

THE UNIVERSITY OF HULL

The Experience of Bereavement for Individuals with Learning Disabilities  
– A Qualitative Study

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By

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## **Abstract**

The aim of the investigation was to explore with individuals with learning disabilities their experiences of bereavement. Little research has been carried out in this area, and of the projects that have investigated bereavement in this population many have not involved the individuals with learning disabilities but have relied on carers as informants or have used objective measures of behaviour. This has left a gap in our understanding of the internal experiences for people with learning disabilities following bereavements and has left us unaware of the issues considered most important by the bereaved individuals.

Ten interviews were conducted with individuals with learning disabilities who had been bereaved at some point within their memory, although not within the preceding six months. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis. From the analysis five super-ordinate themes were identified that were thought to capture the essence of the content of the interviews. These themes were Loss, Feelings, Memories of Time Around the Death, Recovery and Obstacles to Recovery.

The results indicate the internal experiences associated with bereavement are the same for individuals with learning disabilities as for people without learning disabilities. However, there were experiences described by the participants that appeared to be particular to people with learning disabilities. These experiences were not directly due to their cognitive impairment but due to the way they were responded to by others, and the general beliefs society holds about learning disability. Clinical implications and suggestions for further research were presented.

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*'I cannot listen anymore. I run and run, finding myself heading for the woods. There, beneath a large tree, next to a thick bush, I hide from the rest of the world. Hugging my knees to my chest, I rest my head on my forearms. I cup my hands over my mouth and scream out in pain over the cruel death of my sister. The sound burns in my throat, fighting to be released, but I hold it in as tears stream out of my eyes.'*

*Loung Ung, First They Killed My Father*

*'No one ever told me that grief felt so like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing.'*

*C.S. Lewis, A Grief Observed*

*'..and I just broke down knowing that I'd been left alone without anyone to talk to.'*

*Interview 1 Line 153*

## 1. Introduction

Death is an inevitable part of life. Regardless of our gender, race, status or beliefs we will all at some point be faced with the pain of losing somebody close to us. Literature is full of accounts of the pain of grief and we can all recognise the feelings described. Sadness, despair, loneliness, anger and fear are emotional responses that are familiar to us all. The experience of bereavement has also become the subject of considerable attention within psychology. Over the past forty years there has been a near explosion of interest within psychological literature, with writers such as Worden (2002), Parkes (1996) and Kubler-Ross (1969) making significant contributions to our understanding of the psychological processes of death and bereavement. Yet despite this increased awareness of bereavement issues the impact of death and loss on people who have learning disabilities has been largely denied. In 1995 the Department of Health estimated that mild learning disability may affect around 20 in every 1000 of the population, and that a further three to four in every 1000 will have a severe learning disability. Individuals with learning disabilities are likely to suffer as many, if not more, losses during their life times, yet research into the effects of loss has been limited. There are perhaps two main reasons why this area has been overlooked. Firstly, in Western society death, grief, disability and other notions of imperfection are generally regarded as taboo subjects (Conboy-Hill, 1992). Taboos elicit fear and avoidance and therefore there has been a subtle lack of discussion around the double taboo of grief and learning disability. Secondly, historically, there has been an accepted myth that cognitive impairment equals emotional impairment (Kitching, 1987). This denial of emotional functioning has conveniently allowed us to avoid confronting the difficult issues of death and dying. With the denial that individuals



with learning disability can feel the same emotions as ‘normal’ people has come the denial that those individuals will grieve the loss of a loved one.

The aim of this section is to clarify definitions of loss, grief, bereavement and learning disability, and to introduce the reader to the main themes of research findings within the field of bereavement in the generic population, with consideration as to how they may apply to a learning disabled population. This will be followed by a discussion of the research findings within the field of learning disability and bereavement, and the strengths and limitations of this research. The section will conclude with a discussion of the context of the research and an outline of the aims of this study.

## **1.1 Definitions**

The focus of this thesis is on the bereavement experiences of individuals with learning disabilities. But what exactly is meant by bereavement, how does it differ from grief, loss and mourning, and what exactly is meant by learning disability. Each of these terms may be understood very differently by different people. The definitions below are not necessarily the ‘right’ ones, but it is important the reader appreciates the author’s understanding of the terms in order to clarify communication.

To lose something or somebody is to be deprived of and separated from a presence (Martin and Weston, 1998). Grief refers to the experiences associated with the loss of something that one has an emotional attachment to. Grieving is associated with pain, sadness and distress (Littlewood, 1992). Mourning is the process that is gone through leading to an adaptation to the loss (Worden, 2002). Bereavement has been defined as the loss of a close relationship, which often leads to grief (Raphael, 1983).

Bereavement can be associated with loss of a close relationship not due to a death, but within this research bereavement will only refer to loss of relationship due to a death.

Defining learning disability can be a complex task. Without entering into lengthy discussion around the issues of diagnostic procedures, discourses of disability and past labels, the definition I have chosen to use for the purpose of this research is the American Association on Mental Retardation's (AAMR) definition. The AAMR states,

Mental Retardation refers to substantial limitations in present functioning. It is characterised by significantly subaverage intellectual functioning existing concurrently with related limitations in two or more of the following applicable adaptive skills areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18.

(AAMR, 1992, p.5)

Whilst the AAMR refers to mental retardation, the term learning disability will be used throughout this thesis, in keeping with service provision in Great Britain.

## **1.2 Themes of Research Findings in the Generic Bereavement Literature**

Whilst research into the experience of bereavement for individuals with learning disabilities has been limited, over the past forty years an extensive literature has been developing that has aided our understanding of the emotional, cognitive, behavioural and physiological consequence of bereavement within the generic population.

In particular, the common experiences associated with grief, the likely patterns of grief reactions and the vulnerability factors associated with abnormal patterns of grief have been extensively researched. It would not be possible to review the entirety of this literature here, however, the main findings will be discussed as we may predict

the internal experiences of bereavement for those with and without learning disabilities may be very similar.

### **1.2.1 Common Experiences Associated with Normal Grieving**

Although information about grief has been collected by different people, using different methods and for different purposes, the descriptive literature on the experiences associated with grief is remarkably uniform (Littlewood, 1992). As early as 1944 Lindemann described what he termed, the pathognomic characteristics of normal grief following his observations of 101 recently bereaved patients. His five characteristics were; somatic or bodily distress of some type, preoccupation with the image of the deceased, guilt relating to the deceased or the circumstances of the death, hostile reactions and the inability to function as one had before the loss. Over 50 years later Worden (2002) states that despite the methodological flaws of Lindemann's study the bereaved patients within his care behave very similarly. The common experiences associated with grief may be sensibly divided under the headings 'feelings', 'thoughts', 'physical sensations', and 'behaviours'.

#### **Feelings**

Common feelings associated with grief are sadness, anger, guilt, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief, and numbness (Lazare, 1989; Osterweis, et al., 1984; Raphael, 1983; Worden, 2002).

Sadness and a sense of yearning are perhaps the feelings most commonly associated with grief (Parkes, 1970). Sadness is often, but not always, associated with crying (Littlewood, 1992). Anger is also a very common feeling associated with grief (Bonanno, et al., 1999) but also perhaps one of the most confusing and distressing

reactions for the bereaved individual. The anger is sometimes directed towards the deceased, sometimes towards those that were perceived to be responsible for the death or those that failed to prevent the death, or against the self. Feeling guilty following a bereavement is not uncommon. The guilt is frequently irrational and centred around something that happened at around the time of the death (i.e. 'I should have called the doctor sooner'). Anxiety may also be felt by those who are grieving (Bonanno, et al., 1999). The anxiety may be focused on being unsure as to whether they can survive/cope without the deceased, and in this way can be associated with a feeling of helplessness, or it may be associated with the heightened awareness of their own mortality (Littlewood, 1983). Those who have lost a spouse often particularly report loneliness. This may be both an emotional loneliness due to a broken attachment as well as a social aloneness (Stroebe, et al., 1996). Feelings of tiredness, apathy or fatigue are also common in the bereaved. Emancipation and relief are sometimes felt after a death that followed a long illness or when the bereaved had a particularly difficult relationship to the deceased. However, feelings of relief are often accompanied by feelings of guilt (Worden, 2002). Although all these feelings are common, bereaved individuals also often report a lack of feelings, or numbness, particularly early on in the grieving process (Parkes, 1996). This numbness may represent a normal defense against what would otherwise be overwhelming feelings (Parkes and Weiss, 1983).

### **Thoughts**

There are a collection of thoughts that have been found to be common following bereavement. Disbelief that the death has occurred is frequently felt (Shuchter and Zisook, 1993). This is most frequent for individuals who did not have contact with the deceased immediately before the death or did not see the body after the death

(Littlewood, 1992). Recently bereaved people often feel confused and may have difficulties concentrating or ordering their thoughts (Bonanno and Kaltman, 2001). It is as if all their mental energy is being consumed by thinking of the deceased. Preoccupation with the deceased is reported by many recently bereaved people. Worden (1996) found that preoccupation in the form of intrusive thoughts, occurred most frequently for bereaved who had had a highly conflictual relationship with the deceased. Common experiences for the recently bereaved are also a sense of presence and visual and auditory hallucinations of the deceased (Rees, 1971).

### **Physical Sensations**

Worden (2002) provides a list of nine commonly reported sensations experienced by those whom he sees for grief counselling. A sensation of hollowness in the stomach, lack of energy, tightness in the throat, over sensitivity to noise and a sense of depersonalisation or unreality are common (Parkes, 1996). Also symptoms that are generally associated with anxiety such as breathlessness, weakness in the muscles, tightness in the chest and dry mouth may be experienced (Worden, 2002).

### **Behaviours**

There are several behaviour disturbances associated with grief. Sleep disturbance, either in the form of difficulty falling asleep or early morning wakening is not unusual particularly in the early stages of grief (Worden, 1996). Disturbing dreams about the deceased may also occur (Littlewood, 1992). Appetite disturbances normally in the form of loss of appetite frequently follow bereavement, though in some cases overeating may occur (Worden, 2002). Absent-minded behaviour may also be witnessed in the bereaved. This is likely to be connected to the preoccupation in thought of the deceased and the difficulties with concentration. It is also not unusual

for the bereaved to socially withdraw. Again this may be linked to a preoccupation with the deceased in which all other relationships seem insignificant (Littlewood, 1992). Some bereaved individuals may want to carry around objects that belonged to the deceased or treasure them in a special place. This is often associated with a fear of losing memories of them (Worden, 2002). However, whilst some individuals become preoccupied with the deceased, others may find it too painful to think of the deceased and may go to great lengths to avoid reminders, such as avoiding the cemetery, the place where they died, or hiding away photographs (Parkes, 1996). Parkes (1970a, 1996) has written about the desire often felt by the bereaved to search for the dead person. Bowlby (1961) reviewed the literature covering bereavement and separation in lower mammals (E.g. chimpanzee, domestic dogs). Typically these animals protested the loss and attempted to search and recover their loss. This behaviour clearly has a survival value for an individual in attempting to recover the lost mate. Parkes (1996) suggests that the impulse to search for the lost loved one is also present in humans, even if we may know that there is no point searching for a dead person. The bereaved may search in a direct way in places that they might have found the individual when they were alive or in some cases through the use of spiritualists or mediums, or through more indirect forms, such as through creative art work (Bowlby, 1980). For some individuals searching may involve actually calling out for the deceased (Parkes, 1996). Bereaved people may also complain of feeling restless and agitated. This may well be related to the urge to search (Littlewood, 1992). Finally, crying is perhaps the behaviour that is most commonly associated with grieving. Crying may have a number of functions. Crying is a signal of helplessness and can arouse in others sympathy and a wish to help (Parkes, 1996), but tears also help to relieve emotional stress and so have value even when there are no witnesses to the crying (Worden, 2002). However, the absence of crying is not abnormal and does not

necessarily indicate a suppressed grief (Littlewood, 1992). The expression of sadness through crying is socially constrained and many attempt to control their tears as they fear they will cause others further upset.

All these experiences are considered normal during the process of mourning and resolve themselves over the course of time. It can be seen that the experiences of bereavement for people without a learning disability have been found to be wide ranging, however, there are many experiences that are shared by those who have been bereaved.

### **1.2.2 Phases of Grief**

Many of the major researchers in the field of bereavement in the generic population have suggested that grief is a process that involves a number of stages, phases or tasks. The experiences that were discussed above do not occur all at the same time and then resolve, but tend to occur in clusters at different points during the various points in the process of grieving. Parkes (1996) notes, 'Grief is not a set of symptoms which start after a loss and then gradually fade away. It involves a succession of clinical pictures which blend into and replace one another' (Parkes, 1996, p.7).

Kubler-Ross (1969) suggested there are five stages of dying and these have been applied also to the grieving process. Her five stages are denial, anger, bargaining, depression and acceptance. The difficulty with describing the process of grieving as stages is there is a tendency for them to be interpreted in a very concrete way as distinct steps, which occur in a specified order. Others have put forward the idea of phases of grief. Parkes (1996) suggests four phases; numbness, yearning, disorganisation and despair, and recovery, and Sanders (1999) suggested five phases; shock, awareness of loss, conservation-withdrawal, healing and renewal. Rando

(1992) chose to refer to six processes of mourning that must be successfully completed in order to avoid complicated grief. She suggested the six 'R' processes of 1) recognising the loss, 2) reacting to the separation, 3) recollecting and re-experiencing the deceased and the relationship, 4) relinquishing the old attachments to the deceased and the old world, 5) readjusting to move adaptively into the new world without forgetting the old, and 6) reinvesting.

Worden (2002) does not entirely reject the idea of phases, but chooses instead to refer to tasks of mourning, so as to emphasize that grief is not something that one goes through in a passive way but that there is work for the individual to do in order to resolve their grief. He suggests four tasks of mourning; to accept the reality of the loss, to work through the pain of grief, to adjust to an environment in which the deceased is missing, and to emotionally relocate the deceased and move on with life.

We may presume that individuals with learning disabilities will go through the same process of grief as those without learning disabilities, however, we may predict that the process may be complicated by a number of factors for these individuals. For example, in order to achieve the first of Worden's tasks, to accept the reality of the loss, the individual must, at both a cognitive and emotional level, come to understand the facts of the loss, the meaning of the loss and the irreversibility of the loss (Dorpat, 1973). We may predict that this may pose more difficulties for some individuals with learning disabilities who have a restricted understanding of the concept of death. In the second task of mourning, to work through the pain of grief, the sadness and despair must be experienced. As Parkes notes, '...anything that continually allows the person to avoid or suppress this pain can be expected to prolong the course of mourning' (Parkes, 1972, p.173). As Oswin (1992) discusses, the atmosphere in residential care is not always allowing of sadness and grief. Activities tend to be en masse, and finding a quiet, private place to be sad may be difficult. It is natural for



staff members to want to make their residents happy, and therefore they may tend to 'jolly people up' rather than allow them to be sad. Obviously, individuals living in such conditions may be at risk of prolonged mourning. To achieve the third task of mourning, to adjust to the environment in which the deceased is missing, may also prove to be more difficult for some individuals with learning disabilities. As will be discussed in more detail later, when an individual is bereaved of their parent, who is their primary carer, they may be faced with adjusting to numerous losses. The roles performed by this parent may have been wide ranging, from the person who helped with dressing, to confidante, to cleaner, to interpreter, to home provider, etc. For some individuals with learning disabilities there may be substantial external adjustments to be made following a bereavement.

There is no reason to suppose people with learning disabilities will not need to accomplish the same tasks of mourning as those without learning disabilities, however, it may be they are at greater risk of getting stuck at certain points due to their impairment and due to society's attitudes. Bonnell-Pascual, Huline-Dickens, Hollins, Esterhuyzen, Sedgwick, Abdelnoor and Hubert (1999) concluded from their study that individuals with learning disabilities might grieve for longer than those without learning disabilities. This may be due to difficulties in working through the tasks of mourning.

### **1.2.3 Vulnerability Factors Associated with Abnormal or Complicated Grief**

The majority of bereaved people successfully work through the tasks of mourning, however, there are huge individual differences in the intensity and length of people's grief. There are also some individuals who do not grieve or who grieve abnormally. Research within the generic population has identified a number of mediators of grief

and factors associated with complicated grief reactions. Firstly, the nature of the relationship between the deceased and the bereaved affects the grieving process. Obviously the closer the relationship, or the greater the intensity of love between the individuals, the greater the loss (Wayment and Vierthaler, 2002). However, the nature of the attachment can have a large affect on the mourning process. An insecure attachment, where the survivor relied on the deceased for their sense of security and self-esteem, will lead to a more difficult grief reaction and an ambivalent relationship, in which the survivor felt almost equal amounts of love and hate for the deceased, may lead to great deal of guilt and anger at being left being felt by the bereaved (Raphael, 1983). A relationship between the bereaved and the deceased that was characterised by significant conflict can also lead to feelings of guilt for the survivor. Not having resolved this conflict whilst the loved one was alive can lead to a stuckness in grief associated with a feeling of unfinished business (Worden, 2002). A dependent relationship in which the survivor relied on the deceased for practical support in daily living may also lead to a more complicated grief, as the bereaved has greater adaptations to make (Rando, 1992; Parkes, 1996). Dependency in relationships clearly is a potential complicating factor in bereavement for many individuals with learning disabilities, and insecure or ambivalent attachments and conflictual relationships are also potential complications. Some adults with learning disabilities who live with and are cared for by their parents, whilst loving them very much, may feel significant frustration and anger about needing care. Similarly, their parents, whilst loving their child, may feel frustration at having their adult child living with them and sadness that the expected family life events have not happened. It is easy to see how this mutual ambivalence could lead to a conflictual relationship. In this way it may be that some individuals with learning disabilities may be more at risk of complicated grief due to the nature of the relationship.

Secondly, the way in which the deceased died has been found to mediate a person's adjustment to the death. In particular, ambiguous deaths (for example military personnel listed as 'missing in action') (Lazare, 1979), traumatic deaths, such as deaths caused by suicide or murder (Kallish, 1985; Gamino, Sewell and Easterling, 2000), preventable deaths (Gamino, et al., 2000) and multiple losses (Kastenbaum, 1969) have been associated with lengthy or complicated grief. Parkes (1996) cites numerous studies in which unexpectedness or suddenness of death was correlated to the first year of grieving being more difficult.

Thirdly, the generic bereavement literature indicates that losses can be cumulative. Multiple deaths in a short space of time (Kastenbaum, 1969) or additional crises in close proximity to a bereavement (Gamino, et al., 2000; Parkes, 1996) have been found to complicate the grief reaction. The vulnerability of many people with learning disabilities to multiple losses around the time of bereavement has been mentioned above and will be discussed in more detail below.

Fourthly, variables within the bereaved individual have been suggested to play a role in mediating the grief reaction. The individual's attachment style, coping style, ego strength, cognitive style and assumptive world have all been suggested to be related to their adjustment to bereavement (Worden, 2002). As was discussed above, an insecure attachment style can lead to greater difficulties in coming to terms with bereavement. Those who tend to have relationships characterised by anxious over-dependence, or ambivalence are likely to find separations particularly difficult. A persons coping style and cognitive style have also been found to mediate grief.

Optimistic cognitive styles, in which situations can be redefined to find the positives, have been found to be associated with lower levels of depression during bereavement (Worden, 1996), and active rather than passive coping mechanisms have been found to be more effective (Worden, 1996). For example, Gamino, Sewell, Easterling and

Stirman (2000a) found that involvement in the planning of the funeral provided a way of coping actively with the loss. It may be hypothesised that some people with learning disabilities might be prevented from utilising active coping strategies following bereavement. The research has suggested that many people with learning disabilities are prevented from attending the funeral (i.e. Strachan, 1981; Hollins and Esterhuyzen, 1997). We may presume they are often also not involved in planning the funeral or helping out with the practical arrangements. This would deny them many opportunities for active coping.

In terms of ego strength, those with low self-esteem, or those who relied on the deceased for their sense of worth, and those with low self-efficacy are likely to find bereavement more difficult (Worden, 2002). In terms of our underlying world assumptions, some deaths can challenge our basic beliefs about the world. For example, if our basic belief is that 'bad things only happen to bad people' or that 'the world is safe and predictable' an unexpected death of a loved one is likely to cause a crisis of our world assumptions and make grief more complicated. However, some world assumptions that have particular spiritual elements may be protective following a death. For example the belief that 'all things that happen are part of God's larger plan', or that 'we will be united one day in heaven', may make a death easier to bear (Wortman and Silver, 1989).

Fifthly, the generic bereavement literature suggests social variables can mediate the effect of a loss. Emotional and social support from others is important in overcoming a bereavement. This support is needed not just at the time of the death but also throughout the grieving process, and the support must also come in a form that is satisfactory to the mourner (Worden, 2002). Having various social roles (i.e. friend, employee, relative) has also been found to be helpful in adjusting to a death (Hershberger and Walsh, 1990). This may be linked to having support from each of

these different areas, or may be because a sense of worth is gained from each of these roles so the loss of one of many is not so catastrophic.

Finally, whilst some change is inevitable following a bereavement, some individuals suffer significant secondary losses following a death and these can have an adverse effect on grief. Worden (1996) found that parents who experienced large numbers of life changes following the death of their spouse had the highest levels of depression and had children who had particular difficulties functioning.

It is clear there are many varied factors that play a part in determining the grief felt by a bereaved individual, and they need to be considered as a whole. For example, whilst research may suggest that a sudden and unexpected death can lead to a complicated grief we must not assume this is the case for everybody. An individual with positive cognitive, coping and attachment styles, high self-esteem, good support systems and few secondary losses may come to terms with an unexpected bereavement satisfactorily with no significant problems.

The generic bereavement literature is vast and a short review of this nature is unable to do it justice. However, it is important to consider the main findings of this research as it gives an indication of the areas that may pose difficulties for individuals with learning disabilities.

It is interesting to note that many of the behaviours witnessed in bereaved people without a learning disability may well be labelled as challenging behaviours if displayed by somebody with a learning disability. Researchers within the learning disability field (Strachan, 1981; Emerson, 1977; Hollins and Esterhuyzen, 1987) have found that staff frequently do not recognise normal grief reactions in those with a learning disability and may refer individuals to specialist services due to their difficult behaviours. If communication is problematic for an individual with a learning

disability and they are unable to explain their actions, searching for their lost one, refusing to be parted from the deceased's possessions, getting up in the early hours of the morning, or refusing food may all be challenging behaviours for carers. Similarly, confusion, difficulty in concentrating and forgetfulness may be attributed to the learning disability, particularly if unfamiliar people are caring for the individual following the death of a primary carer. Even when the individual's behaviours are correctly attributed to their grief it is easy to imagine how care staff may find some normal grief behaviours difficult to cope with, particularly if they themselves have unresolved feelings about death and bereavements. For example, an individual with learning disabilities who does not recognise the very subtle social 'rules' about not crying excessively in public, or not calling out for their loved one in the local supermarket where they used to shop together, or not talking constantly about them (even if they are thinking about them all the time), may well make their carer feel uncomfortable.

As will be discussed in the following section, many of the behaviours that are considered normal during mourning in a non-learning disabled population have also been witnessed in bereaved individuals with learning disabilities. There therefore seems to be little reason to believe that individuals with learning disabilities do not also experience the other feelings, thoughts and physical sensations associated with normal grief reported in the generic literature. However, as previous research within the learning disability field has relied predominantly on observable behaviour many of these experiences may have been missed.

### **1.3 Previous Research into Bereavement amongst People with Learning Disabilities**

There are few accounts of systematic research into bereavement within a learning disabled population in the published literature. There is some case study based literature (i.e. Kitching, 1987; Kloepfel and Hollins, 1989; Oswin, 1991, 1992, 2000) a collection of papers in which professionals describe their understanding of bereavement within this population (i.e. Emerson, 1977; James, 1995; Kennedy, 1989; Mcloughlin, 1986; Moddia, 1995; Read, 1996), a collection of papers which describe counselling services and groups that have been set up specifically for people with learning disabilities who have been bereaved (i.e. French and Kuczaj, 1992; Read, Frost, Messenger and Oates, 1999; Read, 2001, ) and three quantitative studies of the reactions of people with learning disabilities who have been bereaved (Strachan, 1981; Hollins and Esterhuyzen, 1997; Bonnell-Pascual, et al., 1999).

As was mentioned above, perhaps one of the reasons this area has been sparsely researched is connected to the historical denial that people with cognitive disabilities were able to function emotionally. The denial of emotionality (see Sinason, 1992) led to the belief that people with learning disabilities would not grieve. However, there is no evidence to suggest that the emotional reactions of those with learning disabilities are any different to those experienced by others. It is only as this came to be accepted that research into the area could begin. In 1977 Emerson reported that of those clients who were referred to him for behavioural and management problems, 50% had suffered the death or loss of an individual close to them precipitating the onset of their symptoms. This loss was not recognised by the referring carers as being connected to their distress. These individuals were clearly suffering as a result of their losses, but as their carers did not expect them to grieve their behaviour was not identified as a grief

reaction. Following Emerson's article, in the early 1980's Maureen Oswin began writing about the experiences of people with learning disabilities who had been bereaved, based on her experiences as a professional. Her work drew attention to the fact that rather than being protected from grief due to a lack of understanding, people with learning disabilities may be in fact be more at risk from complicated grief. She stated that there was no reason to suppose people with learning disabilities would not suffer any of the normal reactions to bereavement and that they may have additional difficulties in coming to terms with loss (Oswin, 1991). And these additional difficulties are vast, ranging from difficulties expressing feelings and wishes, to the attitudes of those caring for them, to the inadequate services set up to support them. Much of the literature that followed Emerson's 1977 article focused on these additional difficulties. The main themes from this body of literature will be discussed below.

### **1.3.1 Complicating Factors for Bereaved Individuals with Learning Disabilities**

#### **Cognitive Ability**

The limited cognitive ability of those with learning disabilities was long assumed to be a protective factor for those bereaved. 'If they can not comprehend the death they surely will not grieve' was the belief of many. As was noted above, historically there has been a mistaken belief that cognitive impairment equals emotional impairment. However, research with children clearly shows that although very young children may not understand the concept of death, they still miss people who have died, i.e. they grieve (Read, 1996). Far from being a protective factor, not understanding only complicates the reaction to bereavement. If an individual is unable to make sense of a loss they will find it harder to come to terms with it. If the finality and irreversibility



of death is not understood the individual may be left wondering when their loved one will be coming back, and if it is not understood that the loved one did not choose to die they may wonder why they left. As McLoughlin (1986) points out 'those with a more sophisticated concept of death may be better equipped to work through the normal grieving process, while those with a vague concept may be more vulnerable and less able to resolve their grief' (p 258). Bihm and Elliot (1982) suggest the development of the concept of death in people with learning disabilities is related to their cognitive level as defined by Piagetian tasks rather than chronological age. Those at the pre-operational stage had less understanding of death than those at the higher level of concrete operational functioning. Thus concept of death should be considered when helping an individual work through their grief. Those with a weaker concept may require more help in understanding and accepting the finality of death.

### **Carer's ability and skill in supporting the individual**

Staff that are responsible for caring for individuals with learning disabilities often feel their training has not equipped them to cope with a person suffering a bereavement (Moddia, 1995). They feel they simply do not know how to help and additionally may have personal unresolved issues that may make them feel uncomfortable discussing the subject (Read, 1996). In dealing with a bereft individual our anxieties about our own losses can be heightened. As Worden (2002) states, '...working with the bereaved may make us aware, sometimes painfully so, of our own losses' (p. 173). He goes on to discuss how dealing with the bereaved can also make us more anxious about our potential losses and more aware of our own eventual death.

The training that staff generally receive tends to focus them on looking for signs of abnormality rather than normality. The attention tends to be on the disability rather than the individual. For example, in a study by Hollins and Esterhuyzen (1997) using

a sample of bereaved individuals, in the majority of cases any aberrant behaviours were assumed to be due to the innate personality of the client or to the learning disability itself, rather than the bereavement. Similarly, French and Kuczaj (1992) note that until recently people with a learning disability were expected to continue with daily life as if nothing had happened following a bereavement due to the belief they did not feel the same emotions. Any alterations in behaviour following the loss were then attributed to the original diagnosis rather than the loss.

### **Communication Difficulties**

Many people with learning disabilities may have difficulties expressing themselves verbally. Their limited communication skills might hinder their expression of grief and their distress might go unnoticed (Kitching, 1987). In many cases the bereavement may have been closely followed by a move of accommodation (typically from the family home to residential care). Sometimes, the one person who was able to understand what may be a very individual means of communication is the one who died, thus complicating the loss even further (Hollins and Sireling, 1991). New carers who are unfamiliar with the individual may not pick up subtle communications or changes in mood and behaviour.

As was noted in the discussion above about the generic bereavement literature, many normal behaviours following bereavement may be misinterpreted as being due to the disability, or may be perceived as challenging behaviours. As was found by Emerson's (1977) study, many of the individuals that were referred due to behavioural problems were found to have suffered a major loss. Behavioural problems such as voluntary mutism, withdrawal, self-injury, anorexia, loss of continence skills and aggression (Conboy-Hill, 1992), may be best understood as communication of unhappiness. Even with a lack of words to express unhappiness, distress may become

apparent through behavioural reactions. However, these behavioural communications may be missed or misinterpreted.

Limited verbal communication skills and the misunderstanding of behavioural communications may leave many individuals at increased risk of being unsupported through their grief.

### **Misguided Kindness**

One of the most distressing problems for a carer or relative is how to tell a person with learning disabilities that someone close to them has died. Sometimes this task is handled well, sometimes badly, however, in some cases researchers have found it is either postponed or not done at all (Bicknell, 1983; Oswin, 1991). Carers and relatives may worry how the individual will react, may believe they would not understand or believe they are doing the right thing by protecting them from the upset (Oswin, 1991). From a mixture of kindness and the carers own anxiety or distress the individual may not be told about the death. This may well lead the individual to be left confused as to why a loved one no longer visits or contacts them, and may eventually cause them to find out the truth in a roundabout or casual manner from an inappropriate source (Oswin, 1991).

As described above the taboo around death also causes a reluctance to talk about it in an open way. Euphemisms are often used, for example 'gone to sleep', 'passing on', 'gone away', that are intended to soften the breaking of bad news but that can be very confusing and misleading. Ambiguous statements such as these can leave the individual believing that the deceased may come back or wake up, or that they made an active choice to leave the bereaved person behind (James, 1995).

Kennedy (1989) summarises by saying;

Indeed it now seems clear that the common reaction of shielding a mentally handicapped person from the unpleasantness of a bereavement is in many cases misguided: very often it simply adds to the difficulties the handicapped individual may have in coming to terms with his or her loss (p36).

### **Involvement in Events Before and After a Death**

Hollins and Esterhuyzen (1997) found that most of the participants in their study were not helped to say goodbye to their dying parent, but were kept away from the sick bed. This was generally to avoid upsetting them, but Hollins and Esterhuyzen also suggest their presence may have been painful for the parents. However, upsetting such a time may be there is great benefit in the individual with learning disabilities being involved. Firstly, contact during the terminal illness can help the individual comprehend what dying means (Strachan, 1981). Secondly, it allows the individual time to prepare themselves for the loss, so that when it does occur it is not so traumatic (McLoughlin, 1986). Thirdly, seeing other people coping with grief can help them appreciate how normal the uncomfortable feelings associated with loss are (Hollins and Esterhuyzen, 1997).

Often the individual with learning disabilities is not given the opportunity to attend the funeral or be involved in the final arrangements for the deceased. This is frequently as relatives fear that it will upset them too much or due to the practical difficulties in arranging for them to be present (i.e. long distances between home and the church, difficulties with transport or difficulties with wheelchair access).

However, Strachan (1981) found that many families did not want their disabled relative to attend. Perhaps as they felt they could not deal with the disabled relative's grief as well as their own. Strachan (1981) reported that only 3 of the 19 individuals considered in their study attended the funeral, while more recently Hollins and

Esterhuyzen (1997) reported 27 of their 50 cases attended. Raji and Hollins (2003) also concluded, after interviewing a selection of funeral directors and religious leaders, that people with learning disabilities are often excluded from funeral rites. Whilst the decision not to invite the relative with learning disabilities to the funeral is normally well intentioned, it can have a detrimental effect on the grieving process for that individual. Strachan (1981) notes that 'funerals allow for a public expression of grief and mark the permanence of the loss of physical contact'. Similarly, Brelstaff (1984, p13) points out, 'Ritual is important at all major 'rites of passage' in life and the bereaved may use ritual to help them accept the reality and finality of the death'. Sheldon (1998) noted that supported involvement in the funeral or visits to the grave reduces both repetitive questions about the whereabouts of the deceased and the frequency or intensity of the difficult behaviour. Exposure to cues related to the bereavement, rather than the avoidance of these, has been shown to be crucial in the recovery from grief (Hollins and Esterhuyzen, 1997).

### **Attachment and Dependency**

It has been suggested that people with learning disabilities may have few, but highly significant relationships (McLoughlin, 1986). Due to their reduced social sphere they may have much greater investments in just a few relationships. The breaking of these very strong bonds may be catastrophic for the individual. Where the person has been looked after at home for many years the degree of attachment and dependency may be very strong indeed (McLoughlin, 1986). As a result of medical and social advances, people with disabilities now tend to live longer (Prosser and Moss, 1996). There is, therefore, an increasing number of elderly carers (Hollins and Esterhuyzen, 1997). The probability of a principle carer dying during the lifetime of an individual with

learning disabilities is high, making the added complication of the grieving process of strong attachment and dependency more pertinent.

However, as Strachan (1981) points out we must not always assume that relationships with close relatives are the most important. In his study of reactions to deaths amongst a group of long-term residents of a mental handicap hospital more marked responses were reported following deaths of other residents on the ward.

### **Simultaneous Losses**

If an individual has been living at home with their parent and carer, and that carer dies, professionals and family are suddenly left with having to make a hasty decision as to how the individual should now be looked after. Often the only immediately obvious choice is an admission to residential care. Hence, it is not an uncommon experience for individuals to lose their closest relative and then also everything else that is familiar to them in the course of a few hours (Oswin, 1991). Hollins and Esterhuyzen (1997) found that 39% of their bereaved group moved home as a result of the deceased parent's final illness. As Oswin (1991) points out the sudden loss of all that is familiar, 'would be a likely cause of breakdown for anyone, let alone a person who may already be disadvantaged by severe physical handicaps and learning disabilities and who may have led a very sheltered life at home with caring parents' (p.79). Adding to this loss is also the lack of control the individual has over their future (Oswin, 1981). Few individuals with learning disabilities are involved in the decision as to where they should live following the death of a carer.

The situation following bereavement for many with learning disabilities may be considered one of multiple losses (McLoughlin, 1986). It may therefore be difficult to distinguish the effect of a loss of a parent from the simultaneous loss of home, pets, neighbours and friends, and personal possessions (Hollins and Esterhuyzen, 1997).

## **Atmosphere in Residential Accommodation**

At a time when an individual is grieving they generally need some time alone.

However, when a person is living in residential accommodation it may be difficult to find a quiet and private place to be sad (Oswin, 1992). Staff are encouraged to keep their residents happy and smiling and so someone who needs to express their sadness may not be allowed to do so. Oswin quotes one lady as saying, 'My mum had just died. I went into hospital the same day. They said I needed looking after. I was very sad. They kept wanting me to dance' (Oswin, 1992, p.16). The majority of staff do not treat bereaved residents with insensitivity, and if they do so it is not because they do not care but rather they do not have the knowledge about bereavement and they are caught up in the culture of the institution in which they work (Oswin, 1992).

### **1.3.2 Findings of Quantitative Research into the Reactions of Individuals with Learning Disabilities to Bereavement**

It is clear that individuals with learning disability who have been bereaved have many potential additional difficulties that may complicate their grief. The literature that has informed us of these factors has been predominantly based on professionals' observations from their work with people with learning disabilities and from case study based literature. There have also been three systematic pieces of research exploring the reactions of people with learning disabilities to bereavement (Strachan, 1981; Hollins and Esterhuyzen, 1997; Bonnell-Pascual, Huline-Dickens, Hollins, Esterhuyzen, Sedgwick, Abdelnoor and Hubert, 1999).

Strachan (1981) interviewed 19 ward nurses who were working in a long stay hospital for people with learning disabilities. He used a structured interview schedule to find out about the reactions of individuals within their care that had lost a parent or sibling.

The nurses reported a notable lack of emotional response within the first 24 hours of hearing of the death. In the longer term, nurses found it difficult to know whether the individuals had understood the nature of their loss. Strachan (1981) recognised that a major disadvantage of the study was the reliance on nursing staff's ability to accurately recall the individual's reactions. In some cases the loss had occurred up to a year previously. There obviously may have been difficulties in accurate recall. Additionally, Strachan (1981) pointed out that the reported responses might have been influenced by the nurse's expectation that the individuals within their care would not grieve. In his discussion, Strachan does note that in the case of one individual, whilst the nurse had not observed any reaction in him following the death, friends who visited regularly described him as considerably distressed. Strachan (1981) found that of those that had lost a relative from a terminal illness, few had been able to maintain contact with them during the illness. Similarly, only three of the 19 attended the funeral. Clearly it may have been difficult for these individuals to understand the nature of the loss if they were at no point able to see their relative declining in health and were unable to take part in the farewell rituals. These individuals, living in a long stay hospital were likely to have had very little contact with death. It is the culture of many medical institutions to keep death discrete and hidden, therefore those living long term within a medical environment are unlikely to have developed any practical knowledge about death.

Strachan's (1981) study focused on the reactions of the individuals following the death of a first degree relative. However, it must not be assumed that first-degree relatives are the relationships of the most importance for those living in long stay institutions. Members of staff and other residents may be primary attachment figures for such individuals. Strachan's (1981) study highlights clearly the difficulties of making assumptions about what may be important for the individuals being



investigated and on relying on the observations and perceptions of those caring for the individuals.

Hollins and Esterhuyzen (1997) took a sample of 50 bereaved people with learning disabilities and a matched control of non-bereaved subjects. The bereaved group had lost a parent at some point in the proceeding two years. Data were obtained from the individual's day centre key workers and in some cases also from carers at home. A semi-structured interview schedule was used alongside the Aberrant Behaviour Checklist (ABC), the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) and the Life Events Checklist. They found highly significant differences between the bereaved group and the control group on the ABC and the PIMRA, and in terms of the number of significant life events experienced. Significant behaviour problems and psychopathology were found within the bereaved group. However, staff and carers did not tend to attribute the difficulties to the bereavement or the associated life events. In the majority of cases staff attributed the aberrant behaviours either to innate personality characteristics or to the learning disability itself.

From the interviews with key workers and carers Hollins and Esterhuyzen (1997) found that the individuals in the bereaved group at very little opportunity to visit their sick relative prior to their death or to engage in rituals following the death. Few had been able to visit the grave and a large proportion of the bereaved sample had moved house as a consequence of their relative's death.

Hollins and Esterhuyzen's study indicated that despite the 16 years since Strachan's (1981) study carers were still not recognising the impact that bereavement could have on people with learning disabilities. One of the major difficulties with the study was that as many of the bereaved group had also experienced numerous major life changes following the bereavement it was not possible for the researchers to differentiate if the

behaviour difficulties reported were as a result of the bereavement or the associated life events.

In 1999 Bonnell-Pascual, Huline-Dickens, Hollins, Esterhuyzen, Sedgwick, Abdelnoor and Hubert published a report of a follow up study to Hollins and Esterhuyzen's 1997 study. They reassessed 41 of the individuals from the original sample of 50, with the aim of investigating whether the significant psychopathology that had been found to be present two years after bereavement, had resolved. By 1999, the individuals had been bereaved for between six and eight years. Bonnell-Pascual, et al. (1999), found a small improvement on measures of psychopathology, with a particular reduction in anxiety. However, for none of the measures of psychopathology was there a statistically significant change. A slight increase in aberrant behaviours was found, with inappropriate speech increasing significantly during the time between assessments. It appeared that the individuals were still grieving for their losses. Bonnell-Pascual, et al. (1999), reported that a continued sense of loss was very evident with individuals still being tearful at times and crying out for their deceased parent. Despite indicating that the majority of individuals may not have resolved their grief five years after the initial study, the results of Bonnell-Pascual, et al.,'s (1999) research are a little unclear. Whilst the results taken together indicate a small reduction in the degree of psychopathology, at an individual level some improved, some showed no change, whilst others who had not scored on measures of psychopathology at initial assessment did so at follow up. The report does not give any indication as to why this might be. However, from the data gained from interviewing the individual's key workers they found that the provision of any formal or informal bereavement support was very variable, and that service provision was haphazard and unplanned. It is clear that in the six to eight years since the bereavement the individuals in the study are likely to have been helped or hindered in

their recovery by a wide range of factors and these factors are also likely to have had a great impact on the ABC and PIMRA results. Bonnell-Pascual, et al. (1999), did note that the six individuals that attended the funeral of their deceased parent showed significant improvement in their ABC scores during the period of the follow-up. Clearly there are endless factors such as attendance of the funeral that will have influenced the grieving process for the individuals in the study.

Bonnell-Pascual, et al., (1999) recognised that their study was limited due to their lack of interviews with people with learning disabilities themselves and reliance on informant questionnaires. They cited lack of ethical approval as the reason for this.

### **1.3.3 Critique of Research to Date**

There is no denying that the body of literature that exists has added greatly to our understanding and increased awareness of the potential difficulties facing people with learning disabilities following bereavement. However, there are some problems with the literature to date. Within the current body of literature there has clearly been a lack of involvement of the individuals with learning disabilities. These individuals have been observed and written about, and their carers have been asked about their perception of the issues, but the individuals themselves have rarely been involved. This brings with it some serious limitations.

Much of our understanding about the possible added complications to grief for people with learning disabilities has developed from case study based literature and from the writings of professionals based on their experiences. Case studies, whilst useful in highlighting some of the important issues, tend only to be written about individuals who have had particularly difficult life events or who have presented with particularly challenging behaviour. They do not necessarily represent typical experiences. As

Strachan (1981) remarked, 'There is a danger, when describing a pattern of response, of focusing on the exceptional case' (p.20).

As most of the current body of research has developed without the inclusion of the individuals with learning disabilities, there has been a heavy reliance on health and social care professional's interpretations of observable behaviour. This leads to a risk of misinterpretation. The behaviours are always going to be interpreted through the filtered perception of the observer. The research discussed above has already indicated that when relying on the observations of those who do not believe those with learning disabilities can grieve, very few bereavement reactions are noted (Strachan, 1981). And we may assume that when relying on the observations of those who have been trained to spot psychopathology, normal grief reactions may be perceived to be excessive (Oswin, 2000). Maureen Oswin's work is perhaps an exception to most of the work written by professionals about their experiences as she does back up some of her interpretations and observations with quotations from the individuals. However, she does not make clear how she obtained these quotations. The reliance on studying observable reactions also restricts our insight into the internal emotional reactions of individuals. Our observations of behaviour may indicate that an individual is displaying a greater degree of hyperactivity or is refusing food but this does not offer us any direct insight as to what the individual's emotional state is.

There is also a problem with inferring the cause of a change in behaviour when relying solely on informant checklists of behaviours. As was noted in the discussion of Bonnell-Pascual, et al.'s (1999) study, the use of informant checklists can indicate change but they do not allow the meaning or cause of this change to be inferred. The research to date has indicated that a major difficulty for people with the learning disabilities who have been bereaved can be the large number of other losses that may

accompany the bereavement. From the quantitative data it can be problematic to disentangle the effects of the bereavement itself and the effects of the associated losses and life changes. Only through the use of very large samples and the partialing out of the huge numbers of variable factors could informant checklists of observable behaviour lead to reliable inferences about causation of behaviour change.

Alternatively, if the individuals in question were to be involved in the research process, their understanding of their behaviours and their internal feelings could give us greater insight into their reactions to and their experiences of bereavement.

Most research articles in this area tend to conclude with stating the need for staff to be trained in dealing with grieving individuals, and much has been written about the importance of counselling services for bereaved individuals with learning disabilities. However, there has been no research that has investigated what the most pertinent issues for these bereaved individuals are, or what they would find most useful following the loss of someone close to them. It is as if the first explorative step of the research process has been missed out.

#### **1.4 Guiding Principles and Context of Research**

Research does not occur in a vacuum but within a social and cultural context. In qualitative research it is particularly important for the researcher to make clear to the reader their understanding of the context of the research and the values and philosophies they hold which will inevitably have an influence on the shaping of the research (Elliot, Fischer and Rennie, 1999; Stiles, 1993). This section will provide the reader with a summary of the social, political and theoretical context within which the researcher conducted the research and the principles that guided the development of the research.

### 1.4.1 Models of Disability

Over the last century disability has in general been understood in terms of individual impairment. Cognitive impairment has been seen as directly creating disability. This understanding of disability has been termed the individual model or Personal Tragedy Perspective (Oliver, 1990). This model has developed over a long period of time, during which it has influenced, and has been influenced by, associated discourses such as modern capitalism (see Oliver, 1990), social Darwinism (see Goodley, 2000), and the medicalisation of disability (Goodley, 2000). The individual model still represents the dominant discourse of disability, as can be seen by definitions of disability used by organisations such as the World Health Organisation (WHO) and policies such as the 1995 Disability Discrimination Act (DDA). The WHO states, ‘Disability is the *effects of the impairment* [italics added] on everyday activities’ (WHO, 1992), and the DDA defines disability as ‘Either a physical or mental *impairment, which has a substantial and long-term adverse affect on a person’s ability* [italics added] to carry out normal day-to-day activities’ (HSMO, 1995, section 1.1).

Whilst disability is located within the individual and learning disability is perceived as individual pathology (Goodley, 1998), the individual is required to adjust to their environment, ‘come to terms with’ their disability, and be the recipient of expert professional / medical attention.

As the individual model represents the dominant discourse it tends to underlie the roles assigned to people in society and the interactions that take place between people assigned different roles. The individual model perpetuates a culture of dependency and non-acceptance (Goodley, 2000), and assigns disabled people a passive role in society. Professionals (in particular medical professionals) however are assigned very

powerful roles due to the belief that disability is a product of individual pathology. Whilst operating (often unconsciously) within an individual model of disability, professionals, including psychologists, reaffirm this power difference. As Cocks and Allen state, ‘...people with intellectual disabilities were further disempowered because their own knowledge of themselves and their physical and mental condition was, by and large, disregarded in favour of the expert judgement.’ (Cocks and Allen, 1996, p.286). Hence, psychologists, acting either as clinicians or researchers, frequently further disempower the very individuals they wish to help by not reflecting on the discourse of disability they are working within and continuing to reaffirm the power difference.

An alternative model of disability, which does not consider impairment and disability as synonymous, is the social model of disability. A key component of this model is the distinction between impairment and disability. A person may be impaired in their ability to learn but this does not necessarily result in a disability. The disability is dependent on the environment and society in which the impaired individual lives. As Goodley states, ‘Disabled people are just that – people that are disabled by a contemporary social, economic, cultural and political climate on the basis of the purported impairments’ (Goodley, 2000, p.31). The discourse of the social model addresses notions of societal problems, social and environmental barriers and independence through self-advocacy (Goodley, 1998). The discourse of the social model relocates the disability away from the individual and into the environment and societal attitudes. It redefines the roles of people with learning disabilities so that their impairment no longer needs to result in dependency, passiveness, and pathology. Psychologists and researchers working within this discourse can help empower people with disabilities by rejecting the role afforded to them by the individual model of the

‘all knowing, expert’ who ‘treats or studies patients’, and instead ‘act together’ with individuals with learning disabilities to help them explore and challenge barriers.

Researchers working within the discourse of the social model have turned to research paradigms that value the inclusion and empowerment of people with learning disabilities such as narrative research (e.g. Booth and Booth, 1994) and participatory research (see Cocks and Cockram, 1995).

#### **1.4.2 Theoretical Position**

Whilst positivism has made a significant contribution to psychology historically, I believe in some areas of research it is now stifling the exploration of significant psychological constructs, such as feelings, beliefs, values, etc. Positivist research, with its focus on observable facts, and objective empirical realities, can at times miss the subtleties of psychological life and deny the individuality of human beings.

Within learning disability research I also feel the traditional positivist approaches have reinforced the hierarchy between the ‘expert’, non-disabled researcher and disabled participant that have developed through the individual model of disability (see Goodley, 2000).

I would describe my theoretical position as fitting most closely to a phenomenological philosophy. Phenomenology deems it possible to research all ‘objects’ that can be thought about. These do not have to be empirical objects but also experiences, ideas, images, concepts, etc. Phenomenology is concerned with presences not existences. These presences can be mental representations of objects in the outside world or they can be mental representations in the inner world (i.e. memories, thoughts, images) (see Giorgi, 1995; Spinelli, 1989). Whilst phenomenologists may believe in the empirical reality of objects in the outside world they would deny that these can be



objectively measured. This is because all objects will be perceived, or experienced as presences, differently by different people. It is their act of consciousness that mediates between the 'reality' and the experience. In this way I subscribe only to a subjective reality.

Despite my unease with some areas of the positivist tradition and my belief in subjective reality I do not reject the aim of understanding human behaviour, thoughts and feelings in a general manner. What I do object to is the attempt to look for general laws without the consideration of the complexities of human individuality and the subjectiveness of experience, and of beginning a search for general laws without first exploring the specifics of individual experience. Galton states this perspective eloquently when he notes, 'Acquaintance with particulars is the beginning of all knowledge – scientific or otherwise...starting too soon with analysis and classification, we run the risk of tearing mental life into fragments and beginning with false cleavages that misrepresent the salient organizations and natural ingredients in personal life' (Galton, quoted in Allport, 1947: 56). Whilst case study type material has been published about the experiences of those with learning disabilities who have been bereaved, it has not been made clear the methods that were used to choose the individuals written about or the methods that were used to gain the information. Whether the individual was chosen as an exceptional or a typical case is not specified, and how much of the information presented represents the feelings of the bereaved and how much represents the opinions of the researcher is not made clear. This limits its usefulness in developing knowledge from which to begin to construct nomothetic research. What appears to be lacking in the bereavement and learning disability literature is an in-depth investigation into the experiences of just a few individuals from which to draw out themes that can then be tested further as general laws on a wider population.

### 1.4.3 Policy

In 2001 the government published a white paper titled 'Valuing People'. This policy begins by making the statement;

People with learning disabilities are amongst the most vulnerable and socially excluded in our society..... This needs to change: people with learning disabilities must no longer be marginalised or excluded.

(Department of Health, 2001, p.2)

The paper recognises the major social difficulties many people with learning disabilities face and puts forward a set of proposals under the four key principles of Rights, Independence, Choice and Inclusion. The policy goes on to state;

People with learning disabilities have little control over their lives, few receive direct payments, advocacy services are underdeveloped and people with learning disabilities are often not central to the planning process. The government's objective is to enable people with learning disabilities to have as much choice as possible over their lives and the services and support they receive.

(Department of Health, 2001, p.4)

Whilst the paper does not refer directly to the needs of people around the time of a bereavement, the sentiments of Rights, Independence, Choice and Inclusion are aimed to be embraced by this research project. It is hoped the research will help investigate the extent to which people with learning disabilities feel included, independent, able to make choices and able to exercise their rights during the time around a bereavement. It is also hoped the research will be conducted in a manner in which the

participants feel included, and the findings of the research may help inform the kinds of services bereaved individuals with learning disabilities may wish to receive.

#### **1.4.4 Researcher's Epistemological Stance**

It may be seen from the subsections above that I ascribe to particular models and hold certain beliefs that are likely to affect the course of the research process.

I believe that learning disability is socially constructed and that the dominant discourses around disability greatly disadvantage and disempower individuals with learning disabilities. I believe it is important for researchers to reflect on the role that is afforded to them by the dominant individual model of disability so as to avoid further disempowering participants of the research.

I am also taking a non-positivist position within the research. Partly because of my own beliefs about how traditional research methods can reinforce the hierarchy between the 'expert', non-disabled researcher and disabled participant, and partly due to current emphasis in recent government policy on service user involvement in shaping service evaluation and provision.

These beliefs will affect the way in which the research is conducted, my understanding of participant's experiences, and the conclusions that will be drawn.

#### **1.5 Summary of Introduction**

In summary of the introduction, a vast literature on bereavement has been developing over the past forty years within the non-learning disabled population, however, there is much less known about the bereavement experiences of people with learning disabilities. The literature within the field of learning disability has generally focused

on observable behavioural reactions, the beliefs of staff members and carers, and the observations of professionals. Whilst this has added to our knowledge of some of the potential difficulties for people with learning disabilities, the individuals with learning disabilities have, for the most part, been excluded from the research process. We therefore know very little of the internal thoughts and feelings of people with learning disabilities who are grieving, and we do not know what they find most difficult following a bereavement.

## **1.6 Aims of the research**

The aims of the research are to;

- Explore with individuals with learning disabilities their experiences of bereavement in order to develop a more elaborate understanding of their thoughts and feelings about bereavement and their experiences around the time around the death and during their grief.
- Consider their experiences in terms of the psychological models of bereavement that have been suggested by researchers working within the generic population.
- Consider the best ways in which to support people with learning disabilities in light of the experiences they describe, and to suggest avenues for future research.

## **2 Method**

### **2.1 Research Aim**

The aim of the research was to investigate the experiences of bereavement for individuals with learning disabilities. The aim was to explore with the participants their experiences of what happened in the time leading up to and following the death, and their thoughts and feelings about their experience.

### **2.2 Overview of Design**

The aims of the research were addressed by conducting semi-structured interviews with 10 individuals with learning disabilities who had experienced bereavement. The interviews were recorded on audiotapes, transcribed, and then analysed using Interpretative Phenomenological Analysis (IPA) to identify the main themes of the individual's experiences.

### **2.3 Qualitative Approaches to Psychological Research**

There has been an increasing awareness of the importance of qualitative methods within psychology over the last decade. This has been related to a move away from positivist and hypothetico-deductivism epistemologies (Willig, 2001) and a discontent with the perceived narrowness of a psychology based on 'laboratory studies, experimental design and statistical analysis' (Smith, Harre and Langenhove, 1995, p.1).

Smith, et al., (1995) talk about a new paradigm in psychology, developing in response to this discontent, which has different philosophies but which can compliment the more traditional methods. They suggest four key principles of this paradigm:

- 1 Research conducted in the real world
- 2 A recognition of the central role of language and discourse
- 3 Life and research perceived as processual or as a set of dynamic interactions
- 4 A concern with persons and individuals rather than actuarial statistics and variables

The methodologies associated with this paradigm are attempting to develop ways of researching human experience that allow the richness and diverseness of psychological life to be represented. The majority of these methodologies are qualitative. Elliot, et al. (1999) describe the aim of qualitative research as being;

...to understand and represent the experiences and actions of people as they encounter, engage, and live through situations. In qualitative research, the researcher attempts to develop understandings of the phenomena under study, based as much as possible on the perspective of those being studied.

(Elliot, et al., 1999, p.216)

Given the theoretical position and research aims stated above, a qualitative method was deemed most appropriate for this piece of research.

## 2.4 Semi-Structured Interviewing

Semi-structured interviews were chosen as a way of exploring people's experiences. This style of interviewing was chosen so as to allow the experience of bereavement in all its senses (thoughts, feelings, behaviour and experience of others) to be explored in its richest form with as little filtering as possible. Much of the past systematic research of bereavement within a learning disabled population has relied on observations. This means that whilst behaviour has been documented, feelings and thoughts could not be accessed. As Darlington and Scott (2002) point out interviews are an excellent way of finding out what a person thinks or feels in relation to a particular topic.

Semi-structured interviewing also allows an exploration of the issues that are most important for the participants, by enabling them to dictate the information they provided rather than only allowing them to respond within given categories. This was deemed particularly important given there is no previous research published that has allowed individuals with learning disabilities who have been bereaved to state what the most important issues were for them. The interviews had to be flexible enough to allow the individuals to discuss the issues that were important to them rather than just speaking within the confines of what the researcher thought were the important issues. In this way the qualitative, semi-structured interviews were also deemed most appropriate in attempting to meet the broader research aims of acting together with the participants in exploring their experiences and avoiding the 'expert researcher' and 'passive participant' roles. Holstein and Gubrium (1997) emphasise the active role of both interviewer and interviewee in stating;

Both parties to the interview are necessarily and ineluctably active.... Respondents are not so much repositories of knowledge – treasuries of information awaiting excavation, so to speak – as they are constructors of knowledge in collaboration with interviewers.

(Holstein and Gubrium, 1997, p.114)

## **2.5 Developing the Interview Schedule**

The interview schedule was produced in the manner suggested by Smith (1995).

Firstly, the broad range of areas that were to be covered was drawn up. The areas were; the person's experiences around the time of the death, how their life had changed afterwards, what their relationship to the deceased had been like and how they had coped with the bereavement.

Secondly, these were arranged in a more logical order. Smith (1995) and Willig (2001) both suggest that more sensitive topics or more private topics are tackled later in the interview after rapport has been established. Goodley (2000) also stresses the importance of being as natural as possible in interviewing and how, in his experience, in approaching an interview with a person with a learning disability it is best to try and 'strike up conversation' rather than interview. Bearing this in mind the themes that were to be covered in an interview were arranged in a logical order that was felt to mirror how a natural conversation about a loss would progress. Hence, the individual's relationship with the deceased (a subject with lower emotional contact) was placed first, followed by the events surrounding the death (predicted to be highly emotionally charged), followed by how their life had changed since the bereavement, with coping to be discussed throughout the interview where appropriate.



Thirdly, questions were developed within each of the themes. The number of questions was kept to a minimum with each of the questions being as open as possible. A series of prompts was written to accompany each of the questions should they be needed in the course of the interview.

The interview schedule was also revised to include an opportunity for the interviewee to add further information and a section at the end in which positives and plans for the future were discussed. A copy of the interview schedule can be found in the Appendix 1.

## **2.6 Ethical Approval**

Ethical approval for the study was sought from the Hull and East Riding Local Research Ethics Committee, and was granted on the 26<sup>th</sup> March 2002.

The participants were fully informed as to the nature of the research and what it would involve, and gave their written consent. If the individual had a carer, the carer also gave their consent to the person with learning disabilities taking part in the research.

The participants were free to withdraw from the study at any point. All information provided by participants has been kept confidential and all identifying information has been removed from material that has been made public. None of the participants were recently bereaved.

## **2.7 Participants**

### **2.7.1 Recruitment of Participants**

The number of participants recruited was decided upon through consideration of the size of the data set that the interviews would yield in relation to time constraints and with consideration of published guidelines (see Turpin, et al., 1997).

The aim of the research was to explore the experiences of bereavement for people with learning disabilities. No distinction was made as to whether these experiences were judged by others to be complicated or uncomplicated. In some senses it was hoped the research could avoid the criticism levelled at many case study based pieces of literature of focusing on the unusual cases, by instead exploring the ‘unremarkable’ experiences of bereavement. Hence, in recruiting participants, rather than approaching NHS led Community Learning Disability Teams who may be in contact with individuals considered to be having difficulties, Social Services funded resource centres were contacted. It was predicted that a greater range of bereavement experiences, not just complicated bereavements, would be found amongst people attending the resource centres.

Within the Hull and East Riding of Yorkshire area five Social Service resource centres operate offering daytime activities for adults with learning disabilities. These centres range in size and in structure. The largest has nearly 200 people regularly attending, the smallest has around 80 people regularly attending. Some of the centres have the majority of the students/service users (the users of the services have chosen to refer to themselves differently in different centres) attending a central base, whilst others have developed smaller community based sites. All the centres in the area were approached and invited to take part in the research. Whilst members of staff reacted

very differently to the research project, all the team leaders were helpful and willing to take part. The team leaders were provided with an information sheet to give to key-workers (see Appendix 2). The key-workers were asked to consider if they could think of any of their students/service users who had memories of a bereavement that occurred at any point in their lives, but not within the last six months, who had good verbal skills, who would be happy to talk about their experiences, and who were predicted not to become overly distressed by speaking about their experiences. Over all resource centres staff members identified 17 individuals who met the criteria whom they would be happy to let me speak to.

Five of the individuals identified did not have a specified carer or were considered by resource centre staff to be able to give informed consent without the help of a carer. For the remaining 12 individuals team leaders were asked to contact the individual's main carers to ask for their consent to allowing me to approach the person. Some centres did this via telephone, others did this with the use of letters with consent slips (see Appendix 3). Four carers declined their consent. This was usually due to concerns that the interview would bring back sad memories and cause upset. Eight carers consented. Key workers then explained the research briefly to the 13 individuals who had either been deemed able to give their own consent or whose carer had consented, and asked if they would be happy to meet with me. Two individuals declined to take part when initially approached by their key-worker. I visited the remaining 11 at the resource centres they attended and introduced the research to them with the aid of the Information Sheet for Participants (see Appendix 4). If they agreed to take part in the research they completed a consent form (see Appendix 5). A time was then booked for the interview. It was made clear to the participants that they were free to change their minds at any point. They were given a copy of the information

sheet and the consent form and asked to continue to think about whether or not they wanted to take part and that they could change their minds.

Two individuals declined to take part after the research was introduced and they had had some time to look at the information sheet. A further individual, who was considered able to give informed consent by the resource centre staff, gave consent to be involved in the study but then could not take part after a worker involved in providing her sheltered housing felt it was not in her best interests.

During the course of conducting the interviews two further individuals approached their key workers and requested to take part in the study. After following the consent procedures these two individuals took part in the research.

### **2.7.2 Characteristics of the Participants**

The 10 participants ranged in age from 29 to 66 years old. Three were male and seven were female. Five of the participants lived with a family member, three lived in residential care, one lived with adult carers and one lived alone with support from outreach services. The time since bereavement ranged from one year to 33 years with the median time since bereavement being 14 years.

The participants all met the criteria for learning disability (they needed to meet the criteria to be able to access the resource centres) but had quite a range of abilities.

They all had relatively good comprehension and verbal expression abilities.

It was acknowledged that by choosing a semi-structured interview method only the more articulate bereaved individuals would be able to take part in the study, and that many less able individuals would be excluded. It is appreciated that further research may be necessary to develop non-verbal ways of involving individuals in research and investigating the experiences of bereavement in the wider learning disabled

population. However, it was considered that given the lack of research in this area that included the individuals with learning disabilities it was important to start somewhere. The opinion of Kennedy (as cited in Goodley, 2000), a high profile self-advocate, was considered in making the decision to start the research process with using verbal interviews. In speaking about his response to those who say he is not talking for all people with learning disabilities he stated;

When people tell me that I am 'higher functioning' than the people they are talking about, I feel like they are telling me that I don't have anything in common with other people with disabilities. It is like they are putting me in a whole other category and saying that I don't have any right to speak.

(Kennedy, 1997, 1)

## **2.8 The Interviews**

The interviews took place in a private room at the resource centre the individual attended, within their normal hours of attendance. The interview began by checking whether the participant was still willing to take part in the study, re-explaining the issues around confidentiality, showing the participant the tape recorder and explaining what was going to happen to the audiotape after the interview.

Whilst the interview schedule was followed in its structure, during the interviews the questions were not always rigidly adhered to. As suggested by Goodley (2000) it is best to think of the interviewer, not the interview protocol, as the research tool. As he states 'Interviewers should continuously appraise the interview situation by opposing sterility, being non-judgemental, letting people talk and sensitively probing.'

(Goodley, 2000, p. 53). I aimed, as far as possible, to conduct the interview as if it

was a natural conversation, with aim of putting people at ease and maintaining rapport. However, a balance was always sought between ensuring the participants were able to bring what was important to them into the interview whilst maintaining the information given was within the confines of experiences of bereavement. The interview schedule was used as a way of keeping the interview focused on these experiences.

The interviews lasted about 45 minutes each and were recorded onto audiotapes. Most participants appeared to enjoy the interviews and some expressed their happiness at being able to tell someone about their experiences. One person, however, became upset during the interview and requested to end the interview early. This participant was still happy to let the partial interview be included in the study.

The researcher then transcribed the recordings of the interviews. The transcription was carried out by the researcher as it was felt to be an important step in becoming acquainted with the content of the interviews and re-listening to the emotional expression linked to the words used (see Charmaz, 1995).

## **2.9 Interpretative Phenomenological Analysis**

Interpretative Phenomenological Analysis (IPA) was employed in analysing the transcriptions of the interviews. IPA is a relatively new method of analysis that aims to capture the quality and texture of individual experiences. It is an approach to research that is informed by the principles of phenomenology. It takes the phenomenological stance that each person's experience of any one event is going to be different, and is concerned with individuals personal perceptions or accounts of an event, or gaining an insider's perspective. However, it recognises the impossibility of gaining direct access to another person's perception. The researcher's understanding

of the participant's perception will always be determined by their own knowledge, beliefs and values, and in fact the researcher's own conceptions are 'required to make sense of that other personal world through a process of interpretative activity' (Smith, Jarman and Osborn, 1999, p.219). Therefore IPA is phenomenological in the sense that it is concerned with individual's personal perceptions, and interpretative in that an understanding of individual's experiences is developed by the researcher.

The transcripts of the interviews conducted with the bereaved individuals in this study were analysed in the idiographic manner suggested by Smith, et al. (1999). As suggested, the transcript of one interview was looked at in detail before the other transcripts were incorporated into the analysis. Interview 1 was chosen to be the first to be analysed, as it appeared to be quite rich in expression. The stages of analysis suggested by Smith, et al. (1999) and Willig (2001) were used. Firstly, the text was read and re-read several times and initial thoughts in response to the text were recorded in the left-hand margin. Anything that struck as interesting or significant in what the interviewee said was noted at this stage. Secondly, emerging themes were recorded in the right-hand margin. Key-words were used to capture the essential quality of what was being said in each section. Thirdly, all the themes identified were listed and an attempt was made to make connections between them. They were considered to see if any of the themes seemed to cluster together, or whether new superordinate themes could help pull together collections of themes. As clusters developed they were checked back against the text to ensure they fitted the source material. Each cluster was labelled in a way that captured the essence of the themes. Fourthly, a master list of the themes was produced with indicators of where in the text instances could be found. As stressed by Smith et al. (1999) care was taken not to let

the researcher's own biases to distort the themes and to ensure that each theme was clearly demonstrated within the text.

This process was repeated with each of the transcripts. Where new themes emerged they were tested against earlier transcripts and naturally the themes of the first transcripts influenced the analysis of the later transcripts. When each transcript had been analysed, the 10 master theme lists were combined to develop a final master list of themes. This was organised into higher order and subordinate themes with examples from the text to support each theme.

## **2.10 Credibility checks**

As the interest in qualitative methods in psychology has grown, several writers have produced guidelines for the production of qualitative research and criteria by which this research may be evaluated (see Cooper, 2001; Elliot et al., 1999; Mays and Pope, 1995; Stiles, 1993; Turpin et al., 1997). Their recommendations have been useful in guiding the course of this study. For example, recommendations such as owning one's perspective/disclosure of orientation (Elliot et al., 1999; Stiles, 1993), and situating the sample (Elliot et al., 1999) have been addressed in the preceding sections and other recommendations such as grounding in examples (Elliot et al., 1999) will be addressed in following sections. It has also been suggested that good qualitative research addresses the need for credibility/validity checks (Cooper, 2001; Elliot et al., 1999; Turpin et al., 1997). Various methods for checking the credibility of qualitative research have been suggested, including triangulation with external factors or quantitative data, comparing two or more qualitative perspectives, using multiple analysts and member validation. The latter of these two methods were employed to check the credibility of the findings of this study. The interview transcripts were



analysed by independent qualitative analysts and their themes were compared to themes the researcher had identified. In addition, one of the interviews was analysed by 3 independent analysts and the themes they identified were discussed during a research supervision group. The participants were also involved in member validation. Following the analysis of their interviews the emergent themes were fed back to them and they were asked whether the themes adequately summarised the main issues for them. Their responses were incorporated into and influenced the final master list of themes.

### **5.1 Feedback to Participants**

Following the completion of the analysis and the development of the final master list of themes, the participants were visited for the results to be fed back to them. At this meeting their views on how the findings of the study could be disseminated were sought. Suggestions included telling staff at the resource centres and residential homes about the findings, presenting the findings to advocacy groups and putting the results on the internet. Arrangements have been made to contact some of the participants later in the year to follow up their ideas about dissemination with them.

### 3 Results

The interviews that took place with the bereaved individuals were transcribed and analysed using Interpretive Phenomenological Analysis. This chapter presents the results of the analysis of the transcripts. The data collected from the interviews was organised into five higher order themes. Each of these higher order themes consists of four or five subordinate themes. Below is a table showing an overview of the themes that were drawn out of the interviews. Each of the themes will be described, with quotes taken directly from the interviews to illustrate each theme. The chapter will conclude with a discussion of what the researcher brought to the research process and how this may have influenced the emerging themes.

Table 1. Overview of Higher Order Themes

| <b>Higher Order Theme One: Loss</b>  |
|--|
| <ul style="list-style-type: none"><li>• <b>Theme One: Loss of person</b><br/>(Their nature; Physical appearance; What they did; Just missing them)</li></ul>   |
| <ul style="list-style-type: none"><li>• <b>Theme Two: Loss of relationship</b><br/>(Closeness; Shared activities)</li></ul>  |
| <ul style="list-style-type: none"><li>• <b>Theme Three: Further Losses</b><br/>(Of family life; Of home, possessions and pets)</li></ul>   |
| <ul style="list-style-type: none"><li>• <b>Theme Four: Loss of consistent care / Loss of primary advocate</b><br/>(Gradual loss of family; Aloneness; Loss of family leading to reliance on paid carers; Instability/frequent moves)</li></ul> |
| <ul style="list-style-type: none"><li>• <b>Theme Five: Other Bereavements</b></li></ul>  |

### **Higher Order Theme Two: Feelings**

- Theme One: **Emotions**

(Sadness; Hopelessness; Shock; Reasoning; Disbelief; Fear/Sense of vulnerability)

- Theme Two: **Showing Emotions**

(Crying; The right times to cry; modelled grief)

- Theme Three: **Breaking down**

(Fear of breaking down; breaking down)

- Theme Four: **Physical Feelings and Difficulties Expressing Emotions**

### **Higher Order Theme Three: Memories of Time Around Death**

- Theme One: **Hearing the News / Memory of the Death**

(Hearing the news; Finding their ill/deceased relative)

- Theme Two: **Time During Illness**

(Caring for them; Knowing that death was approaching)

- Theme Three: **Funeral**

(To go or not to go; Nice or not nice; Memories of the funeral)

- Theme Four: **Exclusion / Marginalisation**

(During time of illness; In making decisions; Visiting cemetery)

### **Higher Order Theme Four: Recovery**

- Theme One: **Support**

(Family; Friends; Staff/Professionals; Just knowing people are there)

- Theme Two: **Things that Helped**

(Talking; Affection; Crying; Time; Medication; Going out; Different things help at different times)

- Theme Three: **Beliefs**

(It's what they would have wanted /They're happy now; Taking Dad's place; Belief in angels/Deceased is still with me; Heaven)

- Theme Four: **Remembrance**

(Memories; Photos; Keeping possessions)

|  |
|--|
| <b>Higher Order Theme Five: Obstacles in Recovery</b>  |
| <ul style="list-style-type: none"> <li>• <b>Theme One: Interaction Between Disability and Social World</b><br/>(Independence v's Help; Lack of control; Feeling different; Understanding)</li> </ul> |
| <ul style="list-style-type: none"> <li>• <b>Theme Two: Inadequate Support</b><br/>(Other people's grief; Little perceived support; Inappropriate support; Not visiting cemetery)</li> </ul>          |
| <ul style="list-style-type: none"> <li>• <b>Theme Three: Manner of Death</b></li> </ul>  |
| <ul style="list-style-type: none"> <li>• <b>Theme Four: Difficult Times</b><br/>(Seeing the body; Christmas)</li> </ul>  |

### **3.1 Overview of Higher Order Theme One: Loss**

There was a strong sense of loss evident throughout the interviews. There was the loss of the deceased person, but there were also numerous other losses felt by the participants. Some of these losses were associated with the loss of the deceased person but others were unconnected.

#### **3.1.1 Theme One: Loss of the Person**

All participants spoke about how they felt the loss of the person who had died. Many spoke about the person in very concrete ways. For example, many talked about the deceased in terms of their physical appearance or in terms of the things that they used to do. Others spoke about the nature of the person who died. Many made very powerful statements of the feelings of loss in terms of the way in which they missed the deceased.

## **Physical Appearance**

Most participants made some reference to the deceased's physical appearance. Some thought back on the deceased's appearance in terms of how attractive they were.

*'Oh she was beautiful'* Interview 4 Line 9

*'He was more like suave and handsome.'* Interview 8 Line 66

Others made reference to the connection between the deceased's appearance and their own.

*A - And what did he look like?*

*P - (points to himself)*

*A - Did he look like you?*

*P - Yep.*

Interview 3 Line 40

*'She wears glasses, she had curly hair. My hair.'* Interview 6 Line 17

## **Their nature**

Some participants made reference to the nature of the deceased person. This was usually in a positive way.

*'Oh she was a lovely soul'* Interview 4 Line 59

*'Well, she was so kind and loving,..'* Interview 5 Line 6

## **What they did**

For many of the participants their memories of the deceased person were closely associated with what they did.

*'Erm, he used to make cranes. Big ones, with gears underneath the things.'* Interview 3 Line 34

*'She used to be a cleaner.'* Interview 5 Line 236

*'And she used to bring two of us up, me and me sister.'* Interview 5 Line 240

*'Oh, that's a good, oh yes, I remember, it was more like, than there, he was what you call it, a football player.'* Interview 8 Line 5

### **Just missing them**

There was a clear sense of the loss of the person in the straightforward way in which participants spoke about missing the deceased.

*'I just miss her a lot.'* Interview 6 Line 352

*'We miss her.'* Interview 4 Line 128

*'Still miss him now.'* Interview 2 Line 108

*'It's like being with it. Like you go in and you go outside and he's not there.'*  
Interview 2 Line 247

*'But I wish she was back down here.'* Interview 5 Line 94

*'I wish she was here now (breaks down into sobs), she was a, a good mother.'*  
Interview 4 Line 95

### **3.1.2 Theme Two: Loss of Relationship**

The loss of the relationship with the deceased came across in the interviews as being much more significant than the simple loss of the person. It was clear from the way the participants spoke that the relationships they were describing were very close and important to them. For many of the participants the deceased was their closest relative prior to their death and their primary carer. In some cases the interviewees described a life prior to the death in which there was a particular closeness with their relative but there was also an apparent isolation from the rest of the world. This made the loss of that relationship even more devastating.

## **Closeness**

The following quotes demonstrate the closeness of the relationships that the participants were describing. The quotes come from four ladies who were bereaved of their mother, aunt, and grandmothers respectively.

*'And I remember I spoke to her and I said, 'Oh, I do love you.'* Interview 4 Line 88

*'Yeah, in the house, there ever so nice, me and her.'* Interview 7 Line 29

*'She spoiled me!'* Interview 6 Line 39

*'I loved her.'* Interview 9 Line 14

The last quote came from a participant who appeared particularly confused about many of the details of her life and of her loss. This statement came in response to the question, 'What do you miss most about your grandma?' The clarity and simplicity of the response made it particularly striking.

## **Shared Activities**

The activities that the deceased engaged in with the participants were clearly important to them. In general, these were everyday activities, such as shopping and cooking. It seemed that it was the little things that they did together that were missed the most. It was the normality of the relationship that made it special.

*'We just did things, that's all. Go out and do something together.'* Interview 2 Line 34

*'We used to do lots of things. It was great fun. I used to run a print with him. I used to go to work with him. That was something we did.'* Interview 2 Line 27

*'We used to do the family tree together'* Interview 2 Line 21

*'I used to go on the bus shopping with her and that.'* Interview 7 Line 15

*'Well, yeah, yeah, I remember now, yeah, I think I remember this far back now, because, what happened was like, I remember the, more like we played, he played lots of games with me.'* *'Well, like err, what do you call, you know like, more like, you know like they call, err, snakes and ladders.'* *'I remember that we played, what do you call that, leap frog you, know when you bend down and you jump over one another.'*  
Interview 8 Line 30, 36, 45

*'Erm, played snooker.'* Interview 3 Line 96

*'Going shopping.'* Interview 9 Line 55

*'She used to tickle me feet.'* Interview 9 Line 28

*'I helped her do baking.'* Interview 6 Line 46

### **3.1.3 Theme Three: Further Losses**

The loss of the person was in itself significant for the participants but in many cases the loss of the individual also then led to further losses.

#### **Loss of Family Life**

For many of the participants the death led not only to the loss of the relationship with the deceased but also to the loss of a sense of family. Even for those who had relatives remaining following the death there was a sense of a loss of normal family life.

*'..So, you know, much to me mam's delight! I, it was good times'* Interview 2 Line 50

*'Well before she died she used to go, er, with my dad dinner dancing. And she had a beautiful dress'* Interview 4 Line 4

For one individual the loss of his mother at an early age was even more devastating as it was followed by the loss of his two sisters.

*A – Do you remember if anything changed in your house after your mum died?*

*P – My sister*

*A – Your sister did? What happened to your sister?*

*P – Gone*



*A – She moved out?*

*P – Two*

*A – Both of them moved out?*

*P – (nods his head)*

*A – Do you know where they moved to?*

*P – Bungalow.*

*A – They moved into a bungalow.*

*P – (nods)*

*P – I didn't.*

*A – You stayed with your dad. Do you know why you stayed and your sisters went?*

*P – (shakes head) Interview 10 Line 384*

### **Loss of home, possessions and pets**

Four of the participants left their family home following the death. The following quote came from one interviewee who was talking about what happened following the death of her aunt whom she had lived with for ten years. This woman's apparently passive role in the organising of her move appeared a sharp contrast to the sensible way in which she had handled the finding of her aunt's body.

*'I went to, I think I went to me cousin's house afterwards, and then they, I stopped with me cousin, till they found me a place to go like.'* Interview 7 Line 355

*'No, no I think I live with me Aunt, with me cousin for a while, and then they found me the D View afterwards when she died, like.'* Interview 7 Line 196

*'Cause she (her cousin) sold the house an all.'* Interview 7 Line 281

The following quotes come from a woman who remained living in the house she had shared with her mother for some time after her death. However, when she finally left the house it was felt as a major loss. She also lost her possessions and almost all mementos of her mother in the move.

*P – Well, me house was in a lot of repairs, and I couldn't afford it, so I asked the social services to move me, to a, what you call it, Q drive.*

*A – What was it like moving out?*

*P – It was terrible.*

*A – Why was that?*

*P – Because I had some happy memories of me mother. Interview 5 Line 64*

*A – Did you take some things with you?*

*P – (Shakes her head)*

*A – No?*

*P – No.*

*A – Have you got any photographs or anything like that that you keep?*

*P – No*

*A – No?*

*P – I've got one*

*A – You've got one picture*

*P – That's all. Interview 5 Line 78*

The participant who was found a new home by her cousin also appeared to have lost much in the move. She was unclear as to what had happened to her aunt's possessions and her aunt's pet dog.

*P – Yeah me Auntie G had a dog.*

*A – Did she?*

*P – Yeah a white dog, a white poodle I think.*

*A – A white poodle. And what happened to the dog, do you remember?*

*P – I don't know. Interview 7 Line 316*

For some of the participants it was particularly upsetting to have somebody else living in their relative's old house.

*P – Yeah, somebody's got that house now.*

*A – Yeah? Somebody else lives there now?*

*P – Yeah*

*A – What's it like having somebody else living there?*

*P – (Says very quietly) It's alright.*

*A – It's alright*

*P – Somebody's got it.*

*Interview 3 Line 698*

*'Well, it's got new people in there. It's strange, it's strange down there. They've got new door, new windows.'* Interview 6 Line 298

### **3.1.4 Theme Four: Loss of Consistency of Care / Loss of Primary Advocate**

There was a strong sense within the interviews of a loss of the one person who really cared about the individual and who would ensure that all their needs were addressed.

The interviews taken as a whole appeared to show a gradual loss of family leading to feelings of aloneness and a reliance on paid staff. Whilst non-relatives were seen to provide adequate care it did not have the same quality. Care from somebody who cares for you because they love you was obviously different from the care that somebody can provide if they are paid to care.

### **Gradual loss of family**

It felt that for most participants there already had been, or there was going to be a gradual loss of family. For many participants it appeared that they had always been cared for by an older generation (parents, aunts and uncles, grandparents), but that this generation was dying out and the younger generations of siblings, cousins, nieces and nephews were not expected to take a large role in assisting the individual.

One participant had lived first with her mother and then her aunt but following her aunt's death she had gone to live in residential care. Neither her cousin nor sister was in regular contact with her any longer.

*'My Mum died first and then me Auntie G, when I live with Auntie G. Me Mum died when I was 16 years old like.'* Interview 7 Line 467

*'No, no I think I live with me Aunt, with me cousin for a while, and then they found me the D View afterwards when she died, like.'* Interview 7 Line 196

*A – So first of all you went to live with your cousin. What was your cousin's name?*

*P – P, but she lives, she had the pub like, and erm, and she really moved pub, and er I saw the pub, and now she lives in a house in Spain.*

*A – Oh, is she? She moved to Spain.*

*P – Yes. She's on the Costa Brava I think.* Interview 7 Line 209

*'Yeah, me sister only comes once a year me sister does.'* Interview 7 Line 251

Another participant had first lost her father, then the following year her mother committed suicide. Her and her sister first moved together into a flat but her sister then left the flat.

*'Well, I lived with my sister for a while, then she got this flat where she's living now, then I was living on my own. I think it was harder when she moved out, you know not knowing what was round the corner, you know what could happen in the process. I kept begging her to stay but she said 'no, I want to move out', so, I thought I can't force her to stay if she don't want to.'* Interview 1 Line 188

Another participant who had moved into residential care at the age of 16 clearly felt quite alone in the world and disconnected from her family. Her grandfather, aunts, father and step-mother and step-sister were still living locally, but since the death of her mother and grandmother contact with her family appeared to have been lost. She felt her granddad was the only family member still in contact.

*'I've got just me granddad now.'* Interview 9 Line 184

Her step-mother (whom she had lived with for some years) had left her father and was no longer in contact.

*'Me (step) mum's gone off with K (step-sister).'* Interview 9 Line 190

During the interview we had a confused conversation about telephones that I felt was strongly symbolic of the way in which she felt cut off from her father and aunts.

*P – How do you cut people off the telephone Alex?*

*A – How do you cut people off the telephone?*

*P – Yes*

*A - I don't know?*

*P – Tell me*

*A – You just put the phone down*

*P – What else?*

*A – I don't know. Maybe unplug the phone?*

*P – Yes*

*A – Why do you ask?*

*P – Can you press the black thing down?*

*A – Yes*

*P – What?*

*A – The button where you put the thingy down, the receiver, you can just press the button instead.*

*A – Have you had somebody on the phone that you wanted to cut off?*

*P – Do you know when I was in town and I ring me dad up at Auntie M's.*

*A – Yeah*

*P - And Auntie B's*

*A – Yeah. You were in town and you rang your dad up at your Auntie M's.*

*P – Yeah*

*A – And did you want to cut him off?*

*P – She, me Auntie M unplugged the phone.*

*A – Did she. Why did she do that?*

*P – To stop me ringing it. Interview 9 Line 206-230*

### **Aloneness**

This loss of family appeared to leave some of the participants with a strong sense of aloneness.

*'I'd had a bad fall at home. It was one Saturday night, I'd fallen in the living room. And what I could do at that time, well at any time up to that stage, I could somehow manage to scramble onto my knees, get hold of my chair arm, and somehow manage to scramble myself up. But I couldn't at this point, no matter how much I tried I was just going back down again. All night Saturday night to late on the Sunday night I was laid on the living room floor without anybody knowing.'* Interview 1 Line 77

*'..and I just broke down knowing that I'd been left alone without anyone to talk to.'* Interview 1 Line 153

### **Loss of family leading to reliance on paid carers**

Following the loss of family many of the participants found themselves relying on paid staff. Whilst the care provided by paid carers appeared to be felt to be adequate by many of the participants it obviously was considered to be second best.

One lady who was living with adult carers, and who appeared quite happy there, expressed regret that her mother's illness had not been diagnosed and her death prevented.

*'Perhaps I wouldn't have been here today if she, she had a new valve, I would have been living with me mum, but err.'* Interview 7 Line 500

Another woman who had moved into residential care following the death of her mother expressed very clearly her feeling that her mother had looked after her well and understood her needs but that since her death she no longer has anybody who really cares.

*'Well, she was so kind and loving, and, she did everything for me.'* Interview 5 Line 6

*'She knew I was backwards and she tried to help me.'* Interview 5 Line 270

*'But I wish she was back down here. Because I'm having a lot of trouble where I'm living now.'* Interview 5 Line 94

*'Well, they couldn't care less.'* Interview 5 Line 330

*'Cause nobody's helping me.'* Interview 5 Line 332

One participant had remained living with her mother following the death of her father. However, the role her father had previously had of taking the participant on outings had been taken over by a paid carer. The outings did not appear to have the same quality for the participant when facilitated by a paid carer rather than a relative.

*'Yeah, because it's like, what is it, like a be, you know like, that, that, you know like S, you know like M? err, she sometimes comes to my house, what I, I sometimes pay her, my mam pays her, as, more like a carer. What happens was that she sometimes takes me out and gives me mum a break a bit.'* Interview 8 Line 348

### **Instability / Frequent Moves**

For three of the residents who had moved following their relative's death their appeared to be particular instability. This was characterised by frequent moves and no clear sense of belonging.

The quote below comes from a lady who had lived with her step-mother and father and then in five different residential homes since the death of her mother. The

residential homes were not restricted to one geographical area but spread around the country.

*A – Do you remember how old you were when you moved to T?*

*P – I was 21 in October.*

*A – So you were a year at T?*

*P – Yeah*

*A – And then you moved ..*

*P – A*

*A – To A. And where did you live before you went to T.*

*P – G. Interview 9 Line 348-355*

*P – Yeah. Then I moved to B H, in P. Interview 9 Line 369*

*P – Yeah, then I moved to G, then I moved to T, then I moved to A. Interview 9 Line 385*

The extracts below come from another lady who had lived in various parts of the country following the death of her mother. After her mother's death, when she was 16, she went to live in a residential home run by nuns. Although she remembers some details of the time she spent with the nuns she clearly does not remember it as a very caring environment. When that home closed she went to live with her aunt. When her aunt died she stayed with her cousins for a short period till they found her a residential home. From there she moved to another residential home and finally then moved in to live with adult carers.

*'When she died like, I think. H, oh, it was St. Mary's home, I went there.'* Interview 7 Line 571

*'I scrubbed the steps, they made me scrub these big, wide steps like.'* Interview 7 Line 587

*'I forget what their names was, just, I think they were nuns, they were nuns I think.'* Interview 7 Line 613

*'That's it, I don't know what happened to that home, whether it got closed down I'll have to I think it got closed down, or, its either closed down or been shut down, I don't know really. I haven't been back to see it, I haven't like really.'* Interview 7 Line 621

*'I went to, I think I went to me cousins house afterwards, and then they, I stopped with me cousin, till they found me a place to go like.'* Interview 7 Line 355

*'No, not long, no. Not until, they found me this house, this home. It was, erm, D View. I went to D View and then I went to W Court afterwards like in erm, N.'* like.  
Interview 7 Line 213

Another woman who had managed to stay in the house she had shared with her mother for a period of time following her death then moved through various residential homes. This lady was very clear about her sadness had having to leave her mothers house and her unhappiness in her current home. She appeared to feel very powerless to control where she lived.

*A – Did you carry on living in that house?*

*P – Yeah, till I couldn't do anymore, and they made me leave.* Interview 5 Line 57

*'But I wish she was back down here. Because I'm having a lot of trouble where I'm living now.'* Interview 5 Line 94

*P – I wish I could get to live in H. Because B where I live I don't like it.*

*A – Don't you?*

*P – No*

*A – What don't you like about B?*

*P – There's nothing nice about it.* Interview 5 Line 307

There was a sense that without the help of a relative who could act as an advocate for the individual and coordinate their care in the long term, the participants had drifted from one residential setting to another. None of the moves appeared to be initiated by participants.

### **3.1.5 Theme Five: Other Bereavements**

Although there was not a question within the interview schedule relating to other bereavements, almost all participants made reference within the interviews to another bereavement they had suffered.



*'..we'd lost our dad in 1983. The 28<sup>th</sup> of January, January precisely 1983.'* Interview 1 Line 21

*'Well, I had two brothers but I lost one of them, a couple of years ago, from a heart attack. He'd been dead two or three days before he was found.'* Interview 1 Line 312

*'Yeah, it's like, we had, like when me gran died.'* Interview 2 Line 156

*'I miss my daddy as well, because me daddy died.'* Interview 5 Line 38

*'...she missed her husband. She had a husband as well. She missed him. He went first and, he was marvellous as well, my, my granddad.'* Interview 6 Line 415

*'My Mum died first and then me Auntie G, when I live with Auntie G. Me Mum died when I was 16 years old like.'* Interview 7 Line 467

*(Is there anybody else in heaven?) 'Me mam'* Interview 9 Line 417

*'And Auntie B died in the toilet. The doors had to all come out, from there, bout that, big doors. All the boys down, smacked all the doors.'* Interview 3 Line 18

*'Yeah, and then we had a bereavement last week. A friend died.'* Interview 2 Line 170

## **3.2 Higher Order Theme Two: Feelings**

Clearly bereavement is a highly emotionally charged process for any person and the participants of this piece of research proved to be no exception.

### **3.2.1 Theme One: Emotions**

A full range of feelings were expressed by the participants. This was to be expected as the participants were at various stages of the grieving process. Some of the participants appeared to have resolved their grief and had difficulty remembering the kinds of feelings they had experienced. Other participants were coming to the end of

their grieving yet could remember their early emotional reactions to the loss. Others were still in the midst of intense feelings of loss.

### **Sadness**

Many of the participants expressed very simply that their loss caused them sadness.

*'I felt sad.'* Interview 9 Line 109

*'It was sad.'* Interview 7 Line 110

*'Sad.'* Interview 10 Line 401

### **Hopelessness**

For other participants there was an overwhelming sense of hopelessness in the face of death.

*'She'd gone for one of the neighbours and just explained that she was trying to do something drastic but by the time they got back it was too late, she'd already gone. Like I say they did call the police and the ambulance, and that was it. There was nothing they could do.'* Interview 1 Line 31

*'Well, I couldn't do anything about it.'* Interview 4 Line 91

### **Shock**

A sense of shock was also evident for some of the participants. Whilst some of the participants could clearly express this, one participant who found it hard to express emotions verbally directly implied a sense of shock in his description of discovering his dad's body.

*'I think it would be delayed shock more than anything.'* Interview 1 Line 157

*'and then I thought ohhh, you know, totally in shock.'* Interview 2 Line 101

*'It was just a shock.'* Interview 5 Line 339

*'We had a shock you know the next day.'* Interview 6 Line 125

*'I just erm, get up, and I found my dad on the carpet, dead.'* Interview 3 Line 4

### **Reasoning**

Two of the participants found it difficult to make sense of the loss and questioned why the death had occurred.

*'I thought blimey, why, why, you know, why him.'* Interview 2 Line 56

*'At first we couldn't understand why and then we sought of put two and two together and thought well could it have been through losing my dad the year before.'* Interview 1 Line 19

### **Disbelief**

One participant remembered clearly a sense of disbelief following hearing the news that his father had died. This feeling of disbelief has continued and he still now finds it hard to believe his dad has gone.

*'Couldn't believe it. Couldn't believe it.'* Interview 2 Line 132

*'He went into hospital and that, and then he died. I can't believe, I still can't believe he's not there. It's hard.'* Interview 2 Line 58

### **Fear / Sense of Vulnerability**

Some of the participants expressed a feeling of fear of the unknown. The death of their loved one had brought home the reality that everybody dies and heightened their feelings of vulnerability.

*'and this happens and you think, you know, think well, it could be me next, I hope not! It's that feeling of fear, you know,'* Interview 2 Line 158

*'..you know not knowing what was round the corner.'* Interview 1 Line 190

### **3.2.2 Theme Two: Showing Emotions**

#### **Crying**

The only way in which the participants had shown others that they were feeling sad during their grief was to cry. Most of the participants made some reference to crying during the interviews.

*'But when I found out it was my own mum that was it I just broke down in tears.'*  
Interview 1 Line 13

*'I absolutely cried'* Interview 4 Line 91

*'I cried'* Interview 4 Line 93

*'I cried when she died'*. Interview 9 Line 113

#### **The right times to cry**

Some of the participants felt that it was not always ok to cry and that sometimes it should be avoided. One participant told me that she avoided crying during the funeral.

*'I didn't cry in the church, I cried outside the church'* Interview 4 Line 138

Another participant told me she cried at night for her mother. It appeared this was a private time for her in a busy residential home.

*'Yeah, for me dear mammy. At night time.'* Interview 5 Line 151

A further participant was very proud that she did not cry whilst talking to me about her bereavement.

*'Of course I am, I wasn't full up was I?'* Interview 6 Line 485

## **Modelled Grief**

One woman appeared to have been unsure as to how she should react following the bereavement. In the following extract she suggests she took her cue from the way in which one of her relatives grieved.

*'Err, it's strange, errrr, yeah, I think I was, a little bit more like, a little bit, a little bit, yeah, a little bit upset, because what happened was me Auntie was upset about it because she really liked him.'* Interview 8 Line 243

### **3.2.3 Theme Three: Breaking Down**

For some of the participants there was a sense that the grief may be too much and they were either afraid of or did breakdown with the overwhelming feelings.

#### **Fear of Breaking Down**

One woman told me she was afraid of going to the funeral directors to view the body as she feared she would breakdown.

*'You know I want even, because I knew how upset I would get I didn't even go up to the funeral directors to see, you know, like a lot of people do, cause I knew I'd break down.'* Interview 1 Line 139

#### **Breaking Down**

Two of the participants described their reactions to the bereavement and the following feelings as a nervous breakdown. One woman's reaction suggested she felt intense anger as well as sadness. However, she was unable to express to me exactly what her feelings of anger had been about.

*'Err, No, I had a nervous breakdown, when I, when she died like.'* Interview 7 Line 114

*'When me Auntie G died, then I had a nervous breakdown, I broke somebody's, I smashed me, I put me hand through a window, that's how I did, I smashed me hand.'*  
Interview 7 Line 134

*'I had a nervous breakdown.'* Interview 5 Line 376

### **3.2.4 Theme Four: Physical Feelings and Difficulties Describing Emotions**

Some of the participants clearly found it difficult to express how they felt and others described physical feelings in the place of emotional feelings. It appeared that some of the participants lacked the knowledge of words for negative emotions. This suggested that the physical feelings may have been used to express the negative feelings.

*'Err, I don't know how to put it.'* Interview 8 Line 253

*'Horrible'*. Interview 10 Line 157

*'I was alright. Only a bit, I don't get much, but a little bit.'* Interview 6 Line 143

*'You get these weird feelings'* Interview 2 Line 330

*A – Do you remember what kind of feelings you had then?*

*P – Not very nice at all, no,*

*A – No*

*P – Woo (shivers)*

*A – Oh it makes you feel like that.*

*P – Yeah, it's cold.* Interview 6 Line 133

*'I felt shaky inside.'* Interview 4 Line 51

*'And I haven't been well with, me legs are hurting now.'* Interview 5 Line 378

### **3.3 Higher Order Theme Three: Memories of Time Around the Death**

All the participants had very clear memories of the time around the death of their relative. For many of the participants the time before the death and the events

surrounding the discovery of the death were at least as significant for the individual as the events that followed during the period of mourning.

### **3.3.1 Theme One: Hearing the News / Memory of Death**

All of the participants had very striking memories of finding out about the death.

Some of the participants had been told the news by a family member or a member of staff, others had discovered their relative either seriously ill or dead.

#### **Hearing the News**

Most of the participants could remember the exact words that were used when they told the news of their relative's death.

*'I've got some bad news for you, your grandma S has died.'* Interview 9 Line 105

One of the participants, who had been in respite care at the time of her dad's death, was told the news by her mother and her aunt. It appears her mother had found it difficult to break the news to her and had attempted to explain her beliefs about heaven to her daughter. However, the concept of heaven seemed a little confused for this participant and did not seem to offer her much comfort.

*'Yes. Well, what happened was, when I got back from respite I was, err, what happened was, my mam's got a sister called Auntie M, and she was there with me mam, and she was talking to me.'* Interview 8 Line 131

*'Err, yeah, what happened was that, it was me mam, right, told me that, that me dad had, she said to me that, she told me he'd died first, and then she came up to me and talked to me about me dad and when he'd died, and she said that, oh yeah, she said, I remember now, she said...'* Interview 8 Line 159

*'Right. And she put her arm around me and said that, that, she said 'your dad is', you know, 'you know where err, heaven is', upstairs, so she that, and I said to her that*

*'heaven is upstairs' and she said that me dad had, I remember now, she said that he'd died of a heart attack.* ' Interview 8 Line 169

Another participant had been at work when the news was broken to her by one of the supervisors. This lady was shocked and upset by the news but believed at some level she knew about her mother's death before she even heard the news.

*'And I was over at the factory, the laundry place, where I used to work when I got to know and I just said oh, it's Mrs B, was the lady, one of the staff, came and told me, and she said 'Your mother's passed away' and I just said 'Oh my God, no.'*'  
Interview 5 Line 407

*'Yeah. She went and told Mrs W, Mrs W was the boss, and she gave me an Aspril, I had a headache and that's how I knew. I had a premonition.'* Interview 5 Line 415

The extract below comes from a man who was at the resource centre when his dad died. He describes feelings of shock on hearing the news.

*'I was here, with my mates outside, and then had to, then T had to come, and I saw T and I said, 'what's up man, what's up boss', then, 'it's about your dad', and I thought what's up with me dad, and then I thought ohhh, you know totally in shock.'* Interview 2 Line 98

The following extract comes from a lady who remembers in detail the events leading up to hearing of her dad's death. She remembers all the details of the police coming to the house early in the morning and asking them to phone the hospital, and then walking to the nearest phone box to speak to the doctor.

*'So I got dressed and went down to the telephone on the estate near where we live and the doctor said my dad had been quite poorly the Thursday night and my sister from A and my ex brother in law had been to see him and he said he had a shock for us and he said 'your dad died at two o'clock this morning''.* Interview 1 Line 265

A year later the same woman returned from the resource centre to find the emergency services outside her house. The memory of the discovery of her mum's death was equally clear for her.



*'Went home the Friday afternoon from here, saw a police car and an ambulance outside our house and I didn't think nothing of it being me mother, just thought oh it may be one of neighbours. But when I found out it was my own mum that was it I just broke down in tears.'* Interview 1 Line 15

### **Finding their Ill/Deceased Relative**

Two of the participants had experiences of finding the body of their relative. One man, who was not very verbally articulate, found it difficult to tell me many of the details of his bereavement and yet told me with great clarity about discovering his father's body.

*'I just erm, get up, and I found my dad on the carpet, dead.'* Interview 3 Line 4

*'I found him dead.'* Interview 3 Line 215

*'Well, found him dead on the floor. In kitchen. Yeah, having a cup of tea.'* Interview 3 Line 406

*'No, all here on his head was bleeding. They took him in hospital.'* Interview 3 Line 412

Another participant had found her mother collapsed in a chair and had rung the emergency services.

*'Yeah, she had a red, I know what, she died in a chair in a red dressing, she had a red dressing gown, she went to bed, she died in a chair with it on. Yeah, in the kitchen like.'* Interview 7 Line 517

*'they give her artificial respiration but they couldn't, err, do, do anything for her, like.'* Interview 7 Line 525

The same woman later found her aunt after she had died in her sleep.

*'No I saw her die, no I saw her, I saw her, died in bed.'* Interview 7 Line 328

*'I phoned me cousin and told her she'd died.'* Interview 7 Line 332

### 3.3.2 Theme Two: Time During Illness

#### **Caring for them**

One of the participants had cared for her mother for a long period of time during her illness. For this participant her experience of bereavement was closely woven with her memories of caring for her mother during her illness. There was little indication from this interview that the participant saw her mother as her carer. Instead it appeared the participant had been her mother's primary carer during her illness.

*'Oh she was ill for a long time'* Interview 4 Line 77

*'I was up all night with her. I've even got my door open, I won't close it, in case she shouts me'* Interview 4 Line 3

*'Before me mam died, me mam said to me, 'Can I have a little drop of sherry or brandy?' cause she used to enjoy that. And I wouldn't give it to her because she was on medication, you see, it would harm her you see. Cause you can't mix drinks with medication. It upset her. Anyway, I wouldn't give her it, because she was on medication, you see, I wouldn't give her it. 'Ah, go on' she said, 'give me a little tod', 'no' I said, 'I can't'. And I wouldn't because it would harm her. It would make her ill, you know what I mean, and er, that's what she said.'* Interview 4 Line 66-72

*'She laid in the front room for quite a while, and then they took her away'* Interview 4 Line 31

#### **Knowing that death was approaching**

Some of the participants had known that their relative was going to die. One lady's mother told her whilst she was ill that she thought she wasn't going to get better.

*'she said to me, 'Oh', she said, 'I'm going to die'. And I remember that'* Interview 4 Line 48

Another woman was present at her father's bedside in hospital when he told her mother that he didn't think he would survive.

*'...he'd just turned round to us and said 'I'll never come out of here J' he said, 'the only way I'll be coming out of here is in a box'. Suppose he must have known he was never going to get any better.'* Interview 1 Line 271

### **3.3.3 Theme Three: The Funeral**

The funeral was remembered by most participants as a major event in the time following the death. However, there were mixed feelings amongst the participants about the funeral.

#### **To go or not to go**

Most of the participants remembered considering whether or not to go to the funeral, or remembered who made the decision.

One lady remembered that when her mum had asked her whether or not she wanted to attend her father's funeral she had said no. However, she later decided she wanted to see his body but she was too late.

*'No, I didn't go to the funeral.'* *'No I didn't, well, wh, wh, what happened was. Me mum said 'do you want to go to your dad's funeral?' and I said no, I didn't.'*  
Interview 8 Line 216

*'Emm, I think I I'll think of it, let me think, err, I did used to go, but then the, it got like, more like, you know at the undertakers right, Sometimes they take his coffin in there, and you know where the little chapel is?'*  
*'And, through the curtains, and they go through the curtains, had a peep through the curtains, but it was too late.'* Interview 8 Line 225

Another participant did not wish to go to the funeral and remembers willing the day to be over. She was unsettled by the idea of seeing the coffin and knowing her mum was inside.

*'That was the worst part about it, the funeral.'* Interview 1 Line 120

*'I think it was when they come to the house, you know, cause they'd come to the house so everyone could go from there. I think it was just seeing the cortège with the coffin in. Knowing mum was inside. You know I want even, because I knew how upset I would get I didn't even go up to the funeral directors to see, you know, like a lot of people do, cause I knew I'd break down.'* Interview 1 Line 136

*'I know a lot of people do, but I couldn't. I just couldn't. I kept thing, I just wish today would, you know, the sooner it was over and done with the better, cause you know they aren't very nice thing's to go to and I've been to a fair few in my life.'* Interview 1 Line 142

Another participant also chose not to attend the funeral. He felt that it was not necessary to attend the funeral in order to respect his father.

*A – Was there a funeral?*

*P – Yeah, but I didn't go. Never been to a funeral before.*

*A – Never been to a funeral before.*

*P – No. A bit too, too....*

*A – Who decided that you weren't going to go? Did you choose?*

*P – Yeah. Not to go to the funeral, not disrespecting, respecting.* Interview 2 Line 189

A woman who had been a child when her grandmother died was at school the day of the funeral. She was clear that she would have liked to have gone.

*(Did you go to the funeral?) 'No I didn't I was at school'* Interview 9 Line 167

*(Did you want to go?) 'Yes, I did'* Interview 9 Line 172

### **Nice or not nice**

Of those participants who attended the funeral there was mixed feelings as to whether they were happy having been there.

*'It was very nice.'* Interview 5 Line 138

*'Quite nice, yeah, nice service.'* Interview 6 Line 200

*'Err, It wasn't very nice really. No, I would sooner go to a wedding, I've been to wedding anyway.'* Interview 7 Line 376

*'Err, it wasn't very nice really.'* Interview 7 Line 534

*'I didn't like the, I didn't like to see her in the coffin really.'* Interview 7 Line 378

### **Memories of the funeral**

For many of the participants the funeral was important in the gathering together of family.

*'We had err, a like, something to eat, after that, and then, all together. And then we had nice flowers.'* Interview 6 Line 246

*'I was with me family then, everyone, yeah.'* Interview 6 Line 202

*'My sister went. And me cousin, all, me cousin did.'* Interview 7 Line 366

*'We had a party.'* *'Having something to eat and a drink.'* Interview 9 Line 303

For one of the men in the study, a strong image had remained for him of seeing the grave being covered in soil. The memory appeared to have a frightening quality for him.

*'Um, big hole in the, grave. Put him in the grave. Put some soil on top of it. Right down T. That church is.'* Interview 3 Line 118

*'Erm, er, soil on top of the coffin'* Interview 3 Line 212

*'Yeah. Two men did it.'* Interview 3 Line 509

### **3.3.4 Theme Four: Exclusion / Marginalisation**

Whilst some of the participants were given the choice as to whether or not to attend the funeral there was still a strong impression of exclusion or marginalisation of the individual during the time around the death.

## **During time of illness**

Many of the individuals who took part in the research recalled being left out to some extent whilst their relative was ill. One man, who was quite young when his mother died, remembered being prevented from seeing her whilst ill. She was at home for much of her illness yet he did not spend time with her while she was ill at home. When she was taken to hospital he was not allowed to visit her.

*'In bed, at home,.'* (makes makaton sign for bed) Interview 10 Line 77

*(Did you sit with her in bed?) 'No, my dad did.'* Interview 10 Line 82

*'Didn't let me go to the hospital.'* (Do you remember what that was like?) *'Horrible'* Interview 10 Line 153, 157

Another participant was told by her mother that she should not visit her grandmother in the nursing home. It appeared her mother thought it would be upsetting for her to see her grandmother when very ill.

*(Did you ever go visit her there?) 'Yes, I did, not all the time, not when she was feeling poorly.'* Interview 6 Line 78

*'cause me mum told me not to come.'* Interview 6 Line 84

*'You don't like people like that, do you?'* Interview 6 Line 94

Another woman did not see her father when ill or visit him in hospital as she was in respite care at the time.

*(What do you remember about the time before your dad died?) 'Err, this is a tough, let's see, I can't remember that one, err, you could say, let's say that I was in the respite then.'* Interview 8 Line 75

*'No I wasn't no, I wasn't there at the time, I was at respite.'* Interview 8 Line 80

*(And did you go into respite care because your dad wasn't well?) 'That's right, yeah, I did.'* Interview 8 Line 98

### **In making decisions**

Two of the participants felt particularly excluded in the time leading up to and following the death in term of making decisions. These two participants appeared to have lived very independent lives prior to their mother's deaths, but were then marginalised in important decisions.

For one of the women the final decision for her mother to be taken into hospital was made by somebody else. This appeared to be in particular contrast to the level of responsibility that had been carried by the individual for her mothers care previously.

*'Well no, she laid in the front room for quite a while, and then they took her away.'*  
Interview 4 Line 31

*'Well me cousin, me cousin M ordered the ambulance, rung up for an ambulance, and took her way.'* Interview 4 Line 85

*'Well, I couldn't do anything about it.'* Interview 4 Line 91

For the other woman the sorting of her mother's possessions and her house and the decision for her to move appeared to have been made primarily by other people.

*'She came over to see to it all, she didn't give me much chance to stand on me two feet.'* Interview 5 Line 50

*'...they made me leave.'* Interview 5 Line 57

### **Visiting the cemetery**

One of the participants, who had not attended their relative's funeral, expressed a wish to visit her grandmother's grave. However, she did not know where her grandmother was buried. It felt that since she had not been allowed to attend the funeral and had since lost contact with much of her family, it was difficult to undo the effect of the initial exclusion.

*A – Do you know what cemetery she was buried in?*

*P – No I don't*

*A – Have you ever been to see?*

*P – No I haven't*

*A – Did you ever want to go?*

*P – Yes I did. Interview 9 Line 264*

### **3.4 Higher Order Theme Four: Recovery**

Recovery from the bereavement was a major theme within the interviews. All of the participants talked of what had helped them through their grief.

#### **3.4.1 Theme One: Support**

Support was greatly appreciated by the participants during their grief. The most important source of support appeared to come from family. This fits with the sense that was discussed under the theme of loss, that care from paid carers always appeared to be second best to care from family.

#### **Family**

Family played an important role for most of the participants in helping them through their grief.

*'My sister did, the youngest one, cause like I say she was at home and my brother in law, well my ex-brother in law, his family and my brother, I think they all helped me through it, you know'. Interview 1 Line 147*

*'..we was all together.' Interview 1 Line 304*

*(Who helped you feel better?) 'Me sister did.' Interview 7 Line 418*

*(And did anybody try to make you feel better then?) 'Yes, my mum did and my family did. Cheered me up, take me out.' Interview 6 Line 145*



Just having family around following the death was important for the participants, even if they were not directly offering support. One participant spoke of how a family wedding that occurred shortly after the death of his father acted as a reason to bring all the family together. He felt this had helped him. This may have been particularly important for this individual as he had chosen not to attend the funeral so had not got together with his relatives at that time.

*'All the family there.'* Interview 3 Line 131

*'It's good to have relatives about'* Interview 2 Line 138

*'We had all the relatives around'* Interview 2 Line 110

*'At the wedding we all got together, the wedding, that wedding helped me a lot'*  
Interview 2 Line 112

Conversely, when relatives were far away or unavailable there was a clear desire for them to have been around.

*'Like I say, my brother Peter, he was in the air force when we lost me mum and dad. He was in Amer, er no, no, he was in Hong Kong while we lost me dad, they had to fly him home and then he was in America when we lost me mam and they had to fly him home. So...Bad job really when you're so far away.'* Interview 1 Line 292

*A – Was she (your sister) any help to you?*

*P – Not particularly, no*

*A – Not particularly. Did she come back for the funeral?*

*P – That's all she come back for.* Interview 5 Line 200

*A – Would you have liked her to have stayed?*

*P – Yeah.* Interview 5 Line 206

## **Friends**

Friends did not feature very strongly as a source of support for the participants.

However, one lady did name a friend as someone whom had helped her. Her friend had also suffered a bereavement and she felt they had helped one another.

*'Yeah, well, the young lady in the office with me, she's always been a good friend of mine. We both help one another, you know I do this for her, and vice versa.'* Interview 1 Line 201

Another woman told me about how she has some imaginary friends who she sometimes talks to. She was unable to say whether she talks to her imaginary friends because she finds hard to talk to mother, but she was clearly comforted by her imaginary friend's presence.

*(Do you remember when your dad died, if you were feeling a bit sad then, who would you go and speak to then?) 'Mm, I sometimes talked to me mam, and I sometimes talk to my, err, I sometimes, more like, err, more like, what do you call it, in my, you know like an imaginary friend, when you just imagine that somebody's there.'* Interview 8 Line 413

*'It's that, what it is right, sometimes when I wake up in the morning, sometimes I still have, like, err, like they say, it's that there's more people in the room with me, and I'm talking to them.'* Interview 8 Line 417

### **Staff / Professionals**

Some of the participants felt that the staff at the resource centre or residential home were able to help them during their grief. One woman also felt her GP had been a particular source of support around the time of her mother's death.

*'Well, there was staff here, and there was my doctor at the time, Dr.'* Interview 1 Line 194

*'..or sometimes when I'm at P, sometimes when I'm there I would talk to my key-worker.'* Interview 8 Line 395

*'Staff at A. They can talk about it with me.'* Interview 9 Line 460

### **Just knowing people are there**

It was important for many of the participants just knowing that there were people there should they need them. Some of the individuals spoke about letters of

condolence and of reminders from family members that they were there if they were needed. Others spoke of physically just having people around.

*'We got a lot of letters, a lot of letters from,..'* Interview 2 Line 167

*'Well, my brother was always there, well my sister is, don't get me wrong, but my brother was always there if I wanted him, because he's often said even though I know he's still quite a way away he's often said if I ever need him, he's only a phone call away. I mean I've got his home address and his home phone number, so I could always ring him. Like I say my sisters only five or ten minutes, maybe a quarter of an hour away.'* Interview 1 Line 165

*'It's nice to know you've got people around. It's like the staff here now, if there's any problems or, I know there's staff around if I need them.'* Interview 1 Line 175

*'Just having them around, you know. You know, it's good.'* Interview 2 Line 140

*'Well they, I remember now, they sometimes, they helped me a hell of a lot, because, sometimes, I remember, because sometimes they make me a drink sometimes, and they sometimes, sometimes when I'm in my salon, I sometimes have other people helping me in me salon and things like that.'* Interview 8 Line 467

### **3.4.2 Theme Two: Things That Helped**

The participants were clear about the ways in which people had effectively supported them when they were grieving and ways they had coped with their loss. As is to be expected, many different ways of helping were suggested by the participants, with some finding some things more helpful than others. It was also clear from what they were saying that what may help at one point in time did not necessarily help at another.

#### **Talking**

Talking about the loss, their feelings and reminiscing with others was a major way in which many of the participants found others could help them. Some participants spoke of a need to let things out rather than bottling feelings up. Others spoke of how,

although talking was helpful, it was not easy and required courage. For some participants it was more useful to talk about the deceased with someone else who was also grieving and had known the deceased.

*'Talk about it, get it out in the open. It's good to talk.'* Interview 2 Line 161

*'You know coming to see me and getting it out in the open, you know, it's great.'*  
Interview 2 Line 343

*'It's been good to talk about it.'* Interview 2 Line 168

*'Err, we sometimes talk about, oh yeah, we sometimes, when I go to the, like the, err, when me mum had, more like, me mum's friend called J, she comes to the house every time, and sometimes, err, she'll bring chocolate and things like that.'* Interview 8 Line 485

*'Well we always talk about her cause we've got a photo of her.'* Interview 6 Line 157

*'Talk, Talk about it. They knew her as well.'* Interview 6 Line 429

*'Staff at A. They can talk about it with me.'* Interview 9 Line 460

*'Like I say, I think talking about it more than anything.'* Interview 1 Line 351

*'I'm able to talk to people about it as well, I couldn't before. I just sort of, I could never talk to people. Now I can, you know, I feel as though I can open up to people and talk to them, rather than bottle it up.'* Interview 1 Line 39

*'It was just a case of me being able to pluck up the courage and talk about it. Now that I can I find it a lot easier.'* Interview 1 Line 236

## **Affection**

Two participants felt that physical affection helped them when they were feeling sad.

*'she put her arm around me back,'* Interview 6 Line 162

*'Yeah, and they sometimes come up to me and cuddle me. And I really like that.'*  
Interview 6 Line 475

*A - Did anybody try to make you feel better when you were sad?*

*P - Dad did.*

*A - How would he make you feel better?*

*P - Hug.* Interview 10 Line 409

## **Crying**

Another participant talked about crying as a release rather than talking. This lady did appear to be quite alone in her grief and so may not have felt there was anybody available to talk to.

*(Do you remember how you made yourself feel better?) 'By crying' Interview 5 Line 145*

*(By crying? That made you feel better?) 'Yeah. Cause I bottled it all up.' Interview 5 Line 147*

*'Have a good cry.' Interview 5 Line 487*

## **Time**

The same lady also spoke about time as a factor in recovery. She felt that with time she was getting over her loss. However, this lady had lost her mother 33 years ago and yet her grief still appeared quite raw during the interview. Whilst time may have healed to some extent, she was obviously still suffering from her loss.

*'Now I do, it's time has healed.' Interview 5 Line 222*

## **Medication**

One of the participants had become very distressed following the loss of her aunt and felt that the tranquillisers that had been prescribed for her had helped in the initial stages of her grief.

*'I had them tranquillisers, you know them tranquillisers, them big tablets, I had them to calm me down, like. Keep me nervous down and that like.' Interview 7 Line 142*

## **Going out**

For another participant keeping busy and getting out of the house was helpful for her whilst she was grieving. This lady had lost her maternal grandmother and was living

with her mother. Her mother was obviously also grieving so it appeared the trips out may have been more cheerful breaks from the sombre house in which everyone was mourning.

*'Cheered me up, take me out.'* Interview 6 Line 147

*'Seeing me family, going out. That makes you feel better.'* Interview 6 Line 415

### **Timing of help / Different things help at different times**

Whilst each participant had found different things helped, some of the participants were also quite clear that different things were needed at different points in their grief. Some participants spoke of how although talking and having people around had helped later on, they did not think it had helped early on following the bereavement.

*(Do you think it would have been useful to (talk) just afterwards?)*

*'No, it would have been horrible. No, not right.'* Interview 2 Line 152

*'Well, what's brought me through a lot of it is talking about. Like I say, I couldn't do that at first because I got too upset but...'* Interview 1 Line 232

*'You know, and now, like I say, now I find it easier to talk to rather than what I could at a particular time.'* Interview 1 Line 155

*'Every time anybody came near me it was as though I was saying, 'no, I don't want you there', you know, 'I don't want you'. I didn't say it but I felt as though I wanted to.'* Interview 1 Line 240

One participant also suggested that whilst at some times he wanted some peace and quite and some privacy, at others he wanted to listen to his loud music or have a laugh with his friends.

*(Does it help coming here (to the resource centre?) 'Sometimes, but sometimes it doesn't. At night time, get away from all the noise. Here it's really noisy.'* Interview 2 Line 285

*(If you feel sad, what do you do to make yourself feel better?) 'Put a CD on.' 'Loud stuff.'* Interview 2 Line 263

*'My mates always make me laugh. He was here, that day. Makes us laugh, you know. It's good to laugh'* Interview 2 Line 142

### **3.4.3 Theme Three: Beliefs**

Various beliefs were stated by the participants that had clearly been comforting to them since the bereavement. Some of these beliefs were quite specific and centred around what they believed would have been the deceased wishes. Others spoke about more general beliefs about what happens after death.

#### **It's what they would have wanted / They're happy now**

One participant had apparently thought a great deal about her mother's wishes. Her mother had committed suicide and she had found some comfort in the belief that her mother had wanted to be with her father and had got her wish. She also had a belief that despite her absence, her mother would have wanted her to carry on the best she could.

*'We'd lost our dad in 1983. The 28<sup>th</sup> of January, January precisely 1983, which was mum's birthday, we wondered if that could have a lot to do with it. Whether she was lonely and wanted to be with him.'* Interview 1 Line 22

*'She most probably wanted to be with dad and she's got her wish.'* Interview 1 Line 46

*'It is but you just have to carry on the best you can. It would be what they would have wanted you to do.'* Interview 1 Line 281

#### **Taking Dad's place**

One man remembered a conversation he had had with his father before he died about continuing the activities they had previously done together. He felt the need to take over his dad's place in the family as he believed this to be his dad's wish.

*'He's got tools for me in the garage, he left all his calligraphy stuff for me in the garage, all his tools in the garage, all his family tree stuff in the house, so 'here, you do it now'. It's my turn, if you can't do it. I said, 'you're right', yeah.'* Interview 2 Line 76

*'Yeah, keep the family going, keep the family going'.* Interview 2 Line 81

### **Belief in Angels / Deceased is still with me**

Another participant had a strong belief in angels that appeared to have developed from a comment made by a friend of her mother's. The participant found the idea of angels comforting and seemed to have generalised the idea so as to believe her father was not entirely gone but was still present with her.

*'..this woman, she came up to me and said to me, 'the angels are all over you', everywhere, everywhere I go they are there looking at me,'* Interview 8 Line 282

*'What happened was, that they, they'd not really died, they're just there, everywhere, when I'm in my bedroom they're there, and I see one of them when I get up in the morning.'* Interview 8 Line 276

*(And do you think your dad is an angel now?) 'I think he is now. Yes he is, yeah.'* Interview 8 Line 301

*'And err, when I, when I, what it is right, when I turn around, right, that's when I see him.'* Interview 8 Line 314

*'Err, I, err, well, the, what happens was right, he just sits on me bed, you know me bedroom and me bed, he sometimes just sits there looking at me.'* Interview 8 Line 318

*'Yeah I do sometimes, yeah, I do sometimes, yeah, I sometimes talk, yeah I sometimes talk to him but sometimes he goes off.'* Interview 8 Line 330

### **Heaven**

The idea of heaven was present in many of the interviews. Although the concept was quite concrete for some of the participants, it was a comforting idea for many.

*(Where do you think of him as being?) 'Up there.' (points to sky) 'I like to think of all the people up there. Lots of people up there, great people, and you know he's one of them.'* Interview 2 Line 71



*A – Do you think about where she might be now?*

*P – Yeah, in heaven*

*A – In heaven. What do you think it's like in heaven?*

*P – A wonderful place*

*A – A lovely place?*

*P – Where everybody's happy. Interview 5 Line 88*

*'In heaven. See Jesus up in heaven. See stars.'* Interview 9 Line 405, 409, 411

*'Err, I'd say, I'd say she's in heaven now. If there is a heaven. But nobody's come back and told us have they really.'* Interview 7 Line 444

*A – When you think about your mum now, where do you think about her being? Do you ever think about where she might be now?*

*P – (points upwards)*

*A – Up there*

*P – Heaven*

*A – In heaven. What's it like in heaven?*

*P – Don't know.*

*A – Don't know. Do you imagine it in your head? Do you think what it might be like?*

*P – Big. Interview 10 Line 426*

#### **3.4.4 Theme Four: Remembrance**

For many of the participants it was important for them that they continued to remember the deceased.

##### **Memories**

Remembering the nice times they had had together appeared to be important. One participant suggested it was easier with time to remember the nice times from before the death and to forget the difficult times from just after the death.

*'You know, mind you she was 74 when she died, but I still remember her.'* Interview 4 Line 51

*'I can just remember the good things.'* Interview 5 Line 226

*'Well yeah, obviously with just losing her at the time, you know, all the sad memories of, but they've all gone now, just the happy memories of remembering her how she was.'* Interview 1 Line 44

### **Photos**

Photographs were kept by many of the participants. Many of the participants were keen to show me the photographs, particularly the photographs of themselves with their deceased relative. It was as if they wanted to prove to me that what they were saying was true and there was a close relationship. For others, photographs were apparently a way of keeping the memory of the relationship alive.

*A – Have you got any photographs at home? Of your mum?*

*P – (nods)*

*A – You think so.*

*P – I've got them in me bag.* Interview 10 Line 227

*'That's where, I ought to show you, I've got a picture of my Auntie G. Yeah, in the house, there ever so nice, me and her, yeah I'll bring them next week, like.'* Interview 7 Line 23

*'I thought, you know, I like to keep them, in case anybody asks for them. I like to keep them.'* Interview 4 Line 13

*'...when I'm sad at night I kiss her.'* Interview 5 Line 82

*'Well we always talk about her cause we've got a photo of her.'* Interview 6 Line 157

*'Stop, so I can remember.'* Interview 9 Line 454

### **Keeping possessions**

In a similar way that photos appeared to be a way of remembering the deceased, some participants told me about keeping a special item they had that had belonged to the deceased.

*'P's (his brother) got his ring on.'* Interview 3 Line 457

*'She left her purse for me.'* Interview 9 Line 204

*'I've got me mother's, got me mother's bed me mother left me a bed.'* Interview 5  
Line 40

### **3.5 Higher Order Theme Five: Obstacles in Recovery**

Whilst a major theme of the interviews had been recovery, all the participants also discussed the obstacles that they had had to overcome in order to progress through their grief.

#### **3.5.1 Theme One: Interaction between Disability and Social World**

Whilst almost all the themes that emerged from the transcripts could easily have come from a collection of interviews with people without learning disabilities, there did appear to be some obstacles in recovery that were specific to people with learning disabilities. However, these obstacles did not occur as a direct result of the disability itself, rather than from the interaction between the disability and the social world in which the individual lived.

#### **Independence Versus Help**

One participant spoke very clearly about the difficulty she had encountered when she had realised that she needed some help. She talked of having striven for independence for much of her life and had therefore found it difficult to accept help. She appeared to see the dilemma as dichotomous. She felt she could not ask for help without losing her independence.

*'I think, as I've said to people here, and even people outside like yourself, I think a lot of it was because I was so independent at home, trying to do things for myself, I just*

*found it difficult to accept the help, that's why I wouldn't say anything.* ' Interview 1  
Line 102

*'Well, as I've said, I think it's because I've been so used to trying to do things while I was at home on my own, I found it difficult to begin with to ask for help.'* Interview 1  
Line 208

*'It's just a case of me asking them if they will do things for me. I know what I'm like for being a bit stubborn.'* Interview 1 Line 204

### **Lack of Control**

For other participants there was a similar difficulty that involved a lack of control over events following the death of their parent. Some participants had lived fairly independent lives with the help of their parents. Or, in one case the relationship may have best been described as interdependent with parent and child relying on each other equally. However, once the parent was no longer able to facilitate this independence/interdependence the participant lost much of the control to shape the course of events.

A striking example of this was a lady who had lived alone with her mother prior to her death. Following her death her sister returned to England from America in order to see to the arrangements. The participants felt that her sister had taken over everything and not given her the chance to manage on her own.

*'She came over to see to it all, she didn't give me a chance to stand on me two feet'. (Didn't she?) 'No, she swiped everything out, the house and everything.'* Interview 5  
Line 53

Another woman felt that control was taken away from her when her mother became very ill. A relative made the decision she should go into hospital, despite the participant having been her mother's primary carer for some time.

*'Well, me cousin, me cousin M ordered the ambulance, rung up for an ambulance, and they took her away.'* Interview 4 Line 86

*'Well, I couldn't do anything about it. I absolutely cried.'* Interview 4 Line 91

A further lack of control that may have hindered the participants' recovery from their bereavement was evident in the arrangements that were made for where they were to live. As was discussed under the theme of loss some of the participants had several moves of home following their bereavement with few having any apparent choice in their moves.

### **Feeling Different**

One of the participants appeared to believe that her grief was in some way different due to her disability. This did not appear to be an accurate belief based on the content of the interview. Perhaps if she had been helped to see her grief reaction as a normal process she may have found it less frightening.

*'But looking at it now it didn't hit me straight away like it would with any normal person.'* Interview 1 Line 150

### **Understanding**

There was a great variability in the participant's understanding of what death was and the causes of death. Whilst some participants appeared to have a very good understanding of what had caused their relative to die others appeared to be struggling to make sense of what had happened. Although the level of understanding may have been partly a result of the learning disability it is also possible that the lack of understanding was a reflection of the difficulty family and carers had had in talking about death with the individuals.

Some participants appeared to have quite a clear understanding of what had caused their relatives death.

*'Cancer, in throat' (points to his neck) Interview 10 Line 73*

*'She had a stroke, a big stroke.' Interview 9 Line 74*

*'Well, she had cardiac and that, yeah.' Interview 5 Line 12*

*'She had pneumonia.' Interview 4 Line 28*

*'Yes, she died with, I know what she died with. I think she broke a, one of her hearts, you know the valve, your valve in your br, in your heart.'* Interview 7 Line 485

*'The valve, something to do with the valve I think.'* Interview 7 Line 487

Other participants appeared confused as to exactly what had happened.

*'I don't know, It was something to do with her leg I think. I don't know how she lived, why she died really.'* Interview 7 Line 325

*'Hardest thing was to understand it more.'* Interview 5 Line 214

*'Well, me auntie D had, a blood blister on her leg, and the doctor said, I remember what he said, she told me mam about it, she said if that blood vessel moves, that's it. And I don't know if it moved or not. But she had it.'* Interview 4 Line 56

*'She had erm, yeah she was a bit poorly, yeah.'* Interview 6 Line 58

*'She started walking slowly and that'* Interview 6 Line 60

*'And she had colds, and all sorts'* Interview 6 Line 62

*'Yeah, you know. She falls much, a little bit'* Interview 6 Line 64

*'I just erm, get up, and I found my dad on the carpet, dead.'* Interview 3 Line 4

One participant appeared to be particularly struggling with understanding what death was. During the course of the interview he told me about many different people and animals that he had known that had died, and the various things that had killed them.

A few examples follow.

*'They got killed, they did, someone right up there, on the roundabout things. At Hull Fair. Got killed.'* Interview 3 Line 428

*'I was watching a film last night, a war film. They shot a girl.'* Interview 3 Line 563

*'On the farm side, shot a big bull. Not me. All the policeman got guns, shot it. Got out in one of the fields, chased a lady.'* Interview 3 Line 661

*'I saw a rabbit, Got mitsametosis. Yeah so I got a stick and I killed one. They're no good those rabbits.'* Interview 3 Line 672

One woman, who appeared a bit uncertain as to what had caused her grandmother to die, also seemed to lack an understanding of the rituals that follow a death. Whilst she had attended the funeral she seemed under the impression that there may have been more than one funeral but she had only attended one of them.

*A – Was there a funeral for your granny?*

*P – Yeah, there was, yeah*

*A – Was there.*

*P – Yeah*

*A – Did you go to that?*

*P – Only once, only once I went.* Interview 6 Line 191

### **3.5.2 Theme Two: Inadequate Support**

The participants saw support from others as being a major help in recovery from their bereavement, however, equally, a lack of support or inappropriate support represented a major hurdle in working through the grief.

#### **Other people's grief**

One major barrier to receiving support appeared to come from the difficulty families had in being there for the participant when they themselves were grieving. While support was wanted most from family, and from those that knew the deceased, these people were also grieving. A number of participants said that they could not talk about the deceased as it upset their family.

*(If you were crying what would your mum do?) 'She'd be upset too.'* Interview 9 Line 288

*A – And do you ever talk to your dad now about your mum?*

*P – (Shakes his head)*

*A – No, you don't talk to him about when your mum died?*

*P – (shakes head)*

*A – No*

*P – No he cries (makes gesture of tears) Interview 10 Line 187*

*'And then me mam, me mam, and me mam was really crying.'* Interview 2 Line 101

*'You know, you know not to say, you know when something happens like that. I didn't talk to them because they get upset about it. Don't talk, talk about it.'* Interview 2 Line 113

*'It's me mum that feels a bit, strange.'* Interview 6 Line 316

*'She does think about her, all, a lot.'* Interview 6 Line 318

### **Little Perceived Support**

Some participants felt quite alone in their grief and did not feel there was much support offered. One participant felt that people could have helped her but that they didn't.

*A – Did anybody help you feel better at the funeral?*

*P – No*

*A – No. Nobody tried to help you to feel better.*

*P – No Interview 3 Line 145*

*A – Was there anybody who helped you? Anybody who helped you feel better?*

*P – (shakes her head) Interview 5 Line 154*

*'They could have helped me.'* Interview 5 Line 159

*A – Could there have been anything else that people could have done to make you feel better?*

*P – The minister.*

*A – The minister? He could have been some comfort to you?*

*P – He could have been, but he wasn't. Interview 5 Line 166*

*A – Was she (her sister) any help to you?*

*P – Not particularly, no*

*A – Not particularly. Did she come back for the funeral?*

*P – That's all she come back for. Interview 5 Line 200*

*A – Would you have liked her to have stayed?*

*P – Yeah. Interview 5 Line 206*



## **Inappropriate Support**

For some of those who took part in the research it appeared they felt that the support they had received was inappropriate and intrusive. Whilst they wanted some support they did not necessarily want somebody to come in and take over completely.

*'I'll always remember, and even though I reported it at the time, I'll never ever forget what happened when I was at home because I used to have, .... and a young woman come one day to see me at the flat, do some tidying up, she'd found this letter on the floor in the door way, she picked it up, and what upset me more than anything, she had the cheek to stand in front of me and open it. And that's one thing I would never ever do, no matter, even when my sister was living with me, I would never ever open any of her mail.'* Interview 1 Line 215

*'She came over to see to it all, she didn't give me much chance to stand on me two feet.'* Interview 5 Line 50

## **Not Visiting the Cemetery**

Many of the participants did not visit the cemetery regularly yet some expressed a wish to do so.

*A – So do you go to the grave very often?*

*P – T does. My sister.* Interview 3 Line 156

*A – Do you know what cemetery she was buried in?*

*P – No I don't*

*A – Have you ever been to see?*

*P – No I haven't*

*A – Did you ever want to go?*

*P – Yes I did.* Interview 9 Line 264

For some the difficulty appeared to be in finding somebody to facilitate the visits.

*'Oh I went a long time ago to my sisters, to N cemetery, but I haven't been, when I went to N, when I went to, when I went for the day, to see, before Auntie S, I went for the day, and me Aunt S came to see me sister and I went then to the cemetery like, to see her grave like. I haven't been since though.'* Interview 7 Line 427

*'We were going to take some flowers, but err, we got no transport.'* Interview 4 Line 107

For one participant there appeared to be some confusion as to where the cemetery was and why she hadn't been there. It appeared that perhaps her mother felt unable to visit her mother's grave and had told her daughter it was too far away. The participant, however, appeared unsure as to whether it was actually far away.

*'No, it's quite a while, erm, I think she's, it's that way, what's it called, erm, m near, erm, what's that name called, down that way'* Interview 6 Line 262

*'No, it's quite a while, quite a long way from here, well it's not far.'* Interview 6 Line 281

### **3.5.3 Theme Three: Manner of Death**

Two of the participants appeared to have had particular difficulties in resolving their grief due to the circumstances surrounding the death of their mothers. One participant's mother had committed suicide and had great difficulty in trying to understand why her mother had done it and had been left with terrible memories of the day.

*'I was here when it happened. Left her on the Friday morning and she'd slept all right. I said oh, I'll see you when I come home this afternoon mum. She says oh, ok. Like I say she slept fine. Went home the Friday afternoon from here, saw a police car and an ambulance outside our house and I didn't think nothing of it being me mother, just thought oh it may be one of neighbours. But when I found out it was my own mum that was it I just broke down in tears.'* Interview 1 Line 15

*'It was because she threw herself out of the bedroom window.'* Interview 1 Line 17

*'She'd gone for one of the neighbours and just explained that she was trying to do something drastic but by the time they got back it was too late, she'd already gone. Like I say they did call the police and the ambulance, and that was it. There was nothing they could do.'* Interview 1 Line 29

*'Well for a quite a while and then we got to that stage where we couldn't any longer because all the memories of her, thinking about her, I think it was about more than anything thinking about the way she died. You know we didn't want that upset over and over again.'* Interview 1 Line 69

Another woman felt her mother's death could have been prevented and had therefore had greater difficulty coming to terms with her loss.

*P – Yes, yeah, she could have, she could have gone in, she could have gone in the doctors but she didn't go to the doctors with the heart prob, the valve broke.*

*A – Oh dear, so she didn't get to the doctors then.*

*P – No*

*A – Were people telling her to...*

*P – She had a valve, she had a faulty valve, they could've mended it but they didn't. They could've done but, er, she could have had a new valve in her heart like.*

*A – How do you feel about that?*

*P – Not, not very good, she could have lived.*

*A – She could have lived, yeah*

*P – Yeah, if they had put a new, a new valve on, the heart. Perhaps I wouldn't have been here today if she, she had a new valve, I would have been living with me Mum, but err. Interview 7 Line 491*

### **3.5.4 Theme Four: Difficult Times**

There were some specific times identified by the participants as difficult times that had to be overcome.

#### **Seeing the body**

One of the participants saw both her mother and aunt following their deaths. She was upset by seeing their bodies and felt that if she was given the choice again she would choose not to see them.

*'Err, I think it upset me when she died, like, cause, err, I kissed her, and when she, and you know what she was like, she was like, this coffin, and she was, pink, dressed in pink.'* Interview 7 Line 98

*'It was alright, but it upset me afterwards, but I've got over it now.'* Interview 7 Line 106

*'No I saw her die, no I saw her, I saw her, died in bed.'* Interview 7 Line 326

*'Err, it weren't very good, I weren't very good, I think it upset me, when she died in bed like. But I get over it now though.'* Interview 7 Line 336

*'I didn't like the, I didn't like to see her in the coffin really.' (If you could choose again, would you choose to see her or not to see her?) 'I don't know. Not to see her I don't think.'* Interview 7 Line 383

## **Christmas**

Many of the participants spoke about Christmas as being a particularly difficult time. Christmas had been a special time before the person had died and remained a time of year in which the deceased was remembered and missed by the participants.

*'We'd take turns. She came to us Boxing day and then I came to her Christmas, I'd come at Christmas and then she come boxing day.'* Interview 6 Line 27

*(Is this the first Christmas you've had without your granny?) 'Yes, it is, yes. It feels horrible.'* Interview 6 Line 327

*'Well, at Christmas time especially, at Christmas I always cry for her.'* Interview 5 Line 28

*'Over Christmas, me and my sister cried'* Interview 4 Line 129

*'But every Christmas we put so much to get, together, to get a Christmas wreath. And father's day and mother's day we tend to put a bouquet of flowers for her to take up. Like she says you can't forget them just because they're no longer with you.'* Interview 1 Line 128

### **3.6 Reflections on the Research Process, and the Effect of Personal Values and Beliefs upon Interpretations**

Within qualitative research it is understood that the researcher cannot attain a position of objectivity with regard to their research. The theoretical orientations, experience within the area, and personal beliefs and values of the researcher will inevitably play a part in shaping the research and will influence their understanding of the data. Hence it is seen as good practice to acknowledge potentially relevant influences on the researcher in order for the reader to assess the findings within the given context (Elliot et al., 1999; Stiles, 1993).

During the course of the research process a reflective diary was kept in which I noted how the research process effected myself and how I effected the research process. For example, during the course of the time I spent conducting the interviews I learned from the participants some of the better ways to approach interviews. In interview number one I found it difficult to get the balance of having to take charge of the interview in some senses whilst being at the individual's resource centre where I was a guest. From this experience I learned to allow the individuals to be the host and to encourage them to take as much responsibility for leading the interview as possible. Throughout the research process I have been undertaking professional training on a Doctorate in Clinical Psychology course. During the course of my training I have had various experiences of working with people with learning disabilities. During the second year of my training I worked for six months within a Community Learning Disability Team, and during the final year of training I elected to spend half of my time working with children with learning disabilities and half my time working within a secure service for adults with learning disabilities and challenging behaviours. Within my work with the Community Team I gained experience of working as a clinical psychologist with individuals with learning disabilities who had been bereaved.

Whilst working with people with learning disabilities I have become acutely aware of the difficulties this group frequently encounter in making others hear their views and shaping their own lives. This has led to a developing interest in the ideas of advocacy and empowerment. This interest is likely to have had an impact on the choice of methodology, the development of the research and my understanding of the interviews. My interest in advocacy also influenced the way in which the results section was written. The voices of the participants were considered to be most

important and hence the results section is primarily made up of extracts of the interviews.

My training in clinical psychology and my interest in the research topic have also led me to read widely on the subject of bereavement. My knowledge of models of bereavement is likely to have influenced my interpretation of the transcripts.

Although my values, beliefs and knowledge base are recognised to have had a potential influence on the emerging themes, all themes were ensured to be well represented in the transcripts. As safe guards to credibility, the transcripts were also second analysed by other qualitative researchers, and participants were involved in validating the findings.

The final themes were also considered by three senior researchers. One of these researchers suggested the collapsing of the higher order theme 'Feelings' into the other higher order themes according to the causes of the feelings. However, this suggestion was not acted upon due to my belief that it was important to make explicit the normality of the feelings experienced by this group.

## **4 Discussion**

### **4.1 Overview of Study**

The aim of the research was to explore with people with learning disabilities their experiences of bereavement. Ten interviews were conducted with individuals who had been bereaved at some point within their memory, although not within the preceding six months. The interviews were analysed using Interpretative Phenomenological Analysis (IPA) and five higher order themes were identified that were thought to capture the essence of the content of the interviews. These themes were Loss, Feelings, Memories of the Time Around the Death, Recovery and Obstacles to Recovery.

### **4.2 Discussion of the Results**

What was striking about the participants was the normality of the internal experiences they described. Listening to their accounts of their bereavement, and later reading the transcripts, at times it was easy to forget that they had a learning disability. The internal experiences were the same as would be expected in any person who had been bereaved. Similarly, the ways in which people found comfort following the bereavement were no different from the ways people without disabilities find comfort. Also, some of the factors that were suggested by the participants to have complicated their grief have been noted in the generic literature. In many respects the experience of bereavement for people with learning disabilities did not appear to be significantly different to the experiences of bereavement people without learning disabilities.

However, there were some experiences that participants spoke about that are likely not to be described by bereaved people who do not have learning disabilities. These experiences were generally not internal but external, and largely dependent on the way in which the outside world had responded to them as a person with disabilities. It appeared the way learning disability has been constructed by society was creating extra barriers to recovery from bereavement for the participants. This distinction between experiences that the participants described that are likely to be found in any adult population, and the experiences that were dependent on the social understanding of learning disability will be used to structure the discussion of the results.

#### **4.2.1 Experiences of Bereavement Described by the Participants that are not Specific to People with Learning Disabilities**

##### **Feelings**

The feelings described by the participants in their interviews were no different to the emotions that are described by people without learning disabilities who have been bereaved. The participants described feelings of sadness, helplessness, shock, disbelief, fear and anger, and thoughts of why they had had to lose their loved one. These feelings could easily have come from a group of ten bereaved individuals who did not have learning disabilities. Balk and Vesta (1998) report a longitudinal case study of a young woman (who did not have learning disabilities) who had lost her father. In her diary she had used almost identical words to describe her feelings of yearning ('I really miss you') and fear ('I am afraid of the future somewhat') as the participants in this study. Feelings of anger and sadness were expressed by two thirds of bereaved non-learning disabled participants in Bonanno and Keltner's (1997)



study. And feelings of shock, helplessness and disbelief are commonly reported in the early stages of bereavement (Sanders, 1999; Kubler-Ross, 1969; Worden, 2002).

Although when the participants described their emotions their descriptions were very powerful, not all participants could easily describe how they had felt. This was initially considered to be significant and a hypothesis of the lack of emotional words in people's vocabularies was considered. However, further exploration of the generic literature revealed that retrospective studies of the emotional experiences of loss in people without learning disabilities had also come across a low level of description. Shuchter and Zisook (1993) reported less than 15% of their conjugally bereaved participants spoke about the emotions typically associated with bereavement. They considered it to be the retrospective nature of the study that had led to this result. In comparison to Schuchter and Zisook's (1993) participants, the participants in this study were in fact relatively expressive in their descriptions.

### **Expression of Emotion**

The way in which the participants expressed their emotions similarly did not differ to the channels of emotional expression used by people without disabilities. The participants had primarily expressed their sadness through crying. Crying has been said to have a dual function of relieving emotional stress (Worden, 2002) and eliciting support from others (Parkes, 1996). The participants in this study that spoke of the times at which they cried spoke of crying in private. For them the main function appeared to be of relieving emotional stress rather than attempting to obtain support or comfort.

Some of the participants talked about having difficulties describing the way they had felt in words and described the physical feelings they had experienced. These physical feelings were no different to the physical feelings reported by non-disabled

participants in other pieces of research. Two participants in this piece of research described feeling 'shivery' and 'shaky inside'. Parkes (1996) quotes one of the widows he spoke to as saying she felt 'ill and shivery'.

One of the participants who appeared to be very stuck in her grief and without emotional support from others spoke of physical ailments (such as aching legs). The failure to express emotions has been linked to somatization of symptoms (Mikulincer, Florian and Weller, 1993). It may be that this lady's somatic complaints were expressions of her grief and a way to show others that she was in pain.

### **Finding Comfort / Help in Recovery**

The ways in which the participants found comfort following the bereavements similarly was not different to the ways in which people without learning disabilities find comfort. Those who provided the most support for the participants during their grief were their families. Morland (2000) spoke of circles of support available to those who are bereaved. Her inner circle comprised of family. The most inner layer of support was provided by parents and children, then siblings, then grandparents and aunts and uncles. This was mirrored by the participants of this study who often appeared to rely on parents the most, and when parents were unavailable would look for support from siblings, aunts and uncles and cousins.

It appeared important for many of the participants in this study that they were able to share their grief with others who knew what they were going through. For some participants this was other family members who were also grieving from the same loss. Reminiscing about the deceased together was important for these participants. As Edelstein (1984) points out, in his discussion of bereavement in the generic population, help from others that knew the deceased is particularly important. He notes that only those who had known the deceased well could facilitate a review of the

events surrounding the death. Similarly, Walter (1996) suggests that the aim of grief is the construction of a biography of the deceased through talking to others who knew the person.

The participants in this research project described several things that had helped during their grief. They spoke of talking, crying, affection, time, medication and going out (or distraction). Again, these are all familiar ways of coping during grief. Some of the participants talked about different ways of coping being useful at different points. Talking in particular was recognised as being unhelpful too soon after the loss but useful later on in the mourning process. Other ways of coping (e.g. listening to loud music, going out, having quiet time alone) appeared to be used intermittently. This fits with Stroebe and Schut's (1999) Dual Process Model of coping with bereavement. They suggest that recovery from bereavement requires the use of two types of coping; loss-orientated and restoration-orientated. Loss-orientated coping includes undertaking the 'grief work' (accepting the reality of the loss, feeling the pain of the loss, relocating emotional energy, etc). Restoration-orientated coping includes attending to life changes, distraction and avoidance of the grief. Mourning involves oscillating between these two, so that the loss is processed but does not become overwhelming, and so that life can move on at the same time.

The beliefs that the participants held that they found comforting were not particularly unusual. Some spoke of believing their loved one was happy now, others spoke of feeling it would have been their wish that they carried on as best they could or continued their work by taking on their roles. Worden (2002) talks about the beliefs that the bereaved have about the wishes of the deceased, as an indicator of their movement through the final task of mourning. This reliance on acting in a manner that is thought to be in keeping with the loved one's wishes frequently gives way to an ability to act without making conscious reference to the deceased.

A belief in heaven was reported by most of the participants, and appeared to offer comfort to many of them. This is in keeping with Shuchter and Zisook's (1993) research in which the majority (82%) of their non-learning disabled conjugally bereaved sample reported feeling comforted by a sense that their spouse was in heaven. The concept of heaven was quite concrete for many of the participants in this study. However, this also does not appear to be particular to a sample of people with learning disabilities. Marrone (1999) describe a general tendency for people with traditional religious beliefs to speak of heaven in a relatively concrete way as a place where their departed loved one has gone.

One woman who took part in the research spoke about a belief in angels and a feeling that her father was still present in the form of an angel. She spoke about seeing him sat on the end of her bed and sometimes speaking to him. It is easy to see how such a belief may be construed as a symptom of pathological grief, yet again this kind of experience is not unusual in the generic population. There are many accounts of hallucinations of the deceased, particularly when the bereaved is in a hypnagogic state (Parkes, 1996). Some writers have suggested that these types of hallucinations normally only occur in the first year or two of mourning (Littlewood, 1992), however, Rees (1971) found that a sense of presence, or visual, auditory or tactile hallucinations were experienced by almost half of his sample for several years. The words used by a participant in Golsworthy and Coyle's (1999) study of older adults following partner loss were remarkably similar to the words of the lady who believed in angels. He said, 'I kind of talk to her as though she's here, I look to her for guidance.'

### **Remembrance**

Many of the participants spoke of remembrance of the deceased, either through the use of memories, photos or possessions. Klass (2001), in discussion of his work with

bereaved parents, talks of the inner representations bereaved people hold of their deceased and the ways in which these offer solace. He discusses how, whilst traditional grief theories suggested the emotional bond with the deceased needed to be broken in order for recovery to occur, it has become clear that the emotional attachment does not need to be destroyed but relocated as an inner representation in a different form. In this way the memory of the deceased lives and the attachment remains, yet the bereaved is able to reinvest emotional energy into other relationships also. He described three common ways in which the bereaved parents he worked with maintained a relationship to their dead children; linking objects (for example in treasuring toys that were special to the child), religious ideas (for example a belief in heaven and the possibility of being reunited one day) and memory. It appears the participants in this study also used their beliefs in heaven, memories and linking objects (in the form of photos or inherited possessions) to maintain their relationship to the deceased. It may also be suggested that the participant who believed her dad to still be with her in the form of an angel was maintaining her relationship with him in this way. Her inner representation of her father, for her, took the form of a sense of presence and a belief in angels.

### **Complicating Factors**

The manner in which the deceased had died appeared to complicate the mourning process for two of the participants. One the participant's mother had committed suicide and another participant's mother had died from a heart attack that the participant believed could have been prevented. The difficulty they encountered is in keeping with the findings of many researchers and clinicians. Preventable deaths and traumatic deaths (Gamino, et al., 2000), unexpected deaths (Parkes and Weiss, 1983)

and suicides (Kallish, 1985) have often been found to be related to complicated bereavements.

### **Difficult Times**

Almost all participants made reference to Christmas as being a difficult time. It was a time for many when the deceased was remembered and when they were most missed. Within the generic literature it is noted that significant dates can cause grief to re-emerge. Bright (1996) suggests dates such as birthdays and the anniversary of the death can be particularly significant for the bereaved or times when the deceased's absence is keenly felt. For the participants of this study Christmas appeared to be the time when the deceased was missed most greatly.

#### **4.2.2 The Social Model of Disability and Experiences Around the Time of Bereavement**

In section 1.4 the social model of disability was discussed. This model locates disability not within the individual but within the interaction between the individual and the outside world. The individual's impairments need not necessarily lead to disability, but the combination of the impairment and an unfacilitating environment and/or the lack of support can result in disability. It appeared there were several elements of the experiences of bereavement the participants described that were more likely to be found amongst a sample of learning-disabled individuals rather than in the generic population. These experiences did not appear to be due to the individual's impairments but due to the way the social world reacted to the individual because of their impairment. These experiences will be discussed below.

## **Events Surrounding the Death**

The participants had very clear memories of the events that happened around the time of the death. Some of the participants were not allowed to visit their sick relative before they died. One of the participants had nursed their sick mother but had then been excluded from the final decisions made about medical care. All the participants could remember the words that had been used by others when they had been told of the death or what it had been like when they discovered the body. None of the participants spoke about being involved in the organising of the funeral, but most of the participants remembered having made the decision of whether or not to attend the funeral themselves. However, some appeared to have been given limited help in making that decision. Few of the participants had been back to the cemetery since the funeral. It was apparent that the participants had had different experiences of the time around the death to the majority of the population due to the way others reacted towards them because of their learning disability.

## ***Exclusion during the Illness***

As was discussed in the introduction, many researchers have written about the way in which people with the learning disabilities are often excluded during the time around the death. Hollins and Esterhuyzen (1997) found that most of the individuals who took part in their study had not been helped to say goodbye to their dying relative. They felt this was mostly due to the belief of carers that for the individual to see their ill relative would be too upsetting. It appears this may have also been the case for the participants in this study. However, in denying people this opportunity to say goodbye carers are denying the individual the opportunity to develop a greater understanding of what causes death (Strachan, 1981), the chance to begin preparing themselves for the loss (McLoughlin, 1986) and the ability to see how others deal with the sadness associated with the loss (Hollins and Esterhuyzen, 1997). One of the participants in

this study, who had been in respite care during her dad's illness, implied that she had not known how to react to her dad's death and had watched her aunt's behaviour for cues. If she had been given the opportunity to be involved when her dad was in hospital she may have had a greater chance to learn about the death and the associated feelings and expressions of emotion.

### ***Hearing the News***

The exact way the participants could remember how they were told of their relatives death indicates just how important it is that this task is done well. Some of the participants did not appear to have any difficulties in understanding the meaning of what was said to them, but one participant in particular appeared to have been given quite a confused message about what had happened to her father. As James (1995) discusses, euphemisms may be used by people when they are breaking the news of a death due to the taboo nature of the subject of death. However, the use of euphemisms can be confusing for some people who have a limited understanding of death or for those people who have a tendency towards concrete rather than abstract thought. One participant in the study was told the news of her father's death by her mother and aunt. It appears they struggled with knowing how to break the news and although they did explain he had died from a heart attack she was left with some slightly confused ideas about heaven being upstairs.

### ***Attending the Funeral***

Six of the ten participants in this piece of research attended the funeral of their relative. This figure is close to that found in Hollins and Esterhuyzen's (1997) research, in which 27 of their 50 participants attended. Although some of the participants had found the service upsetting, none regretted having attended. Two participants were prevented from attending by their relatives and two participants decided they did not want to attend. One of these participants later decided she wanted



to see her father's body but she made the decision too late and missed the opportunity. This highlights the need for people to be given time and help in making decisions, and being given choices. The other participant did not regret having not attended but did speak of the help he felt he had received at a family get together for a wedding not long after. Many of the participants who attended the funeral spoke of the importance of having all the family around. This fits with the wide spread belief that funerals provide a valuable source of social support (Littlewood, 1992). Other important aspects of the funeral are the chance it provides to say goodbye to the deceased, and the help it provides for people in taking in the reality of the loss and making sense of the loss (Weeks, 1995; Dursten, 1998). If individuals chose not to attend the funeral it may be helpful if other opportunities are provided to help them say goodbye, take in the reality and make sense of their loss.

### ***Organising the Funeral***

Whilst most of the participants were given the choice of whether or not to attend the funeral, none of them spoke of being involved in the arrangement of the service. This is despite all of the participants being close family members, if not next of kin, to the deceased. This is in keeping with the results of Raji and Hollins (2003) study in which very few funeral directors had had contact with people with learning disabilities. It is unfortunate in some respects that people with learning disabilities are being considered by many to be incapable or uninterested in helping with the arrangements. It has been suggested that the sorting out of the practical arrangements can provide a good opportunity for active coping following a loss (Gamino et al., 2000a). One participant in this study said very clearly that she felt she was not given a chance to make any of the arrangements despite having lived alone with her mother for many years. She wished she'd been given the chance to 'stand on her own two feet'. By enabling people to be involved in making the funeral arrangements the feelings of

helplessness and powerlessness that frequently occur during grief (Bright, 1996) may be reduced.

### ***Visiting the Cemetery***

Few of the participants had visited the cemetery since the funeral. Some of the participants expressed a wish to visit the cemetery but either lacked the ability to get there or did not know where their relative was buried. Visiting the grave can be useful in helping people understand where their loved one has gone (Sheldon, 1998) and can also be a way of helping people mark special dates such as anniversaries and Christmas.

### **Understanding of Death**

Some of the participants who took part in the research appeared a little confused about what causes death and what happens after death. Some of the participants appeared unsure as to what had caused their relative's death, and one participant in particular appeared to be struggling to understand what causes death in a more general way.

This same participant had very clear, and quite frightening memories of the earth being filled in over his father's coffin. Seeing the burial may have been frightening for this participant if his understanding of death was not very well developed.

As was discussed in the introduction, a difficulty understanding the concept of death may cause a person's mourning to be more difficult. In order to work through Worden's (2002) first task of mourning the individual must be able to accept the reality of the loss. This may be made more difficult if the concept of death is not fully understood (McLoughlin, 1986). Whilst the stage of cognitive development has a bearing on the understanding of death (Bihm and Elliot, 1982), this is dependent on opportunities to learn about death. In a society where death is a taboo subject and

those who are seen as vulnerable are often shielded from such unpleasantness, there may be few opportunities for individuals to learn about death (see Strachan, 1981).

## **Support**

As was mentioned above most of the participants cited their family as the greatest source of support following the death of their relative and this is the source of support most people with or without a disability rely on most heavily following bereavement. However, the next source of support suggested by Moreland (2000) is typically provided by friends. This level of support appeared to be missing for all but two of the participants. It appeared the participants had very few people in their lives they considered to be friends. The outer ring of support suggested by Moreland (2000) is provided by professionals. Some of the participants did mention staff at the residential homes or day centres, or their GP as someone they could talk to. However, the number of people cited as having helped appeared very small in comparison to the large number of people involved in supporting the individuals that were encountered in obtaining consent for the individuals to be involved in the research. It appeared the number of people supporting was disproportionate to the level of support the individuals felt they had had following the bereavement. This may be an indicator of the difficulties carers may have in discussing death, possibly due to their own embarrassment or fears about death (Emerson, 1977). There may also be an issue of everybody expecting (or hoping) that somebody else is supporting the individual. Oswin's (1991) work suggests that this sometimes occurred in large institutions where the responsibility for breaking the news of a death was sometimes assumed by everybody to belong to somebody else, leaving the individual with nobody. Although many of the participants felt that they wanted support from their families rather than anybody else, often the very person they needed support from was also

grieving. Many spoke of their carer's upset when they tried to discuss the loss and one individual even said he felt he shouldn't talk about it so as to not upset his family. It appears that whilst at times it is important to be able to share grief with others who knew the deceased (Edelstein, 1984; Walter, 1996), at other times the family may feel overwhelmed by the loss and outside support might also be needed. This is when the large supporting networks that typically surround people with learning disabilities could provide much support.

One of the issues identified by the participants was one of all-or-nothing support. Two participants spoke of other people's help being intrusive. Whilst they felt they needed some support, they had both been very independent and did not require somebody to take over completely. This appeared to make them feel even more powerless. The supporters may have been well meaning in their actions but the experience of the participants illustrates how important it is to enable others to take control and manage their own affairs and their own grief, rather than taking control away. Support needs to be offered in the way it is felt it is required by the bereaved individual (Bright, 1996).

### **Multiple Losses**

Oswin (1991) and Hollins and Esterhuyzen (1997) have both written of the way in which many people with learning disabilities lose not only their loved one following their parent's death but also their home, their possessions and everything else that is familiar to them. Four of the participants in this study left their family home following the death of their relative. The participants did not welcome the move and they generally seemed to have had little involvement in the arrangements. The move appeared to also be associated with the loss of possessions and mementos of the deceased and, for one lady, pets. The move away from the place that held memories

of the deceased was painful for the participants. One lady who had found the move particularly difficult had in fact lived alone in her mother's house for quite some time following the death. However, this did not make the eventual move away any easier. This appeared to be as the move was still perceived to be out of her control. This indicates that whilst simultaneous losses are very difficult, a time lag is not necessarily helpful if the feelings of powerlessness are still intense.

The loss of home and possessions occurred for individuals who had lost their remaining parent. However, individuals who had some family remaining also suffered from further losses. One individual had suffered the loss of his sisters following his mother's death. He knew that they had moved into a bungalow but did not know why they had moved out and he had stayed with his dad, or where they were now. This obviously made the sense of loss greater. Clearly simultaneous losses can also occur for those who are able to continue living in their house with a member of their family. It is hard to imagine that these losses could occur in this manner for people without learning disabilities. For a move of house to be organised by others, without your consent, to be denied taking more than a few possessions with you, or for you to lose your sisters without any explanation, are experiences that most of us would not normally have to endure. Why then is it that these are experiences that people with learning disabilities so frequently appear to encounter? It appears the assumptions of society that people with learning disabilities have an inherent inability to manage their own lives effects the decision making process of those who care for them. It also appears that the emotions of people with learning disabilities continue to be denied.

### **Gradual Loss of Family**

The interviews taken together appeared to show a pattern of gradual loss of family leading to feelings of loneliness and a reliance on paid staff. It appeared that many of

the participants had once lived with their entire family, but had slowly lost one family member after another. Their grandparents had died and their siblings had moved away. Many of the participants had lost one of their parents and some had lost both. Whilst many of the participants had siblings, the responsibility of care did not seem to be assumed by siblings. Once the older generation of the family had been lost there appeared to be a tendency for the individual to go to live in residential services. There was a sense that all the participants were somewhere along this process of a gradual loss of family.

Many of the participants had either lived with or were currently living with their one remaining parent (or parent's sibling). This relationship with their primary carer appeared to be characterised by high dependency and social isolation. All care and all social activities seemed to be organised through this one carer. Where the bereavement we were speaking about was the death of this carer, the loss was much greater for the individual. As was discussed above this is partly because of the multiple simultaneous losses that occurred. However, it also appeared to be more difficult as the deceased had also acted as the individual's primary advocate. Whilst they had been alive they had facilitated all the individual's activities and had always ensured any decisions made were in their best interests. Following their death decisions appeared to be made by an assortment of other people, none of who knew the individual as well as the deceased had, without much consultation with the individual. Those individuals who had been without their family for some time appeared to have drifted from one residential home to another with no one person overseeing their care, or acting as an advocate. There appeared to be nobody making long-term decisions for the individual, and there was little sense of continuity of care. Without their primary carer/advocate the individuals appeared to be lacking the means to control how their care was provided for them. For some of the participants this left

them feeling either alone and unsupported or stifled by intrusive help. This fits with the findings of other disability researchers of the tendency for people to feel oppressed by imposed care (see Oliver, 1996).

During the time the individual had lived with their one carer there also did not seem to be a need for that individual to develop deep emotional relationships with others.

Their carer acted as their confidante and they facilitated all contact with the outside world. There is a sense from the interviews that those individuals who had been through this process of a loss of family and, at the time of the interviews, were living in residential care were greatly disadvantaged. One lady appeared to be particularly stuck in her grief, despite her mother having died 33 years previously. She appeared particularly lonely although being surrounded by paid carers and other residents. I felt that in many ways she had not been able to complete Worden's (2002) fourth task of mourning of emotionally relocating the deceased to be able to reinvest in new relationships. I felt that she had previously not had any other emotionally significant relationships and had found it difficult to build such relationships in the residential home when she moved there at the age of 59. Neither relationships with paid staff nor other residents appeared to be emotionally invested in.

For other older adults who do not have learning disabilities the loss of parent may be difficult but often it is the younger generations, their children and grandchildren, or friendships or romantic relationships that they reinvest their emotional energy in. For many people with learning disabilities there is not a younger generation to invest in and attitudes towards relationships between residents in care settings are often mixed, making the building of significant romantic relationships difficult.

### **4.3 Conclusion of Results**

The five major themes that were drawn from the interviews with the bereaved participants were Loss, Feelings, Memories of Time Around Death, Recovery, and Obstacles to Recovery. These themes may well have been drawn out of interviews with a group of any ten adults who had been bereaved regardless of level of cognitive ability. In particular, the internal experiences of bereavement were certainly no different for the bereaved participants in this study in comparison to the internal experiences that have been reported by bereaved people who do not have learning disabilities. Similarly, the participants reported many of the complicating factors and many of the ways of coping described by non-learning disabled people. However, there were experiences described by these participants that appeared to be particular to this group of people. These experiences were not directly due to their learning disability but due to the way they were responded to by others and the general beliefs society holds about learning disability.

### **4.4 Study Limitations**

The primary limitation of this study may be considered to be the necessary restriction of participation to only those with a high verbal ability. By limiting the study to those people with high verbal abilities the experiences of a whole section of the population of people with learning disabilities, perhaps the most vulnerable, were not heard about. As was discussed in the method this does not invalidate the findings. The experiences of the more able may well be representative of many others, however, this cannot be assumed.



There is an inherent difficulty with qualitative research with regards to generalisability. As only a small sample of people take part in the research their experiences may not be considered to be generalisable to others. However, the lack of research that has explored the experiences of bereavement for people with learning disabilities had left a gap in our understanding that could only be filled with a less generalisable but more in depth study of people's experiences.

As Groce points out, 'No one person's life can be wholly representative of an entire group, for each individual is unique. Yet I feel that a detailed examination of one life may provide insight into the larger question of how mentally retarded individuals are perceived in societies' (Groce, 1992, 175).

A further limitation of the study is related to the sampling and recruitment methods used. Recruiting participants to the study proved to be far more difficult than expected. For example, in one of the resource centres where 96 people regularly attended, the team leader initially estimated that a large percentage had experienced bereavement and that of that group there would be perhaps over twenty people who would have the verbal abilities to take part in the research. However, project workers, carers and families were very reluctant to allow the researcher to approach the individuals about the study. From the 96 individuals attending this centre consent was obtained from carers to speak to two individuals about the research. Across the entire area, around 530 individuals with learning disabilities attend resource centres, and perhaps a conservative estimate may be that one third of these individuals have experienced a bereavement. However, only 12 individuals had care networks that allowed me to approach them to introduce the research.

Carers who denied consent frequently did so on the basis that they felt speaking about the loss would 'open up old wounds'. There appears to be an assumption by many that

if an issue is not spoken about it is forgotten and cannot affect an individual.

However, many of the individuals who did take part in the study said very clearly that they had enjoyed speaking about their loss and felt that talking was one of the main ways they had got through the bereavement. The difficulties I experienced in gaining consent to speak to individuals may be an indicator of the difficulties individuals with learning disabilities sometimes experience in trying to talk to carers about their grief. It may be suggested that in some instances the supporting networks appear to be behaving in an overprotective manner towards the individual rather than enabling them to make their own choices.

Bearing in mind the apparent tendency of carers to air on the side of caution, it may be suggested that the individuals that were eventually allowed to take part in the research were a group that carers considered to have very few remaining emotional difficulties in relation to the loss. The difficulties these individuals described in the interviews may then be taken as almost the 'tip of the iceberg'. We may conclude that for those who were not able to take part due to the concern of their carers, there may have been more complicating factors involved in their grief.

There was also a potential difficulty within the study due to the retrospective nature of the interviews. Whilst most participants had very clear memories of the deceased and of events surrounding the death, memories of feelings appeared to be less strong. As was discussed above this does not appear to be a difficulty specific to learning disability (see Shuchter and Zisook, 1993), however it does suggest that the exact nature of the feelings associated with bereavement may be best assessed whilst the person is still grieving.

#### 4.5 Clinical Implications

The finding that the internal experiences for people with learning disability are the same as for any other group of adults clearly has implications for the interventions that may be implemented when it is felt an individual requires help during their grief. Previously, the behavioural manifestations of grief reactions were often seen in isolation from the feelings people were experiencing following a loss. This was often as the behaviour was not perceived by carers to be connected to the loss but considered to be due to the cognitive impairment (Strachan, 1981; Emerson, 1977; Hollins and Esterhuyzen, 1987). As a result interventions were frequently behavioural in nature with the aim of reducing what was perceived as problem behaviour. Whilst past research has failed to explore the internal experiences of bereavement for people with learning disabilities this piece of research shows that the feelings that the participants felt were no different from any other population. Any interventions should therefore be aimed at helping individuals work through their grief rather than aiming at reducing symptomology. The results of this research indicate that people with learning disabilities feel the same internal emotions following loss, and that many of the same complicating factors and protective factors written about in the generic literature apply. This indicates theories of grief and bereavement based on the generic population may well be applied usefully in helping people with learning disabilities work through their grief.

Many of the participants suggested they had found speaking to other people who knew what they were going through as important in their recovery from the loss. Support groups have been found to be a useful way of facilitating grief work in many

other populations (Worden, 2002) and it seems they may also be a useful for people with learning disabilities.

Despite much of the generic literature being relevant to people with learning disabilities the research has indicated there are some further complicating factors for people with learning disabilities following bereavement due to the social construction of learning disability. For example, the disempowerment of people with learning disability around the time of the death clearly places them in a disadvantaged position in recovering from their grief and occurs due to the way society responds to people with learning disabilities. Feelings of helplessness and powerlessness are common in grief and can cause complications in recovery from bereavement. People with learning disabilities who are made even more powerless around the time of the death may experience increased difficulties. There appears to be a need for individuals to be empowered by support to be involved in an active way during the illness and in the funeral, and in making decisions about their own life following the death.

There were indications from the results of the study that despite there being large support networks in place for individuals with learning disabilities, individuals often felt the only source of support was family. Family are a very important source of support but there were clearly times when outside support may also have been helpful. The reasons why support from outside was not perceived to be useful/available needs to be further researched. Murray, McKenzie and Quigley's (2000) research suggests that knowledge about bereavement issues within health and social care staff working with people with learning disabilities is high, but confidence in dealing with a grieving individual is not so high. It may be that lack of knowledge does not play such a large part in the difficulties staff have in supporting but that the societal taboos are

more influential. If this is the case the taboo nature of the subject of death, loss and learning disability needs to be addressed.

One of the major disadvantages for many of the participants following their loss appeared to be their lack of multiple social roles. Hershberger and Walsh (1990) suggested that multiple social roles acted as a protective factor for bereaved individuals. This may have been due to the provision of numerous sources of support. The majority of the participants in this study appeared to have lived rather dependent isolated lives with a primary carer. The loss of this one role (dependent child) was quite catastrophic. If families were enabled to help their disabled child to live more independent lives from an earlier age they may be able to develop various social roles and a wider variety of social supports that would act as a protective factor following the loss of their primary carer.

Within the generic literature some researchers have found religious beliefs to help people through the grieving process and in the search for meaning after a loss (see Glosworthy and Coyle, 1999). Within this study the belief in heaven brought comfort to many of the participants, however, the majority of the participants did not speak in any depth about religious beliefs. Religion serves the same functions for people with learning disabilities as it does for anyone else, but people with learning disabilities may require help to be involved in religious groups (Hoeksema, 1995). The facilitating of involvement in religion may be beneficial for some individuals, particularly during their grief.

#### **4.5.1 The Role of the Clinical Psychologist**

It appears it is important for the experience of bereavement for individuals with learning disabilities to be normalised in many ways. Therefore, it may be important for the clinical psychologist working in this field to be careful not to pathologise grief. However, it does appear that the support systems that are already in place around many people with learning disabilities may need help and support themselves in normalising the individual's grief and helping empower the individual during the bereavement. Clinical psychologists working with community teams may have a role in helping carers support individuals through their grief and empower them around the time of the bereavement.

It also appears some individuals may benefit from taking part in support groups where they can speak to other individuals who have been bereaved. This may help normalise the experience for some individuals. These support groups may be best run by the bereaved individuals themselves, and need not be facilitated by a clinical psychologist. However, there may be a role for clinical psychology in providing support to the group if they so request.

Finally, clinical psychologists may have a role in providing individual therapeutic input for individuals who have been bereaved where their grief becomes complicated.

#### **4.6 Evaluations of the Research**

Throughout the design and the implementation of the research Elliot et al's (1999) guidelines for the publication of qualitative research were considered.

Elliot et al (1999) suggested 14 guidelines upon which to judge the quality of qualitative research. The first seven relate to both qualitative and quantitative

research, the final seven relate specifically to qualitative research. The 14 guidelines will be considered in turn.

**Guidelines shared by both qualitative and quantitative approaches;**

- 1) *Explicit scientific context and purpose* – The research project considered the current understanding of the topic area and limitations of previous research. A gap in the literature was identified and the research project had a stated aim.
- 2) *Appropriate methods* – The qualitative methodology, the use of semi-structured interviewing and the implementation of IPA were considered to be most fitting given the identified gap in the literature and the stated aim of the research project.
- 3) *Respect for the participants* – Informed consent was considered to be particularly important within this group of individuals. The nature of the research project was explained carefully and consent was obtained from the individual who was taking part as well as from their carer. All participants were clear that they could terminate their participation at any point and one participant did chose to terminate their interview. All information was considered confidential and participants understood the ways in which information would be made anonymous in the final write up. The research aimed to include the participants actively in the research process. Participants were involved in credibility checks, feedback was provided to all participants and the participants were involved in deciding how the results of the research should be disseminated.
- 4) *Specification of methods* – Detailed descriptions of questionnaire design, and the procedures involved in interviewing and analysis were described in the method section.
- 5) *Appropriate discussion* – The discussion includes a consideration of how the results of the study fit within the current understandings of bereavement in the

literature, discussion of the limitations of the study and the clinical/practical implications.

6) *Clarity of presentation* – Efforts were made to present the research in a clear format with an accessible writing style.

7) *Contribution of knowledge* – The research contributes significantly to the current understanding of bereavement experiences for people with learning disability.

### **Guidelines especially pertinent to qualitative approaches;**

1) *Owning one's perspective* – The researcher's understanding of disability and bereavement were made clear to the reader in the introduction and the researcher's beliefs and values, and reflections on the research process were discussed in the results section. In this way the reader is able to judge for themselves the impact the researcher's beliefs on the development of the research project and their understandings of the results.

2) *Situating the sample* – The participants and their life circumstances were described in detail in the method section in order to aid the reader's understanding of the areas in which the research findings may be relevant.

3) *Grounding in examples* – The results section provided numerous quotes from the interviews to enable the reader to judge for themselves the fit between the raw data and the researcher's interpretations.

4) *Providing credibility checks* – All interview transcripts were second analysed and participants were involved in participant validation.

5) *Coherence* – The results of the study were presented in a way that allowed the reader to understand how the content of the interviews and the meaning that was drawn from them was understood by the researcher.



6) *Accomplishing general vs. specific research tasks* – Limitations of the generalisability of the research findings were discussed.

7) *Resonating with the reader* – Whether or not the research is in keeping with this guideline is for the reader to decide. However, those who have been involved in proof reading have indicated that the write-up has expanded their understanding and appreciation of the subject.

#### **4.7 Further Research**

The aim of this piece of research was to explore with individuals with learning disabilities their experiences of bereavement. In doing so other research questions have come to mind that would be valuable to explore.

Firstly, there was an indication in the results that the individuals who appeared to be struggling to resolve their grief were the individuals who had lost most of their family. It was suggested that this may be related to a difficulty in working through the final task of mourning; emotionally relocating the deceased to allow investment in new relationships. This may be worth exploring further.

Further to this it may be useful to explore all the tasks of mourning for people with learning disability to establish which tasks of grieving are most difficult. This may enable support to be provided at the right points for grieving individuals.

Secondly, it appeared that there was a discrepancy between the size of support systems in place for individuals and the perceived support felt by those who were grieving. It could not be said from the results of this study why this might have been the case. Investigation of the possible discrepancy between perceived support and

support available would be interesting. If a discrepancy is found, understanding the cause of this discrepancy may help the implementation of services in the future.

Finally, the current study was restricted to only those individuals who had good verbal skills. This was felt necessary given the time restraints and the lack of previous research exploring the inner experiences of bereavement for people with learning disabilities. The results of this research suggest the inner experiences do not differ with degree of cognitive ability and indicate extra difficulties experienced by people with learning disabilities are significant, even for those people with relatively mild learning disabilities. It may therefore be interesting to develop more creative ways of exploring the experiences of less verbally able people.

*'She was quite alone. But not alone. She was the same person, Ruth Bryce. But not the same. She loved Ben, and wanted him, and still did not know how she might live for the rest of her life. But Ben was dead, and laid in his grave, and she would move on, from one day to the next. There was winter. There would be spring.'*

Susan Hill, *In the Springtime of the Year*

*'It is drizzling and empty and silent; but then I see a robin, and the robin sees me, yet does not fly away; and as I listen to his voice, sweet enough to pierce the sky, it feels as if the whole park is suddenly filled with birdsong; and a strange, pure, miraculous joy rises from the muddy trodden grass like steam, like somebody else's breath. Life is fragile, impossible... and all we can do is to cherish it.'*

Justine Picardie, *If the Spirit Moves You*

*'It's been hard for us all, and we have hard times and good times, but can get over it'*

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## 5 Appendices

- Appendix 1 - Interview Schedule
- Appendix 2 - Information Sheet for Key-Workers
- Appendix 3 - Consent Letter used by Resource Centre
- Appendix 4 - Information Sheet for Participants
- Appendix 5 - Consent Forms
- Appendix 6 - Letter from Local Research Ethics Committee

## **Appendix 1**

## Interview Schedule

### Experiences of loss and bereavement - When someone close to you dies

#### (A) Relationship to deceased

1. \_\_\_\_\_ has told me your \_\_\_\_\_ died last year/a while ago. What do you remember about them?

Prompt - Can you describe them to me?

Prompt - Have you got any photographs of \_\_\_\_\_?

Prompt - What did you enjoy doing with them most?

Prompt - Was there anything special you did with them?

Prompt - Where did they live?

#### (B) The death

2. What do you remember about the time before \_\_\_\_\_ died?

Prompt - Were they in hospital?

Prompt - Did you visit them?

Prompt - Did you know they were going to die?

Prompt - What was that like? /How did you feel?

3. What happened after \_\_\_\_\_ died?

Prompt - Who told you \_\_\_\_\_ had died?

Prompt - How did you feel?

Prompt - Was there a funeral?

Prompt - Did you go to the funeral?

Prompt - What was it like?

Prompt - Who else was there?

Prompt - What happened after the funeral?

#### (C) Life since the bereavement

4. How is life different since \_\_\_\_\_ died?

Prompt - Did you move house?

Prompt - Did you have to do more things round the house?

5. What do you miss most now that \_\_\_\_\_ has died?

Prompt - company, talking to them, the house you used to live in, pets you used to have, etc (depending on what changed for them after death)

#### (D) Coping (to be spoken about throughout interview)

6. When someone dies it is very sad. What helped you feel less sad?

Prompt - Was there anything else that helped you in other ways?

7. Did anybody help you feel better? How did they help?

Prompt - Who looked after you when \_\_\_\_\_ died?

Prompt - Did you talk to anybody about feeling sad?

8. How do you think of \_\_\_\_\_ now? Where do you think they are?

#### (E) Has anything been missed

9. Is there anything else about when \_\_\_\_\_ died that you would like to tell me about?

#### (F) Positives and looking towards the future

10. (Researcher picks out some positives from the interview, i.e. healthy coping mechanisms, etc.)

11. (Chat about plans for the future, i.e. are you going on holiday this year? Etc.)

## **Appendix 2**

## Information Sheet for Support Staff

### The experience of bereavement in individuals with learning disabilities

I am a trainee clinical psychologist based at the University of Hull. As part of my training I am conducting a research study into the experiences of loss and bereavement in individuals who have a learning disability.

I would be very grateful if you would take the time to read the following information and decide whether you would consider any of your service users to be suitable to take part.

If there is anything that is not clear or if you would like further information, please do not hesitate to contact me.

#### What is the purpose of this study?

The aim of the study is to learn from those with a learning disability how they experienced bereavement. There is little literature published in this area, and of the available literature there are no reports written from the individuals point of view. I intend to talk to individuals who have suffered a bereavement in the past to establish; what the important issues were for them, what they found most difficult in coming to terms with the death, what they found helped them most during their period of grieving, and what they would have liked to have been different.

#### What does the research involve?

I am hoping to interview 15 individuals with learning disabilities who have been bereaved of someone they were close to (i.e. parent, sibling, friend). The bereavement may have occurred at any time in the past but must have occurred more than 6 months ago. The individuals must have good verbal abilities.

I am hoping to interview each individual who takes part in the research once or twice, with each interview lasting no longer than 45 minutes. The interviews will take place in their normal place of residence or at their day centre.

#### It is your choice whether or not you nominate any of your service users to take part.

Taking part in the research is voluntary. You may choose whether or not to nominate any of your service users for the research and the service users are also free to choose if they would like to take part. During the period of the research participants are also free to withdraw at any time.

All participants will be given a participant's version of this information sheet and signed consent form to keep.

#### Will the information gathered be confidential?

All the information gathered from the participants will be confidential. Their names and all identifying information will be removed from the written up study.

#### What will happen to the gathered information?

The results of the research will be written up as a part of my doctoral thesis and submitted as part of my course. I will also feedback my findings to all those who were involved in the research.



THE UNIVERSITY OF HULL  
DEPARTMENT OF CLINICAL PSYCHOLOGY

SCHOOL OF MEDICINE • HULL HU6 7RX • UNITED KINGDOM  
TELEPHONE 01482 465933 • FACSIMILE 01482 466155 • E-MAIL B.J.Leak@hull.ac.uk

What should you do if you would like to nominate one of your service users to take part in the study?

I am hoping to recruit individuals who have a learning disability who;

- Have memories of a bereavement that happened at any time in the past, as long as it was more than 6 months ago
- Have good verbal abilities
- Would be happy to talk to the researcher about their experiences
- You predict will not become overly distressed by speaking about their experiences

If you feel any of your service users fit this description and you are happy for them to take part in the research, I would be very grateful if you could contact me on 01482 869314. I will then visit the individual and their main carer or relative to invite them to take part in the research. They are free to choose whether or not to take part.

If you would like any further information or would like to talk to me in person about the research, please do not hesitate to contact me. My phone number is 01482 869314. Thank you for taking the time to read this information sheet.

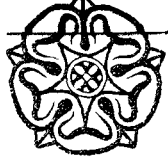
Yours Sincerely,

Alexandra Hamlin



## **Appendix 3**





# EAST RIDING

OF YORKSHIRE COUNCIL

Social Services Priory View Centre Marton Road Bridlington East Riding of Yorkshire YO16 7AL  
Telephone 01262 602477 Facsimile 01262 602477

Joan Rawdon Head of Care

20 September 02

Ref: KH/jp

Dear Parent/Carer

We have been approached by Alexandra Hamlin, (trainee clinical psychologist) to undertake a piece of research. Her research study will examine how people with learning disability have responded to personal loss and bereavement.

..... has been identified as a person who may contribute/benefit from this research study. I attach a copy of Alexandra's information sheet for carers which I would urge you to read.

Would you please complete and return the tear off slip below at your earliest convenience.

Yours sincerely

Kevin Holder  
Team Leader

.....

Student .....

I am happy\*/not happy\* for ..... to be involved in the research study to be carried out by Alexandra Hamlin.

Signed ..... (Carer/Parent)

\* Delete as appropriate.



~~Lonny Hunter~~ Director of Social Services Housing and Public Protection

## Information Sheet for Carers

### **The experience of bereavement in individuals with learning disabilities**

I am a trainee clinical psychologist based at the University of Hull. As part of my training I am conducting a research study into the experiences of loss and bereavement in individuals who have a learning disability.

As you will know I have contacted your local day centre and they have identified you as a carer of someone who has been bereaved.

I would be very grateful if you would take the time to read the following information and decide whether you would consider allowing the person you care for to take part in the study.

If there is anything that is not clear or if you would like further information, please do not hesitate to contact me.

#### **What is the purpose of this study?**

The aim of the study is to learn from those with a learning disability how they experienced bereavement. Little research has been done in this area before, and there are no reports written from the individual's point of view.

I intend to talk with individuals who have suffered a bereavement in the past to establish; what were the important issues for them, what did they find most difficult in coming to terms with the death, what did they find helped them most during their period of grieving, and what would they have liked to have been different.

#### **What does the research involve?**

I am hoping to interview 15 individuals with learning disabilities who have been bereaved of someone they were close to (i.e. parent, sibling, friend). The bereavement may have occurred at any time in the past but must have occurred more than 6 months ago. The individuals must have good verbal abilities.

I am hoping to interview each individual who takes part in the research once or twice, with each interview lasting no longer than 45 minutes. The interviews will take place in their day centre.

#### **The research is voluntary**

Taking part in the research is voluntary. You may choose whether or not you are happy for the person in your care to take part in the research and the individuals with learning disability are also free to choose if they would like to take part. During the period of the research participants are also free to withdraw at any time.

All participants will be given a participant's version of this information sheet and signed consent form to keep.

#### **Will the information gathered be confidential?**

All the information gathered from the participants will be confidential. Their names and all identifying information will be removed from the written up study.



THE UNIVERSITY OF HULL  
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What will happen to the gathered information?

The results of the research will be written up and submitted as part of my course. I will also feedback my findings to all those who were involved in the research.

What should you do if you are happy for the person in your care to take part in the study?

I am hoping to recruit individuals who have a learning disability who;

- Have memories of a bereavement that happened at any time in the past, as long as it was more than 6 months ago
- Have good verbal abilities
- Would be happy to talk to the researcher about their experiences
- You predict will not become overly distressed by speaking about their experiences

If you feel the person in your care fit this description and you are happy for them to take part in the research, I would be very grateful if you could contact me on 01482 869314. I will then visit the individual to invite them to take part in the research. They are free to choose whether or not to take part.

If you would like any further information or would like to talk to me in person about the research, please do not hesitate to contact me. My phone number is 01482 869314. Thank you for taking the time to read this information sheet.

Yours Sincerely,

Alexandra Hamlin



## **Appendix 4**

## Information sheet

### Your experience of when someone you knew died.

My name is Alex and I want to find out what it is like for people when someone they know dies.

I'm going to talk to lots of people who have lost someone close to them.

I want to find out how other people who lose someone they love can be helped to feel better.

I would like to talk to people about their memories of when someone they knew died.

I'd like to know what happened after the person they knew died.

I'd like to know how they felt.

And I'd like to know what helped them to feel better.

I'm going to talk to each person about these things in private and use a tape recorder to help me remember what they say.



I will spend about 45 minutes talking to each person, and I might visit them once or twice.

Everything they tell me will be kept private!

Would you like to be one of the people I talk to?

If you say “Yes” now you can still change your mind if you like.

Nothing bad will happen if you say “No”.

Do you have any questions?

I can come and talk to you before you say “Yes” or “No”.

You can ring me on 01482 869314.



## **Appendix 5**

Consent Form One

Experiences of Bereavement



Name

.....

Date

.....

This consent form is to be signed by the participant's carer/support worker. Before being filled in the carer must have read the information sheet.

1. I, as the representative, understand what the work is for and who will be involved with it.



YES



NO

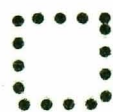


NOT SURE

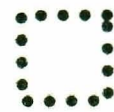
2. I believe that to proceed with the work would be in the interests of the participant.



YES



NO



NOT SURE

3. I have read the carer/support worker information sheet.



YES



NO



NOT SURE

4. I understand that I am free to withdraw from the study at any time without giving a reason.



YES



NO



NOT SURE

5. I agree to take part in the research study.



YES



NO



NOT SURE

Signature:

Representative .....



Consent Form Two

Experiences of Bereavement

Name

.....

Date

.....

This consent form is to be signed by the research participant. Before they answer this they must have read or been read the participant information sheet. Before they answer this, their carer/support worker must have read the information sheet and agreed provisional consent.



1. Alex has talked to me about this work and why it is being done.

YES

NO

NOT SURE

2. a) I understand what the work will be about.

YES

NO

NOT SURE

b) AND I know that I do not have to be involved

YES

NO

NOT SURE

3. I know that the things I talk about with Alex will stay private, unless she is worried about my safety.

YES

NO

NOT SURE

4. I am happy to do the work.

YES

NO

NOT SURE

Signatures:

Participant .....

Carer (key worker, staff support).....

## **Appendix 6**

# HULL AND EAST RIDING LOCAL RESEARCH ETHICS COMMITTEE

c/o Faculty of Health  
Coniston House  
The University of Hull  
East Riding Campus  
WILLERBY  
HU10 6NS

Tel: 01482 466771  
Fax: 01482 466769  
e-mail: k.birtwhistle@hull.ac.uk

26 March 2002

Ms A Hamlin  
17 Morton Lane  
Beverley  
East Yorkshire  
HU17 9AD

Dear Ms Hamlin,

## **The experience of bereavement in individuals with learning disability - a qualitative study**

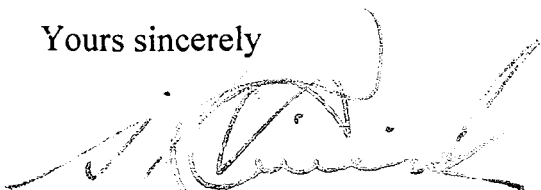
**LREC NUMBER: 03/02/041** [please quote this number in all correspondence]

Thank you for coming to the Local Research Ethics Committee meeting in support of your application for this project, which was held on 18<sup>th</sup> March 2002. As you will have understood from the conversation that we had, the committee had some minor concerns about the methodology. The choice of research participant is being made by individual carers and these may have their own ideas of inclusion and exclusion criteria, which could theoretically lead to a bias. There was also the concern that other significant life changes take place at the same time as bereavement. The committee understands that you are to think about these potential complications and biases and try to modify the methodology accordingly.

The committee is happy to grant ethical approval for the study to commence with the above caveats.

It should be noted that whilst the LREC can provide ethical clearance it cannot approve the application in terms of consent for the research to be undertaken within the Trust and the principle investigator is obliged to ensure that Trust(s) approval is gained prior to the commencement of the research.

Yours sincerely



Professor S R Killick  
Chairman

Hull and East Riding Local Research Ethics Committee Members  
Professor SR Killick  
(Chairman)  
Mr M Davidson

Dr E Baguley

Dr CJ Brophy

Mr G S Duthie

Mrs H Thornton -Jones

Dr R Calvert

Mrs E Dakkak

Mrs C Metcalfe

Dr I Markova