife like she was a queen, and I don't care who says any different, they are talking through their backside, I'll put it politely'

Communication

'so, what sort of heart attack I've never been told….Or what caused it, … nobody knows'

I didn't talk to any doctors about it there was none forthcoming when I, can I put it that way, but I was more concerned about the wife'

Breaking bad news

I knew, I knew what was coming 'coz the nurse said 'He'd like a word'

Relationship with his wife

We're like two peas in a pod, well we was, re-phrase that, was'

'I knew what she was thinking and she would know exactly what I was thinking. It's unbelievable, … yes, absolutely unbelievable'.

'She was more, she was my soul mate, I think so. Very much so.

Guardian / protector

I sat all night on the bed with her talking about it. 'coz you have to, you don't have a choice…. I wouldn't have just popped her off and left her like some of 'em would have done, I couldn't do it, impossible. I was always here from one until eight o'clock at night, guaranteed, and I'd sit by the bed until the nurse said 'Can I change her, or can I do whatever' and I'd move off, but apart from that I never went far, only went in the waiting room, that's as far as I went (c1).

Moving on

'No, I would, …. even today I can't even think of anyone else, it's not possible, it's not possible. Wherever she went, I went. The only time we were ever apart was when I was at work. Never go out with another one I'm afraid, … 'I know, I know how I feel and I know exactly how I will react'. I could predict my reactions to anything or on anybody, it won't make no difference.

'Never mind, never mind. Good old days, they won't come back'
'… and I think as well people don't talk about it. You cannot do it. It's not possible you bottle it up, it's three times as long'

'you never get over things like that, I din't care. You really have to put your best foot forward and keep going. You stop and I think you are stuck, I really do, really stuck.

Continuing bonds

'we had a beautiful coffin for her, mahogany… And we dressed her in silk. We had a silk gown and …We had a beautiful day actually, … surprised me very much. 'Coz we only went to our local church down the road, there was no room, … they was standing outside…..... '

'Yeah, we had horse-drawn one. Because her always wanted, … her said if ever I, I… 'll rephrase that, when it comes to me funeral I would love a horse-drawn one. I said, 'Yes, if that's what you want, that's what you shall have'

'No, she had a beautiful funeral. Apart from the flowers. I've never seen so many, I've got to be honest, beside what the family did, … which was a large cross, a big heart, the open and shut gates, all this we done, we done this one. And there was at least, … we counted fifty four bunches of flowers on the front garden. We didn't know what to do with them. The undertaker said 'I've never seen so many'. He said, we'll have to open the boots and if we can't get them all in our boot ask some of the people who followed the hearse to put them in theirs. But we did get them on eventually, the grave was up there (laughter). You could spot it the moment you went through the gate,

Everyone says how nice the stones are,….Very nice, I think so. There is only four in the cemetery like them, and I've got two (laughter), I've got two. I think they match anything you put on, no matter what flowers you put on. We even had a meeting over that, 'coz I gave them the book, passed the book round the family. I said ' Let's have your verdict, on what sort of stone you'd like for mother'
Not very often, … don't get me wrong I mean I go down the cemetery now two days a week, but it's not anything morbid or anything like that.

 I go down of a Sunday to put flowers on, she must have flowers, got to have flowers, …. she's had flowers even when she didn't have a headstone, she's got to have flowers.

She only ever gets roses, don't get nothing else

'.. I've put her some crocus and some bulbs round the front….So her can't be without a flower. It'll take a while. Takes about a month but they'll come up no problem. Some blue hyacinths and some yellow crocus'

Continuing bonds, contact with people who had died before

'That's another belief of mine, whether it's true or not, I always say someone comes to fetch you. Someone of a late family will come and fetch you. I think so'

'….D always believed it. Her always said 'when I go I hope mom comes to collect me… Silly but um, … I believe it. Unless somebody can prove me different, and I don't think they can'

', … this might have some bearing on what you're after really, the last, … the day before she died I went to visit her, she was in Sandwell, and she was seventy five at the time, and I know the nurse well because her mother lives two doors from me, and her said 'F I hate to tell you this' I said 'Why, what's the matter?' Her said ' I think A's', her name was A, her said ' I think she's going … senile'. I said ' what do you mean her's going senile? She's as sane as I am, saner than me', in fact, she'd got a brilliant head for seventy five. Her said 'Well I popped in the other day, just to give her an injection and her said her was there talking to somebody, rattling away to somebody that wasn't there.   There was nobody there. According to her there was nobody there, not according to A there wasn't, ah, it's silly. Dad, he'd died fifteen years earlier. Her said dad come to see her. And I take her word on anything, anything whatsoever. She may be seventy five but she was all there with her marbles. She had got a better head than me, or did have. Her said 'Dad come to see me,… we was having a right old chat', her said ' Then he left'. I said 'Ah, that's very nice for you'. I've got to be honest I was a bit twitching towards that way, but it seems very strange. They rang me the next day, I was due to go up, at the time, I was about an hour away from going up, and they notified me that she had passed away.

'That's another belief of mine, whether it's true or not, I always say someone comes to fetch you. Someone of a late family will come and fetch you. I think so'

Loss of dreams

'… but I wish she was here I have to be honest. Not from a morbid point of view, no, … but we had such great plans for when we retire, and now they won't fall through, well they won't come to, not fall through. Still, we'll get there. I'm not looking forward to retirement at all, I was, but I'm not anymore'.

'I never forget. No, in actual fact in our wardrobe this present moment in time is her last two presents. There is a Christmas present, which is still in the wrapper, I haven't unwrapped it, I

know what it is so there is no point (laughter), Oh no, I do beg your pardon, I did unwrap it, I took it to the hospital and I showed it her, not that we could talk, we couldn't talk. Her couldn't talk anyway'

Relationship with religious leaders

Her (vicar he wanted for the funeral) talks plain English. I would have loved to have had her because she's a lovely woman, but it doesn't matter, we had the other vicar. I don't reckon he was half as good but I'm biased (laughter), he's not the greatest vicar in the world. I don't know what it is but he ain't, he just hasn't got it. He might be brilliant in services but when it comes to funerals he has not got it, he has not got it. He hasn't got it at all, never mind. It would have been nice though, but it doesn't make no difference'

Relationship with the person who donated their liver

… and I think, I don't know but I think I'm right, is it possible that when somebody donates a liver you pick up certain things off that person, from that liver. It might have been an anorexic that give the liver up, I don't know. But she was terrible from the time that she had it, she was not the same person(c1).

Moving on

'Jesus, I don't know. You never get over things like that, I don't care. You have to put your best foot forward and keep going. You stop and I think you are stuck, I really do, really stuck. Absolutely'.

I don't think today he even excepts it, I don't think so. Deep down inside, no, he doesn't except it. That's fine, he'll have to come to terms with it some other way, …. it's up to him. It's individual'

Relationship with community / neighbours

'and some people they won't speak to you, and are frightened to death, I don't get upset, I don't get upset in that way. There would have to be something very serious to upset me. I'm not that way inclined'.

'Oh no, they kept away, they were like, neighbours were brilliant up until … about a week after the funeral. I don't see many of them these days (laughter). It's one of them things, and yet I am in and out all the while, I'm never still, I'm never still. I'm always, in, out, all over the place. But, I don't know what it does to them. Now, if that was me I'd have to ask them, see how they were doing, anything I can do for them. Mind you I am very independent me, I do all me own cooking, cleaning, everything, I don't, we don't have the neighbour pop in with the duster, no'

 'I think they are frightened of upsetting me, I don't know why'

'I don't know if it was her husband her lost, I don't know, and I only said hello and she looked at me and she started to cry, and I thought ' Better leave that one alone', I was going to ask 'How are you keeping', but I'm glad I didn't',

APPENDIX H

PUBLICATIONS AND PRESENTATIONS AS A PRECURSOR TO, OR ARISING FROM, THE STUDY IN THIS THESIS.

Presentations

Date	Venue and event	Title
May 2006	UHB NHSFT Good Practice Conference; Birmingham	*An analysis of first letters of complaint following the death of a patient*
May 2006	DH/BSA National Bereavement Conference; Birmingham	*When A Patient Dies*
May 2006	Wellcome Clinical Research Facility National Conference; Manchester	*How the WCRF helped me undertake a PhD*
September 2006	Cruse National bereavement conference; Leicester	*Bereavement care for all*
March 2007	University of Central England Masters in nursing advanced practice; Birmingham	*'Bereavement care for all'*
April 2007	Barts and the London NHS Trust Bereavement Forum; London	*Sibling Bereavement*
September 2007	Cruse Bereavement Care National Conference; London	*Bereavement Pathways 'Bridging the Gap'*
February 2008	Bereavement Research Forum AGM; London	*"Bereavement in the Abrahmic faiths"*
May 2008	Birmingham Medical Institute	*Death certification in hospital – cultural and religious considerations.*
June 2008	CRUSE AGM; Birmingham	*Bereavement Pathways*

Date	Venue and event	Title
July 2008	8th international conference on Grief and Bereavement; Melbourne, Australia	*'Bridging the Gap' in Bereavement Care*
September 2008	Cruse Bereavement Care National conference; Leicester	*Bereavement Pathways BSA / CRUSE Project*
October 2008	Primary care live Conference; London	*The bereavement journey and the importance of getting it right*
November 2008	Child Bereavement Charity conference; London	*Personal and Professional aspects of grief*

Publications

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