A LONELY PLACE TO BE:

Children's experiences of living with a parent who is dying

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ABSTRACT

The following research has explored children's experiences when living with a parent who is dying. The findings provide substantial evidence that these children frequently experience a conspiracy of silence which is orchestrated and managed by the adults in their lives.

The findings have evidenced that children are not typically included in information exchanges about their parents' illnesses. This creates feelings of powerlessness and a barrier to 'making meaning' of their current experiences. Exclusion from appropriate and meaningful discourses results in them being unable to develop narratives that are consistent with the peripheral information they are receiving, and which cause them to question their identity and the construct of their family. However, the research has also shown that when children are included in conversations about their parents' illnesses, they generally have a more sophisticated understanding of what is happening and are cognitively and emotionally better able to cope.

The quality and quantity of information that is shared with children of terminally ill parents affects their ability to assimilate what is happening which in turn impacts on their management of, or in many examples, their failure to manage the situation. This thesis explores strategies employed by children in their attempt to begin to make meaning from what is happening and to manage the situation.

The research highlights that these children experience a number of transitions, changes and challenges. Changes in family routines and the shift from the known patterns of family life to a chaotic and unsafe world often present these children with unprecedented challenges that can severely affect how they manage the experience and how they begin to make meaning from what is happening. Within the thesis I argue that children experience a form of 'social death' where previously known social activities and contacts are curtailed because of parents' illnesses. The concept of 'social death' reflects their increasing isolation from a 'normal' social world which intensifies feelings of difference and causes further questions about identity.

The thesis builds on the work of Walter (1996) suggesting that not only is there a 'last chapter' to be written following the death, but that children with terminally ill parents are also critically involved in writing a 'penultimate chapter' during the latter phases of their parents' illnesses. This 'chapter' forms the narratives that accompany this challenging and rapidly changing time in the children's lives. The 'writing' of the chapter provides, in part, a framework for the children to construct their biography and consequently develop an understanding of what is happening. However, when they are not included in conversations about the illness the 'writing' of the chapter can be severely compromised thus causing them to write an inaccurate account and create incongruent narratives.

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CHAPTER ONE: INTRODUCTION

It is estimated that 53 children experience the death of a parent everyday in the United Kingdom (UK) (Child Bereavement Network 2008). Whilst it is evident from the review of the literature that during the last decade, service provision for bereaved children has gained momentum (Rolls and Payne 2004, Miller 2005, Willis 2005), as has research into the effects on children when a parent has died (Holland 2001, Ribbens McCarthy 2005), it would appear that there remains less recognition of the needs of children when a parent is at the end of life (Saldinger et al. 2004). Kennedy et al. (2008a) suggest that 'childhood bereavement literature is growing exponentially but coverage of pre-bereavement is less evident' (p. 164). Furthermore, these children, within the UK are not recognised by the Children Act 1989 either as Children in Need or Children at Risk. Moreover, in the Government initiative Every Child Matters, there remains no acknowledgment of the needs of bereaved children and their families (Willis 2005) or children who are living with a parent who is dying. The limited research that has been published into the pre-bereavement period for children has been primarily undertaken outside of the UK: in the United States of America (Beale et al. 2004, Christ et al. 1993, Christ et al. 1994, Christ 2000, Christ and Christ 2006, Dunning 2006, Saldinger et al. 2003), in Australia (Turner 2003, Turner et al. 2007) and in Europe (Thastum et al. 2008).

It was planned that the research would be a prospective study, in so much as the primary participants, the children, would be living within the experience of parental terminal illness, and not a retrospective study where they would be asked to recall their experience as bereaved children. I wanted, by adopting a prospective approach, to capture the current perceptions and experiences of the children, their parents and the professionals involved in their care. It was my intention to access participants, the children and their families, through support groups based in adult hospices. I anticipated that I would become a volunteer in the support groups and through participant observations develop an understanding of the children and their families' experiences of support. In addition I intended to undertake semi-structured interviews with the professionals involved in the families' care. A qualitative methodology was adopted in recognition that the lived experiences of children in families where a parent is dying is largely unresearched. The decision to adopt ethnographic methods, incorporating a narrative approach, and using semi-structured interviews and participant observations, was that these would provide the participants with the opportunity to share their experiences and thus provide rich, explanatory data, that would not be as possible from quantitative methods. Thereby developing a greater knowledge and understanding of their lives, cultures and feelings.

I was aware from the outset that my aim and objectives were potentially ethically challenging and that I was likely to encounter some difficulties in gaining ethical approval. I recognised that the combination of researching children and death and dying were two ethically contentious areas that required much thought and planning. The process of gaining favourable ethical approval from both the University of Derby and the National Health Service (NHS) Ethics Committees, ensured that the research would be ethically sound and that the participants' wellbeing was the primary consideration.

Following gaining favourable ethical approval I experienced unexpected barriers and challenges from gatekeepers within hospices. These seemingly impenetrable barriers caused me to reconsider my initial plans and consequently amend the objectives for the research. The objectives that I had originally planned were:

- To investigate with the children what professional support they are receiving
- To explore with the children their perceptions of the support they feel they would wish to receive
- To examine how the anticipated death is impacting on the children within the changing family dynamics
- To develop a model of support for children that can be replicated across palliative care provision
- To develop a theoretical framework that will inform further academic research and influence policy

The objectives were amended to accommodate the changes. The modified objectives were:

- To explore bereaved children's experiences of the support they received when their parent was at the end of life

- To investigate with the professionals the support offered to children
- To develop a model of support for children that can be replicated across palliative care provision
- To develop a theoretical framework that will inform further academic research and influence policy and practice

However, the aim of the research remained fundamentally unchanged:

> To critically examine the nature and availability of professional support and its contributions to children's wellbeing when a parent or carer is at the end of life within selected palliative care settings.

Following the amendments to the research objectives I contacted independent bereavement support projects and adult hospices that offer support to bereaved children. Through these contacts a combination of purposive and opportunist sampling was achieved and as a consequence, I interviewed seven young people who had been bereaved of a parent or significant carer, four bereaved parents, one terminally ill parent and sixteen professionals (Sec 3.2.6 and Appendix 1). In addition, I was privileged to meet with nine young people in a bereavement support group. This represents a small sample and I am aware that it would be incorrect to suggest that the accounts from my sample represent the experiences and perceptions of all children and families living with a parent who is dying. However, the findings, discussion and conclusion, including the recommendations, may resonate with the experiences of other children living with a parent who is dying, their families and the professionals involved in their care.

The participants' experiences have been central to the research, and through this, their accounts of how they interpret and understand the issues of living with a parent who is dying have been fundamental. It has become evident that whilst similar themes have emerged, the construction of the participants' accounts have, inevitably, been different. The professionals' accounts have been well-rehearsed and, it would appear, reinforced through experience, whilst the children's are generally less well-rehearsed. This highlights how, for children, there are limited discourses readily available about living with a terminally ill parent, and consequently the construction of their discourse is not able to be built on previous knowledge or awareness. My research has evidenced that this is compounded by a lack of information and frequently an exclusion from what is happening and an instinctual desire to avoid the reality of their families' crises. However, this research has also highlighted that when children do receive information and are included in what is happening, they are able to begin to attach some meaning and develop appropriate, if difficult, discourses to the situation.

As the research progressed and my reading of the literature developed, I began to recognise that the initial aim was too nebulous. The early interviews and the participants' accounts indicated that these children had strong feelings about many more aspects of their parents dying than just about the support they had or had not received. This caused me to reconsider and modify the initial aim. As a consequence, the thesis focuses on three important components that are significant for children living with a parent who is dying. These are:

- Communication and information sharing
- How the children manage their current lived experience
- The transitions and changes that children experience when living with a parent who is dying

The analysis of the data, along with my reading and critiquing of influential theorists has culminated in my proposition that children are frequently disadvantaged in writing 'the penultimate chapter'. This concept helps explain how lack of information sharing and exclusion may disable children's narratives during the terminal stage of their parents' illnesses. The notion of this 'penultimate chapter' extends the work of Walter (1996, 1999) who writes about the importance of the bereaved being involved in the writing of a 'last chapter' if grief is to be successfully resolved. Walter's presentation deals with a fairly 'natural death' and hence does not address how, in the case of terminal illness, 'the writing of the last chapter' may be preceded by a 'penultimate chapter' that is 'written' during the illness. Walter (1996) does allude to the writing of a penultimate chapter when he writes about the work of Marshall. However, this is a different context and relates to older people's reminiscences of their life. Furthermore, the literature relating to anticipatory mourning does not acknowledge that during this period people are involved in 'writing' a chapter about the process. Moreover, Saldinger et al. (1999) highlight that literature about anticipatory mourning fails to address the issues experienced by children whose parents are dying. Therefore, the study has contributed to my thinking and through this I have built on existing theory to contribute to new understanding in the death and dying literature.

The impetus for the research came from a number of sources. Firstly as a service manager for a national children's charity, I began to notice a pattern with the referrals that the service was receiving. Many of the parents who were referred described, during the support sessions, how they had experienced a significant bereavement in their childhoods. Their grief and management of these bereavements had been contained until they had become parents and then the anguish and pain had resurfaced and had caused them to question their identities, roles and relationships with the deceased. A second major event that heightened my motivation to undertake a piece of research occurred when a close friend's partner had a life threatening industrial accident. I was concerned to learn that the social work team based within the intensive care department of the hospital had no resources available to provide parents with information about talking with and supporting children when a parent was critically ill. As my interest in social aspects of death and dying began to emerge, it felt appropriate that I should combine two areas of social life that particularly interested and challenged me – children and death and dying. Before beginning the PhD, I completed a post-graduate certificate in palliative care; it was during this period that I began to clarify the area of research I wished to pursue.

The motivation for undertaking the research at doctoral level was as the result of two interrelated perspectives. Firstly from a professional point of view, I felt I had reached a junction in my career and I needed to decide which direction I wanted to steer my professional life. Through observations and the limited reading I had then completed, I recognised that there was little research concerning children living with a parent who is terminally ill. Furthermore, there appeared to be limited resources available to support these children. Correlated with this professional desire was the personal ambition to achieve at the highest academic level.

The thesis is presented in nine chapters. Chapter Two examines the literature review and Chapter Three the methodology. In Chapters Four, Five and Six, I present the analysis of the major findings. Chapter Seven is a case study, again drawing on the findings but focussing on the accounts of one young person I met on two occasions. Chapter Eight discusses the findings in relation to theory and practice implications and finally in Chapter Nine I present the concluding comments.

I present, in Chapter Two a review of the literature; this includes a synopsis of the influential theories and models of grief, death, dying and mourning. The chapter then considers literature relating specifically to children experiencing the death of a parent. Research considering the children's attachment during this period is discussed along with the current thinking about the emotional effects on children. Within the chapter, literature relevant to the pertinent issue of communication is reviewed. Communication and information sharing has emerged as the theme that all the participants returned to again and again as being one of the most important facets for this population of children. I then review the literature about social death. The notion of the children experiencing a form of social death was described in many of the interviews and highlighted a particular set of changes and challenges that the children were often required to navigate when living with a parent who was dying. The latter section of the literature review compares research relating to children's experiences of parental death with parental divorce and then the experiences of children of military personnel who are deployed to active service.

Chapter Three examines the methods I have used to collect the data and explores the advantages and disadvantages of these chosen methods. Along with this is a discussion about the process undertaken and the challenges and opportunities experienced during the research; this includes a detailed account of the analysis of the data. Within the chapter, I discuss the ethical implications of undertaking sensitive research and describe the process of gaining favourable ethical approval. The thesis contains many references to the journeys taken by children when a parent is terminally ill. Within this chapter I also present an account of the journey I as the researcher have travelled.

In Chapter Four I present the primary findings that underpin the thesis and which are tightly entwined with all the findings in subsequent chapters. The two most significant and related themes which have emerged from this study are 'information sharing' and 'communication'. Throughout the thesis I have argued that these two aspects of the social context are of imperative significance for children when they are living with a parent who is dying. The term 'information' is used here specifically to describe the knowledge that children gain about their parents' illnesses. It includes both factual knowledge about prognosis, extent, severity and stage of the illness, and emotional knowledge about feelings, fears and hopes for the future. The term 'communication' is used in this thesis specifically to describe *how* children come by this information. Within the thesis the predominant form of communication is verbal, as this was the primary way participants described how information was presented to them. However, it should be acknowledged that forms of non verbal communication also impacted on the awareness and impressions which children gained about their parents' illnesses. Information may also be acquired by children from sources such as books or the Internet. However, as I describe in Sec 8.1.4, the Internet has limitations, as a source of information, because of the range and generic nature of illnesses covered and its potential lack of relevance to the children or families accessing it.

The findings highlight how there is often a 'trickle effect' with regards to communication. The professionals involved with the family are reluctant to discuss the illness in relation to the children, this then obstructs the parents' capacity to talk with their children which in turn limits the children's capacity to articulate their emotions and fears. I begin the chapter by presenting evidence to suggest that children value being included in conversations and information sharing about their parents' illnesses. Being included helps them to understand what is happening and is important for them to begin making sense of their current lived experience. However, the second part of the chapter offers evidence suggesting that when children are not included in these conversations they are less well equipped to make sense of their parents' deaths.

Drawing on Walters (1996) argument about the importance of biographical narrative in 'coming to terms' with the death of a significant person (which he refers to as 'writing the last chapter') I argue that children who lack information during their parents' terminal illnesses may struggle to write the last chapter because they have been excluded from involvement in this 'penultimate chapter'. The term 'writing' is used here to describe all of the ways in which children 'represent' their experiences in ways which capture 'the stories of their lives'. 'Writing' therefore is used as a metaphor to encompass all attempts which children make to build a self-narrative that links their identity with their social circumstance. Some of the children described how they 'made up' stories about the situation and how these accounts of imagined events created unnecessary stress and anxiety. The use of language is therefore crucial and its level of accuracy and appropriateness directly affects the quality of the information on which children build their self-narrative. Participants described how euphemisms add to the children's uncertainty and confusion and the sometimes serious consequences when euphemistic language is adopted.

The final part of the chapter moves away from the perspective of the children to consider how the practice of professionals can support or hinder these information exchanges. Professionals interviewed for the research described how they had observed colleagues actively avoiding engaging in conversations with children because of personal anxieties about making the situation worse or not knowing what to say. Underpinning this chapter is the work of Glaser and Strauss (1980) and their presentation of the different awareness contexts they observed. From this theoretical position and from my analysis of the data I suggest that the children's acquisition of information may be identified within a 'communication continuum' ranging from a closed to an open awareness of what is happening to their families (Appendix 2). One of the main arguments in this thesis is that the quality and quantity of information provided and the communication style adopted by adults imparting the information has a significant impact on where children are placed on the communication continuum and how, from this position, they begin to make meaning from their current situation. Furthermore, their positioning on the continuum reflects their ability to 'write a meaningful penultimate chapter' and subsequently the 'last chapter'. Hence the continuum represents a conceptual model illustrating the range and diversity of potential situations children may encounter, depending on the information they receive.

Chapter Five focuses on how children *manage* their passage through their parents' terminal illnesses. The findings outline ways in which children manage or fail to manage the changes in their lives that they encounter during the illness and death of a parent. In this chapter, I draw on the work of Van Gennep (1977) with particular reference to his writings about rites of passage and liminality. I suggest that children frequently move into what I term an 'alien landscape' when living with parents who are in the terminal stages of their illnesses. I use the metaphor of an alien landscape to try and capture the impression gained from this research that many children feel a sense of disorientation arising from the loss of much that was previously known and familiar.

The children's view of their world takes on new and difficult meanings and any control or autonomy they felt they previously enjoyed is frequently lost or diluted. Family routines are interrupted and the ill parent's illness and treatment become the nucleus of family life. Furthermore, some of the different cultures that make up the children's world can be affected and become increasingly uncomfortable and contradictory. The culture of the family is often the primary example of a location where these children feel that they are living in an unpredictable and unfamiliar place. Patterns of communication frequently alter along with the parent's established parenting style. These changes contribute to the children feeling that their known worlds are becoming disrupted and different. Once the familiar boundaries and routines are lost the children's sense of who they are and what their family represents are questioned and as a consequence has the potential to turn what was once familiar and safe into an increasingly frightening and alien landscape.

The culture of school is a further example. The metaphor here helps capture the feelings of difference and isolation from friends and from school routines which children of very ill parents may experience. Common ground is lost as their preoccupation with changes at home eclipse the demands of education. This may not be the case for all children, as school and its routines may provide a welcome refuge from the insecurity of home life, but for many, dread of the future and others' lack of empathy for their predicament may turn the school setting into a strange and irrelevant place to be. Close enduring friendships may be crucial in offering support, but where these are not yet formed, do not exist, or where they fail to adapt to the child's changed needs and circumstances, school relationships may only be a further symptom of an alien landscape where common identifying markers are lost and distance begins to develop between children whose parents are terminally ill and children whose parents are healthy. I argue throughout the thesis, that the extent to which this 'alien landscape' intrudes upon children's normal functioning is largely determined by the amount of communication that they are privy to, along with the availability of support from people who understand, can empathise and act as guides through the unknown terrain.

I describe the different strategies that the participants discussed for managing these changes, recognising that these may produce both positive and negative behaviours. Balancing home life and school life was seen to present many children with challenges and was often an issue for them in trying to manage the situation. I then present findings that highlight how for many children the only conduit for expressing how they are feeling is through inappropriate behaviour. Some behaviours that were described were risky and placed the children in a position of potential harm and danger. Whilst I acknowledge that some of these behaviours are not unusual in children and young people generally, the participants all noted that these difficult behaviours had not been manifested prior to illness entering the family. The final part of the chapter moves away from the pre-bereavement period to consider how children cope following their parents' deaths. The accounts of the children and professionals highlighted that how children manage their experience is not subject to any specific timescales. The process of trying to cope with and negotiate the journey of their parent's deaths, and the alien territory that they find themselves in, is a continuous ongoing event that often needs re-visiting at different times in the children's lives. At the end of the chapter, I include a quote from my reflective journal and from this suggest that the bereaved become members of an 'exclusive club' where non-members are not able to totally understand the cognitions and emotions of the bereaved.

Through the process of trying to manage the situation of living with a parent who is terminally ill and beginning to make some sense of the life changing events that are unfolding in their lives, the participants described some of the emotions experienced. I use the term 'emotions' as an umbrella term to broadly describe the different feelings experienced, including those of sadness, dread, despair and fear. I also recognise that reactions to events not directly related to the parent's illness, such as anger, rudeness, lethargy, disinterest and detachment may also be a part of the strategies some children use to 'manage' their changed circumstances. Howe (2008) writing about negative emotions suggests that 'the emotion leads to some kind of action the purpose of which is to reduce the negative feeling and get us into a different place, either physically, psychologically or socially' (p. 27). This is relevant in developing an understanding of the behaviours exhibited by children as conduits for their emotions which are discussed in detail in this chapter.

Chapter Six presents the final key theme to emerge from the research. This chapter considers the transitions, changes and challenges faced by children whose parents are at the end of life. I begin the chapter by suggesting that childhood is typically marked by a progression of changes, however, when a parent is at the end of life, the children are likely to experience many changes and challenges that are unique and specific to their current circumstances. The move from living with a parent who is healthy to living with a parent who is dying is one of the most traumatic of these. Within this huge upheaval are many secondary changes including adjustments to family routine, especially as the illness becomes the nucleus of the family and all family life begins to revolve around the illness. The participants spoke about how these changes can affect the children's identities and make them question who they are and their position within the family. The construction - or deconstruction - of identity is discussed particularly in relation to young people who often struggle when the added challenges of living with a terminally ill parent compound the typical identity issues seen amongst teenagers. I then present evidence that highlights how the medical care of the parent can create changes and challenges for the children. The accounts of the participants suggested that these challenges were evident whether the parent was being nursed in a hospital, hospice or at home.

A significant change centres around the social activities in which the children participated prior to their parents becoming terminally ill. In this section, I introduce the notion of a 'social death' for children and compare my use of this concept with the work of Lawton (2000). Lawton focuses on the social death of hospice patients as they become socially isolated from family and friends. She argues that the relationship between social networks and social interactions are central to the maintenance of the self and she describes how terminally ill patients often 'become fully dislodged' (Lawton 2000, p.153) from interpersonal relationships. The concept of social death developed in relation to a parents' terminal illness similarly recognises how children's 'normal' identities may become 'dislodged' from the social life they had known prior to their parents becoming terminally ill. Social activities are, typically, conduits for children to begin developing some autonomy and independence from their home environment and are crucial in the socialisation process. I argue within the thesis that when a parent becomes terminally ill, the demands on family life are such that social activities inevitably and understandably become a low priority within the family. Opportunities to engage in social activities can be curtailed because of the competing demands of caring for the ill parent and maintaining family routines. This interruption to the children's social world may be temporary, in comparison with the patients in

Lawton's study, but can have a significant impact on their present lived experience and can contribute negatively to the 'writing of their penultimate chapter'. The loss of social markers that contribute to the children's identity may influence the narratives they develop about the experience of parental terminal illness and the meaning their life takes on during this period. Therefore, the social death I write about represents a dislocation and marginalisation for the children from their social worlds. Furthermore, by incorporating the metaphor of the alien landscape in this social death, it is possible to conceptualise how children detach from familiar experiences and enter into a place that is unfamiliar and full of uncertainty.

The inability to participate in previously taken-for-granted activities is a further marker that suggests to the children that they are different from their peers. The issue of difference and not fitting in is discussed throughout the thesis and I suggest that this is significant in relation to how the children perceive themselves and their relationships with others. Moreover, the feelings of difference, whether real or imaginary, can contribute substantially to their narratives of parental terminal illness and the meaning making process they attach to this period. The final section of this chapter again moves from the pre-bereavement period to the time following the parents' deaths. I describe some of the changes that occur, including issues of residency and the potential upheaval that can be caused after a parent dies, especially if the family has to move home.

Chapter Seven is a case study that, through the experiences of one young person, brings together the key findings that have been presented in the preceding chapters. Neimeyer and Hogan (2007) propose that '...the case study is a time-honored [sic] "N of 1" investigation of the unique features of a single individual or event' (p. 109). The accounts of the young person who is the subject in the case study, are unique to her, however, they also have many similarities with the experiences of the other participants. 'Jennifer' was a young girl when her mother was diagnosed with Multiple Sclerosis (MS). Jennifer and her older sister were the main carers for their mother until her death some twelve years after diagnosis. The underlying theme throughout Jennifer's narratives was the exclusion she experienced during her mothers illness. Jennifer described how she was placed at the closed awareness end of the communication continuum both by the professionals involved in her mother's care and by friends of the family. Jennifer's story vividly tells the effect this lack of information had on her ability to 'write a meaningful penultimate chapter' and all subsequent chapters. I present Jennifer's story in a chronological order from when she was a young carer to the period following her mothers death and the intervening years.

Within the Discussion Chapter, I bring together the key findings and present them within a theoretical framework. I begin this chapter by discussing in detail the implications of the findings. I explore the importance and relevance of communication and information sharing, and consider how positioning on the communication continuum is so important for children in their attempts to manage the family crisis they are experiencing. I discuss the role others have in supporting the children and how my research has evidenced that people who can empathise and travel a similar journey are generally the most effective in offering appropriate support. Findings from the research would suggest that the parents are the most appropriate people to initiate conversations with children about the situation. However, the evidence also reveals that often they are too emotionally bound to comprehend their role, or alternatively try to protect their children by not discussing what is happening. I then discuss Walter's (1996) contribution to the literature and his promotion of a 'biographical model' of grief. The significance of bereaved people 'writing the last chapter' was an influential part of Walter's new model of grief, but it did not encompass the circumstances of terminal illness or explore the possibility that 'the last chapter' is preceded by the 'penultimate chapter' that is being 'written' during the terminal stage of the illness. I propose that the 'writing of the penultimate chapter', by the children, is heavily influenced by the quality and quantity of information that the children receive about their parents' illnesses. As the illness progresses it is likely that many draft editions of the chapter are written and the plot alters as the illness trajectory moves closer to the death. The Discussion Chapter concludes with me arguing that the professionals involved in the families' care have a pivotal role in helping the development of the 'penultimate chapter'.

The Conclusion draws together the findings and discussion chapters. I begin by summarising the main findings from the research and commenting on the relevance of these for all children living with a parent who is dying. The chapter then moves to a more personal focus as I write about the learning journey I have been on during this doctoral study. I reflect on perhaps the most significant part of the journey that has been the transition for me from practitioner to researcher, and identify the limits to my claims and conclusions. I end the chapter with five recommendations based on the findings. Included in these are recommendations for the children, their parents, and professionals who, in the course of their work come into contact with children and families.

The initial aim of the research, to include children as the primary participants, did not happen because of the barriers that have been briefly discussed above. However, I have been very fortunate to meet with a small number of children who have greatly influenced the thesis. For the purpose of the research I have adopted the Children Act 1989 definition of children and therefore have included all children, bereaved of a parent, up to their eighteenth birthday. Therefore, for brevity within the text I will write generically about children (rather than using the phrase children and young people) unless I am specifically describing adolescents' and older children's experiences of living with a parent who is dying. In these instances I will refer to them as 'young people'.

Throughout the thesis, I refer to 'the family' and 'families', however, within these generic terms, I recognise and acknowledge the diversity of family composition. Similarly, I write about 'parents', however, this also includes, for the purpose of this research, carers who have had a significant role in caring for the children.

In line with ethical considerations and issues of confidentiality the names of all participants have been altered to protect their identity. Furthermore, no site specific information has been provided in order to conceal locations, institutions and services.

CHAPTER TWO: LITERATURE REVIEW

There is a plethora of literature now available reflecting the continuing and developing sociological interest in death and dying. The literature review for this thesis is underpinned by work pertaining to children and specifically children when a parent is at the end of life. However, in recognition that many theorists argue that bereavement is a 'trajectory' or 'continuum', literature relating to post bereavement issues has also been considered.

The literature review begins by providing an overview of the influential theories and models of bereavement that have been postulated during the last century. The early research and writings into bereavement focussed almost exclusively on the adult perspective and thus within the original theories children's experiences, if considered at all, were amalgamated into the overarching adult theories. This review traces the development in thinking from traditional theories and models that for many years dominated the bereavement literature to more recent theories that have started to emerge during the last few years. Where appropriate the theories and models have been discussed in relation to children and their experiences of death and dying. Following these discussions attention is given to attachment theory and specifically the work of Bowlby. This introduction provides the framework for a more detailed analysis of attachment theory in relation to children's experiences when a parent is terminally ill.

The review of the literature then moves from the overarching theories to more specific issues pertaining to children living with a parent who is dying. Attention is given to the emotional effects for children identified by research along with significant issues such as parenting capacity and communication.

To conclude this review of the literature I consider research pertaining to divorce and the effects on children experiencing parental divorce. This is followed by an exploration of children's experiences when military parents are deployed to active service. These comparisons are used to consider some of the similarities and differences experienced by children when a parent is either dying or separating or when the separation is as a result of military action.

2.1 THEORIES AND MODELS OF BEREAVEMENT

2.1.1 'Traditional' theories of grief

The focus of this first section of the literature review considers theories and models of death and dying. An important consideration requiring acknowledgment is the question regarding the appropriateness of these theories in relation to the children being studied for this current research. Bereavement research and subsequent theories and models pertaining to bereavement have generally focused on adults' reactions and behaviour. As Dent (2005) acknowledges, whilst research into adult bereavement now has some longevity, it is only in recent years that the needs of bereaved children have come into the professional and public domain. Furthermore, Holland (2001) cautions that extending adult models of grief to children is problematic when the assumption is made that children's experiences of bereavement will be similar to adults.

Freud presented in his 1917 seminal book *On Murder, Mourning and Melancholia* a detailed description of death, dying and bereavement. He suggested that:

> This cultural and conventional attitude towards death is now complemented by our complete collapse when death comes to someone close to us, a parent, or spouse, a sibling, child or dear friend. We bury our hopes, our demands, our pleasures with that person, we are inconsolable and refuse to replace them (Freud 2005, p.184).

Freud goes on to write about the process of mourning and how it is not enduring and will, in his view come to an end, allowing the bereaved to move on to new relationships:

> We know that mourning, however painful it may be, comes to an end of its own accord. Once it has renounced everything that is lost, it has also consumed itself, and then our libido becomes free once again, so that as long as we are still young and active, it is able to replace the lost object with objects, that are, where possible, equally precious, or with still more precious new ones (ibid p. 199).

Freud suggests that there are marked differences between 'normal' mourning and 'unhealthy' melancholia. He acknowledges that mourning creates 'severe deviations from normal behaviour' (2005, p. 204) but also claims that it will be overcome after a certain period of time and furthermore, that interfering with it would be pointless or even damaging. Conversely, Freud describes melancholia as 'a profoundly painful depression' (p. 204). Critiquing Freud's work, Hedtke and Winslade (2004) describe how grief is seen by Freud as a temporary abnormality like an illness and that the way through the illness is to detach from the deceased. People who remember the deceased are labelled as being pathological, a trait that 'is hardly encouraged' (Hedtke and Winslade 2004, p. 22).

Freud's work formed the foundations of the subsequent theories and models of grief that became the dominant thinking, along with informing the practice within which bereavement counselling emerged. As Silverman and Klass (1996) describe, Freud's work 'generated a world view for those who followed him' (p. 6). In recent years, this dominant thinking has been challenged and the more recent arguments and propositions will be discussed below.

Bowlby was an influential theorist whose initial observations were based on children's behaviour when separated from a primary attachment figure. However, his contribution to the research and theories of bereavement was not solely concerned with children. Bowlby collaborated with Parkes to develop a phase model of grief that was a generic model for adults and children (Payne et al. 2000).

Bowlby worked closely with Parkes who was interested in developing an understanding of the problems experienced by the bereaved and why these problems necessitated them in seeking psychiatric help. Parkes (1996) discusses the psychosocial transitions that occur for the bereaved. 'When somebody dies, a whole set of assumptions about the world that relied upon the other person for their validity are suddenly invalidated' (p. 90). Through this he suggests that the person's view of the world must change as the loss threatens their inner assumptions about the world. As a consequence, the bereaved need to develop a new identity. Parkes' contribution to bereavement literature includes his four phase model:

- Numbing
- Pining
- Disorganisation
- Despair and recovery

Within the model, Parkes suggests that each phase has different characteristics and that people will experience each phase differently both in terms of duration and form. Furthermore, he suggests that the phases are not static and that people can move between them even years after the bereavement. This is echoed by Raphael (1994) who also purports that the bereaved work through a number of phases, and cautions that they are not fixed and that the bereaved can pass backwards and forwards amongst them.

Another influential theorist was Kubler-Ross. This research, although generally acknowledged today as a bereavement model, was initially used to describe the grief of terminally ill patients. Kubler-Ross and colleagues interviewed over 200 terminally ill patients and from their stories the five stage model of grief was developed. These stages are defined as:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Kubler-Ross (2001) suggested that 'these will last for different periods of time and will replace each other or exist at times side by side' (p. 122). In critiquing the theory, Payne et al. (2000) suggest that the model may be criticised for being too simplistic, however, they argue that the findings from the research played a significant role in challenging the then practice of 'protecting people by surrounding them with conspiracies of silence' (p. 73). It is interesting to consider this in the context of my research that would suggest that in respect to children who are living with parents who are dying there remains an overwhelming conspiracy of silence.

In contrast to the stage or phase models of grief, Worden (1995) argued that following a bereavement, people must, to re-establish their equilibrium, work through tasks of mourning. The bereaved, according to Worden need to accept the death both intellectually and emotionally. As Payne et al. (2000) describe, 'Worden's model places more emphasis on the cognitive, social and behavioural aspects of grief than earlier phase models' (p. 74). Worden's four tasks of mourning are to:

- accept the reality of the loss
- work through the pain of grief
- adjust to the environment without the deceased
- emotionally relocate the deceased and move on with life

It would thus appear that Worden's tasks have similarities with the earlier stage models insofar as the proposed outcome is that the bereaved should be encouraged to move on and separate themselves from the deceased. Melvin and Lukeman (2000) writing about the traditional theories and models suggest that:

> ...while each of these models provides helpful ideas for understanding reactions to grief, they can lead to a rather prescriptive approach to the provision of help. The sense that there is a right way of doing it for everyone can lead to feelings of failure or regret if some tasks were not possible or not achieved (p. 526).

It has been suggested that in relation to children's mourning, Worden's tasks present 'additional difficulties and risks for children in comparison with adults' (Young and Papadatou 2003, p. 198). The authors suggest that children's development and immature understanding of death and dying are key factors compounding the difficulties. However, in addition they argue that this lack of understanding is exacerbated by a dearth of accurate and age appropriate information from adults. This has resonance with the current research and is a perspective that is the cornerstone of the findings of this thesis.

2.1.2 Attachment theory: the significance for bereavement theories

The seminal work of Bowlby is generally recognised as providing the early theoretical proposition of the nature and development of human attachment relationships. Stroebe and Schut (1999) suggest that 'it is probably true to say that the most impactful in the field of bereavement today is Bowlby's attachment theory' (p. 198). However, in the intervening years Bowlby's theories have been both developed and criticised (Smith and Cowie 1991, Howe 1995). Attachment theory is incorporated into psychological and sociological teaching and underpins many assumptions about child parent relationships. Furthermore, the significance of the theory is recognised in relation to children's emotional development (Aldgate and Jones 2006). The theory is rooted within the psychoanalytic school of thought.

Bowlby (1991) argued that children develop internal working models that enable them to make predictions about the availability of assistance from protective figures when needed. This was based on the notion that attachment behaviours are a biological response to harm which involve the individual to seek security from an attachment figure (Aldgate and Jones 2006). Bowlby's (1980) clinical observations led him to incorporate into the theory of attachment an influential role for the processes of separation and loss. Bowlby observed the behaviour of young children when separated from their primary caregiver, which in Bowlby's research was normally the mother. It was from these observations that Bowlby developed the theory of separation and loss that was influential for both theory and practice throughout the latter part of the twentieth century. Bowlby (1973) suggested that people experience separation anxiety and grief whenever a close relationship is lost. Furthermore, as Holmes (1993) observes, the grief reaction was a special case of separation anxiety because bereavement is an irreversible form of separation. Bowlby (1973) suggested that there were observable differences in the attachment behaviours of children whose parents had divorced and children whose parents had died. He noted that children whose parents were divorcing tended to display anger and hostility whilst children experiencing the death of a parent were more likely to exhibit sadness and despair. The sadness and despair were as a result of the child recognising that the attachment figure was no longer available (Bowlby 1980). However, Bowlby also argued 'that depression did not have to be the inevitable outcome of a childhood bereavement experience' (Hurd 1999, p. 19). Hurd suggests that Bowlby's theory delineated that children had the capacity to mourn the death in either a healthy or unhealthy manner. This was dependent on the quality of environmental factors within the family construct, including the parent child relationship, the emotional and psychological support the children receive following the death and communication within the family.

More recently Bowlby's theory has been re-evaluated. This is particularly evident in the more contemporary theories of grief that started to emerge in the latter part of the twentieth century. Bowlby proposed that when experiencing separation from the primary carer, children would move through four phases of mourning. Holmes (1993) suggests that the early phases, (i) numbing and (ii) yearning, searching and anger, consisted of an intense form of separation anxiety. The final two phases (iii) disorganisation and despair and (iv) reorganisation, resulted from the:

> confusion and misery that arise from the realisation that the secure base to whom the bereaved individual would turn for comfort in distress is the very person who is no longer available (p. 90).

The final phase exemplifies the traditional theories of grief where the aim is for the bereaved to work through their grief in order to 'let go' of the deceased. Silverman and Klass (1996) emphasise how Bowlby's model perpetuated the idea that the purpose of grief is to sever the bond with the dead. More recent theories and models of grief, particularly those presented by Silverman and Klass (1996) have critiqued the earlier ideology of working through the mourning period to achieve a severance of the relationship.

2.2 MORE RECENT THEORIES – MOVING AWAY FROM THE MEDICAL MODEL

2.2.1 Continuing the bonds and maintaining a relationship with the deceased

In recent years there has been an intellectual shift and movement away from the notion of letting go and separating oneself from the deceased. It is generally agreed by contemporary writers that the dominant clinical ideology of the twentieth century was that the bereaved were encouraged to detach from the deceased and move on into new relationships (Silverman and Klass 1996, Walter 1999, Riches and Dawson 2000, Hedtke and Winslade 2004, Stroebe et al. 2005). However, recently, new theories have started to emerge which question the dominant thinking and offer a different perspective.

Whilst the traditional theories have tended to originate from a medical perspective, the later theories generally provide a wider scope incorporating social and cultural perspectives (Thompson 2002) as well as psychological and emotional narratives.

The notion of the bereaved maintaining a relationship with the deceased is discussed by Silverman and Klass (1996). The authors question the dominant idea of the bereaved severing their bond with the deceased and offer an alternative model whereby the mourner has a continuing bond with the deceased. Furthermore, and in opposition to the dominant thinking it is suggested 'that these continuing bonds can be a healthy part of a survivor's ongoing life' (p. 22).

Silverman and Klass (1996) suggest that within the dominant ideology 'maintaining an ongoing attachment to the deceased was considered symptomatic of pathology' (p. 5). The bereaved were encouraged to work through their grief in order to relinquish their relationship with them and thus move on. The Continuing Bonds model suggests that the bereaved move through a process of adaptation and change after the death, and through this, construct and reconstruct new connections with the deceased. It is suggested that 'people are changed by the experience [of being bereaved], they do not get over it, and part of the change is a transformed but continuing relationship with the deceased' (Silverman and Klass 1996, p. 19). In acknowledgment of the shift in thinking that has recently been evident, children's relationships with deceased parents have also been discussed (Silverman and Nickman 1996, Normand et al. 1996, Christ 2000, Schultz 2007).

The in-depth study by Christ (2000) highlights poignantly that children want in some form to maintain a relationship with their deceased parent. This desire was manifested in different ways depending on their age but nevertheless demonstrates how the notion of continuing bonds is equally pertinent for children as it is for adults.

Silverman and Nickman (1996) analysed how children spoke about deceased people they had been close to. From these conversations it was evident that the children were maintaining an ongoing relationship with their dead parent. Moreover, it has been suggested that the Dual Process Model is an equally suitable model for children as it is for adults (Dent 2005).

2.2.2 The Dual Process Model

The Dual Process Model (Stroebe and Schut 1999) was developed from the belief that the existing models about coping with bereavement were inadequate in their explanations. The model suggests that there are two aspects involved in adapting to bereavement, a dialectic or 'blended grief' (Cox 2005) consisting of both a loss orientation and a restoration orientation. The loss orientation is a mental state or mind set in which the bereaved need to express emotions and actively mourn. 'Loss-orientation refers to the concentration on, and dealing with, processing of some aspects of the loss experience itself, most particularly, with respect to the deceased person' (Stroebe and Schut 1999, p. 212). The restoration- orientation includes taking on and mastering the tasks previously undertaken by the deceased, coping with everyday life and building a new identity. Stroebe et al. (2005) stress that the restoration-orientation should be seen as part of the coping process as it involves dealing with all the changes that have occurred because of the loss. Stroebe and Schut (1999) suggest that their model is different, in part, from the dominant theories because 'it is not a phasal model, we do not propose a sequence of stages, but rather a waxing and waning, an ongoing flexibility over time' (p. 212). Furthermore, they propose that whilst the model was originally developed to understand coping with the death of a partner, it has the potential to be applied to other bereavements. In Chapter Five, I will be drawing on Stroebe and Schut's Dual Process Model when presenting data about how, particularly young people, oscillate when trying to cope with living with a parent who is dying.

2.2.3 Walter's biographical model

Developing the idea of continuing bonds, Walter (1999) explores further the notion of maintaining a relationship with the deceased. His biographical model delineates in detail the social context of death, dying and bereavement in the contemporary west. He describes how 'both the dead and the bereaved must somehow find a place in, and be integrated into, society' (p. 19). This is an important consideration when adopting the idea that children's understanding of death is socially constructed and that their interpretation of how to behave and how to grieve is learnt in part through observing the adults around them. Furthermore, Walter (1999) suggests that the people who are supporting them but who are not intimately involved, are primarily concerned with the bereaved returning to emotional stability irrespective of whether this involves remembering or forgetting. This is a pertinent observation in relation to my research, which has highlighted how professionals involved with supporting the bereaved regularly struggle to work with the children. It would appear that for the majority of workers their desire is at best for the children to return to a state of status quo or more typically for their needs to not be acknowledged. (Fearnley 2010).

The notion of professionals not acknowledging the needs of children experiencing the death of a parent has resonance with disenfranchised grief. Disenfranchised grief is a concept developed by Doka (1989) and is grief that is not perceived by others to be socially accepted and therefore is not openly acknowledged or supported. Rowling (2003), writing specifically about school communities, suggests that grief can be hidden within this community because 'it is unrecognized [sic], unaccepted, or there is stigma attached' (p. 152). This again has resonance with the current research particularly in relation to the findings that evidenced that children experiencing the death of a parent are frequently 'invisible' and not acknowledged as potentially children in need as defined by the Children Act 1989.

Walter (1996, 1999) suggests that an important element following a death is for the bereaved to be able to talk to others about the deceased, and through this to develop a 'durable biography'. This durable biography allows the bereaved to learn more about the deceased but also about themselves. He suggests that the process by which this is achieved is through conversations and discussions with others who knew the deceased. Walter (1996) describes in detail the death of a close friend and his role in planning her funeral and memorial service. Through this process he had many conversations with the family and friends of his friend and suggests that 'through these conversations I began to find a stable place for her in my life' (p. 13). Walter has described this process as 'writing the last chapter' (1996). He suggests that 'the last chapter is written after the death by the survivors as they too go over the life lived and, separately or together, make sense of it' (1996, p. 14). The last chapter can be either shared in the public domain through an obituary or at the funeral or remain an informal process between family and friends. The role of the social discussions which follow the death are necessary according to Walter as they allow the deceased's life story to be agreed and ratified, but also importantly the discussions help to maintain a relationship with them and thus has a role in the continuing of bonds.

Walter (1999) discusses how children need to be included in the 'writing' of the last chapter. The work of the charity Winston's Wish is described with particular reference to the 'Camp Winston' which is for bereaved children. During the camp, the children write questions to a medical doctor and as Walter suggests 'they get the doctor to tell them the last chapter' (p. 86). The work of Winston's Wish, with particular reference to the questions posed by children to the doctor, is explored in Thompson and Payne (2000). The research identified five topics of questions presented to the doctor, these were: cause of death, lifespan, doctors, dead body and grieving feelings. The authors suggest that 'by demonstrating that the majority of the questions to the doctor were seeking reasons and cause for the death, this study confirms young persons' desires to increase their understanding' (p. 92). This provides further evidence that children need to be involved in the last chapter. However, Walter (1999) warns that the last chapter is sometimes too painful and people may prefer to erase it but cannot. This could be especially true for children if they are not provided with appropriate information or included appropriately in their parents' illnesses and deaths.

The notion of the 'writing of the last chapter' is significant for this thesis because this has been developed within the research and underpins one of the core theoretical developments of the findings.

The biographical model has been critically analysed for not being empirically tested (Payne et al. 2000) and because of the implications made in relation to the role of bereavement counselling (Arnanson 2000, Payne et al. 2000). However, one school of thought within counselling advocates this ongoing relationship and will be explored in detail below.

2.2.4 The narrative approach and continuing bonds

The narrative approach in therapy has developed both the notion of continuing a relationship with the deceased and maintaining conversations about them. As Field (2006) highlights, practitioners as well as theorists have accepted that an ongoing relationship with the deceased is normative. Narrative therapy is a developing genre in counselling which focuses not on giving advice or solutions but where the 'clients' become 'the primary authors of their lives' (Morgan 2002, p. 86).

Within the literature of narrative therapy, there is a growing discussion about support for people who are either facing death themselves, or are the friends and family of people at the end of life (White 1989, Waldergrave 1999, Vickio 1999, Hedtke 2000, Hedtke 2001, Hedtke 2002). A significant underlying tenet of narrative therapy is that 'personhood continues to live on long after the body dies' (Hedtke and Winslade 2004, p. 8).

A common theme running through all the narrative therapy literature is the notion of encouraging the bereaved to maintain an ongoing relationship with the deceased, to remember them and to talk about them. Hedtke and Winslade (2004) suggest that:

> Encouraging people to speak about past events is like harvesting the fruits of a lifetime. These fruits can provide sustenance during the transition into a future in which the deceased is accorded an important place of membership (p. 52).

This approach has resonance with the later models that have been characterised as giving the bereaved 'permission' to maintain a relationship with the deceased. Furthermore, by allowing the bereaved to be the primary author it recognises individual difference, thus providing a form of support that can be extended for adults and children alike.

A number of grief theories, models and practical applications have been outlined here. These have provided a historical overview of the development of critical thinking in relation to the understanding of how people typically 'manage' death, dying and bereavement and some of the influential thinking relating to the area. Within this overview, issues pertaining to children have been discussed. The focus will now move to published research about the practical realities for children when living with a parent who is dying.

2.3 LIVING WITH A PARENT WHO IS DYING: RESEARCH, DEBATE AND DIALOGUE

2.3.1 Communication and information sharing

Communicating and sharing information with children is widely acknowledged as an important factor in supporting children when a parent is terminally ill or has died

(Waskett 1995, Christ 2000, Rauch et al. 2002, Christ and Christ 2006). However, Huizinga et al. (2005) conclude that 'little is known about the effect of a stressful event such as cancer on communication patterns in families' (p. 1957). Anxiety is heightened, according to Beale et al. (2004), when the children are not provided with adequate information about their parents' illnesses. This is supported by Christ's (2000) research where nine to eleven year old children reported that regular medical updates about their parents' illnesses were helpful. Furthermore, Christ and Christ (2006) report that children stated that they valued open communication with both parents about the illness. The value of having information and being party to conversations with parents about their illness was also evidenced in research by Thastum et al. (2008). The findings from this research showed that 'all the children knew the name of their parent's illness: with few exceptions they had been informed by their parents shortly after diagnosis' (ibid p.129).

Anxiety in children is increased when information is available but no opportunities are provided to allow them to discuss the information (Beale et al. 2004). Providing clear, honest information prevents misunderstandings, which may lead to frightening fantasies and fears (Saldinger et al. 2004, Turner et al. 2007). This notion is supported by Siegel et al. (1990) who suggest that:

> The extent to which children can successfully resolve their feelings and grieve appropriately largely depends on correction of their distorted fantasies, and this can best be achieved through open parent-child communication (p. 171).

Furthermore, Siegel et al. (ibid) argue that failure to provide honest information about the illness can affect the children's trust in the surviving parent. Moreover, Lewandowski (1996), writing about children living with a parent with cancer, observes that:

> Many families in which a parent has cancer seem to function under an implicit "don't ask, don't tell" communication system. In these cases the children and adolescents are unlikely to be asked directly about their thoughts, worries, and feelings and are unlikely to feel free to volunteer this information (p. 4).

Rando's (2000b) discussion about information sharing is not exclusive to children and includes any adult who is in a close relationship with the dying person. However, the following quote whilst being non-specific to children has resonance with other literature and the findings from my research:

> A lack of information about what is happening to the loved one and what they can do to help often prompts intimates to feel resentment, frustration, and infantilization, as well as a sense of being out of control and unprepared (p. 348).

In the same chapter, Rando also suggests:

> Offering information minimizes the uncertainty and fear of the unknown with which the intimate must contend. It legitimizes and normalizes feelings, thoughts, and impulses that heretofore may have been unacceptable – and therefore conducive to anxiety and the assorted mechanisms mobilized to handle it (p. 342).

MacPherson (2005) describes one of the difficulties associated with providing children with information:

> There can be little doubt that the task of telling a child that their parent is dying is heart wrenchingly difficult for the dying parent, the well parent and the health care professionals involved in their care (p. 113).

This is in concordance with Beale et al. (2004) who observe that:

> It is not surprising that parents dying of cancer, who are coming to terms with the existential issues surrounding dying, are often at a loss as to when, how and what to tell their children about cancer and death (p. 388).

The importance and value of age-appropriate, open, honest communication with children is discussed in Rauch et al. (2002). However, research would suggest that younger children are less likely to receive the same amount of information as older children (Christ and Christ 2006). This is highlighted by Raphael (1994) who describes how younger children are often 'actively excluded from knowledge of a parent's or sibling's fatal illness, in the mistaken belief that this will protect them from the pain' (p. 87). Moreover, Melvin and Lukeman (2000) evidence how even very young children will have enhanced coping skills if they are provided with clear and honest information about their parents' illnesses. Research undertaken by MacPherson (2005) found that not sharing information and communicating with the children was directly related to the parent's ability to talk together about the illness. It was found that the dying parent influenced the decision about whether the children were informed about the prognosis and the well parent followed their example. Beale et al. (2004) suggest that a reason why parents do not share information with their children is because of their belief that the children are not aware of what is happening within the family. However, according to Christ and Christ (2006), children as young as three have a limited understanding that something is wrong even if they do not have the cognitive ability to conceptualise the permanence of death.

Turner et al. (2005) describe how parents often experience uncertainty about how to discuss their illness with their children. The parents in the research stated that they did not receive any support or guidance from professionals involved in their care about communicating with their children. Furthermore, the respondents in a later study stated that the health professionals did not engage in any discussions about the impact of the cancer on their children (Turner et al. 2007). This is congruent with findings from Elmberger et al. (2005). In their study mothers with cancer reported that professionals did not explore their concerns about their children and furthermore, no support was offered. However, Baile and Beale (2001) discuss giving bad news to cancer patients and present their argument using the case study of a mother with cancer who has a three year old child. The authors conclude that:

> [I]t would be beyond the abilities of most oncologists to know what to do about Mrs E's children. But identifying the problem and helping guide the patient to support, such as a counselor (sic) or social worker, is part of the role of the doctor (p.2577).

MacPherson (2005) argues that it is crucial that palliative care services offer specialised advice and support to couples in order to help them talk to their children about the illness and prognosis. Lewis (1990) suggests that in order for patients and families to manage the illness they need to be provided with medically related information. This is supported by Christ and Christ (2006) who advocate that:

> When death is imminent, physicians and other health professionals can help prepare parents by providing specific concrete information and

> practical advice to facilitate coping and meeting children's needs at this very stressful time in the family's life (p. 199).

Ribbens McCarthy (2007) suggests that the lack of communication within families could highlight the position of young people in relation to power dynamics within the family, but that it could also evidence the young person's belief that not talking about the death is a form of protecting other family members. The data from my research would suggest that young people will, on occasions, actively choose not to talk about the situation as a way of shielding other family members.

Underpinning many of the recent debates about communication and information sharing is the sociological theory proposed by Glaser and Strauss (1980). Their research suggests that within interactions between medical staff and patients there are four awareness contexts. These contexts range from a closed awareness, where the patient is not aware of their impending death despite the nursing staff being aware of it, through to an open awareness context where all involved know and acknowledge that the patient is dying. Glaser and Strauss (1980) write that:

> The impact of each type of awareness upon the interplay between the patients and personnel is profound, for people guide their talk and actions according to who knows what with what certainty (p. 11).

The awareness contexts described by Glaser and Strauss were based on their observations of hospital personnel, patients and the patients' families, however, within the thesis I have incorporated their ideas into the experiences of children.

The language employed when talking with children is also an important consideration, especially the use of euphemisms, which could contribute to their misunderstanding of information (Waskett 1995). The detrimental effect of the use of euphemisms is highlighted by Raphael (1994) who discusses how children found the term 'gone to Heaven' very difficult to comprehend. Rauch et al. (2002) also discuss the use of euphemisms and suggest that this practice can lead to confusion and anxiety for the children. The use of appropriate or inappropriate language can have a significant bearing on how the children make sense of what is happening, this is expounded in Chapter Five. Dunning (2006) explores this when she writes:

> When one really understands children's misconceptions and especially their belief that the disease has come because of something they did or did not do, it is easy to see the role guilt plays in the acting out (p. 504).

Furthermore, as Christ (2000) suggests, open communication and information sharing between the surviving parent and child following the death is associated with better psychological outcomes for the children. However, problems associated with parents sharing this information in the post bereavement period are explored in Rolls and Payne (2007). These difficulties include knowing how to inform the children of the death and the timing of this information sharing.

Riches and Dawson (2000) offer an alternative perspective relating to the use of euphemisms. They suggest that by employing such language the dead are 'removed' from normal life and therefore 'the living can continue with their lives' (p.71). This use of language can, therefore, have the effect of compromising the children's cognitive understanding of what is happening and thus contribute to their feelings of isolation, confusion and distress.

2.3.2 The emotional conflict for children

The challenges experienced by families when a parent is terminally ill are wide ranging including organisational, financial and emotional. However, as Saldinger et al. (1994) have suggested, the emotional challenges are particularly relevant when there are young children in the family. For the children experiencing the death of a parent the emotional conflict is multi-faceted, especially as younger children are dependent on their parents for their physical survival and emotional wellbeing (Saldinger et al. 1994). It has been suggested that the dying parent is often unable to reach out to their children because of their physical, mental or emotional deterioration (Saldinger et al. ibid). The children can perceive this withdrawal of affection as an indicator of the rupturing of their relationship with the parent. This is compounded further when the well parent is also 'unavailable' for the child because of their own emotional struggle (Saldinger et al. 1999, Thastum et al. 2008). Therefore, being given the opportunity to maintain a meaningful relationship with the dying parent can help children's sense of emotional stability thus alleviating some of the multiple issues faced during the illness period (Saldinger et al. 2004). However, their research highlighted a significant variation in the dying parent's ability and desire to maintain a relationship with their child. The authors suggest that 'parent-child intimacy during a terminal illness is possible only if the child and dying parent can tolerate spending time with each other' (p. 937). However, my research has highlighted that the physical deterioration of the parent can have negative consequences on the parent-child relationship and that the parent sometimes has little or no control over their circumstances.

Siegel et al. (1990) suggest that parents and children experience the greatest distress and family disorganisation during the period leading to the terminal phase and for several months after the death. This is further supported by Christ et al. (1993) whose research has highlighted that latency aged children (between seven and eleven years of age) experience high levels of distress because of the life changes associated with their parent's terminal phase of the illness. They write '[o]ur clinical experience indicates that, for many of these children, the stress experienced before the parent's death is greater than that experienced afterwards' (p. 425). Corr and Corr (2000), writing about anticipatory mourning suggests that 'encounters with dying also include a need to cope with new and often heretofore unexperienced sorts of challenges that are likely to arise' (p. 236). The focus of this quote is not solely written about children however, as Chapter Six describes, children living with a parent who is dying experience many challenges that are unique to their situation.

2.3.3 Children's emotional wellbeing

The children's emotional wellbeing is considered in many of the articles reviewed. In a literature review, Turner (2004) explores the impact of advanced breast cancer on children and families. The review identifies loneliness, apprehension and helplessness as being three significant emotions manifested in children. However, the article does not state the age of the children or their attachment relationships with their mother. Similarly, Beale et al. (2004) highlight that separation from the primary caretaker is a cause of anxiety for children. Their research suggests that anxious behaviour is manifested differently depending on the children's development. However, again the authors do not provide any age or developmental examples of these manifestations. Findings from the research indicate that all the children expressed fear at the outcome of the disease. The research concludes that children of parents with cancer are at a higher risk of psychological disturbance than their peers. This is congruent with findings reported in Christ and Christ (2006). Furthermore, Christ et al. (1993) suggest that children's psychological development is threatened when they experience the death of a parent. However, Christ et al. (1994) caution that the level of children's social and psychological development is crucial in determining their responses to their parents' illnesses. An example of this was when the typical developmental tasks of adolescence were in conflict with the young people's need to deal with the practical, psychological and social tasks demanded by the illness. 'The illness often required adolescents to become more emotionally involved with their parents at the very time when parent decathexis is the normal developmental task' (Christ et al. 1994, p. 607).

Making sense of and finding ways to manage parents' illnesses can have a positive effect on children's emotional wellbeing. Dunning (2006) suggests that children who are prepared for the death and who understand what is going to happen tend to cope more effectively emotionally when they begin the mourning process. However, this would suggest that there is a set time when 'mourning begins' and does not take into account the fact that the disruption and chaos that is typically associated with living with a parent who is dying has no time frame.

Beale et al. (2004) delineate that opportunities for children to make sense of their current situation can be obstructed because there is often a discrepancy between the children's cognitions about their parents' illnesses and the parents' assumptions about what the child knows. This highlights the necessity for age appropriate communication and information sharing to be supported between parents and their children. Dunning (2006) argues that information about the disease, its cause, treatments and prognosis are essential in helping the children make sense and manage the current situation. Whilst Dunning is referring to younger children, Christ et al. (1993) suggest that latency age children are also likely to be misinformed and have misconceptions about the parents' illnesses. Again age appropriate information and being party to conversations about the illness can help to alleviate some of these misconceptions and aid the meaning making process. Christ et al. (1994) delineate how adolescents in their research 'developed philosophical perspectives about the meaning of cancer, its role in their lives, and the inevitability of death' (p. 610). They also suggest that this search for meaning was often a powerful coping strategy for the young people.

Dunning (2006) describes some of the behaviours manifested in young children when trying to make sense of what is happening in their lives. She suggests that for some children there is a move from ‘passive-into-active’ (p. 506) thus giving them a feeling of power and control. Conversely she writes that other children will become regressive and more adult dependent. These findings correlate with data from my research that is presented in Chapter Five.

Helping the children to make sense of their current situation is discussed by Melvin and Lukeman (2000). They suggest that if:

> ...there is no attempt to help them develop a narrative or include the death in their existing life narrative, there is a risk that the death and surrounding events may become ‘separated off’ and not integrated into everyday functioning (p. 528).

Two contrasting views are presented by Siegel et al. (1990) and Dunning (2006) about the value of children being ‘separated off’ from the current situation. Siegel et al. (1990) advise that during the parent’s terminal stage of the illness, nonessential separations of the child from the family should be avoided. Conversely, Dunning (2006) advocates that it might be beneficial for the children to temporarily be accommodated away from the family home.

Teachers interviewed by Dowdney et al. (1999) reported that bereaved children were significantly more withdrawn, anxious and depressed than their peers. However, the research does not compare their behaviour prior to the bereavement and therefore questions of validity and reliability on a small sample of children (n. 45) need to be raised.

Howe (1995) argues that parental divorce is more damaging to children’s psychological development than parental death. This argument is based on the emotional conflict surrounding the divorce. However, research into parental terminal illness and death would suggest that this too can significantly impact on children’s emotional and psychological wellbeing. Research by Beale et al. (2004) suggests that children of parents with cancer are at higher risk of psychological disturbance than their peers.

Furthermore, Slaughter and Griffiths (2007) have suggested that death as a concept carries substantial emotional impact.

Participants in Turner et al. (2007) reported that they received no information from professionals about the likely impact of the cancer on their children in relation to their developmental stages. Furthermore, all of the women stated that they would have appreciated this information.

These findings are significant for my current research, both at a practical and strategic level. Despite the recent increase in research into parental death and the effects on children's mental wellbeing, Christ and Christ (2006) warn that this remains a largely unexplored area of research. This proposition is echoed by Turner et al. (2007), furthermore, Sharpe et al. (2006) argue that:

> ...although the research literature on young people and bereavement has grown significantly over the last two decades, there continues to be a dearth of research which looks specifically at their own perceptions and understandings (p. 53).

2.3.4 Anticipatory mourning

My presentation of the literature relating to anticipatory mourning is centred around the work of Rando (2000a,b), however, I will begin by delineating research undertaken by Saldinger et al. (1999) where specific consideration to children and anticipatory mourning is given.

Saldinger et al. (1999) highlight that literature about anticipatory mourning fails to address the issues experienced by children whose parents are dying. Furthermore, they suggest that the anticipation of death may be less beneficial for children than adults. Reasons cited for this include children's developmental level and their cognitive ability to understand the finality of death, parents' frequent failure to acknowledge the impending death with their children and the fact that forced identities can be assigned to children which are inappropriate and unhelpful. Results from the research undertaken by Saldinger and colleagues tended to demonstrate that forewarning of the death of a parent was not associated with more adaptive mental health outcomes than sudden deaths. However, the authors acknowledge that the results showed inconsistency across the measures used and that this might have been due to coding problems.

In a later paper, Saldinger et al. (2003) return to the notion of anticipatory mourning in children. Here they argue that whist there is an assumption that anticipated deaths are 'good deaths' the reality is often that there are many strains placed on all the family when a member has a life threatening illness. Within the conclusion it is suggested that children are exposed to traumatic stimuli long before the death itself. The authors list ten potential special stressors for children with dying parents. These include fear of the unknowable, separation anxiety and the loss of the sense that the world is a safe, predictable place.

Rando (2000a) describes the value of anticipatory mourning for people who are dying. However, she also delineates the value for the intimates of the dying person. Rando suggests that through anticipatory mourning, the intimates are able to relate to the dying person, and that if there are failures in the process, the bereaved are more likely to experience poorer bereavement outcomes. Factors that Rando suggests can hinder the anticipatory mourning process include premature detachment, poor communication and negative interactions with the ill person. Maintaining a relationship with the dying parent, being party to age appropriate information and enjoying positive interactions with the parent have all been highlighted in the current research as being key factors for children living with a parent who is dying.

Rando (2000a) suggests that:

> anticipatory mourning is not solely relegated to the major loss of death, which has yet to occur, but in fact pertains to losses throughout the illness experience, in the past, present and future (p. 8).

One of the significant findings from my research has highlighted the changes and challenges that children typically go through when a parent is terminally ill which could be associated with these different temporal losses. Attig (2000) writes about the transition from 'loving in presence to loving in absence' (p. 115) and how anticipatory mourning can facilitate this shift.

Describing the role caregivers can play, Attig (2000) suggests that 'caregivers can help us appreciate the many choices we have and support us as we decide what to do with our feelings' (p. 126). However, the findings from my research would suggest that children typically have limited choices when living with a parent who is dying and furthermore that there are few opportunities whereby they can explore their feelings with adults who are willing or able to listen.

Dunning (2006) suggests an alternative perspective on anticipatory mourning:

> The powerful losses and changes experienced by a child during a family member's disease process define the real meaning of "anticipatory grief". It is not imagined post-death grief begun early, rather it is loss in the child's here and now life and its accompanying grief (p. 505).

2.3.5 Parental capacity

The death of a parent is one of the most stressful events in a child's life (Christ and Christ 2006) and can represent one of the most intense losses experienced in life (Kennedy et al. 2008a). An important factor during this period is the parent's capacity to provide consistent parenting. It has been suggested that the well parent's feelings of incompetence, both during the terminal illness stage and following the death of their partner have contributed to their inability to parent (Siegel et al. 1990, Christ et al. 1993, Saldinger et al. 1999, Kirwin and Harmin 2005, Christ and Christ 2006). Saldinger et al. (2004) studied family relationships when a parent was dying and suggested that at the time when children are most vulnerable and in need of support, their primary caretakers are least available. Similarly, Lewis (1990) reported that studies into the effects of, amongst other factors, chronic parental illness, can 'result in the parent being physically and emotionally inaccessible to the child' (p. 755). Lewandowski (1996) suggested that when parents are unable to provide as much physical and psychological care for their children this can have a negative impact on the children's feelings of security. This is supported in later research by Saldinger et al. (2003) who describe how parenting capacity is compromised when a parent is terminally ill:

> Our study showed that many parents, already physically and emotionally drained by caring for a dying spouse, were too depleted during the illness to tend to their children's needs in *any* arena, be it exposure to graphic stimuli or helping them with math homework (p. 173) [italics original].

Saldinger et al.'s (2004) review of the literature also highlighted how both the well and ill parents felt that they did not have the same parenting efficacy as prior to the illness. This is congruent with Christ et al. (1993), who suggest that during the terminal phase of the illness, the parents experience a significant decline in confidence in their parenting competence. Furthermore, following the death of a partner, it is likely that the surviving parent is preoccupied with their own grief and therefore is emotionally unavailable for their children (Siegel et al. 1990, Melvin and Lukeman 2000).

The conflicting demands on the well parent to care for their partner and their parenting role have been discussed in recent literature. Kennedy et al. (2008b) suggest that this led to the children often not having their needs met and that they had to take 'a back seat' (p. 233). Furthermore, in a retrospective study, Rolls and Payne (2007) highlight the importance of parenting on the children's wellbeing when a parent has died. However, none of the papers offer suggestions why parents experience such feelings. Whilst this may be self-explanatory, empirical research would provide practitioners and policy makers with robust evidence to enhance the support available to families experiencing the death of a parent.

Elmberger et al. (2005), writing specifically about mothers with cancer suggests that mothering is a biological and moral activity. Findings from their research suggest that during the illness, the mother's image of what a good mother is, changed. They write that:

> The process of redefining mothering consisted of: interrupted mothering; facing a life-threatening illness and children's reactions; striving to be a good mother; dealing with moral responsibility; and coming to terms with mothering (p. 257).

Their research concludes that women experienced feelings of guilt at being ill and that as a consequence of the illness their children suffered.

Parental capacity during the illness and into the bereavement is closely linked to the 'availability' of the parents for their children. Christ et al.'s (1994) study of parental death during adolescence, demonstrated how it was often the parent who needed emotional and practical support. This sometimes led to a 'role reversal', where the adolescents were caring for the adults.

It has been suggested that the surviving parent needs to provide three elements for their children's wellbeing (Siegel et al. 1990). These are (i) physical and emotional support, (ii) an environment where the child can express distressing or conflicting thoughts and (iii) stability. The value of a supportive, stable family along with the accessibility of professional intervention was also highlighted by Beale et al. (2004).

There is a significant correlation between the parent's capacity to provide consistent, adequate parenting to children both during the terminal illness and following the death of a parent and the child-parent relationship. Research suggests that there is a strong relationship between the level of parenting provided and the strength of the child-parent attachment (Schaffer 1977, Bowlby 1991). Child-parent attachment is discussed below and delineates the relevance in relation to children experiencing the death of a parent.

The parent's 'availability' is not only in relation to the emotional and psychological support for their children. Research would suggest that when children are living with a parent who is dying, they often take on roles and responsibilities within the household. Thastum et al. (2008) report that in their research, children mentioned actively helping with household duties and helping practically and emotionally. The findings would indicate that the children in the sample 'experienced increased strain in association with the practical responsibilities, but most children said that helping gave them a sense of mastery and being of value to the family' (p. 132). The premature taking on of additional household responsibilities has been highlighted as a constant theme in my research and has presented the children with different challenges.

Rando (2000b) identified nine stressors that are frequently associated with living with terminal illness. Included within these were social isolation and differences in school and work experiences. She goes on to suggest that:

> ...an additional source of stress is that the normal developmental tasks of the family and its members must be played out in an atypical context, where the ill member's special needs or changing medical condition

> interacts with the tasks, often exacerbating demands and hardships (p. 314).

Whilst these relate generically to all family members and intimates, the themes can be specifically applied to children whose parents are dying. The social isolation that Rando refers to can contribute to the children's feelings of being different from their peers, and thus creates challenges to their identity.

The review of the literature has highlighted the role of professionals in providing support and help to families, both in relation to awareness of the needs of families (Dowdney et al. 1999, Christ 2000, Beale et al. 2004) and with regards to their training requirements (Saldinger et al. 2004). The lack of resources available to clinicians to distribute to patients was discussed in Turner et al. (2007). Whilst information is available for newly diagnosed patients, the research suggests that the specific needs of parents with terminal cancer are neglected.

2.3.6 Attachment behaviours and children experiencing the death of a parent

Some of the major issues encountered by families when a parent has a life threatening illness are discussed by Saldinger et al. (2004). However, it is argued that perhaps the greatest challenge is for the children who are dependent on their parents for all their care. Fundamental to this is the parent-child relationship. Within the literature pertaining to attachment, two important strands appear to be relevant to this literature review. The first relates to the attachment behaviours and quality of the attachment between the child and their parents. The second area for consideration is the debate about maintaining or relinquishing attachments following the death of a parent.

Saldinger et al. (2004) describe a retrospective study undertaken with bereaved children and their families that considered how attachments can be facilitated between children and their dying parents. The research considered the trajectory before and after the death of the parent, and how relationships are maintained during this period. The authors labelled this function as 'anticipatory relationship facilitation' (p. 919). The findings illuminate how children desire to maintain a relationship with the dying parent even when the parent is either not physically or emotionally able to reciprocate. However, they contend that little has been written on the issue of relationship facilitation, and it would appear that this is an area requiring further research: 'Absent [from hospice literature] in this discussion is any aspect of the relationship between a dying parent and a minor-aged child' (p. 917).

A potential limitation of the Saldinger et al. (2004) research is that within the substantial eligibility criteria there is no mention of the previous attachment history between the children and their deceased parents nor is this referred to in the discussion.

Christ et al. (1994) studied the impact of parental terminal cancer on adolescents. The research highlights that the pre-diagnosis relationship was a contributory factor to the adolescents' emotional responses to the illness. When the parent-child relationship had been significantly conflictual prior to the diagnosis, it was found that the adolescents had a particularly difficult time adapting during the illness. Furthermore, the adolescents whose relationship with the well parent was limited but who had a more positive relationship with the ill parent reported feeling more abandoned and alone.

In an earlier study, Christ et al. (1993) focussed the research on parental terminal cancer and younger age children, aged seven to eleven years. Findings were similar to the later study and again suggested that the nature and quality of the children's relationship with both parents pre-diagnosis significantly affected their reactions to the changes in the relationship post-diagnosis. A similar pattern emerged whereby the quality of the relationship pre-bereavement to the well and ill parent affected how the children felt. It was suggested that in some cases, the children feared the loss of their special ally and worried about the potential changes within the intrafamilial power structure.

A study focusing on pre-school aged children and parental bereavement also highlighted the importance of pre-existing and post death relationships between children and their parents (Kranzler et al. 1990). Results from the study suggested that the children who had enjoyed a highly involved relationship with the parent who had died and had a less emotionally involved relationship with the surviving parent were more likely to exhibit emotional symptoms. The authors argued that 'these findings regarding parental emotional involvement with the child prior to the death suggest a titration-of-loss effect. The more the child has lost, the worse the outcome' (p. 519). In addition they noted that the depression displayed by the children was combined with anxiety symptoms. It is

suggested that this may be further evidence of Bowlby's theory of separation anxiety in grieving children and the association between attachment related symptoms and later depression. When the children were in situations where they were separated from their carers they demonstrated significantly more fear than the non-bereaved controls.
Research into psychological disturbance and service provision for parentally bereaved children postulated that bereaved parents with pre-school children were less likely to be offered professional support than parents of older children (Dowdney et al. 1999). It is interesting to speculate about the potential implications of this in relation to the breadth of knowledge that is available about the importance of attachment in the very early years. This notion is supported by research undertaken into attachment relationships with pre-school children when their parents have divorced (Page 2001). The conclusion to this paper advises practitioners working with young children from post-divorce families that parental availability and consistent support are vital for the children's sense of emotional stability or social relationships. This is equally valid for young children who have experienced the death of a parent. However, the Dowdney et al. (1999) research would suggest that families with young children are not offered support. This correlates with my current research, where the projects that have been involved in the research generally offer support to school aged children and older.

A study to explore the effects of parental depressive symptoms on children's perceptions of family functioning was undertaken by Cummings et al. (2008). Whilst their research does not specifically address family relationships when a parent is at the end of life, it does explore in detail parental depression and attachment which has significant importance within the current study. Their study suggests that there is a correlation between parents with symptoms of depression and deficits in the parent-child relationship. Furthermore, the authors propose that the likelihood of having a secure attachment is reduced when a parent is experiencing depression. These findings are significant as research would suggest that patients with a terminal illness are likely to experience depression and anxiety (Pessin et al. 2005, Ryan et al. 2005) thus potentially also having an adverse effect on the relationship with their children.

2.3.7 Identity development

Living with a parent who is dying can cause children to question their identity, who they are and their identity within the family construct. Giddens (2002) writing about self-identity suggests that:

> Self-identity...is not something that is just given, as a result of the continuities of the individual's action-system, but something that has to be routinely created and sustained in the reflexive activities of the individual (p. 52).

Within the children's developing construct of the world, it is generally the family that has the first significant role in facilitating this. '[f]amilies provide the basic social geography through which we negotiate our paths through life' (Wasoff and Dey 2000, p. 1). Furthermore, 'much of children's understanding of the world around them, their patterns of behaviour and their coping styles are processed through the family' (Melvin and Lukeman 2000, p. 527). This is congruent with Riches and Dawson (2000) who suggest that 'family roles often provide the core constructs of our identity' (p. 20). They go on to outline how the family provides young children with a picture of self and the world in which they live. However, as the child grows, external influences also begin to shape this knowledge including 'teachers, friends and the mass media' (ibid p.22). The relevance of the role of schools in developing a sense of self in children's identities is also discussed by Korn (1998). She suggests that 'early childhood teachers are important contributors to children's developing stories of themselves. They mediate children's experiences, helping them to make meaning of events' (p. 224). This is salient in relation to my research which has indicated that teachers, peers and the school environment can have a significant and at times negative influence on children's conceptions of self and their current experience when living with a parent who is dying. Furthermore, as Eppler (2008) suggests 'children manifest their grief at home, at school and with their peers' (p. 189).

Quinton (2006) suggested that identity formation and development are crucial for the child to develop in part an idea of self. The disruptions and chaos experienced by the family when a parent is at the end of life can have a significant effect on this idea of self. Rowling (2003) discusses the development of identity in relation to adolescents and talks about how the bereaved experience a sense of loss of control. She goes on to say that the 'developing identity of a young person can be threatened by the death of a parent' (p. 24). This is congruent with Melvin and Lukeman (2000) who, discussing adolescence state that it is 'a time of transition when ambivalence and conflicts with parents and school are commonplace' (p. 526). Moreover, the influential work of Erikson (1963) describes the adolescent period as being a time of identity crisis where the young people need to find a definition of who they are whilst at the same time deal with the upheaval and confusion that is often associated with this period. Findings from my research highlight, how, if during this period the young people also need to manage the upheaval of living with a parent who is dying, they are forced into coping with additional stressors that can severely compromise their definition of self.

Ribbens McCarthy (2006, 2007) discusses how whilst close friends have a significant role to play in supporting young people in their bereavement, research would also indicate that young people are also likely to experience isolation and stigma from their peers. This results in them being seen to be marginalised and different. Thompson and Payne (2000) describe how children in their research asserted to be different from their peers and confirmed that they were teased at school. They conclude that these children 'appeared to have insight into why they were teased and had already perceived the lack of language about and awkwardness with death in our society' (p. 88). This was substantiated with a quote from a young person who stated that '[b]ecause you're different, and people are afraid of what they don't know' (p. 88). Furthermore, McNamara (2000) writing about stress in young people suggests that '[a]dolescent peer groups are highly influential in determining the sources and outcomes of stressful life events for young people' (p. 41). The issues of being different and fitting in with peers have been recurring themes in my research and are an underpinning factor within the findings chapters.

2.3.8 Transitions and young people

A consistent theme throughout the thesis relates to the transitions and changes children experience when living with a parent who is dying. Childhood is marked by a number of transitions that children typically navigate and these are often seen as potentially challenging to their identity, sense of self and security. A significant transition is as children develop and mature from early childhood into adolescence. McNamara (2000) writes that:

> Adolescence may be defined as the period of transition from childhood to maturity with universal changes and morphology, physiology and cognitive ability. It is characterized by rapid processes of change in social and psychological functioning, as well as marked physical growth (p. 30).

She goes on to describe adolescence as being an exciting but also vulnerable time and how the experiences of young people during this period can have important consequences for their adult lives. Henderson et al. (2007) offer a definition of adolescence that is congruent with McNamara's; they suggest that:

> ...youth is also seen as a phase in the life course that we all experience, involving a notion of developmental stages leading from dependent childhood to independent adulthood. From this perspective, 'adolescence' can be seen as a period of experimentation, when identities are tried for size and boundaries tested (p. 18).

Furlong and Cartmel (2007) note that 'the life experiences of young people in modern societies have changed quite significantly' (p. 1). They observe that as a result of economic, political and social changes, young people are likely to experience a set of risks that were largely unknown to previous generations. Their assertions suggest that all young people experience many challenges that need to be negotiated, however, the challenges faced by young people experiencing the death of a parent are not acknowledged within their writings.

Furlong and Cartmel's (ibid) notion that the experiences of young people have changed in modern societies is congruent with Henderson et al. (2007) who suggest that:

> Late modern approaches to the lives of young people have emphasised intergenerational change and the view that the predictable life patterns of the past (which tended to be powerfully shaped by social class and gender) have eroded, leaving young people faced with the challenges of forging futures without a map (p. 23).

They discuss how this move away from mapped out and predictable life course trajectories results in there being 'few agreed routes and high levels of anxiety about whether individuals are 'doing the right thing' (ibid p. 24). This is in contrast to the earlier writings of Van Gennep (1977) and highlights how recent socio-economic changes have impacted on previously constant rites of passage. Van Gennep observes that: 'For every one of these events there are ceremonies whose essential purpose is to enable the individual to pass from one defined position to another which is equally well defined' (1977, p. 3).

McNamara (2000) writing about the stresses young people experience when managing the transitions also suggests that these can be difficult to manage:

> Transitions presuppose vulnerability at any age and the progression from childhood to adulthood includes multiple developmental transitions. These transitions may be biological, social or psychological by nature, and can be perplexing and disquieting for many teenagers (p. 39).

Within the thesis, I suggest that when children are living with a parent who is dying they typically enter into an alien landscape where frequently there are no guides and few landmarks to help them traverse the land. The above quotes are congruent with my findings and provide further support to the claim that young people experiencing the death of a parent have multiple stressors that require careful and appropriate support.

Findings from my research have shown that school can become a safe haven for children experiencing the death of a parent or a hostile, lonely environment. McNamara (2000) writing about schooling per se for young people observes that:

> Feeling unhappy at school can cause significant stress to young people as well as having important consequences for their prospects for personal and career development (p. 41).

These stressors include, according to McNamara, homework, isolation and worries about the future, however; omitted from the list are worries about parental terminal illness.

When I was a practitioner working within family support, I noted how regularly parents who were referred to the service for support had unresolved bereavement issues from their childhoods. My observations are congruent with McNamara (2000) who, writing about stress in adolescence note that:

> The decisions made in adolescence hold important and often irreversible consequences for occupational and social status in adulthood. Furthermore, there is a growing conviction that many mental health problems experienced in adulthood have their roots in adolescence (p. 33).

Furthermore, Furlong and Cartmel (2007) suggest that there have been recent increases in the levels of stress in young people leading to higher incidences of mental health. These observations are based on the youth population per se and not specifically young people experiencing the death of a parent, however, findings from my research would suggest that this compounds the stress and furthermore, complicates the process of transition.

The general consensus in recent research is that transitions into young adulthood are often difficult to negotiate and that the socio-political climate has the potential to compound these difficulties. If these transitions are experienced in parallel to living with a parent who is dying they are further complicated and complex as Chapter Six discusses.

The work of Van Gennep (1977), which was mentioned above, is important in directing the thinking about the transitions and has been incorporated into the findings chapters. Van Gennep states that:

> Transitions from group to group and from one social situation to the next are looked on as implicit in the very fact of existence, so that man's life comes to be made up of a succession of stages with similar ends and beginnings (p. 3).

Van Gennep proposed that rites of passage are sub-divided into rites of separation, transition rites and rites of incorporation. Each of these are important within the context of living with a parent who is dying and take on particular significance as the illness progresses and following the death. Van Gennep writes that 'during mourning, the living and the deceased constitutes a special group, situated between the world of living and the world of the dead' (1977, p. 148). Hockey (2002) critiquing his work suggests that this period is 'betwixt and between fixed social positions' (p. 213). I argue that during the pre-bereavement period, the children are forced into the liminal period where they are living betwixt and between positions and that this causes them to question and explore their identities.

2.3.9 Social death

Lawton (2000) undertook an ethnographic study into the patients' experiences of palliative care. One chapter is dedicated to findings that she has delineated as the invisible suffering, the social death. Within the research Lawton explores how patients experience a loss of self which stems from a loss of relationships. A consequence of the illness, according to Lawton, relates to how the patients' view of the world is not congruent with how family and friends see it. This incongruence results in the family's inability to empathise with the patient and there being little common ground between the patient and their family and friends. Furthermore, the patients in the study became isolated and demoralised because friends and family started withdrawing from them. This withdrawal and the inability to empathise contributed to the feelings of a social death and of having lived too long. A further limiting aspect of the illness trajectory that contributed to the patient's social death was often their increasing mobility problems that affected their ability to access social activities, thus creating further isolation and a heightened sense of being 'socially dead'.

Some patients, as opposed to living too long, were described as dying too soon. Lawton suggests that these patients typically were young people with families, who had recently learned of their prognosis and whose health had deteriorated rapidly. Because of this they and their family had limited time to 'prepare' and come to terms with the impending death. Lawton went on to describe the degenderisation of patients and how they lost relationships through which their gender could be interactivity reflected and affirmed.

Lawton's notion of a social death from the patient's perspective is an important proposition and has many parallels and similarities to the experiences of children whose parents are at the end of life. However, whilst Lawton's work follows a medical trajectory, insofar as the social death of the patient precedes their clinical death, the social death for the children crosses the boundary from the medical to a social issue.

This has been a significant finding in my research and will be returned to in later chapters within the thesis.

Sweeting and Gilhooly (1991) describe the notion of the social death in patients. They suggest that social death is 'the point at which a person "dies" in the social sense' (p. 251). Furthermore, they describe how the social death marks the end of an individual's social identity. The notion of a social death for patients with cancer has been described by Raphael (1996). A graphic description of how the disease takes over the body is provided, culminating in a suggestion that the condition may spread from the patient and contaminate friends and family. This, Raphael suggests causes the patient to become isolated from friends and family and thus results in their social death long before the clinical death. Walter (1999) proposes that the social death is the death feared most by westerners.

Ribbens McCarthy (2006) discusses the social context of a young person's bereavement experience that can be likened to the notion of a social death. She states that 'bereavement experiences occur within a web of pre-existing and ongoing social contexts, which are also quite central to individuals' own perspectives of such life events' (p. 89).

Christ et al. (1993) discuss how latency aged children in their research showed distress because of not being able to participate in extracurricular activities or have contact with peers away from school. The authors suggest that a number of factors contributed to this exclusion including the concentration on caring for the patient, financial implications because of the illness and demands on the well parent. They go on to observe that '...loss of an activity or an important peer relationship was especially disturbing for the children at a time when their whole world seemed to be disrupted' (p. 424). This has clear resonance with the notion of the social death for children.

The social death for children can be inadvertently exacerbated because of the physical and emotional cost placed on the well parent when caring for the ill parent. Saldinger et al. (2003) describe within their research that many parents 'were too depleted during the illness to tend to their children's needs in *any* arena' (p. 173)[italics original]. Furthermore, Dunning (2006) suggests that the well parent becomes in effect a single parent during the illness and has 'little patience for normal parenting tasks' (p. 500). However, Rauch et al. (2002) in their set of guiding principles for parents with cancer, advise that 'children do best with a regular schedule and should be encouraged and supported in continuing "life as usual" (p. 4400).

Writing about transitions following a death, Van Gennep (1977) writes that 'during mourning, social life is suspended for all those affected by it, and the length of the period increases with the closeness of social ties to the deceased' (p. 148). Evidence from the research above and my findings highlight how this suspension can be transported back into the pre-bereavement period and that for many, the known social life is lost because of the demands placed on the children whose parents are dying.

2.4 DIFFERENT PERSPECTIVES ON LOSS AND SEPARATION

This literature review now moves to literature which examines differences and similarities relating to children experiencing the death of a parent, and children whose parents are separating or divorcing, along with research pertaining to the experiences of children of military personnel when their parents are deployed.

2.4.1 Literature relating to children and divorce

One striking similarity between the two different life experiences is the potential longevity of the two journeys: the parent's illness trajectory and death, and the process parents go through during separation and divorce. Westberg et al. (2002) discuss this 'divorce is not a single event that takes place in one moment of time, but a process that begins long before separation and for some, lasts the entire lives of everyone in the family' (p. 525). This observation has clear resonance with the families where a parent is dying. Firstly the recognition that in both circumstances the trajectory may be for a number of years and that the process does not stop when death or the divorce occur. The literature would also suggest that there is an anticipatory period for the children similar to anticipatory mourning (Saldinger et al. 1999, Rando 2000a). Westberg et al. (2002) identified that for some children the period between the parents separating and divorcing could be as much as two years. The participants recalled how they felt relieved that it was finally over once the divorce had been finalised. This may be likened to the findings of Saldinger et al. (2003) who argue that anticipated deaths are not always the 'good' deaths that they are frequently portrayed as being. Rather they suggest that the anticipation of death 'may provide one of the biggest strains of all during this period of forewarning' (p. 169). Furthermore, they highlight some of the risks an anticipated death may pose for children in relation to the frightening fantasies and frightening reality that seem inevitable even within the most protective environments. The stress for adults and children during an anticipated death is discussed in Dunning (2006) and suggests that longer trajectories increase the incidence of stress.

2.4.2 Disclosure of the divorce

Similarities were also evident in how terminal illness and separation and divorce are disclosed to children. Westberg et al. (2002) describe their retrospective research with adults whose parents had separated and divorced when they were children. The research highlighted that disclosure about the divorce generally did not happen with all family members being present. Half of the participants (n. 9) were told the news by their mothers whilst the other half were told by their fathers. However, they suggested that they would have preferred to have been told by both parents. Furthermore, some elucidated that their parents had told them of the divorce to prevent the harmful effect of them hearing the news from a third party or during an argument. The participants recalled how they felt parents should explain the divorce to them and keep them informed of what was happening. They related this information sharing as a preventive measure to protect the children from becoming frightened about what was happening. This is similar to findings relating to communicating and giving age appropriate information to children when their parents are dying (Beale et al. 2004, Turner 2004, Rauch et al. 2002, Melvin and Lukeman 2000).

Effective ways of facilitating communication between divorcing parents and their children is discussed by Hawthorne et al. (2003). Their review highlighted the importance of communication for the children along with providing age-appropriate information. This is echoed by the children's views from research into parental divorce (Cashmore 2003). Children in this research stated that generally they wished to be kept informed with regards to what was happening within their family. However, as with information sharing when a parent is dying, children of divorcing parents are often not informed of what is happening. It has been suggested that this may be because the parents want to protect the children from distress and anxiety (Dunn and Deater-Deckard 2001). However, research suggests that children who receive adequate information throughout the period leading up to the divorce adapted more easily to changes within their family post-divorce (Halpenny et al. 2008). Whilst there is some evidence to suggest that parents keep information from their children, Halpenny et al. (ibid) highlight that conversely some of the children within their interviews stated that they did not want to cause further upset for their parents by talking to them about the divorce. This is congruent with the Ribbens McCarthy (2007) research that is described above.

Westberg et al. (2002) suggest that it would be beneficial for parents to be supported in how to communicate with their children about the divorce. This again has also been discussed in end of life and bereavement literature (Dunning 2006, Saldinger et al. 2003).

2.4.3 Social and emotional experiences of divorce

Many of the children involved in the Halpenny et al. (2008) research discussed their feelings of being different from their peers whose parents had not divorced. Furthermore, the respondents stated that they perceived there to be a stigma attached to having parents who were divorcing and this fear of being singled out from other children was a barrier that prevented them from accessing support services. Similarly, Raphael (1994) suggested that children who have been bereaved ‘may face the trauma of being “different”, singled out, because a parent has died, or because he [sic] no longer has two parents’ (p. 102).

In a retrospective study Mack (2001) compared the typical differences seen in adults who had experienced parental divorce or death as children. The findings from this research suggest that adults who experienced parental divorce had higher levels of self-confidence than adults from intact families, whilst adults who had experienced the death of a parent as a child had lower self confidence. Furthermore, by comparison, the adults whose parents had divorced also demonstrated lower levels of depression in adult life. The paper suggests that there is a significant relationship between the attachment behaviours exhibited during the divorce or death of a parent and subsequent adult well-being. The author draws on Bowlby’s research to explain the different attachment behaviours the two cohorts of children exhibited. Parentally divorced children were more likely to display anger and hostility whilst children whose parents had died were more likely to show sadness and depression. Moreover, the research highlighted differences in the parent–child relationship between divorced and bereaved families. Adults whose parents had divorced when they were children tended to describe lower levels of relationships with their parents whilst children whose parents had died did not report significantly different levels compared to adults raised in intact families. The conclusion drawn from this is that 'prolonged separations such as divorce, rather than permanent separations such as death, are more likely to cause lasting damage to family relationships' (Mack 2001, p 437).

Haine et al. (2003) offer a different perspective as to why parentally bereaved children often exhibit lower levels of self confidence and esteem. They delineate that a possible explanation for the decrease in self esteem is as a result of a reduction in life experiences that generally enhance esteem, for example, positive interactions with caregivers and involvement in activities where they receive positive recognition. Congruent with this and building on the propositions, Wolchik et al. (2008) suggest that the stressors faced by the surviving parent can cause them to spend less time with their children, be less supportive to them and not provide consistent boundaries to regulate their behaviour.

2.4.4 The experience of children of military personnel

Mmari et al. (2009) provide a comprehensive exploration of adolescents' experience when a parent is deployed to a war zone. The article provides many similarities to the literature relating to children experiencing the death of a parent, and discusses the effect on the adolescent's health and wellbeing. The research highlighted how, particularly, teenage boys in the sample externalised their anxieties as a way of coping with emotions. Interestingly a finding from the research showed that the adolescents described emotional strain in relation to their 'predeployment sadness about the parent's departure, anxiety regarding a parent's death in the war, and concern about the stress and worry of the parent remaining at home' (p.462). Each of these elements has significant resonance with the emotional concerns of children when a parent is at the end of life. A further similarity was the changes in family roles and responsibilities.

Adolescents reported an increase in responsibilities within the home environment, including housework and caring for younger siblings.

The young people in the Mmari et al. (2009) research discussed the constant shifts in how they were parented when a parent initially left the family home and then returned. The research evidenced that the parent's return from deployment often caused more stress than when they went to war. This was in part due to the changes in the household routine once the parent returned. This again can be equated to the current research and the changes that the children need to make when a parent returns home following hospitalisation or receiving palliative care in the hospice environment.

The issue of communication and information sharing was discussed and again had many similarities to my research. Mmari et al. (2009) found that if the adolescents were informed about the forthcoming changes they were able to handle their stresses more effectively. Furthermore, Cozza et al. (2005) writing about injured service personnel suggest that:

> [T]he nature of the information that parents share with children may or may not be developmentally appropriate and may be based more on the anxieties of parents, rather than the needs of the children (p. 374).

The discussional section of the Mmari et al. (2009) paper suggests that 'there is a critical need to understand impacts of the deployment process ... on the wellbeing of youth and their families' (p. 470). This salient point is echoed by the current research.

Summary

The literature review has considered published research and conceptual approaches that have been influential in the development of current thinking about death, dying and bereavement. This includes tracing the development of theories and models relating to thanatology and considering how they have contributed to the current knowledge base. The review of the literature has highlighted how early theorists predominantly adopted a medical model to explain bereavement and mourning and how the optimal outcome was for the bereaved to work through their mourning to a state where they could 'let go' of the deceased and move on into new relationships. This was followed by a review of some of the literature relating to the later theories that have come to the fore over the last few years. Recent theories have challenged dominant, largely psycho-medical models and have questioned whether the ideology of letting go from the deceased is necessarily helpful or healthy. Furthermore, later theories have moved away from the medical model and have incorporated social and cultural perspectives along with psychological and emotional narratives into their discourse. In recent years children's bereavement has also been considered more in its own right as opposed to being, at best, amalgamated into the prevailing adult perspective and frequently not recognised at all. However, there remains a dearth of literature relating specifically to children in comparison to the plethora of work into adults' experience of death, dying and bereavement.

The work of Bowlby was explored with some exploration of attachment theory per se and in relation to children experiencing the death of a parent. The research highlighted how the children wanted to maintain a relationship with the dying parent but also how the pre-diagnosis relationship had a significant bearing on how the post-diagnosis relationship was managed. The limited research would suggest that the parent-child relationship has been afforded little acknowledgment by researchers and academics in the field of death and dying.

The emotional conflict typically experienced by children was discussed. Within the literature it could be argued that there is a correlation between emotional conflict, the parent-child relationship and children's experiences of living with a parent with a terminal illness. This section of the literature review also discussed communication which again has been shown to play a major role within the experience and outcomes for children when a parent is at the end of life.

The literature review concludes with an exploration of the literature relating to children experiencing their parents' separation and divorce. The literature highlighted a number of similarities for these children and children whose parents were at the end of life or had died. A significant similarity was the potential longevity of the two journeys and the impact this could have on the children's lives. Furthermore, an issue raised in the divorce literature was about communication and how the parents disclosed to the children their plans to divorce. It was evident from the literature that there are similarities in how this information is conveyed both for children whose parents are divorcing and when a parent is at the end of life.

The literature review has provided an account of the development of bereavement theories and models along with an exploration of some of the key factors children experience when a parent is at the end of life or has died. However, a significant feature of the review is the scarcity of literature relating to children experiencing the death of a parent in comparison to the wealth of research into adults' experiences of death and dying. This therefore, highlights the importance of the current study and the contribution it will make to developing knowledge and awareness of this issue for children.

CHAPTER THREE: METHODOLOGY

The aim of this chapter is to describe the processes undertaken and the challenges and opportunities experienced during the planning stages, the data collection process and the analysis of the data. Included in this will be a discussion about the challenges encountered in gaining ethical approval for the research to proceed and the process undertaken for participant sampling. Following on from the ethical and sampling discussion there will be a descriptive account of the composition of the participants and an explanation of the data collection and analysis process. The chapter will begin by placing the research in context followed by a discussion about the choice of methodology and methods and an exploration of the advantages and disadvantages of the chosen methods.

3.1 PLACING THE RESEARCH IN CONTEXT

3.1.1 Adopting a qualitative methodology

From the initial planning stages of this study, it has been my intention to research children's experience of living with a parent who has a terminal illness. By listening to their accounts, I hoped that I would develop my understanding of their experiences and to provide an insight into the culture of parental terminal illness from the children's perspective. I believe that the children's stories are imperative in this process and that through listening to and analysing their narratives a deeper understanding about the similarities and differences of their experiences can be developed.

'If the researcher cares about the ongoing relationship to the participants as well as to the ways the research account is read and for what purpose, it will make a difference to the way the research account is written' (Clandinin and Connelly 1994 p. 423). This epitomises the underlying principles of this thesis and the fundamental reasoning for adopting a qualitative approach. An important factor is my affiliation to working with people and to practicing in a sociological context where their life experiences and stories are essential in developing relationships and learning more about their social world. Throughout the planning stages of the research and the subsequent discussions and negotiations, a prerequisite has been that the research should be driven by the desire to give the children who are experiencing the death of a parent the opportunity to share their stories. Therefore the appeal of adopting a qualitative methodology that employs ethnographic methods has been influenced by this precondition.

3.1.2 Methodological considerations

Locating the research with children as the primary participants forced me to consider the type of methodology I should adopt for the research. Mishna et al. (2004) suggest that 'qualitative research provides an opportunity to tap into the richness of children's thoughts and feelings about themselves, their environments and the world in which we all live' (p. 450). Tapping into the richness of children's thoughts, feelings and experiences is at the core of this research. Furthermore, as Kraus (2005) delineates in a discussion about qualitative research, the unique goal of this methodology is the facilitation of meaning making. This is echoed by Gilbert (2002), writing about narrative approaches in grief research, who begins the paper with the message 'we live in stories, not in statistics' (p. 223). Meaning making is an important facet in my research, in relation to the development of a more informed understanding of how children make sense of their current lived experience and the personal learning that has been achieved. Moreover, whilst the review of current literature has revealed that there is limited research available, where children are the primary participants, Brookes (2006) offers a succinct reminder about the value of including children as participants:

> The body of research that already exists on children's participation indicates that when young people are included in decision-making they don't just demand free Smarties, but respond with often astonishing maturity according to the circumstances in which they find themselves (p. 13).

In the introduction to the book *Doing Ethnographies* the authors describe the research methods employed when undertaking ethnography as being participant observation, interviewing, focus groups and video/photographic work. They suggest that through these methods, the researcher is better able to understand 'parts of the world more or less as they are experienced and understood in the everyday lives of people who 'live them out' (Crang and Cook 2007, p. 1). This is congruent with the principles underpinning this thesis, and whilst it needs to be acknowledged that this has not been an ethnographic study per se, I have adopted an ethnographic approach. Consequently, Crang and Cook's discussion begins to validate the debate for employing a qualitative as opposed to quantitative methodology.

There is an ongoing debate about qualitative versus quantitative research (Wainwright 1997, Bryman 1992), the former being presented as 'soft' and lacking rigor or validity. However, in developing an understanding of people's social worlds, employing techniques that elicit their stories, feelings and emotions need to be appropriate in order to meet the aims and objectives of the research. Silverman (2000) writing about the difference between 'good' and 'bad' research, where the implication is that the more scientific quantitative methodologies are good, suggests that the main factor in determining which approach to adopt is based on what you are trying to find out, or more precisely the aims and objectives of the research.

Robson (1999) describing participant observation discusses the potential subjective nature of this type of method and how it could be seen as 'bad' science. However, he argues that 'when working with people scientific aims can be followed by explaining the meaning of the experiences of the observed through the experiences of the observer' (p. 194). May (2004) compares the inductive nature of participant observation where the researcher develops ideas from their observations, with deductive methods whereby ideas are tested. He suggests that whereas researchers who employ questionnaires develop ideas and test these with their questions, within the participant observation genre, no firm assumptions are made about what is important 'instead… researchers…immerse themselves in the day-to-day activities of the people whom they are attempting to understand' (p. 148).

Describing qualitative and quantitative research, Jackson et al. (2007) suggest that the difference between the two is that they do not share the same epistemology. However, Bryman (1992) argues that 'the tendency to view the two research traditions as reflecting different epistemological positions...has led to an exaggeration of the differences between them' (p. 105). He suggests that consequently quantitative and qualitative research approaches are seen as mutually exclusive models. The epistemological position for this research is discussed later in the chapter and highlights the value of adopting a qualitative methodology when researching a social phenomenon, where the development of knowledge comes from the participants' lived experiences.

This is echoed by Krauss (2005), who writes that the techniques for data analysis within qualitative research are guided by an epistemology that attempts to acquire social knowledge.

Within the qualitative methodology of this current research, the emphasis is on the narratives of the participants. Wittenberg-Lyles (2006) discusses how narratives give individuals the opportunity to recall experiences and in so doing re-examine the associated feelings. She further suggests that within the process of storytelling the individual can create meaning and make sense of reality. This is congruent with Fraser (2004) who writes how narrative research 'is orchestrated around storytelling' (p, 184). Furthermore, Riessman and Quinney (2005) suggest that 'a central area of narrative study is human interaction in relationships – the daily stuff of social work' (p. 392). When planning the research, an important consideration was that I should adopt a methodology that would allow the participants maximum opportunities to share their experiences in a 'natural' way that did not feel constrained and under 'experimental' conditions.

One of the issues in the qualitative versus quantitative debate concerns the question of validity and reliability. This is highlighted by Pyett (2003) who describes how, within quantitative research, validity is connected to accuracy, relevance and reliability of measurements, whereas qualitative research is about the understanding, representation or explanation of something which is usually a complex social phenomenon, and not about measurement. Within the same article, Pyett asks how researchers can be confident that their account of the research is an accurate representation. In part she argues that this is achieved during the process of analysis, whereby the researcher tests initial interpretations by further examination and checking. Moreover, included within this is the examination of the researcher's own construction of meaning. The researcher's construction of meaning is discussed by Crang and Cook (2007):

> ...ethnographers cannot take a naïve stance that what they are told is the absolute 'truth'. Rather, research must involve the struggle to produce *inter-subjective truths*, to understand why so many versions of events are produced and recited (p. 14) [original emphasis].

Whittemore et al. (2001), discussing the validity of qualitative research, suggest that the research process should be critically presented and that the findings must provide the reader with the opportunity to critically reflect on the content. Chapter Seven is presented as a case study based on two interviews I was privileged to have with 'Jennifer', a young adult, whose mother had died when she was a teenager. Jennifer's accounts offer an understanding of the complex social issue of parental bereavement and as Willig (2006) suggests provides, through the description, 'a better understanding of, the nature of the phenomenon under investigation' (p. 74).

Throughout the writing up of the thesis, I have endeavoured to present the participants' accounts and represent their experiences, observations and perceptions accurately. I have tried to honour the accounts and reproduce them without subjecting them to my opinions or beliefs. Where possible, I have requested that the participants proof read the sections of the thesis salient to their stories and comment on my representation and presentation of their experiences. Through these processes I hope I have been true to the participants and provided valid and trustworthy accounts of their lives based on the information they have shared.

3.1.3 Ethical considerations when employing qualitative methods

One of the significant ethical considerations relating to the nature of the research was the need to adhere to the principle of non-maleficence, that is, not causing harm to the participants. Fraser et al. (2007), state that ethical research should consider the interests and needs of the participants. Through adopting a qualitative approach, I hoped that the methods selected - participant observations, semi-structured interviews and focus groups - would allow an understanding of participants' 'lived' experiences (Crang and Cook 2007). The value of adopting a participant observer's role is discussed by Lawton (2001). She describes how the staff team, based in the hospice where she undertook her research, thought her adoption of this method was appropriate as it allowed the patients' thoughts to be captured but also because of the non-invasive and unobtrusive nature of the data collection. This basic tenet was significant when I was in the planning stages of my research and was an important factor when ethical approval was granted.

The very nature of research with children who are experiencing the death of a parent and the participants' potential vulnerability dictates that the process for conducting the research must be undertaken sensitively and with respect for their current situation. It was therefore appropriate to adopt a methodology where the focus was on listening to the children's stories and capturing their perspective of issues that affect their lives. As Gilbert (2002) suggests, within the narrative approach, deep meanings are looked for and the important emphasis is on how and why things are said, and not simply on what is said. This notion, for me, relates to the proposition that the children are the 'experts' in their lives and the meaning they give to their stories is the important element within the research. The notion of 'experts' is echoed by Eppler (2008) in her research of parentally bereaved children. However, within my research, I have also recognised that some children have limited understanding and knowledge about the situation they and their family are experiencing. This is discussed in detail in the later chapters of the thesis.

Children who are experiencing the death of their parents are not living in a vacuum, and many factors may influence their thoughts, feelings and behaviour. It is an inevitable consequence of researching the needs of children that their parents, wider family and social contexts should also be considered in detail. Furthermore, this is in line with the Framework for the Assessment of Children in Need and their Families (Department of Health et al., 2000).

3.1.4 The process of gaining ethical approval

Gaining ethical approval was a major concern for me. My anxieties stemmed from the very nature of my proposed research. I was worried that ethical approval would not be granted because of the two potentially contentious key areas – children and bereavement. Initially consent was given from the University of Derby and then followed the second major challenge of my research journey.

Any research within the UK that involves National Health Service (NHS) patients or users must receive ethical advice from the NHS Research Ethics Committee. Prior to any research commencing it is a requirement that the committee gives approval for the research to proceed (Balen et al. 2006). When considering research proposals the committee is required to consider a number of factors that should have been evidenced within the proposal. The Local Research Ethics Committees (LRECs) were set up in the early 1990s to give ethical advice on research proposals (Randall and Downie, 2005). The committees consist of between eight and twelve members and are made up of medical professionals and lay persons. However, Morrow and Richards (1996) suggest that they are unaware of any committees that recruit children or consult children about research that involves them.

There was some uncertainty and ambiguity in the guidance and help I received from the NHS National Research Ethics Service because the research was to be based in hospices which are charitable organisations and not NHS premises. Furthermore, the primary participants were the children of patients, not the patients themselves. However, following a number of telephone conversations, it was confirmed that I was required to submit an application for ethical approval.

The process of completing the necessary ethical forms was initially an anxiety provoking activity. Anecdotal stories had been shared about the time taken for approval to be given. Furthermore, I heard stories of people not being given approval because of the age range of their participants. I worried that approval would not be given for my research and the consequences this would have on my planned work. The process of completing the necessary forms proved to be an extremely helpful exercise. This was an intense piece of work which helped me to focus my thinking about the research, the ethical implications and my practice. I was helped in the process by members of staff from the University of Derby and I am grateful to them for their help and support.

There are deadlines to meet when submitting the forms and the Lead Investigator is then invited to the ethics committee meeting to answer questions and discuss in more detail the proposed research. Completing the forms had helped to prepare me for this meeting, however, it clearly remained at the forefront of my thinking as an entry in my reflective journal illustrates:

> I dreamt last night that I was called in a day early for the COREC meeting. It was with [name of the Research Governance Lead for my local Primary Care Trust] and the secretary and without much questioning I was told that I had been granted it – I was so excited (19.07.07).

In reality the meeting was not quite so straightforward and I was asked a number of questions including ones about my methodology and the informed consent of the participants. Following the meeting, I was required to make some slight amendments to my proposal. I was delighted by this outcome. I felt that I had achieved a great deal in navigating my way through a potentially difficult process.

Prior to gaining ethical approval, I prepared the necessary information letters and consent forms for the participants (Appendix 3). One of the alterations required by the ethics committee was that the information letters and consent forms should be written in a 'child friendly' and age appropriate manner. My annoyance at myself was evident in an entry in my reflective journal:

> I could kick myself, how long have I worked with children and then I go boring. I think I must have been so wrapped up in getting the ethics right I forgot the audience and my fundamental principles – an important lesson (26.07.07).

The issue of providing appropriate information is discussed by Mishna et al. (2004). They suggest that by providing children with detailed and comprehensive information they will be in a better position to make informed decisions about participating in the research. However, they do not discuss how that information should be presented and do not acknowledge the importance of providing age appropriate information which is presented in an easy to understand manner.

Reflecting on the fundamental omissions I made in the initial submission to the ethics committee, I can now appreciate the importance of providing age appropriate information that is presented in an appealing and considered manner. The quality of the presented information reflects the respect which is afforded to the participants but also allows them to have a clear understanding of what they are being asked to do.

I had naively anticipated that once I had been granted favourable ethical approval, I would be able to proceed with my research in quite an uncomplicated way. Prior to submitting the forms to the ethics committee, I had worried that gaining approval would be the most difficult part of the research. Whilst it was crucial that I gained approval for the research to go ahead, this proved not to be the biggest challenge to my project, and upon reflection I had probably been over simplistic in my thinking. The discussion in Sec.3.2 clearly illustrates the actual barriers that were encountered in attempting to undertake the research.

3.1.5 Informed consent

An issue that I have been acutely aware of throughout the research has been the concern of informed consent. 'Informed consent is an ethical guideline requiring that subjects learn about foreseeable risks and discomforts before agreeing to participate in an experiment' (Singleton and Straits 2005, p. 166). Furthermore, the authors state that potential participants must be made aware that their participation is voluntary. However, a caveat to the word 'voluntary' should be made explicit, having in my professional role encountered misunderstandings with service users who have inferred the meaning to be 'non-paid' as opposed to the notion of 'free choice'.

Morrow and Richards (1996) suggest that in the UK consent is generally acknowledged as coming from the parent and thus they argue that children are 'to a large extent seen as their parents' property, devoid of the right to say no to research' (p. 94). When planning my research, the children's rights were of paramount importance and strategies were put in place to give the children as much choice and autonomy as possible.

When initially planning the research, I had intended that the staff from the hospices or hospitals would identify families with children who were receiving support and in the first instance approach them on my behalf. I hoped that following this initial contact, I would meet with the parents, discuss with them my research, and in addition provide them with written information. I did not stipulate whether it would be both parents that I would meet or the well or ill one. I felt this should remain flexible to allow the parents choice. I believed that it was important to not only provide written information about the research, in the form of the information letters but also to discuss in person the details of the research. There were a number of reasons for this, particularly because of the sensitive nature of my request but also my awareness of some people's difficulties with literacy skills.

I had planned that following the meeting with the parents, if they gave consent for their children to be involved in the research I would meet with the children to discuss my plans with them, including the nature of my involvement in the groups and the participant observation role that I would be employing. I emphasised that if the parents gave consent but the children did not want to participate, the children's wishes and feelings would be respected. The information letters for the children highlighted that if they decided not to participate, this decision would not affect the care that their parent was receiving or their attendance at the support group. I also intended to state this point when I met with the children. In addition, I highlighted that the children would be able to withdraw from the research at any point and again this would not affect their attendance at the support group or their parent's treatment.

A concern I had, when planning the participant observations within the group, was that some children may agree to participate and others may request that they were not involved. I recognised that if this occurred I would need to disengage from the group as I would not be able to observe some members and not others. However, as the research progressed and the barriers with gatekeepers were encountered, this no longer became a concern.

When I was initially planning the participant observations within the groups, I was aware of the sensitive nature of the research and how my involvement in the groups could potentially cause emotional difficulties for the participants. Because of this when I was having the preliminary discussions with the gatekeepers, I ensured that some support would be available for any child who was affected by my involvement. I had planned that I would be responsible for identifying a counsellor, however, the managers at Hospice A and B both said that they had staff who could offer this support. I also planned to allow time at the end of each session for a brief de-briefing to take place. This was going to be held after all the sessions with children and adults.

The professionals involved were also to be provided with written information about the research and verbal information to clarify and provide additional information about their involvement. The participants who were involved in the research were asked to sign two consent forms, one, which they retained, and one, which I kept.

3.1.6 Confidentiality and anonymity

A significant element in the information process for all the potential participants was the subject of confidentiality and anonymity. I emphasised that all the information would remain confidential and that names would be altered to protect their identity. Furthermore, the locations of the participants would be vague and non-identifiable. The children who have been involved in the research have all been given the option of choosing their pseudonym.

The issue of confidentiality when undertaking research with children is discussed by Williamson et al. (2005). The article's focus is on child protection protocols and research with children and highlights some important considerations for all research with children. When planning my research, I was aware of the dilemma between stating that the research would be confidential and also being aware of my duty if I was told something that would indicate that a child or young person was at risk of harm. All the information sheets that I produced for children and adults contained a sentence about confidentiality with the caveat that I would need to pass on information if I was worried that someone was at risk of being hurt (Appendix 3).

In addition to the support mechanisms that I put in place for the participants, I also took into account my own safety when conducting the research. Because the process for data collection needed to be amended, I adapted my research proposal to accommodate off site visits, either in people's homes or in public places other than hospices. In recognition of this I arranged with staff from the projects that I would inform them of the visits I was undertaking. This included information about the location of the interview and the time and date of the planned meeting along with the estimated duration. In addition, it was agreed that I would telephone the member of staff once the visit had been completed. I also recognised the potential emotional impact the research may have on my wellbeing. I arranged with 'Sally' (*all names are pseudonyms), the Project Manager at one of the projects, to provide regular supervision. Sally generously offered this support as she was aware of the emotional impact such work can have. Rowling (1999) writes about the emotional impact of research and discusses how when undertaking sensitive research she has utilised her reflective journal. I too have found that my journal has been invaluable in allowing me to write down feelings and emotions in the safe knowledge that I had the 'power' to decide what if anything I did with the contents. I knew that if necessary I could share the contents with my Director of Studies or with Sally in supervision, or alternatively I could leave them on the page having fulfilled their role.

3.1.7 Epistemological position of the research

Gilbert (2002) writing about the narrative approach suggests that narratives are 'always representations of a lived experience and are subject to change and reinterpretation' (p. 225). This is an important recognition, especially in relation to my research. I was aware that the stories and information shared by all the participants were their representations and interpretations of the events they were experiencing. Furthermore, I was very aware that the interpretations would be different for individuals and dependant upon their circumstances within the experience. Therefore, young children's narrative were likely to be very different from a teenager's experience and equally a parent's or professional's narrative would again be likely to be markedly different. Furthermore, as became evident during the research, professionals' experiences are determined by their role, the culture of the environment in which they work and their previous experiences and cognitions. Goodwin and Horowitz (2002) discuss the issue of interpretation and question how researchers can 'determine the meanings that others attach to their actions' (p. 39). However, as Gilbert (2002) says, when adopting this approach, the researcher is looking for deeper meaning and the important element to explore is not just what the participants say but how and why it is said. This tenet again fitted well with my epistemological position that within the research one of the things I was seeking to develop was an understanding of the emotional and social factors for children when a parent is at the end of life. This too is acknowledged by Gilbert (ibid) who suggests that 'this approach also taps into the emotional as well as the intellectual experience of the participants' (p.235).

The methods employed in narrative therapy have many similarities to the approach adopted in narrative research. Whilst it must be acknowledged that the role of therapist and researcher are very different, some of the fundamental principles of both approaches are closely related. Besley (2002) writing about narrative therapy suggests that the role of the narrative therapist is not to be a distant and neutral expert who has the solutions to the problems but rather to be curious and interested in the person's story. In many respects this was the position I felt I should adopt in this research. From the outset of the research I was conscious that the study was exploring an extremely sensitive subject area and that my approach needed to recognise and respect that. It therefore felt imperative that I demonstrated a curious, interested and sensitive method to my research. By adopting a narrative approach, incorporating a number of ethnographic methods I have been able to achieve this.

By adopting a narrative approach, I was attempting to understand how children construct meaning in their lives, how they represent their experiences and how they translate these experiences into their personal 'knowledge'. Therefore, the epistemology for this research was concerned with how children create meaning in the context of their experience of living with a parent who is terminally ill. The children's stories are their account of what is happening to them and their interpretation of events and therefore, I do not claim to be 'discovering truths' about their lives. As Crang and Crook (2007) have suggested 'stories told in the research encounter are not simply to be regarded as means of mirroring the world, but as the means *through which it is constructed*, understood and acted out' (p. 14)[original emphasis]. The important factor for this research was how the children make sense of what is happening and how within this they interpret their experiences. I was not therefore looking for factual versions of events and was aware that within a social constructionist epistemology the knowledge is open to change and is mediated by the cultural traditions of those who 'discover' it. As Fraser (2004) reminds her readers 'rather than hoping to produce 'the right' knowledge, or indeed, 'the truth' narrative researchers realize that there are multiple possibilities for representing stories' (p. 195).

3.1.8 Epistemological issues when children are the primary participants

Krauss (2005) suggests that 'epistemology poses the following questions: what is the relationship between the knower and what is known? How do we know what we know?' (p. 759). These questions could pose difficulties when undertaking research with children, particularly if Fine and Sandstrom's (1988) assertion that researchers often assume that their 'view' of the world is the same as the child's view is correct. Balen et al. (2006) discuss undertaking research involving children and present a different perspective. The article focuses particularly on securing informed consent from the children and includes a discussion about children's rights in relation to being active participants in research. Within this discussion, the authors consider how children are 'knowing subjects' about their lives and how researchers should move away from constructing the children's experiences from adult centred ideas. Within this debate the authors suggest that 'children are *epistemologically privileged* in that they are better placed than adults to produce 'situated' knowledges that prioritize the importance of their everyday experiences' (p. 31)[original emphasis]. This resonates with the two questions posed above, particularly in relation to the adult researcher's understanding of the child's view.

As the research progressed and circumstances forced a shift in emphasis, the accounts and stories of the professionals outnumbered the children's. However, this required movement did not detract from the initial epistemological position that the primary reason for the research was to develop knowledge and an understanding of how children make sense of their lives when a parent is terminally ill. Although I was required to make adjustments to the planned primary participants, the underlying epistemological position remained the same.

I am aware that the narratives and information shared in the research are not representative of all children experiencing the death of a parent, nor do they represent all the professionals working within palliative care. I am therefore conscious that the knowledge and understanding developed as a result of the research is not representative of all children but is a representation of what I hope are typical narratives and experiences and a summation of the experiences of those involved in this research. Furthermore, I am cognisant that the professionals' accounts, which have contributed to the research, are their interpretations of what is happening to the children and are likely to be different from the children's accounts of their experiences.

3.2 THE RESEARCH PROCESS: BARRIERS, CHALLENGES AND OPPORTUNITIES

3.2.1 Identifying the sample

As the research was being planned, it was my intention that the primary participants would be children experiencing the death of a parent. I intended the study to be a prospective one where the children were 'living' with the experience as opposed to a retrospective study where they were reliant on their memories and rehearsed narratives of the experience. I planned that children from three distinct age groups - pre-school, primary and secondary school - would be involved, thus representing children as defined by the Children Act 1989. It was my intention that I would become a member of the children's support groups within identified hospices and specialist hospitals and adopt a participant observer role within the groups.

It was envisaged that obtaining the sample would be dependent on opportunities from within the hospices and hospitals and thus consideration was given to the nature of the support groups and the potential unpredictability of numbers of children attending at any specific time. I was aware that the potentially small numbers involved in the research would mean that it was not a representative sample, but what the children's involvement would have provided was an introduction to the salient issues and a foundation on which future research could be built.

In addition to the children's support groups I also planned to undertake focus groups within the identified hospices and hospitals with the parents of the children. I also planned semi-structured interviews with professionals involved in palliative care.

I had planned that the sample for the research would be a purposive sample of children, their parents and staff, all of whom would be accessed through the hospice and hospital environment. Singleton and Straits (2005) explain that within purposive sampling 'the investigator relies on his or her expert judgement to select units that are "representative" or "typical" of the population' (p. 133). I had used my 'expert' judgement when making the assumption that the hospice and hospital environment would be the most appropriate and suitable places to provide me with my sample. Whilst this understanding was in fact correct at one level, I had severely underestimated the resistance of some of the gatekeepers, in particular the managers, in allowing me entry into these establishments.

The process of trying to gain entry is described in greater detail below. Suffice to say that the barriers and frustrations I encountered during the early part of the research required me to be flexible in my approach and to re-visit my initial plans. As the time progressed and I experienced seemingly impenetrable obstacles in gaining access to the children, it became apparent that contact with professionals working within palliative care settings would be the principal entree for the research.

Wright and Flemons (2002) suggest that few qualitative studies in research with the terminally ill have included family members, and no specific mention is afforded here to the children of dying parents. Alderson (1995) notes that children have in the past been denied the right to participate in research and have their voices heard. Furthermore, it is argued by Christensen and James (2001) that children's lives are traditionally explored through the views and understandings of their adult caretakers, and this was something I particularly wanted to avoid. Goodwin and Horowitz (2002) question whether there are 'groups whose voices we do not (or cannot) hear' (p. 39). This is a significant question in relation to children experiencing the death of a parent, who are not generally included in research.

As the research progressed the sampling of potential participants became a combination of purposive and opportunist sampling. I continued to rely on my 'expert' judgement and as Robson (1999) suggests used a purposive sample that allowed me to satisfy my needs within the project, albeit in a different form from originally planned.

3.2.2 The process of gaining access to participants

At the outset of the research, contact was made by letter with four adult hospices and key personnel from the oncology and palliative care departments at local hospitals. One hospice replied stating that due to changes within the establishment they would not be in a position to accommodate a student. Two hospices did not reply to the initial letter and were then contacted by telephone. One hospice responded positively to the initial letter and requested a meeting to discuss my proposal further. One senior member of staff from a specialist palliative care unit at a hospital agreed to meet with me. We met once; however, this person's interest stemmed from the academic aspect not the practical element of the proposed research. No other contacts were offered by personnel from the hospital units.

The hospice where the positive response was given (Hospice A) did not currently provide support to children. However, fortuitously, my letter coincided with some of the nursing staff identifying that there was a need for such a group. The staff members had approached 'Mary', the acting matron, to discuss their ideas. Mary observed that my research would contribute to the establishment of the group. She felt that my request was timely and appropriate and welcomed my involvement.

Following telephone conversations with the two other hospices, I established that Hospice B provided a monthly support group for children and employed a member of staff specifically to work with children and their families. The support group was for children who were experiencing the death of a family member and bereaved children. The hospice worked in partnership with a local project and staff from both services co-facilitated the groups. The other hospice did not provide any support and whilst the member of staff acknowledged that support was needed for children, she also observed that due to staffing, funding and resources it would not be possible for them to develop such a programme.

A positive meeting was held with 'Christine', the manager at Hospice B. She, like Mary, agreed, subject to ethical approval to me joining the group as a volunteer and participant observer. I then met with 'Joan', the member of staff from Hospice B who worked with the children. I had some anxieties after this meeting, I was left feeling that she was not happy about me joining the group and that she did not feel comfortable having me work alongside her. Her body language and behaviour appeared negative, and furthermore, her comments were not encouraging.

The two positive meetings with the managers pleased me and somewhat surprised me. I had read how one of the major obstacles in research is the preliminary agreement from gatekeepers (Wright and Flemons 2002). Lawton (2000) discusses how she initially faced seemingly impenetrable barriers when setting up her fieldwork. Lawton's fieldwork has some similarities with the current research insomuch as it was undertaken in a hospice, participant observation methods were employed and to some degree the research was being used by staff to implement change within the setting (Lawton 2001). Lawton (2000) delineates some of the reasons she believes she had difficulties initially gaining permission from the stakeholders. In comparison and interestingly, I did not initially encounter such obstacles. The two hospice managers who agreed in principle to the research were in the beginning welcoming, supportive and excited by the prospect of my involvement. Although I did not have a medical background, I believe that my status and experience as a manager of a family support project in the Third Sector along with my early years background represented the credibility that was necessary to determine my entry into the field and gain the trust of fellow professionals.

3.2.3 The frustrations and barriers in gaining entry

The period when I was awaiting final ethical approval became quite frustrating as illustrated in my reflective journal:

> ...more worrying is the fact that I telephoned [Hospice B] last week to share my news / update Christine. She was really pleased for me and again reiterated how good it would be for the hospice. However, she also informed me that she is leaving (and will have left now). A big worry is what if the new person isn't so keen for me to do the research? What if they do not appoint anyone? Hospice B is my only 'active' contact and so I really need to maintain the relationship / agreement (02.08.07).

The frustrations continued throughout August 2007. Hospice B did appoint a new manager, 'Tracey', and I met with her. I left that meeting with doubts and anxieties about whether she would give permission for the research to proceed. I sent all relevant documentation to her, as requested, and became increasingly frustrated when the letter of approval from her, which was required by the ethics committee, did not arrive. After waiting some time for the letter of approval from Hospice B, I made the decision not to continue pursuing this potential option. Although this was a difficult decision to reach, I felt that I needed to make it. I was unable to complete and return the required amendments to the ethics committee without the letter of approval from the hospice. I therefore felt that I needed to make a decision regarding the progress of my research. I had received a letter from Hospice A stating that they were happy for the research to proceed. I therefore felt confident that I would have continued contact with one hospice.

Regular meetings continued to be held at Hospice A to discuss the setting up of the support group. The initial meetings were positive and I felt that steady progress was being made towards a group being established quickly. My reflective journal for 29.08.07 captured my optimism:

> One of the nurses said about running the group weekly – music to my ears!

However, as the monthly planning meetings progressed they became more laboured and my initial optimism that the group would be established quickly was soon questioned. The staff began to question whether a support group was necessary and whether children would attend. They also discussed the remit of the group and whether it should be solely for bereaved children and not be available to children whose family member was accessing the hospice for support and care. A reason that was proposed for this was that the well family members 'have enough to think about'. Whilst this fact cannot nor should not be disputed, the limited research that is available about pre-bereavement issues for children demonstrates that support pre-bereavement can alleviate post bereavement issues (Beale et al. 2004, Dunning 2006).

I recall that during this meeting I felt very uncomfortable and inwardly angry. No one appeared to consider that the children should have a choice about attending. It is probable that some children may choose not to attend but they have a right to make that decision. I thought about the ethos of the hospice movement and how it was founded to support the dying and their families. I privately questioned whether Hospice A had 'bought' into this ethos. In the meeting I suggested that a simple questionnaire could be developed to be used to survey the children and families about the necessity of a group. I was assigned the task to create some draft examples. These were then circulated at the following meeting. It was subsequently agreed that the questionnaires would be given to patients at the hospice to ascertain their thoughts about the feasibility of a group. However, I became aware later that this line of enquiry was not pursued.

Mary attended some of the meetings and appeared to be creating barriers to the group starting. These observations were also noted by other members of staff at the meeting. She stated that funding and resources were two issues that could prevent the group from being viable. I had previously researched three potential grants for the work. In the meetings along with mentioning the grants I also offered to become a volunteer within the hospice and to take responsibility for developing the group. These offers of support were not 'heard' by Mary. I reflected on this and endeavoured to answer why she was seemingly reluctant to accept my offers of help.

In March 2008 I attended a planned meeting at the hospice; however, when I arrived I was informed that it had been cancelled. The member of staff told me that a new matron had been appointed and Mary no longer worked at the hospice. The new matron had been informed about the planned support group and had made the decision to 'put it on the back burner'. I left the hospice reluctantly knowing that it was unlikely that the support group would be developed during the lifetime of my research.

3.2.4 Reflections upon the frustrations

The changes in direction initially caused some concern as I worried that I was in danger of losing sight of the fundamental proposition that I held about the children being active participants in the research and being given a voice on a subject where they are generally not included. My frustrations echoed Crang and Cook (2007) who state that 'one of the more nervous and dispiriting times during a research process is when you receive a steady stream of rejections to initial enquiries' (p. 21). My experience was not so much a steady stream of rejections but more an incredibly frustrating silence and inertia. The two primary contacts which had initially appeared so positive quickly became sources of frustration. Reflecting back on that period, the frustrations were multi-layered. At one level there was the concern that my research would not be able to proceed because of the barriers erected by gatekeepers but also the worry that barriers would prevent me from involving children in the research and therefore preventing them from having the opportunity to influence the research process.

Upon reflection, as I am now some distance from this period, I question where my frustrations stemmed from, particularly in respect to my earlier comments about Hospice A. I wonder whether the feelings of being 'uncomfortable and inwardly angry' stemmed from my personal belief that a support group would be beneficial for the children or because of my eagerness to become involved in a group and to have the opportunity to access some participants. I wonder whether, during the early days of the research, I became too embroiled in the processes that were unfolding and as a result lost sight of my role as researcher. Conversely though, the passion in my research has been the driving force that has sustained the commitment throughout the doctoral journey.

3.2.5 Significant turning points

During this period of frustration, I did meet with a young adult, Jennifer, whose mother had died when she was a teenager. My Director of Studies, who had been her lecturer, had introduced me to Jennifer. Jennifer's story will be presented in detail in Chapter Seven, however, this again illustrates the value of purposive sampling where the introduction was made with specific intent. Jennifer became a key informant and contributed significantly to the research.

I had through the process of trying to gain entry into Hospice B been introduced to a Third Sector project that provided bereavement support to children aged between five and thirteen years. The project worked in partnership with Hospice B, with workers from both teams co-facilitating the monthly support groups for children, both pre and post bereavement. The initial contact with the Project Manager, Sally was very positive, however, once I had made the decision not to pursue the research with Hospice B, I telephoned Sally to update her about the research. During this conversation the possibility of me undertaking an evaluation of the project was first discussed (please refer to section 3.2.7).

As the above evaluation was being undertaken, I also employed purposive sampling in contacting three more hospices. These contacts resulted in me undertaking semi-structured interviews with the social workers and family support staff within the hospices. Furthermore, one of these encounters resulted in providing me with the opportunity to support a social worker, 'Charlotte' to undertake a small feasibility study with children and families who had previously accessed the hospice to ascertain their views on pre-bereavement support for children. This hospice did not at the time offer any specific pre-bereavement support to the children of patients.

Charlotte provided me with the name of another social worker, 'Christopher', working in a hospice that I had not previously contacted. Christopher became a key informant and through our meetings signposted me to colleagues who I interviewed. These colleagues included other social workers, nurses and a palliative care doctor. Christopher also arranged for me to attend, as a participant observer, a support group for bereaved children that he facilitated. This gave me the invaluable opportunity of meeting with a small group of young people. Prior to the meeting, Christopher obtained informed consent from the young people's carers and the young people.

During a semi-structured interview at one of the hospices, the worker suggested that I contact the local branch of a support group for people with a specific neurological disease. I contacted the chairperson of the group who was very supportive and helpful. As a result of this discussion, I was able to contact a young person 'Luke' whose mother had died from the disease some years previously. The meeting with Luke proved to be very informative and illuminating and will be described in detail throughout the findings chapters and the discussion chapter.

Further opportunist sampling occurred as the research progressed. The first was through the reading of an advertisement in an academic journal for a forthcoming conference. One of the speakers at the conference worked as a specialist nurse some 200 miles from my initial contacts. 'Hannah' became a key informant in the research and throughout the second half of the study we have had extended contact.

The second opportunist sampling occurred following a discussion at a conference. During a conversation with another delegate, I heard about an independent service whose remit is to support children through any loss or bereavement. This again proved to be a serendipitous meeting. During the initial meeting with 'Pat' the manager, the idea of me evaluating the service was discussed. It was agreed that I would independently evaluate the service and use the data for my research. Pat was responsible for identifying potential participants for the evaluation. These included children and their families and professionals who had referred children to the project. However, as the evaluation progressed it became evident that there was little data that could be transposed from the evaluation into my research. This was in part due to the aim and objectives of the evaluation that did not correspond with my research. Notwithstanding this, the time spent with Pat was invaluable and I learnt much during the process.

3.2.6 The composition of the sample

The individual experiences and accounts of seven children were included in the research. Within this, two young adults who had been bereaved of a parent as children were interviewed. One of these young adults, a female, was introduced to me by my Director of Studies, she was fifteen years old when her mother died. The other young adult was a male whose mother had died when he was fifteen years old. Initial contact was made with him via the chairperson of a local support group for people with a neurological disease.

The five children who were interviewed had also experienced the death of a parent or significant carer. Two females, aged ten and seventeen, were involved in the feasibility study and were interviewed within the hospice environment. The seventeen year old had been bereaved of her mother when she was fourteen. The ten old year was nine when her grandfather died. Three children participated in the project evaluations and I met them in their homes. Two of these children were female siblings aged six and eleven years. Their father had died two years prior to our meeting and they had received support from an independent organisation following his death. The other child was a nine year old boy whose grandmother had died when he was five, he too had received professional support following her death.

In addition to the seven individual accounts, I also observed nine bereaved young people in a support group which was organised by one of the professionals who became a key informant. The group was held in a community building that was not connected to the hospice where their parents had been nursed. The young people had been meeting together weekly for eight weeks when I observed one of their sessions. The sessions were facilitated by the worker from the hospice.

Five parents were interviewed. I met with one terminally ill parent who was the mother of two children. She was receiving care from a hospice, I met her at her home following an introduction from one of the professionals who was a key informant during the research. I did not meet with her children. Four bereaved parents were interviewed. Two were involved as part of the feasibility study at a hospice and were interviewed with their children. One had experienced the death of his wife, the mother of his two daughters, and one the death of her father. The grandfather had played a significant role in caring for his granddaughter and she described him as 'my best friend in the world'. The other two parents who participated in the research were receiving support from the independent organisations that were evaluated. One, a mother, bereaved of her husband was interviewed with her two children, the other also a widow was interviewed alone and I did not meet her three children.

Sixteen professionals were interviewed. Seven were employed in four different hospices. Of these, four were social workers, one a bereavement co-ordinator, one a community palliative nurse and one a bereavement counsellor. They all worked directly with children whose parents were dying or had died. Three participants worked within the hospital environment. One was a nurse practitioner, working in a specialist palliative care unit. A percentage of her contract was dedicated to working directly with children and their families. Two were palliative care nurses working within a general hospital, their roles were not to directly work with the children of patients, however, through the course of their work they did meet with the children. Four participants worked for independent or voluntary organisations. Three of these professionals worked predominantly with bereaved children and their families and one worked both pre and post bereavement with children and their families. One participant was a palliative care social worker employed by a Primary Care Trust whose role was to work with children and families. One was an Education Welfare Officer working in a comprehensive school. Her role was not primarily to work with bereaved children, however, through the course of her work, there were many occasions when she supported them. Fourteen of the professionals were females and two were males.

In addition to the participant observations I undertook within the bereavement support group, I also spent time observing the day to day work of an independent service. Along with interviewing staff, I was given the opportunity to observe, with the informed consent of the families, sessions with children and their families. Appendix 1 provides a summary of all the children, parents and professionals who participated in the research.

3.2.7 Ethical issues encountered in the research process

During the research process I experienced an ethical issue that required consideration, thought and reflection. As the frustrations during the early stages of the research escalated, I met with Sally, the service manager of a Third Sector project, where support to bereaved children and their families was provided. Initially, as stated above, it had been planned that the involvement with this project would be peripheral; staff from the project worked in partnership with Hospice B that provided a support group for children. Therefore, my early involvement, with the project, had been to outline my planned work with the hospice and obtain permission from the manager. After I had made the decision not to pursue the research within the hospice, I contacted Sally to inform her of my decision.

Sally was very interested in offering what support she could to the research, and during our conversations, suggested that I might consider undertaking an independent evaluation of the project, subject to agreement from her manager. The purpose of the evaluation was to establish service user's thoughts and opinions about the project, which in turn would be presented to funders in an attempt to secure continued funding for the project. Sally suggested a reciprocal agreement, whereby any relevant findings from the evaluation could contribute to my research. This offer represented to me an opportunity to gain access to participants and to counteract the frustrations that I was feeling at the time. However, I was concerned whether this was ethically sound practice, I was worried about the implications for the participants and how they would perceive their involvement in the evaluation. I reflected on this and then discussed the dilemma with Sally. We explored how the findings could be synthesised for both the evaluation and my research and the possible implications with regards to the participants. Through these discussions, it was acknowledged that potential participants would be informed clearly from the outset of the dual purpose of my involvement and would then be able to make an informed decision about their involvement.

As the research progressed two further project evaluations were undertaken. However, it became apparent that there was limited information being provided from the evaluations that could contribute directly to my research. The aims and objectives of the evaluations were sufficiently different that the majority of the findings related directly to the support offered by the services as opposed to the children's experiences. Whilst these findings were helpful in offering me a wider perspective along with some incidental information, they provided few detailed accounts that contributed to the findings for the thesis. However, the experience increased my knowledge and awareness with regards to planning, undertaking and managing evaluation projects.

3.3 DATA COLLECTION AND ANALYSIS

3.3.1 Data collection

At the outset of the research it was planned that the primary method of data collection would involve me becoming a member of support groups for children within hospices and adopting the role of participant observer. In addition, semi structured interviews and focus groups were going to be employed with the professionals involved in palliative care and the children's parents.

However, as the research process progressed and I was required to alter my proposal to circumvent the challenges faced by the early encounters with reluctant gatekeepers, I was forced to modify my original plans. As the focus moved away from the children to the professionals involved in palliative care, the methods of data collection also needed to be re-considered. Nevertheless, in the subsequent data collection process, to a lesser degree, participant observations were undertaken, particularly when I developed a researcher relationship with a number of interviewees who became key informants. However, the majority of the data collection employed semi-structured interview methods.

I entered each interview with a number of key prompts which I used during the interview. However, as the interview progressed, and the interviewee shared more information about their role or experiences, supplementary questions or prompts were also used. This allowed me to develop within the interview a conversation which had a purpose (Robson 1999). Before each interview began, I went through a protocol with each interviewee, this included re-confirming informed consent and explaining about confidentiality and anonymity. Prior to beginning the interview I also asked permission to audio tape record the interview. Recording the interviews was invaluable as it allowed me to give my full attention to the conversation. (Appendix 4 – information letters and consent forms).

The length of the interviews ranged from forty minutes to two hours. Robson (1999) writing about the length of interviews suggests that less than thirty minutes will not be valuable and anything over one hour will be making unreasonable demands on the interviewee's time. The interviews that lasted two hours were the ones with Hannah, a key informer whose contribution is discussed at length throughout the thesis. Hannah and I met twice during the data collection period and it was Hannah's suggestion about the length of time allocated. This was in part because of her generous recognition that I had travelled some distance to meet with her and also because of her interest in the study and her willingness to play an active role in my research.

All the interviews were undertaken at the professionals' place of work. The small number of interviews that I completed with children were held at a venue of their choice. At the end of each interview an endings protocol was followed which included thanking the interviewee for their participation, checking out whether there was anything they wanted me to omit from the interview and establishing whether I could contact them again.

The four interviews that were undertaken in collaboration with Charlotte, from the hospice, for the feasibility study were planned together. However, Charlotte took the lead role during the interviews. I asked some supplementary questions but predominantly took the role of observer. This was a really useful exercise as it allowed me to observe the interview process from a different perspective which was not necessarily possible when I was the sole interviewer.

3.3.2 Data analysis

The process of analysing all the data has been very time consuming but an immensely powerful and engrossing procedure. Crang and Cook (2007) suggest that the analysis of data is a formal stage within the research process where the data is looked at carefully and critically in order to see new themes and patterns within the data. It is therefore imperative that sufficient time is allocated to the process. The process has been ongoing since I began the data collection. Throughout the research I have used my reflective journal, however, during the data collection and analysis process it became an invaluable research tool that augmented the rich data that had been collected. Furthermore, it has been utilised for considering my emotional reactions to the research and helped in the reflexive process. Rowling (1999) highlights the importance of reflexivity in qualitative research but suggests that in research on loss and grief it is vital.

When I was planning the research I reflected whether I should undertake the process of transcribing all the data or whether I should delegate this to a professional transcriber. However, I decided very early in the research process that I should be responsible for transcribing the data. Although I was aware that this would be time consuming, I was also conscious of the nature of the material and protecting confidentiality, but also the importance for me of being able to begin to submerge myself in the data from the outset. I realised that, in my opinion, a precious opportunity would be lost if someone transcribed the material on my behalf. Fraser (2004) writing about transcribing data suggests that '[W]hile time consuming, transcribing the interviews yourself carries many benefits. The main benefit derived is how close you are able to come to the stories' (p. 187). Moreover, Tilley (2003) writes how the transcriber's perspective may influence how the data is transcribed which, she suggests has the potential to influence the researcher's analysis of the data.

3.3.3 The process of analysing the data

Following each interview a similar pattern emerged. As soon after the interview as possible, I transferred the audio recording from my digital recorder to a dedicated memory stick on my personal computer. I then listened to the recording and began transcribing the data. I did this firstly by hand, writing the interview out verbatim. I included within the transcripts all the pauses, laughs, sighs and other utterances. Although it could be argued that this was a longer and more laborious system than just typing the interview as I re-listened to it, it felt the right process for my learning style. It allowed me to concentrate on the dialogue and reproduce accurately what I was hearing. Furthermore, by adopting this method I was able to submerge myself immediately into the data and re-acquaint myself with the interview. An early entry in my reflective journal captures the value of this process:

> Finished just before tea transcribing Hannah's interview. Managed 30 minutes all day! Was getting really tired but didn't want to finish, it was so riveting and engrossing to re-hear and write down what she was saying (21.08.08).

Once I had hand written each transcript I checked for accuracy and then began copy typing it. When each interview was typed up, I firstly re-read it on screen to check for accuracy and any typing errors. I then printed off the transcript and carefully read through, numbering the sentences and marking each one with the interviewee's or my initials for ease of identification, in effect coding them into chunks of text. These codes were then transferred onto the electronic version of the transcript. This version was then printed off.

I opted to employ a simple technique for the analysis which included the use of coloured pencil crayons. My journal entry for 15.11.08 demonstrates this:

> I am getting on with the data analysis – not particularly high powered technical stuff- lots of crayons and paper.

As I read through each transcript I began to identify 'big' themes that were emerging. Each 'big' theme was allocated a colour, for example, communication was a red crayon and psychological and emotional issues a brown crayon. The paper version of each transcript therefore ended up with a patchwork of colours underlining the corresponding sentence. Some of the data slices were relevant to more than one 'big' theme and were therefore coded with a number of different colours. Crang and Cook (2007) suggest that at this stage the important themes or categories should be emerging.

3.3.4 Reflections on the use of electronic or manual system for analysing the data

Prior to beginning the process of analysing the data I considered using a computer software package. However, for a number of reasons I decided against this option, primarily, because I felt that as a novice researcher it was important that I undertook the process manually. Riessman (1993) writing about her experience of data analysis suggests that:

> ...the task of identifying narrative segments and their representations cannot be delegated. It is not a technical operation but the stuff of analysis itself, the 'unpacking' of structure that is essential to interpretation (p. 58).

This is congruent with Gilbert (2002) who discusses how employing computers in the process of analysing data should be used with caution. She suggests that whilst computer packages can be helpful in the organisation of information, they can also fragment the text and disconnect it from the wider narrative. The process of manually transcribing and analysing the data was important for me as it allowed me to really begin to grapple with and understand the complex nature of the children's experiences.

3.3.5 Becoming immersed in the data

After completing a number of transcriptions I then created new computer files with the corresponding identified 'big' themes each having their own file. The colour coded sentences from each transcription were then cut and pasted into the new document thus creating files containing the composite data slices.

Once all the data had been collated into the relevant new 'big' theme files, each file was printed off. I then began the next low-technical part of my analysis. Each chunk of data was cut into its own strip. All the strips were then placed on the floor and I began grouping them into smaller categories therefore developing sub-headings and creating 'smaller' themes for each category. This process is discussed by Crang and Cook (2007). They suggest that there are a number of ways to undertake this process and that different factors will determine the best method for each researcher. These factors, they suggest, include the amount of material requiring analysis and the time available for the process. They discuss the use of qualitative data analysis packages but also suggest that it is 'equally possible to do this sorting manually by cutting up chunks of notes and transcriptions and placing them in coded piles on your floor' (p. 140).

During this process I continued re-reading the full transcripts from each interview to submerge myself further into the data. This was an ongoing activity. Through reading the whole transcripts and the smaller categories the major themes which correspond to the findings chapters began to emerge.

I noted when re-reading the transcriptions how whilst reading them I was ‘taken back’ to the interview. I clearly heard the interviewee with their distinct accents and moreover, I was transported back into the room and re-experienced the emotions and feelings that had been provoked within me during the interview, some of which had been lost with the passage of time. Furthermore, and in congruence with Riessman (1993) this repeated listening led to insights that helped shape my interpretation of the interviews and thus the identification of key themes for the thesis. This too is recognised by Riessman (ibid) as being important to the researcher’s epistemological position, their values and personal biography.

Summary

The focus of this chapter has been an exploration of the methodological processes undertaken for this research. The chapter began by delineating the rationale for the choice of methodology and methods. This included how the underlying principles of the research determined that a qualitative methodology adopting an ethnographic approach would be the most appropriate choice for this piece of research. Tapping into the richness of the children’s thoughts, feelings and experiences underpin the aims of the research and are thus congruent with a qualitative methodology that aims to capture the stories of the participant’s experiences in a specific situation. The debate about qualitative versus quantitative methods was briefly discussed, this included an exploration of the validity and reliability debate.

The focus of the chapter then moved from the theoretical to the practical and there was a detailed account of the processes I went through in obtaining favourable ethical approval from the NHS Research Ethics Committee. Within this I described some of the anxieties experienced along with the learning and development opportunities that the process provided. The chapter described in detail some of the issues relating to informed consent. Because of the sensitive nature of the research and the young age of the participants it was essential that I was able to provide sufficient information to the ethics committee to evidence that I had clearly considered the issue of informed consent. Within the discussion about ethical considerations there was reference to ethical issues that I encountered during the research and how these were managed. These related to the rights of the participants and my responsibilities as researcher in upholding those rights and providing the participants with open and honest information about their involvement in the research.

The epistemological position of the research was discussed and this was followed by a discussion about identifying the sample. This included a detailed account of the sampling methods employed, the process undertaken to gain access to participants and the frustrations and barriers I encountered in gaining access. When I was encountering the barriers, which were erected by the gatekeepers, I felt frustrated, disappointed and angry. However, as the barriers remained and I had the opportunity to explore the feelings of frustration with my Director of Studies, a clearer understanding developed which assisted me to locate my feelings and to understand better the process of research. The feelings of frustration and anger were turned into an understanding not only of the process of research but also a recognition of some of the issues encountered by children experiencing the death of a parent, which became a core theme throughout the thesis.

From the frustrations and barriers came some significant turning points and opportunities which were discussed within the chapter. These opportunities led to the privileged encounters I had with some very dedicated professionals within palliative care and a small number of children who generously shared their stories to develop my understanding.

A brief section discussed the data collection process and the protocols employed with the semi-structured interviews. This was then followed by a detailed discussion about the analysis of the data and the process undertaken whereby the rich and valuable data was processed and the foundations for the thesis developed.

CHAPTER FOUR: COMMUNICATION AND INFORMATION SHARING: DON'T IGNORE THE ELEPHANT IN THE ROOM

Living with a parent who is dying has the potential to be an isolating event. The children enter a new and difficult environment, where all that is familiar is at risk of becoming alien. The routines of family life are likely to be rocked and the family's identity transformed. The new environment has no guidebook or instruction manual and examples from my data suggest that there are few fellow companions to travel alongside the children. Therefore, the necessity for information and for being party to conversations about the illness and prognosis are essential.

One of the overarching themes to emerge from my analysis of the data, the one that all the interviewees consistently discussed, was the importance of open, clear and appropriate communication. Related to this was the importance of information sharing, seen equally as a priority. However, participants' accounts also suggested that there is frequently reluctance, on the part of parents and professionals, to engage children in such conversations. The metaphor of the Elephant in the Room is used to illustrate how children whose parents are dying are often invisible within society and are frequently not included in conversations about what is happening in their family.

My findings indicate that there is a continuum of information sharing and communication between adults and children and there are parallels here with Glaser and Strauss's (1980) writings about awareness contexts. The children are 'placed', in terms of their inclusion and awareness, on the continuum and their positioning is determined by the quality and quantity of information that they receive. Therefore, the more they are involved the more they enjoy an open awareness and are positioned towards the 'open' end of the continuum. Conversely the children who do not experience such levels of involvement are more likely to be placed on the 'closed' end of the continuum and have a closed awareness. There are a number of factors that contribute to their positioning on this continuum. The quality and quantity of information is a significant factor, however, equally, the use of language, the professional's confidence and competence in communicating with children and the quality of the professionals' training contribute to this positioning. Furthermore, the parents' and professionals' desire to 'protect' the children impacts on the information exchange, along with the embedded cultural perspective of 'ignoring the elephant in the room'.

The chapter will begin by examining examples where children are included and appear to receive age appropriate information about their parents' illnesses and the prognoses. This will include children's opinions about the value of being included along with examples where children expressed a desire to be included and provided with regular information. This will be augmented with data from the professionals' interviews exploring the value of including children in discussions and information sharing.

In contrast, the second section of the chapter examines examples where children have not been included in the communication and information sharing process and here I argue the relevance and necessity of this with regards to their positioning on the communication continuum (Appendix 2). Some of the accounts indicate that parents may see this exclusion as a way of protecting their children. This is followed by evidence that some children would prefer not to be included and I will explore occasions when they appear to make the decision not be involved in the discussion and not to express their feelings and opinions. The emphasis will then move from the children's to the parents' perspective and the wider issue of talking to children when one parent is terminally ill. The data offers explanations about the parents' ability to talk to their children along with the inhibitors that may prevent such conversations from taking place. This section will also describe the professionals' accounts of how they try to encourage and facilitate communication between parents and their children. This will be followed by a section highlighting the participants' views on information sharing, including the timing of providing information.

The following section examines examples of language use. A particularly valuable theme to emerge relates to the use of euphemisms and the importance of communicating in an age appropriate way. The accounts show how the use of euphemisms can lead to the children misinterpreting and misconstructing the information they have been given. This will be followed with examples provided by the professionals involved in the research who shared evidence of the use of euphemisms. The final part of the chapter examines data from professionals and their attitudes towards becoming involved with talking to children when a parent is at the end of life.

The findings provide evidence that where children are included and where information is freely available, they appear to cope better. However, the accounts discussed in the chapter illustrate that many children are excluded from knowledge of, and involvement in, the care of their dying parents. The chapter examines the accounts of the participants and explores the themes which offer explanations of this exclusion.

4.1 CHILDREN BEING INCLUDED

4.1.1 'I was glad you told me': The value of being included

Being included in communication and information sharing is imperative for children in helping them to begin to manage the enormity of the life changing events that are associated with parental terminal illness. This was a theme that was consistently returned to by all the participants. Likening the children's experience with the work of Glaser and Strauss (1980), this sharing of information and inclusion in conversations, could be paralleled with open awareness where 'all involved are willing to share information or concerns that each may possess, and such sharing is actually implemented' (Corr and Corr, 2000, p. 238).

The value of receiving regular information about the illness and thus enjoying an open awareness was evidenced by 'Georgina'. I met Georgina, an articulate ten year old, and her mother during the feasibility study. Her maternal grandfather had been nursed at home for a number of months before he was admitted to the hospice for palliative care. Georgina's mother described how she had made a conscious decision to keep her as fully informed as possible throughout her grandfather's illness. Georgina said to her mother during the interview:

> I was glad you told me [about her grandfather's prognosis] or I would have been more shocked...I wouldn't like it to be hidden, I knew something was wrong, I would rather have the shock then instead of a big shock at the end.

Georgina's mother's response to the comment highlighted her opinion of being proactive in communicating, sharing information and thus establishing an open awareness:

> You can never fully prepare children, but they need to be as much as possible.

An interview with 'Luke', a young adult, whose mother had died from a degenerative neurological disease when he was fifteen, further highlighted the theme of being included in conversations about the illness. Luke explained that he was nine years old when his mother was diagnosed with the disease. He talked about the communication and information sharing that he had been involved in with his family and highlighted how this process had developed as his mother's health had deteriorated:

> I suppose in the first couple of years there wasn't as much to talk about because it was just like a steady progression so it was probably like three years in when you start getting to notice things were actually significantly bad and that's probably when we spoke about things more.

Luke discussed the value he felt from being included in familial conversations and the benefits associated with this involvement:

> I think one of the worst things is not knowing things. If there is something bad happens and you don't know much about it that would have made it a lot worse. I am glad that I knew as opposed to not knowing because it meant you are able to do things and say things because not everybody gets that chance so I suppose that was beneficial.

Not having information can have a detrimental impact on the children's understanding of what is happening and can create confusion and fear. During the interview with Luke he spoke about his belief that typically children do want to be included in discussions and information sharing and how this helps in developing a more informed awareness:

> Erm definitely because like I said not knowing is the worst and especially from a child's point of view because they've got, they probably don't understand things as well anyway but if they are in a situation where you know something bad is happening and they don't fully understand it, it's going to be a lot better for them to be able to associate what is going on with the specific things and know the details about it because that will, well it helped me knowing what was coming and how to deal with it definitely.

'Samantha', a seventeen year old, whose mother had died from cancer, described during our interview how she and her younger sibling had been included in all the conversations with her parents about her mother's illness. She commented on how she felt this had been of value:

> It was useful to know what was happening and I would have preferred to know because I didn't want to be making up stories all of the time.

Furthermore, she discussed her cognitions about what might happen if children are not included in the conversations:

> We found out a lot from dad because mum was a nurse, but if people don't know about medicine they wouldn't know what's happening. If people don't know what is going on they would feel helpless.

Georgina offered an observation about a friend whose grandfather had died and within this compared their experiences. The account highlighted Georgina's perception of the value of being included in conversations. Georgina remembered how her friend had not been party to any conversations about her grandfather's illness and death. This had apparently resulted in her thinking that she had been to blame for his illness and that she had done something wrong.

The professionals involved in the research provided similar accounts about the value and importance of children being included in conversations about their parents' illnesses. During my interview with 'Christopher', a social worker in a hospice, we discussed some of the issues and behavioural manifestations children typically experience when a parent is seriously ill or has died. This led Christopher to discuss the values he feels are associated with children being given permission to talk about their situation:

> ... and I suppose even if it is just the one chance they get to say it they are voicing their own fears or thoughts or feeling yes it does make a difference.

'Hannah' discussed the value of including children during the pre-bereavement stage. Hannah is a specialist nurse who I interviewed on two occasions and who became a key informant for the research. The following quote is from my first meeting with her where she was discussing her opinion regarding the importance of providing support for children when a parent is at the end of life, with particular emphasis being placed on the role professionals play in supporting and facilitating these conversations:

> Because I think that's the opportunity, because if we don't [include the children] what it means is that there is a potential for children to be excluded at a time when they should be included or they are included in a way that is either appropriate or inappropriate and it could be that the families do that not because they are always, you know incompetent or difficult or anything like that, they just do it because that's how it falls and being able to give much more supportive care to families at an earlier stage might be much more helpful and again families might not want it in which case that's fine you can only offer.

The importance and value of including children in conversations about their parents' illnesses is evidenced in the accounts of children and professionals. Whilst the professionals' accounts are based on their practice and knowledge the children's are taken from experience and their memories of the period when their parents were ill and following their deaths. However, similar themes emerged from both sets of accounts.

4.1.2 'Just knowing that there is someone there': Children having the opportunity to talk about what is happening

Receiving regular information and being party to conversations about the parent's illness from family members was one aspect that the children discussed as being positive. However, the value of extending the conversations from family members to include non-familial members and group support was also explored. Luke discussed this and explained how he felt having support from outside his family would have been beneficial:

> Erm but I suppose just knowing that there is someone there that you can talk to somebody that's just easy to talk to where you feel you can tell them things and discuss really like your feelings and how it has affected you, where its not like I said with your family, where you can just be open and say this is how I feel and probably not necessarily where anything has to be done about it but just being able to talk through how you feel cos that always, I always think if you talk it makes it easier.

A retrospective interview with a family of three young children whose father had died two years prior to our meeting highlighted the value of ongoing support, particularly within a group setting with peers who are fellow travellers and who have lived through similar experiences. 'Kirsti' was an eleven year old and the eldest of the children. She suggested:

> ...like you know a lot of people sometimes lose people at the same time, like seeing people you know and talking to them. So you've got a group, and you know how other people feel and you are not the only one.

There are occasions when talking with parents is problematic or difficult for the children and the value of having someone to talk to who is not a family member can be beneficial. This was exemplified in the interview with 'Sonny' and his mother and highlights the value of non-familial support. Sonny was nine years old when I met him, he lives with his parents and two younger siblings. His mother described how he felt unable to talk to his parents but could talk to his support worker. Sonny's paternal grandmother had lived with the family until her death four years previously. Sonny had experienced a difficult period following his grandmother's death and had been referred to a children's bereavement worker. His mother recalled:

> ...there were loads of questions which he had never been able to ask us but that he could openly ask [name of worker].

Giving children the opportunity to engage in dialogue about the parent's illness was also discussed from the professional's perspective. Christopher described his thoughts during our interview:

> I think for certain kids its yes very very valuable, yes just to be able to talk and often I suppose I'd forgotten this, you get ingrained in work don't you, this seems a process not a reflection but sometimes I'll meet with kids and think "God that's the only time they have ever talked about this with someone outside the family" so I think that is very valuable.

The value of being included in conversations is evidenced through the accounts of the participants. But equally, acknowledgment and recognition that this support needs to be available from a number of sources and not be left solely as the family's responsibility, should be recognised. Within this, consideration needs to be given to the parents' ability to instigate such conversations when they too are likely to be emotionally burdened. Furthermore, the children's opinions and preferences also need to be considered and respected.

4.1.3 'It feels like you can't talk': The issue of privacy and confidentiality

The issue of privacy and confidentiality when talking with others about parental illness and death was raised during the interviews. 'Emma', aged six, the younger sibling of Kirsti, highlighted this during the interview with her family. She was discussing the support she had received from a bereavement support service and was pondering how the service could be developed. The following is taken from the transcript and is part of the conversation I observed between Emma and her mother:

> Emma. I think you should have trap doors so nobody could actually listen; they could be inside school, no glass so nobody can see you.
>
> Mum. Do you feel when we were at school [accessing the support] that people could hear you through the doors and windows, and that bothered you so you think that wherever you are needs to be closed off so nobody [emphasised] knows what you are doing or saying.
>
> Emma. It feels like you can't talk.
>
> Mum. Its right, who's to say there was nobody ever outside the door, we don't.
>
> Emma. They could actually just put their ear to the door and listen.

The following observations made by 'Dr Jones', a medical doctor who works for an independent cancer charity, highlight that for some children there is not only the concern of privacy and confidentiality but also having a 'safe environment' in which to discuss their concerns. The first example was a general observation made by Dr Jones, whilst the second was a more specific example from her practice:

> There have been lots of children that I have seen where having both parent and child together has been so productive [emphasised] and so revealing, not just to me but to them about what might be getting in the way of discussions and sometimes I'm just kind of the third person in the room and they are having a conversation between themselves and that's fantastic and presumably the reason that it is happening here and it hasn't happened at home, perhaps other homely things have got in the way or the child knows that it is their time or there is a safety on having a third person present.
>
> I was seeing a young boy in a session and his mother was present. He said something and his mother looked at him and said "I didn't know you felt

> that" and they had a conversation and then mum chose to go out for a while, he stayed and I said to him something about the fact that mum hadn't known about his feelings and he said "no". So I asked him why he thought it was and he said he hadn't told her because he thought she was going to be upset. And I said, "did you think she was going to be upset this time" and he said "no" so I asked him what what's different here and he said "well this is a place where you come when you are upset".

This first section has presented examples from the data that highlighted that, for the majority of children, being included in conversations about their parents' illness was important to them. I presented evidence to suggest that typically they wanted to be included and placed an emphasis on the value of being party to the conversations. Being provided with this opportunity alleviates the risk of children misunderstanding what is happening in their family and constructing false interpretations of the current experience. The value of having people other than family members share information was discussed by some of the participants and highlights that it is important that a number of different opportunities are presented to the children. This included sharing experiences with peers in a group setting. The following section presents evidence from the findings that indicate that this open awareness does not always occur and that frequently children experience a closed awareness where they are not party to information sharing and conversations.

4.2 CHILDREN NOT BEING INCLUDED

4.2.1 'Wrapping up in cotton wool': parents protecting their children

The interviews with children consistently suggested that being included in conversations and information sharing was seen to be positive in helping them navigate the alien land of parental terminal illness. However, the research also highlighted examples where the children were not included in the conversations and where a closed awareness (Glaser and Strauss, 1980) was maintained.

This section of the chapter will consider the difficulties and problems that arise when children are not included in conversations about their parents' illnesses. I will begin this section with a quote taken from my first meeting with Hannah which highlights some of the difficulties when children are not included. Hannah was describing a session where she had been working with a seven year old girl whose mother had a degenerative neurological disease that had caused amongst other things paralysis:

> It's quite fascinating working with the girl, very bright, very, who can't express anger who is absolutely stuffed full of it and that is something that we have already recognised, but who doesn't know how to express it and is always expected to be a good girl and is expected to be well behaved and is actually very frightened of letting her anger out because she knows that it will get her into trouble. And so we were doing, I was working with her on her own a little while ago and using a kind of, very much a narrative and a family therapy technique. I was getting her to think about the anger externally from her because it felt like it was a safer place to be. And we named the anger and what were the causes of the anger, and the biggest cause is her mum's illness and she was able to think about that so I said "okay so if we were able to think about the illness separately and we were to give your mummy's illness a name, what name would we give it?" And she named it "No Voice" [pause] and, and that fits with because its not just about the fact that her mummy has got no voice, it is that she has got no voice and that the illness has rendered the whole family with no voice and no voice to say the things that they really want to.

This account provides an example of how the young girl was being excluded from the family crisis, however, it also provides a wider perspective of how not being included can affect children at a number of levels. It evidences how non-inclusion may not only inhibit the children's ability to comprehend what is occurring but how this in turn causes them to think and behave differently.

A number of the professionals I interviewed talked about how often, when parents do not include their children in conversations or sharing of information, it is perceived as being a protective behaviour. 'Harriet', a specialist palliative care nurse, offered this observation:

> ...yes and they [the parents] think that they are protecting the children by not talking about it and not letting them see them being upset, but it is good for the kids to see the adults crying and getting their emotions out, it gives them permission to do it as well...there is that sort of wrapping up in cotton wool and protecting them.

Within the same interview Harriet discussed in more detail her observations of parents protecting their children and offered a suggestion about a potential disadvantage of not talking to the children:

> I think there is very much this wanting to protect the kids, but I don't think they are doing them any favours by not telling them what's going on because they are not daft you know, they know what's happening, they know something's not right and to suddenly hit them, you know, with mummy or daddy has died, I don't think that is fair at all. I think it's that that causes the long-term problems.

'Anne', a community palliative nurse, offered a similar perspective. Anne described how she routinely advised the patients who had children to talk to them about their illness. However, she too went on to explain that in her experience parents often try to protect the children by not including them in discussions and excluding them from this major family episode.

The accounts of other professionals contributed to the theme of parents protecting their children from the distress of their current experience by not discussing with them what is happening. Dr Jones discussed this act of protection and suggested a potential negative consequence for the children:

> When children are facing that kind of crisis in their lives, the best people to support them are the family or extended family. And at that point to be whisked off to see a stranger is potentially counter productive because it can give the message to them – oh you know this is too hot to handle in the family, its too painful and dangerous to talk about to us so you've got to go and talk to a professional. It is one more confusing event in their time of turmoil.

'Charlotte', a social worker working in a hospice, offered a different perspective again in relation to parents not talking and thus presuming that they are protecting their children from information sharing. Charlotte provided me with an account of a patient that had recently died in the hospice. The mother had emphatically informed her family, friends and staff at the hospice that they must not inform her son about the seriousness of her illness. When her anxieties were explored further, her reasoning became apparent. When she had been ill previously with cancer, her son, aged nine, had been bullied at school. In preventing any discussions with her son about her illness she hoped to protect him from further incidences of bullying.

'John', a bereavement care manager working in a hospice, offered a wider social-cultural perspective about children being shielded from any information relating to death and dying:

> I guess we are still fighting in a culture that doesn't want children to be part of death.

Whilst the professionals in my research suggested that this non-communicative position could be associated with the parents protecting their children, it could also be evidence of a cycle of vicarious avoidance (Trickey 2009). Here the adult perceives that the child does not want to discuss a sensitive issue and therefore does not engage in conversation, the child then interprets this silence as the adult not wanting to talk about the issue and again does not mention the subject. This then creates a cycle where neither party instigates the conversation, and the elephant remains in the room. Protecting children and shielding them from unnecessary worries is a natural response to caring and keeping them safe, however, it could also be seen as a death denying reaction removing any power or autonomy from the children.

4.2.2 'Very British stiff upper lip': families not talking about the current situation

Findings in the previous section indicate that parents frequently try and protect their children, by not engaging in conversations or the sharing of information about the illness and prognosis, in an attempt to shield them from the pain of having to think about what is happening within their family. However, a recurring theme from the accounts of the professionals was that frequently families do not talk together about what is happening and consequently no family discourse emerges whereby the children can begin to develop a consistent narrative. Harriet observed:

> You get some families that are very British stiff upper lip that don't show their own emotions so they are certainly not going to discuss issues with the children erm so that's a barrier.

Christopher expressed a similar opinion when he was talking about the families he works with in the hospice:

> I think the biggest issue for me is that all the way through I don't think families talk about it and that has a knock on effect on the children.

Christopher also discussed his observations of children and their need to ask questions but which are often not voiced:

> Yes they don't know the whole story of what is going on. When we have done the children's days, it was evident when we asked the doctor questions; they'd got all these questions that hadn't been answered. So yes I think they are often left out.

Being willing to listen to children and hear their concerns is an additional factor in promoting or inhibiting these conversations. John suggested that it is not necessarily that families do not always talk to each other, but rather that people are unwilling to listen to what is being said:

> ... what you often find with children and their families, pre-bereavement is that it's sometimes a battle to get everybody to listen to each other and children often get sidelined, right, not intentionally but they do.

Hannah's account provided a different perspective which suggests that families do take a pro-active role in managing their current experience:

> I think for some families not thinking about things and not talking about it is a way of managing and that's not denial and I think that's one of the things everybody thinks "oh this family is in denial" but they are not, they just talk about it when they need to talk about it but to talk about it all the time just is too much and they have to get on with a sense of living.

Dr Jones talked about some of the difficulties professionals encounter when they are working with families who have not discussed the illness with the children. Furthermore, her observations also highlight some of the potential consequences for the children if their family does not talk about what is happening:

> It is very hard working with children at this stage. Sometimes we are asked to see children where things are very unclear in the family. It is still possible but it doesn't feel comfortable, if there is something major that has been kept from the child I feel how can the parent expect the child to be able to open up if that is against some big secret that the child will sense, they hear their parents talking, they hear things from their friends at school because their friend's parents know more about what is going on than they do.

Making judgments about the amount of information that should be shared with children is potentially very difficult and needs to be based on a number of factors including, as MacPherson's (2005) research evidenced, family dynamics. Hannah discussed a family she had been working with whose experience highlights the intra-personal dilemmas and conflicts that may occur within family constructs:

> I had a session a few weeks ago and it was mum who was an inpatient here, she had been told two months ago that she had got really advancing disease and that the prognosis was very short, possibly months but maybe weeks. She felt a real desire to finish business that was important to her, she wanted to talk with family and friends, but the children had actually no idea how ill mum was despite the evidence to the contrary. Her husband actually wanted to tell the children much much earlier and she had resisted and he had capitulated to that. We had a session when they felt they needed to tell the children so I spent time with her and her husband about what the message was going to be and how they were going to do it. For the twelve year old it was confirmation of what she already knew, but for the nine year old it kind of really hadn't sunk in.

Hannah described another situation she had encountered where she had the dilemma of balancing the dying father's wish to give information about his condition to his children with the children's need not to be given overly detailed or inappropriate information:

> I had a family here, two parents, dad wanted to talk about his illness, he had been diagnosed with a brain tumour and he wanted to be very upfront about it, so you know but how do you do that in a respectful way so the children don't hear things they don't want to hear at this stage...some families want to be too open or some people want to be open and some people don't you know it is respecting different places, different positions in a family too.

The professionals' accounts support the view that families often struggle to know the most appropriate way to deal with talking individually and as a family about the illness. As has been noted some families protect their children by not talking about it whilst others want to be too forthright in their discussions. Finding a balance that meets individual family requirements therefore needs to be managed sensitively and with respect for the family's culture and values.

4.2.3 'There was no help forthcoming at all': professionals not including children

The previous section has highlighted the complex nature of these 'difficult' conversations and how professionals have a role in recognising these difficulties and supporting families to make informed choices. However, the children's accounts also indicated that there was frequently a lack of any communication exchange between the professionals and the children.

Samantha described how her family included her in all discussions about her mother's illness. However, she recalled that she had been unable to talk to her mother's Macmillan nurse despite a desire to obtain more information about her illness from a professional who was not so closely linked with the family. Samantha commented:

> We (Samantha and her younger sibling) were told that we could talk to the nurse but we never got chance because she always visited when we were at school.

Luke talked ambivalently about the medical team's information sharing with regards to his mother's illness and prognosis even though he regularly attended the hospital appointments with his mother:

> They did make an effort to explain anything if we asked but I think the main focus was on my mum as opposed to us, which I didn't mind, I thought that was best because obviously she was the one with the illness.

Georgina's mother reflected on the lack of support she felt she had received from the medical team in relation to talking to Georgina about her grandfather's illness. She commented:

> No one approached me; there was no help forthcoming at all. Absolutely nothing.

The theme of professionals not talking directly to children and not supporting the parents in the conversations are congruent with the findings presented in the Literature Review. The accounts describe how children generally want to receive information from different sources and yet are frequently marginalised and are thus placed towards the closed end of the communication continuum.

4.2.4 'I don't want to do that now I just want to get on with the day to day': children preferring to not be included

Being included has important relevance for children and can help them to cope emotionally and cognitively with their parents' illnesses. However, whilst the theme of children wanting to be included was prevalent in many accounts, other children's experiences highlighted how some actually prefer not to be included.

During the interview with Samantha she indicated that she would have liked the opportunity to talk to professionals before her mother died but also stated quite clearly that she would have found it difficult following the death. Samantha was responding after being asked whether she would have found professional support helpful after her mother had died. She observed that:

> I don't know I think it is a big thing to talk to somebody you don't know and sort of say, "I don't know you but here's my heart".

Professionals working directly with children provided similar accounts which support the notion that some children prefer not to be included. Hannah observed that:

> What happens is that I will be referred a family or a child so that I can talk [emphasised] with them about mummy or daddy's illness and actually they don't want to talk, or the number of times I've had from them "actually Hannah I do know what's happening and I do know what the future holds but its actually too painful and I don't want to do that now I just want to get on with the day to day".

Furthermore, 'Susan', a colleague of John's provided a similar account:

> I have worked with at least three children who have been made to come usually by their mothers, who actually stated to me that they don't want to talk. That their way of dealing with it is just to forget...

The interviews with the professionals highlighted that it is frequently during the teenage years when young people would prefer not to be included and actively choose not to be party to too many conversations about their parents' illnesses and prognosis. Susan talked about this in relation to balancing what is perceived as typical teenage behaviour:

> A lot of families struggle pre-death with, they don't want to talk at home and I think they forget that's a normal teenage development thing and it is their need [the parent's] it's their need for them to talk.

Susan went on to say that in her experience teenagers often would prefer to receive support from their peers instead of their parents. However, John cautioned that in his opinion this might also create difficulties:

> A lot of their behaviour is adapting to suit their carers or friends because they can't really be themselves, you know, for example, one young person came to me and said its alright for me not to talk about it isn't it to anyone, because she didn't want to, you know so a lot of them do know their own mind. So the thing about the pressure of having to adapt to protect or suit your parents and then er to be with their friends who won't talk about it because they don't really know what to say, it's really really tough.

An observer could interpret the children's behaviour as denial and an avoidance to consciously think about what is happening within their family. However, an alternative hypothesis could be equally relevant. Stroebe and Schut's Dual Process Model of grief (1999) offers a potential explanation for their behaviour. Within this model, the authors assert that the bereaved oscillate between coping behaviours – loss orientation and restoration orientation. The former encompasses grief work whilst the latter includes making lifestyle adjustments and developing a new identity. Stroebe and Schut argue that it is important for the bereaved to take time off from the emotions of grief in order to cope with what has happened. In a similar way, children's 'avoidance' of thinking about, and being in the midst of their parents' illnesses could be a protective psychological mechanism that allows them to move away temporarily from the uncertainty and pain to a safer, known environment, where they can 're-charge' their 'emotional batteries'. Furthermore, by having some 'non-illness' time they can re-engage with their pre-illness identity and albeit briefly enjoy their preferred identity. Lastly by adopting this oscillating behaviour they are exercising some control and autonomy over a situation where they have very little control or autonomy.

4.2.5 'I was aware that there was a lot of pressure on my dad': self-imposed silence by the children

Within the previous sections I have presented findings that suggest that being included in communication and information sharing are necessary for achieving positive outcomes for children and moreover this is valued by the children. However, for some children whilst being included is really important, there is also pressure on them to maintain a silence and not instigate conversations about the illness. Accounts from the children and professionals provide evidence that this self regulated silence is employed by children in an attempt to protect their parents and family members. During the interview with Luke he spoke about this self-imposed silence, and whilst he had previously acknowledged that as a family they spoke openly about his mother's illness, he suggested that he would not instigate the conversations:

> I never really talked about how I felt about things with my family because I knew there was a lot of pressure on my step-dad because he was going to work everyday and coming home and caring for my mum.... So I was aware that there was a lot of pressure on my dad, that's why I didn't always express how I was feeling because I knew obviously that he was probably going through worse because he had to go and do all that.

Children's fear of upsetting their parents was discussed in the interview with Kirsti, Emma and their mother. Their mother was talking about the professional support they had received as a family following the death of the girls' father:

> You know I found a lot of things out but there were things that they probably wanted to talk about but were scared of making me upset and I think because sometimes, especially oldest one, well she does worry about, they all worry about upsetting me.

Children 'protecting' their parents was evidenced within the professionals' accounts. Christopher observed:

> There are themes that I have noticed, children not telling their parents what they feel because they don't want to upset them.

In the interview with 'Elizabeth', a palliative care social worker, an example of a young person trying to 'protect' their ill mother was described. Elizabeth was talking about a situation she had recently encountered with a family where the mother was terminally ill. The parents had separated and the mother made the decision that her son would, after she had died, live with an aunt. The boy had tentatively agreed to this situation, however, following his mother's death, he expressed a desire to live with his birth father.

Developing a self imposed silence highlights a further isolation experienced when a parent is terminally ill. Whilst the desire to be included remains, there is also an inherent need to 'protect' their parents which results in the children not communicating their worries or being able to ask questions to help inform their understanding. This burdensome position has implications for their inclusion, or exclusion, but also is evidence of them taking on roles and identities that are not congruent with their status. There is in effect a reversal of roles where the children assume adult responsibilities.

4.2.6 'It is scary stuff and for them...they need a bit of hand holding': professionals' perceptions of their role in supporting parents to instigate difficult conversations and information sharing

Parents are generally the most appropriate people to engage in conversations with their children about the illness and prognosis. They typically have the strongest relationship with the children and, generally under normal circumstances, know instinctively how to communicate with them. However, when the communication involves dealing with such heart wrenching discussions as a parent's death, and for the reasons described above, it often becomes an incredibly difficult task and support from professionals is required.

The professionals recognised this and offered a consistent theme in their accounts. Hannah reflected about her role in supporting these conversations:

> So a lot of the work that I do is helping parents with those kinds of conversations because I do feel that parents are actually the people who are best placed and best suited to do that work but it is scary stuff and for them to need a bit of hand holding but also too looking at the dynamics of what happens to them when illness lands in a family and what it does to family functioning.

John also discussed how in his opinion family members are the most appropriate people to have the conversations with their children and to provide them with information:

> ...what we try and promote is really simple, we give people adequate information because how we work is a child can be told anything, anything, it just has to be told by people who know him or her.

'Carol', a bereavement counsellor, also talked about how she will encourage parents to engage in conversations with their children:

> ...so I do encourage relatives to try and be open and honest without frightening the kids really. If they haven't talked about it you know I say, and I know its hard and I know its upsetting, but you know it's more upsetting for children you know to suddenly find out that mum or dad has died when there might be issues that they want to resolve you know.

During the interview with John he too spoke about encouraging parents to be pro-active in the discussions with their children and to include them in all aspects of their current situation, however, he developed the notion of inclusion beyond just talking with the children:

> ...what we are saying to the parents, the guardians is you need to talk and you need to talk to your children. Why not explain to them what happens, why not take them to a funeral?

Whilst it is acknowledged that parents are the most appropriate people to talk with their children about the illness and prognosis, it is also evident that this is a difficult task to undertake. However, introducing professionals into the children's lives at the point of crisis has the potential to further de-stabilise their cognitions and emotions and can create additional fear and anxiety. Children who are feeling uncertain and who are then introduced to 'a professional' are likely to interpret this as being highly significant. Whereas if the parents, with support, can initiate and sustain the conversations the children are more likely to feel that the situation, whilst being very difficult, can be managed.

4.2.7 'The right time to talk': timing of information sharing

The timing of information sharing is a further potentially difficult area to manage. Being faced with the prospect of giving children difficult news is stressful and daunting for parents and associated with this is the timing of the conversations.

The professionals' accounts highlighted that as well as encouraging parents to have what was described as 'those difficult conversations' with their children, they also performed the task of providing information and advice with regards to the timing of when the conversations should take place. Elizabeth made the following observation:

> One of the most interesting areas I think is when people talk about trying to find the right time to talk about the subject. And I always help them explore well when you are going to talk about any difficult subject to anybody you always try and find a right time and there never is a right time because you always find it is near some anniversary or near the weekend or near the beginning of school or near this so sometimes it is about getting rid of some of those myths, barriers that people put in the way because they are frightened it is so difficult.

The idea of timings was echoed in the interview with Dr Jones, however, she developed this further by also discussing the importance of giving the children permission to be involved and included:

> There is a kind of grey area about what is the right time for children to know and that I don't want them to be upset before it is necessary, and when is necessary, because it starts to be necessary when the child becomes aware that the parent is weighted down by something awful that is going to happen because even though it is the worst thing that can happen in one sense, children may fantasise even worse around abandonment. But if they understand, you can't spare them the pain but at least if they understand they are not being excluded, going to be kept informed and that it is going to be okay to talk about how it makes them feel, all of these things are the best you can do.

Hannah talked about the timing of information sharing but also about the amount of information given within any one discussion. Within this she expressed her opinion about the value of this for the children in relation to their cognitive development and understanding:

> I think that it is more beneficial for children to be given information in bite size chunks, but what we tend to do is go for the ruddy big chunk right at the end. So yes I think the bite size chunks bit can be a really important part of what's going on erm helping the children talk about maybe their concerns for the future you know, sometimes, again a lot of it will be around timing, a lot of it is about experience about asking future orientated questions and what children see as being the future...

This section has considered examples from the data where the children have not been included in the communication and information sharing process and where a closed awareness has been adopted. It was suggested that this exclusion was in part the parents' way of protecting their children in the belief that they were saving them from additional worries and anxieties. Accounts from the children suggested that there were occasions when they adopted a self-imposed silence in an attempt to protect their parents. However, the ramifications of this could be a 'cyclical silence' where communication and information sharing becomes very limited and the children are not able to engage in any meaningful discussions that would support them to process what is happening in their family, to adjust their biography accordingly and to begin to make sense of what is happening in their lives.

4.3 THE USE OF LANGUAGE IN FACILITATING OR INHIBITING CHILDREN'S UNDERSTANDING

4.3.1 'Gone to sleep': how the use of language can inhibit children's understanding

The chapter to date has presented the findings relating to communication and information sharing within families. Examples of the views and opinions of the children and the professionals have been described. The focus is now going to move to the use and application of language. The language employed, with particular reference to the use of euphemisms is a significant factor in relation to facilitating or hindering children's assimilation of the information being shared. The use of euphemistic language, especially with younger children whose cognitive development is still at the literal stage, can create misunderstanding and fear.

I will begin this section with an example of the negative connotations euphemistic language can have on children's understanding and will draw on the accounts of Sonny and his mother to illustrate how language can severely affect children's understanding.

Sonny's grandmother lived with the family; she had had a terminal illness and was nursed at home where she died. Following her death, Sonny's sleep routine was disturbed. He refused to sleep in his own bedroom, demanding instead to sleep on the floor of his parent's bedroom. During the night he would regularly wake his parents, requesting a drink or assistance to go to the lavatory. Sonny generally managed no more than three hours sleep per night. After almost two years, the family sought help. It was during the subsequent support sessions that Sonny shared his paralysing fear. When his grandmother had died, he had been told that she had 'gone to sleep'.

This euphemism had become entrenched in Sonny's literal mind and had spread fear and total anxiety. His fear of sleeping related to the fact that his grandmother had 'gone to sleep' and had not woken up again. Not only did Sonny worry about the consequences of him sleeping but also for his parents, hence the many requests for drinks and visits to the lavatory during the night. Sonny's mother observed that she believed that by him waking his parents he was checking that they were alive and had not also 'gone to sleep' like his grandmother.

Carol discussed the use of language, from the professional's perspective, with particular emphasis being placed on the use of euphemisms and how from her experience this can have a negative effect on children's understanding. She talked about the language frequently used with children when someone has died:

> Immediately it's not got that connection and then the things that people traditionally say about stars out at night, you know it's the brightest star out at night, well if they are not out where are they what's happened to them so then they [the children] are very worried because on this particular night they are not out. And using the things like you know we've lost somebody and then they want to find them and you do get an awful lot of things. One that often comes up is er they have been told that that person, they will always be with them but they can't understand that if they are with them how can they be with, how can they be with my cousin then and how can they be with my brother and my auntie [laughing] you know and they can't be with everybody so that, that can be difficult but I think its just in a safe world it suddenly becomes unsafe and I think that brings a lot of things for them.

Harriet suggested similar thinking and again related the use of language and how it can affect the children's cognitive understanding and processing of what is happening. Harriet's observation highlighted her opinion that providing clear unambiguous information can help prevent misunderstandings. Harriet's observations have similarities with Georgina's account about her friend not being given any information about her grandfather's illness and again highlights the need for accurate information. Harriet observed:

> They may feel that mum or dad is poorly because they've been naughty, you know, you think differently as a kid don't you, so they need to be told things to save them getting it wrong.

Her observations provide evidence of the importance of clear, age appropriate language. She went on to discuss how children could misunderstand what they are being told if the language is not clear and age appropriate:

> I think kids have a lot of weird ideas around death and dying and if things aren't explained to them they will never learn.

The meaning or miss-meaning that children attach to conversations has important consequences for their understanding. Dr Jones provided an example from her practice where a child had overheard a comment made by her mother and had attached a literal meaning. The young girl's grandmother had died and her mother 'was devastated by this bereavement'. The family had been referred to see Dr Jones because of the deterioration in the girl's behaviour in school. During the fourth session with Dr Jones the girl spoke of the anger she felt towards her mother when her mother talked about wanting to kill herself. In the following session, where the mother was also present, the girl again referred to the same comment. Dr Jones observed that:

> ...the mother looked at her and said "you know I didn't mean that" and I asked her how did she know that and they then talked and had a conversation. Mum had just not realised that a child would take it literally and would hold on to the comment.

Dr Jones went on to say that following the session it was noted that the girl's anxieties were reduced and her behaviour in school became less challenging. By being able to explore the misunderstanding the girl was able to rectify her misinformed belief and re-engage with her preferred cognitions.

Christopher discussed observations from his practice about parents talking to their children and giving accurate and age appropriate information about their prognosis:

> Parents will tell their children that they are ill and that they have cancer, but they won't say "I'm dying", even if they don't say it in those words.

Examples from the research would suggest that it is not only the parents and families who use euphemisms and ambiguous language when talking about death and dying to children. Some of the professionals described how they have observed their colleagues adopting euphemisms in their discourse. Hannah highlighted this:

> Yes and even within a specialist unit here when we are talking about when we are doing our sort of bereavement you know er round up if you like when we are talking about people that have died over the previous week, there is a lot of language around er "and she passed away peacefully" and, and it makes me smile kind of inwardly in that even here where we are dealing with death and dying on a daily basis that we have a real difficulty about saying the words dead, died, dying...I think it is really important to be naming this as being something that people are thinking, so you know why are we so, why does it make it harder to talk about somebody having died than having passed away because the end point is the same.

The choice of language used with children has a significant bearing on their understanding of what is happening within their family, their meaning making process and how they cope with the pre and post bereavement period. Examples from the data support the argument that the use of euphemisms has the potential to add further confusion, uncertainty and insecurity to children's already disrupted worlds. The final section of this chapter will examine examples of how professionals working in palliative or social care often struggle with their language when communicating with children.

4.4 THE PROFESSIONAL'S ROLE IN FACILITATING CONVERSATIONS: CONFIDENCE AND COMPETENCE

4.4.1 'You can open the can and it doesn't necessarily have worms inside': the professional's view of their role

This final section of the chapter moves away from the primary focus of the children and their families to the professional's role in working with children. Professionals have a pivotal role in supporting parents to instigate conversations about the illness and, where necessary, adopt the role of fellow traveller with the children. However, the review of the literature and findings from my research suggest that professionals who are not directly working with children in palliative care do not necessarily have the competence or confidence to offer such vital support.

A theme to emerge from the professionals' accounts was about the 'professional fear' typically exhibited by colleagues who do not work specifically with children. John evidenced this when he suggested:

> We find a lot of people and services aren't really [emphasised] available for children because either through fear of getting it wrong or they think they are going to make it worse when the worst has already happened, the diagnosis has been given, the bombshell has been dropped and the person has died or the person is dying so there is nothing we can do to make it worse. That's actually quite comforting when the children hear that. People can't make it worse for you because you feel hurt enough.

John's colleague Susan who also participated in the interview concurred with his observation:

> Some people are very honest and they will admit that they are terrified of saying the wrong thing.

Personal beliefs and values contribute to the fears professionals have about communicating with children. Hannah exemplified this when she related her observations to a piece of research she has undertaken within her practice:

> ...my research demonstrated that nurses were very fearful of doing this and it felt too painful, too emotive because most of the families were young and so you kind of equate it with your own experience of being either a parent or being parented or whatever it happens to be and so that gets in the way of having these conversations.

Professional fear and their dominant held view that talking with children is too emotionally fraught for both the children and themselves prejudices their perspective and influences their cognitions and practice. This can have the effect of embedding their narratives in a problem saturated context. Hannah exemplified this when she described encounters she had experienced with colleagues:

> So many of the things are around them being that these conversations will take too much time, you know the mythology of all of this the fact that if you open it up you will be opening a can of worms and that you won't have the skills or you won't have the emotional reserves to be able to manage it. All of which in practice we know that's kind of, well it is true but its not true and actually you know if you have the skills you can open

> the can and it doesn't necessarily have worms inside. It may have something that is very different and you know it is being able to see it and you know it is interesting that we use these kind of metaphors, can of worms, Pandora's Box, you know all those kind of things that really signify that somehow lurking down there is all horrible and actually it isn't and so one of the things is about unlocking those stories of greatness as well and there are a huge number of those. But there is a real fear...

She went on to observe:

> I think that sometimes the language that professionals use is overly optimistic and that is not always useful [pause] and that is partly our [emphasised] culture of not wanting to confront death and dying

The fear of saying the wrong thing can impact on professionals and cause them to become ineffective in their role, thus maintaining the presence of the elephant in the room. Fundamental to this are the fixed narratives the professionals have about their competence as practitioners along with their positioning of children in society and their concept of death and dying. Practitioners whose remit is to work with children, present a different perspective about their role and the inclusion of children, from staff who work indirectly with children. The former are more cognisant with the needs of children and are better positioned to see the value of open communication.

4.4.2 'I think really such as myself needs more training to deal with children': Professionals' training needs

The discussions about the genuine fears professionals have about talking to children about death and dying is closely linked to the quality and quantity of training they receive, both during their initial training and as part of their continual professional development. Themes to emerge from the research suggest that the training professionals receive may be problematic. In the interview with Harriet I asked whether she was aware of the availability of any training pertaining to communicating with children. She made the following observation:

> I think really such as myself needs more training to be able to deal with children erm I mean you know if I went and said to my managers I need some training on child bereavement issues, they would say "what for you are an adult service" you know and I would say "well you know I've got relatives whose kids need help" and they would say "well refer them to social workers, let the teachers know, refer them to the children's

> community Macmillan nurse", but she certainly wouldn't be seeing children of adult patients just for psychological problems.

Hannah's observations about professionals' confidence and competence in communicating with children about death and dying extended beyond her own profession. She described how school personnel sometimes draw on her knowledge and experience. She explained that school staff telephone for advice when they have a pupil on roll who is experiencing the death of a parent:

> ...the thing that many teachers ring about or head teachers is about worrying about doing the wrong thing erm saying the wrong thing and actually part of what I will do often is going in and talking to the teachers and classroom assistants about their own fears and beliefs about death and dying and it is often more about their own stuff than it is about managing the children because they are taught how to manage children and as long as they know what's going on they can be very you know sympathetic, empathetic to what's happening.

This final section has considered how professionals' behaviour can impede communication and information sharing with children. This is sometimes as a result of them using non-specific language, especially euphemisms, but also their fear of talking about death and dying. Professionals within palliative and social care have a pivotal role to play in supporting families and encouraging familial conversations and consequently they should have the necessary training to support their development (Fearnley 2010). However, findings from my research suggest that this training is not seen as a priority and consequently is not a feature of the curriculum.

Summary

The chapter has considered findings from the data that illustrate the importance and relevance of communication and information sharing with children experiencing the death of a parent. The findings indicate that the children's experiences of open or closed communication have similarities with the work of Glaser and Strauss (1980). A theme to emerge was of children being party to information and involved in conversations about their parents' illnesses. Their accounts illustrate that this involvement, and being involved in an open awareness context, contributed to their ability to cope in traversing the alien landscape that living with a parent who is dying typically presents. Conversely, a theme of closed awareness also developed, where they did not receive information and were not party to conversations about the illness and prognosis. This closed context led to feelings of fear, isolation and confusion. Within this it was evidenced that when children were included and where information was readily available, they appeared to have more sophisticated coping mechanisms and were better equipped in their meaning making process.

The different contexts have massive implications for how the 'penultimate chapter' is written, the content of the chapter and how the plot is developed during the different editions that are drafted. The concept of the 'penultimate chapter' has developed through the research and proposes that children 'write' a prospective chapter about their experiences during the terminal stage of their parents' illnesses. The 'penultimate chapter' builds on the work of Walter (1996) and extends his proposal of a 'last chapter' being written following the death. Chapter Eight presents a detailed account of the 'penultimate chapter'. When children enjoy an open context they are better able to 'write' a more meaningful chapter that has a strong story line that can be understood. As the illness progresses, and depending on the amount of information that is available, the children edit the 'writing' of this 'penultimate chapter' to incorporate their understanding of their lives. When they experience a closed awareness or have limited and inaccurate information, these editions are likely to be thin and without any significant meaning.

The data has highlighted that there is a communication continuum and the quality and quantity of information that the children receive determines where on the continuum they are placed. The continuum is not static and the children's positioning on it can be fluid, depending on the information they are receiving. Different factors contribute to the children's positioning on the continuum, these include, the use of appropriate or inappropriate language by adults, adults willingness to initiate conversations, the belief that by not talking about the illness the children are being protected and professionals' competence and confidence in working with children.

The chapter began by considering the findings relating to when children are included and receive age appropriate information about their parents' illnesses and the prognosis. Included within this was the value children place on being included and receiving regular information and the importance of having the opportunity to talk about what is happening. This was augmented with the professionals' perceptions about the value of including the children in discussions and information sharing. A consistent theme to emerge was that being included was important to the children and assisted them in finding ways to manage the fear and anxieties that were associated with what was happening in their family.

The next section of the chapter presented examples where children have not been included in the communication and information sharing process. It was suggested by the participants that this is sometimes perceived by the parents as a way of protecting their children. However, the detrimental effects of not understanding and misinterpreting what is happening were highlighted. This was followed by a presentation of the findings about how there are occasions when the children have asserted their preference for not being included and how they have provided considered reasons to support their choice. Examples were provided whereby the children deliberately chose not to talk about what was happening. Whilst some observers may perceive this as denial and avoidance, it was suggested that it was actually a pro-active coping mechanism that has resonance with Stroebe and Schut's Dual Process Model of grief (1999). This will be discussed in greater detail in Chapter Five.

The emphasis then moved from the children's perspective to the parents and the issue of communicating with children when a parent is dying. This included commentary and observations provided by the professionals who participated in the research. This included the professionals' accounts of how they encourage and facilitate communication between parents and their children. This was followed by a section highlighting the participants' views on information sharing, including the timing of providing information.

The following section considered the specifics of language use. Particular emphasis was given to the findings relating to the use of euphemisms. This included evidence from the accounts of families relating to how the employment of such avoidant language has led to children misinterpreting and misconstructing information about their parent's illness and death. Examples of the use of euphemisms highlighted how critical the use of language is in facilitating understanding.

Finally the chapter moved specifically into the domain of the professionals and the importance of their role in communicating with children. A 'professional fear' was described along with a reluctance at times by professionals to instigate conversations with children. There was a notable difference in the way professionals who work with children, and colleagues who are not directly involved, perceive the importance and value of communication.

Living with a parent who is dying is a fearful, stressful and confusing time for children. Being involved in information sharing and communication about what is happening, in line with their wishes, are important factors in helping them traverse the unfamiliar, alien landscape that they find themselves in. Ignoring the elephant in the room can have severe detrimental consequences for the children. The professionals involved in the care of the family have a significant role to play in acknowledging the elephant and thus supporting the children (Fearnley 2010). The following chapter will consider findings from the data that develops the notion of the alien landscape and explores how the children attempt to manage the situation.

CHAPTER FIVE: MANAGING THE EXPERIENCE OF LIVING WITH A PARENT WHO IS DYING

A consistent theme to emerge from the research was how children living with parents who are dying attempt to manage the considerable changes that occur within their families as the parents' health deteriorates and following their death. By examining the accounts of children and the professionals who work with them, I have identified a number of strategies or coping mechanisms which they use during the challenging period of parental terminal illness.

The aim of the chapter is to examine how the children manage, or fail to manage, this significant time in their lives. I will be drawing on the work of Van Gennep (1977), with particular reference to his writings on rites of passage and liminality. In addition, Stroebe and Schut's Dual Process Model of grief (1999) will be included to illustrate the challenges faced by children living with a parent who is dying.

The chapter will begin by examining examples of the emotional challenges children experience when their worlds are shattered with the news that a parent is terminally ill. The fear and uncertainty that they encounter is discussed along with issues of identity and 'fitting in' with peers. The section will also examine findings relating specifically to the teenage years and how young people attempt to manage their experience. These findings highlight that balancing home life with school life present particular challenges to the children.

The second section of the chapter considers specifically the children's management of living with a parent who is dying, and their behaviour. This was a consistent theme which the interviewees described in detail and which appeared to be a significant factor in how the children attempted to externalise their management of the situation. Examples from the data of how the behaviour is manifested are presented from the children's perspective along with the accounts from the professionals' interviews.

The final section of the chapter moves from the pre-bereavement period to consider ways children manage the situation after their parent has died. A particularly valuable theme to emerge relates to the need they have to re-process the experience and to re-visit their emotions and cognitions about the events. Evidence from the accounts shows how the children are not static in the processing of their experiences and that ongoing support is valuable in helping them to re-visit what has happened. I will begin this section by examining the findings that highlight that whilst their grief may not be constantly at the forefront of their lives, it is never far away and always has the potential to be triggered by events and or memories. I will then present findings that illustrate how children need to revisit their cognitions of what has occurred as they mature and develop. This will be followed by a brief exploration using one young person's narrative and an account from my reflective journal, of not only the liminality that the death of a parent can cause but also the feeling of belonging to a club where membership is exclusively for the bereaved and which therefore is alien to peers who have not experienced the death of a parent.

5.1 THE EMOTIONAL MINEFIELD OF PARENTAL TERMINAL ILLNESS

5.1.1 'You Are Just Left in This Confusing Place': Fear and uncertainty

Living with a parent who is dying often forces the children to enter an alien landscape. The uncertainty of this new landscape and what is happening means that at times the children struggle to manage the situation and find strategies that help. Fear and uncertainty are two emotions that can be constant companions and severely impact how the children cope and manage. These feelings may in part be attributed to the children not knowing what is happening and neither receiving sufficient information nor being party to conversations about the illness and prognosis as suggested in the previous chapter. The findings demonstrate that consequently feelings of being lost and the anxiety of living with the knowledge that the parent is going to die means that some children are in a liminal position that forces them to consider how they can manage the situation.

Being forced to cope with the knowledge that a parent is terminally ill is traumatic and has the potential to throw the children's worlds into turmoil. Hannah described this succinctly:

> It is just really hard and it's a very scary place for children to be, you know, to be living in it.

The fear and uncertainty, coupled with all the changes that occur within the family as the illness progresses can have a massive impact on the children's cognitions and emotions. Issues of identity surface as the familiar, secure life patterns that the children know change. Relationships within the family alter and every aspect of the children's lives are disrupted, exacerbating the feelings of fear and confusion.

The impact on emotional identity for children is highlighted in the account Hannah shared about the family whose mother had a degenerative neurological disease. Hannah was describing a session she had undertaken with the young girl. The girl's narrative highlights some of her worries about how she was managing the situation and offers insight into how her emotional identity was being questioned:

> For this little girl, what her mum embodies for her is love and one of the things that she is really struggling with is being able to give love unconditionally. I think it is the same for the mum too because obviously the only way she can communicate is with having an interpreter doing all of the typing and so they never have moments of privacy, true privacy. And this little girl was saying to me a couple of weeks ago "what's really hard is that everybody tells me to kiss my mum goodbye" and she said "I don't need anybody to tell me that and I want my mum to know that I do it because I love her and not because people tell me to". And it is losing that spontaneity really that I think is really difficult for both of them, they can't just be [emphasised] in a relationship. And she doesn't mind that mum doesn't do a lot of the physical things or the practical things but they just can't actually be together in quite the same way. They can't share a joke in the same way because her mum can't even laugh. So those are the things that she really misses.

Hannah then described the impact of the terminal illness on the girl's relationship with her mother. The account exemplifies the huge emotional challenges that living with a parent who is dying has on children's lives:

> ...she seems to be in a little world of her own now and because she has this story about her being made to kiss her mum she kind of almost has turned that on its head and she thinks that people are doing things to her because they are in turn being made to do them, they have to rather than it being intrinsic. So when other people show her love and affection she can't see it for what it is. It has changed her whole way of being.

Trying to cope with parental terminal illness and finding ways to manage the situation has the potential to turn the children's worlds up-side down. All that was familiar has started to change and underlying this their emotional security is being tested.

5.1.2 'Kids don't like being different': Children's desire to be seen to be the same as peers

Children typically desire to 'fit in' and be the same as their peer group. However, when they are struggling to come to terms with the knowledge that a parent is terminally ill, their secure base of 'being the same' is shattered. The common bonds that they previously enjoyed with friends are lost as they take on different discourses.

Fitting in and being the same as friends was a theme that developed from a number of the interviews with professionals. Susan highlighted this in our interview:

> ...usually what you get is that children are really, really don't like being different.

Susan talked specifically about the period before the parent dies and how some of the children that she has worked with have attempted to manage this time by not disclosing any information about their parent's illness to others:

> The thing with pre-death is that children don't usually want other people to know that their parent is dying.

Hannah also suggested from her practice, that children living with a parent who is dying prefer not to be different. She was talking about the children being involved in social activities with their friends:

> ...children don't do the same things as other kids do and that makes them very different and kids don't like being different.

Being perceived to be the same as peers is important in the young person's social and emotional world and plays a significant role in identity formation. Similarly participating in typically observed teenage behaviours is seen as part of the rites of passage of growing up in the industrialised West. A dilemma for parents and professionals that was highlighted in the interviews referred to a particular aspect of avoidant behaviour that young people often employ when trying to manage the situation of living with a parent who is dying. It was suggested that the dilemma was whether the behaviour was characteristic for a teenager or as a consequence of their desire to temporarily avoid the situation. Carol succinctly highlighted this during our interview:

> I think it can be often a withdrawal straight into a bedroom and then you are weighing up what's normal for a teenager who goes straight in their bedroom anyway and lives there most of the time [laughing] and is it to do with the illness or is it just how they are...

Susan described similar teenage behaviour that she had witnessed when working with families. She was making an observation about how parents sometimes interpret the young people's behaviour and described one family's experience:

> Yes "why can't they come to me" you know and it is just normal stuff isn't it, but when it is death or dad's dying, its even more sensitive isn't it, er but a lot, I can think of one family again it's brain tumours where the change in personality where the kids literally just went out the teenagers went out all the time and it was really upsetting the mum, you know and we said to her would they have done this normally. "You know and me dad's just sat in front of the telly you know you've got to watch what he's watching so we go out" was their answer to that one which was quite simple it wasn't a big thing but it was asked and it has alleviated hopefully her worries...

Hannah provided a further example of what could concurrently be interpreted as typical teenage behaviour or avoidant behaviour because of the current situation. She was describing her observations of the behaviour of a young person who had been referred to by her parents as 'the Lazy Cow'. Hannah observed that the dilemma experienced by this young person was her wish to be involved with the family whilst also wanting to go out with her friends:

> ...she wanted to be part of the family and it was really important for her to do her bit but not that much, she also wanted to be exploring life outside of her family with her friends.

The young people's struggle to manage by temporarily avoiding having to think or be part of the situation could be evidence of them undertaking the psychosocial task of Identity versus Role Confusion as described by Erikson (1968) or correspond with the Dual Process Model of grief as postulated by Stroebe and Schut (1999). The young people's strategy of avoidance allows them to temporarily move away from contemplating the fear and confusion that surrounds their situation, take time off from their emotions and re-engage with their pre-illness life. There needs to be an acknowledgment that the pain associated with the knowledge that a parent is dying is emotionally exhausting and the children at times need to move away from the reality that has become their lives.

5.1.3 'They may well be dreading coming home': Coping with home and school

School attendance is a major features of children's lives, and for the majority of children is a cornerstone in their routines and identity. Being part of the school environment is closely associated with 'fitting in' with peers, however, just as relationships with friends alter when a parent is dying so can the relationship with school.

Balancing the worries and fears of home life with participating in school life has the potential to challenge children's coping mechanisms. This was highlighted in two interviews with professionals who both expressed similar opinions. Firstly Carol observed:

> They've gone to school they are okay, and yet they may well be dreading coming home [pause] worrying about what they are going to find and what that day is going to be like and this person who is ill how are they, relationships are changing because of the illness but also they've got to live within it haven't they.

'Amanda', an Education Welfare Officer, held a similar opinion:

> They [the young people] have a real worry about what they are going to find when they get home, will mum or dad be okay will they have had a good day, will they have had to go into hospital. All these things impact on their day in school but teachers don't tend to recognise that.

The familiar, safe and predictable environment of school can inevitably be rocked when a parent is dying. The children are required to try and cope not only with the worries and anxieties about their parent's health as evidenced above but also with their identity and attempting to fit in with peers. The issue of trying to manage school and home life was discussed by the children I interviewed. Being different from friends, because of the parent's illness and death made them more likely to become victims of bullying. This then created yet more challenges for the children and was to them further confirmation that they were different and as a consequence they often avoided any overt signs of their current situation. Being bullied as a result of the parents' illnesses was a theme that emerged from the children's and professionals' accounts.

One young person I observed at the bereavement support group described the conscious decision she had taken to try and 'blend in' with peers and hide what was construed as her being different. She was recalling some of her experiences when her father was terminally ill and into the period after his death. She described the difficulties she had with:

> ...putting a smile on my face when I go into school and pretending that I am okay.

Georgina eloquently described this as she attempted to explain the emotions she experienced following the death of her grandfather.

> It is the worst combination in the world when somebody has died and then you are bullied at school.

The children's experiences were reinforced by the parents and professionals' accounts. 'Diane', Kirsti and Emma's mother, made an observation about the bullying her children had experienced following the death of their father:

> A lot of people do make fun and you've, well all three of you have had some very hurtful remarks you know because they don't understand basically.

She discussed specifically the bullying her son had encountered in school:

> I mean he's had quite a lot of problems at school with being bullied you know and things like that...

Carol discussed bullying from a professional's perspective. Her observations highlighting the vulnerability of children and how they are seen as being different, she commented:

> ...but the knock on effect can be very much, sometimes it can result in some sort of bullying because they will draw back and change and appear

> to be vulnerable and it can it can sort of erm [pause] you do get some issues around bullying.

The examples highlight how school routines and the school environment are so important for children and can offer some semblance of security and normality. When routines are absent the worries and fears that accompany parental terminal illness are compounded and the risk of the children not being able to cope with the situation is increased.

5.2 BEHAVIOURAL MANIFESTATIONS

5.2.1 'He was doing stories of rescue and him being a superpower: Superheroes

Moving from the safe boundaried world of living with parents who are healthy to living with the knowledge that a parent has a terminal illness and is going to die has the potential to create confusion, chaos and uncertainty. My examination of the accounts of the children and professionals has identified a number of coping mechanisms which children use to help them manage this challenging period in their lives. Some of these mechanisms are perceived to be positive whilst others are seen as being less so.

One coping mechanism employed to overcome these feelings was the development of fantasies of strength and power. Hannah described a play session she had undertaken with the young boy whose mother had the degenerative neurological disease. Her description of the coping mechanism that he adopted matches Rubin and Livesay's (2006) account of superheroes. Rubin and Livesay (ibid) suggest that the role of superhero fantasy play can help children to work through past crises and cope with current problems. Hannah described the session with the young boy:

> ...about a month ago and we were playing...and he was doing stories of rescue and him being a super power, you know a sort of superhero who could rescue people and actually one of the things is I made a comment, at that point he was very into you know Superman and so on, now he doesn't, you know when I said to him are you still a superhero he said "I'm not". So I actually think for him there is something that has shifted fairly recently that he realises that he doesn't have power so he has to show things in a different way.

The young boy in Hannah's account was four years old. Rubin and Livesay (ibid) note that this adoption of fantasy play is typically observed in younger children. Similarly, writing about young children's ability to cope with traumatic events Salmon and Bryant (2002) suggest that because of their limited language development, they are reliant on discussions with adults to help them cope. This is congruent with the evidence presented in the previous chapter relating to communication and information sharing. The following example from the findings illustrates a mechanism adopted by an adolescent and highlights one of this young person's strategies for coping.

Luke described one way in which he coped, during his mother's illness. This was by maintaining hope about her prognosis and the outcome of her illness. During the interview there were a number of occasions where he returned to the subject of hope. The first instance was when he was discussing the longevity of his mother's illness and how typically the life expectancy for people with the same disease is generally approximately four years from diagnosis. Luke described his feelings once his mother had passed the critical four year milestone:

> ...more than anything I was more positive about the fact that it was four years had gone and she was still with us and cos then I suppose part of you thinks, it was probably partly on my mind as well because I thought well maybe she won't... But as I say I knew she would but there was always that hope but [pause and nervous laugh].

Throughout the interview, Luke followed a sequential time-line from his mother's initial diagnosis to the period following her death. During the latter stages of the interview he returned to the notion of hope, but this time in relation to his feelings and cognitions following her death:

> And there's always that part of your mind where you think maybe she will come back.

These two examples illustrate how children develop narratives as a way of compartmentalising or wrapping up painful thoughts. Through these strategies they are able to have some control over the containment of the situation and consequently develop positive ways for managing what is happening.

5.2.2 Boys (and Girls) Behaving Badly: The negative behavioural manifestations resulting from the experience of living with a parent who is dying

The uncertainty and turmoil of living with a parent who is dying can create feelings of anger and powerlessness within children. If appropriate support is not available and the children are not helped in managing these feelings, the emotions can seep out through inappropriate behaviour. For many children, the behaviour, that is as a consequence of their anger, is the only way they have to express their feelings. Not being able to communicate their feelings and not feeling as though they are being listened to can exacerbate the frustration resulting in aggressive outbursts.

The following accounts are from the bereavement group I attended with young people who had experienced the death of a parent from a life limiting illness. I observed them explaining how by struggling to comprehend what was happening, they had been forced to find a conduit for their feelings of frustration in the unfamiliar land they had entered:

> I was really angry, I used to take it out on people, I was really angry thinking why did it have to happen to my mum because she didn't do anything wrong.
>
> I didn't show people how I wanted to be treated, well I wanted people to treat me good but I didn't treat them good.
>
> I was really angry and I used to punch walls and stuff.

The interviews with parents provided further evidence of how their children's behaviour changed following the diagnosis of a terminal illness. Furthermore, the following account succinctly illustrates how appropriate support is vital in helping children to recognise and manage their feelings and emotions. 'Mandy', a young, single mother with terminal cancer had two children, a daughter aged fourteen and a son aged eleven. The son had accessed professional help to support him during her illness; however, Mandy informed me that her daughter had not engaged with the worker. Mandy described the inappropriate behaviours that her daughter had engaged in. Mandy shared with me that these behaviours had only started after she had been told that the cancer was terminal. These behaviours included her truanting from school on a regular basis, becoming very argumentative and physically aggressive and regularly consuming excessive quantities of alcohol. Mandy expressed her opinion that these behaviours were being exhibited as a result of her daughter's frustration and anger at the prognosis. Furthermore, she noted that whilst her son had initially shown signs of anger, since he had accessed professional support, his behaviour had returned to the pre-diagnosis state.

'Dawn' discussed the support her children had received following the death of their father. She recalled how her son, the middle child of three, became very angry after his father died and as a result was physically aggressive towards his siblings. Dawn noted that as well as being very angry he became much quieter than he had been previously and some of the confidence he had formerly enjoyed had disappeared.

A consistent observation made by the professionals highlighted how the children's inappropriate behaviour was a typical manifestation of their anger. Hannah described the behaviour, that the two children whose mother had a degenerative neurological disease, were exhibiting and within this discussed a session she had recently completed with them. It is interesting to note that Hannah stated that this behaviour had been witnessed following the boy's reluctant acceptance that he no longer had 'superhero powers' (Sec 5.2.1):

> ...I have been working with the little boy who is four and the daughter who is seven and we have been painting together and painting out feelings and we have been talking about feelings and we have been using that to describe what is happening in their family and they are perfectly amicable together, went down to the other end he saw mum. As soon as the little boy saw mum he suddenly goes into a rage and kicking out and being really difficult and of course everybody sees that he is a naughty boy.

In addition she observed:

> The young boy is really actually so angry, and I think he's demonstrating the anger for the whole family and he's kicking out and he's biting and he's doing all those sort of things. You know and that's how it is being seen, he is a naughty boy and he is so not, well he is but he is not a naughty boy and he is just furious and he is four and he doesn't know how to do it other than to kick.

Unknowing observers would typically assume that the behaviour they were witnessing was 'normal' for the child, and would be unlikely to make an assessment of their behaviour on anything other than the visual cues they were seeing. A difficulty here is that the child is then labelled as 'naughty', and the antecedents to the behaviour, the feelings of anger and powerlessness in light of parental terminal illness are overlooked.

'Pat', the manager of an independent child bereavement support service, discussed in depth her work with children; she described how when working with them she regularly utilises 'feeling charts' which consist of an outline of an amorphous body. The children are invited to colour in different feelings on the chart and to indicate where these feelings are located within their body. Pat observed that frequently the children, when completing the chart will put red, which symbolises anger, in their feet and fists. Pat clarified this observation by stating that when children are hitting out and being angry it is their feet and fists that they use.

The findings reveal that anger may be manifested in inappropriate behaviour which is often the only way the children know to externalise their feelings. The anger is often directed at the well parent. This was highlighted by Pat when she discussed an example from her practice. Here she had observed a young person becoming angry with their surviving parent following the death of the ill parent. Within their verbal exchange between the young person and their parent, Pat observed the young person asking with much venom:

> Why mummy and not you?

'Julia', a bereavement support worker, also gave an example of angry outbursts that can be the children's response to the death of a parent and their attempt to find some rationale for what has happened. She was describing a piece of work she had been involved with where the father had died following a short but intense illness. The young boy in the family had asked his mother with acrimony:

> Why didn't you marry a healthy daddy?

The manifestations of the behaviour do not necessarily appear at the point when the children are living with the situation and it can be some years following the death when something triggers certain emotions or cognitions. Julia recalled a family she had worked with. The young boy was five when his father had died of cancer. The boy appeared to be initially coping well with the death. However, Julia said that when he was eight, his behaviour significantly deteriorated especially in school, where he was displaying angry outbursts. Julia supported the young boy and established that the catalyst for the change in his behaviour was when he started playing football for a junior team. He observed that all his team mates had their fathers supporting them at each match and he did not. The realisation of what he was missing had caused his anger and grief to be manifested through his behaviour.

Attempting to assimilate and manage the knowledge that a parent is terminally ill has the potential to result in inappropriate behaviour if the children are not supported and if they do not receive adequate information about the situation. A theme to emerge from many of the accounts illustrate how difficult and problematic this can be for the children. The following section continues the theme of inappropriate behaviour however, the focus moves specifically to risk-taking behaviours that children become involved with when their parent is dying.

5.2.3 'She's running away, she's self harming, she's doing this, she's doing that': Risk-taking behaviours

Having some control over the situation is important for the children when all the known boundaries in their lives become unclear. One way young people attempt to take some control is by engaging in risk-taking behaviours. This allows them to feel as though they have some control of their actions, but also the physical pain often associated with such behaviours means that the emotional pain is briefly blocked.

A number of the professionals described their observations of risk-taking behaviours that particularly young people had engaged in. Hannah suggested that in her opinion, young people frequently undertake these activities as a way of them being noticed and gaining attention.

Amanda offered examples of young people engaging in risk-taking behaviours following the death of their parents. The first example was of a young person whose behaviour had altered following the death of her grandfather. This young person had come to Amanda's attention because of her behaviour in school. Amanda described her behaviour:

> ...she's running away, she's self harming, she's doing this, she's doing that ...

Amanda then talked about another young person she had worked with in school whose father had died. Within the discussion, Amanda discussed some of the risk taking behaviour that the girl had started to engage in:

> ...the relationship she has got as well with an older boy isn't ideal. So she's chosen negative relationships...

Pat gave anecdotal evidence about an adolescent male she had worked with following the death of his father. This young person had again chosen to engage in risk taking behaviours. Pat described how her assessment of him, from his skin tone and facial reactions, informed her that he was using illegal drugs. Pat explained to me how she had talked to him about this and how he had been very honest with her. She told me that he had confirmed to her that he was using drugs and said that it helped him block out the pain. He went on to say that he did not think about what had happened when he was under the influence of the drugs.

Pat introduced me to her colleague 'Alison' who is a Play Therapist. During our interview, Alison also returned to the issue of anger and frustration in children living with a parent who is dying. She described how, within her practice, she has worked with children who have experienced these feelings when a parent is dying or has died. Alison reflected about how a significant number of the young people that she has worked with, as she described it:

> ... have used drink and drugs as an emotional sticking plaster.

Emotional 'sticking plasters' come in a variety of forms and are regularly used by the children to mask the pain, as an expression of their frustration or as a way of taking some control. Whichever form of 'sticking plaster' the children utilise they are likely to be putting themselves at risk of harm. Furthermore, this will only provide a temporary solution or escape from their anguish. A first step in helping them to understand what is happening and to assist in their meaning making process, is the availability of information and allowing them to be party to conversations about their parents' illnesses. Furthermore, having a fellow traveller to support them through the difficult period can also have significant, positive outcomes.

5.2.4 'She thinks she is ugly, she thinks she is fat': Loss of self-esteem

The emotional traumas of living with a dying parent can affect every part of the children's lives. Anger and the consequential negative behaviour was a theme to emerge from the research. However, the findings also evidenced that this period in children's lives can affect their self esteem. It is recognised in psychological theories that having a positive view of oneself and high self-esteem are contributing factors to positive mental health (McNamara 2000). However, findings from my research suggest that experiencing the death of a parent can have serious detrimental effects on the children's confidence and self-esteem. Amanda's account clearly demonstrates how for one young person the death of her father, after a terminal illness, had had a deleterious effect on her mental wellbeing. Amanda included in her observations evidence of both emotional and physical frustrations:

> She immediately started going off the rails and she was truanting but not enough for me to get involved, Erm her school work has gone down, how she feels about herself, she thinks she is ugly, she thinks she's fat and she's not either. She can't build good relationships with teachers in school and is regularly being kicked out ...

My observations of the support offered to children at Pat's project revealed how much of the work focused on promoting positive mental health. Pat had strong convictions that a distinct remit of her project was preventative mental health work along with creating an environment where the children could re-engage with their self esteem.

The erosion of all predictable, safe boundaries and the shattering of the children's concept of their worlds creates insecurities in all facets of their lives. It is probably significantly more difficult for young adolescents who, by the nature of child development, are entering a liminal period and who are exploring the construction of their identities. If during this period they experience the additional difficulties and pressures of parental terminal illness then their concept of self is also likely to be questioned and destabilised.

5.3 EXPERIENCES FOLLOWING THE DEATH

5.3.1 'Something can happen or you can see something that triggers it off': Revisiting the emotions in the bereavement period

Within the chapter to date, I have presented data evidencing that children experience many different emotions when they are attempting to cope with the knowledge that their parent is dying or has recently died. Strategies that are employed in an attempt to cope with the situation, along with some of the behaviours that are typically manifested have been described. The focus of the chapter is now going to move away from the immediacy of living with a parent who is dying to the bereavement period. Managing the experience is not subject to any specific timescales and trying to cope with and negotiate the journey of parental death, is a continuous ongoing procedure that often needs re-visiting at different times in the children's lives.

The findings evidence that whilst the children's grief was not constantly at the forefront of their lives, it was never far away and had the potential to be triggered by events and memories. Diane discussed this when she was talking about the support her children had received following the death of their father:

> You could have seen somebody like [name of worker] for two months, three months, whatever and six months down the line you feel like there is something happening to your life and you need to talk again. I think just to be able to phone somebody up or you know can I talk to you? You know you might not phone them for another six months but at that moment in time you might just want somebody to speak to, you know because obviously nothing ever disappears but something can happen or you can see something that triggers off and you might just think "oh I could really do with talking to so and so.

Carol, the bereavement counsellor, talked about this from her experience of providing counselling to bereaved children:

> Er but certainly I've often had children that have come back at various stages so you might meet when they are twelve then when they are fourteen they come back and all of a sudden fifteen, sixteen and just have a couple of session almost as if they've got some resilience and they just want to boost it a little bit, something is happening and they know that they have done this before and its worked so I will just see whether this can help and they seem to get erm [pause] use counselling more [pause] more as a reinforcement for strategies that they have begun if you like...

The process of re-visiting the experience of the illness and death provides children with the opportunity to construct some meaning of what has happened, to develop a 'durable biography' (Walter 1996) and moreover, to have some control over the management of the situation. This again needs to be an on-going process that occurs as the children are growing up and maturing developmentally and cognitively.

'Martha', a social worker based in an adult hospice, made the following observation:

> ...with children's bereavement you may have to re-visit, if a child loses somebody at five their cognitive understanding at nine or ten about that bereavement will be different and you often have to go back to it again in the light of their new understanding.

'Catherine', a community based palliative care nurse, also discussed the time element and how it can affect children's understanding:

> Sometimes people are diagnosed and are ill, or not very well for quite a long time and the children are living with a progressive illness for a long long time and then there can be a rapid change and somebody dies so they might have started off as fifteen year olds but now are nineteen, and that's a major time in their lives where their development is going all over the place quite often.

Hannah's observations helped develop this theme. She was describing a piece of work she had undertaken with a sixteen year old girl whose mother had died from cancer the previous year. Hannah had supported the young person pre-bereavement. Following the mother's death, she had contacted the family offering support, which was declined. However, some months later, the young person then re-established contact with Hannah:

> ...about two months ago I got an email from [name of young person] asking whether I could answer some questions about cancer...And she came in and what she wanted to do was to talk about missing mum and the fact that there are big life changes for her...But there is all this weight of expectations and change and she needed to talk. And she needed to talk to somebody who knew her mum and she needed to talk with someone who'd understand that actually she is missing mum and it hurts...It is interesting she's reprocessing now and also she wanted it legitimised that it was okay to be talking about these things because it is a year and you know you are expected to be over it. And so being able to say to her ...there will be times in your life when you will need to do this again and you will need to talk to somebody whether it be me or whether it be somebody else and there will be important parts in your life. And that felt

> like it was really important to her to know that she would continually re-visit her relationship with her mum as she grows up and her relationship without her mum physically in her life.

Acknowledging with children that the need to re-visit their feelings is a normal and healthy part of the grief process gives them permission to explore their emotions. This is congruent with the more recent models of grief that advocate continuing bonds and the maintenance of an on going relationship with the deceased. However, for this permission to be offered, practitioners need to be cognisant of the value of such information and furthermore, share the principles with the children and their families.

5.3.2 'It was a bad time for that bad thing to happen': Revisiting memories of the death

In addition to the internal emotional and psychological factors that need to be explored and understood in more detail as the period following the death progresses, external stimuli also have the potential to invoke memories. Luke discussed how particular situations caused him to re-visit his feelings about his mother's death and associated memories of her:

> Yes probably because erm [pause] mainly because at times like when you, especially things are difficult at home and it happened, well when my mum died it was [pause] I think I was just starting my GCSEs so that was, I mean it was a bad thing to happen anyway but it was a bad time for the bad thing to happen erm and I suppose a lot er support then would have been helpful because it threw me off track that I mean I still did quite well. But I mean it's one of those recurring things, whenever I have exams or revision to do, it's something that I think about again because obviously it was quite a big event to happen at that time and it triggers memories.

Significant life events have the potential to cause children to revisit their memories of the experience of living with a dying parent and their death. Carol highlighted how in her experience, young people will often re-process what has happened to them when they reach significant events and milestones in their lives:

> ...one of the things I notice and I wonder if this is about the early, when I was saying about it comes to a head early twenties perhaps is that all of a sudden that young person wants to do something significant in their lives like get married or they find that they are going to have a family and all of a sudden that huge impact that they are never going to see this, my mum,

> my dad are never going to know, er and that can be a time that I've noticed it can trigger yes that's a trigger time something is happening for them or they particularly need a mum or you know and they are not there.

Adults involved with the children, both professionals and family and friends, have a role to play in acknowledging that they will need to re-visit their emotions and that this is an ongoing normal, healthy situation that is not time limited. However, Harriet's observations, from her practice as a specialist palliative care nurse, provided an example of adults dismissing their needs:

> Yes I think it is and I think a lot of people, it is normal to be upset after you have had a loss obviously and they just accept things don't they you know. It's probably years down the line when the kids are still having problems they may think or somebody may flag up to them they think they've got a problem, you know because its "oh they'll get over it you know they are bound to be upset".

Linked closely to the children's need to re-visit their emotions and feelings is the need for them to re-process what is happening to them. Georgina, from the children's perspective, illustrated how young people re-process their emotions and cognitions, when she was talking about some thoughts she had recently had about her grandfather:

> It has been awful lately thinking that I will never have a hug again, it's quite scary.

Diane discussed this, particularly in relation to her son and his working through of what had happened:

> I have tried to sort things out…I feel like nothing is ever getting sorted. I'd even say he's still having a lot of problems. I even actually had one teacher say to me when he was in Year Four last year er "don't you think it's been a few years now he should be alright". Well me being me I lost my temper, you know, I really seriously lost my temper. But it's like I said he'll never get over it. You know it's not just a year or two or three or ten years, you know its something he will never get over and I was really annoyed. He's still suffering I think. I don't think he's dealt with anything.

Diane's observations resonate with Hockey's (2002) suggestion that '…the lack of an extended period of liminality as highly problematic' (p. 216), both for those who are in the period betwixt and between but also for outsiders looking in. However, Diane's account also reveals that awareness by professionals is, on occasions, limited which then creates further pressures and more difficulties for the liminal period. Re-visiting memories of the deceased along with re-processing what happened during the illness period has many benefits and helps the children to make some sense from what has happened along with giving them permission to maintain a relationship with their parent.

5.3.3 'You just want to be left to have that bad day': The inaccessibility of peers to the alien landscape of parental bereavement

Having a fellow traveller, to traverse the alien landscape which children often enter through parental terminal illness and death, can be of significant benefit. However, there are a limited number of such companions and people who have not shared the experience can not completely understand the emotions, feelings and cognitions.

In this section, I will present evidence, drawing on Luke's account and an entry from my reflective journal, which highlight the continuing struggle the bereaved experience when their alien landscape is not accessible to those who have not experienced similar journeys. Luke was describing the continuing effect his mother's death has had on him and how periodically he continues to want to avoid the emotional management and containment of his feelings. He gave an example of a close friend who had limited understanding of bereavement and the frustrations that this can create:

> Er yes because I mean like its, it sounds daft I suppose but my friend... doesn't know a lot about [name of disease] and that's not her fault obviously I don't talk to her about it much but er there are times when I just have a day where I feel like crap and er not so well not that I'm not sure why but I just, its there's no specific event that's happened other than obviously that that's made me feel like that. Er I don't think she always understands and but its difficult to put it across to someone who hasn't experienced it that its how you feel and just having a bad day and it being alright, you just wanting to be left to have that bad day.

Luke's account would suggest that he continues to feel isolated in his bereavement when he is amongst people who have not experienced a similar life-changing event and who do not know the contours of his map. This can be related back to the earlier findings about children wanting to be the same as their peers and fitting in, however, it also develops the notion that experiencing the death of a parent can be an isolating and lonely event and that 'members' of this group are cut off by their difference from others in society. A few weeks after my interview with Luke I read an article in a national newspaper and captured my thoughts in my reflective journal:

> I have read an interesting article in the Guardian today 'I Need him Less but Want him More' (Manzoor). He was writing about the effect his father's death had on him when he was a boy. He wrote 'I have become increasingly fascinated by the before and after, that divide between those who know what it is like to have lost a parent and those with good fortune to have parents who are still alive'. The quote really captured me. I was reflecting back on the conversation I have had this week with [name of partner] about the canoeist who has "come back from the dead" [the canoeist who faked his death for pecuniary gain]. I got the feeling from the discussions that [partner] just can't grasp the point I am making about the wish/desire that bereaved children have about wishing/hoping that your dead parent would return and the link to what message this person's re-appearance could have for bereaved children. Having read that quote I wonder if it is about not understanding until you have been there – almost an exclusive club where the death of a parent is a pre-requisite. Although [partner] understands an awful lot of my experiences and my research maybe he can't understand it all or grasp what I mean because thankfully he has never had to experience that hope/wish that his parents would come back...(26.7.08).

This section of the chapter has considered how children often need to re-visit their emotions and feelings for many years after the death of their parent and how the triggering of memories can force them into this. Findings were also presented with regards to how parentally bereaved children need to re-process the death as they develop and mature. The final part of the section developed the notion of being in an alien territory and how this new land is often not completely accessible to people who have not shared similar experiences. Within this I argue that the bereaved become members of an exclusive club where membership is only available to those who have experienced the death of a parent. Having people who can share similar experiences may be helpful in the construction of narratives that help children to make some meaning from their experiences and help them to a meaningful biography.

Summary

The chapter has examined how children attempt to navigate and manage the experience of living with a parent who is at the end of life or has died. A consistent theme to emerge highlighted that children cope with this challenging situation in a variety of ways. Some of these management strategies are seen as being positive, whilst others are viewed as being negative. Children's and professionals' accounts included anger and powerlessness as being the antecedents to difficult, negative behaviours. The exclusion from communication and information sharing about the illness has a significant role in contributing to the management or mismanagement of the situation. However, equally important is support from adults, both professionals and family and friends. An issue that compromises the children's ability to successfully manage the situation relates to feelings of being different and not 'fitting in' with peers. Recognition and an understanding of their current situation would contribute to this and give them 'permission' to be themselves and not have to feign identities.

The first section of the chapter presented evidence about emotions that children experience, with particular emphasis being on the fear of the 'scary place' parental terminal illness represents. During this period they enter a liminal state where they are 'betwixt and between fixed social positions' (Hockey 2002, p. 213). Being between these social positions singles the children out as being different from their peers which presents further challenges and often forces them to feign identities.

Related to the notion of 'fitting in' was evidence that children cope with the situation by employing avoidant strategies. Whilst it could be suggested that these avoidant behaviours are behaviours typically seen in young people and represent a time in their development where they are moving from dependence to independence, evidence suggests that they are employing coping strategies to help them traverse the unfamiliar contours of their lives. Adopting strategies that allow them to move away from the situation permits them to oscillate back into their previously known life that represents order, safety and comfort. This notion would concur with the work of Stroebe and Schut (1999) and the Dual Process Model of grief. Stroebe and Schut suggest that the bereaved need to take time off from grieving. Equally important is children taking time off from the illness. Living constantly with the uncertainty, fear and worries is emotionally exhausting. Therefore, temporarily moving away from the situation allows the children to reinvest their energies and concentrate their thinking on other aspects of their lives. This may be an unconscious process but it is effective in 'protecting' the children from constant emotional conflict.

A theme that was discussed by the children and professionals related to the expression of feelings through behaviour. This was often witnessed as 'naughty' behaviour or inappropriate behaviour. This finding correlates with the premise in Chapter Four regarding communication and information sharing. The different accounts from the children, their parents and professionals suggested that there is a correlation between being given information and being party to discussions about the parent's health and their ability to manage the situation. Those who received regular information and were included in discussions offered accounts of resilience and more adept coping mechanisms. Conversely the children who were not included tended to be the ones that engaged in inappropriate behaviours. These were the young people who were more likely to be angry, who reported not feeling safe and who construed their current experience to be living in an alien land.

The final part of the chapter moved away from the situation of living with a parent who is dying to focus on children's experiences of their bereavement. The theme of non-specific time frames was again referred to, with particular emphasis being given to the need children have to re-visit their emotions and cognitions about their parent's death again and again. This often occurs as the children are developing cognitively, physically and emotionally and specific landmarks in their lives are achieved. The need to re-visit and re-explore their bereavement again can be framed in Van Gennep's work which is described by Hockey who suggests that during this intermediate period the bereaved pass from their previous social status to a new one. The example provided is from wife to widow, however, there is no corresponding status for bereaved children to pass through (Saldinger et al. 1999) and the research has evidenced that their 'map' is frequently lacking in appropriate safe routes. The need to re-visit and explore the bereavement can also be located in the work of Silverman and Klass (1996) and Walter (1999) who describe the importance and significance of maintaining a relationship with the deceased. Through the process of re-visiting their relationship with the deceased and the meanings attached to their death, they are maintaining the relationship with their parent.

The findings have highlighted that children whose parents are terminally ill face many changes and challenges that need to be managed as their parent's health deteriorates and following their death. Some of the strategies and processes for this management have been considered, the following chapter is going to present findings relating to the many changes and challenges that the children experience during this often complex journey.

CHAPTER SIX: TRANSITIONS, CHANGES AND CHALLENGES WHEN A PARENT IS TERMINALLY ILL

The childhood years are typically marked by a progression of transitions or key turning points through which children grow and develop a sense of identity, belonging and family membership. This may not always be a positive experience, and adolescence is characteristically marked by crises of self-confidence, uncertainty and ambivalence. A theme that has been consistent throughout my analysis of accounts from both children and professionals has reinforced the uniqueness of the transitions experienced by children living with a parent who is dying. These changes affect children irrespective of their age, gender or previous relationship with the parent. The children may move from living within a safe boundaried world to experiencing uncertainty, chaos and confusion and they are forced to enter a world where their taken for granted lives are lost. Furthermore, the confusion and fear is exacerbated by the unpredictability of terminal illness. The aim of the chapter is to present these different and often difficult transitions and to consider them in light of the notion, introduced in earlier chapters, of the children entering an alien landscape. Analysis of the data would again suggest that Van Gennep's (1977) work has particular relevance to the findings, especially the 'tripartite structure comprising rites of separation, threshold rites and rites of aggregation' (Hockey 2002, p. 212). Furthermore, Kelly's (2008) definition of liminality is important, she suggests that:

> [T]o be in liminality is to be in limbo, in the threshold of between here and there, without socio-cultural classification or a medical diagnosis of where "there" is, will be, or if the ritual subjects ever make it there (p. 336).

The chapter will begin by considering the significant transition children experience of living with a healthy parent to living with the knowledge that their parent is dying. This includes accounts of changes in family routines, and particularly how the illness appears to take control of all family life and becomes the nucleus of the family, thus disrupting the children's view of their worlds. Changes and challenges that adolescents encounter, including the taking on of additional household responsibilities, are also explored.

The specific changes and challenges that children encounter in relation to their parents' medical care is then examined. These relate equally to when the parent is being nursed in hospital or a hospice or when they are receiving care at home. The accounts illustrate that these experiences present particularly difficult challenges for the children to navigate both emotionally and cognitively.

Changes experienced by the children in relation to their social worlds are examined. Firstly I present participants' accounts that illustrate how living with a parent who is dying can create major upheaval and potential chaos. This is followed by examples from the data that indicate that family routines are severely compromised during this period and that this often precludes children from engaging in the social activities they previously enjoyed prior to illness entering the family. This is followed by professionals' accounts of times children have been excluded from social activities because of their parents' illnesses.

The final section of the chapter moves from the changes and challenges experienced before the death to explore the changes that children experience following the death. Issues of residency are discussed and highlight that these changes are often traumatic and difficult to manage both for the children and their parents. Accounts from professionals are incorporated to demonstrate how children sometimes experience feelings of relief after the death of their parent. However, these feelings often create a sense of confusion for the children, as the feelings are contrary to the typically held cultural assumptions about acceptable emotional responses following a death.

6.1 ENTERING THE ALIEN LANDSCAPE

6.1.1 Transitions for the Children – Moving from living with a healthy parent to living with a parent who is dying

One of the most difficult and painful challenges that children are forced to contemplate when a parent is diagnosed as having a terminal illness, is the shift from having a healthy parent to knowing that the parent is ill and is going to die. This was succinctly observed by Hannah, the specialist nurse, who I interviewed on two occasions:

> There is a real transition for children having a parent who is dying rather than having a parent who is living who then goes into a terminal phase of illness. There is a real shift sometimes between suddenly everything is very different and I think that is quite catastrophic for a lot of children.

Within this life-changing event, children are forced to cope with a number of different transitions psychologically, cognitively, emotionally and socially. Each one of these can create changes and challenges (Way 2009), at the individual level but also within the construct of the family and the wider social community. Hannah described these changes in family dynamics when a parent is at the end of life when she observed:

> Illness can change the dynamics of family, your family as you know it and trust it.

Catherine discussed some of the changes that she has witnessed children experience when a parent is at the end of life. She began by making a comparison between sudden death and when the death is anticipated:

> The type of death that a lot of the children we would be involved with is different from sudden deaths, because if your dad has dropped dead or has been run over by a truck or you know something quick happens, I think the management of that can sometimes be quite different to the patients we see where the child is sometimes watching a patient become a non person almost, you know the role that they have fulfilled as a mum or dad has changed dramatically. Sometimes they can't do any of that anymore can they, or they've seen them in pain or other distressing symptoms...The main issue is the parent not being there anymore but the process, because a lot of the time when you are preparing adults it is the preparation isn't it that by the time they die sometimes they've got their head round some of the things, they've done practical things and although it is still awful, its not as bad as it might have been because you're kind of half way there with some of the issues whereas acute, traumatic events none of that happens. But on the other hand that waiting to die, because they know its going to happen is really traumatic for children isn't it, you know the anxiety of not knowing what's going to happen from day to day...

One of the most difficult changes for the majority of children is the move from the safe predictable boundaried world of living with well parents to the knowledge that the taken for granted world has been shattered and instead there is uncertainty, chaos and confusion. Furthermore, the unpredictability of the illness creates further confusion and chaos. The medical profession is generally reluctant to offer specific time scales in relation to the trajectory of an illness (Lawton 2000). This can create difficulties in relation to when the children should be given the information that their parent has a terminal illness. Hannah highlighted the dilemma of timing in relation to the changes and challenges experienced by children and exemplifies the sudden transition for children from living with the knowledge that their parent is well to receiving the news that their parent is dying:

> They [the children] are confronted with dying very rapidly because they are told definitively at a point at which a parent is failing, so they don't have any way of fixing in their minds the possibility of having an illness that is not actively dying.

Furthermore, younger children who have limited concepts about time struggle with the notion that their parent is likely to die in a specified time span. For younger children their level of cognitive development and their lack of understanding of death and dying compound this. This was poignantly highlighted by Georgina when she was talking about her grandfather:

> I thought he would live for ever, then when I got older I thought he'd live to 100 cos he was so great and everything and I never thought he would die at 79, I had so much faith in him living. A few days before he died I saw him and thought, he's not going to live, I was wishing he would make it to my birthday. I didn't want the day my best friend in the whole world to die would be on my birthday.

The uncertainty along with the dramatic changes in all aspects of family life, associated with the pre-bereavement period, may represent a more difficult time to manage than the period following the death. Knowing that a parent is going to die and anticipating the changing future forces the children into a liminal period where their known life is suspended. Critical turning points occur throughout the illness trajectory, however, these are often unpredictable and cannot be planned for with any certainty. As a consequence the children are compelled to pass through this period with little control. The suggestion that the pre-bereavement period is more difficult to manage was a theme that emerged from a number of the professionals' accounts. Dr Jones highlighted this:

> The pain is intense [following the death] but the worst has happened and now everyone's task is to find a way through it, whereas when they are still facing the death of a parent there is so much that is uncertain, difficult to resolve because you can't yet, things are on hold.

John described, how from his professional experience, the pre-bereavement period, for children, is often a more painful and difficult time to negotiate:

> ...it is absolutely fearful in the extreme for a lot of people pre-bereavement.

Catherine's account supported this:

> Once an event has happened [the person has died] it has happened and you have to deal with it but I think sometimes that protracted 'what if and maybe and when' is much harder for children to deal with.

The accounts from the three practitioners above come from their professional practice and are based on the observations they have made of children they have worked with. Samantha's account below provides a recollection from her experience of living with a parent who is dying:

> Afterwards [following the death] you just want to get back to, try to get back to normal and adapt to it and the new way of things. But before it is random and not like normal life.

However, Luke offered a different perspective from his experience:

> ...it was probably a lot worse afterwards because then there's obviously the sensitive issue the fact that my mum had died.

Luke's account provides a different perspective and demonstrates how his experience, perceptions and memories are different from Samantha's. Furthermore, Luke offers an insight that is different from the professionals' view thus highlighting the importance and relevance of including children as participants in research about issues that affect their lives. The children's accounts are based on the narratives they have developed of the lived experience of parental terminal illness, whilst the professionals' accounts are derived from their observations and experiences as practitioners and possibly fellow travellers.

6.1.2 'All that is happening in this family is this cancer': Family routines, the illness takes control

The fractured world of living with a parent at the end of life has a consequential effect on the whole family. Whilst the children may feel that their world is imminently going to implode they also may feel that their family's world is about to explode. The embedded and well-rehearsed routines of family life are thrown into turmoil when a parent is at the end of life. The predictability and known safe boundaries are rocked as the disease or illness takes over family life. The family follows Van Gennep's model and move out from a previous phase or social status into a threshold position of being betwixt and between (Hockey 2002). This was highlighted in the interview with Elizabeth:

> I think it is the effect upon their family life, once they have got over the initial devastation of the diagnosis its then living with it day to day, the consultant hospital appointments, the treatment, the financial implications, the demands upon their time, they are kind of not in control of their lives anymore, the disease is in control of their lives, it calls all the shots. Everything else has to be dropped because if somebody is poorly that day or they have had side effects from the treatment or bloods aren't right or treatment is cancelled you might have got this regime that your treatment is going to be like that but then your blood might not be right so its cancelled until your bloods are right. You might have to have a blood transfusion. Its that constant uncertainty of what's happening but no matter what, it's the disease that's kind of dictating what will happen week in week out. And that is also difficult for the patient because they are trying to hold on to their own identity and they are losing it because everybody else talks about how they feel today, how's the treatments going and everybody who sees them, everybody who rings up so they stop talking about everything else in their life because all that is happening in this family is this cancer.

Elizabeth's quote offers a number of significant issues about how terminal illness affects the functioning of the family and the changes that they experience. She talked about the anger that is sometimes manifested towards the illness. Similarly other professionals interviewed for the research also described, from their experience how the children become angry with their parents, both the patient and the well parent, because of the illness and the prognosis. The previous chapter (Sec 5.2.2) discussed how this anger is typically manifested and how the children sometimes employ inappropriate behaviour as a way to manage their feelings. The findings evidence that often the behaviour is an outlet for the transitionary, liminal period for the children between living with a healthy parent and living with a parent who is dying.

6.1.3 '...they bring up one of the children into that parental subsystem': Teenagers taking on responsibilities

Examples from the research have shown that some young people living with a parent who is dying are required to take on more responsibility, both in terms of caring for the parent but also in relation to the care of younger siblings and housework. For some young people these additional responsibilities are undertaken willingly and provide them with the feeling of being helpful and contributing in a positive way to the current situation. However, for others these new roles are seen as an imposition and are, as such resented. Hannah commented on this during our second meeting:

> ...they move into some of these roles because first of all it feels like it is just nice to be helpful but then suddenly you find yourself stuck in custom and practice doing all the tasks that you wouldn't necessarily expect a child to be doing.

Taking on additional responsibilities may be seen as a significant change for the young people, where they experience a sudden shift from the dependent child role into the role of carer with additional responsibilities placed on them. Generally this is a gradual process for children, which is part of their growing maturity and development and represents part of their rites of passage. However, for children living with a parent at the end of life this is not necessarily so. Additional roles and responsibilities are thrust upon them and examples from the participants' accounts suggest that they could be elevated into the co-parenting dyad. Hannah exemplified this:

> What I have seen quite often is you get a couple that have been co-parenting in whatever way then one of the parents gets ill and what they do is they bring up one of the children into that parental subsystem and so the ill parent gets excluded from parenting which I think is a real death for many, particularly women but also too the child gets brought up into that so they end up making the rules for their younger siblings or they take on responsibilities and I think this happens quite often when you have teenagers and it is that cultural thing of stories that we give to children about being good and about being brave or you know you are the man of the house now and all of this kind of phraseology that we use that is really quite offensive.

Elizabeth made a similar observation but also noted that for some young people this move into having a more responsible role may have occurred naturally irrespective of the illness:

> ...older children in the family might have to take on more responsibility, perhaps a bit more prematurely, it might have been the right time for them to do it no matter what they would have had to do it at some point in their life but they see it as its kind of forced upon them because this illness suddenly came.

Whichever position is taken these untypical roles and responsibilities contribute to a new and different identity for young people. Taking on some household responsibilities, as Elizabeth observed, is generally to be the norm for the majority of older adolescents in modern British culture and another marker in their developmental map. However, the taking on of additional roles may bring into question issues of power and the children's position in the family especially when, through these new roles, children take on non-preferred identities.

Much of the adolescents' identity is about belonging to the peer group and having the cohesion of a group identity. For young people taking on caring roles they are not able to subscribe to the group dynamics as they may have done previously and as a consequence need to pose the question 'who am I?' Hannah's account of her work with young people illustrated this notion:

> They are given power but not necessarily the experience or the kind of skills to be able to manage and it also gets in the way of what they should normally be doing. So if I think about families where there have been expectations of teenagers to do lots of things in the house and actually there is this real other culture of the school or playground or your peer group which is going down to the mall and hanging out and generally getting up to allsorts of mildly naughty behaviour or even very naughty behaviour which is part of the teenagers rites of passage and actually being denied part of that can be really difficult. So you don't actually fit with anything properly and I think for most of us what we are wanting as we go through life is to fit and the whole life cycle thing allows us to change our position and have another bit of fit but this isn't the case [pause] and how children manage all of that is very different.

The changes and challenges are seen across the family and can be particularly difficult for the well parent to manage whilst trying to maintain family routines and complete necessary household tasks whilst also caring for their partner and children. Hannah illustrated this when she observed:

> ...we have got a man who is managing with four young children, trying to work, trying to do all of these things so inevitably the children have to take on, particularly the older one has had to take on some additional kind of semi-parental responsibility and she has actually been drawn up into that parental dyad.

The sudden elevation into more responsible roles can be an additional challenge for children already trying to cope with the confusion and chaos that parental terminal illness can bring. This may be particularly difficult for adolescents who, during this period, are often experiencing doubts about their identities and questioning their roles and positions within the family construct. The additional complicating factor of knowing that a parent is dying can force the to 'grow up too quickly'. The following section will explore this with particular reference to challenges to their identity.

6.1.4 'This is how I want to be and all of a sudden that person is poorly': Identity transitions

Being forced to 'growing up too quickly' can have implications for children's identity and their constructs of the world. Examples from the professionals' accounts illustrated this. Carol, the bereavement counsellor, talked about this, with particular reference to male identity and teenage boys. She suggested that there was an early transition into adulthood for these boys and that they struggled with their self-identity which had previously been based on their father who had been their role model. She described her perceptions of their thinking:

> This is how I want to be and all of a sudden that person is poorly and this sort of big strong person becomes poorly and weaker and that can actually have quite an effect on them.

Similarly, during the interview with Elizabeth she described the experiences of a family she had been working with where one of the teenage children had difficulties accommodating her identity in light of the illness. There were two teenage daughters in the family, their parents had divorced when they were young and their mother had re-married. Elizabeth told me that the girls had developed a positive relationship with their stepfather. However, he was diagnosed with cancer and his health deteriorated rapidly. The eldest daughter, a fifteen year old was struggling with his prognosis, Elizabeth commented:

> ...she kind of re-mapped her life out with this man playing a significant part in her life as her new father, so when he started to deteriorate it really did start to impact on her because she realised that her mental map of life that she had drawn with him playing a key role and he wouldn't be there

> and she had even to the extent that she was expecting him to give her away in church when she got married.

Elizabeth discussed succinctly this cognitive and emotional transition that children are exposed to:

> It's a bit like having a blackboard or whiteboard, you've drawn it all out and then you have to erase it and start again.

This has resonance with Rando's (2000a) writings and her discussion that within anticipatory mourning it is not the person that is let go of 'but the hopes, dreams and expectations of a long term future with that person' (p.8).

This section of the chapter has presented findings from the professionals' accounts about the transitions, changes and challenges that children typically experience when a parent is dying. They suggest that the shift from living in a safe, predictable world to entering an alien landscape, where all known scripts and routines have been lost can have massive implications for the children's sense of self and their identity.

6.2 THE IMPACT OF THE PARENTS' CARE ON THE CHILDREN

6.2.1 'Mum's care is so institutionalised...it gets in the way of something that is really important to both of them': Institutionalised care

The research has highlighted that there can be a major shift for children when their parent becomes increasingly dependent on nursing care. Hannah discussed this in relation to the family who have featured throughout thesis. She talked about the changes that the young girl was experiencing in the relationship with her mother:

> Mum's care is so institutionalised, she has to have carers with her all the time, it gets in the way of something that is really important to both of them.

This quote exemplifies the adjustments children are required to make when a parent is hospitalised. Spontaneity is lost and suddenly the children are reliant on others to facilitate the visits to the hospital, thus again removing some control from their lives. Furthermore, a parent's physical deterioration and subsequent hospitalisation can impact on the growing child's memories of their pre-illness relationship. Hannah described how during one of the sessions with the young girl, she had attempted to explore this with Hannah:

> She is losing her memories of her mum, of her walking, talking, her being, and that is quite difficult for her.

This graphically illustrates the changes that children experience and the movement from having a healthy parent living at home to having a terminally ill parent being constantly cared for by others in a hospital environment.

Examples from the research have illustrated how the parent's admission to hospital or a hospice can be a major challenge for the children. The interviews with children highlighted some of their experiences when visiting the hospital or hospice and how this impacted on them. One young person I observed compared her experience of hospice and hospital visiting. She discussed some of her feelings in relation to visiting her mother in hospital and talked about how disconcerting it felt because of the behaviour of some of the other patients:

> Well I don't mind the hospice, I felt safe there, but I don't like hospitals because they creep me out because there are loads of different people there with different illnesses, like when my mum was in [name of hospital] there was this old lady, she had something wrong with her and when I wanted some fresh air with my grandma, she said erm that we weren't allowed back because it was her house. She was really scary.

Samantha recalled her experiences of visiting her mother in the hospital and then the hospice. She described how her mother was an in-patient at the hospital for a number of months and how during this period she developed some positive relationships with the nurses. She went on to recall visiting her mother in the hospice. She remembered that this had been a problematic time because of the competing demands of completing homework and spending time with her mother.

Georgina recalled some of the emotional difficulties she experienced when she was visiting her grandfather in the hospice:

> I made friends with people in granddad's room, then they weren't there and I was told that they had passed away, that was really awful.

The children's experiences highlight how their relationship with the parent becomes strained and loses the previously known spontaneity. These accounts are consistent with the observations made by the professionals. Both the children's and professionals' accounts suggest that the hospital or hospice environmental plays a role in the loss of relationship and is further evidence to the children that their known, secure world has been fractured.

6.2.2 'It seemed like a never ending parade of people coming in the house': Implications of being nursed at home

The research has highlighted that difficulties were also encountered when the parents were being cared for at home. Having regular visits from the medical team into the home creates changes from 'normal' family life into a very different home life. Georgina's mother described this when talking about the care her father received:

> It seemed like a never-ending parade of people coming in the house. Dad wanted to be at home but we didn't realise the implications of the numbers of people coming and going, it was all a bit befuddling sometimes.

Georgina's comments added to this observation and highlighted how the change of having 'serial' carers coming into the house became an indicator of the seriousness of the situation:

> When all the people were coming into the house this was the time when you realise that it is serious.

Georgina's mother also reflected how the care her father had received was orientated to the practical medical and nursing elements and that there had been no emotional or social support offered either to the patient or family.

Hannah discussed some of the issues experienced by professionals and families when a person chooses to be cared for at home. These resonate with Georgina and her mother's experience. Hannah's discussion was through the lens of a practitioner and focused on the concentrated amount of physical care that is necessitated in nursing someone at home. Within this Hannah questioned whether the medical team providing this care had always received the appropriate training and whether aspects of the holistic care could be missed. It was Hannah's opinion that the support is focused on practical care and not on the emotional needs of the patient or family members.

Georgina and her mother highlighted further implications when the dying person is cared for at home. Georgina's mother observed how Georgina experienced difficulties being in her grandfather's house as his illness progressed and his health deteriorated, she observed:

> You found it difficult to be at his house as time went on.

Georgina clarified her feelings by commenting that:

> I still do, its really empty. When he died I went into his room and saw the bed and he wasn't there, that was really horrible.

Luke recalled similar feelings following his mother's death and the difficulties he experienced in managing the transition from her being at home every day for four years to not being there:

> ...for her to be there all the time and suddenly not be it was a big shock and you don't know how you are going to feel and you don't know if what you are feeling is normal.

The accounts of both the children and professionals suggest that children may experience significant changes and challenges as a result to their parent's medical treatment. These changes occur whether the parent is cared for within an institution or the home and are often traumatic for the children to navigate. The children's accounts highlight the strength of the messages they receive when a parent is in receipt of regular and sustained medical care. This acts as further confirmation about the seriousness of the illness and the prognosis. Furthermore, all the control is removed from family members and is placed within the professional's domain, thus again highlighting to the children their limited power within the situation.

6.3 THE SOCIAL DEATH FOR CHILDREN

The embryo of this section of the chapter was conceived following my first meeting with Hannah. I reflected on the then emerging findings from our discussion, with particular reference to the accounts of the family where the mother had a neurological illness. These initial discussions about the changes this family were experiencing, and the developing theme from other participants, caused me to consider their lives in correspondence to the research by Lawton (2000) with particular reference to her writings on the social death of patients. Whilst the Lawton research focuses on the social death for the patients, the findings that form the basis of this section relate to the children's world and the transitions they experience within the context of their social world. Although the children's social death will not result in the physical death as in relation to Lawton's respondents, the findings exemplify how their social world is ruptured, albeit for the duration of the parent's illness.

In the second interview with Hannah, I explored with her the notion of the children's social world being disrupted when a parent is at the end of life. Within our discussion she asked the following rhetorical question:

> At what point does it become a social death as opposed to social living with a life threatening illness, and why might there be a difference for some people?

6.3.1 'The sheer physical consequences of serious illness gets in the way of doing so many things': Transitions in family activities

Children may, as a result of their parents' illnesses experience restrictions on their previously known social life and, as a consequence, face further difficulties and hurdles which they are required to overcome. When a family is living with the knowledge that a parent has a terminal illness the routines of family life are inevitably disrupted. A theme to emerge from the professionals' accounts is that family life begins to revolve around medical appointments, treatments and visits from professionals. Elizabeth highlighted this in section 6.1.2, Hannah also described this, in relation to social activities, when she discussed a family she had been working with, she observed:

> They found that they'd got quite a lot of social life coming into their house. You become so on display because you have got the world and his dog coming through your home in terms of professional services casting an eye over you and that your life actually can sometimes become structured around professional visits. So that creates an artificiality sometimes that contributes to this whole idea of no time to get in the car and go off to [name of seaside town] for the day and have fish and chips on the pier, because you are waiting in for the district nurse or the GP. I suppose it is the extent to which the illness does take over your life or you allow it to take over your life.

The circumstances of the illness will also dictate the structure of family life and how that is transposed onto the children. Hannah talked about the cycle of professional visits impacting on a family's spontaneity in being able to go out for the day. The interview with Luke graphically highlighted, from a young person's perspective, how the circumstances of the illness can also affect this spontaneity. He discussed his mother's debilitating illness that rendered her housebound. Luke described this in relation to not being able to go out for the day or have holidays. Within his account he also emphasised how during the course of his mother's illness the situation had became 'the norm':

> ...there are certain things just adding to make it worse but, it's like holidays actually I suppose because [the disease] sort of leaves you very much housebound erm I mean it is possible to go places but you need a lot of equipment and stuff with you erm so and just like I suppose like planned or people helping to plan visits somewhere or days out just to get you away from that normal daily routine ...so not just for the family but for the person with it because obviously my mum spent like all day everyday in the house just in this room. But with that it was always a four, five hour preparation thing so if you wanted to go out it had to be all arranged and sorted.

Routines and safe boundaries are important for children and their sense of connectedness. However, the research has evidenced that maintaining routines when a parent is at the end of life can be problematic. During the interview, for the feasibility study, Samantha's father spoke about how he tried very hard to maintain some semblance of normality for his two daughters when their mother was terminally ill:

> We kept life as normal as possible for the girls, going to school, sports activities, etcetera, which made life very hectic and busy. We tried to keep a sense of normality about life and the rhythm of life.

However, the findings also indicate that being able to maintain this sense of normality is often very difficult to manage. Accounts from children and professionals suggest that the illness impacts on the known social world and creates another challenge that the children are exposed to.

6.3.2 '...kids don't get invited round for tea or to play': Changes in children's social activities

The research has evidenced that when the illness becomes the nucleus of family life this can severely limit the opportunities children have to engage in social activities. Barriers to the children accessing leisure activities, which they had previously engaged in, are then created. The changing dynamics within the family and the huge shift in priorities may have a bearing on this. The professionals described some of the challenges they understood children to experience. Hannah suggested from her observations that:

> ...there are all sorts of pockets of social life for us and sometimes it maybe that actually the children stop going to things like Brownies or Cubs or things that are actually important to them. So again it's about the functioning of the parent in their ability to keep some things normal and specific. So actually those families who do pretty well are often those that despite enormous difficulties manage to help children retain their sense of identity, for example being a Brownie, which might be the single most important thing to them.

Living with a parent who is dying can therefore constrain social activities away from the home that children typically enjoy; however, the research has evidenced that social activities within the home can also be limited because of the current situation. Hannah talked about a conversation she had had with the parents of the two young children who have been discussed previously. Within the discussion with them she explored the notion, particularly for the young girl of having friends to stay, having sleepovers and experimenting with make up which are all explorations typically experienced by young children:

> ... and asking them what their thoughts were about that and how they manage that. And actually that is something that is a non-starter for them and what that might mean in terms of them mixing with other families. Again when you have got small children many of your friends are connected to school and you meet at the playground and those kind of

> things are often taken away from you too, so there's that kind of parents don't talk to each other so kids don't get invited around to tea or to play.

The children's lives being 'interrupted' as a result of the illness can be a significant challenge that requites appropriate acknowledgment and support. Dr Jones, provided the following quote which exemplifies the difficulties:

> ...things are on hold and the child's social life is on hold because they can't go to this after school thing or that party and for the parents to be able to maintain some sort of normality and stability at that time is a huge thing to ask of them...

Elizabeth's account, again from a professional's perspective contributed to the development of this theme:

> ...it filters through from everything and sometimes the children have to sacrifice what they normally do or what they would want to do because they know the disease is there and this is where sometimes there becomes a lot of anger towards the disease because of how it is kind of over taking the family and it becomes the most important thing in the family.

Social experiences have a significant part to play in structuring children's identity and helping them in widening their social networks and thus in the developmental process of becoming more autonomous. However, the limitations placed on children when a parent is living with a terminal illness and the contraction of their social life that is created as a consequence can have far reaching implications. The discussion with Hannah evidenced this in relation to the young girl whose mother had the neurological disease. Hannah was describing a session she had undertaken with the girl and how during the session the girl had told Hannah that she did not have any friends. Hannah mused:

> ...whether it is because she hasn't had the opportunity to engage with the "come round to my house and I'll come round to yours" that she isn't seen as part of that social after school parties kind of life style ... she appears to be in a little world of her own.

Being in a 'world of her own' highlights how children can be dislocated from the typical social activities and be seen as being different from their peers. However, the young girl's narrative may have been very different about this situation. This again demonstrates the importance of the children's voice in research and their inclusion to provide direct narratives and accounts.

Children living with a parent who is dying face a particularly challenging set of changes and hurdles that affect their social worlds. Entry into the liminal period of parental terminal illness can have the effect of decreasing opportunities for social interaction and engagement with peers. The typical norms of pre-illness connectedness with peers through social activities can be severely compromised because of the illness and opportunities to participate are limited. This can further reinforce the children's feelings of being different from their peers and of being isolated. The final section of this chapter is going to move away from the pre-illness status to examine transitions that occur following the death of a parent. Evidence from the findings would suggest that the children remain in a liminal position and are faced with further challenges and changes.

6.4 TRANSITIONS FOLLOWING THE DEATH

6.4.1 Residency and children's care

The research has emphasised that the transitionary period from living with a parent who is dying to experiencing their death can be a particularly traumatic time for children. After the parent has died the children enter a new phase of uncertainty and confusion. Some of this uncertainty is as a result of the safe boundaried world being fractured.

At times the children may encounter the problem of who they will live with after the parent has died. The issue of residency and the transition of moving to live with an estranged parent or other relatives can be an emotionally and socially problematic period which compounds the realisation that the ill parent has died. Henderson et al. (2007) discuss the impact of family fragmentation on young people when parents divorce or because of parental death. They suggest that the young people in their research were forced to reconfigure the meaning of home, including having to deal with 'the practical realities of their current home status' (p. 126).

Pat discussed this issue when she was talking about young people she had worked with whose parents had separated before illness entered the family. She gave anecdotal evidence about a young teenager whose parents had separated. Following the death of his mother this young person was forced to move away from what had become his home town to live with his father and his new partner. In this process, the young person had experienced multiple losses including his peers, school and environmental markers that were significant to his identity and the memories of his mother.

Mandy expressed similar concerns for her two children. Mandy talked about how it had been agreed that following her death her children would live with their birth father. Mandy said that the children had a good relationship with their father and that she was not worried about that aspect of the move. However, she expressed concerns that they would be leaving their home town as their father lived in another part of the country. Mandy was worried about the potential disruptions and the uprooting of all that was familiar to them which was likely to occur with the move.

Single parents who are terminally ill are likely to experience many additional problems and worries from people who are in relationships. The issue of residency being just one of these concerns. Hannah discussed some of the issues and potential problems that are particularly pertinent to them, which they are forced to consider when they are terminally ill:

> ...increasingly now we are seeing more parents who are dying who are single parents and the issues around who's going to care for the children and how are they going to make the transitions to another carer and thinking about, sort of certainly thinking about lots of attachment work.

The findings suggest that the children of single parents are therefore likely to experience a number of issues and threats to their emotional security that are unique to their situation. Experiencing the death of a parent is undoubtedly one of the most difficult life changing events that children are exposed to. However, when this is further complicated by the realisation that they must live with someone who would not normally take on the role of primary carer this can be exacerbated significantly.

6.4.2 'She is different and she knows she is different': Difficult transitions following the death

The terminal phase of a parent's illness and their death have huge implications for children's identity and how they cope with the transition of living with a healthy parent to having a parent who is dying and a parent who has died. The following accounts are from the second interview with Hannah and support the notion that the death of a parent has the potential to challenge children's identity and sense of self. The young person described by Hannah had experienced the death of both her parents within six months of each other. As a result of this she was forced to face many changes and challenges, one of these being the relationship with a younger sibling. Hannah described this:

> She is a young girl who is struggling because her younger sister, this girl is seventeen and her younger sister in ten and she wants to remain really close to her sister but her sister doesn't particularly want to be close to her. And the younger sister is able to be taken in and nurtured by the rest of the family in a way that the older one can't and so people respond differently to her...

How the family responded to the young girl suggests that she had been forced to not only cope with the liminal period following her parents' death but also the liminality of transition from child to young adult. The adults' expectations of her were inconsistent and created uncertainty for her as the following quote from Hannah suggests:

> She says its really hard because sometimes they treat her as being really grown up and they ask her to make decisions which actually she wants some help with like when she was choosing her options for her A' levels. Everybody said you choose the subjects that you want to, but she wanted somebody to go with her and yet she feels that people try to make rules and regulations about things that she thinks she should have a right, you know as a young woman to be able to make.

Within the same discussion, Hannah returned to the issue of relationships with peers and again referring to this young person's experiences highlighted how managing parental death can be very challenging:

> I think it creates chaos, death can create chaos in terms of those rules that we have and actually again not knowing how you fit in. So if you don't feel that you fit its really hard. And she sees herself as so, she's a sociable girl, very popular but she said, there are one or two people and when she is with them it's brilliant but actually most of them it's so hard because they are talking about things that she doesn't have anymore and they talk about them with such ease and she is different and she knows she is different but she has to hide it and not talk about it.

Hannah's accounts of this young person's struggle to cope with the many changes and challenges that she was experiencing highlight, from a professional's perspective, how dealing with parental death can be very difficult. The young person's account may have been different and may have offered a different insight into her narratives. Nevertheless, the account supports some of the themes that have emerged from the research. Hannah's observations in the final section once again highlights how, during both the pre and post bereavement period, children are frequently forced to feign personalities that are not congruent with how they are feeling in order to appear the same and fit in with peers. This being congruent with other accounts from both the children and professionals.

6.4.3 '...it means they can re-enter back into a life': Experiences of feeling relief after the death

The huge shift from living with a parent who is dying to living with the knowledge that a parent has died is sometimes experienced almost as a relief. This was highlighted in a number of the interviews for this research. Hannah described this:

> The fact for some children that there is an end to it is a relief because it means that maybe all of the things that they haven't had or have been put on hold can be recaptured. So it means that they can re-enter back into a life and a relationship with all those other things that they had.

However, there is a need to acknowledge that children's experiences and circumstances are inevitably different, and how they respond following the death is likely to be affected by previous experiences. Hannah discussed the experience of one young girl that she had been working with. There was palpable relief for this young girl when her father had died because of the specific circumstances of her life. Hannah informed me that the young girl's father had been physically and emotionally abusive towards her and her sibling. However, the young girl had struggled to cope following his death because of the confusing and conflicting support she had received, from adults in her life, that was not congruent with her feelings. Hannah explained:

> ...and what's really hard for her is the received wisdom when we are doing bereavement work is kind of to create stories about the dead that are good and meaningful but actually she hasn't got many...

This young girl's experience has similarities with the work of Ribbens McCarthy (2006) who suggests that 'the death of someone who is a significant if difficult part of one's life may still be associated with strong emotions, even if the grief experience may be less central' (p. 39).

The findings have shown that feelings of relief are, at times, the result of the children's believe that their parents are no longer experiencing pain and suffering as a result of their illness. However, Pat cautioned that often this was a temporary emotion that was subsumed by feelings of loss and guilt.

6.4.4 '...people muddle through and continue in the same way that they have always muddled through': Evidence of resilience in families following the death

The research has evidenced that additional support for children, during their parents' illnesses and following their deaths, is often recognised as being valuable and can help the children to navigate the different challenges, changes and turning points they experience. However, the findings have also provided examples where this support is not needed. Not all families will require or desire help from external sources and this needs to be recognised when professionals are planning their work.

Hannah provided an account from her experience that recognises the diversity of families and supports the notion that not all families will need professional intervention:

> Some families don't need support because they've got the structures that are so supportive that the death is almost, it's a huge transitional point but it doesn't destroy everything. It is just a transition in life in the same way that a birth or a marriage or divorce can be and it is managed for want of a better word. You can't always know how that happens, it just does, people muddle through and continue in the same way that they have always muddled through.

Having resilience and being able to cope with the death of a parent provides evidence of how there can be opportunities for positive growth for the children. Linked closely with this is how the children have managed the experience of living with a parent who is dying. If this has been managed by the adults sensitively and the children have been included throughout, it is likely that their ability to cope following the death is strengthened. The value of information sharing and being involved in conversations about what is happening with the family may be evidenced here. The pre-bereavement period is important as it provides valuable opportunities for the family to work together to support the children and to help them develop positive coping strategies.

Summary

The chapter has considered themes from the data about the transitions children experience when their parent is at the end of life or has died. Whilst I suggested that transitions are a typical feature of childhood which are necessary for healthy development and progression, my findings would indicate that children experiencing the death of a parent encounter many different challenges that would not be typically associated with childhood.

Frequently, the children find themselves in a liminal position as the parent's health deteriorates and they become less well, the children witnesses the changes, however, whether they are able to conceptualise these is a different matter. The research suggests that the children have a constant struggle between maintaining a semblance of normality and therefore control and allowing themselves to step into the new world which is abnormal, frightening and somewhere they really would rather not be. This again has resonance with Van Gennep's Rites of Passage (1977).

The chapter began by examining examples from the data that suggests that a significant transition for the children is the move from the safe, predictable view of the world that their parent is healthy to living with the knowledge that their parent is dying. I presented data relating to family routines and accounts from the professionals who described how in their opinion the illness takes control of all family activities and becomes the core of family life. Transitions that are frequently imposed on teenagers and older young people were described. Accounts from the professionals suggested that whilst these roles are often taken on willingly initially, the young people might become resentful that they have been burdened with such responsibility, especially when it impacts on their social life. The first section of the chapter concluded with an example of how one young person has been required, in the light of illness, to reconsider her 'map of life' and who has had to re-draw her cognitions, dreams and hopes for the future. This young person's account offers a glimpse into the process of anticipatory mourning as described by

Rando (2000a) whereby it is not the person that is let go of but the hopes and plans for the future together that needs to be re-assessed.

In the second section of the chapter, I presented data where the specific emphasis was on the experiences of children in relation to the medical care their parents were receiving and how this impacted on their lives. This was firstly described in the context of institutionalised care and included the children's memories of visiting their parent in hospital or the hospice. This section described some of the difficulties that were encountered. The accounts suggested that this was potentially a difficult period to navigate and created problematic challenges for the children. The final part of this section moved away from care within institutions to care in the home. The data suggested that nursing the parent at home created challenges for all the family. This was highlighted by one participant who talked about the never-ending parade of people visiting the home. Furthermore, this procession of serial carers became significant as an indicator of the seriousness of the illness and thus acted as an unspoken confirmation that the patient was gravely ill.

The following section of this chapter considered the social changes that children are often forced to encounter when a parent is terminally ill. This section of the chapter paralleled the work of Lawton (2000) and her writings about the social death of patients. A recurring theme evidenced from the professional's perspective, was that the children experienced some form of disruption in their social lives as the patient's health deteriorated. The uncertainty brought about as a result of the illness brings chaos and upheaval into family life which impacts on all aspects of their experiences. Many of the typical social activities in family life that act as markers for the family are compromised when a parent is at the end of life. This can have the effect that the children's social world is compacted and opportunities for them to participate in activities with their peers are severely diminished. This creates a social death for the children, and whilst this will not result in their own deaths, as with the patients in the Lawton study, there is a significant transition that occurs which requires them to adjust their view of the world.

Within the final section of the chapter I considered some of the changes and challenges experienced by children following the death of a parent. A potentially difficult change that was discussed by the participants related to residency and where and with whom the children would live following the death of their parent. The data suggests that this was a particularly major upheaval to be navigated by some of the children as it frequently involved numerous associated changes. The result was a compounding of what was already a difficult period into an accumulation of challenges and changes that the children were confronted with.

I offered examples from the data that indicate that it is not uncommon for children to experience feelings of relief after the death of their parent. The circumstances of family life prior to the death can impact on how the death is perceived by the children. The example from the data was the overwhelming feeling of relief for one young girl following the death of her abusive father. However, these feelings did not correspond with the typically held assumptions of the adults involved in her care who advocated that she should maintain positive and happy memories of him. This was contradictory to her feelings and created confusion and anxiety. It was also suggested during the research that children often feel relief that the death of the parent means an end to their pain and suffering. The data also evidenced that this relief can quickly be substituted with feelings of guilt.

The chapter has considered a number of transitions that are typically encountered by children living with a parent who is dying. The data would suggest that these transitions create a number of challenges and changes which the children are required to navigate. The familial and professional support provided at this time is pivotal in determining whether the transitions are successfully or more easily accomplished. The quality of information sharing and communication with the children has a significant part to play in achieving the preferred outcome and how the changes and challenges are managed. The following chapter will present a case study of a young person I met during the research. Her story describes in detail the changes and challenges that she was forced to face when her mother was living with a life threatening illness and following her death.

CHAPTER SEVEN: 'A LITTLE GIRL LOST': JENNIFER'S STORY

In this final findings chapter I present in detail a case study from the interviews with 'Jennifer'. Jennifer's interviews provide a sequenced account tracing her experience of living with her mother who was ill, her death and the subsequent years of trying to cope with her bereavement. Jennifer's story shares many similarities with those of my other participants, and the case study offers a detailed insight into a young person's world when living with a parent who is dying. Moreover, the case study highlights the importance of interpretation and the meanings children attach to what has happened to them.

The chapter will begin with a brief introduction about Jennifer and her biography. This will be followed by an exploration of one of the significant elements in Jennifer's narrative, her exclusion from any conversations or information sharing about her mother's deteriorating health and imminent death. This absence was pervasive during the interviews with Jennifer and echoed similar accounts from my other participants.

The second section of the chapter will present Jennifer's recollections of her life when her mother was ill. This period in Jennifer's life provides evidence of her attempts to manage the situation, the weekly routines that she was engaged in as a young carer and the effect this had on her identity and sense of self.

The final section of the chapter moves to Jennifer's story following her mother's unexpected death and focuses on the difficult transitions that she was forced to make. Jennifer's narrative is about the dearth of professional or community support offered to her and the challenges she encountered in attempting to cope with the new alien landscape she had moved into.

I met with Jennifer on two occasions, initially during the early stages of my fieldwork and again towards the latter part of the research. In addition, we maintained contact throughout the research through email communication. Jennifer is a young adult who as a child lived with her mother and older sister. Her parents had separated before she was born, her father moving to live in another country where he died when Jennifer was young. Jennifer stated that she had no memories of her father. Her mother was diagnosed with Multiple Sclerosis (MS) when Jennifer was three years old. Jennifer was fifteen years old when her mother died. During the years of her mother's illness, Jennifer and her sister increasingly took on the role of carer for their mother.

Jennifer's experience was different from my other participants insofar as following her mother's death she was not cared for by a surviving parent and apart from her older sibling had no relatives to support or care for her. Four months after Jennifer's mother died, and following her sixteenth birthday, her sister moved away from their home town, leaving Jennifer to live alone in the family home.

7.1 COMMUNICATION AND INFORMATION SHARING

7.1.1 Living in a closed awareness context

Jennifer's biography highlights how communication and information sharing are so important, particularly in relation to the awareness contexts proposed by Glaser and Strauss (1980). Jennifer's recollections of the period when her mother's health was deteriorating and she was becoming increasingly reliant on nursing care are an exemplar of adults not including children in conversations about their parent's health or the prognosis. Jennifer's biography highlights how this form of closed awareness, that she experienced, has had long term implications for her sense of self and wellbeing. Furthermore, Jennifer's narrative is about a collusion of silence which was established early during her mother's illness and became embedded in the culture of her family.

The nature of Jennifer's mother's illness caused her to have many periods of hospitalisation which Jennifer and her sister 'coped with'. These periods became the norm for Jennifer and as she described became part of what she expected to happen in her family. Throughout this period, Jennifer could not recall being given any information about her mother's illness or 'constructive' professional support. Jennifer observed that:

> ...the social worker she used to come in and see how we were doing. I don't really know what she was like supposed to observe or monitor but I always remember her coming because my mum hated it and she hated her. I think I do vaguely remember like the odd nurse but not really that much. I don't really remember much medical attention it was just like sorting out

> medication and that was it I don't really remember anything else. Sometimes the odd hospital visit that was it really.

Jennifer's experience can be contrasted with Luke's. Luke's mother had a degenerative neurological disease, which caused increased paralysis. However, his accounts suggest that he was, to a degree, involved with the medical care that his mother received and moreover was involved in discussions about her illness and care, to the extent that he attended some of the hospital appointments with her. Jennifer's experience was very different and would suggest that she was isolated and excluded from any professional support. Furthermore, Jennifer's account highlighted that little productive support was forthcoming from the community either:

> I mean I guess one of the main things was how people kept their distance as mum got more and more ill, people were always very aware of the fact that it was me and my sister looking after mum...

Jennifer's memories of the period before her mother died suggest that no professionals engaged with her in conversations about her mother's illness, prognosis and possible death. For Jennifer this collusion of silence remained even when her mother was terminally ill and nearing death.

Jennifer recalled a time when she had been visiting her mother in hospital and the vicar also visited and prayed for her mother. She spoke about how within the prayer, the vicar asked for support for her mother as she was dying. Jennifer remembered this incident with deep anger and hurt. She recalled how even the vicar must have known the seriousness of her mother's condition and yet she had not been told.

7.1.2 A conspiracy of silence

Jennifer was the only participant to describe her memories of the day her mother died. The significance of the experience and the relevance in relation to her narrative of not being included in any conversations or information sharing about her mother's death was evident during the re-telling of her memories.

During my first meeting with Jennifer she recalled vividly the day her mother died. She spoke about being called out of school. Her mother's friend had collected her and had taken her to the hospital. The friend did not provide a reason why they were going to the hospital other than Jennifer should be there. Jennifer remembered not feeling alarmed by this change in routine and actually thought to herself that it would save her visiting her mother in the evening. Jennifer's sister was already at the hospital having been summoned from work. The curtains were closed round her mother's bed, but still she did not think that anything was wrong. The friend suggested that Jennifer and her sister may wish to hold their mother's hand but gave no explanation as to why this might be appropriate. None of the nursing staff said anything to Jennifer. When Jennifer's mother died, nurses came and ushered her and her sister away from the bed through the curtains and into the main body of the ward. Jennifer said she remembered thinking that even the patients must have known what was happening and yet she was not privy to this information.

Following our meeting I recorded my observations in my reflective journal:

> Jennifer was very fluent when telling her story and it was only later upon reflection that I realised how this story must have been rehearsed many times (reflective journal 05.07).

In my second meeting with Jennifer, we again discussed the emotions and feelings she had experienced at the time of her mother's death. I asked Jennifer if she could recall how not being informed had affected her, Jennifer observed:

> Erm just I guess anger er because I think well if I knew then I could have spent, I would have spent more time with my mum. And I remember when I was talking to my sister and we were talking about how we didn't know and how everyone else knew even the day that she died it didn't seem to like click in my head that she was going to die and how it was all kind of arranged like call the girls get them here and put them, you know they can go round the bedside put the curtains round and that kind of thing and it still didn't click in my head. It was only actually when she stopped breathing that I was like oh okay and then it kind of hit me and then obviously it was far too late erm. It's almost like we should have realised that our mum was always ill that's all we have known her as. I didn't really know about the disease and what happens, I just knew it gets worse and worse but I just thought, you just still don't envisage it because it is completely opposite to what everything you ever knew you just can't comprehend it. Er so yes I can I was just angry and yes when I was talking to my sister about it and I, we were getting quite upset about it because we realised like how frustrated we felt not being about not knowing...

During my meetings with Jennifer she returned on a number of occasions to the issue of not receiving any information or support and how in her opinion this had severely compromised her ability to manage the bereavement. The conspiracy of silence, from all the adults, and the failure to provide her with accurate information about her mother's prognosis caused her to lose a valuable opportunity to 'write the penultimate chapter' of life with her mother. A theme that was palpable throughout the interviews with Jennifer was her feelings of not being involved in 'writing the penultimate chapter' and lost opportunities to talk with her mother and to say the things that she wanted to say. Furthermore, Jennifer's account suggests that because of the unexpectedness of her mother's death, compounded with the lack of information from any adult, she was denied an opportunity to share important messages with her mother. Jennifer queried this during our second interview:

> I don't really know I mean I guess even if I was, if we were told would we have, I guess probably would have tried to make things clearer and talk about things saying things you want to say [long pause].

The lack of information had further implications for Jennifer. She described how, when visiting her mother, the weekend before she died, she had spent some time with her and then prepared to leave for home. She recalled how her mother had asked her to stay a little while longer, but with painful regret she had chosen not to stay:

> I think she died on the Tuesday and I just thought when I was talking to my sister about it crying thinking why if I'd known then I would have stayed and I shouldn't have gone and I always regretted it...

Jennifer's narrative of the period leading up to her mother's death has strong associations with the knowledge that she was excluded from any information and was 'protected' by all the adults who adopted behaviour resembling a closed awareness context.

Jennifer's story has similarities with the accounts of other participants who also described not being included in information about a parents' terminal illness. However, Jennifer's narrative suggests that her experience was different because of the extent to which she was excluded. Furthermore, the deleterious effect this had and continues to have on her sense of self, suggests the value and importance that should be placed on adults establishing appropriate information exchanges.

7.1.3 Pre- bereavement narrative

During the second interview with Jennifer, we revisited the period before her mother's death and I asked whether she could recall this time with particular reference to the changes that occurred in her life because of her dominant role being that of young carer. Jennifer commented:

> I don't know when I think about before my mum died it was really quite cloudy, I think about after it's a bit clearer to me but before it just seems a completely different life, it's almost like that didn't really happen to me anyway it's like it was just something, it's in my head but that wasn't me it was just someone I knew or like a book you read about someone's life you know it just doesn't seem like it was me everything was just really fuzzy [pause].

Jennifer's observation has resonance with the findings in Chapter Five and the attention placed on how children manage the period when they are living with a parent who is dying. The unreality of the experience, the diversification from what is typically perceived to be 'a normal' life caused Jennifer to feel that she was witnessing the drama unfold but that she was not a participating actress in the play. Jennifer's memory of the observer role offers an insight into the way she managed the period and how she attempted to adapt cognitively, emotionally and psychologically to the situation. Being in an alien landscape, with no reference to act as a guide or to forewarn of imminent crisis, resulted in Jennifer being unable to remember clearly all aspects of the period before her mother died. Had she been party to information and discussions about her mother's health and the subsequent deterioration, she may have been more able to live through the experience as opposed to now having the feeling of being a bystander witnessing someone else's life.

One feature of her life that Jennifer was able to recall was the role of young carer that she adopted. Jennifer described a typical weekday to me:

> Yes I would just go to school as normal and er yes but after like, we would have carers in the morning and the evening but we would still, me and my

> sister would still have to wake up at six o'clock in the morning to help my mum get out of bed and put her on the toilet and then the carers would come in and help her get dressed. But we would still do a lot, helping her get dressed and getting up and give breakfast and all those sort of things so there was yes morning and night and then go off to school as normal and then try and forget about my life as it was and then get back home at four o'clock and erm yes then it would just begin again.

Jennifer's account can be compared with the other participants' experiences when their parents were dying. Luke described how his stepfather took on much of the caring role for his mother and he gave little indication that he was catapulted into the role of carer. Conversely, the professionals spoke about how, for many children, taking on a caring role, similar to Jennifer's is the norm.

Jennifer's observation that when she was at school she could 'try and forget' about her life indicates that the routines of school, prior to her mother's death, allowed her an oasis from the pattern that had become her life. The school environment provided a semblance of normality and routine which was a valuable release from the day-to-day reality of living with an ill parent. This can be compared with the findings in Chapter Five where professionals described how children are often apprehensive about returning home after a day at school because of the uncertainty of the situation. This contradiction may provide evidence of how the accounts of professionals differ from those of the children and how this could reflect the differing perspectives of people 'looking in' as opposed to the opinions of those 'looking out'.

7.1.4 'Fitting in with peers' and a small oasis

Issues of identity and being the same as peers were two constant themes to emerge from the interviews with children and the professionals involved in the research. The data suggests that living with a parent who is dying compromises the young people's notion of self and can make them stand out as being different from their peers. Jennifer's account suggested that this was an important construct in her life. When she was discussing her life before her mother's death she observed:

> I just felt I didn't fit in with the other people my age [pause].

However, when Jennifer was talking about her schooling, prior to her mother's death she noted that for a brief period she was in fact able to identify with a small selection of close friends. Jennifer's comments reveal that these friends were a source of escape from the life that she was living:

> Erm I think school for me especially in Year 9 up to then, then it went kind of down hill, especially in Year 11 obviously but I had two really close friends and school you know it was fun at that time we would, you know it was, we didn't talk about home life or what, they obviously knew that you know my mum was ill in a wheelchair and I didn't have a dad but we all actually had a kind of slightly messed up families, like I think that's why we all connected as well all of us had parents who were divorced or we didn't have a dad or stuff like that...

The oasis of school life and support from friends was important for Jennifer in coping with her life and in providing a chapter that was enjoyable and typical for a young person to be experiencing. The comment from Jennifer relating to her friends experiencing similar disruptions in their lives correlates with the notion in Chapter Five about fellow travellers and people who belong to the same 'club' who can empathise and have a shared understanding of what is happening. Jennifer continued to recall the time spent with friends:

> ...but yes it was fun we would just laugh and laugh around and I have good memories of that time and I guess that helped me get through. I suppose I was stuck in a bit of a dream world at the time, I would just dream about like my life and how it could be different and I still did that up to sixth form time I always thought that erm you know if I got to a good university I would have my own life and I would have all these friends and I would have this nice boyfriend and I really had it on my mind and I think now oh my God how could I have planned it so much all those different things I would do and erm clothes I would wear and [laugh] when I think how its turned out like it's nothing like I expected erm but yes that's what really got me through those dreams [pause].

Jennifer's account provides an insight into the dreams she created which helped in part sustain her through the period when her mother was increasingly reliant on help and care. These dreams and the planning of life have some resonance with the young person's experience in Chapter Six, where she had drawn a map of life. However, in Jennifer's example, she had created a dream world that she had aspirations to move into when she was older and thus offer her a glimpse of hope for the future.

Within the constraints of caring for her mother, Jennifer noted that there were brief and occasional periods when she could move away from the identity that had been forced onto her and she was able to enter a preferred identity. When Jennifer began talking about these excursions into typical teenage life, I observed that her non-verbal behaviour altered. She became more animated and her body language suggested more confidence and positivity. Jennifer spoke about the occasions when she went out socially with her friends:

> Yes I think it was and then on the rare occasion when we did all go to the cinema like with my friends or we would go shopping to like [name of city] or something erm even just town er you know that would be a great event. Like so look forward to it and I would really have to work up to ask my mum if I could go and it would be a real task even if I did manage to go just you know and then obviously just dreading going back home and seeing, never knowing what to expect and just hating that kind of let down when we'd be having so much fun and we would plan what we would wear and you know or just planning to go to Pizza Hut would be such a great event for us you know. So yes because they were such contrasts to my day to day life I guess so yes I could just be myself. I just felt I could be myself and I [pause]...

These days out with her friends provided Jennifer with the opportunity to briefly move into a young person's typical world, however, the account also contains a sense of conflict and tension, a dichotomy between preferred and forced identities. Jennifer's observations support the notion of the social death children frequently experience when a parent is at the end of life. Jennifer had a strong desire to go out with friends and be part of the social milieu and yet that was severely curtailed because of her mother's illness. She observed that:

> ...it was like it wasn't like I was completely not doing things but at the same time you are not really out there or there are things that you miss out on like just watching, I always remember that I always wanted to watch, sit and watch Saturday morning TV and watch 'Top of the Pops' and things like that. I never did because, well Saturday mornings were cleaning days for one so we could never watch TV then... I remember not doing those little things as well erm so you just don't feel fully part of, that's why I felt like I could never fully relate to what other people my age were doing [long pause].

Jennifer discussed the rare occasions she had excursions out with friends, but she also described outings that as a younger girl she had enjoyed with her mother and sister. She talked about summer holidays they enjoyed at the coast and day trips that her mother planned. However, she recalled how, as her mother's health deteriorated, it compromised opportunities for the family to enjoy these outings away from the home. This has similarities with the other participants' accounts. Luke spoke about how it became increasingly problematic and too complex to organise times away from the home for his mother and how this impacted on the family's sense of normality.

During the second interview, Jennifer suggested that her memories of life before her mother died were 'fuzzy' and that she often felt that she was an observer looking in; however, her story also provided some richly detailed accounts of this period of her life. Many of her observations have similarities with those of the other children involved in the research. The role of young carer forced Jennifer to enter an alien, hostile landscape where she took on roles that are not generally the norm for young people. Within this she struggled to identify with her peers causing her to experience feelings of difference. During this period, school offered routines and a semblance of normality that Jennifer valued. Jennifer also noted that there were very occasional outings with her friends which she held as treasured memories. However, her narrative is about how these rare excursions into typical teenage behaviour were often fraught with anxieties because of the expectations placed on her to care for her mother.

7.2 EXPERIENCES FOLLOWING THE DEATH

7.2.1 Post death narrative

Jennifer's story provides an insight into the complex and often confusing alien landscape that children typically find themselves in when a parent is dying. Examples from Jennifer's accounts are significant as they exemplify how moving through the liminal period of a terminal illness into the bereavement period is also fraught with difficulties. Whilst it needs to be recognised that Jennifer's accounts are her narrative and thus are not necessarily typical, they highlight some of the potential emotional, social and cognitive issues faced by children living with a terminally ill parent.

This section of the case study focuses on Jennifer's life after the death of her mother. The accounts begin with the period immediately following her mother's death. I asked about the support she received from friends and the local community. Jennifer observed:

> I don't remember anybody being supportive. Er there was my mum's best friend who kind of put herself tried to put herself in the position of like a mother which was by inviting us round at Christmas and then just inviting me round for meals on occasions when [name of sister] had left... But aside from her there wasn't anybody like after the initial er kind of everyone coming round to give their condolences... But anyone I knew before when mum was alive they all kind of just disappeared I didn't have contact with anybody...But yes I can't remember, I just remember being on my own basically.

The overt lack of support from the local community has resonance with Rosenblatt (2000). Here the emphasis is on parental grief following the death of a child, however, the sentiment remains the same and Jennifer's experience can be equally applied to the following quote:

> To bereaved parents communities do not seem to mourn much or long; they do not seem to acknowledge in the same way parents do that this is a death that will affect them for decades (Rosenblatt, 2000, p. 3).

Jennifer described how her sister made the decision to move away from the family home a few months after their mother had died. Jennifer recalled the dilemma she faced when her sister made the decision to move:

> She went to live with her boyfriend at the time erm because she just, I guess for her she didn't see any reason to stay in [name of town] well besides me I guess but there was nothing for her here, no jobs so I guess she didn't want to stay here so I can't really blame her she was only eighteen she didn't she wasn't in the position I guess to start looking after me even though I wanted her to, you know I wanted somebody to. But obviously I was angry with her at the time, didn't speak to her for a while.

Jennifer then described the period after her sister had left the family home and how she was alone:

> So yes I guess it was just strange living in that big house on my own, it felt quite strange and none of the neighbours ever came round to see how I was or anything. Maybe they didn't know what to say or I don't know what they

> felt really because they were the adults in the situation and you think they should know the way [pause].

This lack of support from the neighbours can be compared with Jennifer's account about an occasion, prior to her mother's death, when a neighbour had anonymously telephoned Social Services because they had heard shouting coming from Jennifer's house. This prompted a visit from a social worker. Jennifer recalled that this was the only occasion she spoke directly to a social worker or any other professional. However, following her mother's death when Jennifer was alone any kind of intervention or support from neighbours was not forthcoming.

7.2.2 The relationship with school

Jennifer described how, being alone, she had managed the period following her mother's death and the further changes that she was required to make. One of the key features of this management that she described during both our meetings was her relationship with school:

> ...after my mum had died the lack of well there was initially recognition from teachers and stuff at school, like "oh sorry to hear about your mum" but I guess you know everything just goes back to normal for everyone else... and [pause] a few months down the line, I started skiving from school. I would kind of go to school in the morning and then I would quickly sneak out at break time or lunchtime just because I hated being there really.

Jennifer then described what happened when the school staff discovered her truanting. Her account places an emphasis on the teacher's lack of recognition of her current life experience and his insensitivity to her needs:

> I guess I can't remember exactly how I felt but erm I got caught one day finally even though it had been quite a while that I had been skipping classes and stuff and I remember the Head of Year like coming to have a chat with me well tell me off basically. And er it was just not once, I just remember like standing there no expression didn't say anything and he was just going on you know "I can't believe you". I can't even remember but at no point was there any recognition like oh not even "oh I know your mum has just died a few months ago so you might be feeling slightly traumatised or you are living on your own now and that's quite a hard thing to deal with at sixteen". But there was none of that at all even though I think he must have been the same person that gave an assembly to the

> whole year informing them you know that my mum had died which I wasn't there to attend thankfully. Although I would have loved to have known actually you know be actually a fly on the wall that day and just see what he said and everyone's reaction to it [pause]. And I guess I just didn't really feel anything I just thought well you've given me more reason now because I hate school and I hate you and all of them for not having any kind of consideration.

Jennifer described how she did continue to attend school despite her feelings of ambivalence towards being there. Within this she acknowledged that it offered some distraction from the monotony that became her existence. However, her comments also reveal the deep despair and feelings of utter hopelessness that she experienced:

> I guess when I was going to school I had some distractions from myself and I needed to do it and I had no interest in the subjects, I don't even know how I got, took my GCSEs but I think now why did I even bother going. No one even cared if I did my GCSEs or not, there was no one that was ever going to you know care either way. I could have just like you know just gone all rebellious. It didn't really matter at that time but I still just took myself along to school and put my uniform on and sat my exams and sometimes I just think why? I guess that there was something in me that knew that I had to, I had to do it, I had to because I had to make something of my life or I didn't want to stay in that way of [pause] I don't know.

In contrast to the feelings of despair and hopelessness Jennifer's account also offers a view of her resilience and an inner drive to help her manage the situation. However, it again also reflects the despondency that she was experiencing:

> I guess there was always something in me that always thinks okay I have to [pause] like do my degree there's something in me like forced me to try and get the best grade you know even the fact that I was like falling apart.

Jennifer's narrative of her relationship with school offers an insight into some of the difficulties she recalls encountering following her mother's death and how within this she struggled with internal conflict when trying to manage the situation.

7.2.3 'A little girl lost': Journeys into despair

Jennifer's story contained examples of the often complex and frightening changes associated with parental terminal illness. Throughout both the interviews, Jennifer's accounts were interspersed with references to the changes that appeared to be constantly occurring. Each change brought new challenges and forced Jennifer to reassess her life. One of the most difficult and traumatic transitions for Jennifer was the period following her mother's death. Jennifer spoke about the utter loneliness she felt as she was forced into a different alien landscape with no support or guidance. She described the months following her mother's death; her account evokes the feelings of the utter despair that she experienced:

> At the time I just remember a lot of just being on my own. Its like you are in a daze and I would write a lot like in my diary about how each day was just dragging by. I could have just curled up and died.

Jennifer described how the move from having the role of carer to being alone was the most difficult change she was forced to make following her mother's death:

> Yes because I had always been a carer so for me it wasn't like my mum was quite ill and I needed to quite quickly change I'd always been looking after her that was what I knew rather than her looking after me so yes from looking after someone all the time to not looking after anyone just being on your own that was certainly the biggest change. When my mum was alive that was just how my life was that's everything I knew and that's, it made sense within that but when she wasn't there it didn't obviously it just didn't make sense anymore or I didn't, what was my purpose, I didn't have one I didn't have a routine I just had myself and no one really around to say to help me understand who I was or what I was supposed to do and I guess in a way I am still left with that feeling now because I don't just, not having a parent there or family or those kind of people to guide you or just kind of to have that safety net not to have that there just to have yourself.

Jennifer's account traced her biography and highlighted the emotional and psychological struggles she has been forced to try and overcome. Jennifer spoke about her battle with depression and her feelings of great insecurity. During the interviews she reflected on her past and how it has remained an influence as she has grown older:

> I think I guess academia came in, stepped in when I needed, really needed something in my life you know I was nineteen and I'd just dropped out of one university doing a course that I didn't want to do and I was back in [name of town] working at [name of high street store], on anti-depressants. I was just like a nobody I was very aware that I'd never done anything in my life that I was proud of, I thought what, when you are at the bottom and that's how I felt and I haven't got anything just doing anything is

> going to be an improvement and then that's when I started at university and I thought okay how shit can it get.

Whilst academia provided Jennifer with a focus and offered her the potential of an alternative identity, her observations reveal the omnipresent nature of the deleterious effect of parental bereavement:

> ...my life kept getting in the way [of writing up her studies] and kept having problems thinking why am I still having these problems why do I still have depressed thoughts or when I thought about moving out of [name of town] and doing my degree then I'd feel better and writing my dissertation for the undergraduate degree I thought writing that would help me face things and I'd be able to move on and it just didn't happen like that...

Jennifer's narrative suggested an ongoing struggle to find answers to her experiences and to be able to move on from this alien landscape which has become her reluctant home:

> Even now I still feel I'm this little lost girl I don't know where I am going or what to do or I still feel I'm this kind of bag of insecurities or I just feel like I'm and I know it's that point in my life when I've got to take responsibility and be strong and being adult and grow up now and make my life, its just I'm still not yet fully sure of myself and I guess that's just part of growing up anyway but its more pronounced when you don't have that kind of safety net.

However, within the second interview, there were also glimpses into Jennifer's sense of hope and recognition of moving on:

> ...and everything that happened and her death it's just always going to colour my present or my future it's always going to be there instead of thinking I could just cut it out or let it go just realising that's part of me and that because she died then everything that's happened after that was because is in a way not a direct consequence but it's effected by that and you know its not just the bad it's the good as well.

Jennifer's narrative is of being 'the little girl lost' and this reflects the meaning that she has attached to her life experiences. This embedded narrative has influenced Jennifer's account and has clearly influenced the experience and how, through this she has constructed her meaning making process. Jennifer's narratives have provided the research with a rich insight into one person's experience of parental terminal illness.

7.2.4 Relationships and the continued struggle

Following her mother's death, Jennifer's only surviving family member was her older sister. Once her sister had made the decision to move away from the family home, Jennifer was alone. This has had a huge impact on her identity but also initially put a strain on the relationship with her sister. However, Jennifer's observations suggest that during the subsequent years the have made reparation:

> So yes we have a good relationship now even though it's almost I feel like we skirt around some of the issues like some truths that neither of us talk about but I guess it is just because we are trying to like move on or not think about these things...well she [Jennifer's sister] doesn't really talk about it with me and I know she doesn't talk about it with anyone else. It's strange in a way but I guess like we both need that and to try and just like we know that we haven't got anyone else we only have each other [pause].

During the second interview, Jennifer made comparisons of her life with that of her sister:

> ...I think she's still trying to be that older sister in a way by being quite, she never fully like, it always seems like I am the one having issues or floundering and she's always been quite stable and er she did her nursing degree like er the same time I started at [name of university] and she's been working as a nurse for two years now and I still don't know like what I am going to do and [laugh]...

She went on to observe:

> ...why can't I get myself together and that's how I really felt and I guess I still do now it's why can't I get myself together why can't I make decisions for my life and why can't I be satisfied with all the things that other people are satisfied with...

Jennifer's comments reveal the continuous struggle she has with developing an understanding of who she is and the purpose of her life. Her sister is epitomised as being someone she respects and looks to for support and guidance in the absence of a parent. However, not having a role model or a guiding figure has proved very difficult for Jennifer as her observations reveal:

> ...I think in a way part of that was to do with not having anyone saying to me it's okay, you are okay as you are, not ever having that in life not ever having that unconditional acceptance of like it is okay being as you are that you would hope you would get from a mother or a parent or some kind of guardian figure.

Jennifer's account indicated that during the intervening years since her mother's death, there have been occasions when she has been tormented with grief and her narrative of 'the little girl lost' has been reinforced. She spoke about feelings of being 'lost' and feeling like 'a bag of insecurities', compounded with this Jennifer has received medical support for depression. During our second meeting, I asked Jennifer about the huge responsibility that had been thrust upon her when her mother was ill. I observed that taking on such a caring role is not typical behaviour for a young person and whether she thought that has impacted on her life, both at the time but also into her developing adult years. Jennifer reflected on these experiences:

> Yes I didn't really fully take it in at the time because you just can't anyway but now when I think back and I think well that explains a lot as to why I am how I am now and why I will be certain ways in the future er yes definitely had a great effect.

Jennifer continued with this thought process and speculated about her life today and the lasting effect her mother's illness and death has had on her, with particular reference to being a young carer with huge caring responsibilities:

> ...which is probably why now I hate responsibility and taking charge of my own life because I am just so tired of it I want somebody else to do it for me now...

Jennifer's comments are evidence of a further long lasting consequence for children living through the death of a parent, this being the amount of responsibility that they are frequently required to manage.

Summary

During the second meeting with Jennifer, I made an observation about the generally held opinion in western society that grief is something one 'gets over'. Jennifer offered this insightful comment:

> It's been nine years this year I don't know, it changes because you change and life changes and how you feel about it changes and if you really think about it and really explore the issues around it then it doesn't just it's not something you just seal off and close that chapter you know and move on its like something that just stays with you all the time because it's part of you and...

Jennifer's observation suggests that at times as she struggles with her grief, she is also continuing to 'write the last chapter' of her life with her mother whilst integrating the chapter into her current life experiences. Jennifer's account highlighted the significance of communication and information sharing and graphically demonstrated the negative consequences of not involving children in their parent's terminal illness. These consequences have had a long lasting effect on Jennifer, her concept of self and her wider view of life.

The complete dearth of information sharing and communication prevented Jennifer from actively 'writing the penultimate chapter' with her mother. She has written a 'last chapter' (Walter 1999), which contains much despair and sadness along with unanswered questions. Some questions have remained unanswered because of the lack of support from the community that contrived to prohibit the chapters. Furthermore, the exclusion of information precluded Jennifer from having meaningful conversations with her mother that could have reduced the embedded feelings of regret that she now holds. These factors have contributed to Jennifer's feelings of depression and uncertainty and the development of her narrative of being 'this little lost girl'.

Jennifer's experience suggests that for some children experiencing the death of a parent, the liminal period of betwixt and between (Hockey 2002) has no time limits and can, without support and guidance be enduring. The struggles Jennifer has experienced in trying to manage the emotions and cognitions during her mother's illness and following her death highlight Van Gennep's tripartite structure (Hockey 2002) and the transitions through the three rites. For Jennifer, these transitions have been complex and difficult and it is difficult to ascertain from her story whether the final rites, 're-entry into a new social position or period' (Hockey 2002, p. 212) has been partially or successfully achieved.

Jennifer's truanting from school is an example of a coping behaviour, but also highlights the problems children experience when they are forced into an alien landscape with no support or guidance. Jennifer recalled that she did not have anyone to monitor her school attendance or to supervise her behaviour and actions. As she observed 'no one even cared' about her education. However, through this difficult period, Jennifer's resilience is evident. Whilst she questions where the notion of her needing to attend school was derived from, she did attend and now recognises that school offered some routine and distraction from the monotony of her life.

Jennifer described in detail the struggles she experienced with the question of who she was and her sense of identity when her mother became more reliant on care. Jennifer's account is about how she took on a role that is very different from the norm and caused her to feel different from her peers. Feelings of difference and not fitting in with peers often causes children to feign personas and to attempt to display a preferred identity. Taking on the responsibility as carer is one factor in the social death for children when living with a parent who is dying. Opportunities to participate in typical activities are curtailed and the occasions to meet friends socially are limited because of responsibilities within the home. Jennifer spoke about the few times she was able to go out with friends and how those times became very special respites for her.

The case study provides an insight into the chaos, confusion and difficulties children experience when living with parental terminal illness and death. The study exemplifies the importance of communication and information sharing and how it is imperative that children are included in what is happening. The closed context awareness that was evident in Jennifer's story illustrates graphically the importance of the 'penultimate chapter' and how vital it is that children are given the opportunity to 'write' this chapter. Jennifer's story also offers insights into the transitions and changes children are forced to make when a parent is dying and how these impact on their identity and the notion of their social death.

CHAPTER EIGHT: DISCUSSION

One of the objectives of this research was to enable children experiencing the death of a parent to be given a voice. Before being given ethical approval, I was aware that the research was potentially a minefield of ethical obstacles that would require sensitive management. However, once I had received favourable ethical approval from the university and the NHS Ethics Committee, I naively anticipated that a major obstacle had been overcome and I would be able to proceed without too many significant obstructions. As the Methodology Chapter describes, obstacles were encountered when I attempted to gain access to participants. The difficulties arose with the gatekeepers of the palliative care centres that I had initially identified as being potential sites for the fieldwork. Changes in key personnel at critical moments were the impetus for these difficulties and as a result forced me to reconsider the primary objectives for the research. The gatekeepers' rationale for their reluctance was never explicitly explained to me and I was left to develop probable hypotheses for their behaviour. One reason I deduced was that their concern stemmed from the notion that the involvement of a researcher in the children's lives would present the children with additional and unnecessary stress.

As the fieldwork progressed I encountered services that were more open to the possibility of accommodating a researcher and allowing access to children and their families. It was only when these contacts began to develop that I experienced the openness and willingness of children to share their stories. The richness of their accounts has been fundamental to the research and have provided me with the opportunity to present not only the experiences, views and opinions of professionals working in health and social care, but, importantly, to represent the voices of children, albeit in a diluted form in comparison with my original objectives.

The involvement in the research of children, their families and professionals has provided differing accounts and perspectives about what is important to children living with a parent who is dying. There have been occasions when the views of children have been different from the perspectives of the professionals and this highlights the different priorities emphasised by people who are 'looking out' or 'looking in'. Throughout the findings chapters, I have presented the participants' accounts of selected aspects of their experiences as they recollect them. The meanings attached by professionals provide a 'one step removed' perspective which is clearly influenced by their practice and specific role within the team and consequently is different from the children's perspective. However, all the accounts provide examples of the key themes to emerge from the research. And whilst the emphasis may be different, similar core principles have been identified.

8.1 THE IMPORTANCE OF COMMUNICATION AND INFORMATION SHARING

8.1.1 Communication and information sharing: the key resource

The overarching theme to emerge from the research, the one that underpinned the other key findings concerned communication and information sharing. The importance and relevance of age appropriate communication with the children was evidenced in all the participants' accounts and echoes the previous research discussed in the Literature Review. The findings from my research evidenced that the quality and quantity of information given to children corresponded with how well they coped, or in some cases did not cope, during the period of their parents' illnesses and into their bereavement.

The accounts exemplify how different communication styles impact on the way children manage the situation of living with a parent who is dying. When the accounts of two participants, Georgina and Jennifer, are compared, the stark difference between open and closed communication can be clearly evidenced. Georgina was included in conversations about her grandfather's illness and received age appropriate information about his prognosis. During the interview she described how she was pleased that she had been kept informed and had been included. She discussed the value of this and made observations about the importance in relation to her own experience and that of friends. Georgina's discourse suggested that whilst she deeply missed her grandfather, she was also maintaining a continuing bond with him and was managing her grief positively. Georgina's experience highlights how by adopting an open awareness context (Glaser and Strauss 1980), her mother managed the situation and provided Georgina with some emotional scaffolding to support her through the many changes. Conversely, Jennifer's account provides rich evidence of a closed awareness context (ibid). Jennifer was not included in any information about the deterioration in her mother's health and there was little communication about the prognosis throughout the illness trajectory. The intervening years since Jennifer's mother's death have been difficult and contain many stories of confusion, emptiness and a pervading sadness that Jennifer is struggling to cognitively and emotionally process and to disconnect from.

The aim of Glaser and Strauss's research was to 'contribute toward making the management of dying – by patients, families and health professionals – more rational and compassionate' (1980 p. vii). Their sociological enquiry, now some forty years old, described different contexts that patients, hospital personnel and the patients' families encountered when someone was terminally ill. These contexts can be transposed into the current study and reveal that despite burgeoning academic interest in issues of death, dying and bereavement, and a more informed approach to communicating bad news with patients, a stubborn silence remains where children are concerned. Typically the cultural adage that 'children should be seen and not heard' remains, especially it would seem, in relation to parental bereavement.

8.1.2 The professional's role

The notion of context awareness in relation to children was also evidenced in the interviews with the professionals. They too discussed in detail the importance and relevance of communication and information sharing. Providing examples from their practice, they highlighted how they had a 'helicopter' view of the value of regular, age appropriate information being shared with the children. The practitioners described how they, wherever possible, encouraged the parents to engage in meaningful and purposeful dialogue with their children. However, they acknowledged that this was often an immensely difficult task to undertake and the parents required support to help facilitate these difficult conversations. Furthermore, the professionals described how, from their experience, their colleagues were often reluctant to engage in initiating the conversations and therefore valuable opportunities were lost. Reasons cited for the professionals' reluctance included their own death denying attitude and fear of talking about the subject, particularly with children. It was suggested that the fear often originated from the professionals not wanting to upset the children and to make the situation 'worse' for them. However, it was recognised by the professionals that the worst *had* happened, the parent had received a terminal diagnosis and it was improbable that anything more could contribute to the children's feelings of confusion and sadness and that in fact this silence was counterproductive and prohibitive.

The discussions with the professionals highlighted the dearth of training available to practitioners, both during their initial training and within their continual professional development, around communicating with children when a parent is at the end of life. The professionals involved in the research suggested that the managers, at a strategic level, often did not recognise the need or importance of training in relation to communication and children. Smith (1999) talks about children as being the 'forgotten mourners' and Doka (1989) introduced the concept of disenfranchised grief. This is a form of grief that is not perceived by others to be socially accepted and therefore is not openly acknowledged or supported. Findings from my research highlight that children experiencing the death of a parent are frequently invisible or forgotten both in the period before their parents' deaths and as 'mourners', and furthermore, experience disenfranchised grief because of society's dismissal of their needs.

The importance and relevance of communication and information sharing has been interwoven throughout all the participants' accounts. A key theme to emerge from the findings relates to how the children manage, or in many examples, do not manage the experience of living with a parent who is dying. The quality and quantity of information that is shared with the children and which they are privy to has a significant impact on their ability to manage the situation. Chapter Five presented data that highlights how living with a terminally ill parent presents children with a plethora of challenges as they enter into an unfamiliar landscape. A key feature underpinning the chaos, confusion and loneliness is the quality and quantity of communication and information sharing. However, interwoven with this is the children's cognitive understanding and their ability to process what is happening.

8.1.3 The communication continuum

The findings have evidenced that there is a communication continuum that children experience when living with a parent who is dying. Georgina and Jennifer's accounts are exemplars of the two extremes of this continuum. When children are not included in communication and information sharing it is generally the adults who create the barriers. There were a number of examples evidenced in the research where children made the decision not to engage in conversations about their parents' illnesses. However, these were often conscious decisions that demonstrated agency and autonomy. Furthermore, these self imposed silences were not absolute and the children entered the 'communication arena' when they felt necessary. Typically, though, it was the adults, either the parents or professionals involved with the family, that exercised their power and maintained the silence.

Georgina and Jennifer's accounts highlight the two extremes of the continuum, however, there are many points along this continuum and the children's position on it is rarely static. The fluid nature of the continuum is the result of a number of factors. The quality and quantity of information, whilst being the primary factors, are not the only variables to affect the children's positioning on the continuum. Children's narratives of parental terminal illness are derived from a number of sources and as Rosenblatt (2000) reminds us, narratives are not simply stories that are made up, in this instance by the children, but are stories made up of ideas. Consequently if information, in a variety of forms, is not readily available from key people in the children's lives, an important opportunity to develop the ideas into a firm understanding is lost. The analogy of a jigsaw is appropriate in developing this thinking. If each piece of the jigsaw represents a further piece of information that can help in the process of developing a wide range of discourses, the children will have a variety of opportunities to create a more durable understanding of what is occurring in the family. Consequently having information from different sources, parents, professionals and wider society in the form of quality media representation of terminal illness and death, the children are more likely to enjoy an open awareness context, be positioned towards the open end of the communication continuum and produce a more complete jigsaw.

The parents' enforced silence could be attributed to a number of circumstances. In many instances their reasoning was, as Hannah suggested, 'laudable' as they were trying to protect their children from what they perceived to be unnecessary pain and anguish. However, this protective behaviour has a number of ramifications. Firstly the non-inclusion can act as a signal to the children that they are living in the midst of a family secret that they are not permitted to be part of. However, the general consensus amongst the professionals involved in the research was that young family members are invariably aware that something serious is occurring within their family and that if a conspiracy of silence is maintained their imaginative minds will be likely to run riot. Samantha highlighted this from the perspective of a young person. She described how it had been helpful for her to know what was happening following her mother's diagnosis of terminal cancer, and how she preferred that so as to prevent her from 'making up stories all of the time'. The imposed silence by adults can thus create extreme fear and uncertainty but furthermore can develop a culture of mistrust. Children typically perceive the relationship with their parents to be built on trust which in turn creates a sense of security and belonging. When the trust has been dented it is often difficult to undertake reparation and rebuild those feelings.

When there is some acknowledgment within the family that a parent is terminally ill but few conversations and limited information sharing, the family can succumb to a cycle of vicarious avoidance (Trickey 2009). In this situation the children make a conscious decision not to talk about what is likely to be uppermost in their cognitions for fear of upsetting their parents, the parents interpret this silence as the children not wanting to discuss the subject and therefore remain silent. The children read the silence as an indicator that they should not speak about the situation and the cycle continues, thus moving the children's position towards the closed end of the communication continuum.

Different factors that might underpin the parents' rationale for not including their children in conversations about the illness include the family's history of communication styles. If the family has previously engaged in a form of closed communication, the additional burden of living with the knowledge that one of the parents is terminally ill is likely to compound their current pattern of communication. The research by MacPherson (2005) delineated the differing styles and combinations of communication between parents and their children and this has been evident from the accounts of the professionals involved in the current research. The culture of the family will also have a bearing on communication styles, the dominant embedded practice is likely to be prevalent at times of crisis, such as when a parent is terminally ill. Carol spoke during our interview about families maintaining 'a stiff upper lip' and as a consequence not showing emotions or discussing what is occurring within the family. The attachment styles and intra-familial relationships can also have a significant bearing on the levels of open or closed communication that is seen within families. Once again the prevalent styles are likely to be adopted when the family is experiencing stress.

The analogy of a jigsaw was introduced above to demonstrate the different pieces that have the potential to contribute to the children's development of a meaningful and appropriate narrative. The role of the parents is key in the jigsaw; however, other people also play a significant part. The research has emphasised the importance of both professionals and peers in the development of narratives and consequently the children's positioning on the communication continuum. Examples of their roles are discussed throughout this chapter and highlight the significance they have in many aspects of the children's lives, both positively and negatively. The research findings have highlighted how children draw on and use the narratives that are available to them. Consequently, if people do not talk to them about what is happening within their family they are denied access to valuable discourses. It is likely that the family's discourse will have changed considerably following the diagnosis of terminal illness. How the family reacts and manages these changes will have an impact on the discourses made available to the children and in turn their understanding of what is happening and how their stories are made up of ideas (Rosenblatt 2000).

8.1.4 External sources of information

The media and popular culture can also have an influence on the development of the children's narratives. If, as a consequence of being positioned predominantly towards the closed context of the continuum, the children will be forced to look for alternative sources of information to help them process what is happening within their families and to develop their stories. The World Wide Web is now commonly available and accessible to the majority of people and can provide helpful information. However, the accuracy of this information may be subject to question and furthermore, accessing the Internet can be a private activity and thus a responsible 'knowing' adult will not be policing the information the children are accessing and filtering out inappropriate or unhelpful material. An alternative medium for offering insights into issues of death and dying is through the media and popular television programmes. However, the portrayal of such important themes is generally focussed towards sensationalising the event for maximum effect. Thus if the children's primary source of information is from such external sources their knowledge of death and dying and their only available discourses are likely to be inaccurate, sensationalised and probably horrific.

Each of the above factors has the potential to contribute to the children's positioning on the communication continuum. Furthermore, the fluid nature of the continuum can also be evidenced, particularly how the children's awareness oscillates along the line, depending on the quality and quantity of information they are currently in receipt of. It is probable that the amount of information that is exchanged will not be a constant and will vary depending on who is providing the information, the time available to them and their competence in offering such information.

8.1.5 Non familial communication: an additional source of support

Along the communication continuum there is evidence that some families engage fully in conversations about the illness and the children are involved and subscribe to an open awareness context. The research has shown how valuable this is to the children. However, this open approach is sometimes not sufficient and the 'specialist' view from professionals is also wanted. Samantha spoke about this in our interview. She acknowledged that her parents had been forthright with information, for which she had been very grateful, however, she also expressed that she would have liked the opportunity to talk with the palliative care nurses about her mother's illness. This specialist view could present the children with a more comprehensive account of what is currently occurring in their family and solidify their narratives, but it could also act to reinforce and substantiate their parent's conversations. Sonny's mother expressed her opinion about the value of professionals talking with children. She felt that the value of this related to the children trusting professionals and believing that they would provide truthful, accurate information.

The enforced silence by parents also brings into question the wider position of children in British society today. The parents' behaviour could be understood in relation to power and the dichotomy that pervades the present sociological construct of childhood. On the one hand children are seen as being vulnerable and in need of protection, whilst concurrently being perceived as mini adults with the associated adult responsibilities (Foley et al. 2001). Furthermore, this poverty of narratives is the result of the dominant cultural perspectives where the adults 'manage' and suppress the children's voices, rendering them silent and locked in their own emotions. Referring back to Hannah's comments about the No Voice family, the girl was 'stuffed full of anger' and had no way of expressing that. Other young people in this research indicated that they too were 'stuffed full of emotions' and when appropriate channels for expressing these feelings are either blocked or absent alternative outlets need to be found. This state of confusion can be difficult to manage for any child but one who is living with a parent who is dying, whether they are cognisant of the situation or not is left once again in an unfamiliar alien landscape.

8.1.6 The professionals' reluctance

When parents are not engaging in conversations about the family situation, the professionals involved with the family should have a responsibility to help facilitate the dialogue. However, the findings from my research have highlighted that on occasions the barriers to open communication with children are as a result of the professionals' confidence and competence. A recurring theme amongst the professionals interviewed for the research was the frequently observed reluctance of colleagues to engage in conversations about the illness with children. Hannah spoke about colleagues being concerned that the conversations would take too much time and about the uncertainty of where such conversations might lead. John contributed to the findings by suggesting that there was a 'professional fear' and that services were *not really* [John's emphasis] available for children because of the fear of getting it wrong.

The reluctance of professionals to engage in conversations about death and dying with children is a reflection of the wider societal held death denying view. Whilst it must be recognised that in recent years death and dying has become 'more accessible' to the public, through, for example, the increased interest and portrayal in the media (Walter 1991) children's relationship with death continues to be uneasy. This can be evidenced in the dearth of research pertaining to children and bereavement compared with the current plethora of sociological and psychological enquiries being undertaken into adults, palliative care, death and dying. However, this commonly held fear by professionals is intrinsic to the quality of support children have access to and can expect to receive when living with a parent who is dying. I have discussed in detail professionals' competence and confidence in communicating with children (Fearnley 2010) and within this have argued that more training is required across professional boundaries to ensure that the workforce has the necessary and relevant skills to support children when a parent is at the end of life. Hannah observed that parents often need some 'hand holding' to help them begin to navigate through the sensitive, difficult and emotionally burdened landscape of communicating with their children about their health and prognosis. It is essential that this is undertaken by professionals who are competent and confident in their practice and who can support the parents most appropriately. Evidence from the research suggests that this is not generally the situation and as a consequence potentially vulnerable children experience a double jeopardy.

The general consensus among all the professionals involved in the research suggested that parents are the most appropriate people to have the difficult conversations with their children. However, when the professionals do not feel able to instigate the conversations themselves, they are increasingly unlikely to support or encourage the parents to do so. The consequence, both in the short and longer term, of this silence is evidenced in Jennifer's story of emotional struggle and conflict.

8.2 THE ALIEN LANDSCAPE OF PARENTAL BEREAVEMENT

8.2.1 Entering an alien landscape: the benefits of fellow travellers

The children's accounts have presented robust evidence to suggest that when they are living with a parent who is dying they typically enter into an alien landscape that presents many changes and challenges. This landscape is a strange and new environment that contains many different landmarks and features. These landmarks present the children with a range of emotional and social threats, challenges and obstacles, the majority of which will have not previously been encountered. Entry into the landscape represents the children entering into a liminal period in their lives. Kelly (2008) described liminal spaces as being 'between cultural states, making them an in-between place, a non-place. In this space, initiates are between social roles, cultural expectations, and status' (p. 336). How the children traverse these different landscapes and manage all the changes is dependent on a number of factors. Some children are fortunate enough to meet experienced guides who can support them through the terrain. These guides have a number of resources available to help the children and travel alongside them. The research suggests, as I have previously discussed, that the most supportive guides are the children's parents but frequently they too are forced into an unknown and frightening landscape, which presents different challenges from the children's, and therefore they struggle to provide support to their children. Alternative guides, who have a significant role are the professionals involved with the family. During the research I have been privileged to meet some very experienced guides who know the terrain well, however, I have also found evidence to suggest that these are the exceptions and the majority of children entering the new landscape of parental terminal illness are left to explore the land alone.

Having support to traverse these new experiences is an important factor in helping the children to cope with the many challenges, some of which are enduring and life changing, that they will encounter. The findings indicated that this support is rarely forthcoming from friends and peers. Living with a parent who is dying is a unique experience that is generally not understood by people who do not have shared knowledge. The value therefore of support groups, facilitated by experienced staff, and open to children experiencing similar life events can be of huge benefit to the individuals. The young people I met in the bereavement support group paid testimony to this. Their accounts were about common bonds and shared knowledge, about being able to be themselves and not feign a preferred 'safe' identity for the benefit of unknowing friends and peers. This being congruent with the recent research by Werner-Lin and Biank (2009). Dr Jones spoke about the benefits she had observed of children being given permission to discuss their feelings, worries and anxieties, in a safe environment. This was concordant with Kirsti and Emma's accounts when they spoke about the support they had received following their father's death. However, the research also highlighted that such support, pre and post bereavement is not readily available and generally not seen as a priority. Issues around funding can be attributed to the lack of resources, but a more endemic reason is lack of awareness of the needs of these children. When support is available it is frequently seen as a 'postcode lottery' and much rests on the relationship with the location to adult hospice service. This notion was supported by a comment from Mandy, the mother with terminal cancer, who stated that the support she and her children had received was 'like winning the postcode lottery'. Typically hospices are built in more affluent locations and furthermore are limited in the number of patients that can be supported. These two factors contribute to the exclusion of all but the minority of children. Furthermore, evidence from my research would suggest that even within some hospice settings, the needs of children are of low priority.

The lack of awareness, or the pervasive preference to not see the needs of these children, results in them being denied opportunities to develop appropriate language or a meaningful narrative about their parents' illnesses and death. A further complicating factor for the children is the use of euphemistic language that makes little sense cognitively. The findings demonstrated how the use of euphemisms, which are often used as a buffer from the 'harsh' language of death and dying, could have detrimental consequences for the children. Sonny's account highlights the negative effects the misuse of language can have. Using language to 'protect' him created a paralysing fear that totally enveloped his existence until he accessed non-familial support and was offered an alternative discourse. Again, Rosenblatt's (2000) notion that stories are made up of ideas demonstrates how for Sonny he created a story that was frightening and misleading.

8.2.2 Oscillating between the alien and safe landscape

The 'harsh' language of death and dying was frequently seen in this research as an adult phenomenon that rendered the professionals unable to use such discourse. However, for some children the experiences in which they were living were equally too harsh and brutal for their cognitive and emotional wellbeing, thus contradicting their rehearsed notions of self-identity. The findings suggest that for some children, the preferred coping strategy was at times to move away from the reality that was their existence, attempting to turn away from the alien landscape to a safer, known terrain. This was often manifested in a withdrawal to their bedroom or snatched opportunities to spend time with friends.

Whilst this behaviour is typically seen in young people and is evidence of their developing maturity and them exercising some control over their lives, a number of the professionals involved in the research suggested that this was a coping mechanism, a behaviour that they adopted to help preserve some feelings of control and normality in the uncertain and ever changing world of parental terminal illness. I suggested in the findings chapters that this presented evidence of similarities to the Dual Process Model

(Stroebe and Schut 1999) and that it allowed the children to move away from the uncertainty and pain of their current situation to a safer, known terrain. By adopting this oscillating behaviour they are exercising some control and autonomy over a situation where they have very little control or autonomy.

However, there are potential implications here that are fundamental to the findings of this research. If children exercise their autonomy on a regular basis and move into the safe terrain to the extent that they cease to acknowledge what is happening in their family, they are at risk of severing any communication channels that they had and consequently enter a self imposed exile. This has ramifications and can affect how they make sense of what is happening during their parents' illnesses but also following their deaths. Consequently this 'protective behaviour' may, if taken to the extreme, become maladaptive behaviour and prevent them making the necessary adaptations that are required to manage what is occurring within their family.

8.3 CHILDREN 'STORYING' THEIR EXPERIENCE

8.3.1 Walter's biographical model of grief: 'writing the last chapter'

The value of communication and information sharing is central to Walter's (1996) article, which questions the dominant theories of grief and presents a new biographical model that incorporates 'the writing of the last chapter'. Walter argues that the main emphasis within early theories, including the work of Freud, Parkes and Bowlby, was that the purpose of grief was for the reconstitution of an autonomous individual who could leave the deceased behind and in so doing form new attachments. The process that occurred for this to happen was by working through the grief and the resolutions of feelings. Within the article, Walter questions the seemingly contradictory nature of the writings of these early theorists. Their primary assertion was that the bereaved were required to 'get over' the death and to detach from the deceased whilst conversely suggesting the continuing presence of the dead. Walter (1996) suggests:

> We may say, therefore, that in the classic texts there is a major theme emphasizing detachment achieved through working through feelings, and a minor theme emphasizing the continued presence of the dead in a continuous conversation with and about them (p. 8).

Walter presents his biographical model of grief through the use of personal case studies. The biographical model, which he suggests was a 'revolutionary' approach, argues for the notion of 'continuing bonds' and keeping the spirit of the deceased alive. Walter describes the importance of being given permission to talk about his deceased father as opposed to the dominant thinking that the bereaved should move on without the deceased. The maintaining of the relationship is substantially achieved by talking about the deceased with others who had known them, sharing stories and memories, adding previously unknown information and also challenging previously held assumptions about them. Walter suggests that this is an external process where others contribute to the stories about the deceased. Through the process of talking and sharing stories about the deceased, the bereaved are developing a broader, more comprehensive understanding about the life of the dead person. In turn through this process they are able to develop an understanding of how the deceased influenced their life and thus their role in creating an identity and a sense of self. Furthermore, Walter proposes that through the conversations, the bereaved are more able to develop an understanding about the death. The writings of Walter have similarities with narrative therapy where a significant underlying tenent is that 'personhood continues to live on long after the body dies' (Hedtke and Winslade 2004, p. 8). Here too there is the notion of encouraging the bereaved to maintain an ongoing relationship with the deceased, to remember them and to talk about them.

8.3.2 'The writing of the last chapter'

Part of the process of maintaining a relationship with the deceased and finding a stable place for them is achieved through 'the writing of the last chapter'. 'The last chapter is written after the death by the survivors as they too go over the life lived and, separately or together, make sense of it' (Walter, 1996, p. 14). The discussion raised by Walter has equal salience for children as it does for the adults that were the primary focus of the model. However, it could be argued that some of the barriers to the 'writing' of the 'last chapter' proposed by Walter are magnified for children. Walter suggests that 'the last chapter' may be made public, for example in an obituary or at the funeral or that it can be informally constructed between family members and friends. The potential barrier here for children is that they are often excluded from attending the funeral service and are 'protected' by adults (Holland 2004). Thus they lose the opportunity to participate in a ritual that has the potential to help them hear stories about their parents' lives and consequently develop meaning about who their parents were, along with being able to 'piece together how this person affected their own lives' (Walter, 1996, p. 14). This lost opportunity may have the consequence that they are not able to make meaning about the death and that in turn affects their sense of self and own identity. Relating this to the findings from my research, this exclusion once again contributes to the feelings of difference that children frequently feel when living with a parent who is dying and following their death.

Walter (ibid) provides further reasons why mourners in modern Western societies may not be able to talk, as frequently as in previous decades, with people who knew the deceased. One reason that has resonance with the findings from my research concerns how the norms for talking about death are changing. As a consequence of these changes, Walter suggests that different generations may no longer know how to communicate with each other. The findings from my research corroborate and endorse this. Furthermore, my research has highlighted how within the communication continuum children are more likely to experience the closed rather than an open context. Within these findings, there is evidence that parents and professionals frequently experience difficulties in communicating with children when a parent is terminally ill or has died.

Walter (1996, 2009) suggests that the division between work and home is also a contributory factor that inhibits conversations and shared understanding and acknowledgement about the death. As a result of the massive shift in economic activity, family and friends are generally unlikely to have more than a passing acquaintance with work colleagues and visa versa. Walter (2009) writes about the grief and the separation of home and work and within this acknowledges that children experience a similar situation between home and school. The accounts of the children in my research indicate that school can become either a safe release from all that is happening around them, providing a semblance of normality and routine or an incredibly lonely, hostile environment. However, the division between home and school tends to remain such that there is little common ground for the children experiencing the death of a parent. Staff and peers alike frequently struggle to know what language to use with bereaved children and are rendered incapable of sharing meaningful conversations about the bereavement or to even, on occasions acknowledge it.

Furthermore, the current research has evidenced that frequently the link between home and school is more tenuous for older children. School personnel in junior and infant schools generally have more involvement with parents than colleagues in secondary schools. Consequently unless the young people disclose what is happening in their families, school staff are unlikely to be aware and therefore unable to accommodate their needs. However, my findings are not congruent with Holland (2000), whose research within secondary schools evidenced that 'they [the school] usually found out about parental deaths directly, by phone or personal contact' (p. 35). McNamara (2000) writing about stress per se in young people suggests that the transition from the relative security of primary school to the anonymous atmosphere of secondary school can be a particularly stressful time for young people. This stress would be potentially magnified if the young people were living with a parent who was dying.

8.3.3 Children's inclusion or exclusion in 'writing the last chapter'

Analysis of my data has highlighted how vital communication and information sharing is for children experiencing the death of a parent. This has the potential to have huge implications for them if they are to 'write' a meaningful 'last chapter' that can help them to make sense of what has happened. The extent to which the children are allowed to be included in the adults' conversations about the death and the deceased will also have a significant bearing on the development of their understanding of who the deceased parent was in relation to them. However, the research has shown that other factors can also inhibit 'the writing of the last chapter'. The lack of communication and information sharing can be associated also with limited involvement in the events surrounding the family. Dr Jones, Carol and Hannah discussed the value of including children, appropriately, in the care of their parents. Conversely the findings also revealed that additional responsibilities are frequently placed on children during the parents' illnesses. These forced responsibilities can be different from informed involvement that can be helpful for the children, the former being potentially an added stress whilst the latter providing feelings of participation and inclusion.

Living with a parent who is dying can affect the relationship dynamics within the family. Children's relationships with the ill and well parent are likely to alter as the illness progresses. Examples from my research emphasise how as the illness progresses, family life begins to revolve around the illness and it becomes central. This, accompanied with the inevitable changes in the parent child relationship, can have a significant bearing on the children's ability to relate to the ill parent and also the opportunities to make sense of what is happening in their lives. How the many changes that are occurring in this situation are handled and how the children view their relationship with the ill and well parent during this period can affect how they begin to construct the 'penultimate' and 'last chapter'. The period between when the parent is dying and following their death can therefore have a significant effect on how the children 'write the last chapter'.

Walter's introduction of the biographical model initiated debate and thinking in relation to the process of grieving and offering an alternative to the dominant theory of 'working through' and 'getting over' the death. Within this, he discussed alternative forms of support if friends and family are not available to be involved in the process. Walter suggested that self-help groups or counselling could be substitutes, however, he also contended that these forms of support are 'second best when there is no-one available with whom to talk about the deceased' (1996 p.19). Within this, Walter suggests that individuals grieve in different ways and thus counsellors need to be aware of such diversity and incorporate flexibility into their practice. This supposition fails to acknowledge that likewise, children adopt different ways of grieving and furthermore their grief process is typically very different from adults. Therefore, support for children needs to be considered in the light of this knowledge.

8.3.4 'The penultimate chapter'

The findings have indicated that being excluded from conversations and information about the death means that children are denied any opportunities to develop a meaningful narrative following the death of their parent. They are therefore prevented from beginning to 'write a meaningful last chapter' about their parent's life and death. The importance and relevance of Walter's biographical model must be recognised and acknowledged as an influential addition to our understanding of grief and the maintenance of bonds with the deceased. However, through the analysis of the participants' accounts, particularly the children's, I propose that children also benefit from the 'writing' of a 'penultimate chapter'. This 'penultimate chapter', if written sensitively and taking into account the needs of the children can offer a meaningful addition to their narrative. The 'penultimate chapter' is written during the parents' illness and forms the narratives that accompany this challenging and rapidly changing time in the children's lives. The contents of the chapter may be consciously acknowledged, be understood as being part of the biography that is currently being written or not consciously recognised. However, how the unfolding narrative is perceived, the chapter presents the opportunity of creating a valuable resource that can be drawn on in the present and future.

Walter's (1996) account is about 'writing the last chapter' after somebody has died; my contribution to the literature is that children are inevitably 'writing' a chapter during the palliative care stage of their parents' illnesses. This chapter is a prospective chapter that goes through a complex series of editions that encompass all the challenges and changes that are endemic when living with a parent who is dying. The 'writing' of the 'penultimate chapter', or a chapter that has meaning, is facilitated by open communication and information sharing between all the adults in the children's lives and the children. Building on the earlier assertion that open communication allows for a trusting relationship to be maintained, the notion of involving children can be extended to incorporate the 'writing' of the 'penultimate chapter'. However, when children are excluded from open communication and the sharing of information, their planning of this chapter is jeopardised, the preparation is not as thorough and the content is often patchy and lacking a meaningful plot.

Children's involvement in communication and information sharing offers them opportunities to be involved in the 'writing' of the script for the chapter. The unpredictability of terminal illness means that often there is no pre-determined script to work to and the authors are forced to alter and amend the 'writings' on a regular basis, thus producing a number of edited drafts. Therefore, regular updates and an ongoing dialogue helps in the 'writing' and re writing of the chapter.

8.3.5 Characters and plot

The point at which this chapter begins is dependent on a number of associated factors. The accounts of my participants suggest that the 'writing' of this chapter often begins before the children have been told that their parent is terminally ill. For many children they become aware that there are concerning changes within the family and will use visual cues to assimilate their knowledge. Furthermore, changes in the parent's health and physical symptoms may offer some clues about what is happening, along with changes in routines and typical family activities.

Hannah described the behaviour of one young boy that she had been asked to work with. At the point of his referral he had not been given any information about his father's terminal illness, however, the changes in his behaviour indicated that he was aware that something problematic was occurring within his family. He was unable to begin to 'write' a meaningful 'penultimate chapter' until he began to receive support from Hannah. Through the support that she offered him and his family a more constructive chapter started to be 'written'. Conversely, Georgina was able to begin 'writing' an accurate early draft of her chapter because she was party to an open awareness context and thus received regular information about her grandfather's illness. Furthermore, because this approach was adopted, Georgina felt able to ask questions and seek any information she required. Through this process she was enabled to edit appropriately the story line, make sense of what was happening and develop a more secure identity. At the opposite end of the continuum, Jennifer, although living amidst her mother's illness, did not have an opportunity to 'write' a meaningful 'penultimate chapter' because of the complete dearth of information provided by anyone. Furthermore, as Jennifer's account revealed, the 'writing' of the final and subsequent chapters has been difficult, complex and interspersed with stories of uncertainty and unresolved grief.

The quality of the content of this 'penultimate chapter' is again significantly determined by the information that is shared between adults and children. This in part prescribes how much of the chapter is 'written' by the children and how much is pre-scripted and 'written' by the family and society. Constraints placed on the children by family members and society in general can determine how the chapter is allowed to develop. The reluctance of professionals to acknowledge that the children are living with a parent who is dying plays a significant part in the restriction of the 'writing' of the chapter. Their reticence can in effect create a 'writer's block' that prevents the authors, the children, from completely entering into their own world and 'writing' a meaningful or accurate account of what is happening.

Within the 'writing' of the 'penultimate chapter', there are some key characters who can help to shape how the chapter will develop. The children's parents play a significant role in this and as has been previously discussed their contribution in relation to the information provided is pivotal in the development of the chapter. Their positioning on the communication continuum is noteworthy in the contribution they inadvertently make to the 'writing' of the chapter. There are many factors that contribute to how the parents' communication style help or hinder the 'writing' of the chapter. These were explored above. However, it is appropriate to once again draw attention to the relevance of the family's previous patterns of communication and how this is likely to impact on their current practice.

The professionals involved with the family are also key contributors in relation to how the chapter is 'written' and their role within it. There are primary and tertiary professionals involved with the children and their families and the amount of their involvement is secondary to the quality of their support. The research has provided many examples where practice amongst the primary professionals, for example palliative care medical and nursing staff, social care professionals and General Practitioners, has been limiting and obstructive in the development of any meaningful dialogue. The participants have suggested that this is in part due to a lack of confidence and competence in communication and a fear of talking with children about death and dying. How the professionals present themselves to the children and how involved they become will have a serious bearing on how the chapter is 'written'. Salient memories are also being created in these interactions and can have an enduring effect on the children. The children involved in the research tended to describe memories of unhelpful professionals who were not available for them. Some reported positive memories that they were able to incorporate into their narratives and therefore include in the 'penultimate chapter' but these were fewer in number. For the majority, the chapter included memories of unhelpful and obstructive professionals who did not enhance the 'writing' in any constructive manner. Tertiary professionals, for example school personnel, are also key contributors in the 'writing' of the 'penultimate chapter', and again how they handle the situation will have a significant bearing on the content. Some participants described how teachers were often quite dismissive of the situation the children were living in and some exhibited little understanding of the alien landscape the children had entered.

Some children are fortunate enough to meet with fellow travellers who can travel parts of the journey alongside them. Within my research these supporters have tended to be professionals who have the specific remit of offering support to children and families within palliative care settings. The involvement of these specialists have helped facilitate robust paragraphs within the chapters and have added substance and meaning to the 'writing'. The fellow travellers have been able to co-author parts of the chapter and through this have become key characters in the plot.

The research has provided clear indications that friends and peers are also key characters in the 'penultimate chapter'. However, the findings have shown that frequently peers are not able to identify with the children because of not understanding the construct of their current situation. When attempting to 'write' the 'penultimate chapter', having friends who can begin to empathise is valuable to the children, however, this is rarely the norm. I have suggested that experiencing the death of a parent catapults children into an 'exclusive club' where membership is restricted to those who have had a similar experience. Therefore, being perceived as being different and not fitting in once again creates difference that contributes to the script within the chapter. Having the opportunity to meet with others who are or have recently experienced similar life changing events can be particularly helpful in the 'writing' of the 'penultimate chapter'. Their involvement is especially useful in contributing to the sections about identity and the complex transitions of living with a well parent to living with a parent who is dying. Hearing other people's stories and experiences can help to validate and normalise feelings, and thus conceptualise what is happening.

8.3.6 Plot development: Identity and roles

Walter (1996), writing about the 'last chapter', describes how through conversations with others, the bereaved begin to form durable biographies about the deceased but also develop a more comprehensive understanding of how the deceased influenced and shaped their lives. In a similar context, through the process of 'writing' the 'penultimate chapter', children attempt to negotiate many of the significant questions that they face when living with a parent who is dying. These questions include issues of identity and maintaining a sense of self. Being able to maintain a strong sense of identity when in the alien landscape of parental terminal illness is imperative if the terrain is to be traversed successfully. Questions regarding identity both for the individual and their family are likely to surface. Typical questions include not only an exploration of who the child is, but also who they were before the illness entered the family. Furthermore, there is a likelihood that within the confines of the family structure there will be questions about the children's position within the family and in relation to their peers. Giddens (2002) provides a timely reminder here of the importance of self identity in relation to biography and narratives:

> A person's identity is not to be found in behaviour, nor – important though this is – in the reactions of others, but in the capacity *to keep a particular narrative going* (p. 54, original emphasis).

Giddens goes on to suggest that the individual's biography must process external events, for example the parent's illness, 'and sort them into the ongoing 'story' about the self' (ibid, p. 54). It is essential that children living with a parent who is dying keep particular narratives going in order to help them make sense of what is happening and to mange the inevitable transformations within their identity. Importantly, in relation to the 'penultimate chapter', which requires constant editing and re-drafting as the parents' illnesses progress, Giddens describes how self-identity 'has to be routinely created and sustained in the reflexive activities of the individual' (ibid p.52). The value therefore of regular information sharing is evident. The relationship between the sense of self, narratives and maintaining a durable biography are closely interrelated and forms the outline to the plot of the 'penultimate chapter'.

The 'writing' of the 'penultimate chapter' also provides some structure and an understanding about what is happening within the family. The 'writing' of the chapter can help children to process who is available to offer them support and can focus their attention on the people who are willing to listen and hear their concerns and worries. Furthermore, by exploring their writings, the children have the opportunity to explore and attempt to make sense of what is happening to their previously safe boundaried world that is no longer feeling safe, controlled or boundaried.

The participants' accounts suggest that the 'writing' of the 'penultimate chapter' is important within both the current context of their lived experience but also for their future. Living with a parent who is dying creates many transitions, some relate to the present, others to the future. Professionals involved in the research described domiciliary arrangements following a parent's death as being a key change requiring navigation. Therefore, being involved in writing a chapter before the parent dies can help in this process. The contents of the chapter can include issues of planning around who will care for the children following their parent's death, where they are going to live and other associated changes. The key characters in the chapter who were introduced above play a significant role in this process and if maximum effect is to be achieved, 'joined up' communication and agreed discourse can facilitate a focussed plot in the chapter.

My argument about the 'writing' of the 'penultimate chapter' provides a new understanding of the experiences of children living with a parent who is dying. Being able to 'write' a meaningful 'penultimate chapter' is important and necessary in their attempt to successfully manage the situation and navigate the different emotions and challenges into which they are thrown. The 'writing' of the chapter significantly contributes to the story of their lives and the development of a secure identity. However, this is dependent on their inclusion in what is occurring. Children who are towards the end of the communication continuum where non-involvement is the norm are presented with unknown obstacles that severely limit the opportunities they have for making sense of what is happening and 'writing' the chapter. This can be amplified for young adolescents who are typically struggling with issues of identity, relationships and transitions. When these processes are interrupted because of the additional stresses of living with a parent who is dying, the young people face additional burdens in their quest for developing a stable identity. The autobiographical account by Pearce (2008) provides robust evidence of how living with a parent who is dying throws into question the notion of gaining a stable identity and the rupturing of transitions typically navigated by young people.

8.4 TRANSITIONS, CHANGES AND CHALLENGES

8.4.1 Narratives of change and upheaval

Prominent changes in youth culture and the lives of young people have been described in the literature review. These changes have undoubtedly contributed to the stressors typically experienced by young people living in a post-modern society. The review of the literature suggested that socio-economic changes and a restructuring of the labour market have contributed to the changes in family lifestyles that have resulted in young people remaining dependent on their families for longer periods (Furlong and Cartmel 2007). The literature highlights the complexity of the transitions experienced by young people today and how for a growing number, the transitions and changes are becoming more difficult to negotiate. The move from education into employment is increasingly difficult because of the current economic crisis and as a result more young people are struggling to find employment when they leave school. This results in them not having the opportunity to move through the transition from school to work and the accompanying rites of passage this transition affords. These transitions may be even more difficult for young people living with a terminally ill parent. The findings from my research have evidenced that typical rites of passage are severely affected when living with a parent who is dying. A conclusion from the findings is therefore that young people experiencing the death of a parent encounter many additional difficult transitions than their peers, all of which contribute to their feelings of difference.

There are a number of factors that contribute or inhibit the children's ability to adapt to the inevitable transitions and changes they experience during this period. The children's previous levels of resilience and their past experience of coping will be contributory factors. My career as a children's practitioner provided me with examples of children's resilience and coping mechanisms within adverse conditions. Some of the children I worked with appeared to have developed strong coping skills from an early age, whilst others struggled and experienced social and emotional difficulties as a result. Reflections from my career, though not empirically sound, would suggest that the children who exhibited resilience in times of adversity were typically the ones who enjoyed stronger attachments with their parents and were more embedded within the construct of the family and community. The evidence from my research suggests that the two primary factors in resilience and coping strategies are again communication and information sharing.

The age of the children will also be a factor in how they manage the transitions and changes. Younger children who are dependent on their parents for all the physical and emotional needs will be likely to find difficulty in comprehending the changes. Young people who are less emotionally bound to their parents, but who are exploring their own emotions and identity, will also be likely to experience conflict and confusion when faced with the changes. Furthermore, as the research has revealed, these transitions and changes are not definite and static. The unpredictability of terminal illness causes the changes to regularly alter, ebb and flow, depending on how the parent is reacting to their treatment or palliative care. This uncertainty complicates the process of adaptation and can compound the challenges.

The participants' accounts told of the transitions and changes faced by children living with a parent who is dying. Some of these were temporary whilst others were major and potentially life changing. However, irrespective of the extent of the change, it was evident that they all required careful management if they were to be successfully handled, thus supporting further the discussion that the role of fellow travellers is of paramount importance.

Some of the changes centred around the family and home life. A significant shift that needed to be worked through for many of the children was the pervading way the illness took over family life. Participants spoke about the illness becoming the crux of the family and how everything else revolved around it. Elizabeth noted how in her experience, all conversations and routines are structured around the illness and the health of the patient. As this focus becomes more embedded in family life, there is a suspension of normal life. This can create a huge change for children to navigate. Younger children may struggle because of the inevitable changes in routine that are occurring but equally older young people may also find it difficult to adapt to the changes. It is particularly difficult for teenagers who are developmentally ready to exercise more autonomy and extend their boundaries away from the home.

A further significant change within the home that is typically experienced by young people is the taking on of additional responsibilities. The professionals involved in the research explored how at times household tasks and responsibilities are taken on willingly and the young people feel that they are contributing in a practical way to support their parents. However, it was also noted that there are occasions when these roles are placed on the young people and they are grudgingly accepted. A consistent theme from the participants' accounts was that children living with a parent who is dying experience feelings of being different from their peers. The taking on of household responsibilities has the potential to considerably affect this notion of difference. Jennifer's account pays testament to this. She spoke with great feeling about the caring responsibilities that she had taken on during her mother's illness. Reflecting on this in our interviews, she felt that she had lost many opportunities to engage in typical behaviour generally enjoyed by young people and was prevented from participating in activities away from the home with friends. This had resulted in feelings of isolation but also of being different from friends and not having any 'common ground'. Jennifer, like so many other young people had entered the alien landscape and in so doing had become different from friends and peers.

8.4.2 Barriers to identity formation

The differing transitions and changes encountered by the children are likely to contribute to the development of their identity. When the uncertainty, changes and challenges are presented to them in the form of parental terminal illness, it is inevitable that these variables impact on identity development. Giddens (2002) writes about 'fractured' self identities and how within this notion 'no continuous "narrative" can be sustained' (p. 53). Entering the alien landscape has the real potential to fracture the sense of self and disrupt the children's narratives. Part of this process is once again very much dependent on communication and information sharing. Creating a sense of identity and selfhood, are formed internally but external forces also contribute to them. The reactions of friends and peers can have a significant role here and can strongly influence the direction of the identity development. Having friends who can begin to empathise and understand is really important in this situation; however, the findings would suggest that this is rarely the situation. Friends and peers can play a significant role in affirming or denying identities. Furthermore, as youth culture becomes more embedded within the 'manufactured' identities of celebrities and icons, the struggle to remain in vogue and the same as friends, and idols, is increasingly demanding. As Giddens (2002) observes, '[T]he mass media routinely present modes of life to which, it is implied, everyone should aspire' (p. 199). All the constraints that have been discussed, when living with a parent who is dying, limit opportunities to be in vogue and create identities that are consistent with popular mass culture.

Furthermore, significant adults in the children's lives, who are not celebrities but who can influence their identities and sense of self, also have a role to play. However, as discussed above, these adults, the primary and tertiary professionals involved when a parent is terminally ill, frequently lack the necessary resources that could help make a difference for the children. This lack of confidence and competence in working with and supporting children living with a parent who is dying raises questions about the training and continual professional development of health, social care and education professionals. Invitations to contribute to a consultation document 'Developing the End of Life Workforce in Health and Social Care' (Skills for Care 2009) were made public in 2009. The purpose of the document was to outline the support required for the training and education of all practitioners working with families when a patient is at the end of life. The consultation document presented amongst other things seven core principles for health and social care workers. The principles, whilst encompassing many aspects of end of life care completely omitted any mention of children. Utilising the then emerging findings from my research I responded to the consultation, it was encouraging to note that the final version of the document did make reference on a number of occasions to children and their needs (National Health Service (NHS) et al. 2009).

8.4.3 Coping with uncertainty: Managing whilst a parent is terminally ill

Examples from my research highlighted how the majority of the participants felt that the pre-bereavement period was more difficult to cope with and manage than the period following the parent's death. This was in part because of the uncertainty and unpredictability of terminal illness. Children who are struggling to make sense of what is happening and to find any recognisable markers on their journey are likely to struggle when their safe, boundaried world is thrown into turmoil. Again the extent of their involvement on the communication continuum has a significant role to play in facilitating or obstructing the process of making sense of what is occurring.

The research highlighted that children are likely to experience difficulties and challenges when the parent's health is such that they require hospital or hospice care. Children in my research described visiting hospital or hospices as problematic. The change from having the parent at home to receiving institutionalised care can be traumatic; the change in routines along with the realisation that the parent's health has deteriorated can act as a marker of the seriousness of the illness. This can be the period where the children realise that their parents are terminally ill and the seriousness of the situation. However, when parents are nursed at home, the changes in routine can also have a significant bearing on their lives. Georgina's mother talked about the 'never ending parade of people' coming into the house to provide nursing and medical care. These home visits provide the professionals with a good opportunity to engage with the families in conversations about how the children are coping and the level of their understanding. However, the research suggests that because the remit is to offer medical and nursing care the social and emotional needs, especially of the children, are not addressed.

The opinions of the participants that the pre-bereavement period is more difficult to navigate further supports the discussion about the 'writing' of the 'penultimate chapter' and the inclusion of this as a development in the understanding of parental terminal illness. However, in addition it reveals that appropriate support is vital for the accomplishment of a meaningful chapter. Observations made during the research suggest that professionals who are specifically employed to work with children and families experiencing terminal illness offer valuable support and can play a significant part in contributing to the 'penultimate chapter'. Their involvement facilitates the navigation of the alien landscape, contributes to the meaning making process and can also offer future orientated thinking that can help the children begin to consider life without their parents. This package of support adds important subheadings to the 'penultimate chapter' and contributes significantly to the quality of the plot and text. The children's accounts indicate that in addition, this support provides them with the confidence to share their 'penultimate chapter' with others, thus enabling it to be more durable and to reduce the feelings of isolation. This is an important proposition when the highly personal nature of the account is considered. The contents of the chapter are such that the children may decide that they do not want to share them with others. Furthermore, it is probable that the people who are allowed to share the chapter will be carefully selected and will need to demonstrate an understanding and commitment to the reading of it.

8.4.4 Transitions following the death

The research indicated that inevitably, following the death there are more changes and challenges that children are forced to navigate. The death of a parent can be another difficult period that requires careful negotiation. Jennifer spoke about the weeks and months following her mother's death. Initially when she returned to school there was some limited acknowledgment of what had happened but this was very brief and she quickly became invisible within the school environment and the local community. This movement into a new and equally unknown environment creates fresh challenges for children to overcome. However, evidence would suggest that for the majority of children, society's stubborn refusal to acknowledge their needs results in them experiencing disenfranchised grief (Doka 1989). Dedicated support for bereaved children, whilst not as fragmented as pre-bereavement support, remains patchy and inconsistent (Rowling 2003). There continues to be little acknowledgment of the needs of these children and as a result they potentially remain vulnerable and at risk of significant and enduring mental health, social and physical problems.

The professionals provided a different perspective with regards to the changes following the death. They expressed how for some children there is a feeling of relief that the parent has died. This relief could be misinterpreted by observers as being uncaring and callous, but in reality it is more frequently because of recognition that the uncertainty and unpredictability that has been prevalent within the family has concluded. As Hannah noted, for some children this means that the things that have been on hold can be recaptured and they can re-enter into life. However, the feelings of relief can be short lived and be followed by feelings of guilt and remorse for experiencing relief and lead to confusion and further questioning about identity and the relationship with the deceased. These mixed emotions could have an impact on the 'writing' of the 'last chapter', however, if a meaningful 'penultimate chapter' had been included in the children's biography this could have contributed to their understanding and meaning making process, thus reducing the emotions being encountered.

8.4.5 Social death: A further significant change

A significant change that was described by the participants, which children experience during parental terminal illness, was the notion of them encountering some form of alienation and marginalisation from their social world and more specifically the social activities that they had enjoyed and participated in prior to the parent becoming ill. The review of the literature discussed previous research that has focussed attention on the social death of patients (Sweeting and Gilhooly 1991, Raphael 1996, Walter 2006). Significantly for this current research, the ethnographic study by Lawton (2000), dedicates a chapter to describing her observations of terminally ill patients in a hospice setting and how they experienced 'a loss of self which stemmed from a loss of relationships' (p. 148).

My research has identified similarities with the ideas discussed by Lawton and can be transposed into the worlds of children living with a parent who is dying and particularly the impact their parents' illnesses has on their identity and sense of self. The social death that I am proposing is a temporary 'death'. However, I would argue that there are no fixed time limits and the puncturing of the children's social world may be enduring, and is yet another liminal period that children living with a parent who is dying experience.

The notion of a social death was initially identified following the first interview with Hannah. In this interview she returned on a number of occasions to describe the experiences of the family whose mother had a degenerative neurological disease. As I was transcribing the data from this interview, I was regularly drawn to considering the work of Lawton, and into making comparisons with the similarities that were being described. Following this interview with Hannah, when transcribing interviews, I began noting how frequently participants described the social isolation and difference that was experienced when living with a parent who was terminally ill. From these observations the idea that children experience a particular change that I refer to as a social death began to emerge.

One of the notable elements running throughout the course of the two interviews with Hannah was the barriers to social activities that are frequently erected and create difficulties for family life, especially the typical social routines which are often taken for granted normative activities which act as agents for the social glue of family life. Hannah highlighted that a major barrier within many families is as a result of the ill parent's physical limitations due to their illness. They no longer are physically able to contribute to the social activities. Compounded by this is often the well parent's overwhelming role as carer that inhibits them from also managing the typical tasks undertaken before illness came into the family.

The emphasis here is on the connectedness of family life and how terminal illness can get in the way of this. Some of the examples described in the research relate to children's social activities being curtailed because of the parents' illnesses. The barriers to accessing such activities could be numerous. The physical barriers of taking the children to the session could be because time constraints are placed on the well parent. If the activities coincide with hospital or hospice visiting times this could have a detrimental effect on the children's ability to engage in social activities outside the home. Moreover, if the well parent's routine is focused on the ill parent, the pre-illness activities enjoyed by the children could be in jeopardy. Furthermore, the review of the literature highlighted how frequently the well parent becomes absorbed emotionally and physically in the care of the ill parent to the detriment of the emotional security of the children, thus having the potential effect of reducing contact with previously known routines and activities. The financial cost of attending activities could also have implications for the children, thus contributing further to their social death. This is particularly salient when one or both the household incomes are depleted or lost because of the illness.

The examples of non-participation in social activities are paralleled by Lawton's (2000) discussion of social death. Lawton's example is of an elderly person being unable to meet friends socially at the public house due to mobility problems and therefore feeling trapped at home. The children whose parents are at the end of life may also feel trapped both physically and metaphorically. Jennifer's account clearly presents evidence of her feelings of being bound by the care of her mother and the disabling effect this had on her in relation to her social life. It is perhaps most marked for young adolescents who are developmentally moving away from their parents care and who are wanting to explore the wider environment. There is a dichotic struggle between wanting to be 'typical' teenagers and 'hang around' with friends and the constraints placed upon them because of their parents' terminal illness. The reduction or sometimes total loss of opportunities to engage in social activities creates yet another environment of difference and further compacts the feelings of isolation and being different from peers.

8.4.6 Losing common ground with friends and peers

The findings have evidenced that the social death for children is not limited to activities away from the home. The limitations that can be created on family life also have a bearing within the home environment. The typical activity of having school friends for tea or a 'sleepover' are also inhibited because of the family circumstances and consequently the children may no longer be part of that social culture. This with the possible disengagement of peers can contribute further to the social death. Hannah described how from her experience children have spoken about how they lose 'common ground' with their friends, their daily life experiences becoming removed from their peers and as a consequence the cement of shared life experiences begins to crumble. This being congruent with Jennifer's account. Children like to belong within their peer groups and do not want to be perceived as being different (Raphael 1994, Christ et al. 2002, Shultz 2007). Feelings of difference are exacerbated by the fact that peers often do not know how to talk to the children about what is happening or how to handle the situation (Pennells and Smith 1995). It is evident that the children are drawn into an alien world where friends, peers and the community are unable to empathise having not necessarily visited this 'new strange place'. Not having a fellow traveller to accompany the children creates feelings of isolation and abandonment and further feelings of disconnectedness from the 'real' world.

Identity formation and development are crucial for children to develop in part an idea of self (Quinton 2006). Their experience of living with a social death can severely compromise their current sense of self and their ongoing identity formation. Children involved in the research described feelings of being different from peers and the need to adopt alternative identities to appear the same as their friends, thus having the potential to create further feelings of alienation and difference from peers and community.

Parental terminal illness has significant social implications for the children and may well lead to them experiencing a social death. Within this phenomenon consideration needs to be given to their role as son or daughter and whether this is affected by the experience of living with a parent who is dying. The accounts of participants involved with the current research have highlighted how living with a terminally ill parent has certainly caused them to question issues of identity and relationship. For some children, there was an expectation that they would take on additional roles within the home. This movement into often premature responsibility did have an impact on the relationship with the parents but the defined role of son or daughter fundamentally remained the same and it was the role of the parent that was the changing variable. Certainly for the family described by Hannah, where the mother had a degenerative neurological disease, the children's role remained the same and it was the role of the mother that was being severely compromised because of her illness.

Hannah described in detail an incident she had observed where the young boy within the family had displayed challenging behaviour when with his mother. Hannah spoke about how the professionals around him had managed his behaviour while his mother helplessly observed what was happening. This provides a very tangible example of the social death for the mother, but it also highlights the social death in the context of the children living within an environment of terminal illness. Following the interview with Hannah I speculated what this meant for the children. Presumably under typical circumstances the boy's mother would have intervened and taken control of the situation. However, paradoxically, had the mother not been in the current situation, would the boy have felt the need to express anger and frustration in such a way? His concept of the world had been forced to alter dramatically and I speculated how he might now perceive his world: *'now when I am naughty some other people take over mummy's role and try and do what mummy would have done'.* The loss of prescribed familial roles therefore has a significant impact on the social death for the child.

As a result of the terminal illness, the mother had lost her 'mummy role' and had become reliant on other people to take on all the roles she had previously undertaken. These observations are congruent with Elmberger et al. (2005) who describe the mother's role when she has cancer as being 'interrupted mothering' (p. 257). The incident presented by Hannah was very specific, but could be transferred to a plethora of similar familial situations where the ill parent has lost their role as 'engaging parent'. Lawton (2000) describes the observations she made of patients in the terminal stage and how they frequently experienced degenderisation; how they lost relationships through which their gender could be interactively reflected and affirmed. Parents experiencing the loss of the 'mummy' or 'daddy' role also experience a form of degenderisation and this in turn can have a huge impact on the children's identity, sense of self and containment. Returning to the experiences of the two children that Hannah described, the loss of the 'mummy role' had the potential to have a devastating impact on their sense of security, knowledge of the world and feeling of being boundaried. In relation to the children what did this mean? The predictable patterns of family life, which they had known, had been lost. The mummy these children knew had changed along with her role. Within this all that had previously been predictable and safe had become very unpredictable and unsafe. These changes will inevitably effect how the 'penultimate chapter' is 'written'. The two children in Hannah's example will have been forced to 'write' a number of editions to their chapter and adjust the content as their mother's health deteriorated and new variables were introduced. For them, one of the major plots was about the changes that had occurred within the family and how this included their mother being forced to relinquish her role as 'mummy' to other people.

8.4.7 The isolating effect of the alien landscape

Lawton (2000) discusses the isolation felt by patients when family and friends begin to withdraw from them and visiting becomes less frequent. Similarly children living with a parent who is dying often experience feelings of isolation. Jennifer's account typified this and was congruent with other stories I heard during the interviews. The feelings of isolation are as a result of a number of factors. Findings from the research have evidenced how the familiar common ground, previously shared with peers, is lost when a parent becomes terminally ill. The unfamiliar landscape creates difference and as discussed previously signifies huge changes that are not understood or accessible to peers. Whilst the peers may contribute to the 'writing' of the 'penultimate chapter' and are a times key characters, they are rarely able to read the text or understand the plot; their involvement is totally peripheral.

Lawton's (ibid) observations highlighted that in her research some patients 'died too soon'. She provided the example of Tony, a young father who died before he was able to resolve emotional and social concerns. Children too need time to resolve emotional and social concerns when their parent is dying and again the value of communication and information sharing can be emphasised. Having opportunities to talk about what is happening within the family and being involved in the current situation enables the children to begin to comprehend what is occurring, start to make sense of the experience and attempt to manage the situation more effectively. The research has clearly indicated that when children are situated in a closed context awareness (Glaser and Strauss 1980) the opportunities to process social and emotional concerns are limited and therefore they are more likely to experience unresolved issues. Furthermore, this again relates to the prohibition of the 'writing' of the 'penultimate chapter' and a lost opportunity to make a meaningful contribution to the ongoing biography for the children.

Summary

The findings provide compelling evidence suggesting that when living with a parent who is terminally ill, children experience a number of unique transitions and changes that can have an enduring effect on their lives. The accounts of the participants highlight how these transitions and changes contribute to the forced journey into an alien landscape where few known markers can provide guidance or reassurance. The changes that are experienced compel the children to further question their identity and preclude them from being able to construct a meaningful understanding of self.

One of the most vital components in supporting them through these changes is the consistent availability of information and the inclusion of them in conversations about their parents' illnesses and prognosis. The responsibility for this cannot be left solely with the parents. They are generally struggling to make sense of what is happening and furthermore, frequently believe that by not including the children they are protecting them. Therefore, the professionals involved with the family have a significant role to play in facilitating these difficult conversations. However, it has been noted through the accounts of the participants that often professionals are not sufficiently confident or competent to engage in such conversations. Through the course of the research, I have met some very empathetic practitioners who understand the needs of children living in these circumstances and who recognise the importance of working with them. It would appear, however, that these professionals are the minority and tend to work in isolation from colleagues who are not as cognisant with the needs of children living with a parent who is dying. Furthermore, it has been noted that not all families will require or desire external support. Therefore, this needs to be taken into consideration and their wishes and feelings respected.

I have presented the concept of the 'penultimate chapter', the development of which is from the accounts of my participants and the work of Walter (1996, 1999). Age appropriate communication and information sharing forms a cornerstone in the 'writing' of the 'penultimate chapter' and is influential in contributing to the outline of the chapter. However, within this consistency there appeared that a common denominator was missing. This missing theme has become the 'penultimate chapter'. The 'writing' of the chapter is so vital for children to begin to make sense of what is occurring. Through the process, if handled sensitively, they can develop an understanding of self and create an identity that is consistent with their life trajectory. Furthermore they can, if party to age appropriate information, begin to augment the chapter with a thick plot that helps make the story more robust and meaningful. It is imperative that the chapter has key characters throughout. These characters have a vital role to play in the editing of the chapter and the building up of the plot as the parent's health deteriorates. However, it also needs to be noted that some key characters may have a limited understanding of the plot and whilst they are involved in the 'writing' of the chapter, their influence could potentially have a negative effect. It is therefore, important that professionals involved with the family, and the children's peers have a greater understanding of the issues faced when 'writing' a 'penultimate chapter'. This can only begin to be achieved by more acknowledgement of the needs of children living with a parent who is dying. The need for a more comprehensive and robust training programme is required and would be the first step in ensuring that the needs of these children are included on the social and political agenda.

CHAPTER NINE: CONCLUSION

The findings have provided substantial evidence that typically children are not included in information exchanges about their parents' terminal illnesses. When children are living with parents who are dying there is frequently a conspiracy of silence, orchestrated and managed by the adults involved in the children's lives, rendering them powerless and unable to make any meaning from their current experience. When children are not included they do not have the appropriate pieces of the jigsaw to enable them to make sense of what is happening and to begin to develop a biography that is consistent with the peripheral information they are receiving. However, the research has also highlighted that on the occasions when children are included in conversations, they are generally better equipped to make sense of what is happening because of having an informed understanding. I have suggested that there is a non-static communication continuum, and where the children are situated on the continuum is dependent on the quality and quantity of age appropriate information that they receive. The key informants for children are typically their parents; however, for a number of reasons they often do not initiate the conversations with their children. This is sometimes because they too are so emotionally burdened that they do not have the capacity to include their children in the discussions. At other times parents perceive that they are protecting their children by not including them in information sharing about what is occurring. Whatever the reasons and motives are, I have argued that the professionals working with the family have a significant role to play in supporting them to initiate the conversations and to ensure that there is ongoing dialogue.

The findings have evidenced that when children are accompanied through the journey of parental terminal illness with people who understand what they are experiencing, they are better supported and consequently have more available resources to help them begin to make sense of what is happening in their lives. These people often provide a viable discourse that can be incorporated into the meaning making process and add clarity for the 'writing of the penultimate chapter'. The fellow travellers in my research have been predominantly professionals who are specifically employed to work with children and families experiencing parental terminal illness. The professionals' role is in part to support the parents to instigate the conversations with the children about the illness and to encourage regular dialogue. However, findings from the research suggest that when practitioners are not specifically employed to work with children they frequently do not have the confidence or competence to provide the necessary support. The limited access to training and continual professional development, even at a basic level, precludes them from having rudimentary knowledge and awareness about children living with a parent who is dying and the wide variety of needs they have that are not generally recognised.

The findings have evidenced that it was predominantly professionals who provided the role of fellow traveller, however, observations from the children's bereavement support group highlighted how peers, who have shared similar experiences, can also be particularly valuable. Peers who have or are experiencing a similar family crisis can help in the construction of shared biographies and act as guides through the alien landscape. Having a fellow traveller who is a peer can be of enormous support and comfort. They too belong to the exclusive club of parental bereavement and can begin to understand some of the feelings, emotions and cognitions associated with parental terminal illness. A significant benefit of sharing the journey with a peer is that the children will not have such a great need to feign an identity that is not congruent with how they are feeling, they can be themselves, safe in the knowledge that their peers have an informed understanding of what is happening.

A second key empirical finding from the research was that children experience a number of transitions and changes when living with a parent who is dying. A significant transition that needs to be comprehended emotionally and cognitively is the change from living with a parent who is healthy to living with a parent who is dying. Accompanying this huge transition are many associated changes and challenges that the children need to accommodate. These include the changes in family routines and the shift from a safe boundaried world into an unsafe world where everything that was predictable is no longer. How these changes are managed is very much dependent on the communication and information sharing process the children are privy to and thus where they are placed on the communication continuum.

My analysis of the data and a developing understanding of different propositions and perspectives were influential in my development of the work of Walter (1996, 1999) and the introduction of the notion of the 'writing of the penultimate chapter'. The 'writing' of this chapter is dependent on a number of factors, the primary one being the extent to which the children are involved in the information sharing process about their parents' illnesses and the extent to which they can add some meaning and make sense of what is happening. The findings suggest that the more the children are enabled to be involved and included the thicker the plot for the chapter and the more able they are to 'write' durable editions. I suggest that, regardless of the children's inclusion or exclusion from the 'writing of the penultimate chapter', they are regularly updating the chapter. Because of the nature of terminal illness and all the likely changes in the parents' health, there are many drafts and editions written, however, the accuracy of the editions will be very much dependent on the quality of information that the children are privy to. Furthermore, as new characters are introduced to the family, in the form of different professionals, the plot is again likely to change. The quality of the involvement of the professionals and other key characters will influence the writing of the editions and will affect how robust the chapter will be.

The initial aim of the research, which was 'to critically examine the nature and availability of professional support and its contributions to children's wellbeing when a parent is at the end of life within selected palliative care settings', was modified to meet the early challenges I experienced from gatekeepers. The barriers I encountered forced me to make compromises, which I now understand to be part of the research process, however, through these compromises, opportunities developed which led me to secure significant support from a number of dedicated professionals. In turn, these contacts provided me with access to a small number of bereaved children whose accounts have contributed significantly to the findings and the direction of the thesis.

During the initial stages of the fieldwork and analysis of the data, the strands that have been brought together to form the basis of the thesis appeared to be discrete pieces of information. However, through analysis of the data and consideration of all the observations made during the fieldwork all the different factors have developed into a unified whole. Through comparing the different experiences that were presented to me in the accounts of the children, their parents and professionals I was able to make the connection between the quality of communication and information sharing and how the children attempt to manage all that is happening within their lives. After identifying the key themes for the thesis, I began developing broad frameworks for each findings chapter and from this the connections between the themes began to emerge.

Adopting qualitative methods for the research has been invaluable. This has allowed the richness of the stories to emerge and the importance and relevance of the participants' accounts to come to the fore. This would not have been as possible had a quantitative approach been adopted. Furthermore, this approach has ensured that the children's voices have been included. Reflecting on the quote from Brooks (2006), when children are enabled to participate in research they do respond with maturity and are very capable of informing the research process. However, the limitations of the research methods need to be acknowledged. Through adopting a qualitative approach, the research sample was small. The barriers I experienced with some gatekeepers, especially during the early stages of the fieldwork, potentially compounded this. Furthermore, because of the initial difficult encounters with gatekeepers, I was forced to amend the original proposal and the research became retrospective as opposed to the planned prospective study. Had it been permissible to work within the original proposal, I intended to meet with the children, their families and the professionals involved in their care, thus hearing the perspectives of all key people. It was intended that this would provide more reliable and robust data that could be validated. However, the data was validated through member checking and the revisiting of the data with the participants. The accounts of the participants were rooted in their experiences of living with a parent who is terminally ill or working with children experiencing the death of a parent, rather than factual information. As a consequence, I am not claiming that the thesis is representing the 'truth'.

The research has been limited because I was unable to include as participants children who are in the care of the Local Authority as a result of parental terminal illness. Their current lived experience would, by the nature of their circumstances, be likely to be very different from children living with their parents. Their stories would provide a different perspective on the transitions and challenges experienced by children living with a parent who is dying.

Throughout the thesis I have written about the journey that children living with a parent who is dying travels. I too have, through the doctoral process been on an intellectual and emotional journey of self discovery. During this journey I have learnt about the need to be flexible and reflective when undertaking research. The early difficulties I encountered with gatekeepers taught me much about the process of research and how aims and objectives may need to be adjusted in order for the research to progress. Probably the most significant element that I have learnt throughout this journey has been about the personal transition from practitioner to researcher. During the early stages of the research, I, at times struggled with this transition and had a number of external conversations with my Director of Studies and internal dialogues with myself. I struggled with what felt like difficult and competing issues, my identity was firmly rooted as a practitioner and moreover a practitioner who had to find solutions to problems. Being in the position of hearing typically troubled and emotionally ladened stories I had the urge to be proactive and try and intervene. Two entries in my reflective journal highlight the dilemmas and the development. The first entry was written during the very early stages of the research and relates to a conversation I had with my Director of Studies during a supervision session:

> Gordon highlighted the importance of keeping the roles of researcher and service provider separate. I can see and understand the necessity of this at an academic level, and am totally aware that this is going to be one of the major issues for me during this research – not being a practitioner. But at a 'me' level it is a struggle. I have always tried to provide a service and worry that because I am a 'doer I will not cope with the transfer over to researcher. I need to think through this and clarify in my own mind what I am doing. I know my role really; it is just getting it clear (08.05.07).

The second entry was written towards the end of the fieldwork after I had been to visit Mandy. I had previously interviewed her and we had arranged that I could undertake a follow-up visit. However, when I arrived at her home, her health had significantly deteriorated, she had spoken to her Macmillan nurse and was being admitted to the hospital for blood tests and a scan. My reflections evidence the continued struggle but also a shift in my perceptions of my identity:

> …as I write this she will be in [name of hospital] having blood tests and a scan. She said that when she is feeling better she will telephone me. I said I looked forward to that call. I don't really care about the interview, I just want her to be better, but somehow I doubt I will see her again. I left her feeling so very sad. I had a two way conversation with myself as I drove home – I tried to work out whether I felt as I did because I had my

> practitioner's hat on or because I have been affected like anybody with compassion should be bothered. I know I'm not a practitioner and even if I was I would be unable to do much to help, this is the raw emotional side of research, in the briefest of meetings with Mandy she has given so much to the research. Her insights and courage are yet again a concrete reminder of why I am doing this research. Mandy's stories are further evidence that can be used to inform the research and contribute to the development of knowledge of parental terminal illness… (22.07.09).

Reflecting on the process, I believe there are things that I would do differently if I was to start the research again. A regret has been that I was not able to undertake a prospective study and hear the voices of children as they were living through the experience of parental terminal illness. Therefore, if I was undertaking the research again, I think I would be more proactive in securing access to participants that met with the original criteria. In addition I would endeavour to undertake a longitudinal study whereby I followed families through a pre-determined period and at intervals met with them to hear from all the members how the illness was impacting on the children. If along with the children's and their parents' accounts I involved the professionals working with the family, I would be able to compare and contrast the significant character's perceptions and understandings of the needs of the children.

Based on the findings that have been presented throughout the thesis, there are number of recommendations that I wish to propose. Firstly, whilst it should be acknowledged that not all children experiencing the death of a parent would welcome interventions or support of any kind, a recommendation, based on the accounts of the participants, is that appropriate support is available for children in the pre-bereavement period. This support should be flexible to meet individual children's needs and could be provided through both individual and group support. Appropriate services should be routinely available and they should be staffed by qualified and competent workers who understand the needs of children who are living with a terminally ill parent.

A second recommendation is that easily accessible resources should be made available for parents which will help them to develop a deeper understanding about the importance of communicating with their children and the need to provide them with age and developmentally appropriate information about what is happening. These resources could be offered to parents by the professionals working with them and include advice about when and how to tell the children, resources that could be put in place to support both the children and their parents, and an explanation of possible behavioural reactions from the children. The research has shown that parents often feel unable to talk to their children about what is happening because of fear and uncertainty. Therefore, having a range of resources, including information leaflets or simple information guides that can be referred to as and when required may go some way to alleviate this fear.

The findings have highlighted that there is a lack of professional training available with respect to working with children experiencing the death of a parent. Consequently, a recommendation is that all practitioners, who in the course of their work come into contact with children and families, should undertake initial and continuing professional training, where the focus is specifically on children's experiences and needs when living with a parent who is terminally ill. The research has evidenced that frequently professionals involved with families where a parent is dying do not recognise or acknowledge the children within the family, and as a consequence do not provide any support either directly or indirectly. The core of the training should be an exploration of communication styles and practices. Professionals in the research described examples, from their practice, where colleagues have been forthright in stating that they have a fear of talking with children. Furthermore, accounts from other participants, suggested that they would avoid if possible working with children because of not knowing *what* to say or *how* to say it. Therefore, the recommendation of training for practitioners should include time reflecting on personal fears of dying and death along with a practical emphasis where communication skills and working with children are explored. Elements within the training should be practice specific, for example targeted at the particular professional domains, i.e. nursing, social work, teaching, but should also incorporate inter-professional and inter-agency training across the disciplines.

A further recommendation for health, social care and education professionals, is that within their own domains, there is recognition that children who are experiencing the death of a parent are recognised as being potentially Children at Risk as defined by the Children Act 1989. Furthermore, these children are likely to experience many changes and challenges that could rupture their sense of self and create vulnerability both emotionally and physically. A more sophisticated understanding of these children's behaviour, their development in relation to their understanding of death and dying, and the varied ways they manage the situation, when living with the knowledge that their parent is dying, would help equip practitioners to be more empathetic and competent in their practice, whilst also ensuring that appropriate safeguarding procedures are imbedded in practice. For such training to be incorporated into the curriculum, there needs to be recognition at a strategic level of the value and necessity of including specific training, and a commitment to providing it for students and qualified staff as part of their continual professional development.

A final recommendation is that further research is required to develop the practical and theoretical understanding of children's experiences when living with a parent who is dying. The consistent finding from the current research has been that communication and information sharing significantly contribute to the children's ability to begin to make meaning from the experience of parental terminal illness and through this to develop narratives about their lives. This conclusion needs to be researched in greater detail, using a more comprehensive number of participants over a longer period and to once again include the children's parents and professionals involved in the care of these vulnerable families.

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APPENDIX 1 – Research Participants

Children	Age when interviewed	Relationship to deceased
Jennifer	24 years	Daughter
Luke	22 years	Son
Georgina	10 years	Granddaughter
Samantha	17 years	Daughter
Kirsti	11 years	Daughter
Emma	6 years	Daughter
Sonny	9 years	Grandson

Parents	Status	
Mandy	Terminally Ill Parent	
Diane	Bereaved Mother	
Dawn	Bereaved Mother	
'Georgina's' Mother	Bereaved Daughter	
'Samantha's' Father	Bereaved Husband	

Professionals	Profession	Agency
Hannah	Nurse Practitioner	Hospital
Dr Jones	Counsellor	Independent Organisation
Elizabeth	Palliative Care Social Worker	Primary Care Trust
Christopher	Social Worker	Hospice
Pat	Service Manager	Voluntary Organisation
Harriet	Palliative Care Nurse	Hospital
Carol	Counsellor	Hospice
John	Bereavement Co-ordinator	Hospice
Susan	Social Worker	Hospice
Amanda	Education Welfare Officer	School
Charlotte	Social Worker	Hospice
Martha	Social Worker	Hospice
Anne	Palliative Care Nurse	Hospital
Alison	Play Therapist	Voluntary Organisation
Julia	Bereavement Support Worker	Voluntary Organisation
Catherine	Community Palliative Nurse	Hospice

APPENDIX 2 – The Communication Continuum

'...we were getting quite upset about it because we realised like how frustrated we felt not being about not knowing' (Jennifer)

'...we didn't know and how everyone else knew' (Jennifer)

'...if we were told ...I guess we would have tried to make things clearer and talk about things' (Jennifer)

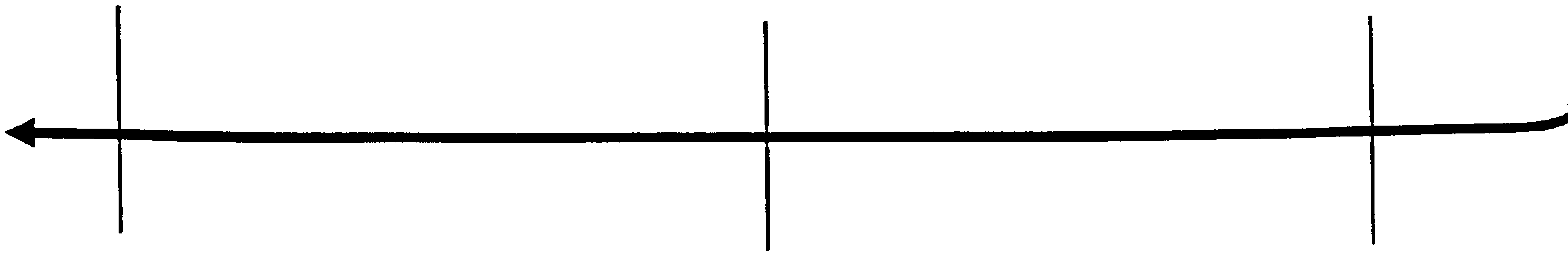
I never really talked about how I felt about things because I knew there was a lot of pressure on my step-dad' (Luke)

'...not knowing is the worst and especially from a child's point of view... they probably don't understand things as well anyway' (Luke)

'I think one of the worst things is not knowing things' (Luke)

'If people don't know what is going on they would feel helpless' (Samantha)

Closed Communication



"Totally closed communication - no information, no opportunities to share fears with anyone"

"Mostly closed – very little information, some opportunities to share fears"

"Partially closed -some information and some sharing, but highly coded and unclear, fears not recognised or dealt with"

'I think the biggest issue for me is that all the way through I don't think families talk about it and that has a knock on effect on the children' (Christopher)

'...they don't know the whole story of what is going on...' (Christopher)

'...but there were things that they probably wanted to talk about but were scared of making me upset' (Diane)

'...they think they are protecting the children by not talking about...there is this sort of wrapping up in cotton wool and protecting them' (Harriet)

The chart represents the communication continuum. The quotes at the 'closed' end provide examples of the problems and difficulties experienced when children are not included in information exchanges. Conversely the accounts at the 'open' end highlight the value and importance they place on having regular conversations with others about the illness, its prognosis and the future. Some children chose to 'place' themselves towards the closed end of the continuum, preferring not to be included. However, this could be seen to be a protective psychological mechanism, used to act as a barrier from all that is happening.

‘I am glad that I knew as opposed to not knowing …I suppose that was beneficial’ (Luke)

‘I suppose just knowing that there is someone there that you can talk to’ (Luke)

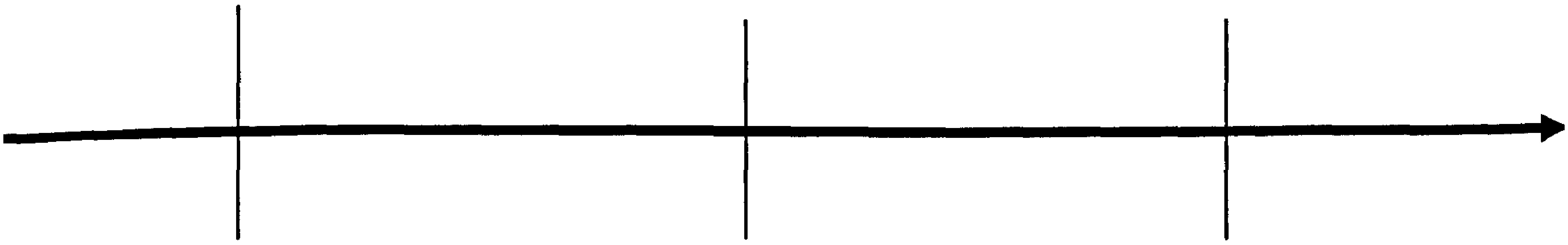
‘We were told that we could talk to the nurse but we never got chance because she always visited when we were at school’ (Samantha)

‘We found out a lot from dad’ (Samantha)

‘It was useful to know what was happening’ (Samantha)

‘I was glad you told me or I would have been more shocked’ (Georgina)

Open Communication



‘Partially open – some clear information but limited opportunities to share it’s meaning’

‘Mostly open - regular updates of information and some opportunities to share knowledge with adults’

‘Totally open – kept fully informed throughout and given open access to adults/ parent’s feelings and responses’

‘There were loads of questions which he had never been able to ask us but that he could openly ask [name of worker]’ (Sonny’s mother)

‘You can never fully prepare children, but they need to be as much as possible’ (Georgina’s mother)

The quotes in the middle of the continuum demonstrate factors that may constrain the children’s positioning on the continuum. ‘Sonny’s’ example provides evidence about the use of euphemistic language and illustrates how this can cause confusion and therefore inhibit the movement towards the open end of the continuum. Luke’s account provides an example where the self imposed silence by the children again impacts on their positioning on the continuum. The children’s positioning is not static and can move along the continuum depending on the quality and quantity of the information they receive at differing times during their parents’ illnesses.

APPENDIX 3– Initial Information Letters and Consent Forms

REC reference number: 07/H1310/23

Information Letter (Infant)

Hello, my name is Rachel. I would like to come to your group at XX (name of Hospice).

I want to know more about how people are helping you while your Mum or Dad is poorly.

I would like to join in the group with you. I will be able to see what you do. I can listen to what you are talking about.

I hope I can learn more about how you are feeling. I hope I can learn more about who is helping you at the moment.

I am doing this for my work at University. I shall write about the things I hear and see but I will not say who told me. So you do not need to worry that someone outside the group will know what you said.

I am doing this because I want to find out the sorts of things that help children whose Mum or Dad is poorly.

Every time I come to the group, I will ask everybody if they are happy for me to be there.

If you or somebody else says they do not want me in the group, I shall not stay.

Your Mum or Dad will still be looked after at XX (name of Hospice) if you say you don't want me to come to the group.

XX (name of counsellor) is going to be part of the group. He/she will be there to help if you would like to talk to somebody else about how you are feeling.

Thank you for reading this letter.

Rachel

REC reference number: 07/H1310/23

Information Letter (Infant - bereaved)

Hello, my name is Rachel. I would like to come to your group at XX (name of Hospice).

I would like to join in the group with you. I will be able to see what you do. I can listen to what you are talking about.

I hope I can learn more about how you are feeling. I hope I can learn more about who is helping you at the moment.

I am doing this for my work at University. I shall write about the things I hear and see but I will not say who told me. So you do not need to worry that someone outside the group will know what you said.

Every time I come to the group, I will ask everybody if they are happy for me to be there.

If you or somebody else says they do not want me in the group, I shall not stay.

XX (name of counsellor) is going to be part of the group. He/she will be there to help if you would like to talk to somebody else about how you are feeling.

Thank you for reading this letter.

Rachel

REC reference number: 07/H1310/23

Information Letter (Children Junior)

Support you would like from professionals, when your parent is in XX (name of Hospice)

Hello, my name is Rachel and I am going to be coming to the support group at XX (name of Hospice). I like to find out what children think about things that are important to them, this is sometimes called doing research.

One of the big questions I would like to know more about is how people are helping you whilst your Mum or Dad is poorly.

I would like to join the support group and join in the activities, but before you say that it is okay for me to come along to the group, it is important that you know why the research is being done and what will happen when I am in the group.

I will join the group and take part in the activities you do. During the session I will be watching and listening to see what is important for all the children.

After I have been in the group, I will write about the things I have seen and heard. This will be used for some work I am doing at University. Even though I will be writing about the things I have seen and the stories I have heard, I will change everybody's names so that nobody knows who I am writing about.

Anything that I hear or see in the group will not be talked about to anyone else (unless I am worried that someone in the group is at risk of being hurt by another person or themselves).

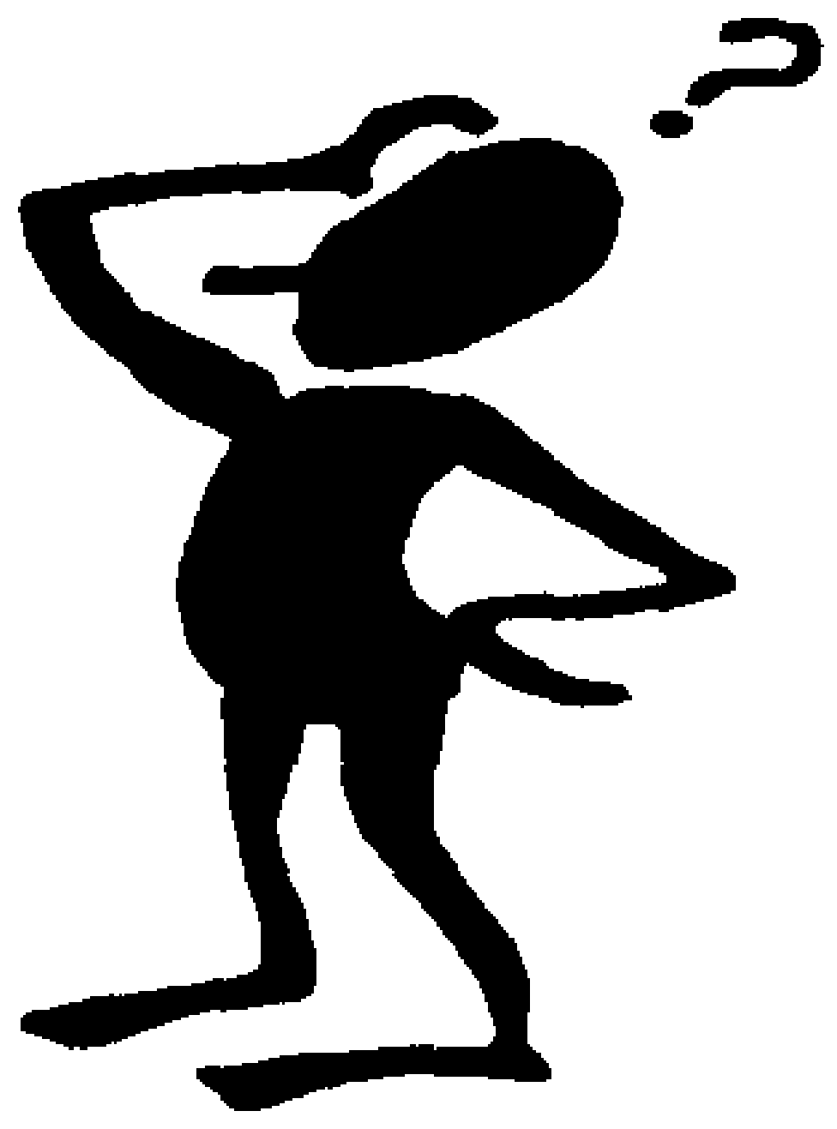
It would be good if I could come to the support group, join in the activities, and learn more about the support and help you are getting, but I also guess that at the moment you are feeling lots of different things and might not want me in the support group. That's okay you can still come to the group.

Every time I come to the group, I will ask everybody if they are happy for me to be there.

If you or somebody else says they would prefer me not to be at the group, I will not stay, but the group will still carry on and you will be able to stay.

Whatever you decide about me being in the group will not affect how your Mum or Dad is being looked after.

XX (name of counsellor) is also going to be part of the group and he/she will be there to help if you would like to talk to somebody else about how you are feeling.



Thank you for reading this letter.

Rachel

REC reference number: 07/H1310/23

Information Letter - (Junior - bereaved)

Support for Children when their Parent is in XX (name of Hospice)

Hello, my name is Rachel and I am going to be coming to the support group at XX (name of Hospice). I like to find out what children think about things that are important to them, this is sometimes called doing research.

One big question I would like to know more about is how people help children when their mum or dad is being cared for at XX (name of Hospice). I am writing to you because I understand that you are attending the group because your Mum/Dad (*type accordingly)* has died. I am sure that this must be a very hard time for you at the moment and that you are feeling lots of different things.

I would like to join the support group and join in the activities, but before you say that it is okay for me to come along to the group, it is important that you know why the research is being done and what will happen when I am in the group.

I will join the group and take part in the activities you do. During the session I will be watching and listening to see what everyone is doing.

After I have been in the group, I will write about the things I have seen and heard. This will be used for some work I am doing at University. Even though I will be writing about the things I have seen and the stories I have heard, I will change everybody's names so that nobody knows who I am writing about.

Anything that I hear or see in the group will not be talked about to anyone else (unless I am worried that someone in the group is at risk of being hurt by another person or themselves).

It would be good if I could come to the support group, join in the activities and learn more about the support and help you are getting, but I also guess that at the moment you are feeling lots of different things and might not want me in the support group. That's okay you can still come to the group.

Every time I come to the group, I will ask everybody if they are happy for me to be there.

If you or somebody else says they would prefer me not to be at the group, I will not stay, but the group will still carry on and you will be able to stay.

XX (name of counsellor) is also going to be part of the group and he/she will be there to help if you would like to talk to somebody else about how you are feeling.

Thank you for reading this letter.
Rachel

REC reference number: 07/H1310/23

Information Letter (Young People)

Support you would like from professionals, when your parent is in XX (name of Hospice)

Hello, my name is Rachel Fearnley and I am a student at Derby University. My study is looking at the support needs of children when their parent or carer is being cared for in a hospice. Part of my study is to become a member of the support group at XX (name of Hospice) and become involved with the activities. This is so that I can learn more about the support young people like you are receiving from professionals and the support you would like.

I feel that it is really important that adults listen to young people and don't make assumptions about what you are feeling or thinking. When I am in the support group, I will not be asking you direct questions, but will be observing what is happening. If during the group we begin talking, or I hear or see something which I think is important to the research, I will, after the group make notes about what has been said.

These notes will then help me to understand more about the support you and the other young people at the group are receiving and would like to receive. The notes will be written up in more detail and be used as part of my research. Whenever possible, I will share these notes with you to check for accuracy and to make sure I have got it right.

Anything that I hear or see in the group will be treated in confidence (unless I am concerned that someone in the group is at risk of being hurt by another person or themselves). When I am making my notes and writing up the research in detail, I will change everybody's name and the name of the hospice so that no one will be able to identify who I am writing about.

I would appreciate it if you would think about being involved in the research. However, I understand that at the moment there is a lot happening and guess that you may be feeling lots of different emotions so if you decide not to be involved I will understand and respect your wishes.
Whatever your decision is about the research, it will not impact on you attending the group or the care your parent is currently receiving from XX (name of Hospice).

Every time I come to the group, I will remind everybody why I am in the group and check out that you are happy for me to be there. If you or somebody else says they would prefer me not to be at the group, I will not stay, but the group will still carry on and you will be able to stay.

XX (name of counsellor) is also going to be part of the group and he/she will be there to help if you would like to talk to somebody else about how you are feeling.

Thank you for reading this letter.

Rachel

REC reference number: 07/H1310/23

Information letter - Young People (Bereaved)

Support children would like from professionals, when their parent is in XX (name of Hospice)

Hello, my name is Rachel Fearnley and I am a student at Derby University. My research is looking at the support needs of children when their parent or carer is being cared for in a hospice. I am *writing* to you because I understand that you are attending the group because your Mum/Dad (type accordingly) has died. I guess that this is a very difficult time for you and I really don't want to add to all the feelings.

I am going to be become a member of the group at XX (name of Hospice) and become involved with the activities. This is so that I can learn more about the support young people are receiving from professionals and the support they would like. I feel that it is really important that adults listen to young people and don't make assumptions about what they are feeling or thinking.

When I am in the support group, I will not be asking you direct questions, but will be observing what is happening. If during the group we begin talking, or I hear or see something which I think is important to the research, I will, after the group make notes about what has been said. These notes will then help me to understand more about the support you and the other young people at the group are receiving and would like to receive.

The notes will be written up in more detail and be used as part of my research. Whenever possible, I will share these notes with you to check for accuracy and to make sure I have got it right.

Anything that I hear or see in the group will be treated in confidence (unless I am concerned that someone in the group is at risk of being hurt by another person or themselves). When I am making my notes and writing up the research in detail, I will change everybody's name and the name of the hospice so that no one will be able to identify who I am writing about.

I would appreciate it if you would think about agreeing to me being in the group. However, as I said above I understand that at the moment there is a lot happening and that you may be feeling lots of different emotions so if you decide not to be involved I will understand and respect your wishes. Whatever your decision is about the research, it will not impact on you attending the group.

Every time I come to the group, I will remind everybody why I am in the group and check out that you are happy for me to be there. If you or somebody else says they would prefer me not to be at the group, I will not stay, but the group will still carry on and you will be able to stay.

XX (name of counsellor) is also going to be part of the group and he/she will be there to help if you would like to talk to somebody else about how you are feeling.

Thank you for reading this letter.

Rachel
Rachel Fearnley

REC reference number: 07/H1310/23

Information Letter - Adult

Research at XX (name of Hospice) looking at the support needs of children when a parent or carer is at the end of life

My name is Rachel Fearnley and I am a PhD student at the University of Derby, under the supervision of Dr. G. Riches and Dr. K. Aune. My research is to explore the support needs of children and young people when their parent or carer is at the end of life. It is planned that I will become part of the support group at XX (name of Hospice) and will work alongside the children and staff. Whilst I am involved in the group, I will be joining in the activities and observing the group. I will not be directly asking children questions, however, if we become engaged in conversations I will be noting the content of our discussions. Following the groups I will make notes of my observations and these will be analysed later and written up. I will not be taking photographs or videoing during the sessions.

In addition to my involvement with the children's group, I would also like to talk to you and hear your views on the professional support available to your child/ren. These meetings, where practicable will be tape recorded and transcribed, by myself. Any tape recordings made will be destroyed once the research is completed.

The findings from the research will contribute to my PhD and it is intended that it will also inform practice and policies. I will make my findings available to XX (name of Hospice) and will be happy to share the information with you.

The participant's anonymity and confidentiality are assured and names and locations will be altered to protect the identity of everyone who is involved. No personal information will be stored. However, if I am told something that would indicate that a child is at risk of harm, I will then follow the necessary procedures.

The support and treatment provided by XX (name of Hospice) will not be compromised for the families who participate/choose not to participate in the research. Furthermore, families who do agree to participate can decide, during the research that they no longer wish to be involved. This again will not in any way impact on the treatment or support they or their family receives.

XX (name of Hospice) is providing a qualified counsellor to be part of the group to offer support to the children both during and after the research.

I am a qualified social worker and do not have a medical background. The research I am undertaking relates to social and emotional support and is non medical.

Thank you for reading this information sheet.

Many thanks
Rachel Fearnley

REC reference number: 07/H1310/23

Information Letter – Adult (Bereaved)

Research at XX (name of Hospice) looking at the support needs of children when a parent or carer is at the end of life

My name is Rachel Fearnley and I am a PhD student at the University of Derby, under the supervision of Dr. G. Riches and Dr. K. Aune. My research is to explore the support needs of children and young people when their parent or carer is at the end of life. I am writing to you, as I understand your child(ren) attends the support group at XX (Name of Hospice). I respect that this is a difficult time for your family, and do not wish to cause any more distress.

It is planned that I will become part of the support group at XX (name of Hospice) and will work alongside the children and staff. Whilst I am involved in the group, I will be joining in the activities and observing the group. I will not be directly asking children questions, however, if we become engaged in conversations I will be noting the content of our discussions. Following the groups I will make notes of my observations and these will be analysed later and written up. I will not be taking photographs or videoing during the sessions.

The findings from the research will contribute to my PhD and it is intended that it will also inform practice and policies. I will make my findings available to XX (name of Hospice) and will be happy to share the information with you.

The participant's anonymity and confidentiality are assured and names and locations will be altered to protect the identity of everyone who is involved. No personal information will be stored. However, if I am told something that would indicate that a child is at risk of harm, I will then follow the necessary procedures.

XX (name of Hospice) is providing a qualified counsellor to be part of the group to offer support to the children both during and after the research.

I am writing to request that you give permission for me to approach your child/ren to ask for their consent to take part in the research. If you or your child/ren decides that they do not wish to be part of the research, your decision will be respected. However, this will not impact on your child(ren) attending the support group. Furthermore, if you initially agree but subsequently decide that you do not want me to be involved in the group, again this decision will be honoured.

I am a qualified social worker and do not have a medical background. The research I am undertaking relates to social and emotional support and is non medical.

Thank you for reading this information sheet.

Many thanks
Rachel Fearnley

REC reference number: 07/H1310/23

Letter to professionals

Dear

Support for children when a parent or carer is at the end of life

My name is Rachel Fearnley and I am a PhD student at the University of Derby, under the supervision of Dr. G. Riches and Dr. K. Aune. My research aims to explore the support needs of children and young people when one of their parents or carers is at the end of life. The primary participants in the research will be the children and this will be a collaborative piece of work, involving children, their parents and staff from health, education and social services. I feel that it is important that the children's stories are listened to in order to better support them during and after the death of a parent. The research will be undertaken using a number of approaches –firstly through my role as a volunteer at the children's support groups at hospices within the north of England. Secondly, I will be meeting with the children's parents or carers in order to develop an understanding of their perspectives about the support their children are receiving.

Thirdly, I would like to meet with the professionals involved in palliative care or who work with children, I am therefore writing to you to ask if I could meet with you to undertake a semi-structured interview, the duration of which will be no more that one hour. The purpose of the meeting is for me to discuss with you your own experiences of the support given to children when their parent or carer is at the end of life. I hope that by working with the children and meeting with their parents and the professionals involved with the family at this time, I will be able to develop a broad understanding of the major challenges facing children, of their support needs, and of the best practice currently in place to support them.

The findings from the research will contribute to my PhD and it is intended that it will also be used to inform practice and policies.

Confidentiality and participants' anonymity will be assured and names and locations will be altered to protect the identity of everyone who is involved. No personal information will be stored, and all paper notes and tape recordings will be stored securely. All computer based material will be double pass-word protected. This research is subject to legislation regarding Safeguarding and hence I have to note that, if I am told something that would indicate that a child is at risk of harm I am bound to follow the necessary procedures.

I would like to request that our meeting is tape recorded to reduce the necessity to make notes during the interview and for greater accuracy. However, I appreciate that it can feel uncomfortable and can inhibit conversation and I will respect your wishes if you prefer it not to be tape recorded. All data will be destroyed once the PhD has been awarded.

I am a qualified children's and families social worker and do not have a medical background. The research I am undertaking relates to social and emotional support and is non medical.

Thank you for reading this letter. If you would be prepared to be involved in the research, or are aware of colleagues who would also participate, please complete the enclosed consent form and return it to me in the stamped addressed envelope. I will then contact you to arrange a date and venue for our meeting.

With many thanks

Rachel Fearnley
Post Graduate Researcher
The University of Derby.

REC reference number: 07/H1310/23

Consent Form *(Younger children pre and post bereavement)*

Name of Researcher: Rachel Fearnley

1. I have read the letter from Rachel about her coming to the support group. ☐

2. I know why Rachel is coming to the group. ☐

3. I know that I don't have to join in with Rachel. ☐

4. It is okay for Rachel to come into our group. ☐

5. Rachel can write about the things she sees and hears in the group. ☐

6. I know that Rachel will change everybody's name so that nobody will know who she is writing about. ☐

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My name	Date	Signature

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Name of person taking consent	Date	Signature

When competed, 1 for child; 1 for researcher; 1 (original) to be kept at the Hospice.

REC reference number: 07/H1310/23

Consent Form *(Young People)*

Name of Researcher: Rachel Fearnley

1. I have read the letter from Rachel about the research she would like to do at XX (name of Hospice) in the support group. I have also had the chance to talk to other people about the research. ☐
2. Rachel has also talked to me about why she would like to be part of the support group and has explained what will happen when she is in the group. ☐
3. I understand that if I do not want to be part of the research I do not need to be, but that I will still be able to come to the group. I also know that whether Rachel is part of the group or not this will not affect the care my Mum or Dad is getting from the Hospice. ☐
4. I understand that Rachel will not want to look at any medical notes about my Mum or Dad. ☐
5. I agree that it is okay for Rachel to come into our group and join in the activities. ☐
6. I agree that Rachel can write about the things she sees and hears in the group. I know that Rachel will change everybody's name so that nobody will know who she is writing about. ☐

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Name of Young Person	Date	Signature
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Name of person taking consent	Date	Signature

When competed, 1 for young person; 1 for researcher; 1 (original) to be kept at the Hospice.

REC reference number: 07/H1310/23

Consent Form *(Young People - bereaved)*

Name of Researcher: Rachel Fearnley

1. I have read the letter from Rachel about the research she would like to do at XX (name of Hospice) in the support group. I have had chance to think about the letter and ask questions and these have been answered. ☐
2. Rachel has also talked to me about why she would like to be part of the support group and has explained what will happen when she is in the group. ☐
3. I understand that if I do not want to be part of the research I do not need to be, but that I will still be able to come to the group. ☐
4. I agree that it is okay for Rachel to come into our group and join in the activities. ☐
5. I agree that Rachel can write about the things she sees and hears in the group. I know that Rachel will change everybody's name so that nobody will know who she is writing about. ☐

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My Name	Date	Signature
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Name of person taking consent	Date	Signature

When competed, 1 for young person; 1 for researcher; 1 (original) to be kept at the hospice.

REC reference number: 07/H1310/23

CONSENT FORM *(Parents)*

Research at XX (name of Hospice) looking at the support needs of children when a parent or carer is at the end of life

Researcher: Rachel Fearnley

Please initial box

1. I confirm that I have read and understood the information sheet dated ....for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that .... (Name of child) participation is voluntary and that he/she can withdraw at any time without giving reasons, and without his/her involvement at the support group being affected. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason and without the medical care and support my family is receiving from .... (Name of Hospice) being affected. ☐
4. I understand that no medical information will be required in this research and no medical notes will be accessed. ☐
5. I agree that Rachel Fearnley can talk to .... (Name of child) about the research and seek their consent and understand that his/her decision will be respected. ☐
6. I understand that the information from the research will be stored until the PhD programme is completed and will then be irrevocably destroyed.
7. I agree that .... (Name of child) can take part in the study. ☐
8. I agree to take part in the above study. ☐

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Name of parent	Date	Signature
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Name of person taking consent	Date	Signature

When competed, 1 for parent; 1 for researcher; 1 (original) to be kept at the Hospice.

REC reference number: 07/H1310/23

CONSENT FORM – *(Parents – bereaved)*

Research at XX (name of Hospice) looking at the support needs of children when a parent or carer is at the end of life

Researcher: Rachel Fearnley

Please initial box

1. I confirm that I have read and understood the information sheet dated .... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that ....(Name of child) participation is voluntary and that he/she can withdraw at any time without giving reasons, and without his/her involvement at the support group being affected. ☐
3. I understand that no medical information will be required in this research and no medical notes will be accessed. ☐
4. I understand that the information from the interview(s) will be stored until the PhD programme is completed and will then be irrevocably destroyed. ☐
5. I agree that Rachel Fearnley can talk to .... (Name of child) about the research and seek their consent and understand that his/her decision will be respected. ☐
6. I agree that .... (Name of child) can take part in the study. ☐

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Name of parent	Date	Signature
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Name of person taking consent	Date	Signature

When competed, 1 for parent; 1 for researcher; 1 (original) to be kept at the hospice.

REC reference number: 07/H1310/23

CONSENT FORM *(Professionals)*

Research looking at the support needs of children when a parent or carer is at the end of life

Researcher: Rachel Fearnley

Please initial box

1. I have read the information letter from Rachel Fearnley and agree to be involved in the semi-structured interview(s) for the research. ☐
2. I understand that the information shared in this interview will be used in the research study. I also understand that all personal information will be anonymised and confidentiality will be assured, unless there are concerns for a child's safety. ☐
3. I understand that the data from the interview(s) will be stored until the PhD programme is completed and will then be irrevocably destroyed. ☐
4. I understand that no medical information will be required in this research and no medical notes will be accessed. ☐
5. I agree to the interviews being tape recorded. ☐
6. I agree to take part in the above study. ☐

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Name of professional	Signature	Organisation

Date

When competed, 1 for professional; 1 for researcher.

APPENDIX 4 – Amended Information Letters and Consent Forms

Information Letter (Children)

Hello, my name is Rachel, I like to find out what children think about things that are important to them, this is sometimes called doing research.

One of the big questions I would like to know more about is how people helped you when your Mum or Dad (type accordingly) was poorly.

I would like to talk to you about when your Mum / Dad (type accordingly) was poorly, but before you say that it is okay for me to talk to you, it is important that you know why the research is being done and what will happen when I see you.

When we meet I will ask you some questions about how people helped you when your Mum / Dad (type accordingly) was poorly

After we have met, I will write about the things I have seen and heard. This will be used for some work I am doing at university. Even though I will be writing about the things I have seen and the stories I have heard, I will change everybody's names so that nobody knows who I am writing about.

Anything that you tell me will not be talked about to anyone else (unless I am worried that someone in the group is at risk of being hurt by another person or themselves).

It would be good if I could meet you and hear what happened when your Mum / Dad (type accordingly) was poorly, and learn more about the support and help people gave you. But I also guess that at the moment you are feeling lots of different things and might not want me to talk to you, that is okay, I understand.

Thank you for reading this letter.

Rachel

Information letter – Young People

Hello, my name is Rachel Fearnley and I am a student at Derby University. My research is looking at the support needs of children when their parent or carer is terminally ill. I am writing to you because I understand that your Mum/Dad (type accordingly) has died. I guess that this is a very difficult time for you and I really don't want to add to all the feelings.

I am writing to ask if I could talk to you about how people helped you when your Mum/Dad (type accordingly) was poorly. This is so that I can learn more about the support young people receive from professionals and the support they would like. I feel that it is really important that adults listen to young people and don't make assumptions about what they are feeling or thinking.

If you agree for me to meet with you, I will ask some questions about the support you received when your Mum/Dad (type accordingly) was poorly. When we have met, I will make some notes about what we have talked about, but I would also like to ask whether you would agree to me tape recording our meeting. This will help me to remember everything that we talk about. However, if you would prefer it if I didn't tape the meeting then I will not.

After we have met, the notes will be written up in more detail and be used as part of my research. Whenever possible, I will share these notes with you to check for accuracy and to make sure I have got it right.

Anything that we talk about will be treated in confidence (unless I am concerned that someone is at risk of being hurt by another person or themselves). When I am making my notes and writing up the research in detail, I will change your name so that no one will be able to identify who I am writing about.

I would appreciate it if you would think about agreeing to meet me. However, as I said above I understand that at the moment there is a lot happening and that you may be feeling lots of different emotions so if you decide not to be involved I will understand and respect your wishes.

Thank you for reading this letter.

Rachel

Information letter - parents

Research looking at the support needs of children when a parent or carer is at the end of life

My name is Rachel Fearnley and I am a PhD student at the University of Derby, under the supervision of Dr. G. Riches and Dr. K. Aune. My research is exploring the support needs of children and young people when their parent or carer is at the end of life or has died.

I am writing to ask whether it would be possible to meet with you to talk about your experiences when your partner was ill. The meeting will be approximately one hour in length. I would like to request that it is tape recorded to reduce the necessity for note taking when we meet and for greater accuracy. However, I appreciate that it can feel uncomfortable and can inhibit conversation and I will respect your wishes if you prefer it not to be tape recorded. All data will be destroyed once the PhD has been awarded.

The findings from the research will contribute to my PhD and it is intended that it will also inform practice and policies. Information from interviews may also be used in research papers and at conferences or during training events. I will be happy to share the information with you both during the writing up period and once the thesis has been completed.

The participant's anonymity and confidentiality are assured and names and locations will be altered to protect the identity of everyone who is involved. No personal information will be stored. However, if I am told something that would indicate that a child is at risk of harm, I will then follow the necessary procedures.

If you agree to take part in the research but then feel that you would like to withdraw your consent, all information will be immediately destroyed.

I understand that this is an intrusive request and respect your wishes if you do not want to be involved.

I am a qualified social worker and do not have a medical background. The research I am undertaking relates to social and emotional support and is non medical.

Thank you for reading this information sheet.

Many thanks

Rachel Fearnley

Information letter – parents: requesting their children's involvement

Research looking at the support needs of children when a parent or carer is at the end of life

My name is Rachel Fearnley and I am a PhD student at the University of Derby, under the supervision of Dr. G. Riches and Dr. K. Aune. My research is exploring the support needs of children and young people when their parent or carer is at the end of life or has died. I am particularly keen to meet with children who have experienced the death of a parent as I feel that it is important that their opinions and views are listened to.

I am writing to ask whether it would be possible to meet xxxxx (name of child) as part of my research. The meeting will be approximately one hour in length. If you agree to me meeting xxxxx (name of child) I will explain to them why I have requested the meeting and try to ensure that they fully understand why I am making the request and that they have a choice about being involved. If you agree to them being involved we will arrange a convenient venue, if you or child requests that you remain with them during the meeting this will be respected.

The findings from the research will contribute to my PhD and it is intended that it will also inform practice and policies. Information from interviews may also be used in research papers and at conferences or during training events. I will be happy to share the information with you both during the writing up period and once the thesis has been completed.

The participant's anonymity and confidentiality are assured and names and locations will be altered to protect the identity of everyone who is involved. No personal information will be stored. However, if I am told something that would indicate that a child is at risk of harm, I will then follow the necessary procedures.

If you agree for xxxxx (name of child) to take part in the research but then feel that you would like to withdraw your consent, all information will be immediately destroyed.

I understand that this is an intrusive request and respect your wishes if you do not want xxxxx (name of child) to be involved.

I am a qualified social worker and do not have a medical background. The research I am undertaking relates to social and emotional support and is non medical.

Thank you for reading this information sheet.

Many thanks

Rachel Fearnley

Information letter – professionals

Support for children when a parent or carer is at the end of life

My name is Rachel Fearnley and I am a PhD student at the University of Derby, under the supervision of Dr. G. Riches and Dr. K. Aune. My research aims to explore the support needs of children and young people when one of their parents or carers is at the end of life.

I would like to meet with the professionals involved in palliative care or who work with children, I am therefore writing to you to ask if I could meet with you to undertake a semi-structured interview, the duration of which will be no more that one hour. The purpose of the meeting is for me to discuss with you your own experiences of the support given to children when their parent or carer is at the end of life.

The findings from the research will contribute to my PhD and it is intended that it will also be used to inform practice and policies.

Confidentiality and participants' anonymity will be assured and names and locations will be altered to protect the identity of everyone who is involved. No personal information will be stored, and all paper notes and tape recordings will be stored securely. All computer based material will be double pass-word protected. This research is subject to legislation regarding Safeguarding and hence I have to note that, if I am told something that would indicate that a child is at risk of harm I am bound to follow the necessary procedures.

I would like to request that our meeting is tape recorded to reduce the necessity to make notes during the interview and for greater accuracy. However, I appreciate that it can feel uncomfortable and can inhibit conversation and I will respect your wishes if you prefer it not to be tape recorded. All data will be destroyed once the PhD has been awarded.

I am a qualified children's and families social worker and do not have a medical background. The research I am undertaking relates to social and emotional support and is non medical.

Thank you for reading this letter.

With many thanks

Rachel Fearnley
Post Graduate Researcher
The University of Derby.

REC reference number: 07/H1310/23

Consent Form

Name of Researcher: Rachel Fearnley

1. I have read the letter from Rachel about her coming to talk to me. ☐

2. I know why Rachel is coming to see me. ☐

3. I know that I don't have to join in with Rachel. ☐

4. It is okay for Rachel to come and talk to me. ☐

5. Rachel can write about the things we talk about . ☐

6. I know that Rachel will change everybody's name so that nobody will know who she is writing about. ☐

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My name	Date	Signature

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Name of person taking consent	Date	Signature

When competed, 1 for child; 1 for researcher.

REC reference number: 07/H1310/23

CONSENT FORM *(Young people and parents)*

Research exploring the needs of children and young people when a parent is at the end of life

Researcher: Rachel Fearnley

Please initial box

1. I confirm that I have read and understood the information sheet about the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I can withdraw at any time without giving reasons. ☐
3. I understand that all personal information will be altered and that anonymity is assured, unless there are concerns for a child's safety. ☐
4. I understand that the information from the research will be stored until the PhD programme is completed and will then be irrevocably destroyed. ☐
5. I confirm that I give permission for the information to be used for the PhD and any subsequent publications. ☐
6. I agree to take part in the above study. ☐

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Name of participant	Date	Signature
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Name of person taking consent	Date	Signature

When competed, 1 for participant, 1 for researcher.

REC reference number: 07/H1310/23

CONSENT FORM *(Professionals)*

Research looking at the support needs of children when a parent or carer is at the end of life

Researcher: Rachel Fearnley

Please initial box

1. I have read the information letter from Rachel Fearnley and agree to be involved in the semi-structured interview(s) for the research. ☐
2. I understand that the information shared in this interview will be used in the research study. I also understand that all personal information will be anonymised and confidentiality will be assured, unless there are concerns for a child's safety. ☐
3. I understand that the data from the interview(s) will be stored until the PhD programme is completed and will then be irrevocably destroyed. ☐
4. I understand that no medical information will be required in this research and no medical notes will be accessed. ☐
5. I agree to the interviews being tape recorded. ☐
6. I agree to take part in the above study. ☐

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Name of professional	Signature	Organisation

Date

When competed, 1 for professional; 1 for researcher.