An exploration of the impact of early parental death on adult life: a narrative study

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Abstract

The death of a parent is one of the most significant and stressful events children can encounter. There is limited research exploring the impact of early parental death in childhood as it is experienced over time, particularly from the UK. This research study employed qualitative methodologies and narrative analysis to explore the experiences of those that had experienced the death of a parent(s) in childhood (before the age of eighteen), to better understand how they perceived its impact on adult life.

33 individuals (7 men and 26 women) were recruited to the study and provided their narratives (5 written and 28 oral). In analysing the data it was clear that, whilst individual experiences of bereavement in childhood were unique, five common themes were identified across the narratives which impacted on bereavement experience over time: disruption and continuity; recognition of loss; family dynamics: roles responsibility and context; the public world of bereavement, and identity: aspects of personal growth. These themes were expressed in relation to fifteen sub themes which illustrate the complex nature of the bereavement experience over time. Key dynamics are also identified which appear to be of particular importance. In contrast to most studies of childhood loss which operates exclusively from an impairment focus stance this study documents the long-term personal growth that may result from the experience of parental death in childhood.

Two models of bereavement support anchored in the experience of the collective data are presented. The first model suggests key elements that may help both individuals and their families achieve more favourable outcomes following parental death(s). The second model may help practitioners and other providing bereavement support to identify those children who may be more vulnerable to less favourable outcomes in adulthood.

Declaration

This thesis is the result of my own work. The material contained this thesis has not been presented nor is currently being presented, either wholly or in part for any other degree qualification. I was solely responsible for all data collection and analysis.

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Chapter 1: Introduction

1.1 Rationale

The study of bereavement in adults has provided a rich context for research and practice. Studies of the grieving process have contributed to our understanding of the identification of psychological risk factors (Stroebe et al., 1993). However, the research on childhood bereavement lags behind (Thompson & Payne, 2000). Bereavement (that is the loss of a loved one through death) is a universal human experience (Centre for the Advancement of Health, 2003). The death of a parent is one of the most significant and stressful events children can encounter (Auman, 2007), one that could have a serious impact on adulthood.

The death of a parent is not something that a dependent child expects to experience in the western world, although clinical services indicate that it is not uncommon. It is estimated that approximately 53 children and young people under 18 are bereaved of a mother or father every day in the UK, equating to around 20,000 bereaved children and young people each year (Winston's Wish, n.d.). However, as Thompson and Payne (2000) point out the data from these services may well reflect only the proportion of children exhibiting some problem with their grief and therefore will not indicate the size of the group nationally. The chances of a father dying are greater that a mother; 80 per cent of childhood parental death in one study were paternal (Ward, 1994). Unfortunately, the UK does not collate information relating to parental death but approximately between 5 and 15 percent of children in the United States (US) lose one or both parents by the age of 15 (Harris, 1991). More recent statistics state that 6.1 percent of adolescents between the ages of 13-17 have experienced the death of a parent [73.9 percent death of a father; 25 percent death of a mother: 1.1 percent has experienced the death of both parents] (Ayers, Kennedy, Sandler, & Stokes, 2003).

The likelihood of children experiencing bereavement will vary by locality and social circumstances, since life expectancy varies significantly by social class, geography and locality (Mitchell, Dorling, & Shaw, 2000; Shaw, 1999). In view of these findings it could be expected that the death of a parent would vary accordingly. Variations in mortality rate according to ethnic group however are not so well established in the UK (Ribbens McCarthy, 2007). But Nazroo (2001) argues that an analysis of variations in mortality and heath between ethnic groups requires careful attention to issues of social-economic class, as well as racial identity and experiences of racism.

1.1.1. Bereavement support services

Overall it is clear that a significant number of children experience death of a parent before the age of 18, particularly from some localities and social groups. This has major implications for the organisation and delivery of mainstream and specialist support services, including and voluntary service provision. Over recent years there has been an enormous proliferation of children's bereavement services and support and counselling is now routinely offered to children whose parents die.

However these services have typically been formulated locally, involving only informal assessments of bereavement support needs. Winston's Wish, a charity providing bereavement support for children states that the needs of bereaved children have largely been missed by governments, policy makers and statutory authorities. As a result, charities, hospices and volunteers have often been left to 'pick up the pieces' (Rolls & Payne, 2004).

Bereavement support, as a formal service, is a developing provision across the health service. This may be partly explained by the UK policy shift in relation to children, as illustrated through the Children's Act (HMS, 1989) the UK government ratification of the convention on the Rights of the Child (1989) in 1991, and the framework of Every Child Matters (DfES, 2004).

At the heart of the development of these services are implicit assumptions about the development of the child; that bereavement has an impact on them and that supporting children and young people following bereavement will have a favourable influence on their present and/or future life. According to Rolls (2004), these assumptions provide the basis for the development of childhood bereavement services; the models and practices on which service provision is based and for what is considered best for helping children and young people.

The origins of bereavement support are associated with the Alder Hey Report (Department of Health, 2001). The structure and process of these services are outlined in recent recommendations for the development of bereavement care pathways (Department of Health, 2005). The purpose of these pathways is to increase access to services for bereaved people, and to establish a partnership between the NHS and the voluntary sector by linking hospital and community-based services. The pathway work is in progress as a joint project between CRUSE and the Bereavement Services Association (BSA) funded by the Department of Health (DoH) (through the Adult Mental Health funding stream (Bereavement Pathways Project, 2007). Despite this funding source the consultation document acknowledges that the pathways project takes account of the needs of bereaved children and young people. Therefore, it is timely that this research has been conducted so that its findings can be used feed into the development of these pathways.

1.1.2. Research into childhood bereavement

The dominant theoretical frameworks underpinning bereavement and children and young people are based in psychological theories of child development on the one hand and so called "normal" grief process on the other. Indeed the concept of bereavement itself, as Ribbens McCarthy (2007) points out, is strongly rooted within the psychological and medical perspectives. One pervasive theme of the literature thus concerns children's and young people's cognitive and intellectual understanding of death. Another concerns the implications of significant (most generally parental) bereavement on mental health issues, particularly depression, and other aspects of individual social and psychological welling being (Ribbens McCarthy, 2006).

These studies are predominately quantitative in orientation; framed within a positivist paradigm which is typical in grief research that is "often atheoretical, objectivistic, superficial, and decontextualized" (Neimeyer & Hogan, 2001, p. 108) "dismisses the subjective experiences of people and minimizes the importance of relationships in the human experience" (Silverman & Klass, 1996). However, there are potential benefits to quantitative research and it is important that these are acknowledged. These benefits are summarised by Niemeyer and Hogan (2001). These authors maintain that the scales that are often used have several legitimate uses including; fine-grained measurement of grief responses in different groups of bereaved persons; diagnoses of populations potentially "at risk" for developing complicated courses of grieving and tracking of attenuation or intensification of grief symptoms over-time in response to treatment. Moreover, they assert that their ability to assess grief intensity as a continuous variable permits investigators to identify a broad range of covariates of post bereavement functioning (and outlined in the literature review), such as the closeness of attachment to the deceased, pre-existing mental health risk factors in the bereaved person.

1.2. Developing a research question

Numerous qualitative research methods exist that have demonstrated relevance to the study of bereavement per se of which expand considerably the characteristic focus of quantitative measures on an individual's grief symptomology (Neimeyer & Hogan, 2001). Perhaps related to the reliance on quantitative methods is the dearth of research on the experience of grief from the perspectives of the bereaved themselves. There is little that prioritises the “voice” of those that have experienced the loss of a parent in childhood from their perspective as it is experienced over time, especially in the UK.

1.3. Aim and key research questions

The principle aims of this study therefore was to explore the individual experiences of those who had experienced the death of a parent(s) before and age of eighteen and investigate how such experiences were perceived to impact on adult life.

The knowledge generated will be used to inform bereavement services so that they can be better tailored to meet client’s needs.

Three objectives were pursued to achieve the aims of the study:

1. To reveal the meanings and processes that characterises individual’s stories of bereavement
2. To identify the bereavement support needs of children who have lost a parent before they were 18.

3. To make recommendations for good practice regarding the support needs of children who parent(s) die and their families so that these experiences can be seen in context.

Four research questions underpin the study:

1. What is the lived experience of bereavement regarding early parental loss?
2. How does this experience impact on adult life/sense of self?
3. What are the social and cultural dynamics that influence the bereavement experience?
4. How can the knowledge gained from this study be used to inform policy and practice regarding bereavement support?

1.4. Outline of thesis

Chapter Two: This chapter explores the literature with regards to the above aims in order to a provide the rationale for this study

Chapter Three and Four: These chapters describe and justify the methodology and the methods underpinning this study. The chapters also highlight important ethical considerations and the issue of validity in relation to this research. This chapter concludes by outlining how the findings will be presented in the subsequent chapters.

Chapter Five to Nine: In these chapters the key findings from the study are presented. These were organised around five common themes which were identified across the narratives and were seen to impact on the bereavement experience over time: disruption and continuity; recognition of loss; family dynamics: roles responsibility and context; the public world of bereavement, and identity: aspects of personal growth. These themes were expressed in relation to fifteen sub themes which illustrate the complex nature of the bereavement experience over time.

Chapter Ten: This chapter presents two models of bereavement support anchored in the experience of the collective data. This first model presented suggests key elements that may help both individuals and their families achieve more favourable outcomes following parental death(s). The second model may help practitioners and other providing bereavement support to identify those children who may be more vulnerable to less favourable outcomes in adulthood.

Chapter Eleven: In this chapter a summary of the findings is presented. The strengths of the study are then discussed in terms of what they add to the research literature with regards bereavement research as are the limitations of the study. The findings are then discussed in relation to models, theories and other published work in regards to early parental loss and its impact on adulthood in a critical and comparative manner. The chapter concludes by discussing the implications of the results with regards to future research and practice regarding bereavement support.

Chapter 2: Literature review

In reviewing the existing evidence it was apparent that the dominant theoretical frameworks underpinning research on bereavement in children are based in psychological theories of childhood development on the one hand and of 'normal' grief process on the other. Much of the early evidence on the effect of early parental death is premised on the traditional theories of grief.

In this chapter both traditional and contemporary theories of grief are reviewed. Within this section both stage and task based model of grief are compared and contrasted. A more contemporary model of mourning is then presented. Next, the major findings on the effects of early parental loss are reviewed. The following section examines mourning in the context of childhood and adolescent development. Next, a brief review of adult development was explored. Additional factors that influence the child's adaptation to loss are then discussed. A summary of the literature review completes the chapter. Firstly, however the search strategy used for the literature review is outlined.

2.1. The search strategy

A literature search was conducted, between October 2006 and October 2007 (and was repeated again in 2009) through CINAHL, Pyschinfo, Medline, Scopus and Sociofile using a combination of the following key words and terms "early parental death", "bereavement in childhood", "parental loss", "impact of early parental death in adult life/adulthood", "effects of early parental loss/death" and "stories/narratives of loss". In addition, related documents and reports were identified and obtained via the Department of Health (DoH) website and the internet using the search engine Google. A 'snowballing' approach to the collection of other source material was also undertaken through a series of contacts with universities, colleges and libraries and from the reference list of key articles and books. References were also obtained from colleagues working in the area and during conference attendance. More than two hundred and twelve articles and reports were accumulated. These were then classified according to the following criteria:

- Origin of research
- Year of study
- Authors
- Theoretical frameworks
- Study design

- Data collection methods
- Participants
- Main findings /conclusions

2.2. Traditional theories of mourning

Freud (1917/1957) developed the psychoanalytic theory of mourning based on his extensive research in this area. Until the 1960s his theory has dominated clinical understanding, in the US and the UK, of how children perceive and respond to the death of a parent (Saler & Skolnick, 1992). Freud explored the psychological process of mourning with individuals who lost a parent through death. He normalised the process of grief and mourning by identifying health responses to loss. He also recognised the challenging work of mourning and noted that, although grief reactions during this work were intense in nature, they should not be considered abnormal.

Freud (1917) presented his theory of mourning in a paper entitled “Mourning and Melancholia” in which he differentiated between healthy and unhealthy mourning. Freud’s theory primarily focussed on the individual process of mourning. He proposed that individuals develop attachment or love to significant others who are involved in satisfying their needs: the more important the person, the greater the attachment. Love is defined as the cathexis of libidinal (psychic) energy to the love object (the person). When the loved object is lost through death, the survivor's libidinal energy remains connected to the deceased through thoughts and memories. Freud argued that detaching or severing energy from the lost object is necessary. This process which Freud refers to called hyper-cathexis is achieved by reviewing all of the person's memories of the deceased. Whilst Freud acknowledged that the process of letting go of the lost object is painful he sees detachment as critical in order to free the ego so that it can invest in new relationships. Thus, psychoanalytic theory proposed that if hyper-cathexis did not occur, melancholia (i.e. lowered self-esteem caused by the unresolved ambivalence in the relationship with the deceased) or unhealthy mourning would result. Freud's theory referred to the adult experience, but succeeding generations of Freudian practitioners inferred that children and adolescents would be vulnerable to melancholia when a parent died because of their dependence on the parent and their developmental capacity for decathexis or 'grief work' (i.e. withdrawing psychic energy- usually libido- away from where it had been attached to a person or object).

Freud's understanding of loss and grief may be challenged because he worked from a psychiatric perspective and most of his theories were based on clinical experiences with depressed people and not on data from normal populations (Payne et al., 1999). Nevertheless, as these authors point out, Freud's concept of grief work and the need to confront grief in order to gain detachment has had a powerful influence on both subsequent theory and clinical practice both in the US and the UK.

Pollock (1961) extended Freud's theory of mourning. Pollock suggested that the main purpose of mourning is to facilitate the work of coming to terms with life without the deceased parent. According to Pollock, the process of mourning occurs in stages. The first stage is shock, which is followed by a period in which the work of mourning takes place. The final stage included a separation reaction in which the presentation of the love object is restructured from present reality to that of memory.

Bowlby (1980) originated the theory of attachment. This theory proposed that people instinctively establish bonds with others throughout life. According to attachment theory the purpose of attachment behaviour is maintain proximity to these attachment figures. Bowlby extended his theory of attachment and moved away from Freud's intrapsychic (or individual) model of grief. Instead Bowlby began to focus more on the bereaved in a psychosocial context, citing the work of the biologist Charles Darwin (1872) which explored the relationship between muscle reflexes and expressions of grief, fear and anxiety. Hence he recognised the physiological nature of loss and separation.

Bowlby examined grief and mourning in light of attachment bonds (1960; 1961; 1963; 1977; 1980). He studied infants after losing their first love object and found that their response began with (a) a protest and searching, then moved on to (b) disorganisation, despair and finally resulted in (c) reorganisation, which involved transferring previous attachments with the deceased and reinvesting in new relationships. Bowlby theory claimed that such responses to loss were universal, innate survival responses.

The protest behaviours and searching in mourning were identified as instinctive responses to separation, and natural attempts to retrieve or maintain proximity to the lost object/person (Corr & McNeil, 1983). Bowlby also drew on the work of sociologist Shand (1920) that argued that the powerful longing to recover the lost person was a biological response to loss. Shand proposed that the origin of crying comes from a primitive, instinctive response of the young to call back their caregiver. Searching behaviour, in the form of denial or clinging to the image of the lost person, was also identified as a natural reaction to loss. Such responses were considered a normal part of the grieving process, which reflected a longing to bring back the lost loved one.

Bowlby (1977) also proposed that a person's reaction to major loss would be either normal or pathological depending on the type of early attachment style established between the parent and child. Bowlby classified attachments in terms of a secure or three insecure attachments styles which include: anxious, avoidant and compulsive care giving. From his observational research on children Bowlby found that those who experience parental rejection, threats by a parent to leave or commit suicide, or discontinuity in parenting were more vulnerable to develop insecure attachment styles in adulthood.

2.3. Stage compared to task based models of grief

The traditional theories of grief were based on a stage model for understanding and defining the process of grief. This stage model is a linear progression in which the bereaved person moves through specific stages or phases of grief in order to reach the goal or stage of resolution. The first stage of grief involved denial, shock and feelings of numbness. The second stage includes acute symptoms of grief such as intense emotional pain, social withdrawal, physical symptoms and identification with the deceased. The final stage of grief included a return to normal functioning and reintegration (entailing a letting go of the loved one). Success or resolution was determined by the extent to which the bereaved was able to give up his or her original attachment with the lost love one (Wilcox-Rittgers, 1997). Many of the stage theorists such as Parkes (1986) proposed fluidity in this linear model whereby the bereaved may move back and forth between the stages of grieving before moving on to resolution. Kuber-Ross' (1969) stage model of the grief of terminally ill people is often applied to other loss situations such as bereavement.

The stage model of grief is a linear progression in which the bereaved moved through specific phases or stages of grief in order to reach the goal or state of resolution. In this model the bereaved is perceived as being relatively passive in terms grieving (Holland, 2001). This theoretical perspective has become an established basis for professional training and self help literature in the field of bereavement (Ribbens McCarthy, 2006).

The stage-based model is criticised for having limited empirical evidence to support the existence of such stages in the grieving process (Shuchter & Ziscook, 1993). The early studies that informed these models have been criticised, particularly for the dominance of young, white middle class widows (Payne et al., 1999). Stage models of loss are also criticised for not accounting for diversity and individuality of reactions and for neglecting resourcefulness (Holland, 2001; Ribbens McCarthy, 2005).

One alternative to stage models is the task model of grief whereby bereavement is seen as a series of tasks to work though rather that just being a series of stages through which the individual has to pass (Worden, 1982, 1991). Here the bereaved plays an active rather than a passive role in the grieving process.

Lindenmann (1944) developed the first task-based model of grief. He isolated three main tasks necessary for successful grief resolution. These tasks included: (1) severing ties with the deceased, (2) adjust to one's new environment without the decease loved one, (3) creating new bonds with others. Again, the task of breaking the emotional bonds was considered the ultimate goal of grief work.

Worden (1982) refined the phases of grief. He proposed that as grief is a process and not a state, people need to work through their reactions in order to make a complete adjustment. His model the 'task of mourning' has been extremely influential and is widely used by those that work with bereaved people. In relation to parentally bereaved children, grief is seen as a set of tasks in terms of normal responses that children need to negotiate (Worden, 1996). Worden discusses the tasks in as being:1) to accept the reality of death; 2) to deal with the emotional impact of the loss; 3) to adjust to the environment in which the deceased is absent; 4) and to emotionally relocate the deceased. In the context of the lives of young people, this approach has been further elaborated by reference to what are theorised as the developmental tasks of adolescence, the aim being to achieve a 'healthy' rather than a 'pathological' outcome; that is a medical model of grief (Ribbens McCarthy, 2006).

This linear approach to conceptualising grief, like the stage models, was also criticised for its failure to recognise individual differences, and other relevant factors which may trigger upsurges of grief throughout the bereaved life (Rando, 1988). Silverman (1987) preferred the idea of adaption to the loss over the notion of complete recovery.

Contemporary researchers widened their scope to examine other contributing factors that could influence the bereavement experience. From this broader perspective certain individual, gender, cultural and developmental differences emerged. Further research is needed to illuminate these differences and identify the particular needs of different grieving populations.

2.4. Contemporary theories of mourning

Fox (1988) identified the following tasks for children coping with grief or loss to work through:

1. Understand and make sense out of what has happened
2. Identify, validate and express strong reactions to the loss constructively
3. Commemorate the life that was lived
4. Learn to go on living and loving

Fox also identified other important factors which influence the process of bereavement in children such as their understanding of death; the type of loss and subsequent life circumstances. A potential problem with extending the adult model to children is that it assumes that their experiences of bereavement are similar (Holland, 2001).

Silverman (1986) offered a transitional model of adjustment in bereavement. This model proposed that "grief work" was necessary for healthy adjustment. However, her model emphasised accommodation and change rather that the goal of complete resolution.

Rando (1988), a researcher and clinical psychologist in the area of grief and loss pioneered the first process model of grief. Rando's theory is based primarily on her clinical research with women who have experience the loss of a child. Rando was one of the first researchers to challenge the privileging thought regarding emotional detachment from the bereaved (Rothaport & Becker, 2007). This process model is an alternative to both stage and task based approaches which focused on female bereavement.

Some basic tenants of Rando's process model of grief are defined as: (a) the goal of mourning is to adapt to the loss of the loved one while maintaining a connection through memory; (b) the grief process is not linear, but circular in nature with the final goal being accommodation of the loss, not resolution, and; (c) significant gender differences exist. This model of grief has three phrases: (1) avoidance, (2) confrontation and (3) accommodation. From this perspective it is argued that health accommodation is not defined by the absent or mourning as in the stage or task models of grief. Instead, this type of mourning does not interrupt healthy functioning. The mourner learns to adapt to the loss by moving forward and accepting the reality of death yet upsurges of grief or "STUG" reactions (defined by Rando as significant, temporary upsurges of grief) may still resurface. These reactions can occur long after the death of a loved one. Reminders of the loved one often trigger STUG reactions.

Early theorists often identified this phenomenon as part of complicated grief. Rando argued that STUG reactions are part of healthy mourning and provide opportunities to work through grief. A STUG reaction may cause a strong emotional reaction that may even briefly inhibit functioning. Rando disagreed with Freud's (1957) original perspective on successful mourning which required a complete relinquishment or withdrawal for the loved object/person. Rather, as long as the mourner adapts to the changes, not all connections to the deceased must be severed. In this way, Rando maintains that the mourner redefines a new type of connection with the lost loved one through memories and ritual.

Like stage and task models, these more contemporary models outlined above can also be criticised. Most fundamentally, such models may be accused of asserting an unfounded universalism as to the nature of grief and its associated emotionality and for failing to consider differences, whether these concern broad cultural differences or variations associated with structural differences such as age, status, gender, class or ethnicity (Ribbens McCarthy, 2006). Linked to the charge of universalism is the assertion that these models are closely associated with the medicalisation of grief (Seale, 1998). This may be constructed in psychiatric terms, in that the person may require active intervention to progress through to adjustment and acceptance (possibility in terms of 'successful bereavement'). Seale is a sociologist and he argued that grief, like death has been heavily medicalised in western discourses and practices, leading to it 'its depiction as a disease' (1998; 195). Seale (2001)asserted that this may be understood as a feature of 'the medical profession's tendency to view all human distress as explainable in medical terms and treatment by medical means, and the willingness of the laity to believe that this is so' (Seale, 2001: 46).

More recently some alternative models (though still generally very individualised) have been presented and have received a good deal of support, even though they have not been centralised in professional training. For example, the dual process model (Stroebe & Schut, 1995, 1999) is a more complex model which theorises grief over time as associated with a continuing oscillation between the loss orientation of grief and the restoration orientation to continuity of live. Such an approach is in line with recent discussion of the goal of '*coping'* with bereavement rather than finding a resolution (Corr, 2000). Thompson (2002, p. 7) argues that this dual process model 'alerts us to the complex web of psychological, cultural and socio-political factors which interact to make the loss experience far more complex than traditional approaches would have us believe'.

In summary, the theories or assumptions that underpin these the various grief models are in turn based on various theories of psychosocial processes, such as Feud's work on cathexis and mourning, Bowlby's work and attachment and loss and Parkes' work on psychosocial transitions. Whilst other models have been outlined in this section particular attention was focused on the stage and task models as they underpin professional training.

2.5. Relationship between early parental death and psychological outcomes in adult life

Early research on the long term of death of a parent in childhood often focused on pathology (Birtchnell, 1980; Bowlby, 1961; Brown, 1961; Furman, 1974). Many of these studies found a relationship between early parental loss and later depression. A number of studies found the incidence of parental death during childhood to be significantly higher in certain populations of depressed patients as compared to the general population (Caplan & Douglas, 1969; Forrest, Frazer, & Priest, 1965; Greer, 1964; Mireault & Bond, 1992; Wolfenstein, 1969). Early parental death was found to be more prevalent in severely depressed patients (rather that in all depressed patients) (Birtchnell, 1970). As would be expected with a clinical sample, researchers found bereaved children to be at very high risk of manifesting some type of psychopathology. The strongest evidence came from retrospective studies of adults with mental health problems (Birtchnell, 1972; Brown, Harris, & Copeland, 1977).

Birtchnell (1980) found a significant correlation between early maternal death and later clinical depression. His sample was drawn from both a psychiatric and non–psychiatric population who had lost their mothers at different ages. However, Wilcox-Rutgers (1997) challenged the validity of Birtchnell's results. The author argued that although this grief response looks similar to depression, it could be considered a normal part of adaptation to loss. The significance of these results was therefore criticised for pathologising a non-psychiatric population by failing to identify the range of "normal" grief responses.

Brown and Harris (1978) also studied the relationship the relationship between early maternal death and depression in women. Brown and Harris did not find early mother loss directly caused depression in adulthood but increased a women's vulnerability to depression in that if another major crisis or difficultly occurs later in the life of the bereaved, the chance of developing depression significantly increases.

In a review of the literature Black (1978) concluded that "bereaved children are more likely than children from intact homes to develop psychiatric disorders in childhood and in later life, although the differences are small (Black, 1978: 291). This putative association between parental loss, childhood disturbance and later psychiatric continues to receive support (Black, 1998).

However the validity of such a link has been challenged. First, other studies have not found significant associations between childhood parental death and adult psychopathology. In their review of the literature, Crook and Eliot (1980) concluded that there was no sound evidence for a relationship between early parental death and adult depression. Second, Crook and Eliot concluded that serious methodological inadequacies, including a reliance on hospital samples, inadequate control groups fallacies in deduction and a failure to control for independent or mediating variables, were likely to be associated with outcome. Such criticisms were supported by other researchers including Harris, Brown and Bifulco (1986), Tennant (1988), and Tennant, Bebbington and Hurry, (1980) along with inconsistent definitions of the dependent variable of depression

Childhood loss in relation to separation/desertion from a parent has also been cited in the literature as linked to depressive and anxiety disorders in adulthood. Nelson (1982), for example documented the emotional upset of both boys and girls following loss of father by either death or divorce, which persisted one to two years later for the children than their mothers. They were not able to ascertain from the cross-sectional data whether such reactions were transitory or potentially more long-standing problems.

A number of studies have compared the effects of parental separation versus parental death. They have found that prolonged separation is a more robust predictor of depression that parental death (Agid et al., 1999; Canetti et al., 2000; Kendler, Sheth, Gardner, & Prescott, 2002; Oakley Browne, Joyce, Wells, Bushness, & Hornblow, 1995). However, these studies may be criticised for oversimplifying the evidence (Ribbens McCarthy, 2006). In such studies parental death was discussed in simplified terms, because the focus of interest was about the implications of divorce/separation for children.

2.6. Risk factors and protective factors

Evidence has mounted that death in and of itself, does not necessarily increase risk of depression. There is evidence that the lack of adequate parental care following the death is a more stable predictor of later adult impairment that the simple fact that the parent has died (Harris, Brown, & Bifulco, 1986). It has also been suggested that certain characteristics of the parent-child relation might place a child at risk for later depression (Parker, 1983a, 1983b). Tennant (1988) for example, stated that poor parenting is a risk factor for depression regardless of loss. Bowlby (1977) theorised that parents need to provide their child with a secure base and be available and responsible to care for the child. At the same time, he maintains that parents must encourage the child to explore that base. He theorised that where a parent does not provide a secure base or allow for exploration the child would develop an "anxious attachment" style. He described this in terms of anxiety, insecurity, overdependence and immaturity, which under stress might lead to more severe symptoms, such as depression (Bowlby, 1977).

In his review of the literature and research Parker (1983b) maintained that factor-analytic studies demonstrated that parental behaviour and attitudes have two dimensions: care and protection. Having empathic, affectionate and warm parents who also allow a child to be independent and autonomous, he claims has been found to protect individuals against depression in adulthood. In contrast, having cold, indifferent and rejecting parents, who are overprotective and intrusive has been found to be related to the development of depression (Parker, 1983a; Parker, Tupling, & Brown, 1979). Blatt et al., (1979) for example, found that depressed patients remember their parents providing insufficient care or being overprotective. Parker (1979) explained the link between depression and overprotective parenting by suggesting that parental overprotection might inhibit social competence and thus hinder the development of self esteem. He proposed that an overprotective parent, who controls, infantilises and discourages independence foster in a child the belief that consequences are not related to a child's response which in turn he believes might lead to depression. Parker (1983a) also suggested that insufficient parental care may predispose an individual to depression by impairing the development of self-esteem.

The literature on children's immediate reactions and short-term adjustment to parental death also highlighted the important role of the surviving parent and the family environment in mediating the impact of early parental death (Biller & Berlinsky, 1982; Bowlby, 1980; Furman, 1974; Krupnick, 1984). In their review of the literature Siegel, Mesago and Christ (1990) concluded that a child's adjustment to loss is influenced by the extent to which the surviving parent can provide 1) physical and emotional support; 2) an environment in which the child feels able to express distressing or conflicting thoughts, feelings and fantasies about the loss and 3) stability and consistency in the child's environment.

Later studies identified a much broader range of risk and protective factors (sometimes referred to as mediating and moderating variables in the literature) as possibly contributing to children's adjustment to parental death. These included, bereaved child's age, gender, relationship to the deceased, mode/circumstances of death, adjustment of remaining caregiver, presence of siblings, participation in intervention and participation in rituals such as funeral (Cerel, Fristad, Weller, & Weller, 2000; Raveis, Siegel, & Karus, 1999; Rotheram-Borus, Stein, & Lin, 2001). None of these factors have been examined to any great extent and existing studies have produced conflicting results.

One particular factor about which researchers have drawn opposing conclusions involves the circumstances surrounding death. In the literature comparisons are usually made between anticipated death and sudden death. Researchers have compared the adjustment of children who a lost a parent to suicide to those that have lost a parent to terminal illness. Saldinger et al., (1999), for example, found that the longer anticipations of death were associated with worst post-death adjustment. The authors conclude that this may be because that anticipation of death or the stress of awaiting an impending death may be more difficult on a child emotionally and cognitively. The authors hypothesized that this may be because the anticipation of death or the stress of awaiting an impending death may be more difficult on a child emotionally.

Hope and Hodge (2006) found that most of the respondents (professional social workers working with bereaved children) in their study agreed that sudden deaths such as suicide, present a more difficult adjustment task for children (Cerel et al., 2000). However they noted that some respondents brought up an interesting point that has not previously been mentioned in the literature about how each death is unique and that categorizing a death as sudden or anticipated is not always as easy as it sounds. Hope and Hodge concluded that the findings from their study did not generate support for the research of Saldinger et al., (1999) in that anticipated deaths actually result in worst post-worse death adjustment in children. Indeed several participants in Hope and Hodge's (2006) study emphasised how in their experience, both sudden and traumatic deaths were equally traumatic for children.

Other studies that have compared the effects of different modes of parental death on children have concluded that children bereaved by suicide are actually more at risk for psychopathology. Cerel et al. (2000) looked more at the traumatic value of the mode of death rather than the anticipator factor. They concluded that children bereaved by suicide displayed more overall symptoms of psychopathology, behaviour problems and anxiety than did non-suicide bereaved children. The authors concluded that these differences were due to the more traumatic nature of a suicide death as opposed to a death from illness. However, the authors also found similarities between the adjustment of these two groups of children, leading them to believe that the circumstances of death may not make as much of an impact as some other factors. Pfeffer et al., (2000) found that children whose parents died for suicide, reported significantly more depressive symptoms involving negative mood, interpersonal problems, ineffectiveness and anhedonia (i.e. the inability to seek pleasure for pleasurable experiences) than those whose parents died of a terminal illness.

Research has also been varied with regards to whether males or females are vulnerable to distress or negative consequences following the death of a parent (Thompson et al., 1998). Raveis et. al. (1999) interviewed a group of children three to eighteen months following the death of a parent from cancer. The authors found that depressive symptomatology was significantly related to child gender, and anxiety symptomatology correlated to a child's age.

Worden (1996) raised the issue the impact of the child's gender would have on adjustment would very likely be somewhat dependant on the gender of the diseased parent. He did find some gender-related differences in relations to death that seemed to be independent of the deceased gender of the diseased parent. Girls, regardless of age, expressed more anxiety and somatic symptoms than boys over two years of bereavement. Boys were more likely to have poor conduct and learning difficulties during the first year.

Dowdney (2000) stated in an annotation that grief and disturbance appear to fluctuate over time with and between bereaved children, such that children reported depressed as not depressed at one time point can so at another time point. In the Children Bereavement study Worden (1996) found that while bereaved children showed a variety of behaviours many of these so called "disturbed behaviours" were short lived and drop out without any intervention. He maintains that the focus should not be on the presence of a symptom or behaviour but on its duration.

Of further concern is the possibility that some bereaved children, may appear to doing fine, but are actually "quietly disturbed" (Offer, Ostrov, Howard, & Atkinson, 1988) making others think they are functioning well when they are actually hiding their distress. A quote from a college student in a study by Balk and Vesta (1998) illustrates this point by saying that "she has spent most of her college career coping with loss and being sick and trying to hide it" (Balk & Vesta, 1998:17).

Dowdney (2000: 828) states that "inconsistencies in the literature relate to rates of disorder or disturbance rather that to the manner in which children manifest distress. Differential rates of disorder derive from variations in sample ascertainment, inclusion criteria and sample size". The highest rates of child disturbance are found in studies that included referred children or those from less stable backgrounds or under resourced family environments (Dowdney, 2000; Sanders, 1989; Worden, 1996).

Christ and Christ (2006) maintain that in adequate resourced stable family situations, those with clinical level symptoms extending beyond one year after the death of a parent are about 20%. For example, Lin reported that 40% of bereaved children had clinical symptom levels in a sample of children whose families were seeking bereavement services and who were subsequently entered into a parent-child skills training programme (Lin et al., 2004). By contrast the Harvard Bereavement Study reported on 19% of their publicly recruited sample of bereaved children had clinical symptom levels on the same measure at approximately the same time since the parent's death (Worden, 1996). These studies did not include longer term outcomes. Worden reported an elevation of symptoms two years after the parent's death, suggesting an elevation of symptoms. Worden found that the degree to which a surviving parent copes is the most important indicator of the child's long term adaption. Children whose surviving parents are unable to function effectively in the parenting role show more anxiety and depression, as well as sleep and health problems, than those whose parents have a strong support network and solid inner re-sources to rely on. Worden (1996) also found the children who were doing the best after two years, were those in families that coped actively with the loss rather than passively and managed to find something positive even in difficult situations.

This longitudinal study has been seen as particularly noteworthy for being more robust that most, involving 70 families (120 children) accessed through general community based services such as funeral parlours, selected prior to for counselling and interviewed at four months, one year and two years after the death of a parent. Control groups were also included. The research instruments involved a variety of psychological adjustment scores, but also some qualitative insights. However, as Ribbens McCarthy (2006) points out that this study is limited to one particular type of locality and replications are needed in others areas and other societies. The study reflected the large Roman Catholic population of the Boston area as 70% of participant's were Catholics. He also does not state the ethnic composition of this sample. Both these factors may affect the generalisability of the findings, especially in relation more diverse ethnic/religious communities. In addition, as previously stated this study did not include longer term outcomes.

Over the years a broad range of risk and protective factors have been indentified that continue to be explored, refined and utilised in developing interventions and service programmes. Christ and Christ (2006) have summarised these and they are presented below.

TABLE 1: Risk Factors Impeding and Protective Factors Promoting Reconstitution (Christ & Christ, 2006)

Risk Factors Impeding Reconstitution
Concurrent stressful life events
A negative or non-supportive relationship with the surviving caregiver
A poor relationship with the parent who died
Low self-esteem and an external locus of control
Pre-existing mental health problems in the adolescent or the surviving parent or caregiver
Circumstances of the death, such as violent or traumatic death
Protective Factors Promoting Reconstitution
Having a relationship with surviving parent or caregiver characterized by open communication, warmth, and positive experiences
Surviving parent able to sustain parenting competence
Feeling accepted by peers and other adults, such as relatives and teachers
Higher socioeconomic status
Internal locus of control, religiousness
Intellectual and social competence
The opportunity to express thoughts and feelings about the deceased parent and have them validated by others

Nevertheless, it should be noted the model provided is based on the idea of bereavement outcome as "reconstitution" defined as the extent of a return to pre-bereavement state.

Prospective and retrospective studies also confirm the critical role of the surviving parent or caregiver in helping children adapt to a parent's death. The quality of the relationship with the surviving parent and their competence in parenting bereaved children are the most consistently indentified mediating variables (Kwoh et al., 2005; Siegel, Karus, & Raveis, 1996; Tremblay & Israel, 1998). Caregiver attributes that are seen to contribute to a child's adaption include more active coping, less depression, more parental warmth and family cohesiveness (Kwoh et al., 2005; Lin, Sandler, Ayers, Wolchik, & Luecken, 2004).

Better psychological outcomes have also been associated with broader characteristics including openness of general communication with the surviving parent and the sharing of information about the parent dead (Raveis et al., 1999; Siegel, Raveis 1996). They found a higher level of open communication to be related to lower levels of depression and anxiety in bereaved children (Raveis et al., 1996). However, the absence of longitudinal studies makes it difficult to assess accurately the duration of disturbance beyond the first year (Dowdney, 2000).

The remarriage or re-partnering of the surviving parent after parental bereavement is also mentioned as an issue in some studies, but again the evidence is confusing. Worden (1996), for example, actually found that this seemed to reduce children's anxiety levels and concerns about the safety of the surviving parent.

2.7. The effect of parental death on parenting

Another long term effect indentified in the literature explored the impact of early mother loss on becoming a parent. Edelman (1995) surveyed 154 women, living in the US, who had lost their mothers during childhood by means of a postal questionnaire. Edelman suggested that women whose mother had died in childhood faced special challenges when becoming a parent. This suggestion was also supported by Harris (1995) who explored the stories of sixty-six adults who suffered the early parental death. This study was also based in the US. Harris explains that when a bereaved daughter losses her mother at an early age she also loses her primary role model and social guide. Harris noted that this was especially evident in girls who had lost their mother through death before the age of twelve. Harris found that new mothers were often stuck with intensified feelings of loss as they experienced the absence of their own mothers during this important time.

Another study by Altschul and Beiser (1984) found that parents who had previously lost their own parent during latency (defined as 6-12 years) had the most difficult adjusting to the role of parenthood, especially if it was a same sex dyad. The generalisability of this study is limited because the sample was drawn for a specific population already seeking psychoanalysis for parental conflicts.

Porterfield, Cain and Saldinger's (2003) qualitative study explored the ways in which an adult's childhood experiences with death subsequently influenced their parenting of their own bereaved children. Porterfield et al. (2003) found that the links between subject's reactions to their childhood losses did not follow a simple pattern. A mother who remembered being shut out of the family's mourning of her cousin's death made great efforts to involve her children in memorialising their fathers. A subject whose family encouraged children's contact with the body of the deceased similarly facilitated her children's comfortable engagement with their father's body. Another participant they found made conscious effects to do things differently than was done for them, whilst some found that they unwittingly recreated painful family dynamics that they intended, even vowed to avoid. Porterfield et al. concluded that for some parenting behaviour was strongly swayed by identifications, re-enactments and trauma-base avoidance. For others she found that the linkage between childhood experiences and their own bereavement parenting were more complex; decisions and actions shaped as much by generational shifts as by personal memories; active engagement with children around flexible decision-making. She also found the use of childhood experiences more generally were seen to enhance parental empathic awareness of their children's feeling and unspoken questions.

Another challenge for parents of early mother loss was the over-identification with the child (Edelman, 1994; Harris, 1995). The child often represented the parent's own young internal grieving self. As a result, these parents tended to overprotect their child (Harris, 1995).

According to Zall (1994) survivors of early parent loss were more prone to depression, suicide ideation and more frequent drug use during adolescence. However, Zall found no significant difference in adulthood or parenting functioning. From the results Zall concluded that parenting can either lead to parenting difficulties or serve as a catalyst for healing among parents who have survived early parental death.

Social class and material circumstances are significant issues in the pattern of outcomes associated with bereavement and parental death (Harrison & Harrington, 2001; Worden, 1996). Paternal death in particular may have implications for maternal well-being (Elliot, Richards, & Warwick, 1993), which vary with social class, and affluence appears to mitigate some of the outcomes of parental death (Ribbens McCarthy, 2006).

The ways in which race interrelates with class and material circumstances has not received attention within the literature (Ribbens McCarthy & Jessop, 2005). Minority ethnic groups may already have experienced significant losses of various kinds in their lives, through experiences of migration, disadvantage and racism, which may increase their vulnerability when dealing with the loss of bereavement (Desai & Bevan, 2002). This may be important in the context of other evidence showing that there may be increased risks in relation to bereavement outcomes if an individual has also experienced increased vulnerability for other reasons, or additional losses. Thompson et al. (1998) argued that minority youth may have developed a repertoire of coping skills to deal with traumatic events or may have a broader kin net work that serves to buffer the negative impact of parental death. In other words, certain minority groups may have specific protective factors present in their lives that serve to decrease or wipe any long-standing negative repercussions of parental death on the developing adolescent.

Gender, as previously highlighted, has been shown to make a difference to experiences of early parental death both in terms of the child connected and in terms of surviving parent (for example, Black 1978: Worden 1996). There have also been suggestions that it may be more disruptive to daily life if a mother rather than a father dies (Balk & Vesta, 1998; Tyson-Rawson, 1996; Worden, 1996). Worden (1996), for example, found that motherless children were more likely to experience changes in daily living routines and less likely to have their emotional needs meet.

Additionally, with regards to different individual, family and structural variables outlined in the literature, there may be complex interactions between the different factors. For instance as previously stated Worden (1996) found the children who were doing the best after two years, were those in families that coped actively with the loss rather than passively and managed to find something positive even in difficult situations. But other factors may have also come into play in accounting for such differences in parent functioning, since passive coping style was also associated with other difficulties experienced by the family, which relate to features of the social structure, such as class, ethnicity and material circumstances.

Such interwoven factors of individual differences, family relationships and features of the social structure and culture appear to have a considerable bearing on outcomes for bereaved children. As Ribben McCarthy and Jessop highlight (2005) these issues may mediate the 'risks' or likelihood of bereavement leading to particular 'effects', cautioning against any simplistic generalisations about a particular event or family type (for example, a widowed single parent) and specific outcomes. They may also account for the apparently opposite 'effects' between different individuals. The general failure of the studies outlined in this literature review to take account of these factors may help to explain of the multiplicity of contradictory findings in this area. Hence more research is needed to help understand the complex interplay between the different dynamics.

2.8. Positive aspects of childhood bereavement

The literature that has been described here operates from a pathologising or impairment-focused stance, focusing exclusively on negative outcomes of early loss and ignoring any potential competency-building that may accompany (Porterfield et al., 2003). Interestingly, some researchers have found what may be regarded as positive outcomes i.e. increased maturity, better coping skills and improved communication in those who had experienced bereavement. It was also found that the bereaved adolescents valued other people more than they did prior the loss (Martinson, Davies, & McClowry, 1987; Martinson, McClowry, Davies, & Kuhlenkamp, 1994; Oltjenbruns, 1991).

Balk (1995) in particular has paid this issue considerable attention, in relation to American adolescents bereaved of a sibling. He found that such young people either came close to, or had better, scores on psychological scales measuring positive self-concept compared with other adolescents. Such higher self- concept scores have been found to occur even seven or nine years after the death (Martinson et al., 1987). However, Balk (1995) found great variation around this issue, alongside reports of continual confusion, suicidal thoughts, fearfulness and eating difficulties among some individuals.

In contrast, Worden (1996) fond that parentally bereaved children believed that they were less able to affect change that their non-bereaved counterparts. By the second anniversary of the death, bereaved children reported significantly lower self-worth that the control group.

A qualitative grounded theory study was conducted by Tyson-Rawson (1996). Tyson-Lawson in discussing parentally bereaved adolescents, refers to ' the opportunity inherent in crisis [to] give rise to a stronger sense of self and the value of others'(1995:158) although her own work suggests that they may feel more vulnerable and less in control.

These findings are important as they broaden our understandings of bereavement. However, their findings are limited as they often negate the socio-economic and cultural circumstances of bereaved children's lives. Individual differences in a person's experience of death may be influenced by myriad factors, such as family, cultural background, experience and environment which are often related to socioeconomic status or race (Morin & Welsh, 1996).

2.9. Conclusions

The review of the literature began with a look at the foundation established by the early theorists on the subject of grief and mourning. Early models of grief were criticised for failing to indentify other important factors that strongly influence the bereavement process and for failing to account for diversity and difference.

Much of the literature reviewed in this chapter was concerned with indentifying a broad range of risk and protective factors that impact on bereavement experience. These included the child's age, gender both in terms of the child connected and in terms of the surviving parent, relationship with the deceased, adjustment of the remaining caregiver, presence of siblings. None of these factors have been examined to any great extent and many of the existing studies have often produced conflicting results.

The bulk of this research was essentially quantitative and predictive in nature in that it seeks to identify psychological distress in bereaved children or adults that have experienced parental death in childhood. The studies usually aim to clarify the causal links that led up to problematic reactions that are presumed to generalise across different cultures and settings.

This perspective is inherently positivist in nature in that it is premised on the belief that applying scientific methods to the study of the social world can reveal its basic truths (Giddens, 2001). Knowledge gained from this type of research is seen as objective and value free. Moreover, what is defined as 'normal grief' is based on Western values (white and middle class), is overly deterministic, cultural biased and often value laden.

Furthermore, the standardised measurement instruments used in the more quantitative studies may capture no more that surface responses. This important point is illustrated by a respondent in Balk and Vesta (1998) study that used standardised measurement tools supplemented in conjunction with an individual case study by Balk and Vesta (1998). As she wrote at one point when filling out IES (Impact of Events Scale) "most of these items are surface issues, I can portray how I feel but inside feel differently (p 36)." Another point noted by Balk and Vesta was that her IES scores indicated little if any avoidance or intrusion, but her journal entry for the same period was replete with vacillating moods, feeling alone and misunderstood and a constant battle with self– image and confidence. Hence Balk and Vesta found her non-directed open-ended comments to be more descriptive of her.

Balk and Vista asks the question should we trust qualitative data more that the quantitative? Silverman and Klass (1996) would have bereavement researchers consider most carefully the emerging qualitative focus that marks the study of grief. Balk and Vesta draw on Stake, a strong advocate of qualitative research, but also very much at home with statistical analysis, who has argued since the 1970s for a turn to the qualitative to gain rich understanding of complex human phenomenon (Stake, 1978, 1994, 1995).

Dowdney (2000) would tend to agree with Balk and Vista. She believes that the use of standardised questionnaires have their own advantage, such as ease and completion of (and hence increased respondent compliance) and the provision of data to compare with standardised norms for a given age groups. However, although they can provide a satisfactory screen for possible clinical disturbance, they cannot easily provide information that is specific to bereavement, such as anxiety concerning further loss, nightmares about the deceased or other expressions of grief or distress. Dowdney believes that this type of data is better gained from one-to-one interviews. Descriptive data can provide material rich in the detail of individual children's experiences, and as such provide rich insights of relevant to bereavement support. To go beyond this and make a theoretical or research contribution in this relatively uncharted area, data needs to be gathered and analyse with an appropriate qualitative framework. Such rigorous, theoretically driven qualitative research is lacking in this area. Dowdney (2000) suggests that the adoption of a rigorous qualitative methodology, appropriate to the specific question being studied, would provide an opportunity for much need theoretical and conceptual development upon which subsequent empirical studies could be built.

In terms of the qualitative evidence of the bereaved perspectives of the experiences of early parental death there were retrospective experiences and case studies and quotes used in the context of more structured psychological theoretical frameworks that drew upon established theories of bereavement and grief processes indentified. However, although the findings from these studies broaden our understanding of bereavement in childhood they were mostly focused on the short terms outcomes. There was very little identified that explored the impact of early parental death over the life course from the perspective of individual, especially in the UK. Hence a further gap is identified in the literature that needs to be addressed.

In view of the recent emphasis surrounding bereavement support it is crucial (and timely) that more research is carried out that recognises that individual grief is profoundly shaped by the context in which it occurs (Rosenblatt, 2002). Research methodologies also need to reflect that those who are bereaved of parents as children are the experts on their own mourning and thus can inform researchers about the impact of such a loss on adulthood and help them to understand the complexities involved (Ellis & Lloyd-Williams, 2008).

Chapter 3: Methodology

3.1. Mode of enquiry

After reviewing the evidence it is clear that much of the bereavement literature regarding the effects of early parental loss is essentially quantitative and reductionist in nature in that it seeks to establish psychological distress in bereaved children and adults. Besides trying to establish descriptive statistics (such as prevalence rates) such studies seek to establish some sort casual connection between the childhood disturbance (bereavement) and later symptomatology and psychopathology and is overwhelmingly medical or psychological in orientation. Much of this work is US based; hence its findings may not be generalisible to the UK populations. Whilst there were qualitative studies identified there was little that was framed by a narrative approach to the understanding of individual experiences which sought to explore how the informants themselves might construct the significance of bereavement experiences in the context of individual life stories. The principle aims of this study therefore were to explore through a narrative approach the individual experiences of those who had experienced the death of a parent(s) before and age of eighteen, and investigate how such experiences were perceived to impact on adult life.

A grounded theory methodology was considered for this study. Since its introduction by sociologist Glaser and Strauss (1969) grounded theory has became the most widely used qualitative method in Thanatology, with especially strong representation in nursing (Neimeyer & Hogan, 2001). The term "grounded theory" itself refers to the inductive method that is at the root of the approach, in which "processes and products" of research are shaped from the data rather than preconceived logically deduced theoretical frameworks" (Charmaz, 1983:110). The data may consist of any of several forms of "thick descriptions" of the phenomena of interest, including transcribed interviews, researcher field notes, dairies and documents which represent with as much fidelity as possible the experiences of the research participants. These materials are then coded on a line-by line basis or by "meaning units" often with the assistance of computerised systems that facilitate text and code management.

However, grounded theory was rejected on the grounds that this process, as Riessman (1993) argues, does not respect the participant's portrayal of their stories in the sense that it fractures the data thus limiting the researchers' understandings of the participant's perspective and portraying a participant's experiences in its fullness.

Context analysis was also considered for this study. According to Neimeyer and Hogan (2001) this is a hybrid method with qualitative and quantitative features. Unlike grounded theory analyses, in which researchers attempt to minimise their preconceptions regarding the phenomenon of interest those using content analysts often approach a text with a formal categorical system in mind and then code material (e.g. interviews) in light of those categories. In most instances, the fundamental data consists of the frequencies of occurrence of each code, rendering the results amenable to quantitative summary or comparison of other measures. The approach is suitable for those testing prior hypotheses or measuring the occurrence of specific concepts or categories (Miles & Huberman, 1994). It is not suitable for understanding the complex nature of human experience. Hence it was rejected.

This concern led to an examination of other styles of analysis that would allow the integrity of each participant's story to be maintained. For this reason a narrative approach was chosen for this study. It is based on the belief that individuals are the experts in their own mourning. Hence one of the major values of this approach is that it affords the opportunity to hear the participants in their own words, albeit it filtered through the choices made by the researcher (Gilbert, 2002). Telling stories "allows narrators to communicate what is significant in their lives, how things matter to them" (Rosalo, 1986:86).

‘Narrative is both a phenomenon and a method’ (Clandenin & Connelly, 1994:416). It brings diverse elements of experience, thought, and feeling together in a unified whole and is connected to a central theme or purpose (Polkinghorne, 1995). According to Bruner (1990) personal narratives (the narratives within which we our lives) are not merely of way of describing our lives but the means by which order is brought to the experiences and information encountered in daily life. This then provides structure to that which is experienced, creating order in disorder and establishing meaning in what may seem a meaningless situation and is done in “the context of interaction with a listener or imaginary audience” (Rosenthal, 1993:63). That is to say, meaning is made by creating and exploring stories in interaction with others.

The central process of bringing order has been termed ‘emplotment’ by Ricoeur (1984), to denote the organising of a sequence of events into a plot. The meaning attributed to emplotted events reflects expectations and understanding gained through participating in a specific social and moral world. Narratives serve to illustrate aspects of experience that might otherwise be unrecognised (Garro & Mattingly, 2000). However, the event has ended before the narrator constructs the narrative. Therefore in telling the story the narrator is aware of the ending and constructs the account from there.

Narratives are representational, that is, they cannot be seen as exact replica of an event being described (Sandelowski, 1991). As such, narratives are always representations of a lived experience and are subject to change and interpretation. Narratives are also evolutionary in that are "like a continually evolving sketch book of memories and life experiences" (Gilbert, 2002:225). Narratives change with each telling (Riessman, 1993). New information gained in a later telling will influence the understanding and deeper interpretation of the story elements. Stories are shaped by experience and part of that experience is the ongoing retelling and re-experiencing of the story. In this way a personal narrative become "an experience of the experience ...understanding is not embedded in the experience as much as it is achieved through an ongoing and continuous experience of the experience" (Ellis & Bochner, 1992:98). From this perspective language is understood as deeply constitutive of reality, not simply a technical device for establishing meaning (Riessman, 1993).

3.2. Theoretical approach to data collection

As a research strategy narrative approaches are very much rooted in qualitative methodologies, with an emphasis on the goal of exploring how people themselves understand their lives, and seek to find and develop a sense of meaningfulness from major biographical events (i.e. in the context of health issues more generally as illustrated by Kleinman (1988)).

In this respect the approach also resonates with spiritual or existential questions (Gilbert, 2002). Narrative research often seeks to elicit life course perspectives and storylines, so that bereavement may then be analysed in terms of, for example, biographical disruptions (Exley & Letherby, 2001) or critical moments within the overall narrative (Thompson et al., 2002).

Qualitative methods such as this are often criticised as 'soft' or anecdotal; lacking in objectivity and hence value-laden (Denzin and Lincoln, 2000). According to these authors this is primarily because most qualitative research explicitly questions the basic assumption of the positivist paradigm with regard to knowledge and its production. More legitimate evaluations acknowledge that different epistemological assumptions underpin the paradigms that govern qualitative research.

The epistemological stance underpinning narrative research emanates from Husserl's descriptive phenomenology which is concerned with the essence of phenomena 'unclouded by subjective opinion' (Yegdich, 1999). However, this study draws on new understandings of phenomenology which has come to mean the study of people's subjective experience (Crotty, 1996), which is based on the early work of Martin Heidegger and is interpretive and constructionist in orientation (Smith, 2003).

Since Heidegger was heavily influenced by Husserl, there are aspects of their philosophies that are shared. However, their philosophies deviated on several important points. Firstly, the origin of meaning: for Heidegger meaning is always in the context of something (i.e. one's humanity, one's culture, one's experience or the practices adopted by a particular group (Rescher, 1996:14), whereas for Husserl ones consciousness structures what is experienced (Howarth, 1998). Second: for Heidegger meaning arises not from consciousness, but from the essential finitude of being. In other words, Heideggerian philosophy sees all human being as existing within a context (past, present and future) which shapes the way that they give meaning to their experiences. Humans exist within a life-world which is how they experience being.

Grounded in this philosophical position the constructionist approach with its emphasis on the relativism of multiple social realities and interpretive understanding does not assume the existence of social reality that is dependent on human action, as in more objectivist standpoints. Rather it assumes that "people create and maintain meaningful worlds through dialectical processes of conferring meaning as their realities and acting within them" (Charmaz, 2000:521). Hence the primary aim of this research strategy is to study experience from the perspective of those that live it with the full and explicit acknowledgement that the final analysis represents only interpretation of reality as it was articulated during the data collection process and understood by the researcher. The justification for the analytical argument is that it is 'consistent with the data and theoretically sophisticated' (Yardey, 1997). It is the pluralities of experiences, which are related through their resemblances the experiences of others, that allows for a credible and reflexive accounting which link the person with the social and political.

Accordingly, a narrative approach was adopted for this study. As a mode of enquiry, it appears to be uniquely well-suited to exploring the underlying meaning and evolving and complex nature of experiences of early parental death, loss and grief, particularly with regards to its impact in adulthood (Ellis & Lloyd-Williams, 2008; Gilbert, 2002). In addition, this approach recognises the socially constructed nature of these experiences.

3.2.1. Ethical considerations

Appropriate ethical conduct is of central concern to researching the views of people that are affected by bereavement. Designing an appropriate methodological approach to the collection of data on this topic posed many ethical problems.

Gaining access to the private worlds of others for purposes that may not be primarily for their direct benefit poses a fundamental ethical tension at the heart of the research process (Guillemin & Gillam, 2004). It is important to give consideration to the role and relationship with between the researcher and the informant (Denzin & Lincoln, 2000; Mills, Bonner, & Francis, 2006). This consideration in not only important in terms of reflexivity it is also important with regards power relationships within interview settings.

In order to take this consideration into account the principles of a collaborative paradigm was adopted in which participants are viewed as active contributors to the research process (Reason, 1988). Though this does not alter the fact that they have not initiated the research process and may not want to participate any further than they have to, it does offer a model that is more empowering (Valentine, 2008).

The research design clearly had far reaching implications for the participants in that the investigation, of necessity, required that they recall events and feeling likely to generate distress. Dyregrov (2004) states that participants in such a study are so vulnerable that special consideration and sensitivity are required in the research design. She also claims that some researchers have advised against research on such populations. However, she goes on to say that there is growing evidence that bereavement research may have a positive effect on participants who have been ‘the focus of interest, concern and caring attention, which they experienced as being taken seriously’ (2004:392).

Indeed Valentine (2008), supported by the bereavement literature, suggests that far from being harmful, taking about bereavement can provide relief and reinforcement. The processes of ‘telling it like it is’ has been found to enable people to explore painful experiences whilst retaining a sense of control (Riches & Dawson, 1996b). The frustration and sense of exclusion that many bereaved people report as a result of being excluded has been well documented (Riches & Dawson, 1996a, 1996b, 2000; Walter, 1996, 2001). It has been argued that taking part in bereavement research can have a therapeutic function by acting as a cathartic mechanism, which may assist the healing process (Rowlings, 1999).

However, as Valentine (2008) states it is important not to generalise about this, but rather to allow for the individual variation that makes it impossible to predict in advance how someone will react. The ethical implications of intruding into the lives of bereaved people can be both positive and negative. Thus, she believes that the onus is on the researcher to give special consideration to the possible implications of such intimate and often painful disclosure for bereaved people.

Such consideration can be fostered through invited feedback from participants and being prepared to learn from this, as was the case in this study in the form of feedback questionnaire. However, the findings from this sub study are not presented in this thesis as they do not germane to the four principle questions being addressed in the thesis.

It can also be done by enabling potential respondents to consider their consent away from the interview. This consideration was recognised in this study (see methods chapter). Interview transcripts were also made available to the participants to enable them to reflect on the implications of their consent. Participants were advised that any part of the transcript they felt unsure about could be discussed and if necessary excluded from the study.

Informed consent is an essential ethical concern. In order to give free and informed consent to take part in the study all potential respondents need to be properly aware of the nature of the study and the extent and implications, of both risk and benefits, of their involvement as research participants. To achieve this comprehensive participant information leaflet was devised (see appendix 1) following the guidance outlined by the Central Office of Research Ethics Committees (2003). Hence, care was taken to ensure that the language was simple and that the document structure was clear and concise without compromising the quality of the information to be provided.

The consent form (appendix 2) was developed using the same guidance and principles as those used for the information sheet. The participants were required to initial a series of statement to indicate that they had a) read and understood the information sheet and been given the opportunity to ask questions, b) understood that they were free to withdraw from the study at any time and c) agreed to take part. The consent procedure then required the participants to endorse the form with their signature and the date of completion. Once completed, a copy was given to the participants for them to keep. Consent forms (two copies) were sent to those who had elected to write their narratives (or have telephone interview with the researcher) with a request to complete them and return one to the researcher in the prepaid envelope provided prior to taking part in the study. In compliance with the Data Protection Act (1998) the second copy was kept on file in the researcher's locked filing cabinet.

Confidentiality was key concern throughout this research project. By consenting to take part in the study participants took the risk that their identity could be discovered. Grinyer (2002), informed by her own research on bereavement, suggests that respondents should be given a choice as to whether a pseudonym or participants own name is used in research. This was acknowledged and respondents were given a choice in this regard. To reduce the risk of comprising anonymity the content of the narratives was kept confidential and the material used was anonymised (apart for the first name(s) of those who had elected to use them). In addition, the transcripts were stored in a locked cupboard and all recordings and electronic data was stored on computer that was password protected in accordance with the Data Protection Act (1998). The researcher was the only person to have direct access to these materials (although it should be noted that access was granted the researcher's supervisors prior to completion of the thesis on the understanding that the same level of confidentially would be maintained).

Participants were advised that the research would result in publications that might include sections of their transcripts. Other than the first name(s) of those that had elected to use them it was highlighted that all indentifies would be removed, unless it distorted the interpretation of the data. Hence it was made clear that absolute anonymity could be not be ensured. However, the diverse geographies of those involved in the study made it unlikely that individuals would be easily identified.

It was also recognised that repeatedly listening to and reading stories of bereavement stories can be emotional costly for the researcher and can lead to burnout (Gilbert, 2002). In order to minimise this risk the researcher was able to discuss, in confidence, issues and concerns that arose through debriefing sessions. These sessions took place as and when required as defined by the researcher and were provided by Clinical Psychology Advisor at the University.

3.4. Subjectivity and reflexivity

A key theoretical issue which arises when considering qualitative methods is subjectivity and how this affects objectivity. Subjectivity guides any research project, beginning with the selection of the topic, right through to choosing an appropriate methodology and analytical approach (Elliott, 2006). In qualitative methodologies in particular, researchers are encouraged to reflect on their values and experiences to consider how these interact with the research. As Valentine (2008) notes, a reflexive approach to research fosters recognition and appreciation of one's own as well as our participants' subjectivities.

Attention to reflexivity is a means by which researchers explicitly position themselves in relation to the meanings that are constructed through the research process. In an effort to foreground the constructed nature of the knowledge produced in this thesis, the following section highlights how reflexive processes have influenced how I have engaged in the research process. It is presented in the first person as I recognise that it is "is difficult to express your self-awareness and reflexiveness to others without employing some first-person narrative" (Myerhoff & Ruby, 1992:322).

In addition to the reflexive approach in regards to the ethical considerations outlined above, I have been reflexive in my justification for using a narrative approach in that it gives a voice to whose experiences would otherwise remain undocumented and unheard (Grinyer, 2006). Yet as Grinyer states there is an ever present danger of exploitation, of taking the lived and often painful experiences of vulnerable people and using them for the advancement of an academic career or for the benefit of others involved the research and publication process. I was mindful throughout of these issues and have tried to act with integrity and sensitivity towards those individuals whose stories are told in this study.

I have also tried to be self-aware and continuously to reflect on how social positioning and personal experiences were being brought to bear on the research process and my interpretations. As a wife whose husband lost his mother when he was seven and the daughter of parents who also lost their parent(s) during childhood I can empathise strongly with the participants in this study. I also lost my own father whilst conducting this research. Thus at many levels the research was emotionally demanding and I was frequently moved to tears by the narrative material. Nevertheless, I feel privileged to have been allowed access to these stories and thus was keen to ensure that the participants' voices were heard throughout the thesis. However, I am aware that the process of telling one's story in an interview setting contributes to an altered understanding of that story for the teller (Riches & Dawson 1996b). In effect participation in research influences the narrative of the research participant. The researcher then becomes a collaborator in the new and evolving story. Hence I recognise that that stories that were heard were co- constructed by the informant and myself.

I also acknowledge that I have come to this research project informed by my previous experiences and will 'see' only part of the picture. Hence I have tried to be aware how my own narrative limits me and of the implications of this in terms of my analytical interpretations as they may have been affected by my culture and personal experiences.

Critics of qualitative methods might argue that my personal experience or subjectivity might be a barrier to the experiences of 'others' as I seek to understand experiences of early parental loss through my own value system. Rather, as Carter (2002) suggests, I believe that reflexivity and subjective processes can serve to enhance our comprehension of the world, and further develop understandings of bereavement and loss and its impact on adulthood.

3.5. The issue of validity

There is an ongoing debate around how clinical and sociological research views the 'validity' and usefulness of narratives, which draws on long-running philosophical, social theory debates about what 'truth ' is in narrative text. As Riessman (1993: 21) noted, this is a "thorny problem in narrative research". But as Ricoeur (1984) argued in his extensive theorizing on the relationship between text and our perceptions of truth as expressed in stories, the narrative is transformative, an opportunity for reflection on events; connecting the surface history of the narrated events with personal reactions infused by cultural and individual meanings. He thus draws out the complexity of the narrative for both the narrator and the reader, noting that the reading of the narrative adds yet another dimension "the same story can be read in different ways because it is multi-layered (Ricoeur, 1993: 298). Riessman (1993) drawing on similar sociological debates on validity suggests that fundamentally "narratives are interpretive and in turn, require interpretation (Riessman, 1993: 22). Riessman argued, as stated previously, that " a personal narrative is not meant to be read as an exact record of what happened nor is it a mirror of the world 'out there' concluding that this is the case precisely because narratives are always located in discourses (e.g. scientific, feministic and therapeutic)" (Riesman 1993: 64).

In terms of validity of narrative and qualitative research Margarete Sandelowski and Julia Barroso (2007) argued that this kind of research does have validity, being based in the real world experience and as case-orientated data is generalisable from the perspective of that representative sample. They do insist that to maintain and develop valid and valued qualitative and narrative research, researchers must be alert to the basis of their knowledge construction and claims made as a result of interpretation of research "finding". Although the intricacies of the debate raised by Sandelowski and Barroso are not discussed here it is important to note these challenges and debates around the perceived value and evaluation of narrative research.

The point argued by narrative theorists is that the study of narrative is by default less about accessing factual account and more about understanding meanings that individuals create and live by. Narrative analysis is 'valid' only where the truth status of the accounts analysis is regarded as irrelevant (Bingley, Thomas, Brown, Reeve, & Payne, 2008). These authors stated that the accounts function as a sense-making for the narrator, regardless of whether they are 'true' depictions of some other reality not. Narratives have a complex and creative set of functions, which as Czarniaswka (2004) suggested are firmly based in our social lives. Stories are an extraordinarily rich medium, acting to interpret and make since of events, infused with multi-layered meanings, arising from and expressing personal, social and cultural experience. Narrative research conducted rigorously, offers a lens through which a more nuanced understanding of experiences, in this instance regarding early parental loss. The issue of ensuring rigour in narrative research is discussed in the subsequent chapter.

3.6. Summary

In this chapter the mode of inquiry and theoretical approach to data collection used in this study discussed. It has been outlined how the narrative approach chosen for this study will allow the integrity of each participant's story to be maintained as it is premised on the belief that individuals are experts in their own mourning. It has also been outlined how the narrative approach will enable participants to communicate what is significant in their lives and how social and cultural processes impact on the bereavement experience over time. As a mode of enquiry it is uniquely well suited to exploring the underlying meaning and complex nature of the experiences of early parental death, loss and grief, especially with regards to its perceived impact on adult life.

The ethical considerations of conducting a narrative study have also been discussed along with the issues of reflexivity and subjectivity and validity. In the following chapter the methods used to conduct and study and collect the data are described.

Chapter 4: Methods

4.1. The research population

In qualitative research the purpose is not to establish a random or representative sample drawn from a population but to identify specific groups that either characterise or live in circumstances relevant to the phenomenon being studied (Strang, 2000:912)

Purposeful sampling was adopted for this study whereby participants were selected in accordance with the needs of the study. The UK Children Act (HMS, 1989) defined a child as any person under the age of 18. For the purpose of this study early parental death was defined as that which occurred before the child was 18.

As the research was focused on the impact of early parental death in adult life the research population was restricted to those over 18 (primarily living in the North West of England) who had experienced parental death before the age of 18. However, those who expressed an interest outside this geographical area were not excluded from the study. In order to protect participants who may have been particularly vulnerable those that had lost a parent within the previous twelve months were excluded from the study.

According to be childhood bereavement literature social class and material circumstances, (Harrison & Harrington, 2001) affluence, (Ribbens McCarthy, 2006), and gender, both in terms of the child concerned and the surviving parent (Black, 1983; Douglas, 1970; Kiernan, 1992; Worden, Davies, & McCown, 1999) influence the outcome of early parental death. Whilst the ways race interrelates with class and material circumstances has not received much attention within the empirical literature (Amato, 2000) minority ethnic groups may have already experienced loss of various kinds in their lives, through experiences of migrations, disadvantage and racism, which may increase their vulnerability when dealing with loss of bereavement (Desai & Bevan, 2002). The mode of death is thought by some authors to influence bereavement outcome (see literature review).

4.2. Recruitment of participants

In consideration of the above influences and in order to capture the characteristics likely to influence the bereavement experience, a two stage recruitment strategy was adopted for this study. The aim was to identity potential participants, including male and females from a range of ethnic and social-economic backgrounds whose parents had died from various causes before they were 18.

The first stage of recruitment involved sending letters and emails (appendix 3) to a broad range of organisations including bereavement support groups, hospices, charities (e.g. Cruse, Compassionate friends, hospice information services and Age Concern), the Supportive and Palliative Research Experience Collaborative and HEIs inviting them to publicise the appeal for participants through their newsletters and notice boards.

In addition, posters (appendix 3) were displayed at a variety of locations within Liverpool University campus. Posters were also placed in a variety of locations such as libraries, shops, post offices, supermarkets, dentists, church halls, golf clubs and various places of employment within the region. Information leaflets (appendix 1) were distributed at relevant professional conferences and events.

During the first stage of recruitment all those that meet the inclusion criteria and agreed to take part were recruited (n=26). Whilst the age range of these respondents was broad (between 20 and 80) and they appeared to come from a diverse range of social and economic background, all respondents were British (white) and predominantly women.

With regards to the nature of the loss, although there were different experiences of parental loss in terms of sudden or expected deaths identified (refer to appendix 8) at this stage no respondents had come forward whose parents died by suicide (defined as taking their own life).

The second stage of recruitment consisted of an appeal for participants via a press release (appendix 4) which was distributed to regional newspapers and media by University Press Office. In order to broaden the characteristics of the sample to reflect those factors outlined previously as likely to influence the bereavement experience this stage of recruitment was targeted at specific groups, namely, men, those of different ethnic minority backgrounds and those whose parents had taken their own life. Ethnic minority support and community groups in the Liverpool area (n=122) (appendix 3) were also contacted by letter and email inviting them to publicise the appeal for participants through their newsletters and notice boards.

Those interested in taking part in the study then contacted the researcher for future information and were sent an information leaflet (appendix 1) which explained about the study and what was involved. This leaflet also explained about issues related to informed consent, confidentially and data protection. In addition the leaflet contained a photograph of the researcher (for familiarity) and contact details.

In accordance with the ethical concerns identified in the previous chapter participants were given as much time as they needed to decide if they wanted to be involved in the study and offered opportunities to discuss any issues. After reading information leaflet those still interested in taking part in the study contacted the researcher and appropriate arrangements were made for data collection. At this stage three potential respondents didn't contact the researcher so it was assumed that they did not wish to take part in the study.

There are of course limitations to such methods in which participants are self selected. As Grinyer (2006) points out there is a danger that contributors to such an appeal will over-represent a particular socio-economic background. However, it seems from both the form and content of the narratives (and background information) that the participants came from a wide range of backgrounds; both educational and social (refer to appendix 8).

4.3. Data collection methods

Three data collection method were used for this study. Participants could elect to use one of the following:

1) In-depth narrative interviews (face-to- face)
2) Written narratives
3) Telephone interviews

4.3.1. In- depth narrative interview (face to face)

The primary source of material for the narrative researcher is the interview. Unlike the traditional structured interview that has a detailed series of questions to be answered, the narrative interview is designed to provide an opportunity for the participant to give a detailed narrative account of a particular experience (Murray, 2003).

4.3.2. Written narratives

Written narratives are also in keeping with qualitative methods. Participants could elect to write their own stories in their own time in the absence of researcher. This method enables participants to remain in control of the process. If they decide to contribute they can do so at their own time or choosing, at their own pace, picking up and putting down the narrative according to feelings on any given day (Grinyer, 2006). According to Grinyer (2007) there are certain circumstances in which participants may value the written narrative compared with an interview in that it allows the option of how and when to reflect on their experiences . Given that this aim of this research was to recall personal experiences of bereavement which were likely to be a painful recollection, some potential respondents, as Bingley et al (2008) state, may prefer to have the option to select the moment, the length of time devoted to the task and not have to anticipate in advance of an interview's visit that he/she will feel able to engage with the account at a particular moment in time.

4.3. 3. Telephone Interviews

Telephone interviews were offered to those participants who preferred not to write their own story but due their geographical location (and the limited mobility of the researcher) it was not feasible to have a face-to-face interview with the researcher. According to Novik (2008) telephone interviews are largely neglected in the qualitative research literature and, when discussed, they are often depicted as a less attractive alternative to face-to-face interviewing. The absence of visual cues via telephone is thought to result in loss of contextual and nonverbal data and to compromise rapport, probing, and interpretation of responses. Yet, as Novik points out telephones interviews may allow respondents to feel relaxed and able to disclose sensitive information, and evidence is lacking that they produce lower quality data.

4.3.4. Eliciting the narratives

The in-depth narrative interviews (face-to-face and telephone) began with an outline of the research and an expression of interest in the individual experience of each participant. The introduction was designed to increase the participants' sense of competence regarding their involvement in the research and to assure them that their contribution was valuable. This was then followed by a discussion on the consent process and the permission to record the interview was confirmed. Most interviews then progressed to several short answer questions to elicit demographic information. The reason for adopting this strategy was twofold: first to orientate the researcher to the unique situation of each research participant and second to give the interviewee the opportunity to adjust to the focus of research and become accustomed to being recorded. On a number of occasions participants launched directly into the narrative about their experiences. When this occurred a flexible stance was adopted and the demographic questions were deferred until a more timely opportunity arose. However, the narrative accounts often contained these demographic features in the narrative accounts and it was not necessary to ask further questions.

The demographic questions sought the following information: geographical location; current age; age at the time of loss, gender of the deceased parent, cause of death, number of siblings and ethnic background (see appendix 5 for template used for demographic information). The purpose of these simple questions was two-fold to gain an insight into the participants' backgrounds and to enable them to relax into the interview dynamic sufficiently to be able to talk about themselves.

The aim was to focus on bereavement as integral to social life and on those aspects that mattered most to the individuals concerned. Riches and Dawson (1996b) have drawn attention to the way that pre-structured interviews only allow participants to pick out isolated items from their own story. This means that they are in effect filling in the pre-existing narrative of the researcher. So rather that setting out with specific themes chosen in advance, an open-ended informal approach was adopted in which participants were encouraged to set the agenda. Encouraging participants to set the interview agenda and to their story emphasised the value of their perspective and is seen as empowering (Riches & Dawson, 1996b).

To elicit the narrative each participant was invited to tell their story with minimum interruption from the researcher, and to highlight the issues that were important to them. Based on the assumption that people do not relate stories haphazardly, Schultz (2003) contends that the decision about where to begin a narrative frequently suggests enduring personal concerns. Thus the bereavement narrative was elicited by simply asking the question "Can you tell me how the death of your parent has affected your life? Please tell me about the issues that were important to you and how you made sense of them" and respondents were encouraged to find their own starting point.

Where individuals expressed uncertainty as to where to start or what to say the researcher was prepared to offer a prompt. This took the form of suggesting that participant tell the researcher who it was who had died who and when it happened and then probing them for more personal details as advocated by Valentine (2008). Then after reflecting on what the participant had said the researcher sometimes asked supplementary questions designed to obtain clarification, such as 'why do you think that is', or could you give me an example of that' or 'how did it make you feel'.

Initially it was intended that the face-to-face interviews would be held at time and venue preferred by the respondent as this helps to ensure equity of power relationships (Mills et al., 2006). However, it was necessary to ensure that venues were accessible to the researcher due to her limited mobility. When discussing this issue with respondents they often offered to come to the Division of Primary Care within the University campus for their interviews as this venue was fully accessible to the researcher.

Those electing to write their own stories were advised to write them in their own time and then sent to the researcher either in the post (a prepaid envelope was provided) or by email. Issues related to informed consent were also discussed with these respondents by telephone and confirmed by letter/and or email prior to requesting written consent, along with the demographic information required. The same method of eliciting the narrative was used for these respondents as those that had elected to have an interview. Again where the participants expressed uncertainty about where to start the same method was used by the researcher to prompt the participant, only this time this information was provided in a written format.

Bereavement has been identified as being particularly sensitive due to its emotionally charged nature and the way that interviewing may threaten the bereaved individual through emotional stress that may be produced (Lee & Renzetti, 1993). Accordingly all participants were given/sent lists of agencies providing bereavement support (appendix 6) should they have felt that needed to access support.

4.3.5. Field notes

Field notes are considered to be an important part of data collection process in that they enhance the data and hence aid the analysis (Buff, 2005). After each interview field notes were complied that combined a) the researcher's observations about the setting and context; b) theoretical notes about the researcher's interpretive hunches and possible alternative interpretations of the data and c) uncensored personal notes about the interview itself and the informant in particular, including reflections regarding relationships. Also noted were relevant conversations with the participants that occurred after the end of the interviews, as were pertinent conversations with other academics/students. These records were supplemented with other thoughts and nagging questions and potential insights as the analysis proceeded. This ongoing process of reflection considerably enhanced the researcher's understanding of the implications of the findings.

4.4. Data analysis process

All interviews (face-to-face and telephone) were recorded using a digital recorder (Olympus, model: DS-40) and later transcribed. However, translating dynamic talk into linear written text is not a straightforward task and much is likely to be lost (Riessmann, 2008). It is also a deeply interpretive process and, according to Riesman, part of the data analysis process. To ensure as many features of speech as possible were captured, rather than delegating the task to someone else the transcribing was done by the researcher, according to the following protocol:

- Arial, font point 12 normal

- Each line numbered in ascending order
- Interviewer indentified with the letter 'R'
- Participant indentified with the letter 'P'
- Street names, building and place names were omitted and replaced with a letter
- Paralinguistics such as 'laughs' were placed in brackets,
- Extralinguistics such as 'door bell rings' and prosodic features such as whispers were also placed in brackets.
- Break offs (i.e. when someone starts to articulate an idea and stops midstream) were marked with "—"
- Nonlexical expressions such as "uhm" and "uh huh" and discourse markers like "y' know" were left in the transcripts
- Short hesitations were marked with (.) and longer hesitations (...)
- Double quotations marks were used for reported conversations
- Emphasised words were emboldened
- Missing words/letters were inserted into square brackets
- Unrecognisable utterances were marked by "x"

Once transcribed the narratives were returned to the participants for verification, where they had consented to do so. This process of checking out the accuracy of the transcript with the participant enables the participant to identify any inaccuracies in the transcript. In addition to providing an initial validity check by allowing possible areas of misinterpretation to be addressed (Valentine, 2008) it also displays transparency about the research project and enhances the integrity of the findings, and the value placed by the researcher on the respondents.

Of the written narratives, only one was hand written. This was converted into type using a word processer, by the researcher. The remainder of the written narratives were already word processed. Any original emphasis was left in the text.

Following Murray's (2003) recommendations the analysis of narrative accounts was divided into two broad phases- the descriptive phase and the interpretive phase. A thorough reading and re-reading of the transcribed and written narratives proceeded both phases. In reading the narrative accounts, the aim is to familiarise oneself with both the structure of the narrative and the content of the narrative. Then a short profile of each account was constructed to allow each account to 'speak for itself', before fully engaging in the analytic process. Such a reconstructive activity, as Valentine (2008) asserts, serves to preserve the integrity and emphasises the uniqueness of each participant's experience and helps to dispel the resistance to the more deconstructive process of cross-sectional analysis. This process Valentine also sees as an invaluable means of both contextualising and familiarising oneself with the participant's experiences.

Drawing from narrative theory each story was then interrogated to determine how it was emplotted (i.e. how the informants have organised their stories, around what sets of issues, actors, events etc). This process help to establish what informants consider as meaningful. To this end each account was subjected to a series of questions that were designed to elicit specific narrative features and included:

- What sets of issues is the story organised around?
- What events is the story organised around?
- Who are the central characters in the story?
- How are the characters in the study portrayed?
- How is the narrator situated in the story?
- What are the temporal features of the narrative?
- How is the story evaluated?
- What cultural and social context in the narrative situated in?
- How is language being used?

This information was documented separately for each account in turn. Then each account was compared to establish what the stories have in common and where they diverge around specific social or cultural circumstances and variation in meaning for individuals. This approach relates to the aims and objectives of the study, but is also responsive to emerging themes thus allowing the revision of the themes and the development of a framework as new themes arise. The thematic framework was applied to all transcripts and revised accordingly to illustrate similarities and difference in the experiences of participants. The findings were summarised in a final thematic frame and are presented with illustrative quotations relating to the themes.

The transcripts and the emerging themes were reviewed and discussed with the researcher's supervisors (Professor Mari Lloyd- Williams and Professor Chris Dowrick). The emerging themes were also reviewed and discussed with an advisory/steering group consisting of the researcher's supervisor (Professor Mari Lloyd Williams), a psychologist, a social scientist and a lay person whose mother had died when she was fifteen. During these sessions the questions were asked of the data, the emerging themes and consistency of analysis to raw data were discussed. These practices display openness about the research project, enhance the validity and the integrity of the findings, and the value placed by the researcher of those that have experience of the phenomenon being explored.

To complete the process of analysis the findings are discussed in relation to models, theories and other published work in relation to early parental loss and its impact on adulthood in a critical and comparative manner. This is incorporated into the discussion chapter.

4.5. Ensuring rigour

There many frameworks for understanding validity or criterion for describing vigour in research. However, it is important to choose a criterion for evaluation the quality of the research that reflects the method approach taken by the study (Ballinger, 2004).

In considering rigour in quantitative research concepts such reliability, validity and generalisability are well known, but often associated with realist positions in that they assume the existence of a single truth (Ballinger, 2004; Mays & Pope, 2000). For research frameworks that assume the existence of multiply realities and more constructionist (interpretative) and relativist positions, as in this study, such concepts are not appropriate.

Lincoln and Guba (1985) have been instrumental in developing frameworks for understanding the growth in such approaches, particular for constructionist influences (Seale, 1999a). Lincoln and Guba (1985) proposed their own four-point criterion for the naturalistic inquirers for establishing trustworthiness: credibility, transferability, dependability and conformability. Specific aspects of their framework form the basis for ensuring rigour in this study.

The first criterion Lincoln and Guba referred to was credibility. This is a concept that is seen to replace that of 'truth' value (internal validity) used in more conventional inquiry. Whereas internal validity aims to demonstrate confidence between findings and an objective truth, credibility aims to demonstrate confidence between the constructed realities of participants and the reconstructions attributed to them by the researcher (Guba & Lincoln, 1989). For these authors "the most crucial technique for establishing credibility" is through "member checks" (Guba and Lincoln, 1985: 314). Other techniques include prolonged engagement in the field, participant observation and triangulation, and peer debriefing (Whittlemore, Chase, & Mandle, 2001).

Specific mechanisms were identified in this study for ensuring credibility which included member checking of the transcriptions, prolonged engagement in the field (3 years), field notes and peer debriefing. As noted previously in addition to providing an initial validity check by allowing possible areas of misinterpretation to be addressed member checking of the transcripts also displays transparency about the research project and enhances the integrity of the findings, and the value placed by the researcher on the respondents.

A qualitative study is deemed credible if it reveals accurate descriptions of individuals' experiences and that the people have those experiences would immediately recognise it from those descriptions or interpretations (Sandelowski, 1986). This was the experience in this study when the findings and interpretations were reviewed by the lay member on the Steering Group (who had herself experienced parental death in childhood).

In terms of triangulation, this relies on the notion of a fixed point, or superior explanation, against which other interpretations can be measured. As this is a qualitative study, carried out from a relativist perspective, it acknowledges the existence of multiple views of equal validity (Popay and Rogers, 1998). Hence, triangulation was rejected for this study on the grounds that it is not applicable to narrative research (Webster and Mertova, 2008).

The second criterion referred to was transferability. This was used by Lincoln and Guba (1985) to replace the conventional measure of external validity (such as applicability and generalisability). External validity demonstrates the extent to which findings would be applicable in other contexts using other subjects, for example by using random sampling techniques. Transferability on the other hand aims allows the reader to judge the applicability (transferability) of the finding to other context they know.

The use of 'thick' descriptions is considered appropriate for demonstrating transferability (Seale, 1999) and was a technique used in this study to demonstrate this criterion. This was supported with evidence from the data and rich descriptions of the settings and participants backgrounds. The researcher also repeatedly referred back to the data during the analysis and when developing the themes. This is an essential step, actively searching and checking the data for reasons why conclusions should not be trusted (Miles & Huberman, 1994).

The third criterion is dependability and this was considered by Lincoln and Guba (1985) to be parallel to the conventional criterion of reliability (i.e. consistency). Reliability is concerned with the reproducibility of the finding whilst dependability is more concerned with being clear regarding methodological decisions and changes. Unlike in quantitative approaches changes in methodology are expected in qualitative research but it is important to record them. Lincoln and Guba proposed that the 'concept of auditability' be the measure of consistency in qualitative research studies. They suggested that a study may be judged as 'auditable' (and thus reliable) if the reader can follow the 'decision' trail' (Guba and Lincoln, 1981)/'audit trail' (Guba and Lincoln 1985).

This study therefore has been written with a view of allowing the reader sufficient detail and information to check the ‘decision trail’. Dependability was also addressed in terms of equipment employed by the researcher as a digital recorder was used record all interviews (face–to-face and telephone) and the use of verbatim transcriptions. Peer auditing procedures were also used to enhance the dependability of the findings (Seale 1999).

Confirmability was the fourth criterion identified by Lincoln and Guba (1985) and it replaces the traditional notion of neutrality (or objectivity). Both of these criteria are concerned with demonstrating that the results represents more that the researchers imagination. Objectivity requires that the researcher excludes biases and values but for conformability this is demonstrated through the data itself and demonstrated through providing a critical, reflexive account of the research process and the transparency of accounts (Guba & Lincoln, 1989; Seale, 1999a). Reflexivity has been described by Mason as “thinking critically about what it is you are doing and why” (Mason, 2002: 5).

Conformability was achieved in this study by providing a clear, reflexive account of the research process. A further mechanism, member checking, was only used to verify the content of the narratives. The rationale as to why this technique was not used to enhance the confirmabity of the emerging findings is discussed in the discussion chapter. The findings will also be critically discussed in relation to the relevant theories, models and other published work in the discussion chapter.

Later Guba & Lincoln (1989) added a fifth criterion 'authenticity'. It is closely linked to credibility and involves the portrayal of research that reflects the meanings and experiences that are lived and perceived by the participants (Sandelowski, 1986). This criterion was added to the original criteria of trustworthiness in acknowledgement of the criticism that their belief in multiple realities was not consistent with the belief that it was possible to achieve criteria to judge trustworthiness (Seale, 1999). Guba and Lincoln believed that authenticity "is consistent with the relativist view that research accounts do no more than represent a sophisticated but temporary consensus of views about what is to be considered true" (Seale, 1999b: 46).

Authenticity has five aspects:

1. Fairness: this is demonstrated if researchers has represented a range of different realities
2. Ontological authenticity: that is research should help members develop a more sophisticated understanding of the phenomenon being studied

3. Educated authenticity: that is to have "helped members appreciate the viewpoints of other people other than themselves" (Seale, 1999: 46)
4. Catalytic authenticity: to have stimulated some form of action.
5. Tactile authenticity: that is to have empowered members to act

As Seale highlights the view that fairness, sophistication, mutual understanding and empowerment are generally desirable is itself a value-laden, culture bound position (Seale, 1999).

For the purpose of this study, two aspects of authenticity (ontological authenticity and educated authenticity) were rejected on grounds that they do not fit with the theoretical framework underpinning this study and were inappropriate as the purpose of this study was not impact on the practice of the participants themselves but those supporting contemporary bereaved children and their families.

The mechanisms used in this study to demonstrate trustworthiness and authenticity, as defined by Lincoln and Guba (1985, 1989) in order to establish rigour are summarised in the following table (table 2).

Table 2: Criteria for Establishing Rigour

Adapted from Lincoln and Guba (1985,1989)

Criterion	How it was demonstrated
Trustworthiness	
• Credibility	Accuracy of peer examination (debriefing) prolonged engagement in the field, member checking of transcripts, feedback from steering group on developing themes and analysis
• Transferability	Thick descriptions and interpretations supported by evidence from the data and a rich descriptions of the settings and participants backgrounds
• Dependability	A transparent open account of the research process which clearly describes each stage of the process and the methods used which explains and justifying what was done and why. Member checking of the transcripts, peer auditing and the use of data recording equipment
• Confirmability	Critical reflexive account of the research process, transparency of the accounts. dense description of the research method, field notes and member checking of the transcripts and review of emerging themes by the steering /advisory group. Critical review of the findings based on relevant research.
Authenticity	
• Fairness	Description of a variety of experiences
• Tactile authenticity	A focus on participants narrative empowered participants to provide more concrete and specific details about their experience and to use their own vocabulary and conceptual framework to describe those experiences (Elliot , 2005)
• Catalytic authenticity	The development of two models, grounded in the collective data set that support the development of bereavement services

4.6. Ethical approval

As this research did not include NHS patients it was not necessary to apply for ethical approval for COREC. The application to proceed with the study was submitted to University of Liverpool Sub Ethics committee in December 2006 and formal approval was given in January 2007. This committee judged the study against the explicit criteria to assure beneficence, avoid malificence, ensure informed consent, give equal opportunity and assure technical competence. (For a copy of the ethical approval letter refer to appendix 7).

4.7. Summary

This chapter has provided a detailed description and justification for data collection methods, data management and data analysis process used to conduct this study. Data collected methods consisted of face-to-face interviews, telephone interviews and written narratives. It also included the use of field notes. The framework for validity and ensuring rigour has also been outlined and discussed. The chapter concluded by providing information regarding ethical approval for the study.

4.8. Presentation of findings generated from narrative data

Exploration of the narratives revealed whilst the individual stories were unique, they were organised around five common themes which were indentified across the narratives: 1) disruption and continuity, 2) recognition of loss; 3), family dynamics, roles relationships and context; 4) public world of bereavement and finally 5) the impact on identity: aspects of personal growth. Each of these themes will be subsequently presented as chapters and structured according the sub themes. Extracts from the narratives have been used in each of the chapters as exemplifiers which typify similar issues, or where they diverge around specific social or cultural circumstances and variations in meanings. If one of the participant is referred to more than others this indicates that the narrative from those particular respondents were more succinct and 'quotable' than others.

An introduction to the participants and background information is provided (appendix 8) in order to contextualise the participants' narratives.

Chapter 5: Disruption and Continuity

According to anthropologist Gay Becker (1990) in all societies, the course of life is structured by expectations about each phase of life, and meaning is assigned to specific life events and the roles that accompany them. When expectations about the course of life are not met people experience inner chaos and disruption. Death is viewed as a major disruption, particularly when it is the death of a parent(s).

Ideally, parents support their children, both physically and emotionally, they provide a "secure" and "stable" home environment in which children can grow and mature. Also they serve both as the children's protectors and role models. In reality the extent to which parents are able to fulfil these roles varies. Nevertheless, for the majority of children, parents remain their most significant others; in effect their partners in negotiating the essential development tasks that will take them to adulthood (Worden, 1996).

In this chapter using exemplifiers from the narratives, the extent to which the loss of a parent(s) was seen to disrupts the taken for granted world of the child was brought into view. In particular this chapter reveals how the narratives in this study were constructed around two main themes: irrevocably changed lives: fear and insecurity and continuity and change.

5.1. Irrevocably changed lives: fear and insecurity

According to Brown (1999), death is not in the scheme of things when you are a child. It is often premature and unexpected. It is an event which interferes with the normal processes of growing up. In short the death of a parent is shocking and the foundations of a child's life are rocked: their confidence in the world they know is destroyed (Brown, 1999). Hence when a parent dies, life as the child knows it is disrupted and irrevocably changed.

Patricia aged 60 was 15 when her mother died of lung cancer. Patricia had a younger sister and an elder brother. Patricia explains how the death of her mother from lung cancer disrupts her taken for granted world:

> *"I remember thinking I was 15 with a whole future I wanted to do and I realised that life was never going to be the same again.*

> *But I looked to my father for guidance but he wasn't giving me any guidance- he was really inward- he wasn't expecting her to die. 'He wasn't expecting it' that's what he said. Urmmm so then it was this terrible sense that life's not going to be the same – it was never going to be the same again"*

[Patricia 60 aged 15 when her mother died of lung cancer]

The opening and closing statements are suggestive of a denied and uncertain future. Feeling insecure and confused she turns to her father for guidance which she assumed he would provide. Immersed in his own grief Patricia's father was unable to provide the support she needed. This appears to increase her sense of disruption and reinforces the fact that life will be the same again.

Amy now 20 was 17 when her mother died of a brain aneurysm. In the following extract Amy explains how the death of her mother changed her world:

> *"It changes everything, because you know your mum and your dad are the two pillars that hold your world up, you knock one of those out you know you fall over. And you have to pick yourself up and put yourself together again but it never, you know you can't but it back the other again, the same it was. You know you have to put it back together with yourself as the pillar"*

> [Amy, 20, 17 when her mother died of a brain aneurysm]

Explicit in this extract is the assumption that Amy has to take responsibility her own life. In recognising that her life has irrevocably changed she is aware that she needs to take control. Instead of relying on her parents for her security she now feels that has to rely on herself.

Anne Marie was 25 when she took part in the study. Her mother died of a brain haemorrhage when she was eight. She had what she defines as "a bit disrupted childhood" [Anne Marie]. Her father was an alcoholic and she lived with her mother who had mental health problems and her elder sister. Her mother's illness meant that she and her sister were often put into the care of social services or their paternal grandmother.

Whilst there are other examples of discontinuities in the narratives in this study the narrative extracts from Anne Marie's story illustrate a progression of discontinuous events that were exacerbated by her mother's death. Anne Marie explains:

> *"You know, it was just a very, very bizarre kind of setup for me as a child before she (mother) died. Erm, anyway about, about a year before she died she manage to get hold of the depression, she kind of, she was put on lithium and she managed to get her life back on track and she got a job. So life for mum, me and L (name of sister) kind of picked up a bit. We*

> *got a house in North M (name of town) and I settled down for the first time in my life because before that I'd spent lots of time in different schools, erm never really made solid friendships because we were always moving about erm so that was the first time in my life where we'd settled down and got a primary school where I made friends and sort of just dig my roots in a little bit and settled down"*

[Anne- Marie, aged 25, 8 when her mother died of a brain hemorrhage].

So life for Anne- Marie was just starting to have a sense of continuity when her mother died. She describes events after being told that that her mother had died:

> *So L (name of sister) left with my uncle and there was me and my nana, my dad went to the pub and I remember sitting on the stairs in my nana's just desperately, desperately wanting my dad to come home, I just really, really, more than any time in my life just wanted him to come home for two days, I think that somehow had a real, real impact on me. It was like as if for the first time in my life I'd been dropped in the shit on my own, if you get what I mean. It was just like something kind of dawned on me that said you really are on your own if you know what I mean. Urm, since then I have had real issues with loneliness- I've had real, real bad issues throughout my life"*

Bewildered and confused Annie-Marie was unable to turn to her father for any emotional support she feels let down and alone. For Anne Marie these "real issues of loneliness" she has suffered throughout her life which she feels are rooted in the realization that she was on her own. Anne Marie goes on to describe how she felt after the funeral:

> *"I remember thinking I don't know what to do now I just felt completely kind of lost. I didn't know what to do, erm its kind of like, it was, because my mum was dead and she was in charge of my life up until that point I didn't know what to do, I didn't know who to turn to, who to go with, I didn't know where I was going to live so you know cos it like I've got nieces and nephews now and if I was in the room now and I'd got up to leave they'd get up to leave with me because they'd know they were with me but I didn't know who I was with anymore because my mum wasn't there"*

Anne Marie felt alone and lost and hence experienced a profound sense of insecurity both within herself and in the world around her. Annie Marie was sent to live with her parental grandmother after her mother had died without her sister. She explains:

> *"I went to live with my grandma, my dad's mother. Urr my sister didn't want to go because she hated my dad so she went to live with my aunty- my mum's sister. So first of all, that was really strange because I wasn't living with my sister anymore and then just further compounded my feeling of loneliness because now I was stuck with my nana – who I loved- but she was an old women and where's me sister gone. I had no one to confide with, or share it with and stuff like that so that was awful. I remember feeling very, very upset that L (name of sister) wasn't there anymore. Urm and at the time I didn't realize why she didn't want to be there, it was just like well she doesn't want to be with me either. I mean in retrospect I realize that you know*

> *she didn't like me dad- I don't like him either myself now anyway- erm so yeah Lisa went and went to live with my aunty".*

For Anne Marie the death of her mother disrupted her taken for granted world in a major way. The insecurity, fear and loneliness she experienced as a result of her mother's death appears to have been intensified by the lack of support from her father and being 'stuck' with her parental grandmother without her sibling providing support. This relationship with her sibling was very important to Anne Marie. It had been, as far as she was concerned, the only source of continuity that she had been able to rely on in the past, particularly during times of previous disruption. At the time Anne-Marie was unaware of the reasons underpinning her separation from her sister hence she made sense of it by seeing it as rejection which further compounded her feelings of loneliness and isolation. As an adult however she is able to understand reasons underpinning her sister's decision and sees it as justified.

Christina, now 57 lost her mother to leukemia a week before her fifth birthday. She also experiences a profound sense of disruption which started when her mother's condition deteriorated and she was no longer able to care for her daughter. Christina describes her memories of what happened:

> *"So my aunty T [name] and me Aunt M [name] took me away. And for a period of time, and when I think back now I think it must have been close on about 5 months – I was moved from one aunt's house to another and at each one I remember being very, very afraid because everything was different in their house, there was other children, their meals were at different times, this awful feeling of being the odd one out, how inconvenient, she's here type of thing. Even my cousins would get fed up you know 'why do we have to have this bed in this room with me, I've always had this room and now you're on the scene' and I remember I could never fully settle. I remember crying a lot, and not being able to settle in these houses*
>
> [age 57, age 5 when lost mother died of leukaemia].

Again for Christina this unfamiliar constantly changing world filled her with insecurity and fear. To Christina this was a world that was very different to hers; there were children (she was an only child) who seemed to resent her presence. Consequently, Christina felt she was wasn't wanted and that she didn't belong to this world.

5.2. Continuity and change

The following narrative extracts reveal how some of the respondents in this study attempted to negotiate the disruptive impact of bereavement on their social world. According to Becker (1990) people maintain continuity with the past amid the facts of change by interpreting current events so that they are understood as part of tradition. The ongoing interpretation of events and experiences enables people to make sense of their personal worlds. A knowledge world, Becker argues, provides a framework for understanding major events as well as everyday experiences. A sense of continuity is captured in ordinary routines of daily life, the mundane and comforting sameness of repetitive activities.

Freda was two when her mother died of septicaemia and although her father was alive she was brought up by her maternal grandmother. She was an only child and she explains how she felt about being brought up by her grandmother:

> *"It didn't really bother me cos I'd been so young with me mam (grandma) that she was just me mam and I didn't realise that I didn't have a mum till I was older and sort of what can I say. They weren't that old really nana must have been about 38 when my mother died. I wasn't any diff[erent]- there was nothing to it, I never thought anything of it really no. I knew that she wasn't – I must have known that she wasn't me mam – my own mother – but she took her place. So it didn't really come into it I accepted how it was"*
>
> [Freda 75 aged 2 when her mother died of septicemia].

Implicit in this comment is a sense of continuity. Having no conscious memories of her natural mother in her habitual role to Freda her grandmother was her 'mother' as she was the person who was exhibiting mothering behavior. Hence, it was Freda's only experience of mothering. As Freda became older she realised that the 'mother' she knew was not her natural mother but accepted it as "this is how things were". Although her father did not live with them Freda did not experience a sense of disruption as this was the only world she had ever known.

Christina on the other, in contrast to Freda, had memories of her mother in her habitual role. When her mother eventually died it was decided that she would be looked after father's elder sister and her daughter in an unfamiliar part of M [name of city]. This was despite her father being alive. As a child Christina was told that the reason she was not able to live with her father was because "father didn't think it was right to bring up a young girl on his own".

Like Freda, Christina's experiences of growing up were exacerbated by an era when societal norms limited the type of involvement or role a single father could play in a daughter's life. During this period it was not accepted for a father to raise a daughter alone (Voght, 1999) although Christina on reflection suspects "the truth was he probably was afraid of trying to cope with it".

Christina's aunt was in her 60s, very religious, with very set views. At school Christina found it difficult to make friendships. Her aunt's strong beliefs and way of life Christina believed set her apart from her peers. Christina describes what it was like in her aunt house:

> *"The house was like a mini church, each room had a saint's statue in it, there was holy water at the door, there were crucifixes err very, very much that type environment"*

[Christina, age 57, age 5 when lost mother died of leukaemia].

Although Christina had continuity living with her aunt, it felt alien to her. Hence it appears that Christina created a secret place in the hay barn of a local farmer:

> *"I could go up into the barn loft and I could sit there and I knew cos I'd found two, two beautiful leather side saddles, God knows how old these had been but I found them and I had them situated so I could almost lie across them and a couple of bales of hay around. I think it must have been as if I was making my own home … I never once took one of my school friends there, nobody knew about that little corner up in the loft of the hay barn – nobody knew about that as far as I was concerned, that was my area… Absolutely brilliant, that went on for years and years, I think I was about 18 before eventually I left that corner. And I think I only did that because old farmer S (farmers name) had died them and a lot of this land had been sold off and new buildings was being put on it . I think I thought then I'd lost a place that was mine but I had to go from it but I think I was old enough then to understand but still reluctant to do it"*

For Christina this secret place in the barn was a haven where she felt safe and secure. In this place Christina, in her mind, inhabited another world which she had created for herself where she could be herself as she felt herself to be. Crucially, it was somewhere she could control who had access to it and she didn't give any access to anyone. In this world she could go to escape her feelings that she expressed as "always being afraid" (Christina).

Amy now 20 was 17 when her mother died of a brain aneurysm unexpectedly. Although she still had a sister and father at home she still she needed to go back to school and out with friends a couple of days after her mother had died. She explains why she needed to do this:

> *"[I] went back to school because I had to do something. I actually went to my friend's birthday party on the Saturday, just to get out of the house. But it was so easy at school (upset) (.) just to think about the subjects that I was doing and to concentrate on them and it all made sense"*

[Amy aged 20 and 17 when her mother died of a brain aneurysm]

By returning to school and going out with her friends Amy was able to escape (albeit temporary) the intensity of the disruptions that surrounded her and retain at least some sense of continuity in her life. The ordinary routines of school life and her friendship networks were habitual, predictable and comforting and provided a sense of purpose and hopefulness for the future.

Ruth aged 46 was an only child and 16 when she lost both parents within six months of each other. Instead of living with relatives who lived a distance away Ruth choose to go and live with a close friend of the family, aunty O [name), who was in her 60s. She explains why:

> *"I didn't want to go to family – I didn't, I think because, the enormity of what of happened and the fact that I'd lost both parents in such a short time – I had been able to stay with my aunty O[name] it meant that I didn't have to make new friends because it was the one constant – my school and my friends were the world that didn't change. Everything had changed, I'd lost my home, I'd lost my parents, I'd got no brothers and sisters, I'd got nobody but you know nine o'clock or half eight in the morning I went off to school and I came back at say half past three and in that time I was like any other, I was a normal schoolgirl if that makes sense"*

[Ruth aged 46 and 17 when both parents died six months apart]

By expressing her preference to live with her aunt, Ruth (and with her aunt's agreement), was able to maintain the same friendship networks and attend the same school as she did prior to the deaths of her parents. This continuity was particularly important to Ruth. As previously highlighted the ordinary routines of school life and her friendship networks were habitual, predictable and comforting and provided a sense of purpose and hopefulness for the future. According to Becker (1999) these activities give structure and logic to people's lives. They also provided a sense of normality in an otherwise chaotic and disrupted life world where Ruth could escape (albeit temporary) the enormity of such profound disruption.

5.3. Summary

This chapter has illustrated how the loss of a parent(s) through death and illness disrupts the taken for granted world of informants in major ways. Through the interrogation of the narratives it was possible to see that stories were organised around to main issues: irrevocably changed lives: fear and insecurity; and continuity and change.

By investigating how the informants had evaluated their stories in relation to this event and the language used it was evident that for those informants that had no conscious memories of their deceased parent in their habitual role, where the surrogate caregiver (or surviving parent) was exhibiting the parenting behaviour there was little sense of any disruption as this was the only world they had ever known. Such narratives strongly suggest that if the social network picks up all the necessary “mothering” or “fathering” then a child doesn’t appear to be affected.

For those informants that had memories of their deceased parent(s) in their habitual role the disruption of their taken for granted world appeared to take away their hopes and dreams and leave them feeling confused and insecure both within themselves and with the world around them. Through looking social context the story was situated in and the language used could be seen that such feelings appeared to be intensified in those that had experienced a progression of discontinuous events (e.g. changes in caregivers, family, school and friends) and (or) were negotiating the transition for childhood to adulthood.

By exploring the social context in which the stories were embedded it has been illustrated to some extent how continuity had an important role in negotiating the disruptive impact of bereavement on social worlds. Such narratives strongly suggest that if the social network picks up all the necessary "mothering" or "fathering" then a child doesn't appear to be affected. Where this isn't the case the child is going to need support.

The exemplifiers used in this chapter encapsulate many of the dimensions for continuity that appeared other stories in this study. Specifically they illustrate how different contexts for continuity such as family, school and friendship networks shape peoples' social expectations and experiences of bereavement. It has also been illustrated how these different contexts for continuity help children cope with the bewilderment and confusion in the world around them and within themselves.

Continuity was seen to be a resource for negotiating the disruptive impact of bereavement on children's social words. In order to help minimise these disruptive effects bereavement support needs to be structured in such a way as to ensure that the many different contexts for continuity can be maintained.

Chapter 6: Recognitions of loss

In the preceding chapter it was outlined how the narratives in this study were organised around disruption and continuity. In this chapter, the focus is on recognitions of loss as this was another theme that the permeated the narratives. The way in which bereaved people respond to news of the death is individual and dependent on factors such age, life experience, faith or cultural background (Brown, 1999).

Through the narrative extracts presented in this chapter it will be illustrated how recognitions of loss in this study were shaped in terms of age and experience, communication. These dynamics were seen as relational. The narrative extracts also illustrate how recognition of loss may occur before the death of the physical body and that waves of grief, arising from the loss of a parent, can be experienced throughout the life course as intensified feelings of grief.

6.1. Age, experience and communication

For those respondents who lost a parent in infancy or early childhood it was particularly difficult to recognise the loss as a valued core relationship was absent to their experiences. The following extracts from Sarah's and Chris's narratives illustrate this.

Sarah now 53 was the 6th of seven children. Sarah was 13 months old when her father died suddenly (aged 36) in a car accident. Her mother raised Sarah and her other siblings. Sarah writes:

> *"In many ways I did not give much thought to not having a father. It was very much "how things are". I had not known him and as a child I had no sense of missing him (as a real human being). How could I complain about my loss when I'd never known him? I do not remember either asking or learning about how he died. I feel as though I simply grew up knowing that he'd been killed in a car accident. Rather than feeling the loss acutely it was simply part of who I was, in the same way that I had red hair and blue eyes"*

[Sarah 53, aged 13 months when her father died in a car accident].

So for Sarah not having a father was simply part of who she was - part of her identity.

Chris was aged 56 was six when she lost her mother to cancer. She was the youngest of three children. Chris had no memories of mother except for those odd occasions when she went to visit her in hospital with her father. She also had no memories of them all living together as a family.

As Chris says 'there has only ever been me sister, me dad and me so I don't know any different, I really don't, so I don't ask about her at all'[Chris]. Chris explains about the confusion she felt when she was eight (two years after the death of her mother) when was told by another child that her mother was dead:

> *"...And this -kid who was Mrs P(name)'s daughter- who I can't remember the name of-"me mum's got to go in with into you every time you have a medical because you know because your mummy's dead" and I said just said "what do you mean me mummy isn't dead, where do you get this from, me mummy just doesn't live with us" and she said "she's dead" and so I just said no she isn't" and then I went in and asked the teacher. And the teacher just looked at me- I'll always remember that – as thought I was coming from another planet and just went "yeah"- but I didn't know what dead meant"*

(Chris aged 56, 6 when her mother died of cancer).

In some cases respondents were not told that their parent had actually died:

Throughout her childhood Chris says "I never really missed my mother, she wasn't discussed and we didn't talk about her". In fact Chris believed that she was never actually told that her mother had died. In recent years Chris asked her sister "why she had never told her that her mother had died and she said she honestly thought that she knew - it was up to me dad to tell me-she was not the mum" [Chris].

An assumption by her sister that their father had told Chris that her mother had died meant no one had actually explained this to Chris. Hence she appears to have gone her childhood not knowing that her mother had died. According to Chris it was only as an adult that found out that mother had died of lung cancer.

Sam's account also relates to the immense difficulties he had coming to terms with her father's death. Sam now 72 was three when his father died of valvular heart disease (age 36). Sam had some memories of his father "I remember him as a very kind man who doted on my mother and myself, buying almost anything that I asked for [Sam]. Hence Sam, unlike

So while Chris was aware that her mother had did not live with them she had no conscious memory of her as a significant person in her life that she was attached to and so she had not been able to make sense of the fact that her mother had died. So while Chris had experienced a loss it had not, to her mind, had a significant impact on her wellbeing and experiences of “family” and “mothering”.

From the current developmental perspective according Hunter and Smith (2008) children develop concepts that help them negotiate the experiences they have in life. They assert that an important factor influencing children’s conception of death is the child’s personal experience with people and other living things (such as pets) that have died (Hunter and Smith, 2008). Research has demonstrated that children’s individual death related experiences influence their understanding of the concept of death (Hunter and Smith 2008).

Whilst informants’ stories were diverse in terms nature of the loss (e.g. the cause of death, the gender of the dead parent(s), the age of the child, their social background) a central thread in terms of recognition of loss that ran through all the narratives was the issue of communication. In particular, the extent to which they were given information about their parent’s death or the likelihood of death and how they made sense of these experiences.

Sarah and Chris has some significant positive memoires formed of a valued core relationship and was aware of the disruption of his taken for granted world. However, Sam was not told explicitly that his father had died. Early on in his story he talks about this:

> *"I think that my mother's first mistake, it was with the best intentions, was not telling me of his death. She said that he had gone away for a while to a nice place where he wouldn't have any more pain. Because education was disrupted by the war, I did not begin school until I was almost seven and had spent over three years wondering why he never contacted us. On my first day in school we were told of a story of a lady who had "gone to live with Jesus" and when I went home I asked if that was where my father had gone and was finally told "yes". By then I was happy to accept that explanation. Had I been told immediately I would certainly have been upset but I am sure I would have accepted it much more quickly"*
>
> [Sam aged 72 aged 3 when his father died of valvualar heart disease].

For Sam the sudden disappearance of his father was invariably a cause of very immediate concern and distress. Not being told explicitly that his father had died Sam believes contributed to the confusion and anxiety he experienced. Whilst Sam appears to appreciate that his mother was maybe trying to tell in a way that she thought might have been less upsetting rather than trying to mislead him, clearly this tactic didn't work. The significance of this event for Sam is reflected in the fact that he orientates to it at the beginning of his narrative. Only when Sam, through his subsequent life experiences, was able to link abstract associations (such as "gone to live with Jesus") with death was he able to make sense of what had happened to his father. He was then able to able to confront his mother to obtain confirmation that his father had died. Whilst Sam accepts that he would have been upset had he been told at the time that his father had died he feels he would have been able to come to terms with his father's death much sooner. Moreover, he thought that had he been told explicitly that that his father had died the confusion and anxiety he experienced may have been to some extent alleviated. Research has indicated that when parents try to protect children by withholding information from them they foster confusion and increased anxiety in children (Silverman & Weiner, 1995).

Margaret aged 62 was eight when her father died of a brain haemorrhage. She also was not told that her father had died and was sent to Sunday school as usual. She describes how she found out that her father had died. Where she has used capital letters and underlining in her original text these have been reproduced to show the strength of feeing and emotion behind her words:

> *"My father was quite well known in the local community and one of the leaders asked me "how is your dad?" I said he was still in hospital. Another child in this big hall full of children than piped up "<u>your dad's dead</u>"! Obviously, I was very shocked and embarrassed. I protested that he wasn't!!! And having had given him a card. But this child was determined she knew better! My*

> *head was reeling!! It must have been at the end of my meeting because I can remember that I - RAN - SO - FAST all the way home in a panic, tears streaming down my face and my heart pumping in my chest. As far as I remember, my mum was on the doorstep talking to the next-door neighbour. I just blurted out what had been said and my mum had to tell me it was true. I can't remember what she said but I do remember how I felt and I can feel the echoes of it as I write this-the devastation, the embarrassment of not knowing and the betrayal of not being told the truth about something so important"*
>
> [Margaret aged 62, aged 8 when her father died of a brain haemorrhage].

For Margaret the devastation, the embarrassment and the betrayal of not knowing the truth affected her relationship with her mother. The intensity of these feelings is reflected in the language used and also the that fact that they have remained so clearly in Margaret's adult memory. As a result of her experience Margaret felt that she was unable to talk to her mother about her father's death for many years. Eventually, Margaret was able to discuss the issue with her mother:

> *"I did manage to discuss what happened before she died (Margaret was 22 when her mother died) and I did forgive her because as an adult I could empathise with her situation more. But I don't think I will ever understand why she didn't tell me straight away and why she let me go out without telling me"*

Whilst as an adult Margaret is able to 'empathise with her situation more' and forgive her mother she is still unable to come to terms with the fact that her mother did not inform her of her father's death, especially as he was well known in the community and she was on her way to Sunday school at the time. Thus Margaret's believes her trust in the world was deeply undermined as a child, first by her father's death and second by what she perceived as her mother's failure to protect her.

Whilst bereavement literature suggests that Margaret would have been devastated by news of her father's death (Abrams, 1999), had she been told by her mother Margaret believes that their relationship would have likely not suffered in the same way. In addition Margaret feels that had she been told she would have likely not experienced embarrassment and humiliation of not knowing. Margaret goes on to write about how these experiences have impacted on adulthood:

> *"I find it difficult to trust people because I'm scared of being let down my biggest hang-up is about not being included and I don't like secrets or surprises"*

Now in her sixties the legacy of this evasion appears to be still distressing for Margaret. She believes that the fear of being let down still makes it difficult for her to trust others. However, due to her experiences Margaret writes:

> *"I always try to speak up for issues of inclusion in school (I am a teacher) and in church. Also I have always advocated telling children including children in family bereavement because of what happened to me. I find it easy to speak about treatment issues with children. I have had the opportunity to lead Rainbows group which is a course designed for bereaved children"*

Communication was central to Jimmy's narrative regarding recognition of loss. Jimmy's now 48 was 14 when his mother died. He was the third youngest of eight children, born and raised in Ireland. Jimmy's mother was diagnosed with encephalitis shortly after the birth of his youngest sister when he was approximately six years of age. This left her physically and mentally disabled and she was hospitalized for most of that time. No one explained to Jimmy what was happening. Jimmy feels that "in a sense we kind of lost her from much earlier that when she died" [Jimmy]. He explains how he felt about the situation;

> *"…at the time, so kind of bewildered about what was going on around me and not really understanding or having it explained to me. But being a fairly bright kid so, with the ability to make, to create a back story which probably had no foundation in reality at all but, does that make sense?..., Looking back now think that I, you know I think that I'm convinced, well if you don't explain to kids what is happening, the truth or the back story they make up for themselves almost always much worse than*

> *the actual reality. You know I can, I can remember, I can remember being so scared and bewildered , I didn't, nobody had explained to me what the nature of her illness was, how she got there".*
>
> [Jimmy 48 aged 8 when his mother died of encephalitis].

This extract from Jimmy narrative illustrates two important points. Firstly, for Jimmy, loss occurred before the death of the physical body. It occurred when the mother he knew in terms of mothering (being aware of him and caring for him) was lost to him due to her illness.

Secondly communication was lacking at two time points. Firstly, during his mother's illness and secondly when she actually died. This lack of communication Jimmy attributes to contributing to the ensuing fear, bewilderment Jimmy feels he experienced. So intense were these feelings that they have remained in his adult memory. The intensity of this distress is reflected in the use intensifiers (I can, I can remember, I can remember, being so scared and bewildered) present in Jimmy's narrative. Had he been told about her illness and her subsequent death Jimmy feels that he would not have had to create his own back-story which was not necessary helpful.

It is well established that children who are not given accurate information often make up a story to fill in the gaps (see Worden 1996). Sometimes this can be more extreme and frightening than was actually happened, as was Jimmy's experience. Due to his experiences Jimmy is keen to stress that "children should be kept informed of what is happening as it happens". As an adult he is able to reflect as to why he was never informed of what was happening:

> *"Big Irish Catholic family in those days kids were just there...there was no great consideration of what does this mean- what is that child thinking.... it wasn't carless parenting, I'm just saying it was typical parenting of its time"*

[Jimmy 48 aged 8 when his mother died of encephalitis].

So for Jimmy this lack communication surrounding his mother's illness and subsequent death to an extent understood in terms of dominant cultural practices in Ireland during the 1950s associated in parenting.

Colin aged 43 was 16 when his father died. He had two brothers, both younger than him. Colin's father had contracted rheumatic fever as a naval cadet in his late teens. This had resulted in serious illness at the time and bacterial endocarditis leading to heart valve lesions. Colin's father had undergone two episodes of open heart surgery to replace diseased valves. Colin starts his narrative by writing:

> *"One of the issues that made me upset at the time, and still does, is that my parents didn't tell me about this history. I discovered it from my grandparents whilst travelling to their house one day. I also felt deceived when he died. No had ever told me that people could die of this condition"*
>
> [Colin age 43 aged 16 when his father died of bacterial endocarditis].

Not being told of severity of his father's condition and that you could die from it was distressing for Colin both then and now. It also meant for Colin his father's death was "sudden and unexpected" [Colin]. The significance of not knowing is reflected in the fact that Colin orientates to it at the start of his narrative. Colin believes that had he been fully informed at the time he may have better prepared for deal with his father's death and to have experienced less distressed both then and now. He also thought that he may have not have felt so deceived. Colin goes on:

> *"I find it very difficult to talk about death. My children are aware of this and recently my 8 year old daughter said to her brother "You had better change the subject as Daddy doesn't like talking about dying." As a veterinary surgeon I am dealing with death of animals almost daily, but death in one's family is too painful to think about.*
>
> [Colin age 43 aged 16 when his father died of bacterial endocarditis].

For Colin, although he is dealing with death on a daily basis the death of his father is still too distressing to contemplate.

Communication was also central to how the child's reaction was handled (or wasn't handled) in terms recognition of the extent of the child's loss; and the effect it has on the child. Alison now 33 was aged fourteen when her father died of cancer. The failure of Alison's mother to communicate with her about how she was coping with the death of her father appeared to have implications for Alison in terms of how she valued herself. It also meant the extent of her loss went unacknowledged. Alison explains:

> *"I remember one of my aunties coming over and talking to my mum and erm and overhearing a conversation –sort of one of those things were you just wish you have never heard it. But she erm, they were talking about my sister and erm and they said err you know they said "how's Alison doing"- it was sort of stop and think. How do they I'm doing? Erm, and I remember my mum kind of saying "oh yeah you know Alison's been upset" and you know whatever but erm and auntie just made this comment about "but that's just of Alison though isn't it" you know "she'll just get over it cos she'd be friends with anybody". And I remember just thinking oh well my dad's died and thinking you've got, like my mum's got attention cos her husbands died, and my sister has got attention because of, well cos she is creating lots of attention for herself and I remember at that point thinking nobody cares, nobody is interested in me... Yeah it was absolutely having that sense that just being overlooked – kind of in the whole process being unimportant, of being young,*

> *of being yeah you know it doesn't really matter urm it doesn't matter for you in the same way as it matters for sort of my mum or my sister"*
>
> (Alison 33, age 14 when father died of cancer).

For Alison's an assumption about her nature led her mother and her wider family to believe that Alison would 'get over' the death of her father. Hence, nobody actually asked Alison about how she was feeling. This was in contrast to her sister and mother who appeared to Alison to receive plenty of support. Consequently, Alison felt that no one was interested in her hence she felt unimportant and overlooked.

A similar thread was seen to run through Anna's narrative. Anna was eleven when her mother died of breast cancer. Anna had an elder brother who according to Anna 'has never had a diagnosis but is somewhere along the autistic spectrum'. Anna's maternal grandmother came to stay with Anna, her brother and father when her mother died to help care for them. As Anna points out:

> *"So think a lot of attention went on him [her brother] cos I was the one who got on with things but you know'*
>
> [Anna, aged 34, was eleven when her mother died of breast cancer]

Again, nobody communicated with Anna about how she was feeling as she was seen to be the one "who got on with things" whereas he brother was perceived to be more vulnerable due to his condition. Hence, the extent of Anna's grief not only appeared to go unrecognised and it also appeared to be unexpressed.

6.2. Intensified feelings of grief and loss

Early theorists have often defined intense feeling of grief as part of complicated grief which may be seen as abnormal. However, Rando believes (1988) that these intensified feeling of grief, which she calls STUG reactions, are part of healthy mourning that can occur long after the death of a loved one.

The informants in this study structured their accounts these times. Although waves of grief could occur at any time, specific periods of heightened feelings of loss were indentified in the stories. Common triggers included: special events such as Mother's day, birthdays, anniversaries, holidays, graduations, wedding or birth of own children) and illness.

In Sarah's story the birth of her children triggered intensified feelings of grief (or STUG reaction) which was something she had not previously experienced. As Sarah articulates:

> *"Although I have a father-in-law, with the birth of our long-awaited, much-wanted first daughter, I saw first hand what being and having a father involved .... And what I had missed. When R (name) was one (the age at which I lost my father), I did consider what a loss it would be for her, if he were to die. As early as R (name of child) being 3, I recognised that C (husband) was a lot more "fun" as a parent than I could ever dream of being. Is this nature or nurture? "And so what?" Logically of course, I realise that the father C (husband) is to our children, will not be the same as the experience of a father that I missed. However, I feel angry when our daughters "wrap him around their little fingers" (even though he is aware of what they are doing and is happy for them to do so). I feel they don't appreciate him and take advantage of his kind and easy-going nature"*

[Sarah 53, aged 13 months when her father died in a car accident].

For Sarah the birth of her child enabled her to experience for the first time what was involved in being and having a father. Hence she orientated to the past and grieves for what she perceived she had potentially missed. When Sarah's daughter reaches the same age as she was when her father died, this triggers a further intensified feeling of grief as she considers what the death of her father would potentially mean to her daughter. Sarah's intensified feelings of grief also extended to her as she grieves for the type of parent she might had been had her father been there as a role model when she was growing up. The perceived 'taken for granted' nature of her daughters' relationship with their father further compound her feelings of loss and appears to make her upset as she feels they don't realise how lucky they are to be able to have a relationship with their father. This was something she did not 'miss' until she herself became a parent.

Chris, now in her mid 50s, according to her narrative, never missed her mum until she was diagnosed with cancer. Chris explains:

> *"I have never missed me mum – I have never missed her at all right until I got breast cancer. And that's what I wanted most of all was me mum (upset) ...sometimes I would just like me mum and I'm thinking about it more now and this is what I don't understand. The only other time that I ever thought about me mum was when I got married 'cause I wanted her there. But not as much as I had done in the last couple of years when all I want is for her to put her arms around me- to hug, to kiss me, (upset).*

[Chris aged 56 was six when she lost her mother to cancer].

For Chris being diagnosed with cancer triggered an intensified feeling of grief in recognition of a void in her life. Chris was distressed when she recalled these events and talked about how much she continues to miss her mother and how much she needs her to comfort her. Not only was

Chris having to adjust to a diagnosis of cancer she doesn't understand why she is experiencing such intensified feelings of loss. Based on her subsequent experiences Chris appears to have constructed an image of her mother as she imagined her to be. She refers to how her mother would 'comfort her, hug her and kiss her" (Chris) if she'd had still been alive Chris's beliefs about 'normal' grief appear to be at odds to her experience of grief which may help explain why she feels so distressed.

Colin also experienced intensified feelings of loss. His father died when he was sixteen. He is now forty three and he still feels his father's death acutely:

> *"In spite of the years and frequent reflection, I don't understand the basis for my grief. Why do I still find it so upsetting? Is it the loss of a loving parent? Is it the memory of the intense sadness at the time? Is it the tragedy of an intelligent, much-loved man dying so young (he was 42 I think)? Is it a selfish sentiment because I have missed out on the love and support of a father through his untimely death? I have never undergone any counselling, it wasn't really the done thing in 1980. I'm not sure whether it would have helped or not. I have never felt the need to talk to anyone about this, quite the opposite in fact".*

[Colin age 43 aged 16 when his father died of bacterial endocarditis].

Like Chris, Colin also doesn't understand these intensified feelings of loss and clearly finds them distressing. Again, Colin's experience of grief may be at odds with his beliefs about so called normal grief which may compound his distress. For Colin his grief is very private and there is a reluctance to share it with anyone. As Grinyer (2002) points out it may be more difficult for men to express their grief in a society where a man's emotional reaction is expected to remain private. Men are expected to be strong and men's tears may be a cause of embarrassment in a way in which women's are not.

6.3. Summary

Through interrogating how the informants have organised their stories in relation to key events it has been shown how recognitions of loss were organised in the narratives of informants in this study in terms of age and experience, communication, and intensified feelings of grief. These aspects were seen as relational i.e. they were seen to interact with each other.

By exploring how the narratives had been evaluated with regards to recognition of loss and by looking at how the central characters had been portrayed it was possible to see that age and experience and central to recognition of loss. Through this process it could be seen that for those respondents who lost a parent in infancy or early childhood it was particularly difficult to recognise the loss as the loss of a valued core relationship being absent in their subsequent experiences. So while these informants had experienced a loss it had not, to their mind, had a significant impact on her wellbeing and experiences of "family" and "mothering" or "parenting". Through looking at the temporal features of the narrative it was apparent that that it was only when the bereft experienced what parenting involved, through their subsequent life experiences that recognition of the loss occurred.

Through exploring how the key characters were portrayed in the narratives of these respondents and how they evaluated their stories it was possible to see that for those children who had known their parent(s) in their habitual role, their death appeared to be particularly difficult, especially teenagers. It could be seen that not only had these children lost a core valued relationship, they had lost the person that was known to them (the character of the parent that died or was absent through illness). The narratives of these respondents also suggest that when you know people as a personality (or a character) and have a huge attachment to them then there is the room for intense grieving because the surviving parent (or surrogate caregiver) isn't that person who has that character.

Communication was central to recognition of loss at two levels. Where respondents were not told explicitly that a parent was ill and was likely to die (or had died) this was seen to contribute to the anxiety and confusion experienced by these children. It was also seen to lead to children feeling let down by adults which was believed to undermine their trust in the world and the people around them. The legacy of this evasion was seen to extend into adult live.

Recognition of loss was not limited to the death of the physical body. Loss was also seen to occur when the mother/father the informant knew in terms "mothering/fathering" (being aware of them and caring for them) and the character of that person were lost to them due to illness. Such cases need to be considered in any model of support.

The significance of communication with regards to recognition of loss was reflected in the way language was used (for instance the use of intensifiers) and in the temporal features of the narrative in that fact that respondents remembered these events (and the associated feelings) so vividly throughout the passage of time (in some cases more than 60 years). It was also often the first issue respondents orientated too.

Waves of grief could occur throughout the life course, specific periods of heightened grief were indentified particularly in relation to key events, such as birthdays, weddings, illness, birth of their own children. Through exploring how such feelings were evaluated in the stories in relation to these key events it was apparent that such feelings were perceived to compound distress as they were perceived to be at odds with their beliefs concerning so called 'normal' patterns of grief.

How the child's reaction to loss was handled (or not handled) also has had effect on the child. In cases where the surviving parent fails to communicate with the child regarding how they feel about the death of their parent (because they assumed the child (children) was coping with the death of the parent due to their character) the child often felt unimportant and overlooked. Through exploring how the respondents evaluated their stories and portrayed themselves in the narrative in this regards and by looking at the language used it was possible to see that such behaviour appears compounds their distress and impacts on feelings of self esteem and self worth.

Chapter 7:

Family dynamics: roles, relationships and context

As Fowlkes (1991) states loss and grief are embedded in social and relational contexts and the family is important in both of these. The literature on bereavement emphasises that the family is a key resource for supporting the child through disruptions. The exploration of narratives in this study revealed how family dynamics shape the respondents experience of loss and grief and have an impact on adult life.

In this chapter with the use of narratives extracts it is revealed how stories were often organised (in those with memories of their family circumstances) around the following family dynamics: changing roles and responsibilities, changes to the surviving parent, the emotional culture of the family: the expression of grief, communication and relationships, the relationship with the deceased parent and finally, family beliefs and values: spiritual beliefs.

7.1. Changing roles and responsibilities

The loss of a family member disrupts and destabilizes the family. In order that families can continue to function certain roles must be carried out by its members (Jordan, 1990). Tyson-Rawson (1996; 1993) reported on the complex issues facing a family as it struggles to deal with the death of a parent which included reallocating roles within the family structure.

The narratives were organised around changing roles and responsibilities as a result of parental loss. Whilst the extent of this varied in accordance with individual circumstances many found themselves having to take on responsibility for themselves, and (or) for others, such as other siblings and (or) the remaining parent. According to Abrams (1999) the oldest child in the family is usually the most at risk of finding him or herself with a new and often burdensome role after a parent dies. Sometimes this role falls to a younger sibling if for instance she is the only girl in the family and mother has died, or the only boy in the family after a father has died. Whatever the position in the family this 'shoe filling' can create real difficulties: it is deeply confusing to have to 'become your mother or father at exactly the time when you are trying to work out who you are in your own right (Abrams, 1999).

Patricia's mother died when she was fifteen. She had an elder brother and a younger sister and very much took over the running of the household. Despite being young herself Patricia became 'wife' and 'mother' to her father and her sibling, Patricia explains:

> *"And it was sort of assumed that I would take on the role of mother which I didn't want – I definitely didn't want to be mother. And I resented it – and I was a teenager- so I resented this role. School was very good because I was doing o'levels and they switched me to a secretarial course – they thought that with the family background that I would be best doing a secretarial course rather than my GCEs- so I'd missed out there"*
>
> [Patricia 60 aged 15 when her mother died of lung cancer].

A sense of injustice, resentment, loss and disempowerment infuse this extract. Whilst the school's decision to switch courses on the one hand had enabled Patricia to support her family in the maternal role, it meant that Patricia would be denied access to higher education. This responsibility was unwanted and resented and Patricia appeared to resent that fact she would have to act as an adult and miss out on her children. She believed that there would be no room anymore for the part of her that still wanted to be a fifteen. So this responsibility would undoubtedly take away her life a teenager and her teenage identity. Furthermore, for Patricia, the school's decision to switch courses also prevented her continuing with what was potentially a more beneficial option and thus potentially change the direction of her life. Thus for Patricia this decision.

albeit made with the best of intentions, reinforced the sense of injustice and the feelings of resentment and loss she experienced as a result of having to take on the unwanted maternal role. Thus she felt disempowered and that she had missed out.

Amy's mother died when she was 17. Unlike Patricia Amy did not have to take on the responsibility of running of the household. To some extent this was done by her father after her mother died. However, Amy explains how her father struggles to fill the role of her mother:

> *"Certainly there's a lot of things that mum did that he doesn't do that he's you know he's paying other people to do, like the ironing, like having cleaners come around. Urn for instance he has Tesco deliver our groceries most of the time rather than going out and doing the shopping. But he still feels under tremendous pressure I think as a single parent now that he has to do everything himself*
>
> [Amy, 20, 17 when her mother died of a brain aneurysm]

Although Amy is no longer living at home (she is studying at university) she feels a responsibility towards her family (her father; and her younger sister who suffers from a chronic illness) to help care for them: She explains why:

> *But I very much feel that I ought to be able to do more for my sister than I do, at least when I am at home. And I feel like I ought to be helping my dad more... but erm I very much feel*

> *like I need to look after them and make sure they're okay because they're what I have and didn't really think about it before mum died, that they're all I have is my dad and my sister-we're not particularly close to any of our kind of extended family*
>
> [Amy, 20, 17 when her mother died of a brain aneurysm]

Instead of taking it for granted that her family would always be there, as she had prior to her mother's death, the sudden death of her mother brought into view the fragility of this relationship and its importance to her. Hence she feels a need to protect and has a profound sense of responsibly towards them, especially as they have no extended family they are close to.

Winifred aged 63 was also 17 when her father died and the youngest of three children, all female. When her father died she thought that she might not be able to following the career path she had chosen (medicine). But with the support of her mother, her elder siblings and other family members she was able do so. She also felt a sense of responsibility towards her mother and a need to protect her. Winifred explains:

> *I was perhaps quite protective and very much always thinking of my mum's needs as well as my own... When my father was ill I started to feel some responsibility for helping to care for him a*

> *shared responsibility – I was never ever made to, I mean my mother was fantastic, and she used to try – her view was it was her responsibility so she shouldn't go out but I said you know I was quite happy...and I think that just moved into feeling of responsibility for her [mother] not, she didn't need care as such but considering my mother in a way that I possibly wouldn't have done ...it continued until she died*

[Winifred 63 aged 17 when her father died of a heart condition]

Sharing the responsibility for the care of her father for Winifred then evolved into a feeling of responsibility for her mother even though "she didn't need care"[Winifred]. This sense of responsibility Winfred felt towards her mother extended into adult life and lasted until her mother died. The following extracts provide some insight into the reasons for this:

> *As you know it (the death of her father) didn't make any difference to my career, but that is thanks to support of my mother and my sisters. You know they said that this mustn't make any difference that I should be given the same opportunities as they'd had, which I have always appreciated.*

[Winifred 63 aged 17 when her father died of a heart condition]

Winifred also supported her mother financially. This initially started when she was a medical student working in the holidays:

> *I also worked myself in holidays when I could, for the first couple of years I used to work every holiday. I didn't do any electives away from [home], I'd have loved to do electives*

> *abroad or something to expand my experience. But I was just so grateful for having being allowed to still continue with medicine, every holiday I could I used to work and then I used to give a bit of money to my mum cos I always went back home and worked from home and used to give her a little bit of it erm cos as I say I was just so grateful – I always have been for being allowed to still go on to achieve university*

[Winifred 63 aged 17 when her father died of a heart condition]

When Winifred qualified as a doctor she continued to provide financial support for her mother in the form of a regular allowance from her salary each month. She continued to provide this regular allowance to her throughout her married life until her mother died:

> *It was because my mum was a widow and on her own and I appreciated that I'd come to university and I wanted to give her some financial return-she never ever expected it, but I wanted to do it*

[Winifred 63 aged 17 when her father died of a heart condition]

So in addition to the threads of responsibility and protectionism visible in these extracts from Winifred's narrative there is also a strong sense of indebtedness, particularly towards mother. It appears that Winifred the way she was able to show her appreciation (and maybe repay the debt) was in monetary terms, especially as her mother was a widow and as highlighted in other sections of her narrative on a limited income.

A strong sense of indebtedness also ran through other narratives. In particular Ruth's narrative:

> *"I'd been beholden to people, you know got a lot of good people who had stepped in to parental positions but obviously, you know like one couple would do one part of parenting and other couple would do other you know like erm if I went out for the day or if I went on holiday with people. You know there was a family that took me on holiday with them; well they stepped into the parental role while we were on holiday. You know I had a lot people doing various things but it adds to the feeling of beholden on you know. Because I was beholden to them cos they taken me on holiday- whether it was the right feeling to have, that's how I felt, I just felt beholden to everybody".*

[Ruth 46 lost her both parents within six months of each other when she was 16]

So the parental roles undertaken by others after her parents' deaths left Ruth feeling indebted to them, maybe in ways that people are not indebted to their own parents.

Sarah believes that:

> *"Growing up without a parent makes the siblings feel more responsible for the remaining parent and this engenders a closeness which perhaps would otherwise not be present. I can see this in my husband's family since the death of his mother 3 years ago and the siblings' concern for their father and it is*

> *something my husband commented on in the early years of our marriage with regard to myself and my siblings re my mother"*

[Sarah 54, 13 months old when her father was killed in a road accident]

As illustrated in the narrative extracts outlined in this chapter whilst many of the narratives supported this viewpoint others appear to contradict it.

A change in relationships was also a thread that ran through Dan's narrative. Dan, aged 33, was sixteen when his father died. His father had raised Dan and his younger brother after their mother died when Dan was five. Dan and his brother had always been close to one of his dad's brothers and his family and they went to live them after his father's death. His uncle and his wife had three children (all younger than Dan) he talks about how these relationships with this family had to evolve and change:

> *'It was quite crowded...there were different rules and a bit of agro – a bit of tension... were all good friends now and we can kind of laugh about it but it was obviously terrible at the time...lots of relationships changed you know changed and broke down and had to evolve and grow again as a result of what happened and I think that happened with everyone really*

[Dan 33, was five when his mother died and sixteen when his father died, both from cancer]

7.2. Changes to the surviving parent

Many of the narratives were focused on the distress associated with changes to the surviving parent. One of the things that Winfred remembers "very vividly" in relation to immediate period after her father's death was how her mother changed, albeit in the short term. Winfred explains:

> *"And now I understand that 'cos I understand the process of bereavement but I didn't at the time...and my parents were, they disciplined us but weren't over protective I don't think... in those days all children went round alone quite a lot and I used to go on buses and things which was allowed but I always had to tell them actually where I was going, what time I would be home etc, etc you know. So it was if you like controlled freedom. And I remember vividly in the first few weeks after me dad died my mum didn't seem interested in where I was going and what I was doing. You know, if I'd say to her I'm going to a friend's house, okay and she didn't, whereas usually she would have said where exactly is it, if she didn't know or what time will you be in etc, she didn't. And it was a strange feeling on my part – I don't think it was exactly that I had lost two parents but that I lost parent and the other one had changed so much. Now that only lasted a short time, now I understand it, but at the time I didn't and that, that distressed me* quite a, that *distressed me in a way as much as my father dying- that might sound odd but I still remember that"*
>
> [Winifred 63 aged 17 when her father died of a heart condition]

As an adult Winfred was able to understand the change in her mother was due to grief. However, as a teenager she could understand why her mother, albeit for a short period, no longer seemed interested in what she did or where she went. She found this very distressing. The intensity of this distress for Winfred is reflected in that fact that she compares it to that associated losing her father. The impact was such that although in her 60s she still remembers it "very vividly" [Winifred].

The same thread ran through Sue's narrative. Sue, sixty two, was the youngest of seven children and lost both parents, just over a year apart. According to Sue's story, her mother was a very independent person and self reliant prior to her father's death. Sue explains how her father's death affected her mother:

> *"um me mother then to me at that time was like a different person you know ...I understand it, now years afterwards I understand, but it was hard to understand then. It was hard to understand that she was like err what she went through really, you know what I mean"*

[Sue 63 aged 16 when her father died of a heart attack and 17 when
her mother died of a stroke]

Again, it appears it was difficult for Sue as a teenager to understand the change in her mother at the time and what her mother was going through.

Patricia's narrative also refers to the change to her father after her mother's death:

> *"He was just left completely in an emotional state ...It was only years later that I realised that he'd gone into a deep depression"*

[Patricia 60 aged 15 when her mother died of lung cancer]

Jane, an only child, also found it difficult to understand the changes to her mother after her father's death: However, these changes had a greater impact as they were perceived to be much more long term:

> *What she started doing- and this is what happened the day of the funeral as well, when she was going a bit peculiar- she started throwing out- this was another thing that made me feel useless and worthless and I didn't, I felt as if I wasn't wanted. She was throwing everything out in house that belonged to me dad and I was gutted ... but she started throwing things of mine out then and I just felt alone; I had no one to back me up and I couldn't talk to her about it and then it happened every single year after and I'd buy more books to replace what she'd thrown out and she'd do the same and, in the end I had to leave.*

[Jane, aged 51, was seventeen when her father suffered a heart attack and died]

This extract from Jane's narrative suggests that her mother's behaviour added to her grief and affected her perceptions of self worth, especially when it extended to her belongings. Given the fact that this behaviour appears to have continued over time, this seems to have compounded Jane's distress. Feeling that she was unable to talk to her mother about her behaviour and the distress it caused and believing that she had no support elsewhere Jane felt unwanted and alone. Eventually, Jane felt that she had to leave home.

Sally's narrative also refers to the changes to her mother after her father's death. Sally aged 33 was seventeen when her father died. She had an older married sister so there was just Sally and her mum living at home after her father's death.

> *"Because my mum was really cut-up and everything but she emm which unfortunately didn't help- unfortunately got back with my sister's [dad] – her ex husband for a while- so she was sort off and I was sort of left to do my own thing on my own while she was – she couldn't really cope with my dad dying – that was one of her ways of coping...it was a really strange time so I don't think that helped... so I was trying to deal with his man who had never been talked about ever coming back into our lives"*
>
> [Sally, aged 32, was seventeen when her father died from a brain tumour]

So it appears that Sally mother was not able to support Sally emotionally or physically due to her own grief. Sally feels that she not only had to learn to be 'self sufficient' she also had to come to terms with a man she didn't know being brought into the family environment. Although Sally on reflection as an adult appears to understand her mother's behaviour it appears to have made it more difficult for Sally to cope with her loss.

7.3. Emotional culture of families: the expression of grief, communication and relationships

The narratives were also organised around the emotional culture of the family. This was seen to influence the extent to which grief was expressed within family. It was also seen affect communication and relationships. According Dyregrow (2008) children's ability to cope with the loss will, not least be associated with how the remaining parent is able to create a climate in the family where the child can talk about their lost parent over time if they wish to, have their emotional needs cared for and experience understanding.

Peggy 80 was part of a large family: she was the third youngest of seven children (one boy and six girls). Her mother died of cancer a couple of days before Peggy's ninth birthday. Like many of the other families in this study Peggy's family was organised around traditional gender roles. When her mother died Peggy felt that the caring, warm and accepting element in her life had gone. She points out that the maternal role was not easy for her father to fill and he struggled to give the family the emotional support they needed, whilst the household chores for the most part fell to the children. Peggy explains:

> *"Like we were more not a unit – but err you know like a family unit- but more individuals in a family. Where I think she would have kept that unit together you know...You see my dad – god rest him- he had enough to do in the running of the farm and as I say coming to terms with his own loss, do you know. He wouldn't have been much help to us in doing the lessons or. Again, you see at the time the farm work had to be done it was the primary object you see at the time. More then, I think the children were not so precious at that time. It was up to each one of us to kind of erm do our own thing and if you were you know erm bright enough you survived- you did good enough. But as I say we, I know we would have had a different life and a different upbringing all together if er if she had been with us. Because she, my memory of her now which of course would be vague, would be you know that she was the stabiliser of the family. My dad was a reader, what would I say, kind of a bit of a scholar more than a farmer really. But like err, he read books all his life and erm he erm as I said looking he was a good dad, he never left us, he never left us alone at anytime you know we were never left alone as such you know erm do ya know that caring that a mother can do, that only a mother can do".*
>
> *[Peggy 80, nine when he mother died of cancer]*

So for Peggy the emotional culture within the family changed when her mother died and her father was not able to support them in the same way her mother had. The children had to become self sufficient and able look after themselves and no longer functioned as a cohesive unit. On reflection Peggy acknowledges that if must have difficult for her father to cope with looking after the family. Not only was he suffering with his own grief he also had to run the farm and this had to take priority (as it provided their income). In addition, as Peggy points out children were not valued in the same way when she was growing up (1930s) as they are today. Peggy feels being deprived of a mother's love has had implications for her in adult life, especially in terms being able to express her feelings, particularly towards her children:

> *"I'm not a very demonstrative person but they (her children) would know that you see that I would be there for them, you know. And would you know that I do love them... they kind of erm appreciated that they are loved for who they are and erm-you'd only hope they do you know. But as I say for me to tell them openly that I love, I wouldn't be that kind of person. Now if my mum had (been alive) I've now doubt you know she would have you know done that to us you know but erm. But again you see I know in my heart he was a very undemonstrative person whereas erh deep down you'd say he was he was quite loving really but just no demonstrative you know".*
>
> *[Peggy 80, nine when he mother died of cancer]*

Peggy feels that she has been able to express her feeling openly to her children in the same way her father had not been able to express his love openly to his. However, she hopes that they are aware that she loves them in the same way she was aware her father loved them.

Joan, aged 57, was eight when her father died and the second youngest of twelve children. Unlike in Peggy's narrative, Joan's story is reflective of an emotional culture in which the children experienced little love and affection, even prior to the death of their father. Joan explains:

> *"We had parents that never showed us much love and affection but we just put that down to them always working- me mum was always working and then tired all that and I'm a bit like that with me own children. It's just cos I'm not used to it- we never got it when we were kids it just seemed funny to do it sort of thing so I suppose its affected me in that way".*
>
> *[Joan 57, eight when her father died of a lung condition]*

In this extract from Joan's narrative the pressures of providing for a large family are used by Joan to explain the apparent lack of love and affection during childhood. Joan believes that this has impacted on her relationships with her children. She sees it as underpinning that fact that she has found it difficult to show her children explicit signs of love and affection.

The pressures of caring for a large family affecting the emotional culture within the family are also reflected in Lucy's narrative. Lucy, aged 43, was ten when she lost her father suddenly in a plane crash. She was the eldest of six children all of whom were brought up by her mother after her father's death. Lucy's believed that the emotional culture of the family was such that it was unable to support her emotionally, even prior to her father's death. The added pressures of caring for a large family impacted on communication and family relationships:

> *"I can remember periods of being sad when I was young but I don't know if I was sad before that happened or after, I just know there were times when I came home from school and was a bit low. But, there wasn't really an opportunity in the family to sort of talk about that- you just had to get on with it because so many of us -my mum had a lot of demands and even if I had been [sad] before my dad was killed in the crash I might have – he was very busy with his own business, he was very busy so I don't think we would have talked about it anyway".*

[Lucy 43, 10 when her father was killed in a plane crash]

She goes on to talk about the sort of relationship she had with her mother:

> *"she doesn't really approach subjects like sex, bereavement anything, relationships at all we don't have those conversations at all so I think if we had had a frank open relationship from early on then maybe she would have said but I mean I can remember she didn't even tell me she was pregnant with M [name of youngest sibling], I sort of had to piece that together as well so you can see how our family was err I mean if I hadn't have asked would I have just come home one day and found another brother I don't, you know so I think piecing it together was, it was for us to do and it's been like that with so many things, like sex, periods and umm, she never talked about sex or periods so therefore I don't think she would have said anything different when she was breaking the news to me – just dad's not coming home and leaving it for me to work out- that's her way of doing things rightly or wrongly. I don't know what*

> *she told the others urmm I don't know. And we don't talk about it[her father's death] very much amongst ourselves, I do a little with my sister now – a bit more, a bit more but I was just like ermm it was there but not spoken about, which possibly was wrong, I don't know-mum doesn't mention him[dad] very much.*
>
> [Lucy 43, 10 when her father was killed in a plane crash]

These extracts from Lucy narrative suggest that there was very little communication between Lucy her mother and the other siblings, both prior and after her father's death, which Lucy believes to be partly due to the demands of looking after a large family. Whilst Lucy's mum appears to have managed to attend to the physical needs of the children like Peggy's father and Joan's mother she appears not have been able to engage with them emotionally. Thus the emotional culture within the family appears to have been such that Lucy was not able express her emotions or discuss issues openly with her mother, including the death of father. As a child Lucy was able to accept this as "how things were" and acknowledges that this was her mother's "way of doing things". However, as an adult she recognises that this has had an impact on them as a family, both then and now:

> *"I suppose we were all a bit separate in our family and still are- I don't feel that close to my mum, I had to tell her something recently and it's taken weeks of courage to tell her something and I'm not really that close to my brothers and sisters ,slightly better with my sister recently , I think it was because we were separate and left to work things out for ourselves and that's how*

> *it has always been and that as I say how we found out about the accident was piece it together"*
>
> [Lucy 43, 10 when her father was killed in a plane crash]

Lucy believes that she does not have a particularly close relationship with her mother or her siblings. For Lucy this stems from the fact that they have always had to work things out independently rather than being encouraged to discuss issues in an open manner with each other. For Lucy the death of her father exacerbated this.

Similar threads are visible in Anne Marie's narrative. Anne Marie was also not allowed to talk about her mother. Anne Marie refers to the time when she was in school shortly after her mother had died and she became distressed:

> *" I remember kind of stifling these tears, stopping myself crying, wiping my eyes and then the bell must have gone and I'd gone to meet my dad and that was the first memory of me stopping myself from being upset about it. And then that was a recurring theme throughout my life now, it's just- I wasn't allowed to be upset about it because I knew my dad would go mad because I presume he couldn't cope with it- I don't know, I just felt like he would be very, very angry".*
>
> [Anne Marie 25 aged 8 when her mother died of a brain haemorrhage]

The fear of her father's response Anne-Marie believed prevented her expressing her emotions. According to Anne-Marie this has had a profound effect on her life as she finds to difficult to express her emotions. The most essential element in grief resolution in a family is the ability to engage in open and honest communication. If the loss is to be acknowledged as a real and the grief resolution made a collective experience, members must be able to communicate clearly with each other (Brodick, 1993; Jordon 1990). Supportive communication facilitates the discussion of thoughts and emotions and makes it easier for members to share their beliefs about the meaning of loss for them (Gilbert & Smart, 1992). One crucial element that cannot be overlooked is that family members must engage in the simple but difficult act of listening to each other (Gilbert and Smart, 1992).

7.4. The relationship with the parent that has died

The narrators that had memories of their parent(s) often drew attention to the nature of this relationship. It was often compared to the relationship with surviving parent as in the following extract.

Alison was very close to her father. She talks about how she felt when he died:

> *Then I think afterwards for a very, very long time erm feeling very hard done to that he died. And that it wasn't fair and that, and also going through quite a while wishing that it had been my mum that died and not my dad cos I was far closer to him than my mum and thinking well why does that happen. And why does it have to be that way round. Erm, and yeah, and just sort of feeling very, I don't know, just very hard done by for what seemed like a massive injustice urm to have happened*
>
> [Alison 33, age 14 when father died of cancer].

A sense of injustice and anger infuses this extract. Jane also was very close to her father. He made her feel like a significant being in the world. Jane explains:

> *She (mother) couldn't get on with me. It wasn't as if, we didn't even argue a lot. When I was leaving school, what do you want me to do when I leave school mum, just be happy, that was it. You know there was never any, whereas you go to me dad and he'd you know he was full of all kinds of information, he was just brill you know, I could have a much better conversation. Upbringing was really, err sometimes, I think she [mother] must have thought she was a sergeant major in the army kind of, making sure everything was done in a certain way and done regularly whereas errm talking about boyfriends or hobbies was me dad's job. You know, he was the one that encouraged me to do everything I ever did you know. But you, it, me mother had just a bit, I don't know, I got on better with me dad so it was awful when he went.*

[Jane 51 was 17 when he father died suddenly of a heart attack]

Jane believed that she could not relate to her mother in the way she could with her father. Unlike her mother, he was the one that provided information, advice and support. He was the one Jane believes she could communicate with. Hence Jane feels that she had a much closer relationship with her father. Jane goes on to say as an adult how she feels when she sees relationships that appear to be close between girls and their mothers:

> *When I see relationships between girls and their mothers where they're really close and affectionate, I never went back to that cos I don't think I ever had it. Really, so it was more me dad I get a twinge in me throat what's the expression, I get a (.) a lump in my throat when I see girls like with their mums, but - errm I think it's lovely but [it] would have been nice I think. But then again, having said that there was not... you know there was no big, that must have been the way me mother was, maybe that was the way she was brought up*

[Jane 51 was 17 when he father died suddenly of a heart attack]

Seeing what she believed to be close and affectionate daughter/child relationships was emotional for Jane as it was sort of relationship she would have liked to have experienced with her mother. As an adult she is able to see her mother's upbringing as maybe accounting for the lack of closeness and affection between them.

Fiaza was seventeen when her father died after suffering a brain haemorrhage. She was the eldest of four girls. When her father died her parents were living in the UK, together with her siblings. Fiaza however was married with two children and living in the Yemen. Fiaza explained that the extended family (or kinship network) is very important in her culture. Having no brothers to support her meant that her father's death had 'a profound effect on her life' [Fiaza] as the following extract from her narrative illustrates:

> *Now if you've got a brother, if you've got problems in the family and you've got a brother you can turn to your brother and your brother will sort your husband out. Err, I now had no one, I didn't have a dad, I didn't have a brother, err anyway and I didn't have, now I haven't got a dad so I felt that like a hanger on the rail had gone*
>
> *[Fiaza, 17 when her father died of a cerebral haemorrhage]*

For Fiaza her father was perceived to be central to her phenomenological world, especially as she had no other male influences in her life to support her. When he father died she not only lost a father, she lost the ground by which she could make decisions, cry for help, receive protection and access support. He was especially important as she didn't have any brothers (other males) to turn to for support when she experienced difficulties with her husband.

7.5. Family beliefs and values: spiritual beliefs

The following extracts all relate in some way to the families spiritual beliefs and how they have helped or not helped in the bereavement process.

Jess's parents were practising Catholics and their faith and the church were central tenants of family life. Her account suggests that her faith has been of fundamental support to her:

> *"Mum and dad were a very, very large part of the local church, very involved and we were all in the choir and you know mum and dad used to do the readings and all sorts of things at that stage. So, certainly at that stage my faith really helped me through it... well I remember, after mum died I remember actually going to church, I remember going to do a Novena- you go for nine days on the run and do-try and go to mass for like nine days- try and kind of sleep, go and pray and erm worship or this set period of time and I remember choosing myself to go and do that by myself....I think it's partly just to kind of think about the afterlife, because I've had discussions about this with other members of the family you know thinking well mum's up there in heaven you know and she's looking down on us and I could always talk to her cos she was up there in heaven and stuff"*
>
> *[Jess 42, 17 when both parents died within six months]*

For Jess great comfort was derived from her faith, in particular through the ritual of prayer and her belief in an after-life. Her belief in an afterlife enabled her to maintain a link with her mother and talk to her. The ritual of daily prayer was also important as it appeared to provide structure and order and a sense of purpose. Jess's religious beliefs continued to be of support and comfort to her whilst she was at university, although like many of her siblings Jess as an adult no longer believes in God.

Fiaza's family were Muslim. Like Jess, Fiaza's belief in an after-life was comforting to her and continues to be so:

> *"When I pray I say a little verse for him, I used to say it for him when me mum was alive and Islamicly they say that if you read this particular verse or something similar the angels take it on a silver platter up to that person and its like erm it's not like winning a prize but its recognition that you've got, that you the person that's passed away has left somebody behind to remember you- do you get me- and I often used to do that erm every time I prayed unless I was in a hurry or I forgot, but I always did. But now that they have both passed away, I say it for them both".*
>
> *[Fiaza, 17 when her father died of a cerebral haemorrhage]*

Fiaza's prayers then enabled her to maintain a link with her father (and with her mother when she died) and a way in which he could be remembered here on earth.

Lucy aged 43, was the eldest of six children. Her father died in a plane crash when she was 10 years old. Lucy explains:

> *"We were brought up as Catholics and I went to mass every Sunday and I went to a convent school but none of us go to church now, but then my sister mentioned that she went into a cathedral on his anniversary (of his accident) and I always make a point of going to mass on that date because in fact his birthday was the day before the accident so- I do make a point of doing that then but no other time really, just then cos he was a very committed Catholic. But it's the only time I feel that link with having to go the church just to sort of honour my dad and say miss you (upset)"*
>
> *[Lucy 43, 10 when her father was killed in a plane crash]*

For Lucy going to church is a way of maintaining a link with her dad and honouring his memory as she says "he was very committed to the church". However as a child she could not understand "why God has done this to me, you know six of us have just been left" [Lucy]. Hence it seems that Lucy feels let down by God and she is being punished in some way.

Margaret also talks about feeling 'very angry with God' when she was a child for letting her father die. As an adult her faith is very important to her. Through what she calls 'godly plays' she tells her stories in the hope that it help others. Margaret writes:

> *" It is not my story but the method which is important, but this opportunity has also helped me a lot, even after all these years, and maybe it has helped others".*

[Margaret aged 62, aged 8 when her father died of a brain haemorrhage].

Through this process then Margaret feels that she is better able to understand her own grief.

Colin suspects that his deep cynicism towards religion was in part a result of his father's death:

> *"I am firmly atheist and have a deep cynicism towards religion. I think that I was becoming pretty sceptical prior to my father's death but, in spite of much support from the local parish at the time, I suspect that this experience was formative. I regret this as I do feel unfulfilled spiritually. I like to visit churches and cathedrals and enjoy religious music, but find formal religion hypocritical and false"*

[Colin age 43, aged 16 when his father died of bacterial endocarditis].

It appears then that although Colin is an atheist, he still needs to feel fulfilled at a spiritual level. To an extent Colin clearly regrets his lack of religious beliefs as they might have provided the spiritual fulfilment he searches for.

7.6. Summary

In this chapter through the use of narrative extracts it was highlighted how stories of early parental loss were organised around the following family dynamics: changing roles and responsibilities, changes to the surviving parent, the emotional culture of the family, the relationships with the diseased and finally family beliefs and values with regards to spiritual beliefs. In particular it has been shown how roles and responsibilities often change as a result of parental loss.

Whilst the extent of this change varied in accordance with individual circumstances many of found themselves having to take on responsibilities for themselves, and (or others), such as other siblings and the surviving parent. By looking at how these stories were evaluated it could be seen that these changing roles and responsibilities were sometimes seen to be unwanted and resented. It could also be seen that for others these changing roles and responsibilities appeared to be borne out of a protectionism and (or) out of sense of indebtedness or obligation and perceived to be irrespective of need. The impact of these changing roles and responsibilities was seen too often extend into adult life.

By looking how changes to the surviving parent were evaluated by the respondents we get a sense of how this change was perceived to be particularly distressing them, especially in the short term as was believed to lead a temporary reduction in parental capacity which the respondents could not make sense of and it distressed them. Where changes to the surviving parent were perceived to continue over time this was believed to compound distress and effect perceptions of self worth, particularly when there was perceived to be no one to talk to or offer support. This was seen by exploring the temporal aspects of the narrative and the way in which the respondents situated themselves in the narrative.

Through exploring the key issues the story was organised around it how it could be seen how the emotional culture of family affected the bereavement experience in relation to the expression of emotions, the extent of communication between family members and relationships pre and post loss which extended into adulthood, especially in terms of their relationships with their own children and other family members.

By investigating how the emotional culture of the family was organised within the narratives it appeared that many were organised to some extent around traditional gender roles, with mothers providing the caring functions and emotional support more than fathers. In these families when the mother died the father often struggled to establish a warm, open caring climate in the home, especially where there were economic pressures to provide for the family.

In other families the father was believed to provide the emotional support, whilst the mother organised the day to day running of the household at the practical level. According to the narratives of these respondents when this parent died the surviving parent (or carer) although able to attend to the physical needs of the family struggled to provide a warm, caring, environment for the family, again especially where there were economic pressures and (or) large families.

There were also families where the emotional culture was such that parents did not communicate with their children nor engage with them emotionally, even prior to a loss. Through exploring how respondents evaluated this aspect of their stories it was apparent that to an extent this was explained in terms of the pressures of providing for a family, especially where there were large numbers of children. Again, such pressures were perceived to increase when the one parent died.

By investigating the cultural and social contexts in which the narratives were situated it was apparent that the emotional culture of the family, gender roles, beliefs about parenting (and the subsequent value placed on children) and beliefs concerning communication with children were embedded in the wider social and cultural processed and practices. They were also seen to be influenced by economic factors. These dynamics were seen to be historically rooted and change overtime.

Through exploring the beliefs and values of the family with regards coping with the loss that were inherent in the narratives regarding the bereavement process and how they were evaluated it could be seen that spirituality has been of enormous help and support for some respondents. For others God was a source of anger as these respondents felt angry with a God who could allow such pain and loss. By exploring the way in which those that have lost their faith evaluated the stories it could seen that going to church on the birthdays of the deceased or on the anniversary of their death was seen (and continues to be seen) as a way of maintaining a link with the deceased parent and honouring his/her memory. Others felt let down by God for taking away their parent or that they are being punished by him in some way. For others their deep cynicism towards region was in part due to their parent's death.

Family dynamics then shape the bereavement experience in multi-faceted and complex ways. These different elements were seen to be relational and context bound and changed over time.

Chapter 8:

The public world of bereavement: the social and cultural context:

The previous chapter revealed the ways in which the bereavement experiences of those who took part in this study appeared to be mediated by complex family dynamics including roles, relationships and context. As Jessop and McCarthy (2006) point out the complex effects of loss and shifting relationships do not just impact on family networks but also on the social and institutional affiliations in which the bereaved live their lives.

The exploration of narratives in this study also revealed how the wider social practices and context shaped individual experience of bereavement. The narrative themes included others don't understand, the public expression of grief and social support: social and institutional affiliations.

8.1. Others don't understand

The thread that runs through many of the narratives is one which reflects on the impossibility of others understanding the pain, grief and loss experienced by those that have lost a parent. Amy was seventeen when her mother died suddenly of a brain aneurysm. When she took part in this study she was twenty and a student at university. Amy explains:

> *"We were having an ethics class and erm we were talking about whether someone has the right to choose if they want to die when they could be saved when there is medical treatment that would saved them. Urm, and I said that I don't think that people understand what it actually means for someone to die, and for someone near to you to die. They were sitting there going 'I know what it means' and I'm sitting there going,' have you ever lived with someone every single day for your entire life and then one day they are just gone and that's it'. You know I can't even remember what my mother's voice was sounded like anymore and it's very difficult to picture her face without thinking of it in a photograph of her we have. People go no, no, I know what it means my grandmother died and I'm sitting there going it's not the same thing. You know, nobody understands what it's like to die, unless they have died and then obviously then they're dead. But there I sit there and think you really don't get it".*

[Amy, 20, 17 when her mother died of a brain aneurysm]

It is clear from Amy's account that despite well-meaning attempts to offer sympathy she feels that her peers can't understand her pain and loss as she believes them to have no relevant experience of death. The more her peers try to empathise with her, it seems the more she feels irritated that they cannot understand the extent of her anguish. She goes on to talk about her frustration:

> *"And I look at people, even people my own age and they just seem so immature. You know the ones, you can tell the people who things have happened to in a way er, because of the differences, you can tell you know the people who have had something bad happened to them in the past because they often are that much more grown up. I look at the people in my class and admittedly most of them are a year younger than me – I just sit there and go honestly how can you act like this, it's so childish .. I'm probably more selective about who I'm friends with because I don't want to be sitting there going you're such a child".*
>
> [Amy, 20, 17 when her mother died of a brain aneurysm]

Amy's narrative has much in common with others in this study. She speaks of the same irritation at the same well-meaning people who say they know how it feels lose a parent. Also, she feels the same frustration towards others perceived immature behaviour. Like others in this study, she also feels that she can recognise those that have experienced some kind of trauma as they are perceived them to have more maturity.

Shelley, aged 22, having just started high school when her father died and found it particularly difficult to talk about his death:

> *"Umm well obviously like it was pretty difficult cos I just started at high school like, I'd only been there for about three or four weeks cos he died in the October umm so I found that quite difficult ... cos like I didn't know any of the people when I started that school umm and a lot of people who I sort of been making friends with they weren't quite sure what to do about this, like*

> *how to be with me ermm and so you know I found that a bit strange as well cos it meant it was difficult to sort of make new friends ermm to begin with because people all treated me a bit differently than they would have done"*

[Shelley, aged 22, was eleven when her father died of heart attack].

So for Shelley having just started at a new school meant that she had no established network of friends, so there was no one that either knew her, her family or her father. Hence she apparently found it difficult to talk to her peers about her father's death. Furthermore, she feels that her father's death made it more difficult to make friends as they treated her differently.

8.2. The public expression grief: a taboo subject

According to Walter (1996) there may be cultural resistance to talking about death. Jimmy narrative illustrates this:

> *"But I can remember in, even around school people just didn't talk about it so they would know and even before my mother died you know people would, there was a fella who was, you know a fellow erm footballer and basket ball player in the teams*

> *with me and even though his mother was nursing my mother you just didn't talk about it. Just never talked about it- the imperative was whatever you say, say nothing".*

[Jimmy 48 aged 8 when his mother died of encephalitis].

For Jimmy then, culturally death and illness were private matters that should not on any account be discussed in public.

Alison's narrative was also structured around the public expression of grief. She was fourteen when her father died.

> *"I just sort of kind of describe at school as just being permanently traumatised throughout the whole time and really. If I was challenged about anything, err about anything I remember I would just cry. And then I remember one of my teachers who was sort of very much kind of the old school you know belt and braces, you don't cry pull yourself together and so then I realised that I actually didn't cry about anything for about 10 years and I'd almost lost the capacity to be kind emotional about anything urm after repeatedly being told you can't or it's not appropriate to do that"*

[Alison, 33 was fourteen when her father died of cancer]

This extract from Alison's story illustrates the significance of her teacher's response to her expression of grief. Alison believed that her teacher's response to her crying in public contributed to her inability to show emotion in early adulthood.

Freddie was twelve when his father killed himself accidentally in an act that is frequency labelled as sexual aberrancy and one that society would rather not acknowledge (Kirsksey, Holt-Ashley, Williamson, & Garza, 1995). Commenting on his father's death Freddie said that 'it's an unfortunate way to go cos it's embarrassing and obviously quite upsetting at the same time'. According to Freddie's narrative his father's death received extensive media coverage. Hence, Freddie was kept of school for quite a few months and he was prevented from seeing the media coverage. Freddie believes that this was done in order to protect him. Freddie talks about what it was like returning to school:

> *"Well socially it was tricky because obviously if you stay away for a long time it sort of builds into a bigger issue also I think obviously people had forgotten about it somewhat- not, not forgotten about it but it wasn't what they talked about in the same way obviously when I went back everyone knew about it because it had been in the local papers and things. Umm, but people were generally just you know really quite wary of speaking to me at all, at all about it"*

[Freddie 23 was twelve when his father killed himself accidentally]

This extract from Freddie's narrative appears to suggest that this type of death was particularly difficult to talk about in the public world. The reluctance of his peers to engage with Freddie about his father's death to an extent was likely influenced by the details of his father's death being made public. Freddie continues:

> *"I have always had a quite small bunch of friends in school I had some really close friends, but only one or two. Umm, and they knew, again they knew what had happened but I never really spoke to them about it... I spoke to my mum quite a lot and there's a guy I used to go kayaking with quite a lot- he was one of my friends from school I spoke to him quite a bit, I'd known the family all my life – and he'd met my dad umm so I spoke to him briefly about it – it was probably the most I spoke to anyone outside my family. Umm, and obviously because I haven't really spoken to anyone about it properly I don't really know what I think would happen and this [in the interview] is probably the first time I have ever really explained how I felt about it".*

Freddie seems to have never really talked to anyone about this father's death apart from a close family friend and his mother, perhaps for fear about how people would respond. It is likely that he was able to engage with this particular friend and his mother (even though his mother and father were separated) because, unlike his peers, these people appear to have known his father and to some extent maybe shared the loss and thus more likely to be understanding and less likely to be judgemental.

A similar theme runs through Jan's narrative. Jan aged 51, was the youngest of four children and twelve when her father took his own life. Jan's father was an alcoholic. At the time of his death Jan's parents were separated and she was living with her mother who, according to Jan, suffered from "a severe mental illness". Jan refers to her reluctance to talk about the nature of her father's death with others, including her future husband:

> *"there was a terrible stigma with suicide and you don't like to tell people. That was me cos it was "don't tell and all this business, so I actually said to him (her future husband) he died of a heart attack"*
>
> [Jan, 51, was twelve when her father took her own life]

So for Jan the social stigma associated with suicide made her feel that she needed to hide the true nature of her death from others, including those that would be important in her life.

The public expression of grief was also a thread that ran through Fiaza's narrative. Fiaza refers to going to see her father at the mortuary:

> *"When the guy did show me, me dad in the mortuary it was like it wasn't me dad and err somebody was there, a stranger to me who was standing there, you know that's his job you know whatever they call him, the guy who's responsible for the mortuary but I felt I didn't have space to grieve".*
>
> [Fiaza, 17 when her father died of a cerebral haemorrhage]

For Fiaza the physical presence of a stranger in the mortuary with her prevented her from expressing her grief. Being Muslim, public displays of sadness indicate to the community the loss of a valued member (Hendayak, 2006). It also cues others to look after and relieve the bereaved from basic duties for a while.

8.3. Social support: social and institutional affiliations

Narratives were often organised around the extent of support the bereft received from their social and institutional affiliations, such as schools, religious organisations, health alliances, neighbours and friendship networks.

Sue R, aged 51, was nine when her father died. She was brought up by her mother after his death along with her younger brother. Sue said:

> *"I don't think actually when I was younger it [her father's death] had a lot of effect on me because I think I was quite social you know, had lots of friends and erm went to Sunday school and that, church youth club and had a lot of friends there . And I think cos, that I sort of had some friends with dads – they sort*

> *of, they became like surrogate dads really... there was a guy who was like me Sunday school superintendent- who is quite poorly now- but I still see [him]. So erm, I suppose he was like a father figure really"*
>
> [Sue R 51, nine when her father died of a lung condition]

So for Sue the effect of her father's death was mediated to an extent by the males in her social networks who helped to fill the fathering role and provided a role model.

The influence of social affiliations was central to Sam's narrative. Sam writes:

> *"My father's death caused my mother some disillusionment with religion but she was happy for me join a church choir hoping that the Church would exercise a strong moral influence. She was less enthusiastic about my joining the Boys' Brigade as she still remembered its early military associations but soon came to see it providing "manly" activities in a safe environment under the control of dedicated men who were providing a strong masculine influence, which she did accept was lacking in my life".*
>
> [Sam aged 72 aged 3 when his father died of valvalar heart disease].

So for Sam (and his mother) these social affiliations were importance as they provided access to male role models and moral guidance.

Christina also found support from an affiliation with the convent she attended:

> *"It was tremendously important to me, but it wasn't just a faith, the convent had given me security. It wasn't just a place of worship or a holy house. Unlike the other children who had gone off through the school gates and gone home, I'd actually seen the other side of this convent life- that was the security. And better still I could probably walk into most convents now and fall into the routine even now quite naturally. Even there the behaviour habits- their practices-wouldn't be strange to me. I'd now that the ring of those bells meant that it was rosary time, no problem. And it's not, they'd be no awkwardness there, or it doesn't feel right, it was a sense of security as well as a belief"*
>
> [Christina, age 57, age 5 when lost mother died of leukaemia].

So for Christina the relationship with convent life provided a sense of security. It was a world that was predictable and ordered, a place where she knew the routines: a world where she felt safe and secure.

Support was also a central tenant of Gerald's narrative. His father, a retired Presbyterian minister, was well known in the local community. However, Gerald feels that he had no support from his affiliation with this church community:

> *"I think they might have supported my mother- I'm sure they did support my mother very well. I think, looking back on it now I think in an analytical way I think actually what it was, was that they assume that a 17 year old boy can cope and they just didn't do anything or say anything or you know really at all".*
>
> *[Gerald, age 62, was 17 when his father died after varying degrees of ill health]*

Gerald believes then that the support from his church community was directed at Gerald's mother not him. On reflection Gerald believes that the lack of support from his church community was based on the assumption that as 17 years old he did not need support. However, Gerald was able to access support from other sources. He explains:

> *"But I got a terrific amount of support from my friends at school, from my teachers at school, particularly one particular teacher. And as I say from family, friends outside the church circle. And the interesting things is, again looking back on it I mean I'm taking this is just north of P[town]- that area is essentially a large catholic population and most of our friends despite being English Presbyterians, most of our friends who were not church members were actually Catholic. My father was very open minded about all of this he was not at all sectarian and you know I can remember getting a tremendous amount of support from neighbours, you know friends and neighbours who were actually Catholic but it was not given any religious sense it was just afterwards when you sit and think about it all you know"*

[Gerald, age 62, was 17 when his father died after varying degrees of ill health]

So for Gerald most of the support he received had come from friends at school, a particular teacher and neighbours outside of his church community.

A similar thread runs through Jane's narrative. An only child Jane was also seventeen when her father died suddenly of a heart attack:

> *"And erm there was a welfare officer from the police came round to offer some assistance I don't know what, she'd talked to him in another room so I don't know, but nobody came and sat with me. Err, it was always me mum, they'd come and see me mum, I don't know whether she thought you know that I shouldn't be exposed to this kind of thing or whether I was too young to understand it but, the overriding feeling was that I felt left out* . I think it was me age, I think if I'd been older I might have had some kind of, somebody to sit and listen to how I was feeling*"*.

[Jane, 17 when her father died of a heart attack]

Like Gerald, Jane believes that there was support for her mother but not for her. Jane makes sense of this as seeing it as maybe protectionism due to her age. Whilst this may have been done with the best of intentions the result was that Jane felt excluded. As a consequence of this experience Jane says:

> *"And if anybody dies that I know-you know it sounds terrible that doesn't it -I always try to make sure that I take a bit of time out and say some...try and offer something to them so they never feel left out"*

[Jane, 17 when her father died of a heart attack]

Jane then feels that she needs to offer support to others that are bereft in the hope that she may prevent them feeling excluded like she did.

Threads of being excluded also ran through Dan's narrative. Despite having quite a lot of involvement with health professionals when his father was ill Dan believed that nobody engaged with him and his brother:

> *"I mean we had, there was quite a lot of involvement by MacMillan and things like that, but they never- I can't remember any of them speaking to any of us. I can't remember the nurses speaking to us; I can't remember any of my dad's doctors speaking to us. I remember seeing the oncologist as a fairly sinister fellow who seemed a bit uncomfortable with us you know he seemed to get out of the room when we were around. Err he seemed like a suit, a guy in a pinstriped suit- always wondered what he was up to. And maybe, well I am sure it would have been nice if these people had engaged us a little bit, I don't know. It's difficult cos my dad couldn't engage us in these things so how's err, I don't know what a clinician is suppose to do, talk to kids on their own or whatever"*

[Dan 33, was five when his mother died and sixteen when his father died, both from cancer]

Clearly Dan feels that he would have liked the various health professionals to communicate with him and his brother. However, on reflection Dan recognises that this may have been difficult, not least in practical terms.

Jan's narrative also refers to the fact that there was no support for her. She explains how this affected her:

> "*So I think I went through a lot of pain simply because nothing was done. Now people knew this [her family circumstances], families, church people, doctors, the list can go on. I'm not bitter about it, but it would have been quite nice if somebody would have said something and tried to help".*

[Jan, 51, was twelve when her father took her own life]

Jan feels then that she was put through unnecessary pain because nobody acknowledged what she was going through or came forward to offer help or support, despite different members of the community being aware of the situation. Hence she feels let down. She explains how this has impacted on her:

> *"it has made her the person that likes to interfere with everything now(laughs) you know it made me- oh gosh, right something will have to be done about that, if I think that's wrong or somebody needs help I'm the good Samaritan"*

[Jan, 51, was twelve when her father took her own life]

For Jan the lack of support surrounding her father's death has made her keen to help others.

8.4. Summary

The exploration of the narratives in this study revealed how the wider social practices and context mediates individual experiences of bereavement. By investigating the issues and events the narratives were structured around and how respondents evaluated them it was possible to establish which issues were of particular importance in this regard. These included others don't understand; the public expression of grief; a taboo subject and social support: social and institutional affiliations.

The narrative extracts used in the chapter suggested that others cannot understand the extent of their pain and suffering unless they have relevant experience on which to draw. When exploring how these respondents evaluated their stories in this regard it was apparent that this perception had an impact on their relationship with others in that perceived themselves to be more selective about potential friendships with peers as they saw themselves as more mature than others their own age.

The narrative extracts also highlighted that the public expression of grief is often difficult. The exploration of the narratives revealed that this may be due to the fact the deceased parent may not be known within a particular community or friendship networks. When looking how respondents made sense of this it could be seen that this makes it difficult to talk about the deceased as they have no shared understanding of the person that has died. This was perceived to be especially difficult where the death has occurred in socially unacceptable contexts.

Family beliefs and values surrounding the expression of grief makes to difficult to talk about grief in public. This is compounded by the taboo surrounding death and how social and institutional practices serve to repress emotions which may have long term consequences for the bereaved.

Social affiliations may mediate the bereavement experience. By looking at how these social affiliations were evaluated in the narratives and how the key characters were portrayed it was possible to see for some respondents social afflictions provided support in the form of security, surrogate parental guidance, role models and moral guidance. For others these social affiliations were perceived to exclude and isolate children, albeit unintentionally through not including them in discussions. Hence these children often feel let down and alone. These respondents believed their exclusion was either based in that belief that they were too old for support or in order to protect them from further distress.

Chapter 9:

Impact on identity: aspects of personal growth

It should not be surprising that living through what is likely to be a profoundly disruptive experience in their life affects the ways in which people perceive themselves and the world around them. The loss of a parent(s) threatens fundamentally the sense of self, the future and relationships. More than 40 years ago, Caplan (1969) noted that life crises are "turning points" that can contribute to personal growth. However, empirical research in this area has mainly focused primarily on how life crisis, including bereavement, lead to distress, depression and impaired functioning.

In this study it was found that despite the grief and loss that the death of a parent(s) brings the majority of narratives were organised around aspects of personal growth. These included an evolving sense of strength, autonomy, independence, enhanced coping skills and perceived maturity. They also included a deeper appreciation of life, and greater empathy and understanding towards others that had experienced loss.

9.1. Evolving sense of strength, autonomy independence and maturity

Often in these stories there was an evolving sense of strength, autonomy (make decisions for one's self) independence and maturity which respondents thought resulted from having to manage the situation in which they found themselves after their parent(s) death.

Jess was 14 and the second youngest of four children the youngest of whom was four years old when their mother died of leukaemia. Once all the elder siblings had left home to go to university Jess was very involved in her younger brother's upbringing.

> "*So obviously when it was me and just E(name) and dad it had a fairly major impact on my teenage years really. So erm, I don't know how to comment, explain any of it – but I was involved you know [in running the] home, well E(name) was kind of going to nursery and then going to school and stuff so my dad organised a child-minder to help with some of that but it meant that when I got home from school- I used to get a lift to and from school- and when I got home from school I'd have to go down the road and pick him up from the child minders and things like that, I had quite a lot of responsibility like that. I used to have to make his packed lunches for school which I felt 'oh I shouldn't have to be doing this' (laughs) and those kind of things- there were lots of kind of grown up things that I just needed to get on and do you know but erm as a teenager you don't always appreciate that really (laughs)*"

[Jess 44, aged 14 when he mother died of leukaemia]

Taking on adult roles and responsibilities for Jess provided a sense of being mature beyond that expected of a teenager. Whilst this experience clearly restricted her life as a teenager and undoubted had a impact on her social life it also provided her with enhanced management and practical skills although the extra role and responsibly was sometimes resented.

Gerald, now in his 60s, was 17 when his father died suddenly at home one morning after about five years of varying degrees of ill health (he was 51). Gerald was at home at the time. He also had to take on extra roles and responsibilities when his father died as his mother was unable to cope and his brother was only 8 at the time. Gerald had just finished his mock A-levels:

> *"In general I had sort of thought now well what do I do. And, ermm so basically it happened and my mum went completely to pieces. I managed to pack me brother off to a friend, some friends and you know obviously all the business you know- you get the doctor in you know, the undertakers and all that. So I more or less dealt with the whole thing really, I mean not completely directly cos when you are 17 in 1961 you don't err that wasn't on really you know. But what I wanted to happen happened should we say- got people to do stuff you know...I spent a lot of time with me brother, you know I was trying to sort*

> *of, course you can't mitigate it but at less trying to get him though it and I did actually spend on awful of time with him. But I did feel on my own... I think that then changed the way I go about things- it has affected how I have done everything since. I have a tendency not to rely on anybody and I mean personality wise – I'm not saying I do everything myself – I manage people and I'm quite happy to delegate but I don't rely on other people for what, for stuff basically. And I consider it very important to pay my own way and to not owe anybody anything...*
>
> [Gerald 62, 17 when his father died]

Gerald's narrative has much in common with others in this study. He speaks of how taking on these extra roles and responsibilities after the death of his father with little outside support has contributed to him being very independent in adult life. In addition, he speaks of the irritation he feels towards those who don't make the most of their opportunities.

> *"In being that independent erm I do get irritated when either friends or relations don't seem to justify their promise in some way errh that's perhaps the wrong way to put it. Umm, when I see people who have got a chance to do something and they bugger it up or they can't be bothered, it does irritate me"*
>
> [Gerald 62, 17 when his father died]

Threads of autonomy, independence and maturity also run through Helen's narrative. Helen now 35 was 10 when her mother died of breast cancer and the youngest of three siblings:

Urm I think the other funny thing or I think I've got from all this was that my dad obviously didn't take me clothes shopping – hated it urm so he kind of devised a way we had like a clothing allowance and we went off – I was doing this a ten/eleven years of age- having a budget to work to and going out getting my school uniform, labeling it you know- I didn't have to do any washing or ironing , we had somebody else doing that… I had to get everything out of this clothing allowance – there was nothing more. None of this you know going shopping at the weekend I'll go and treat you, none of that actually ever happened. I mean it wasn't my dad being tight it was just the fact that you know that was how I suppose he wants us to learn about money in a way. .. I don't thinks it's all negative – I've got lots of independence from it --found me feet very quickly I think, that's what you have to do and erm you know its ermm yeah… I suppose its erm; it's given me quite a few positives. Urm, so just think about relationships I suppose as I was saying about the independence side of it, it's always , that is me I don't erm I don't have to have somebody all the time I suppose and that was really good for relationships because if you know broke up with a fella or whatever it didn't matter- I could live on my own, I could feed myself, I could fend for myself, I could do all that. Erm I think one time I think me dad even called me bloody-mindedness because I was that stubborn and independent. But that was just me erm and that kind of helped I think with finding relationships err sorry, to survive relationships that break up. Erm, it also means that I can be a bit distant I think as well a little bit erm sometimes my husband says you know come on let me in a bit you know(laughs) no I'm too independent and it's like you know oh come on we're a bit of a partnership now you know

[Helen 35, 10 when her mother died of breast cancer]

Again it appears that Helen is forced to mature early as an indirect result of her mother's death. Whilst Helen feels she has missed out on some aspects of family life she feels that there are many positives. Whilst she didn't have to take on any domestic duties or wasn't responsible for care of others within the family, since ten years of age she has had to learn to be self sufficient and independent which has tended to be useful attributes during adulthood. However, for Helen such independence has also proved to be problematic in terms of relationships as it has on occasion prevented her from sharing things with those close to her.

Autonomy, independence and maturity were not only the result of taking on adult roles and responsibilities, or the need to self sufficient. They were also seen to be structured around how the attitudes of others affected perceptions of self worth and self esteem which in turn served as a driver for independence and autonomy as illustrated in the following extracts:

Jane aged 51 was 17 when her father died suddenly of the heart attack. Jane was an only child. When her father died Jane's mother found it difficult to come to terms with her loss and subsequently suffered from severe mental health problems. Consequently, Jane had to take responsibility for herself, her mother's care and running a home. When her mother's condition worsened she had to be hospitalized. As Jane not legally old enough to live alone she had to live with the mother's brother: This relationship was difficult for Jane as she believed that her uncle blamed her for her mother's illness:

> *"But me mum was out of it and for some strange reason the brother blamed me for urm somehow making me mother peculiar which had literally lived with me all my life which had had all kinds of implications I'll tell you "*
>
> [Jane 51 was 17 when her father died of a heart attack]

She also believed that her uncle did not want her living with them:

> *"He didn't want me there, I felt very uncomfortable living in his house, I wanted to go back to me own house but I couldn't, cos I was under age"*
>
> [Jane 51 was 17 when her father died of a heart attack]

When Jane was 18 she was able to return to family home. However, she was financially dependent on her uncle as she didn't have the financial resources to pay the household expenses. Jane explained how "the whole business" with her uncle affected her:

> *"The whole business with Uncle R (name) made me feel worthless (.) useless, err I'll never rely on anybody else as long as I live I will always make sure I have got enough money to*

> *sort me out , it has made me really not want to ever be in a situation where I had to ask for help ever again cos I felt so, he made me feel so useless and worthless ".*

[Jane 51 was 17 when her father died of a heart attack]

For Jane her need to be independent is related to uncle's attitude towards her and the way her made her feel about her mother's illness and Jane's subsequent financial dependence.

Despite seeing herself as very independent and mature as a result of taking on extra roles and responsibilities when her father died Claire has also suffered from self esteem issues. Claire, now 32, was 13 when her father died due to complications arising from a flying accident years earlier and subsequent mental health problems. However, Claire's inability to express her grief affected her relationship with others, especially her mother:

> *"I was carrying all that guilt around that we had such a bad, bad relationship and when she'd shout at me and say didn't care about your father dying, you didn't love him and you know this that and the other it was just making me feel more and more guilty about it- that was quite you know well I'm right to feel guilty cos mum's telling me all the time that I should feel guilty about it so I did and think my self esteem- I don't give myself very many breaks. I don't sort of see a great deal of positives in my personality if you like. You know if somebody said to you know you're a really lovely person – I sort of say no I'm not "*

[Claire 32 lost her father when she was 13 from complications arising from a flying accident and subsequent mental health problems]

The subsequent guilt Claire experienced as a result of the breakdown of her relationship with her mother, as Claire sees it, was reinforced by her mother's attitude towards her which in turn was seen to have a negative impact on her self esteem and affected her adult life.

9.2. Empathy and understanding

Empathy and understanding were also threads that ran through many of the narratives: Claire's experiences surrounding her father's death has led her to work with alongside people with suffering from mental health problems:

> *Yea cos I think-I work a lot obviously with people with manic depression – I go to their houses to see them um you know sort of see their families a lot as well and I think I feel like I can give something back and can sit and can talk to people and I can understand the situations that they're in. I can empathize with people and it makes me feel like I have got a purpose. Like what I'm doing means something. And I quite enjoy being able to use the empathy that I have and the understanding that I*

> *have to hopefully help somebody somewhere. And I think that's given me quite a lot – its help me self esteem definitely and my self confidence, definitely it has.*

[Claire 32 lost her father when she was 13 from complications arising from a flying accident and subsequent mental health problems]

So for Claire as a result of her experiences feels she can empathise and understand people with mental health problems which in turn helps has helped Claire to become more confident and have a purpose in life.

According to Jess, her experiences have heightened her awareness regarding those who have lost a parent(s):

> *"I think it has heightened my awareness of, well other people who I know have lost parents; I feel I have a kind of bond with them. It's strange I've kind of, other people would probably think oh well like you know I, people I've told in the past may come back and say 'oh you know you going to your mum's for Christmas. You know, I think, 'I've told you, I know, I remember telling you' and you kind of think you know I haven't got any parents – whereas I'm sure I remember if somebody tells me that they lost a parent at some stage, I'm sure I remember it on most occasions and think ohh just like me then. You know I kind of, I don't know err don't know what the word is, empathy or mutual understanding of what they've been through as well, or something. So I think you know I think that's, I've just been more aware of that I think"*

[Jess 44, aged 14 when he mother died of leukaemia]

Margaret also feels empathic and understanding towards other children's suffering from bereavement. She writes:

> *"I always try to speak up for issues of inclusion in school (I am a teacher) and in church. Also I have always advocated telling children including children in family bereavement because of what happened to me. I find it easy to speak about treatment issues with children. I have had the opportunity to lead Rainbows group which is a course designed for bereaved children"*
>
> [Margaret aged 62, aged 8 when her father died of a brain haemorrhage].

9.3. A deep appreciation of life

A deep appreciation of life is exemplified in the following extract from Alison's, Amy's and Sally's narratives:

> *"I'm very much focused on this is what I want for my life, I am going to work towards it now and make sure that I do the things that I want to do because I don't want to waste any of that time you know, I feel like I know what's important is erm".*
>
> [Amy, 17 when her mother died suddenly of a brain aneurysm]

> *"But I guess, but when my dad died I realise you don't just know what's going to happen, especially because my cousin died so quickly afterwards. And I said I've kind of always, I've always lived with this assumption that you don't know what tomorrow is going to bring. Urm which I think started off certainly in my early twenties, I think I was absolutely ruthless in terms of doing what I wanted to do because I might not have the opportunity or the people might not be there or whatever- I think I've kind of got a much better balance on it now but yeah, just in terms of thinking if there is something that I want to do, if there is something I want to see, if there is an opportunity then I might take it. And with my friends I'm like just do it you know because you don't know what will, what's round the corner"*

[Alison aged 33, 14 when her father died of cancer]

> *"you have just got to do, live each day as it is, enjoy everyday- I truly believe that and you know if there is something you want to do, do it you know so maybe another baby in a couple of years (laughs) and you sort of just wanta do and I sort of push M (husband) along yeah lets do this, let's do that and he'll do anything".*

[Sally, aged 32, was seventeen when her father died from a brain tumour]

In all these extracts there appears to be greater recognition of what's important in life, and acknowledgement that nothing can be taken for granted. Hence there appears to be a need to make the most and not waste opportunities or time. This deeper appreciation of life appears to have been brought about by their parents' deaths (and in Alison's case the subsequent death of her cousin) which appeared to make them realise that life is time limited and uncertain. This change in world view suggests that the tragedies that Alison, Amy and Sally have experienced have precipitated philosophical shifts towards more existential orientations (Shuchter & Ziscook, 1993). Whilst this need to live life to the full appeared to overshadow Alison's experience of early adulthood as she has got older she feels that she has been able to put this into perspective. Being younger Amy appears not to have had the opportunity to do this and there is still urgency about her need not to waste time and get on with life.

9.4. Summary

In this chapter it has been shown that the experience of early parental death has the potential to promote growth and development and may help to develop inner resources and strength which can be drawn on in adulthood. This is not to minimise the extreme pain, suffering and disruption the loss of a parent(s) may generate.

In particular it has been shown through exploring how the stories have been evaluated by the informants that taking on adult roles and responsibilities or having to be self sufficient can lead to autonomy, independence and enhance coping skills and maturity in adult life.

By identifying the central characters in the story and investigating how they were portrayed by the narrator it has also been highlighted how the attitudes of others may influence the need to be independent and not to be reliant on others in adult life. By also investigating how the narrator situated themselves in the narratives and the exploring the temporal aspects of the narratives it was also possible to see that this independence was seen to be problematic for some in terms of relationships with others as there was sometimes a reluctance to share matters with others that were close with them. It was also possible to see how the experiences associated with early the death of a parent helps to develop empathy and understanding as they can relate to others that have had similar experiences as they can appreciate some of the difficulties they face.

Through this investigative process it was possible to see how the experience of early parental death may to instil a deeper appreciation of life and what is important. Hence there is often an imperative not to waste time and to make the most of opportunities as the bereaved become acutely aware time -limited and uncertain nature of life and relationships and that nothing can be taken for granted.

These finding are important as they broaden our understanding of the impact of bereavement during, particularly with regards identity in terms to personal growth and allows some understanding of the way in which social processes impact on the bereavement experience in positive ways. More research is needed to in this area to see how these more positive aspects of bereavement can be nurtured and used to inform bereavement support.

Chapter 10:

Supporting parentally bereaved children and their families to achieve more favourable outcomes in later life

In this chapter two models for bereavement support anchored on the experience of the collective data have been developed and outlined. The first suggests key elements that may help both individuals and their families achieve more favourable outcomes following parental death(s). The second model may help practitioners and others providing bereavement support to identify those children who may be more vulnerable to less favourable outcomes in adulthood.

The definition of family is broad and refers to those providing a home for the bereaved child and includes their natural family or their surrogate family.

10.1. A model for supporting parentally bereft children and their families

This model is designed to help those providing informal and formal bereavement supports achieve better outcomes in adult life for those bereaved of a parent before the age of 18.

First, continuity provides a resource for negotiating the disruptive impact of bereavement on children's social words. The findings from this study suggest that in order to help minimise these disruptive effects support needs to be structured in such a way as to ensure that the many different contexts for continuity can be maintained.

So in practical terms it would be helpful if children could go to the same school, with the same school friends and maintain the same friendship networks.

Second, bereaved families, particularly the surviving parent (or carer) needs instrumental social support, which is practical help with the work of daily family survival such as childcare, housework and financial support, to help manage daily life disruptions. The findings from this study suggest that without practical help, some surviving parents (or carers) become too burdened with managing the challenges of everyday life (surviving) and (or) managing their own grief to provide emotional/physical support for their children/siblings precipitated by the death of a parent(s). Especially those cases where families are living in disadvantaged circumstances.

Social networks and affiliations were an important source of emotional and practical support for bereaved children and their families. However, care needs to taken to ensure that the support it directed towards the bereaved children and not just the bereaved parents otherwise children, particularly older ones, may feel excluded and alone.

Third, communication is central to the bereavement experience. In terms of recognition of loss interpersonal communication is important at three time points.

- To prepare child/children that the parent is dying
- At the time of physical death
- When the parent the child knows in terms of "mothering" or "fathering" is 'dead' to them due to their illness

The findings from this study suggest that communication in relation to the above time points needs to timely, open, honest and in a language appropriate to the child's level of understanding and also their life experiences. When used inappropriately language may be a barrier to communication and may foster confusion and anxiety. For example, albeit with the best of intentions, as the narratives suggest, some adults wanted to protect children from the death either with the use of euphemisms or by avoiding the topic.

Holland (2001) explains that because death can be seen as a taboo, adults tend to make use of euphemisms which refer to death in an indirect way. The use of euphemisms avoids mentioning the word 'death' directly and is intended to soften the impact of the word, and was reflected in this study.

Whilst euphemisms are normally understood in children and adults that have developed a biological understanding of death, as the narratives in this study have illustrated, the use of euphemisms clearly didn't work in those that hadn't developed such an understanding. Where this was the case euphemisms tended to foster confusion and increased anxiety as the children would take them literally, as was Sam's experience. Sam was told by his mother that 'his father had gone away to a nice place where he would not have any more pain'. According to Sam's story he literally thought his father had gone away and would return.

Carey (1985) argued that young children's concept of biological entities and phenomena, including the concepts of animal, baby, life death, growth etc are grounded in their more familiar and earlier developing framework of folk psychology and that adult like notions of about the biological world do no emerge until sometime middle childhood.

The recent cognitive development literature generates specific guidelines for talking about death with children, which acknowledges the importance of children's underlying folk biology (or lack of it) to their capacity to conceptualise death.

Slaughter (2005) states that even when adults provide explanations that appear to be clear and straightforward such as 'he died because his heart gave out' or 'the doctors did all they could but her body was too weak to keep living' (p. 184) such explanations may not be appropriate for young children if they presuppose a biological conceptualisation of the human body. She goes on to say that even explanations that frame death in terms of breakdown of the body while concrete and unambiguous are likely to be meaningless to a young child who does not recognise death is characterised and ultimately caused by the cessation of bodily function.

Communication is also important with regards to understanding the child's reaction to 'death' at the previously mentioned time points. How this reaction is handled (or not handled) may have a profound effect on a child Assumptions about how a child is responding or coping (or not coping) may lead to a child feeling unimportant and over looked, as reflected Alison's account. Therefore, it is important to communicate with children to understand how they are feeling, especially when the cause of death is seen as socially unacceptable, as was Freddie's and Janet's experience.

To do this some families may need to re-establish mechanisms for stable, shared emotional culture. The open expression of feelings highly valued in both psychodynamic and stage models of grief, can become destabilising to a family's negotiated rules for shared emotional stability. For example, narratives in this study revealed how many families found that their grief was triggered by the grief of other family members; particularly the surviving parent and they created implicit rules for the communication of thoughts and feelings. In some families in this study the deceased parent could not be talked about at all for fear that family members might not be able to cope with the emotions triggered by a reminder. Families stopped functioning as a unit but as 'individuals in a family' (Peggy). Respondents were often concerned about emotional protecting their bereaved parent (carer) to minimise the emotional and practical disruption in their daily lives.

Shapiro (2001) states that greater the stressors and the discontinuities, and the fewer social supports, the more likely families will be to rely on interpersonal control strategies that limit their ability to adapt. Shapiro (1994) and Silverman (2000), state that such families inhibit their growing children, whose maturing cognitive capacities generate new questions about the death and its meaning from exploring the experience of the death and their images of the deceased family member in ways that enhance ongoing development.

Support that increase stability, continuity and cohesion can be introduced at every level of the family system. Support can range from management of practical household tasks to strategies for improving family communication. Such interventions may help the family as a unit, through interpersonal communication to integrate experience and adapt to changes with few attempts to control thoughts and feelings in ways that impede shared development.

However, such support needs to be sensitive to the family's cultural beliefs surrounding death, dying bereavement and parenting and the wider social /cultural context in which these practices are embedded, which are historically rooted and change over time. Such social and cultural practices may prevent people talking about the deceased or prevent others talking the bereaved or offering support, especially when the death is seen as socially unacceptable.

Fourth, the experience of early parental death also has the potential to facilitate aspects of personal growth, including a sense of strength, autonomy independence and maturity. This experience also has the capacity to foster a deeper appreciation of life and greater empathy and understanding towards others that had experienced loss. However, in terms of relationships such independence was problematic for some as there as there a reluctance to share feelings or issues of concerns with significant others.

Strategies need to be developed to help those supporting the bereaved children and their families in such a way as harness and enhance the potential for personal growth and resilience.

10.2. Prognostic model for identifying parentally bereaved children that may potentially experienced less favourable outcomes in adult life

In conjunction with the above model a prognostic model is offered which may help practitioners and others providing bereavement support (informal and formal) identify those children who may be more vulnerable to less favourable outcomes in adulthood. These include:

1. Children who have experienced a prior relationship with deceased parent(s) and experience further social/familial disruptions due to the following:

    a) Where the deceased was the primary caregiver, especially those who have no other mechanisms for social support

    b) Where children have been geographically relocated and are no longer able to access the same friendship and kinship networks, schools or social affiliations and role models which were seen to mediate the impact of the disruption to their 'taken for granted world'.

c) Older children (especially teenagers) negotiating the transition from childhood to adulthood as the resulting change and uncertainty may be likely to complicate the bereavement experience, particularly for those without other sources of social support.

d) Where the death is seen socially unacceptable and this limits children's avenues for communication and social support.

2. Children whose surviving parent (or caregiver) feels too burdened managing the challenges of daily living (surviving) and/or managing their own grief to offer emotionally and/or physical support to their child/children, again especially where these children and their families (or carer) do not have access to other sources of social support to fill the gap in mothering/fathering .

3. Very young children whose memories aren't the narrative of the deceased parent in their "mothering/fathering" role where the essential "mothering/fathering" isn't filled by the person that takes on that role (for example, the surviving parent, a surrogate parent such as a grandparent or sibling) for whatever reason then that child is going to need support.

4. Children whose families are unable to communicate their thoughts and feelings as there is the potential for them to experience relationship difficulties in adult life.

5. Finally, children that were not been told about their parent(s) death (or told the truth about their parents death) as these may be particularly vulnerable to experiencing issues related to trust in adult life.

10.3. Summary

In this chapter two models have been suggested to help those working with bereaved children that were grounded in the findings from the study.

The first model identified the ways in which children that have experienced early parental loss and their families might be supported to achieve better outcomes in audit life. The second model was concerned with identifying children who have experienced early parental loss who potentially may be at risk of less favourable outcomes in later life so that they can be better supported.

Chapter 11:

Discussion of findings, conclusions and recommendations

In this chapter a summary of the findings is presented. Secondly, the strengths of the study will be discussed in terms of what they add to the research literature with regards bereavement research, as will the limitations of the study. The findings are then discussed in relation to models, theories and other published work in relation to early parental loss and its impact on adulthood in a critical and comparative manner. The chapter concludes by discussing the implications of the results with regards to future research and practice regarding bereavement support.

11.1. Summary of the findings

The principle aim of this study was to explore through a narrative approach the individual experiences of those who had experienced the death of death of a parent(s) before the age of eighteen and investigate how such experiences were perceived to impact on adult life. The knowledge generated was to be used to inform bereavement support services so that it could be better tailored to meet clients' needs.

Through the analytical process (refer to methods chapter) it was revealed whilst the individual stories were unique, they were organised around five common themes which were indentified across the narratives: 1) disruption and continuity, 2) recognition of loss; 3), family dynamics, roles relationships and context; 4) public world of bereavement and finally 5) the impact on identity: aspects of personal growth. These themes were expressed in relation to fifteen sub themes which illustrate the complex nature of the bereavement experience over time. The findings from the study have important implications for how bereavement support should and can be developed.

11.2. Strengths of the study

The strength of the findings presented here, are firstly, that they were developed from the narratives of a non-clinical sample (i.e. participants were recruited from a public appeal and not identified from a clinical population as in many previous studies) that were bereft of a parent(s) before the age of 18, living in the United Kingdom. Secondly, this present study was not limited to short or medium term outcomes, as in many other studies. The unique feature of this present study was its exploration of the impact of early parental death over the life course of the participants up to as long as seventy one years after the death of the parent(s). Crucially, this brought into view the damage and effects on the individual over time as a consequence of inappropriate or neglectful management.

Thirdly, the analysis has not been undertaken through a pre-existing theoretical framework concerning processes of bereavement and grief, but through the use of a general narrative approach.

Fourthly, the findings encompass personal growth as a vital component of early parental loss. This adds to the existing literature (see literature review) in which various aspects of personal growth have been described as a component of adulthood bereavement (Edmonds & Hooker, 1992; Kachoyeanos & Selder, 1993; Lehman et al., 1993; Schwab, 1990). Researchers have also defined aspects of personal growth for bereavement adolescents (Balk, 1983; Oltjenbruns, 1991), and integral to adolescent sibling bereavement theory (Hogan & DeSantis, 1996).

In the methodology chapter it was argued that that taking part in bereavement research can have a therapeutic function by acting as a cathartic mechanism, which may assist the healing process (Rowlings, 1999). This was confirmed by the many respondents that took part in this study, both at the time and later in spontaneous correspondence.

The sample, although limited in racial and ethnic representation, included a wide age range and was broad in terms of socio- economic status and geography. Whilst each experience was unique, at another level, similar themes with indentified across the narratives. The stories of the participants provided a rich and emotional voice that proved to indelible in the researcher's mind. The data collection process through the emotive recollections of the bereaved allowed access into their phenomenological world and provided a base that was rich, reliable and grounded.

From the evidence two models for bereavement support, anchored on the experience of the collective data has been developed and these were outlined in the previous chapter. The supportive model presented in this study reflects the complex social and cultural process and practices that were acknowledged in this study as influencing the impact of bereavement over the life course. The prognostic model also acknowledges these complexities.

11.3. Limitations of the study

One limitation of the present study is its retrospective nature. Those that had experienced early parental death did not tell their stories until they were adults. An inherent limitation within this methodological approach is the recognition that memory is a re-constructive process; hence early memories evolve under reconstruction. Respondents were being asked to recall events that they had experienced in childhood and hence could be subject to bias and distortion due to the time lapse. In addition, these adults may have brought their own prejudices and mindsets into their memories.

In addressing this limitation it is important to clarify that the purpose of this study was to increase our understanding of the subjective experience of the impact of early parental death on adult life. It is thought that even though there may be inaccurate or incomplete recall due to memory attrition, it is the actual lived experience of the participants which is most highly regarded in qualitative research.

Furthermore, it is argued that without the experience of living that has gone through the passage of time informants would have not been able to reflect on how this experience had impacted on their adult lives. Whilst it is acknowledged that some memories may have faded, others appeared to be entrenched in their memories. The significance of these events is reflected in the fact that are remembered and recalled so vividly by the informants, crucially through the lens of an adult's experienced, compassionate mind; being compassionate to the person they were when they were young. Hence the retrospective nature of this study may also be viewed as strength.

A further limitation is that this was a self selected sample. Hence it is recognised that they may be same bias in favour of those who saw value in talking or writing about their experiences. However, given the aims of this study was to explore the lived experience of bereavement this was a pragmatic decision as it was only way that people could be recruited to this study. Furthermore, respondents were given a choice as to whether they were interviewed or wrote their narrative. In this way the study was able to recruit those who would not necessarily have taken part if the only option was to talk about their experiences.

In spite of substantial efforts to recruit a diverse sample (see recruitment strategy chapter 4) the sample was overwhelmingly Caucasian. Whilst there was clearly a recurrence of themes which allowed for the construction of the models presented in this study it was not felt that full saturation in this complex area was reached due to limited racial and ethnic representation The relative racial and ethnic homogeneity of the sample doubtless colours the particulars of the stores related by the informants in this study, limiting the extent to which the findings can be generalised across to populations with a markedly different racial and ethnic composition.

As previously mentioned in the methods chapter respondents were asked to comment of the transcribed accounts to display the openness of the research project, enhance the validity and integrity of the findings and the value placed by the researcher on the participants. On reflection it was recognised that credibility (and confirmability) of the study might have been further enhanced by asking the respondents to comment on the emerging themes as this would have invited potentially interesting and informative reflections on this wider interpretation.

However, it is argued that it might be considered new data and an extension of the research rather than validation. Furthermore, it would be extremely time-consuming for the respondent (and the researcher) and potentially distressing to keep returning to them for verification on such an emotive topic and therefore may not be seen as appropriate. However, it is a technique that the researcher would consider for future research projects.

Recognition of limitations of this study are presented along with clearly described research protocol to all future researchers to replicate, confirm or challenge the results reached in this study. As a result the theoretical and practical implications drawn from the study can be strengthened, clarified and extended.

11.4. Discussion of findings in relation to the research literature

In this section the findings are discussed in relation to models, theories and other published work with regards to early parental loss and its impact on adulthood in a critical and comparative manner. This is presented in terms of the five main themes around which the narratives were organised.

11.4.1. Disruption and continuity

This chapter explored how the loss of a parent(s) through death and illness disrupts the taken for granted world of informants in major ways. The narratives in this chapter were organised around two main themes: irrevocably changed lives: fear and insecurity and continuity and change.

For those informants that had no conscious memories of their deceased parent in their habitual role, where the surrogate caregiver (or surviving parent) was exhibiting the parenting behaviour there was little sense of any disruption as this was the only world they had ever known, as exemplified in the narrative extracts.

For those informants who had memories of their deceased parent(s) in their habitual role, the disruption of their taken for granted world appeared to take away their hopes and dreams and leave them feeling confused and insecure both within themselves and with the world around them. Such feelings appeared to be intensified in those that had experienced a progression of discontinuous events (e.g. changes in caregiver, moving house and/or geographical locations, schools).

Continuity was seen to have an important role in negotiating the disruptive impact of bereavement on social life. The exemplifiers used in chapter six encapsulated many of the dimensions for continuity that appeared other stories in this study. Specifically they illustrated how different contexts for continuity such as family, school and friendship networks shape children's social expectations and experiences of bereavement. These different contexts for continuity were seen help children cope with the bewilderment and confusion in the world around them and within themselves. For respondents in this study continuity provide a sense of normality in an otherwise chaotic and disrupted life world where respondents could escape (albeit temporarily) the enormity of profound disruption, created by their parent(s) death and subsequent life events.

In contrast, where children experienced a progression of discontinuous events (e.g. changes in caregivers, moving home, moving geographical location, moving schools, loss of support networks), as exemplified in Anne Marie's story, they may be more likely to experience emotional difficulties in adult life.

The importance of continuity in the lives of bereaved children is well established in the childhood bereavement literature. Reese (1982) has indicated a positive effect on bereavement adjustment when fewer daily life changes were experienced by the children. Reese also observed that the increased risk for developing emotional problems was associated with the lack of continuity in the child's life after the death, including the surviving parent's inability to provide a stable home for the child. Mahon (1999) found that moving house and separation from friends and family (which he calls secondary stressors), made adjustment to parental death significantly more difficult. Likewise, Thompson et al., (1998) found that the death of a parent led to increased secondary stressors which in turn lead to an increase in distress in the bereaved child. Worden (1996) concluded from the Childhood Bereavement Study that the longer changes and disruptions in daily life continued, the greater the impact they appeared to have on children.

The data from this study clearly suggests that in order to help minimise the disruptive effect of bereavement of children's social worlds bereavement support needs to be structured in such a way as to ensure that the many different contexts for continuity can be harnessed and maintained. So it would be helpful, for example, if the bereaved children, where possible, could remain living in the same geographical location (ideally, in the same house), so that they could maintain the same friendship networks and attend the same school. One way in which this might be achieved is by providing practical support at a very fundamental level (i.e. help with housework, shopping, cooking, childcare, taking the children to school and financial support). This would help minimise the burden on the surviving parent or caregiver, especially in those families that have limited social and economic resources. One of the main findings of this study relates to the damage and suffering experienced by individuals regardless of age when appropriate levels of support are not provided.

The need for this level of social support is documented in the literature. As early as the 1950s Bowlby (1951) emphasised the role of social networks and on economic as well as health factors in the development of well-functioning mother-child relationships.

> *Just as children are absolute dependent on their parents for sustenance, so in all but the most primitive communities. are parents, especially their mothers, dependent on a greater society for economic provision. If a community values its children it must cherish its parents (Bowlby, 1951, p84).*

More recently, Shapiro (2001) stresses the need for 'instrumental social support' to help bereaved families. Shapiro maintains that the greater the domains of family of family life disrupted by the death, the greater the demands made on existing sources of continuity and stability to restore the interrupted work of family development. In the absence of instrumental resources such as economic security or social support, individuals and families are forced to rely on interpersonal negotiated emotional controls as strategies for stability of last resort. Dyregrow and Dyregrow (2008) also acknowledge that there are various types of practical assistance that social networks can contribute, including doing the shopping, help with the cooking, taking care of young children and helping out with caregiving duties in relation to elderly family members. According Dyregrow and Dyregrow, the most importance thing about practical help is, as with all network support, is that it is offered and carried out with respect in relation to the needs of the family. The narratives in this study clearly support this.

11.4.2. Recognitions of loss

Through the narrative extracts presented in this chapter it was also illustrated how recognitions of loss were influenced by age, experience and communication. These different aspects were seen as relational i.e. they were seen to interact with each other. These narratives extracts also illustrate how recognition of loss may occur before the death of the physical body and that waves of grief, arising from the loss of a parent, can be experienced throughout the life course as intensified feelings of grief.

The narratives have highlighted that for those respondents who lost a parent in infancy or early childhood it was particularly difficult to recognise the loss as the loss of a valued core relationship being absent in their subsequent experiences. So while these informants had lost a parent they had not experienced the loss as such and so to their mind, it had no significant impact on her wellbeing and experiences of "family" and "mothering" or "parenting" at the time. It appeared that it was only when the bereft experienced what parenting involved, through their subsequent life experiences that recognition of the loss occurred.

For those children (whose conscious memories were not of the deceased in parent in their habitual role) the narratives strongly suggest that if the social network picks up all the necessary" mothering/fathering" then a child doesn't appear to be affected, as exemplified in extracts from Freda's, Sue's and Dan's narrative. But if, for example, the grief bites in so hard to a particularly important person (such as a surviving parent or surrogate parent such a grandparent or sibling) and the gap isn't filled by someone else doing the mothering/fathering then these children are going to need support. This is an important point and is acknowledged in the models presented in this study.

The significance of such dynamics well documented in relation to Bowlby's theory of attachment. As outlined in the literature review, Bowlby examined grief and mourning in light of attached bonds (Bowlby, 1960;

1961; 1963; 1977; 1980s). From this perspective a child's first and most profound social experience is with their mother, and that relationship influences their psychological and physical development (Chodorow, 1978). As Bowlby (1960; 1961; 1963; 1977; 1980) and other attachment theorists (for example, Tracy and Ainsworth, 1981; Main and Weston 1981; Main and Cassidy, 1988 and Karen and Stewart, 1999) have observed children whose mothers are responsive to their signals and interact socially with them during their first year are likely to become more socially advance and more capable of forming secure attachments. When this first consistent relationship is severed or interrupted any person who is willing to invest time and patience in the child's growth may fill this role (such as a father, a grandmother, an older sister, a family an aunt, or a friend), as the narratives in this study have clearly illustrated. Among children of all ages, the critical factor that determines later distress is not mother loss per se but instead the availability of consistent, loving and supportive care afterwards (Rutter, 1985). Rutter maintains that a child who can attach to another adult after losing a mother has the best chance of developing without serious ongoing difficulties. However, whilst the attachment bond is clearly very important, as the narratives in this study have illustrated, is just one the complex range of factors that influences the bereavement experience with regards to early parental loss. Grief is not merely a set of psychological responses that are largely biological determined (as Bowlby has argued) as patterns of grief and the possibilities for its expression are largely influenced by social and cultural factors (Reimers 2001; Field and Payne, 2003) as the findings from this study clearly illustrate.

Age and experience were also found to affect recognition of loss. Whilst the development of children's understanding of death has been linked to their cognitive development, the narratives in this study suggest that it also appeared to reflect their experience of death and dying, as Sam's story illustrates. This is acknowledged by fairly new approach to understanding of children's concept of learning which has emerged in the cognitive developmental research and theorising in the last ten years (Slaughter, 2005). This model of cognitive development emphasises the role of casual-explanatory models in organising children's knowledge and driving learning about different domains of experience and recognises the importance of conceptual change in children's learning (Carey, 1985; Gopnick & Meltzoff, 1997; Inagakie & Hatano, 2002; Wellman & Geelman, 1992).

One of the seminal works in this new tradition analysed the development of young children's conception of the biological world (Carey, 1985). According to this perspective an important factor influencing children's understanding of death is the child's personal experience with people and other living things that have died (Hunter & Smith, 2008). The narratives in this study tend to support such theories. In doing so they challenge Piaget's (1976) very influential theory of cognitive development, based on the chronological age of the child.

Piaget addressed the ways in which children's thought processes changed over time, regardless of the environment in which they grow. The Piagetian research documenting consistent stages of death established that children's understanding of death is closely tied to cognitive developmental maturation. Within this explanatory framework it is believed that very young children do not have the capacity to understand abstraction such as finality and irreversibility, an understanding that only emerges when the child is capable of operational thinking (Piaget, 1956). Children may in fact see death as reversible. As children grow older, they develop the capacity to understand the abstractions associated with of death (Worden, 1996). From this perspective the development of an understanding of death appears to be most strongly influenced by developing cognitive competency (Slaughter, 2005). Piaget saw these development stages as universal and homogenous and stable across cultures.

Piaget's model has also been challenged by scholars such as Bluebird-Langer (1989). He describes how very young children who are terminally ill or life-threatened have a sophisticated understanding of death through their observation of how adults respond, knowledge of their own symptoms and treatment and interaction with other dying children. Bluebird-Langer recognises therefore that although the development of children's understanding of death has been linked to their cognitive development, it also appears to reflect their experience of death and dying. The findings from this study would support his conclusion.

Broderick (1993) and Jordan (1990) point out that if the loss is to be acknowledged as having occurred there must be open and honest communication. Hope and Hodge (2006) stress the importance of children, regardless of their age, being given sufficient and accurate information about the death. Many of the narratives in this study were organised around communication and the extent to which not being told about the death of their parent, or not being told of the death in a truthful or timely manner had not only compounded their distress but was perceived to leave them feeling let down and betrayed by adults. This in turn was perceived to impact on relationships problems and issues with trust in adult life. Whilst as a mature adult respondents were able to reflect on this experience and appreciate that it may have been done in order to protect them (or was associated with beliefs about parenting that were dominant at the time), it was something they still had difficulty coming to terms with. According to Herman (1992) one of the most important factors that make childhood loss traumatic is the feeling of having been betrayed by trusted adults. The data from this study clearly supports this view.

The narratives in this study also illustrated how communication was necessary to help children cope with the bewilderment and confusion within themselves and the world around them. As in this study, Holland's (2001) retrospective study of adults bereaved as children also found that many lacked basic information around the time of the death, and lacked to power to gain information. Others respondents in this present study were not told of the severity of their parent's condition and that you could die from it. In such cases, this lack of information about the course and prognosis of the disease meant that the death was sudden and unexpected. Again, this was something that was perceived to compound distress, not just during childhood but also in adulthood, as exemplified in Colin's story.

An exploration of the narratives in this study also revealed how recognition of was not limited to the physical death. It was also perceived to occur when the parent that was known to them in terms of mothering (or fathering) was 'dead' to them due to illness. This is an important point and such cases need to be considered in any model of support. Communication was seen to be crucial at both these times points.

This information needs to be communicated in a language that is appropriate to the age, maturity level and lived experience of the child. It also needs to be repeated over time, since children and young people can come to understand the event in a different light over time (Dyregrow and Dyregow, 2008), as reflected in Sam's story. The repetitive questions children ask about a death are, according to Worden (1996), a way for them to grapple with the reality of the death as well as a test to ensure that the story has not changed. Children who are not given accurate information make up a story to fill in the gaps (Worden, 1996). Worden asserts that sometimes this can be more frightening to the child that what actually happened. This was clearly found to be the case in this study and exemplified in Jimmy's story.

Given that the importance of communication regarding the bereavement experience features so heavily in the relevant literature it was not surprising that the narratives in this study should be organised around such times. However, whilst for the need for information around the time of death (or anticipated death) and for regular updates regarding the course and prognosis of the disease (e.g. Dyregrow, 2008; Christ, 2000) is well documented there appears to be little acknowledgement with regards to the need for information and support for the child when their parent is no longer able to fulfil parenting role, due to their illness. If bereaved children are to be better supported this clearly needs to be addressed.

In addition as the narratives in this study highlighted communication between children and parent(s) is not straightforward, it is influenced by a range of dynamics (social, familial and cultural) which need to be understood when providing support for bereavement children and their families. These are discussed later in this chapter.

Through the narrative extracts used in this study it was highlighted how waves of grief could occur throughout the life course, particularly in relation to key events, such as birthdays, weddings, anniversaries, illness, birth of their own children. As discussed in the literature review the early theorists often defined such intense feelings of grief as part of complicated grief. However, it was also noted in the literature review that Rando (1988) defined these intermittent periods of acute longing, which she called STUG reactions (significant temporary upsurges of grief), for the lost loved one are part of the normal mourning process, rather than part of complicated grief as linear models of grief suggest. The narratives in this study would support this view, as virtually all the respondents in this study narratives were organised around such times. Other retrospective studies that have explored bereavement during childhood (e.g. Edelman, 1994; Harris, 1995; Holland, 2001) have also found that grieving can recur at various points in the life course, particular in relation to such key events.

Some informants, particularly those who had no conscious memory of their parent in their habitual role (especially where the surrogate parent wasn't meeting their needs), as an adult constructed an image of their deceased parent based on their subsequent experiences as they imagined them to be. Brown (1999) suggests that idealising the parent that has died or placing them on a pedestal is very common across the five to sixteen age ranges and suppressed any natural feelings of anger directed towards the dead parent that has left them. In such cases, Brown comments the surviving parent may be made to feel inadequate. Whilst Brown makes no statement to this effect, it is assumed that this is also the case for the surrogate parent.

However, whilst there was evidence in this study to suggest that the bereaved adult constructed an image of their deceased parent as they imagined they would have been it is not clear as to whether this was the idealised form (the perfect parent). The evidence appears to suggest that this constructed image was more of a "longed for parent" who would have done the things with them as they perceived other parents would do with their children. This included go shopping with them, taking care of them when they were ill, protecting them or giving them advice. However, some expressed concern that they longed for this parent more deeply the older they became and they found this distressing as they didn't understand why. To some extent this distress may be understood as associated with the traditional models of grief (i.e. that grief is a process with a start and an end point) which appears to inform their understanding of the grief process. Hence, when the informant experienced these upsurges of grief they appear to believe that they were 'abnormal' rather than a "normal" part of the grief process as it was at odds with their beliefs about so called normal grieving. Therefore, this myth (Dyregrov and Dryegrov, 2008) about grieving needs to be dispelled.

Communication was also important regarding the child's reaction to loss. The findings clearly show that how this reaction is handled (or not handled) may have a profound effect on a child. For example, an assumption that a child was coping (when they feel they were not) may result in a child feeling unimportant, overlooked, and isolated, as was Alison's experience. According to Abrams (1999) adults are all too likely to take a child's behaviour at face value, pleased that the child appears to be coping so well, relieved that their are no problems and failing to see that the good behaviour is just the public face of the child's anxiety and confusion. Alison's narrative would appear to support this conclusion.

For others not displaying emotion was perceived to be misinterpreted as not caring about the deceased, rather than a coping mechanism for dealing with the loss, and was perceived to affect their relationships with the surviving parent (surrogate caregiver) as exemplified in Claire's story. In both examples the extent of the child's loss remains unrecognised and unacknowledged and this was perceived to have a profound effect on their adult life with regards to issues of self esteem and self worth.

According to Abrams (1999) children of all ages can feel pushed out by a grief-stricken parent or other insensitive relatives or family friends. She refers to an Australian survey of 255 bereaved children under the age of eighteen that found that nearly all of them were emotionally alone after their parents' death (Rosenman et al., 1994). It was found that very few had an adult that they could talk to or discuss their worries with. One thirteen year old became very withdrawn after his mother's death and how his father entirely misinterpreted his son's behaviour and interpreted it as lack of grief. He was told he was an 'odd shallow little boy'. This appears to be to similar to Claire's narrative. However, given this was a survey of children under the age of eighteen, unlike in this present study, the long term effects are not known.

It is important therefore for those supporting bereaved children and their families to help surviving parents (and surrogate caregivers) to understand that it is important for them to communicate with their children in this regard so that their children's reactions (and their own reactions) are not misunderstood. This may help to elevate the distress and isolation children feel. It may also help to prevent any negative effect their relationships. By putting into words the fact that communication is difficult, and subsequently, what the difficulties are based on, some of the hindrances to communication between parents and siblings can be reduced (Dyregrow and Dyregrow, 2008). But as illustrated in Lucy's story, if children have not been able to speak with their parents about difficult issues previously in life, this is not the point in time to learn how to do so. In such cases, the bereavement was seen to exacerbate something that was already in place.

The philosophy of how to treat bereaved children and how to integrate them into the broader network of grievers, as the narratives in this study have suggested, is tied to cultural beliefs; one perspective should not be treated as universal. Although the knowledge base regarding children's capacity to mourn and their need to be informed and included has expanded over recent years, many children remain the ‘forgotten mourners” as a result of individual circumstances and misguided interventions (Wolfelt, 1983) as the narrative extracts from this study have clearly illustrated. Those providing bereavement support need to be sensitive to such dynamics.

11.4.3. Family dynamics, roles, responsibility and context

This chapter focused on how family dynamics shaped the bereavement experience. The narratives were organised around the following themes: changing roles and responsibilities, changes to the surviving parent; the emotional culture of the family, the expression of grief, communication and relationships; the relationship with the parent that has died and finally, family beliefs and values; spiritual beliefs.

This chapter highlighted how grief within the family consists of the interplay of factors with individual family members grieving in the social and relation context of the family, with each member affecting and being affected by others (Gilbert,1995). The narratives suggested that changes in the family resulting from the loss contribute to the intensity of the loss. When a family member dies, a crisis ensues and the family must be recreated to cope with the existing tasks and new demands (Shapiro, 1994).

The narratives in this study highlighted how roles responsibilities within the family often changed as a result of parental loss. This was not surprising as it is well documented in the bereavement literature (e.g. Dyregrow and Dyregrow, 2008; Worden, 1996). Whilst the extent of this change varied in accordance with individual circumstances many of the informants in this study found themselves having to take on responsibilities for themselves, and (or) others such as other siblings and the surviving parent, especially (but not exclusively) the older girls. These changing roles and responsibilities were sometimes seen to be unwanted and resented; others just accepted this was how things were to be. For some these changing roles and responsibilities appeared to be borne out of a protectionism and (or) out of sense of indebtedness or obligation (maybe in ways that those that have not experienced parental loss are not 'indebted' to their own parents) and was perceived to be irrespective of need and extended into adulthood.

The impact of these changing roles and responsibilities was perceived to be both positive and negative (e.g. take away their opportunities; take away their childhood, impact on their social life; help them to become self sufficient and self reliant and enhanced their coping and practical skills) and extended into adult life. Other children had to adapt to living in a different family environment, in a different house, with different rules sometimes in a different geographical location and had to negotiate their relationship with surrogate caregiver(s) and their families.

The findings from this study provide insight as to how such profound change in the lives of the informants, particularly the older children had to be negotiated within the wider context of their everyday lives (such as going to school, or work, studying, taking exams or preparing to go to university) whilst at the same time negotiating the transition from childhood to adulthood. Hence a very complex picture emerged than much earlier studies and theories would suggest.

It was clear from the narratives in this study that the physical and emotional availability of the parent had a great influence on the child's relationship with that parent. In some cases, the surviving parent (or surrogate caregiver) was not emotionally available (for various reasons including grief) to facilitate the child's grieving through discussing the death and their feelings, as well as not answering their questions. In such cases children then may again become the 'forgotten mourners' being isolated and vulnerable. Such findings are reflected other studies (e.g. Papadatou, Metallinou, Hatzichristou & Palivdi, 2002).

Changes to the surviving parent as a result of grief were perceived to be particularly distressing for respondents, even in the short term. The impact of this temporary reduction in parental capacity which the respondents could not make sense of was exemplified in Winifred's, Sue's and Patricia stories. To Winfred her mother appeared to be no longer interested in where she went or what she was doing after her father died, which she found to be particularly distressing. Riches and Dawson (2000) term this experience the 'double jeopardy' whereby the child not only suffers the loss of a parent but the symbolic or temporary loss (the unavailability) of the other (Bertman, 1991). In fact Winifred believes that this change to be as distressing as her father's death. Through her subsequent experiences Winifred was able to understand that the change in her mother's behaviour was due to grief. Had she been informed that this was likely to happen the extent of her distress might have been alleviated.

Where changes to the surviving parent continued over time, this was believed to not only compound distress but also effect perceptions of self worth as the extent of their distress went unrecognised, especially in cases where there were no mechanisms for support, as was Jane's experience whose mother suffered from mental health issues after her father's death.

An exploration of narratives in this study has revealed how the emotional culture of the family also affected the expression of grief. Families often found that their grief was triggered by the grief of other family members; particularly the surviving parent and they created implicit rules for the communication of thoughts and feelings. In some families in this study the deceased parent could not be talked about at all for fear that family members might not be able to cope with the emotions triggered by a reminder. This was perceived to impact on the way in which the family functioned in that it became less cohesive. As Peggy said "we were no longer a family unit but more individuals in a family". In such cases respondents reflected on how as an adult this experience had affected their relationship with their own children in that they were unable to show them any affection (e.g. they felt unable to tell them that they loved them or give them cuddles or hugs) or it made it more difficult to do so. However, for some this experience was seen to make informants determined to try and promote a more open emotional culture for their children, so that they would not feel isolated as they had done, as exemplified in Joan's narrative. Similar challenges with regarding to becoming parents have been noted in others studies and were referred to in the literature review (e.g. Porterfield Cain and Saldinger, 2003; Edelman 1995; Harris, 1995).

Some families appeared to be organised around traditional gender roles, with the mother providing the caring functions and emotional support more than fathers. Where this was the case, the father often struggled to establish a warm, open caring climate in the home after the mother's death, especially where there were economic pressures to provide for the family. However, not all families were organised in this way. In some families the father provided the emotional support while the mother organised the day to day running of the household at the practical level. In such cases, the mother was perceived to struggle to provide a warm, caring, environment for the family after the father's death, again especially where there were economic pressures and (or) the need to provide for large families. Such cases would appear to contradict those studies (e.g. Saler & Skolnick, 1992) that emphasise that the loss of a mother seems especially difficult for children as they provide the emotional support. The data from this study clearly suggests that this is not always the case.

In some families there was perceived to be no emotional support from either parent, even prior to the loss, this was perceived in part to be due the challenges of caring for a large family. Again, in such cases, families were perceived to function as individuals rather than a unit. Informants in this study were also often concerned about emotional protecting their bereaved parent (caregiver) to minimise the emotional and practical disruption in their daily lives.

The relationship with the parent that had died was also perceived influence the bereavement experience, particularly were the deceased parent had been the one to provide advice, emotional, support and encouragement. In such cases the relationship was often with the surviving parents was often more difficult post death.

The relationship with the deceased parent was also seen to be influenced by the cultural background of the respondent. For the respondent that was Muslim her father was central to her phenomenological world. When he died it has a profound effect on her life, especially as there were no male siblings to support her. In such cases, when the father dies not only does the daughter lose a parent, she appears to lose the ground on which they can make decisions, call for help, receive protection and access support, as Fiaza's story exemplifies.

Much of these findings appear to be supported by social development theory of family bereavement (Shapiro, 2001). From this perspective, in the absence of social resources such as economic security or social support, bereaved families are forced to rely on interpersonally negotiated emotional controls as strategies for stability. Interpersonal control strategies in response to overwhelming grief, such as interactions suppressing differences in shared experience or restricting destabilising change, interfere with the individual and family capacity for open communication, cohesion and mutual support and may narrow the capacity for flexible coping with future development challenges (Shapiro, 1994, 1996), as reflected in Peggy's, Joan and Lucy's narratives. This model recognises that grief reactions are substantially culturally determined process and historically bound.

The role of family dynamics in mediating the bereavement experience is well supported in the relevant literature. Tyson-Rawson's (1996), grounded theory study of paternally bereaved women college students found that several aspects of family relationships could act as mediating factors in the resolution of grief, including the openness of communication in the family; the ability of the surviving parent and others to 'provide stability and continuity in day-to-day life' (Tyson-Rawson 1996: 63) and the emotional context for the expression of distress of bereavement.

As outlined in the literature review, the quality of the relationship with the surviving parent and their competence in parenting bereaved children are the most consistently indentified mediating variables (Kwoh et al., 2005 Siegel, Karus & Ravies, 1996; Temblay & Israel, 1998). As in this and other studies, particularly USA, have identified (for example, Rolls & Payne; 2003 Christ, 2000; Silverman, 1998, Worden 1996) the death of a parent, and the bereavement that follows, threatens the capacity of the surviving parent to meet their children's needs of physical well-being emotional security and social development. As previously noted this can lead to a temporary or permanent reduction in parental capacity. This is of course, nothing that the parent can be blamed for, but as the findings from this study have illustrated, this may disturb the fine-tuned interplay between the parent and the child and add to the child's distress. Indeed, the Harvard Childhood Bereavement Study indicated that the functioning level of the surviving parent was "the most powerful predictor of a child's adjustment to the death of a parent" (Worden, 1996: 95) and this is now widely accepted in the bereavement literature.

Recent research has shown that depression in parents, especially mothers, has a clear negative influence on parental caring capacity, and although grieving parents have not been the focus of much research, there is some that indicates that the capacity to parent is also influenced by grief (Cerel et al 2006). Depression in mothers especially seems to affect emotional regulation among girls (Silk et al. 2006). Such findings, Dryregrov (2008) states make it very important to offer adequate counselling and help to parents of preschool children. Tiffany Field and co-workers (Feijo et al., 2006; Field et al., 1996) have shown that relatively simple advice to parents about physical closeness and contact with their children, including simple body massage, can help counteract such negative effects.

Even for older children the remaining parent's ability to establish positive parenting is important for the child's adaption to loss (Haines et al. 2006). By this it is meant that the remaining parent is able to sustain discipline at the same time as they manage to have a home characterised by warmth care and respect. Dyregrow (2008) states that children's emotional needs must be taken care of while they are stimulated to meet the demands and challenges that follow the age they are moving from. He recognises, as this study does, that it is difficult for parents in grief to ensure that conflict and problem-solving takes place in a positive environment when one is alone with caring tasks and grief itself may drain one of energy. Tein, Sandler and Ayers (2006) maintain that when surviving parents meet in groups that directly stimulates such positive parenting; it leads to good results for children who lose a parent.

Whilst this may be the case, as the narratives in this study illustrated, the ability of the surviving parent to care for their children is effected by a more a complex range of social, economic and cultural factors. So while this type of intervention may be useful at one level it is limited as it negates the socio-economic and cultural context in which grief resides. The relative novelty of the findings from this study with regards to parental capacity (whether short or long term) is reflected the fact that respondents vividly remember the distress and the anxiety it caused, despite the passage of time.

The family's religious beliefs and values were also seen to influence the bereavement process. The strong religious beliefs of some respondents helped them through the bereavement process as it provided routine, order a sense of purpose and a sense of security as exemplified Ruth's narrative. Others felt anger with a God who could allow such pain and loss or that they were being punished in some way. In some such cases these feelings were short-lived and temporary and did not have a negative effect on their religious beliefs and values over time. For others the impact was such that that they no longer practice their faith, even though their faith was very important to them as a family before their parent's death. However, for such families it was often still important for them as a family to attend church services on the birthday of the deceased or on the anniversary of their death as it enabled them to preserve a connection (or closeness) to their deceased parent and to share an aspect of the parent's life that they knew were important to them. For these respondents the ritual marking of these events also enable them to honour the deceased parent's memory, as illustrated through Lucy's narrative. Dyregrow (2008) states that such ritual marking helps to give the bereaved a concrete expression of their feelings surrounding such days.

Such differential responses were documented by Rosenblatt (2000) who cites narratives from parents who have felt that God has helped them find peace meaning and hope. One respondent said that you could still be angry with God whilst keeping your faith (Rosenblatt, 2000: 216). This was certainly found to be the case in this study.

Before their parent's death, some respondents had already started the process of questioning religion and felt that their deep cynicism towards it was in part due to their parent's death, as exemplified in Colin's story. In some such cases respondents regretted their lack of belief in a formal religion as they felt unfulfilled spiritually.

There have been some explorations of the role of religion for bereaved adolescents. For example Balk (1983, 1990) Floerchinger (1991), Gray (1987) and LaGrand (1986) have noted that many bereaved adolescents report religion as helpful. Models for coping with life crises also see the potential value for both religion and spirituality (Moos & Schaefer, 1986; Pargament, 1997). However, it is clear that religion and spirituality are distinct. It is possible to be spiritual without being religious and perhaps religious without being spiritual. According to Balk and Corr (2007) religion involves organised, systematic efforts to provide access to the scared: that is the profound task is in a profound quest for meaning. Bereaved adolescents and bereaved adults alike acknowledge that grief leads them to ask questions and search for meaning. The narratives from in this study would support this.

11.4.4. Public world of bereavement

The narratives extracts in the chapter highlighted the experiences were organised around the broader social context of bereavement and how this mediates the bereavement experience. Particular themes included: others don't understand; the public expression of grief and social support; social and institutional affiliations

The narrative extracts used in the chapter suggested that others cannot understand the extent of their pain and suffering unless they have relevant experience on which to draw. In such cases, respondents often pulled away from parts of their social networks because they found they have grown apart from it. According to Dyregrow (2008), bereaved children and young people can experience that they have suddenly become many years older and those of the same age group now seem childish, immature and concerned with wholly insignificant things, as was Amy's experience. Hence they tend not receive the support from their community of friends and can find themselves isolated and alone. Due to what they have experienced, they do not manage to have fun and be carefree like others, as reflected in the narratives of those that have other family members to care for.

The inability to express grief in public was also perceived to influence the extent to which people felt isolated and marginalised. It was also perceived to prevent informants from expressing emotions in adulthood. The narrative extracts used in this study suggested that there were a number of barriers to the public expression of grief. These included the beliefs and attitudes of significant others (such as teachers and surviving parents or surrogate caregiver) regarding the public expression of grief.

For example, the narratives have illustrated how continually being told that it was inappropriate express emotions was perceived to affect the informants ability to express emotions throughout their childhood and this was perceived to extend into subsequent adulthood, as typified in Helen's and Anne Marie's stories. The public expression of grief was also perceived to be difficult for those ethnic minorities whose cultural expression of grief was different from that of Western cultures and alien to their experiences, as reflected in Fiaza's story.

While cultural issues relevant to experiences of bereavement in the context of multi-cultural Britain have received increasing attention from those professionally concerned with the care of dying and bereaved persons (e.g. Neberger 1987; Parkes et al 1997), Desai and Bevan (2002) point out 'cultural sensitivity' is not enough as a approach to issues of race in bereavement contexts and can even increase discrimination through the dangers of stereotyping, failure to attend to the fluidity and disorderliness of culturally patterned everyday experiences (Gunaratnam, 1997) and the ways in which cultures may change as minority ethnic groups adapt to their new social context (Field et al., 1997). Those providing bereavement support need to be aware of such issues.

Other barriers the narratives were organised around concerning the public expression of grief were perceived to be related to the fact that the deceased parent was not known within a particular community or friendship networks. In Walter's (1996; 1996) biographical model of loss he suggest that bereaved people seek to create a narrative that describes both the person that has died and the part that they played in their lives. Walter argues that because postmodern societies are so fragmented and compartmentalised people relate to others in different ways depending on the social role they occupy at the time. So where the parent was not known in a community there was a reluctance to talk about the deceased as they had no shared understanding of the person that had died as the respondent knew them, especially in cases where the parent had died from what was perceived to be socially unacceptable (such as suicide). This reluctance to talk about the death (or the deceased) with others was compounded by a fear of people being more judgmental, especially where there had been extensive media coverage as exemplified in Freddie's story.

These findings reflect, to an extent, a previously study which referred to grounded theory analysis of the responses of female college students whose fathers had died by Tyson-Rawson (1996; 1993). She found that few peers were willing to talk with her research participants about the bereavement or even about their fathers. Bereaved college students found it dismaying how few non bereaved peers were willing to talk to them about their experience or feel uncomfortable in the presence of someone who is bereaved. However, unlike the present study, this study fails to provide any insight as to why this may be the case.

Wrenn (1999) noted that one of the central issues for grieving college students was learning "how to respond to people who ignore their grief or that they need to get on with life, that it is not good to grieve" (p.134). Rosenblatt (1983) provides some explanations as to why the 'community' may isolate the bereaved. First, people are fearful of doing or saying the right thing for fear of making their grief worse. Second, people may distance the bereaved family because they do not understand what has happened, because they lack the appropriate ritual or etiquette for dealing with them, or because they blame the family itself.

Whilst, this may be the case, the findings from this study suggest that as children the respondents had little or no understanding of such issues and often appeared to have difficulty understanding why those in the community appeared not to be supportive, even when respondents believed them to be aware of this situation, as exemplified in Anne Marie and Janet's stories. In such cases respondents often appeared to feel isolated and alone, which compounded their distress. It was only on reflection as a mature adult who had experienced living that has gone through the passage of time that some were that they had some understanding of such issues, which may be related to general taboos surrounding death and dying (Walter, 1999; 1996).

The narrative extracts referred to in this chapter with regards to the public expression of grief also highlighted the extent to which social affiliations may mediate the bereavement experience. For some they provided support in the form of security, surrogate parental guidance and role models. For others social networks and affiliations were perceived to exclude and isolate children, albeit unintentionally, through not including them in any discussions. Being excluded in this way was perceived to make informants feel invisible and unimportant and alone in their grief, which inevitability had an impact on the feelings of self worth, as exemplified in Alison's story. Social and institutional practices surrounding bereavement were also seen to repress emotions which were perceived to pervade into adulthood as reflected in Anne Marie's and Helen's story.

The role of social networks and affiliations in mediating the bereavement experience is acknowledged in other studies. For Dyregrow and Dyregrow (2008) argue that social network support entails support and consolation, social stimulation information, information, advice participation in routines and rituals and practical or economic assistance for the bereaved. In correlation with more recent theories in the field these authors refer to network support as something that accelerates mastery or that alleviates distress in the following a death (buffer or recovery effect [Strobe et al., 2005]). Dyregrow and Dyregrow (2008) looked at the support needs of young people (adolescence) and found that most young people experience a need for help and support. Because various groups fulfil different types of support needs they found that children want support from family members, friends, the school and healthcare professionals; and for much longer period of time than most are aware of. These authors found that children who do not find support from outside their family can to feel quite alone in their grief, as reflected in many of the narratives in this study. Like in this study these authors also found the influence of the social network and social affiliations on the bereavement experience were not always positive. Drawing from their research and clinical experience these authors found that network support can also be insufficient or even destructive.

Within the developmental literature chronological and development issues are factors in discussions regarding whether there is a particular 'worst time' to be significantly bereaved of a parent. Mack (2001) however found that no effect concerning the age of the child. Others found than children younger than five years (Bowlby, 1980; Elizur & Kaffman, 1982, 1983;

Rutter, 1996) and those in early adolescence (Fristad, Jedel, Weller, & Weller, 1993; Gray, 1987; Raphael, 1982; Van Eerdewegh, Clayton, & Van Eerdewegh, 1985; Wolfenstein, 1969) appeared to be especially vulnerable to poor adjustment after a parent's death. Overall, Fleming and Balmer (1996: 145) point to a lack of 'solid and consistent findings' in relation to differences of age at time of bereavement within the adolescent years. Nevertheless, empirical studies of the significance of age at the time of bereavement involve complex issues, not only because much depends on which particular 'outcome' or developmental task is being measured but also because age at time of death is often confound with time elapsed since death (McCarthy, 2006).

Theories of adolescence question continue to be raised as to whether there are particular issues to consider with regard to bereavement at this development phase. Raphael (1984) indentified adolescence as a key stage when the death of a parent may be seen as problematic. For Raphael this tension is linked with the additional stress associated with bereavement that can lead to a tension between the need to be protected and regress on the one hand (because of the bereavement), and the expectation of maturity (as a developing adolescent) on the other. The bereavement response of adolescence is therefore theorised as being in conflict. A further (socially) based tension maybe the perception of taking on more responsibility as a consequence of bereavement, in contrast to being excluded from decision making within the family (Holland, 2001; McNally, 2005). Such psychological approaches to adolescence as a development phase elaborate particular tasks around individual development and physiological changes such as sexuality and aggression. The work of Fleming and colleagues (Fleming and Adolph 1986; Fleming and Balmer, 1996) is widely cited in the psychological and therapeutic literature (e.g. Doka, 2000) as providing the most relevant theoretical framework for understanding bereavement in adolescent. In this model adolescence is framed defined as 11-21 divided into three periods with specific tasks and conflicts. Bereavement is seen as interfering with this 'natural progression'. Adjustment to death, it is argued, will partly reflect the developmental task that was being faced at the time death. Such developmental theories of adolescence point (generally in a very universalistic way) to various issues in relation to bereavement including particular ambivalence concerning relationships; cognitive capacities; identify formation and particular risks for psychopathology (McCarthy, 2006).

When looking at people's lived experience of bereavement as in this study this relationship much more complex and context bound than these theories of adolescence development would suggest. Interwoven factors of individual differences, family relationships and features of the social structure and culture appear to have a considerable bearing on outcomes for bereaved children. As noted in the literature review, Ribben McCarthy and Jessop highlight (2005) these issues may mediate the 'risks' or likelihood of bereavement leading to particular 'effects', cautioning against any simplistic generalisations about a particular event or family type (for example, a widowed single parent) and specific outcomes. They may also account for the apparently opposite 'effects' between different individuals. Rosenblatt (2001), who draws on his anthropological evidence and uses a social constructionist theoretical approach concluded that 'grieving is malleable, that there is not a simple biological or developmental process that controls and shapes how people grieve a death, how long they grieve or what meaning they give to death' (Rosenblatt, 2001: 297). The data from this study would clearly support this view.

11.4.5. Identity: aspects of personal growth

In this chapter it was highlighted how the experience of early parental death has the potential to promote growth and development and may help to develop inner resources and strength which can be drawn on in adulthood. This is not to minimise the extreme pain, suffering and disruption the loss of a parent(s) may generate.

The concept of growth in this context, according to Dyregrov and Dyregrov 2008, entails the development after a significant loss potentially resulting over time, in an experience of positive change. The growth is accordingly experienced as an unintended positive consequence of something extremely negative (the death). These authors maintain that this is wholly in accordance with many adult experiences and can be connected with that which what is known about personal growth and development in the aftermath of crises, known as posttraumatic growth (Tedeschi et al., 1998).

According to Janoff-Bunman's (1992) analysis of human traumas as disruptions of assumptive world views when a sudden, unexpected death damages a human being's sense of security; it often leads to an existential crisis (Janoff-Buman, 1992). The bereaved feel that the world has 'turn upside down' and 'everything that was safe becomes uncertain,' that existence is experienced as being unfair and that they do not have control, as the narratives of many of those in this study have highlighted. Much of that which was taken for granted in daily life no longer applies and the brutal upheaval imposes difficult requirements with regard to adjusting to that which has happened, at both the mental and emotional level (Janoff-Bruman, 1992). According to Dyregrow and Dyregrow (2008) these difficult requirements lead to most of the crisis-stricken people reviewing both the event and the possibilities that they may have had to influence the outcome. This process can create the opportunity for personal growth through the creation of meaning. These authors maintain that while the bereaved at an early stage after a death want an explanation as to why the death occurred, many are later concerned with searching for or reconstructing meaning on in their existence.

Through their experiences related to their parent (s) death, many respondents believed that they had developed empathy and understanding and hence felt better able to help others that needed help and support. This ranged from being involved in support groups and counselling working to working in the caring professions This way of creating meaning was reflected in the narratives of many in the study including, Winfred, Dan, Jan, Janet , Anne Marie and Sarah. In this way respondents were able to create meaning out of the meaningless. According to Dyregrow and Dyregrow (2008) this manner of creating meaning and mastery has an extroverted, social form and has helped many in similar situations

Early parental death was also shown to instil a deeper appreciation of life as the bereaved become acutely aware of the time- limited and uncertain nature of life brought about by their parent(s) death, particularly for those that had known their parent(s). Some allowed meaning to find expression by emphasizing how that death had enabled them to appreciate in a more heartfelt manner those closest to them as was Amy's experience.

The narratives extracts have also highlighted how taking on adult roles and responsibilities or having to be self sufficient can lead to autonomy, independence and enhanced coping skills and a sense of being more mature. The narrative extracts have also highlighted how the attitudes of others may influence the need to be independent and not to be reliant on others in adult life. However, this independence was seen to be problematic for some in terms of relationships with others as there was sometimes a reluctance to share feelings and plans with those that were closest to them, as was Alison's and Anne Marie's experience.

As stated in the literature review there are a small number of studies that support aspects of these findings as they have also noted the more positive aspects of the bereavement experience. Balk (1983), for example, found that adolescents who lost a sibling emerged from bereavement with increased maturity which was derived, in part, form having coped successfully with their sibling's death and negotiating roles changes, such as becoming the eldest child. Some adolescents also showed improved relationships with family and friends and learned the importance of value people when they were alive.

Davies (1991) discovered that adults who had lost a sibling in childhood reported increased maturity that was reflected in greater insights into life and death. This experience also made them aware of their own mortality, enhanced their understanding of the meaning of life and enabled them to help others who had experienced bereavement.

Martinson and Campos (1991) examined the long-term effects of bereavement on adolescents seven to nine years after their sibling died from cancer at home. Whilst almost twenty percent of the adolescents indicated that their sibling's death had a negative impact on their life most of them reported that the death enhanced their personal growth as well as that of their family.

Oltjenbruns (1991) discovered that most of the late adolescents in his study reported at least one positive outcome following the death of family member or friend. The most commonly cited positive outcome was a deeper appreciation of life. Other outcomes included better communication skills, stronger bonds with other people, increased emotional strength and greater empathy. Some adolescents also reported that they were less afraid of death, more independent and clear about their priorities.

The findings from such studies are important as clearly they broaden our understanding of impact of bereavement. However, for the most part these studies appear to look at personal growth in isolation rather than acknowledging the context in which it resides. Furthermore, the focus is on sibling death.

What is significant about the finding from the present study is that the personal growth associated with the experience of early parental death. This study has also brought into focus how personal growth was fostered in social interaction and is context bound. These finding are important as they broaden and enrich our understanding of the impact of early parental death on adult life particularly with regards identity in terms to personal growth and resilience and allows some understanding of the way in which social processes impact on the bereavement experience in positive ways.

11.46 Supporting bereaved children

From the findings, two models of bereavement support have been developed and presented. The first model presented was supportive in orientation and has a much broader focus that the more traditional models of bereavement support in that it emphasis the practical elements necessary to support and empower bereaved surviving parents (or surrogate caregivers) to enable then to better support their bereaved child (ren). The second model is prognostic in orientation and is concerned with identifying children who have experienced early parental death and who potential may be at risk of less favourable outcomes in adult life so that they can be better supported.

Currently there are various possible formats in the UK which support for bereaved children may be provided or could be provided (Rolls & Payne, 2007). In a survey of childhood bereavement services in the UK (Rolls, 2003) it was found that the bereavement interventions offered were mostly therapeutic and ranged from individual family work (86%), individual child work (62%), group work with families (53%) and group work with children (45%). Others services offered were pre-bereavement support (64%), a drop in service (17%), information and advice (895%), training (32%) and the provision of resources (88%).

However, as previously mentioned in the introduction there is a tendency to rely on counselling. Voluntary organisations have been seeking to develop their services in response to what is seen as an urgent set of unmet needs and there is ongoing debate about how far counselling can appropriately ease the 'normal' distress of grief and more specifically, whether talking can help in this situation.

For example, Harrington and Harrison (1999) question whether bereaved children and young people necessarily neither need, nor will benefit from, counselling interventions. In their subsequent community based research, Harrison and Harrington (2001) found that 87 per cent of bereaved adolescents said they 'had never, rarely or only sometimes talked about the deaths of relatives or friends' (Harrison and Harrington: 163) and 'talking about death was associated with higher levels of depressive symptoms'. The vast majority (88.5 per cent) also said they 'never or rarely needed professional help for the way they were feeling about the deaths they had experienced' Harrington and Harrison conclude that 'there is little support, then, among adolescents themselves for the widespread development of specialised bereavement counselling services.

This was also found to be the case with research by Dowdney et al., (1999) who asked teachers about the experiences of young people but did not ask young people themselves about their experiences and views on desirable support. However, Ribbens McCarthy (2006) is critical of this conclusion. She asserts that it goes beyond of what is warranted of the data as it is not known what sorts of professional help young people may have had in mind, or had experience of, when they said they did not need such help. Furthermore, she says that young were not asked directly if they would like the opportunity to talk about their feelings.

The data from this study would suggest that counselling as an intervention is inadequate to deal with complexities involved in terms of early parental death as it focuses on the individual. In doing so it negates the socio - economic and cultural circumstances of people's lives.

Other formats broader programmes of bereavement support have been developed. Silverman et al (2002) as a result of their study stress the importance of providing support for families with dependent children after the death of a parent. Like Sandler and his colleagues (2003) Silverman et al also acknowledge the need for increasing education opportunities for developing parenting skills appropriate to the needs of the family. The findings from this study provide additional support for this recommendation.

However, whilst it is acknowledged that this type of support is clearly very important the findings from this study suggest that is not sufficient. Support is necessary that increases stability, continuity and cohesion needs be introduced at level of the family system. This support should range from the management of practical household tasks (which includes practical help with the work of daily family survival such as childcare, housework and financial support) to strategies for improving communication. Such interventions may help the family as a unit, through interpersonal communication to integrate experience and adapt to changes with few attempts to control thoughts and feeling in ways that impede shared development. Such a model of support is outlined by Shapiro (2001).

Furthermore in trying to help bereaved children, those providing support (such as psychological practitioners, clergy, physicians, teachers and other professionals) generally operate with a sense of what 'normal' bereavement is. Rosenblatt (1983) points out that in some cases it may not matter whether those standards are culturally appropriate or statistically normal. Whilst bereaved children 'might benefit from a wide range of structuring to their experience' (Rosenblatt, 1993: 109) the professional's perspective might also seriously violate the norms of a bereaved person's culture, what is common in the grief process or be insensitive to the feelings and needs of the person. He goes on to say that the bereaved may be pushed towards meanings that do not make sense, to difficulty with people whose support is important, or to intolerable levels of suffering.

Many of the stage/phase theories are widely taught to student nurses and others working in health and social care. Moreover, they are frequently presented in simplified form, with little acknowledgement of their criticisms (Payne, 2008). In fact, Payne asserts that the pervasiveness of psychological stage/phase models means that they have been incorporated into everyday taken-for-granted assumptions about how people should feel and behave following a loss, as exemplified in the narratives in this study.

As previously highlighted in the literature review, an assumption of such models is that grieving should be virtually complete at some definite point after a significant loss. The narratives in this study did not support this view. As illustrated by the narratives in this grieving may reoccur with intensity throughout the life course. In some cultures, a person bereaved of a significant person will be expected to mourn for a lifetime (Rosenblatt, 1993). Rosenblatt asserts when a therapeutic prescription for normal grieving is so discordant with human experience or with cultural norms bereaved people may reject potentially valuable aspects of therapy or inappropriately question their own mental health, as was Colin's, Christine's and Jane's experiences.

As highlighted in this study people's view of the world was shaped by a variety of factors, including the culture which they live, their early life experiences, which included previously experienced stressful life events, such as their experience of early parental death. As a result of the interplay of these factors, people develop their day-day- day coping efforts.

According to Rosenblatt (1983) these conceptions have to do with the extent to which the world, and the people and institutions in it, are seen as predictable and orderly versus random, safe and, benevolent versus malevolent, controllable versus uncontrollable, fair versus unfair and trustworthy versus untrustworthy. Regarding why things happen when they do, people may be fatalistic, seeing things as part of a larger plan; they may feel people get what they deserve, either on earth or in an afterlife, or they may see the world as a random universe or a "jungle" where things may happen without purpose. As illustrated through the narratives in this study these dynamics are very important in terms of influencing the bereavement experience and need to be reflected in the education and training of those concerned in delivering bereavement support. However, although appropriately trained individuals can offer useful help, it is important to recognise that community-based volunteers, who offer support and access to resources, or bereaved survivors can to helpful to bereaved individuals (Klass, 1998; Silverman, 2000), as the narratives in this study clearly show.

11.5. Conclusions

This study has shown that losing a parent(s) in childhood can have a profound effect on adult life. As collaborators in this study, the participants provide a rich account of their experiences of early parental loss and its impact on adulthood. The narratives reflected the complex, diverse and negotiated nature of experience that disrupts and challenges normal and established patterns of social functioning. The narratives also provide insight into the importance of context for understanding the bereavement experience and how mediates the bereavement experience and impacts on adult life.

Psychoanalytic and stage models of grief tend to suggest that there is a pattern to grieving which individuals pass through. The data from this study and other research studies do not support this. The findings from this study confirm that fundamentally such models may be accused of asserting an unfounded universalism as to the nature of grief and its associated emotionality, and in failing to consider differences, whether these concern broad cultural differences, or variations associated with structural differences such as age status, class or ethnicity. Therefore, to find a pattern for all bereaved children would be to oversimplify the complexities involved. Each of the respondent's experiences of early parental death was unique. Upsurges of grief could appear throughout the life course, particularly in relation to significant events, rather than achieving resolution as the above models suggest. The findings from this study did not view these intense feeling of loss as part of complicated grief, but as a normal part of grieving. However, where such experiences were at odds with an individual's beliefs about so called 'normal' grief process this was perceived to compound their distress.

One particular insight concerns the striking evidence of how apparently similar bereavements may shift individual experiences in quite opposite directions depending on the context in which it is embedded. This is something that may be lost within more quantitative studies.

Although much of the research on adaptation on life crises emphases the painful emotions and psychological symptoms they generate the insight from this study has also shown how life crisis, in this case early parental death, was also the impetus for personal growth and resilience.

In an analysis of the stories it became apparent that the individual accounts were organised around common themes that provided value insight into what were perceived to be key dynamics that appeared to mediate the experience of impact of early parent loss (before the age of 18) on adult life.

These key dynamics are summarised below:

- Maintaining continuity in the lives of the bereft helps them to cope with the process of bereavement
- The importance of communication in terms of recognising the loss at two time points (the physical death and the death of the parent that was known to them in terms of "mothering/fathering"). It was also important with regarding to dealing with the emotional challenges of grief in childhood and in adult life.
- Communication needs to be appropriate to the child's level of understanding which is influenced by age and experience.
- Family processes and practices influence the bereavement experience
- The influence of wider social and cultural process and practices on the bereavement experience
- Having to cope with the changes to life as a result of bereavement may help to facilitate personal growth and resilience

To a large extent the importance of these key dynamics was found to be well supported by the childhood bereavement literature. However, much of this research was found to relate to short term outcomes (typically two years post bereavement) and focused mostly on the negative impact of the early parental loss. The relative novelty of the findings from this study relates to how these different dynamics impacts both negatively and positively in later life.

11.6. Implications for practice and future research

The findings have implications for practice in relation to supporting people in coping with the messy and unpredictable nature of living with bereavement rather than imposing how a model should be as in more linear models of grief. However, it should be acknowledged that although such models are limited and limiting that have provided a framework for dealing with the concept of loss. They have also provided research with a stimulus for the development of broader models which acknowledge the context in which bereavement resides.

Nevertheless, these phase/stage models of grief are so pervasive they underpin the taken-for-granted assumptions with regards to grief and mourning. This has implications for those whose experience of grief is at odds with their beliefs about the grief process and has the potential to compound distress, as the narratives have clearly illustrated. It also has implications for those supporting bereaved children and their families whose training is still underpinned by such models.

From the findings two models for bereavement support were presented which acknowledge the complex nature of the bereavement experience and the social, economic, cultural processes and practices that were reflected in this study as influencing the impact of bereavement over the life course. Hence these models provide a much broader framework that could well help those working with contemporary bereaved children and their families.

The supportive model emphases the practical elements necessary to support and empower bereaved surviving parents (or surrogate caregivers) to enable then to better support their bereaved child (ren). Like that outlined by Shapiro (2001) the model presented in this study recognises that support that increases stability, continuity and cohesion needs be introduced at level of the family system. This support should range from the management of practical household tasks (which includes practical help with the work of daily family survival such as childcare, housework and financial support) to strategies for improving communication. Such interventions may help the family as a unit, through interpersonal communication to integrate experience and adapt to changes with few attempts to control thoughts and feeling in ways that impede shared development.

However, such support needs to be sensitive to the family's cultural beliefs surrounding death, dying, bereavement and parenting and the wider social /cultural context in which these practices are embedded, which are historically rooted and change over time. Such social and cultural practices, as illustrated in this study, may prevent people talking about the deceased or prevent others talking about the bereaved or offering support, especially when the death is seen as socially unacceptable.

The complex nature of the experience is increasing recognised in the literature as is the need for a broader model of support. One of the main findings in this thesis relates to the damage and suffering experienced by individuals (irrespective of current age) over time when appropriate guidelines or 'best" practice are not followed. If bereaved children are to be better supported it is crucial that appropriate guidelines or "best practice" models are followed. However, according to Shapiro (2001) there is limited research literature on grief interventions and these guidelines are often contradictory.

Since its establishment in 1998 the Childhood Bereavement Network has developed a set of guidelines for Best Practice to provide organisations and individual practitioners with a baseline 'best practice' framework for support to parents of bereaved children (CBN, 2006). This set of guidelines is endorsed by all Network members as a criterion of their membership (CBN, 2006). In this document the terms "parent" or "parents" is used to describe any adult who is caring for and/or has parental responsibility for a bereaved child. For example, a widowed parent, grandparent, step-parent, foster carer, adoptive parent or legal guardian.

This set of guidelines represents a significant achievement in the field as there were no previous nationally agreed guidelines in this area of practice (CBN, 2006a). Crucially, these guidelines recognise the importance of supporting parents of bereaved children and acknowledge that parents have the primary role in providing information, guidelines and support to their bereaved children. This set of guidelines also acknowledge that parenting is challenging, varied and long-term, and those parents and families will have a broad range of practical, emotional, social and financial needs.

As this study as highlighted, if bereaved children and their families are to be better supported it also necessary, to ensure that those organisations and institutions providing support (whether it be at a voluntary, statutory or community level) provide their workforce with training and education that is reflective of the complexities involved and not based on outdated models and theories of grief and mourning. This education and training should also recognise the importance of family focused assessment and the need for staff to have appropriate training in this regard. It should also provide staff with knowledge of the parenting role and how this can be affected by bereavement. Importantly, many of these recommendations are reflected in the CBN guidelines.

In terms of future research, more is needed to explore if appropriate guidelines and best practice are followed and if not what are the reasons for this. Strategies also need to be developed to help those supporting the bereaved children and their families in such a way as harness and enhance the potential for personal growth and resilience and to work with the surviving parent at both a practical and emotional level to empower them to support their children. It this is to be achieved it is important to recognise the value of the contribution of the bereaved themselves (and their families) as collaborators in this process. Given the importance of social networks in mediating the bereavement experience more research in necessary in this regard to see how they may be better supported.

Given the multi-cultural nature of contemporary UK society it is also crucial that future research focuses on the experiences of ethnic minorities in relation to bereavement in childhood with regards to its impact on adult life. Again, in developing such research strategies it is important to recognise the value of the contribution from bereaved children themselves as collaborators in the research process.

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Appendix 1

Participant Information Leaflet & Covering Letter

1. Invitation to the study

We would like to invite you to take part in the above study. Before you decide it is important for you to understand why the research is being done and what is involved. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

2. The purpose of the study

This study is investigating the impact of early parental loss (before the age of 18) on adults during later life. By listening to, and reading your personal experiences we will have a better understanding of how such a loss affects people during their lives. The information gained will be used to inform bereavement support services so they can be better tailored to meet people's needs.

Jackie Ellis is a researcher working at the University of Liverpool with the principal investigator, Prof Mari Lloyd-Williams. Jackie is hoping to learn more about how losing a parent before the age of 18 influences people's lives. She will be working on the study for three years.

3. Why have I been chosen?

You responded to our appeal for people living in Merseyside, the surrounding area or North Wales (over 18) who had lost a parent during childhood (before the age of 18) to take part in the study. We are very keen to hear your experiences as we need to understand how such a loss has influenced your life so that we can help others in similar situations.

In total about 30-40 people will be involved in the study so that we can hear about a wide range of experiences.

4. Do I have to take part?

It is up to you whether you decide to take part. This information sheet is yours to keep. If you do you decide to take part you will be asked sign a consent form. However, please note that you will still be free to withdraw from the study at any time without giving a reason. A decision to take part in the study or a decision to withdraw at any time will not affect you in any way.

5. What will happen if I do decide to take part?

If you do decide to take part in the study please contact Jackie. She will arrange a meeting so that you can tell her about your experience of losing a parent and how this loss has influenced your life. Jackie will (with your permission) record the interview so that she doesn't have to make notes and instead can concentrate on what you're saying. The meeting will last about one hour and will take place at a venue convenient to you. Any travel costs will be reimbursed.

If you prefer, you can choose to write down your story in your own words and send it to Jackie at the University (a prepaid envelope will be provided).

Following hearing/receiving your story you will be sent a small feedback questionnaire asking you what you thought about taking part in the study.

6. What are the possible disadvantages of taking part?

It is possible that telling/writing your story maybe distressing for you as you are being asked to recall a traumatic event. If you are being interviewed and become distressed, if you wish, Jackie will stop the tape and discontinue the interview. If you feel able you may choose to continue with the interview after a break. If you prefer you can rearrange the interview for another time/date or you may decide not to continue with the interview process.

If you are writing your story and you find it too distressing it is up to you if and when you choose continue.

7. What are the possible benefits of taking part?

By taking part in this study you can help us find out more about how we can help others that have lost a parent during childhood. In addition research has shown that talking (or writing) about distressing experiences can be helpful to people.

8. Will my taking part in this study be kept confidential?

Please be assured that your stories will be treated in the strictest confidence. Jackie will be responsible for making sure the tapes and transcripts are anonymised (if you prefer you may use your first name or a pseudonym of your choice) and kept safe. The only other person who may see or hear them is the study supervisor Professor Mari Lloyd Williams, Honorary Consultant in Palliative Care.

9. What will happen to the findings from the study?

The findings will be used in Jackie's research and will form the basis of a report that will be sent to key people responsible for local bereavement services. The results of the study will also published in national and international journals and presented a research meeting so that as many people as possible can hear about and benefit from the findings (if you wish copies of these articles will be sent to you). A summary of the findings will also be available to you on request.

10. Who funding the research?

The research is funded by the Clara E Burgess Charity. Registered Charity Number 1072546.

11. Who has reviewed the study?

Ethical approval has been obtained from the University of Liverpool Ethics Committee.

Thank you for reading this information about our study. If you would like to take part in the study or require further information please contact Jackie Ellis (details on the front of the leaflet).

UNIVERSITY OF LIVERPOOL

Understanding the impact of the early death of a parent on adults during later life: a narrative approach

Participant Information Leaflet

Jackie Ellis (Project Researcher)

Academic Palliative and Supportive Care
Studies Group (APSCSG)
Department of Primary Care
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool L69 3GB
Tel: 0151 794 5744
Email: Jacqueline.ellis@liv.ac.uk

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LIVERPOOL

Academic Palliative and Supportive Care Studies Group (APSCSG)
Department of Primary Care
School of Population and Behaviour Sciences
Whelan Building (2nd Floor)
Brownlow Hill

Address

Dear

Re Understanding the Impact of Early Parental Death on Adult Life

Thank you for responding to our appeal for participants for the above study. I would be very keen to hear about your experiences and I have enclosed an information leaflet that tells you more about the study and what is involved. Please have a look at it and if you are still interested in talking part please get back to me and we can make can make appropriate arrangements.

If you have any further questions please do not hesitate to contact me.

Kind regards
Jackie Ellis

Project Researcher

0151 794 5744

jacqueline.ellis@liv.ac.uk

Appendix 2

Participant Consent Form

5. Consent form –VERSION 1-November 2006.

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Participation Identification Number:

Title of Project:

Understanding the impact of the early death of a parent on later life

Name of Researcher: Jackie Ellis

Telephone: 0151 794 5744

Email: jacqueline.ellis@liv.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet dated .... for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason or legal rights being affected. ☐

3. I understand that if I take part in an interview it may be recorded and I give my permission for this ☐

4. I agree to take part in the above study. ☐

Name of Participant ______ Date ______ Signature ______

Name of Person taking consent ______ Date ______ Signature ______

(if different from researcher)

Researcher ______ Date ______ Signature ______

Copy for participant and copy for researcher

Appendix 3

Letter (emails had the same content) sent to support agencies

List of support agencies contacted during first and second stage of recruitment

Posters used to recruit participants

THE UNIVERSITY
of LIVERPOOL

Professor Mari Lloyd-Williams
MD FRCP MRCGP MMedSci ILTM
Honorary Consultant in Palliative Care
Academic Palliative and Supportive Care Studies Group (APSCSG)
Department of Primary Care
School of Population and Behaviour Sciences
Whelan Building (2nd Floor)
Brownlow Hill
Liverpool L69 3GB

Address of support agency

To whom it may concern

Re: Understanding the impact of the early death of a parent on adults in later life- appeal for participants

The Academic Palliative and Support Care Studies Group at the Liverpool University are conducting the above study which is funded by the Clara E Burgess Charity. This study is guided by a Steering Group consisting of lay representatives and experts in the field of narrative research, bereavement support and psychology. Ethical approval has been granted for this study from the University of Liverpool Ethics Committee which adheres to explicit ethical criteria.

We were wondering if there is any way in which your organisation could help us with our appeal for research participants as we are keen to include participants from minority ethnic backgrounds, particularly men. To be eligible for the study, respondents most be 18 or over (there is no upper age limit), reside in the North West and have lost a parent before they were18. To protect those who may be particularly vulnerable those suffering bereavement within the last twelve months will be excluded from the study.

Participants will be assured that participation in this study is voluntary and anonymous (although if participants prefer they may use their first name or a pseudonym of their choice) and the data collected with be treated in the strictest confidence without attribution to any individual.

The enclosed appeal for participants sets out the context for this research and we would be most grateful if you could publicise this via any newsletter, website, notice board, meeting, conference etc to which you have access. To maximise recruitment we need to disseminate widely, hence we have contacted a broad range of organisations and agencies including bereavement and palliative supportive care networks and self help groups (such as Cruse, Winston's Wish, Compassionate Friends and Age Concern) to elicit their support. In addition we have published our appeal for participants via the regional press and local media and posters have been displayed at various venues throughout the region.

The findings from this research will broaden our understanding of the impact of early parental loss on later life and will be used to inform bereavement support services regarding this group. Any articles and a summary of the findings will be available to participants on request. If you have any queries please do not hesitate to contact us.

We hope that you will consider our request favourably and look forward to hearing from you in the near future.

Yours faithfully

Jacqueline Ellis, MSc, BA (Hons) Project Researcher

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LIVERPOOL

Appeal for volunteers

How early parental death impacts on adult lives is the subject of research being carried out at Liverpool University by the Academic Palliative and Supportive Care Group within the Division of Primary Care.

Researchers are keen to hear from people over the age of 18 (there is no upper age limit) that lost a parent before they were 18 living in Merseyside, the surrounding area or North Wales. To protect those that may be particularly vulnerable those suffering parental loss within the last twelve months will not be eligible. By means of personal experiences the research team hopes to understand the impact of this loss on later life. The knowledge gained will add to the evidence regarding the impact of bereavement and will also be used to inform bereavement support services so they can be better tailored to meet this groups needs.

The researchers hope to recruit between thirty to forty people for the three year study, which is being funded by the Clara E Burgess Trust. Please be assured that this participation in this study is voluntary and anonymous and the data collected will be treated in the strictest confidence.

If you are interested in taking part in this study and require further information please contact Jacqueline Ellis at the University of Liverpool or Professor Lloyd-Williams

Jackie Ellis (Project researcher)
Academic Palliative and Supportive Care Studies Group (APSCSG)
Division of Primary Care
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool L69 3GB
Email: jacqueline.ellis@liv.ac.uk
Tel 0151 794 5744

Professor Mari Lloyd Williams
Academic Palliative and Supportive Care Studies Group (APSCSG)
Division of Primary Care
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool L69 3GB
Email: mlv@liv.ac.uk

Understanding the impact of early parental death during adult life

Call for participants: List of Organisations Contacted

Organisation	Address	Postcode	Tel	Date contacted	Contact name	Contact details	Info sent
Cruse Bereavement Service	9 Abbey Rd Bangor	LL57 2EA	0870 2402758 crusecymru@gmail.com	26Feb 2007			19/03/07
Cruse Bereavement Service	Sefton Cheshire		Tel:- 0151 708 5311 HEAD OFFICE info@cruse.org.uk	26 Feb 2007	Catherine Betley	Service & Development Manager Cruse Bereavement Care PO Box 2147 Horwich Bolton BL6 9AZ Tel/Fax: 01204 694904 Mobile: 07951 348174	19/03/07 and 29/04/07
St. Helens Bereavement Service	St Helens Bereavement Service Suite 3B 3rd Floor Tontine House St Helens Merseyside	WA10 1BD	01744 451793	26th Feb 2007	Joan Ashcroft		19/03/07
Liverpool Bereavement Service	Maureen Condon Co-ordinator 4th Floor Rail House, Lord Nelson St. Liverpool	L11JF	708-6706 Liverpoolbereavement@tiscali.co.uk LBS@icliverpool.co.uk		Maureen Condon		2/04/07
Bereavement support, advice, counselling	25 Hope St Liverpool	L1 9BQ	bereavement@waitrose.com 0151 708 6706				2/04/07
Warrington Bereavement Counselling	Warrington Bereavement Counselling Services Care 5 Hanover Street Warrington	WA1 1LZ	01925 631516				19/3/07 (returned wrong address

Organisation	Address	Postcode	Tel	Date contacted	Contact name	Contact details	Info sent
Warrington Bereavement Support	P.O. Box 930 Warrington WA4 9AT		01925 631516(answer phone contactus@wbsupport.org.uk		Judith Guthrie (chairman)	Request forward to next executive meeting(May)	2/04/07
Kings Cross Project.	C/o Trinity Church Peelhouse Lane Widnes Cheshire WA8 6TJ		0151 4204905 enquiries@kingscrossproject.org.uk				3/04/2006
Child Bereavement Trust	Aston House, West Wycombe High Wycombe, Bucks	HP14 3AG	enquiries@childbereavement.org.uk	26/02/07			3/04/07
Childhood Bereavement network	Childhood Bereavement Network 8 Wakley Street London	EC1V 7QE	020 7843 6309				15/06/07
Compassionate Friends			media@tcf.org.uk National office 0845 120 3785	26/02/07	Audrie Norris (public relations officer)	JOHNAUDRIE@AOL.COM Pass on request to members of charity	3/04/07
Lyndale	Knowsley Cancer Support 40 Huyton Lane, Huyton, Liverpool,	L36 9TS.	0151 489 3538 Support@knowsley-cancer-support.co.uk	19/02/07	Eileen McGovern		19/3/07
Winstons Wish	The Clara Burgess Centre Bayshill Road Cheltenham	GL50 3AW	info@winstonswish.org.uk 01242 515157	26/02/07	Julie Stokes	JStokes@wistonswish.org.uk To publicise appeal	14/03/07
Survivors of Bereavement by Suicide	The Flamsteed Centre Albert Street Ilkeston Derbyshire	DE7 5GU	sobs.admin@care4free.net Press office angelasamata@mac.com	26/02/07	Angela Samata (liv office)	angelasamata@mac.com	14/03?07

Organisation	Address	Postcode	Tel	Date contacted	Contact name	Contact details	Info sent
COPE:	The Laura Centre 4 Tower Street Leicester	LE1 6WS	info@thelauracentre.org 0116 254 4341	26/02/07		Would have liked to have helped but have no clients in Liverpool area	3/04/07
West Lancs Bereavement Counselling Service	Malthouse Business Centre 48 Southport Rd Ormskirk L39 1QR		01695 570729	5TH Feb 2008	Audrey Jones	Willing to publicise the appeal Would like information regarding the outcome of the study	
Zig Zag	Website		Zig zag.org.uk h.h.ahmedzai@sheffield.ac.uk		Hilde Hjelmeland Ahmedzai		30/04/07
Building Bridges	John Archer Hall, Old School Building, 68 Upper Hill Street, Liverpool, Merseyside,	L8 1YR	Juliet Morton		Gale Coleman	Gail.coleman@rlc.nhs.uk	19/3/07
Help the Aged	12 Cathedral Rd, Cardiff	CF119LJ	infocymru@helptheaged.org.uk 02920 346 550				3/04/07
Help the aged	207-221 Pentonville Road, London N1 9UZ		info@helptheaged.org.uk 020 7278 1114				3/04//07
Age Concern	Age Concern Knowsley 1 Griffiths Road Huyton LIVERPOOL Merseyside	L36 6NA	Tel: 0151 480 4632 Fax: 0151 443 3898 Email: frank.reppion@acknowsley.orghttp://www.ageconcernknowsley.org.uk				3/04/07
	Age Concern Liverpool Sir Thomas House	L1 6BW	Tel: 0151 330 5678 Fax: 0151 330 5679 Email: mail@ageconcernliverpool.				3/04/07

Organisation	Address	Postcode	Tel	Date contacted	Contact name	Contact details	Info sent
	5 Sir Thomas Street LIVERPOOL		org.uk				
	Age Concern Crosby c/o 2 Norman Road Crosby LIVERPOOL	L23 3DL	Tel: 0151 924 6099				
	Age Concern Halton 44 Church Street RUNCORN Cheshire	WA7 1LR	Tel: 01928 590600 0151 424 9000 (Information Office) Fax: 01928 591455 Email: enquiries@ac-halton.org.ukhttp://www.ac-halton.org.uk				3/04/07
Age Concern North Wales	12-14 Hall Square Denbigh	LL16 3NU	01745 816947 enquiries@acnwc.org				3/04/07
Age Concern North East Wales	Unit 14 Business Park Mold Flintshire	CH7 1XP	08450 549969 chiefofficer@acnew.org, mari.evans@acnew.org.uk		Margaret Hanson		3/04/07
Help the Hospices	Hospice House, 34-44 Britannia Street, London WC1X 9JG		info@helpthehospices.org.uk 44 (0) 20 7520 8200				3/04/07
Nightingale House Hospice	Chester Road Wrexham	LL12 9TA	01978 316800			27/04/07	

Organisation	Address	Postcode	Tel	Date contacted	Contact name	Contact details	Info sent
St Ann's Hospice	St Ann's Road North Heald Green Cheadle	SK8 3SZ	0161 498 3668 mmackay@sah.org.uk		Maggie Mackay Social worker	25/04/07- Enquiring if appeal and be put on website and translated in Mandarin	
St Kentigern Hospice	St Kentigern Hospice & Palliative Care Centre Upper Denbigh Road, St Asaph, Denbighshire	LL17 0RS	01745 585221 st.kentigern@cybase.co.uk			27/04/2007	

List of agencies contacted during second stage of recruitment

IGBO Community Association Liverpool
2 Park Way
Liverpool
L8 1TS

IGBO Women's Association
81 Woodcroft Road
Wavertree
Liverpool
L15 2HG

Imagine Training Team
214a County Road
Walton
Liverpool
L4 5PJ

Indo British Association (North)
14 North View
Edge Hill
Liverpool
L7 8TS

Innervision Community Consultancy Ltd
Mornington Terrace
37 Upper Duke Street
Liverpool
L1 9DY

Inter-nation Roma Organisation o Liverpool
291-299 Kensington
Liverpool

Iraqi Community in Merseyside
7 Fareham Road
Liverpool
L7 0HR

Irish Community Care Merseyside
60 Duke Street
Liverpool
L1 5AA

Jamaica Merseyside Association
c/o Merseyside Caribbean Centre
1 Amberley Street
Liverpool
L8 1TD

Kensington Methodist Church
Kensington
Liverpool
L7 2ON

Kirkdale Neighbourhood Community Centre
238A Stanley Road
Kirkdale
Liverpool
L5 7QP

Kurdish/Turkish Community Organisation / Liverpool
5 Princes Road
Liverpool
L8 1TG

Kuumba Imani Millennium Centre
34 Princes Road
Liverpool
L8 1TH

LASAR
Unit E48, Ayrton House
Parliament Business Park
Commerce Way, Liverpool
L8 7BA

Liverpool Arab Women's Organisation
14 Carter Street
Liverpool
L8 1XH

Liverpool Black Ethnic Minority Network
c/o Unity Youth & Comm Centre
49 Dove Street
Liverpool
L8 0TU

The Liverpool Jewish Youth & Community Centre,
Harold House, Dunbadin Road
Childwall
Liverpool
L15 6XL

Liverpool Muslim Society
25 Scholar Street
Liverpool
L7 4JR

Liverpool Muslim Society Alrahma Day Centre
Alrahma Day Centre
27 Hatherley Street
Liverpool
L8 2TJ

Liverpool PSS
18 Seel Street
Liverpool
L1 4BE

Liverpool Somali Community
57 Granby St
Liverpool
L8 2TU

Liverpool Yemeni/Arabic Club
167A Lodge Lane
Liverpool
L8 0QQ

Local Solutions
Mount Vernon Green
Hall Lane
Liverpool
L7 8TF

Mai Society in the Diaspora Ltd.
109 Lodge Lane
Liverpool
L8 0QF

Malaysia and Singapore Community Association
7 Jermyn St
Liverpool
L8 2XA

Mary Seacole House
91 Upper Parliament Street
Toxteth
Liverpool
L8 7LB

Mencap Liverpool
MENCAP House
Lowerson Road
Clubmoor, Liverpool
L11 8LW

Mersey Volunteer Bureau
35 Lime St
Liverpool
L1 1JG

Merseyside African Swahili & French Community Ass.
73 Hawkins Street
Liverpool
L6 6BY

Merseyside Association of Ghanai
60 Duke St
Liverpool
L1 5AA

Merseyside Bangladeshi Association
101/107 High Park Street
Liverpool
L8 3UF

Merseyside Caribbean Council
1 Amberley Street
Liverpool
L8 1YJ

Merseyside Chinese Community Development Assoc.
Pagoda Chinese CommunityCentr
Henry Street
Liverpool
L1 5BU

Merseyside Community Voice
12 Hanover Street
Liverpool
Merseyside
L1 4AA

Merseyside Cultural Organisation
51/53 Lodge Lane
Liverpool
L8 0QE

Merseyside Development Founda
Booth House
Venture Point Business Park
Speke Boulevard, Liverpool
L24 9HZ

Merseyside Somali Community Association
145 Granby Street
Liverpool
L8 2UR

Methodist Youth and Community Centre
Methodist Centre.
Beaconsfield Street.
L8 2OU

Motor Waste
15 High Park Street
Toxteth
Liverpool
L8 8DX

Multicultural Diabetes Forum
Health & Community Care Forum
163 Lodge Lane, Toxteth
Liverpool
L8 0QQ

Muslim Enterprise Development Services
2 Lodge Lane
Liverpool
L8 0QH

Muslim Youth Association Liverpo
11 Reydale Close
Liverpool
L8 0YF

Navarro Training and Consultancy
14 Ashdale Road.
Mossley Hill
Liverpool
L18 1LU

New Life Centre, The
152 Granby Street
Liverpool
L8 2US

Nigerian Community Association
64 Upper Parliament Street
Liverpool
L8 7LF

NOVAS Ouvertures
Chancery House
Paradise Street
Liverpool
L1 3HE

Nugent Care Society Multicultural Resource Centre
Kelton Training Centre
Woodlands Road
Aigburth
L17 0AN

Ogunsiji Innovations
56 Princes Road
Liverpool
L8 1TP

Osun Arts Foundation
24 Hardman Street
Liverpool
L1 9AX

Pagoda of Hundred Harmony Chinese Community Centre
Henry Street
Liverpool
L1 5BU

Pakistan Association - Liverpool
60 Mulgrave Street
Liverpool
L8 2TF

Pine Court Housing Association Ltd.
1 Nelson Street
Liverpool
L1 5DW

Project 8
129a Lodge Lane
Toxteth
Liverpool
L8 0QF

PSS Gateway Project
Personal Service Society
4 Beaconsfield Street
Liverpool
L8 2UU

Refugee Action
34 Princes Road
Liverpool
L8 1TH

Refugee Skills Development
Garston Community House
2 Speke Road
Garston
L19 2PA

REMISUS
Community Resource Centre,
Toxteth Town Hall,
15 High Park Street, Toxteth
L8 8DX

Rialto Neighbourhood Council
70 Upper Hill St
Liverpool
L8 8JE

Riverside Housing Association
46 Wavertree Road
Liverpool
L7 1PH

Sahir House
P.O.Box 11
Liverpool
L69 1SN

Sierra Leone Merseyside Action
20 Bewey Close
Dingle
Liverpool
L8 6XW

Slic/ Moorhouse NW Media Developments
322 - 324 Upper Parliament St
Liverpool
L8 7QL

Somali Links Society
C/o 6 Wynnstay Street
Liverpool
L8 3UD

Somali Umbrella Group
c/o Remisus
Toxteth Town Hall
15 High Park Street
L8 8DX

South Liverpool Personnel Ltd
50 Upper Parliament Street
Liverpool
L8 7LF

St. Michael's Irish Centre
6 Boundary lane
West Derby Road
Liverpool
L6 5JG

Steve Biko Housing Assocation
19 Devonshire Road
Liverpool
L8 3TX

Sudanese Women's Association Merseyside
15 Millennium Road
Liverpool
L8 2YF

Sure Start
West Everton and Breckfield
33 Everton Brow
Liverpool
L3 8PU

Toxteth Citizens Advice Bureau
15 High Park Steet
Toxteth
Liverpool
L8 8DX

Toxteth Educational Trust
Suite 226
Queens Dock Commercial Centre
67-83 Norfolk Street
L1 OBG

Turkish Community Centre
82 Kempston Street
Liverpool
L3 8HL

Turkish/Kurdish Community Organisation / Liverpool
Streatham Towers
5 Princes Road
Liverpool
L8 1TG

United Sikh Association
16 Wellington Avenue
Liverpool
L15 0EJ

Unity Youth & Community Centre
49 Dove Street
Liverpool
L8 0TU

West African Elders
138 Granby Street
Toxteth
Liverpool
L8 2US

Weston Spirit
66 Lime Street
Liverpool
L1 1JN

Women's Independent Cinema H
40 Rodney Street
Liverpool
L1 9AA

Yemeni Community Association
167 Lodge Lane
Liverpool
L8 0QW

Rwandan Association
29 Robarts Rd
Liverpool
L1

Asylum Link Merseyside
7 Overbury Road
Liverpool
L7 3 HJ

Srilankan Community Merseyside
44 Tunstall Street
Wavertree
Liverpool
L7 1JS

Srilankan Society of Sengalese students &Merseyside Tamil Sangan
57 Sheil Road
Kensington
Liverpool
L6 3AD

Wah Sing Chinese Community Ce
149 Duke Street
Liverpool
L1 4JR

Sikh Community Centre (Gurudawara)

Wellington Avenue

Liverpool

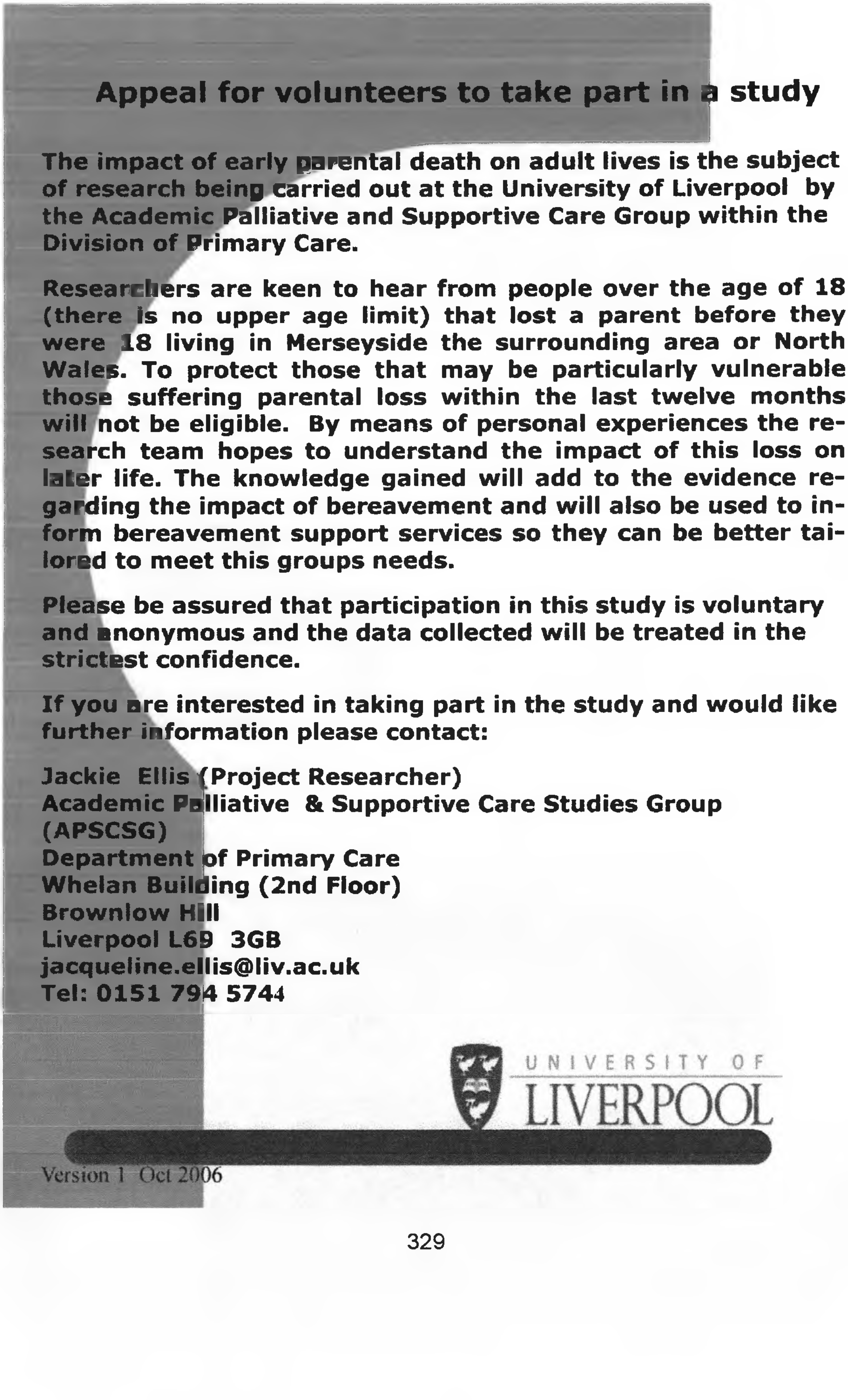
L15

Somali Women Project

171 Lodge Lane

Liverpool

L8



Appeal for volunteers to take part in a study

The impact of early parental death on adult lives is the subject of research being carried out at the University of Liverpool by the Academic Palliative and Supportive Care Group within the Division of Primary Care.

Researchers are keen to hear from people over the age of 18 (there is no upper age limit) that lost a parent before they were 18 living in Merseyside the surrounding area or North Wales. To protect those that may be particularly vulnerable those suffering parental loss within the last twelve months will not be eligible. By means of personal experiences the research team hopes to understand the impact of this loss on later life. The knowledge gained will add to the evidence regarding the impact of bereavement and will also be used to inform bereavement support services so they can be better tailored to meet this groups needs.

Please be assured that participation in this study is voluntary and anonymous and the data collected will be treated in the strictest confidence.

If you are interested in taking part in the study and would like further information please contact:

Jackie Ellis (Project Researcher)
Academic Palliative & Supportive Care Studies Group (APSCSG)
Department of Primary Care
Whelan Building (2nd Floor)
Brownlow Hill
Liverpool L69 3GB
jacqueline.ellis@liv.ac.uk
Tel: 0151 794 5744

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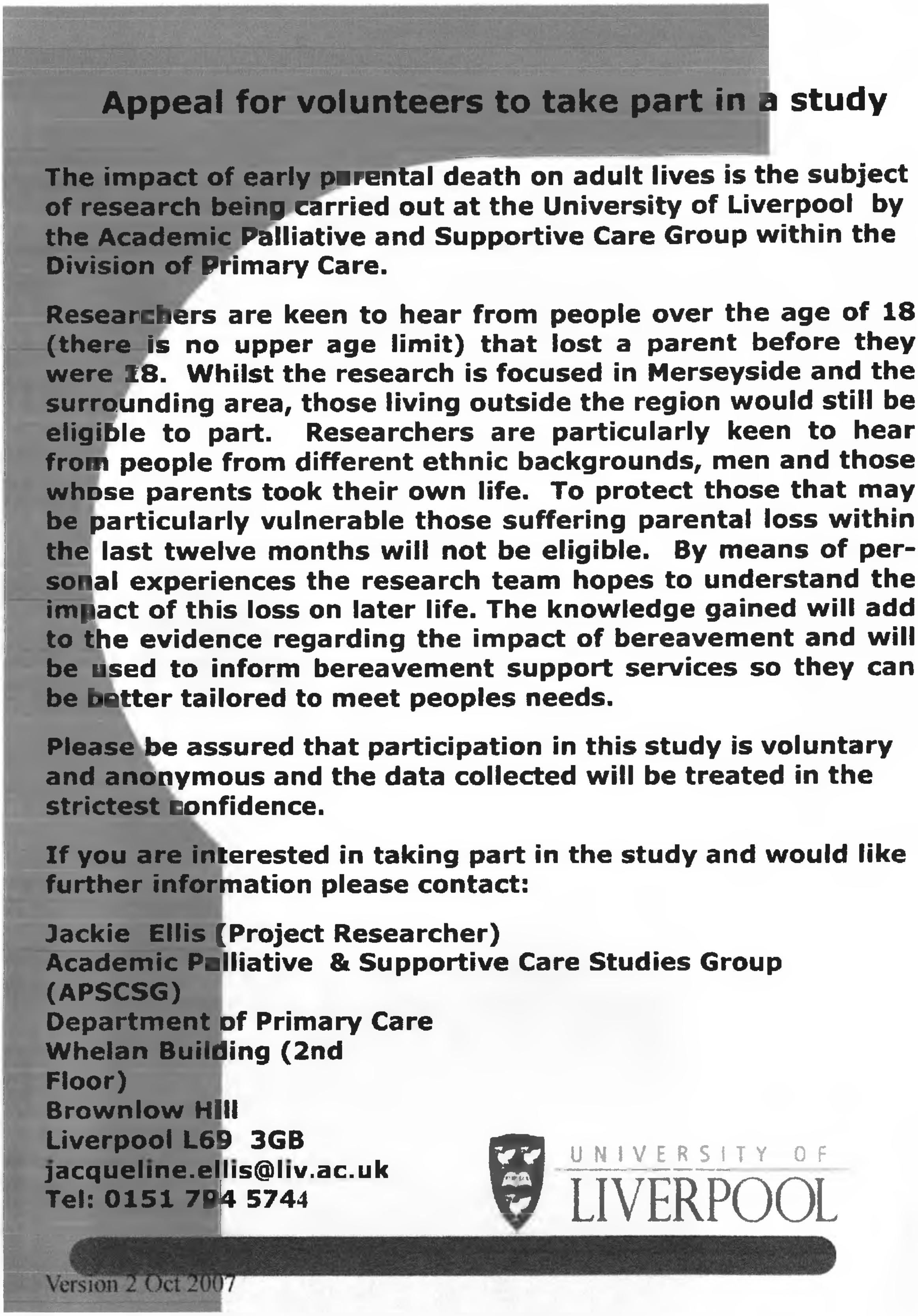
Version 1 Oct 2006



Appeal for volunteers to take part in a study

The impact of early parental death on adult lives is the subject of research being carried out at the University of Liverpool by the Academic Palliative and Supportive Care Group within the Division of Primary Care.

Researchers are keen to hear from people over the age of 18 (there is no upper age limit) that lost a parent before they were 18. Whilst the research is focused in Merseyside and the surrounding area, those living outside the region would still be eligible to part. Researchers are particularly keen to hear from people from different ethnic backgrounds, men and those whose parents took their own life. To protect those that may be particularly vulnerable those suffering parental loss within the last twelve months will not be eligible. By means of personal experiences the research team hopes to understand the impact of this loss on later life. The knowledge gained will add to the evidence regarding the impact of bereavement and will be used to inform bereavement support services so they can be better tailored to meet peoples needs.

Please be assured that participation in this study is voluntary and anonymous and the data collected will be treated in the strictest confidence.

If you are interested in taking part in the study and would like further information please contact:

Jackie Ellis (Project Researcher)
Academic Palliative & Supportive Care Studies Group
(APSCSG)
Department of Primary Care
Whelan Building (2nd
Floor)
Brownlow Hill
Liverpool L69 3GB
jacqueline.ellis@liv.ac.uk
Tel: 0151 794 5744

UNIVERSITY OF
LIVERPOOL

Version 2 Oct 2007

Appendix 4

Press release

29 January 2008: 4:12pm |

Get involved...

- Send your stories
- Send your videos

- Send your pictures
- Join a forum
Home
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- Business
- Liverpool FC
- Everton FC
- Golf
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University seeks volunteers for bereavement study

Jan 24 2008 Liverpool Daily Post

RESEARCHERS at the University of Liverpool are looking for volunteers to contribute towards a study into how bereavement impacts on adult lives.

The findings by the School of Population, Community and Behavioural Science will be used to inform bereavement support services so they can be better equipped to meet people's needs.

Researchers are keen to hear from men and women over the age of 18 who have lost parents before they were 18 years-old

Professor Lloyd-Williams from the Academic Palliative and Supportive Care Studies Group and principal investigator said: "Traditionally, data regarding this area of study have relied heavily on the experiences of women and we are keen to widen this research to include men and people from different ethnic backgrounds. We are also interested to hear from those whose parents may have taken their own life."

The study hopes to recruit between 30 to 40 people for the three year studyt.

If you are interestedplease contact Jacqueline Ellis in the Division of Primary Care on
0151 794 5744

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Appendix 5

Template for demographic information

Understanding the impact of early parental loss in adult life

Demographic information

Participant No	
Own name/pseudonym	
Age(at time of loss)	
Current Age	
Parent Mother/father	
Siblings(n)	
Sex(sib)	
Ethnic Background	
Circumstances of death	
Send narrative to verify	

Appendix 6

List of agency providing bereavement support

List of Agencies providing bereavement support

Cruse Bereavement Care Day by Day Helpline 0844 477 9400 or email us at: helpline@cruse.org.uk Open Monday to Friday 9.30am to 5pm Young Person's freephone helpline 0808 808 1677 or email us at: info@rd4u.org.uk	Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable anyone bereaved by death to understand their grief and cope with their loss. The organisation provides counselling and support. It offers information, advice, education and training services
Cruse Bereavement -Care North Wales Cymru Carolyn Brain (Development Officer) The Town Hall, Rhiw Road Colwyn Bay LL29 7TE Telephone 07986 599330 Helpline No.0870 167 1677 Email: crusenorthwales@btconnect.com	A new group to cover North Wales area, to support and counsel persons suffering bereavement and to enable anyone suffering a bereavement to understand their grief and cope with their loss, and to safeguard their health and social functioning.
The Compassionate Friends **0845 1 23 23 04** - Helpline (Monday -Friday 9.30am - 10.30pm)	Offers emotional support and some local contact details for any adult bereaved of a child – of whatever age and whatever circumstance – run by bereaved

0845 1 20 37 85 - Office www.tcf.org.uk	parents. Also groups for those bereaved through suicide and groups for siblings
The Samaritans **08457 909090** (24 hours a day, every day) www.samaritans.org.uk or email jo@samaritans.org.uk	Offers emotional support for anyone in a crisis
Caring connections www.caringinfo.org	Provides a variety of free resources on topics including: Grief and loss Free Consumer Publications addressing issues including grief and loss.
Survivors of Bereavement by Suicide (SOBS) The Flamsteed Centre Albert Street Ilkeston Derbyshire DE7 5GU Tel: 0115 944 1117 National Helpline: 0870 241 3337 9am - 9pm every day E-Mail: sobs.admin@care4free.net at sobs@ctbworks.co.uk	Aims to provide a safe, confidential environment in which bereaved people can share their experiences and feelings, so giving and gaining support from each other. We also strive to improve public awareness and maintain contacts with many other statutory and voluntary organizations+. Suicide recognizes no age, social, ethnic or cultural boundaries – neither do we. Our groups are open to any individual or family.

Winstons Wish Langley House 27 West Street Chichester West Sussex PO19 1RW Telephone: 01243 775310 General Enquiries: 01242 515157 Fax: 01242 546187 Email: info@winstonswish.org.uk National helpline 08452 03 04 05	Winston's Wish, the child bereavement charity, helps young people re-adjust to life after the death of a parent or sibling. By providing professional assistance before, during and after bereavement they help them to better understand the nature of loss and offer the practical support and guidance that many need in order to cope throughout the grieving process. The Winston's Wish range of services includes the following: national helpline for anyone caring for a child coping with the serious illness or death of a family member group work with bereaved children and their families individual work with bereaved children and their families range of publications, resources and educational films support programme for schools tailor-made training and consultancy for professionals.
Mothers Against Murder and Aggression (MAMAA) www.mamaa.org	MAMAA is a national registered charity which supports and campaigns on behalf of families and friends of murder victims. Each year there is an average of 800 murders across the UK which ultimately affects many more than just the immediate families.

Listening Ear 70 Church Road Halewood Merseyside L26 6LB Telephone 0151 488 6648 listening.ear@btconnect.com	1-to-1 support for children and young people (7-16), parent/s and other caregivers, teachers, schools and other professionals i.e. health visitors group activities for children and young people (7-16), parent/s and other caregivers, teachers and schools telephone information, support and guidance for children and young people (7-16), parent/s and other caregivers, teachers, schools and other professionals i.e. health visitors
Nightingale House Hospice Chester Road Wrexham Wales LL11 2SJ **Telephone:** 01978 316 800 E-mail: anna.perkin@new-tr.wales.nhs.uk	1-to-1 support for children and young people (0-19), parent/s and other caregivers, teachers, schools and other professionals i.e. health visitors group activities for children and young people (5-19), parent/s and other caregivers, teachers, schools and other professionals i.e. health visitors telephone and email information, support and guidance for children and young people (0-19), parent/s and other caregivers, teachers, schools and other professionals i.e. health visitors training for children and young people (0-19), parent/s and other caregivers, teachers, schools and other professionals i.e. health visitors
Warrington Bereavement Support P.O. Box 930	This is a 24-hour answering service — simply leave your name, address and telephone number and the

Warrington WA4 9AT **Telephone:** 01925 631516 Email: contactus@wbsupport.org.uk	co-ordinator will contact you within 48 hours. If you have lost a loved one and would like to talk about your feelings, you are also welcome to come along for a chat over a cup of tea or coffee at **The Coffee House**, Bold Street Methodist Church. A bereavement support volunteer is present **every Saturday morning between 11am and 12.30pm**.
Kings Cross Project. C/o Trinity Church Peelhouse Lane Widnes Cheshire WA8 6TJ **Telephone:** 0151 4204905 Email: enquiries@kingscrossproject.org.uk	Offers counselling service free of charge to the adults of Runcorn and Widnes. Areas Covered in Counselling are: Depression, Bereavement/Loss, Separation/Divorce, Adult survivors of abuse, Domestic Violence, Gender issues, Post Traumatic Stress, Stress Management (Anxiety/Panic attacks), Resolving Childhood Issues, Health Issues/Disabilities.
Halton Integrated Bereavement Service c/o Halton Haven Hospice Murdishaw Runcorn Cheshire WA7 6EP **Telephone**: 01928 791221	This is a free confidential bereavement service to help people cope with the loss of their loved ones. A team of volunteers has been professionally trained to offer support and understanding as part of Halton Integrated bereavement service, funded by the big lottery. If you're bereaved and need someone to talk to call 01928 791331, alternatively drop-in sessions are held from 4:00pm to 7:00pm on the first Wednesday of every month at Halton Haven and on the third Wednesday of every month at Widnes and Runcorn Cancer Support Centre, Alforde Street, Widnes.

Jigsaw Counselling Service C/o Mind Halton The Vine Street Centre, 30a Widnes Road Widnes Cheshire WA8 6AD **Telephone:** 0151 495 3991	
Liverpool Bereavement Service **Maureen Condon** Co-ordinator 4th Floor Rail House Lord Nelson St. Liverpool L11JF **Telephone:** 708-6706 LBS@icliverpool.co.uk Liverpoolbereavement@tiscali.co.uk	Offers a free service to all affected by Bereavement issues. Liverpool Bereavement Service is currently financed by a grant from the Central Liverpool Primary Care Trust and by donations. As such can only accept clients resident within the Liverpool City boundary.

Appendix 7

Ethical approval letter

RETH000029 Ethics Approval

Ethics

Sent: 17 February 2007 09:52

To: Ellis, Jacqueline

Cc: Lloyd-Williams, Mari; Dowrick, Christopher

Mari, Jacqueline,

Following your correspondence after the Committee meeting, your application has been approved.

Ian

Ref:	RETH000029
PI:	Prof M Lloyd Williams (Ellis)
Title:	Understanding the impact of the early death of a parent on adults during later life: a narrative approach
First Reviewer:	Dr Maria Flynn
Second Reviewer:	n/a
Date of initial review:	22/1/07

The application was APPROVED subject to the following conditions:

Conditions

1	Mandatory	On completion of the project, a Final Report form must be completed and sent to the Sub-Committee.
2	Mandatory	On each anniversary of this approval, until the project is completed, an Annual Report form must be completed and sent to the Sub-Committee.
3	Mandatory	All serious adverse events must be reported to the Sub-Committee within 24 hours of their occurrence.

This approval applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Sub-Committee should be notified. If it is proposed to make a substantial amendment to the research, you should notify the Sub-Committee.

Research Governance Officer

Appendix 8

Introduction to participants and background information

5.1. Introduction to participants

A total of 33 participants (7 males and 26 females) were recruited to the study between March 2007 and June 2008, about their experiences of losing a parent(s) during childhood and its impact on adult lives. Their ages ranged for 20-80 and there was a limited representation of ethnic diversity. At the time of loss the participants were aged between 13 months to 17 years. Of the seven male participants one was Scottish, three Irish and the remainder being English. Out of the 25 female participants two were Welsh, one was Yemini Arab, three were Irish, and the remainder were English. Participants were from both Christian and non-Christian backgrounds including, Catholic, Protestant, Muslim and Jewish. In accordance with the National Statistics Socio-economic Classification system (NS-SEC) (ONS, 2007) the information derived from the narratives suggested that the respondents were from a wide spectrum of social backgrounds.

Deceased parents included fourteen mothers and fifteen fathers and four respondents had lost both their mother and father (total of 37). There were twenty nine sudden or unexpected deaths (at least from the perspective of the child), four of these being accidental and one being suicide, the others being from diseases or conditions and included dying trajectories of various lengths. There was one from a stroke, five cardiac arrests, two cerebral haemorrhages, one brain aneurysm, twelve deaths from cancer (including two from leukaemia), one from septicaemia, one from a brain tumour, one from complications following encephalitis, one from complications following a flying accident years previously, five from heart disease, one from tuberculosis and one from other lung condition.

The following brief background sketches were provided to contextualise the participants' narratives and reflect the diversity of the sample. The information used was elicited from the content of the narratives (or background information) provided by the respondents, including their ethnic background as defined by them. The names presented are a mix of both real names and pseudonyms based on the choice of the respondents.

Alison aged 33

Alison, English, was aged fourteen when her father died of cancer. Alison has a sister who is three years older. Her father had been an engineer. After her father's death Alison and her sister continued to be cared for by their mother. Alison works in higher education

Amy aged 20

Amy, English, was seventeen when her mother died of a brain aneurysm. The family lived in Buckinghamshire and her father worked in London. Her mother had given up work to look after the children but returned to work on a part-time basis (although Amy does not say what this work was) when Amy and her sister started school. She and her younger sister were looked after by her father when her mother died. Amy is a student.

Anna aged 34

Anna, English, was eleven when her mother died of breast cancer. Anna was born in London and was raised in Teeside. Her father was a Church of England priest. Anna had an elder brother. He was three years older than Anna and was believed to have autism. After her mother died Anna, her brother and father were looked after by her maternal grandmother and then by her aunt. Eventually Anna's father married her aunt who subsequently also died of breast cancer. Anna works in higher education.

Anne Marie aged 25

Anne- Marie, English, was eight when her mother died of a brain haemorrhage. Her father was unemployed and an alcoholic and they lived in Merseyside. Her parents were not in a relationship. Anne-Marie lived with her mother who suffered with mental health problems and her elder sister. Her mother's illness meant that she and her sister were often put into the care of social services or looked after by paternal grandmother. When her mother died Anne-Marie went to live with her parental grandmother until she died two years later when responsibly for her care fell to her father. Anne- Marie is a medical student.

Bill aged 72

Bill, Irish, was five when his mother died of tuberculosis. He had two elder brothers who were seven and nine at the time. His father worked in the retail industry as a shop manager. When his mother first died his father's sister took on the parenting role. When his father subsequently lost his job (due to his alcoholism) and went to England to look for work the children remained in Ireland where they were looked after by their maternal grandmother. Bill is now retired but previously was involved in research.

Christina aged 57

Christina, English, was an only child. Her mother died when she was almost five of leukaemia. The family lived in Lancashire and her father was a coalminer. When Christina was about three her mother's condition worsened and she was sent to live with a series of relatives. When her mother died she went to live with an elderly aunt who like Christina's parents was a devout Catholic. Christina is retired but is studying to become a counsellor.

Christine aged 56

Christine, English, lost both her parents. Her mother when she was five and her father when she sixteen. They lived in Merseyside. Her mother died of lung cancer and her father had a stroke. She lived with her father, a postman, until his death due to a stroke, but the responsibility for her care fell to her sister. Christine did not actually state what her occupation was although she did refer to having what she called "dead end jobs."

Claire aged 32

Claire, English, was from the North East and was thirteen when her father died. He was a pilot and died due the effects of a flying accident that he had before Claire was born. Her father suffered with mental health problems after his accident but was able to retrain as a teacher. Claire was an only child. Her father's condition deteriorated over the years until her was no longer able to work due to his worsening mental health issues. Claire works as a researcher.

Colin aged 43

Colin, English, was sixteen when his father died and they lived in Merseyside. He had two brothers, both younger than him. Colin's father had contracted rheumatic fever as a naval cadet in his late teens. This had resulted in serious illness at the time and bacterial endocarditis leading to heart valve lesions. Colin works in veterinary medicine.

Dan aged 33

Dan, English, was five when his mother died from breast cancer. The family also lived in Merseyside. He had a brother who was 18 months younger than him. His mother had been a nurse and his father worked as a microbiologist. After his mother's death Dan and his brother were brought up by their father until he died of cancer when Dan was sixteen. Dan and his brother went to live with their uncle and his wife before Dan went off to university to study medicine. Dan until recently worked in paediatric medicine.

Freda aged 75

Freda, English, was an only child. Her mother died when she was two of septicaemia. Her father was a merchant seaman and although he was still alive she was brought up by her maternal grandparents and they all lived in Cheshire. Her father eventually remarried. Although they asked Freda to live with them she chose to remain with her grandparents. Freda is now retired but previously worked in the retail trade.

Freddie aged 23

Freddie, English, lived in Yorkshire and was twelve when his father died accidentally. His parents had separated a couple of years before his father's death. Freddie and his sister spent half of their time living with their father and the other half with their mother, whilst his brother remained with their mother. At the time of his father's death Freddie was living with his father and his sister was spending a week with her mother. On finding his father not home one day he went to fetch his mother. On returning to the house with his mother and his brother it was discovered that his father had accidentally killed himself. Freddie is a postgraduate student.

Gerald aged 63

Gerald, Scottish, was 17 when his father died suddenly at home one morning after about five years of varying degrees of ill health. His father worked in a shipyard but later became a Presbyterian minister. Gerald grew up in Lancashire where his father was ministering until he retired due to ill health. Gerald helped his mother bring up his younger brother. Gerald is a retired school teacher.

Helen aged 35

Helen, English, was ten when her mother died of breast cancer and the youngest of three siblings. Her father's job meant that the family moved around the country and had moved near to Birmingham about a year before her mother's death. Helen lived with her father until she left to go to University. Helen works in academia.

Jan aged 51

Jan, English, was the youngest of four children and twelve when her father took his own life. Jan's father was an alcoholic. The family lived in the Merseyside area. At the time Jan's parents were separated and she was living with her mother who suffered with mental health problems. According to Jan she had a very unhappy childhood due to her father's alcoholism and her mother's mental health problems. Jan remained with her mother after her father's death until the situation became untenable. Jan works with bereaved people.

Jane aged 51

Jane, English, was 17 when her father died suddenly of a heart attack. Jane was an only child. Her father was a policeman and they lived in Merseyside. When he died Jane's mother found it difficult to come to terms with her loss and subsequently suffered from severe mental health problems. Consequently, Jane had to take responsibility for herself, her mother's care and running a home. When her mother's condition worsened she had to be hospitalized. As Jane was not legally old enough to live alone she had to go to live with the mother's brother until her mother was well enough to return home. Jane works as a benefits advisor.

Jess aged 44

Jess, English was 14 and the second youngest of four children the youngest of which was four when their mother died of leukaemia. The family were devout Catholics at the time and were living in Dorset at the time and Jess attended a convent school. Jess's father's job took him away a couple of nights a week. The eldest sister was away at university training to be a doctor. Once all the elder siblings had left home to go to university Jess was very involved in her younger brother's upbringing. Jess is a health professional.

Jimmy aged 48

Jimmy, Irish, was the third youngest of eight children and fourteen when his mother died after contracting encephalitis when Jimmy was around six or seven. His father was a school master and the children were looked after by him during his wife's illness and her subsequent death. The family were Catholics. Jimmy has held a number of senior management positions.

Joan aged 57

Joan, English, was eight when her father died and the second youngest of twelve children (six boys and six girls). Her father worked on the docks and died of a lung condition. There were still six children living at home when their father died and they continued to be raised by their mother. Joan is now retired but previously worked as a machinist.

Lucy aged 43

Lucy, English, was ten when her father was killed in a plane crash. She was the eldest of six children and brought up by her mother. Her father was a civil engineer and had his own business and the family lived in Cheshire. Lucy's parents were committed Catholics and the children were all brought up in the Catholic faith and Lucy went to a convent school. Lucy is a clerical worker.

Margaret aged 62

Margaret, Irish, was eight when her father died of a cerebral haemorrhage. The family lived in Merseyside and her parents owned a bakery shop. Margaret was an only child. She was brought up by her mother after her father had died. Margaret is a school teacher.

Patricia aged 60

Patricia, English was 15 when her mother died of lung cancer. The family lived in Merseyside. Patricia had a younger sister and an elder brother. Her father was a postman. Although they lived with their father Patricia had to take responsibility for the care of her younger sister. When Patricia married she and her husband still lived with her father and sister so that she could continue to look after them. Patricia is now retired but does voluntary work.

Peggy aged 80

Peggy, Irish, was third youngest of seven children. Her parents were farmers and devout Catholics. Peggy was nine when her mother died of breast cancer. Her father continued to bring up the children after their mother died. Peggy is now retired but previously worked as a nurse.

Ruth aged 46

Ruth, English, lost both her parents within six months of each other when she was sixteen. Her father had been a Congregational minister but had a stroke when Ruth was three which left him physically and mentally disabled. They lived in the South of England. Her mother brought Ruth up and cared for her father until she herself died of bowel cancer. After her mother's death her father's poor health meant that he had to go into the local hospital to be cared for where he died six months later. Ruth went to live with a family friend, a retired headmistress and a spinster until she went to do her nurse training. Ruth is a nurse.

Sam aged 72

Sam, English, was three when his father died of valvular heart disease (age 36). This family was also from Merseyside. He was an only child and was raised by his mother after his father died. Sam is now retired, but currently a post graduate student

Sarah aged 53

Sarah, Irish. was the 6th of seven children. Sarah was 13 months old when her father died suddenly (aged 36) in a car accident. Prior to his death her father had worked as a labourer which involved travelling around England and by the 1950s has set up his own engineering company, in London. Her mother raised Sarah and her other siblings after her father died. Sarah has had various clerical jobs and recently trained in alternative therapies.

Susan aged 62

Susan, English, was of the Jewish faith and lived with her family in Lancashire. She was the eldest of two children (both female). Susan's father was a school teacher and her mother a filing clerk. The family, including their parental grandmother, were on holiday when her mother died suddenly of a heart attack when Susan was sixteen and her sister was twelve. Susan is now retired but previously did clerical work.

Sally aged 32

Sally, Welsh, was the younger of two children both girls. Her father died of a brain tumor when she was seventeen when she was studying for her A' levels. Sally continued to live with her mother until see went away to university the following year. Sally is a housewife but previously worked as a trainer for an advertising company.

Shelley aged 22

Shelley, English, and eleven when her father died of heart attack. Her parents divorced when Shelley was 18 months old and she lived with her mother in Cheshire but she stayed with her father every other weekend at his home in Lancashire. He was a grocer and had his own business. Shelley was the only child from this relationship but she has two older half brothers from an earlier relationship her father had and two stepsisters and a half brother from her father's second marriage. Shelley is a student.

Sue aged 62

Sue, Welsh, lived in North Wales. She was sixteen when her father died of a heart attack and seventeen when her mother died of a stroke. Her father was a bus conductor and her mother a seamstress. Sue was the youngest of seven children (four brothers and two sisters). Sue was working at the time in the local bank. When her mother died there was only Sue and her brother left at home living in a council house. As her brother was twenty-one the council allowed him to take over the lease in order to provide a home for Sue. Sue is a publican.

Sue R aged 51

Sue, English (Irish decent), was nine when her father died. The family lived in Lancashire and her father was a coalminer. He had been in ill health for some time and was in hospital when he collapsed and subsequently died. There was some controversy surrounding the cause of death as her mother thought it to be Pneumoconiosis whereas the coroner stated it was natural causes. Her mother brought up Sue and her younger brother was eight when his father died. Sue works in higher education.

Winifred aged 63

Winifred, English, was 17 when her father died and the youngest of three children, all female. Her father was in wholesale grocery business and the family lived in the North East. They were a strong Christian family and Winfred was the only child left living at home. Winifred's father had a heart condition and for two years Winifred had helped her mother care for her father. When her father died she thought that she might not be able to following the career path she had chosen (medicine). But with the support of her mother, her elder siblings and other family members she was able do so. Winfred is now retired but previously worked in the medical profession.

Fiaza aged 41

Fiaza, Yemini-Arab, was Islamic (Muslim) and seventeen when her father died after suffering a brain haemorrhage. Fiaza was the eldest of four siblings, all female. Her father had been a steel worker but had become a retailer in Merseyside when the steel industry was in decline in the 80s. Born in the UK, Fiaza had gone to live in the United Arab Emirates when she married at fourteen. She had returned to the UK when her sons were born but then returned. She was living in the United Arab Emirates when her father died. Fiaza is an interpreter.