BEREAVEMENT IN ADULTS WITH LEARNING DIFFICULTIES

by

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Bereavement in adults with learning difficulties.

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Abstract

Two studies were undertaken to investigate grief in adults with learning difficulties.

Study one involved the construction of an observer rated grief inventory which showed good reliability and certain aspects of validity. Using the grief inventory it was demonstrated that primary carers of learning disabled adults perceived a significant change in clients post bereavement. There was no association between levels of expressive and receptive language or degree of dependency upon the deceased and grief inventory ratings. Similarly no differences were established on the basis of gender, expected/unexpected death, attendance/non attendance at funeral, maintenance/change of residence as a result of bereavement or presence/absence of religious beliefs. Qualitative data yielded significant information regarding specific types of observed changes in clients after bereavement and ways in which clients were perceived to communicate their grief.

In Study Two, four recently bereaved adults with learning difficulties engaged with the researcher in bereavement counselling over a ten week period. Carers completed the grief inventory on two occasions before counselling intervention, at two weekly intervals during intervention and at a two week follow up. Manova trend analysis indicated no significant change in clients grief inventory scores during this period. A structured interview on the concepts of death was completed before and after the intervention. All clients had some understanding of some concepts of death but there was a conspicuous difference between clients' scores. Clients' ratings on the interview before and after intervention were not statistically different. No relationship was found between scores on the concepts of death and grief inventory ratings. Finally a content analysis of three mid counselling sessions for each participant provided some confirmation that bereaved adults with learning difficulties undergo a similar grief process to that described in the general population. Ideas for future research and implications for service delivery are discussed.

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this bound volume are identical to the volume submitted for examination in the temporary binding except for the amendments requested at examination.

This study was conducted while the author was a Trainee Clinical Psychologist in the South West Region based in Cornwall Healthcae Trust.

Signed

Date

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Introduction

Grief is the cost of losing someone we love. It is a natural response to the situation of loss. Since Freud's (1917) monograph *Mourning and Melancholia* there has been a dramatic increase in the scientific exploration of bereavement and grief. There now exists a substantial body of research on the psychological and physical consequences of grief as well as a number of theoretical models of grief. However, to date most research has focused on conjugal bereavement and to some extent has remained at the descriptive level. There are few psychometric instruments for measuring grief. The two most notable are the Texas Bereavement Inventory (Zisook, 1977, 1982) and the Grief Experience Inventory (Sanders, 1979).

Little attempt has been made to explore the effects of bereavement on the learning disabled population. Indeed it is only very recently that the emotional lives of this group have been acknowledged at all. (Conboy-Hill, 1991) This growing recognition that learning disabled people have emotional needs may be related to the introduction of the concept of 'Normalisation' (Wolfensberger, 1972).

Most of the published research on bereavement in people with learning difficulties has been anecdotal, comprising single case studies. Therefore although Oswin (1981) contends that learning disabled people do grieve, Wadsworth at al., (1991), in a review of the literature, suggest that it is still u
uncertain whether learning disabled adults grieve in similar a fashion to the general population.

Although anecdotal descriptions and single case studies are limited methodologically, they have given some insight into the possible responses of this population to the experience of bereavement. The time is ripe for systematic empirical research into particular areas such as learning disabled adults' concepts of death; therapeutic interventions for bereaved learning disabled adults and some objective measurement of their grief responses. Results from research such as this will undoubtedly have implications for service delivery.

This chapter will review literature pertaining to:

(a) bereavement in the general population
(b) bereavement in the learning disabled population
(c) conceptual understandings of death
(d) therapeutic interventions for the bereaved adult with learning difficulties.
Clarification of terminology is useful from the outset. Bereavement refers to the objective situation of an individual who has recently experienced the loss of someone through that person’s death. Thus bereavement is the cause of grief. Grief on the other hand may be said to be the individual’s response to bereavement which encompasses social, emotional, spiritual and physical components.

Researchers have made the distinction between normal grief and pathological grief. The foundations for such distinctions were laid down Lindemann (1944) in his study of those bereaved in the Coconut Grove disaster. Later developments by Parkes (1965) and others have led to the following definitions of atypical grief response.

Pathological grief refers to grief reactions which deviate markedly from the normal pattern and which are associated with maladjustment and psychiatric problems. Pathological grief is often categorised as chronic, delayed or inhibited.

**Chronic Grief:** refers to the indefinite prolongation of grief in which anxiety, tension, restlessness and insomnia predominate. Identification symptoms also often occur. (The most famous paradigm of the person in chronic grief is Queen Victoria who, for example, had a picture of her late husband attached to every bed she ever slept in and who wore black
Delayed Grief: refers to the onset of grief symptoms, normal or chronic, after extensive delay. Until onset, the person may act psychologically normally or may manifest a range of behaviours from 'compulsive' overactivity, to severe depression without a sense of loss.

Inhibited Grief: In this type of grief the affective disturbance of grief is channelled into somatic symptoms. Parkes (1965) suggests however, that there may be no absolute difference between delayed and inhibited grief. The two types of grief may simply represent different degrees of successful defence.

It is important to acknowledge that contemporary research shows that there are still no adequate definitions of what is normal or pathological. Pathology may be determined in terms of the processes that have been suggested in different staging or conceptual models of grief. Consequently grief may be designated pathological or atypical when the processes of resolving the loss do not occur. It may relate to the presence of different phenomena, such as somatic identification with the deceased's last illness. Views of those who have researched this area are wide ranging and the criteria for defining or delineating pathological grief vary.

Psychoanalytic Model of Grief
The classic analysis of grief and mourning invariably referred to is Freud's Mourning and Melancholia (1917). This monograph became the basis for psychoanalytic theory of depression, and also greatly influenced later conceptions of grief.

Freud proposed that individuals are assumed to have attachments to those who are important for the satisfaction of their needs. He conceptualised love as the attachment, or *cathexis*, of libidinal energy to the mental representation of the person. The more important a person is to an individual, the greater the *cathexis* will be. Consequently, when the loved person is lost through death, the survivor's libidinal energy remains attached to the thoughts and memories of the deceased. Since each person has only limited resources, the energy invested in the dead person must be freed and transferred. Grief is thus conceived as the natural reverse of cathetic bonding.

Freud thus presented the psychological function of grief as freeing the person of her/his ties to the deceased. The means by which this was done was through reviewing past memories. He presented grief as an active process where the individual has to "work through the grief in order to come to a resolution of it". This occurs, when the individual transfers the libidinal energy from the deceased to someone or something else. If the individual is unsuccessful in this grief work, or indeed if they refuse to embark upon it at all, then the result is an atypical or pathological grief response.
According to Freud, pathological grief is different to normal grief and is characterised by the presence of guilt, self reproach, and lowered self esteem. He argues that the real target of these accusations is not really the self but the "lost object". He identifies an ambivalent relationship with the deceased as the root of this pathological grief and suggests that the libido rather than being transferred to another, is in fact withdrawn into the ego. That is, the hostile part of the ambivalence towards the deceased is turned inwards and against self. Later however, Freud reviewed his position, and abandoned the position that identification is the only characteristic of pathological processes, in favour of the view that any libidinal energy withdrawn from the lost object is accomplished by means of the individual identifying with lost object.

Freud's major contribution to the understanding of the experience and resolution of grief was to identify the need for an active working through of emotions so as to sever the ties to the deceased. His theoretical perspective forms the conceptual basis of many counselling and therapy programmes. However as a theoretical model of grief it completely ignores the role of interpersonal factors in adjustment to bereavement. Moreover, while Freud proposed that guilt and self reproach and hostility are symptomatic of pathological grief, (Parkes, 1986) has demonstrated that they may be present in normal grieving.

Attachment Theory of Grief
Bowlby (1960, 1962, 1971, 1981) integrates ideas from psychoanalysis and ethology and conceptualises the grief process as form of separation anxiety. Much of his evidence for the theory comes from studies with children and animals. Central to his theory is the assumption that attachment behaviour has a survival value for many species, and that grief is the negative aspect of attachment and a general response to separation. Thus the protest - despair sequence of phases observed in grief is, according to Bowlby, a natural response of many species to the disruption of strong affectional bonds.

Bowlby's contention is that grief like reactions to separation, observed in primates as well as humans, suggest that these reactions/responses have biological roots.

Pathological grief, according to Bowlby, depends upon certain childhood experiences, in particular, the pattern of parental attachment behaviour. He presents three disordered forms of attachment:

**Anxious attachment** is characterised by various expressions of parental rejection, including threats to leave the family. Consequently the child engages in urgent attachment behaviour, remaining in close proximity to ensure that the attachment figure will always be there. In adulthood these individuals form insecure and overdependent attachments to their partners. In loss they are liable to show a chronic grief pattern. Empirical evidence from a study of widows exists to support this hypothesis (Parkes, 1983).
Compulsively self reliant individuals insist in being totally independent regardless of circumstances. They inhibit attachment feeling and behaviour and deny any desire for a close relationship. They will tend to deny their loss and grieving will be delayed for months or years. During this time they may be irritable, strained and depressed.

Compulsive care givers engage in relationships but only in the role as giver. Bowlby hypothesised that these individuals had mothers with either depression or some sort of disability which required the child to care for the adult. Bowlby suggests that these individuals will also be prone to chronic grief.

Bowlby’s model offers a plausible theoretical explanation of normal and pathological grief. It gives meaning to paradoxical behaviours such as searching behaviour involved in grief for example. However it fails to address or explain psychological components of grief.

Behaviour Theory

The behavioural theory of grief focuses on depression rather than on grief. However due to the structural similarity between depression and grief, the behavioural explanations of depression have much to offer the theoretical analysis of grief. (eg Ferster, 1973, Lewinsohn, 1974).

Depression is characterised by a reduced rate of behaviour, associated with negative affective states. Thus behaviourists view depression as the result of a reduction in
the rate of response contingent positive reinforcement. Thus people who suffer loss of a partner through death may, initially, continue in usual patterns of behaviour, but find that they fail to elicit any rewards normally provided by the lost partner. Since many of these activities and behaviours will be an integral part of life for the individual, the extinction of these behaviours will naturally be very painful.

To complement this view Lewinsohn et al, (1979) add that not only is there a reduction in response contingent reinforcement but that there is an increase in aversive events. This increase of aversive events makes individuals less willing to initiate reactions, and more likely to withdraw from interactions which could potentially lead to positive reinforcement.

Lewinsohn (1974) accounts for non behavioural symptoms of depression by suggesting that the reduction of response contingent positive reinforcement, and the increase in aversive events, act as an unconditioned eliciting stimuli for these symptoms.

If grief is, to some extent, a reaction to the reduction in response contingent reinforcement, its severity should vary with the magnitude of this reduction. In grief the reduction of response contingent positive reinforcement will depend not only on the loss from the deceased but also upon the alternative sources of reinforcement, for example, family and friends.
Behavioural theorists discuss a number of mechanisms which could account for the development of pathological grief patterns:

(1) In grief the individual undergoes a prolonged extinction process with an associated increase in aversive events. Thus large sections of the person's behavioural repertoire may be replaced by escape and avoidance behaviour. Thus an individual who previously satisfied all her/his social needs in marital interaction, and who now dreads entering social situations without the lost partner, may simply avoid social settings. Such a response will preclude any possibility of rebuilding a repertoire of social behaviours.

(2) Secondary gain resulting from 'playing the role' of the bereaved person may also lead to a pathological grief response. In this way the social environment may positively reinforce such behaviours. Continuation of such reinforcement may lead, in time, to the development of chronic grief.

A particular weakness of the behaviour theory is that it gives no place to cognitions within the extinction metaphor. Within this framework behaviour should be purely a function of schedules of reinforcement, regardless of the reasons which led to the change, however this is not the case. A woman who coped adequately with prolonged separation from her spouse may be absolutely devastated with the death of her partner. In terms of these situations reinforcement schedules were the same. The difference between the two situations is in expectations. The behavioural theories do not account for such differences in cognitions.
Cognitive Theory

The original learned helplessness model formulated by Seligman (1975) and others (Abramson Seligman & Teasdale, 1978) purported that, when an animal or a person is faced with an outcome that is independent of her (his) responses, she (he) learns that the outcome is independent of her responses. This results in motivation, cognitive and emotional deficits. The view forwarded by the cognitive theorists, was that depression and learned helplessness have parallel symptoms. This formulation which was based on a learning model focused on the uncotrollability of outcomes, rather than aversiveness of outcomes, was reformulated in terms of an attribution model. Essentially the difference between the formulations lies in the understanding that mere exposure to uncotrollability is not sufficient for the cognitive, motivational and emotional deficits to occur. For helplessness, individuals must also expect that future outcomes are uncontrollable. This will depend upon the attributions an individual makes, about the causes and generality of the uncontrollability.

When an individual loses a spouse through death, a decreased sense of outcome control is likely to be generated. This in turn will be accompanied by depression and cognitive disorganisation. The duration of the depression and whether it is accompanied by lowered self esteem will depend upon the surviving spouse's interpretation of the loss. Thus in the normal course of events, bereaved individuals are unlikely to blame themselves for the death in any global sense.
Some individuals however, do take responsibility and believe that they could have in some way prevented the death. Such attributions may lead to pathological grief. Indeed Parkes & Brown (1972) have identified some of the conditions under which people are likely to induce self blame. These conditions include loss due to suicide; marital relationships characterised by ambivalence or unexpectedness of the loss.

Summary

Normal and atypical or pathological grief may be explained, at least in part, in a number of ways. Freud’s analysis conceptualises the death of the person in terms of the lost object to which a great deal of libidinal energy has been cathected. The function of grief is to complete the process of breaking the bond with the deceased person, by means of reviewing past memories. This working through frees the person’s limited resources and permits a reinvestment of energy. Freud underlines the process of actively working through grief and this has implications for therapeutic interventions. However he ignores the role of social support which has been shown to be a salient factor in the course of grief resolution, (Clayton, 1975) and focuses solely on intrapsychic factors. His proposal that guilt, self reproach and hostility are indicative of pathological grief has not been borne out by research.

Bowlby’s attachment theory integrates ideas from ethology and psychoanalysis. Like Freud, Bowlby presents grief as the emotional response to the severing of the bond between the bereaved and the deceased.
He emphasises that loss is not specific to death alone but that the same biphasic protest-despair reaction could be interpreted as a general response to separation. Bowlby contends that the experience of grief, as an aversive emotional response to separation, serves the biological function of motivating animals and humans to remain close to their primary group. This analysis helps to account for otherwise seemingly incomprehensible behaviour of the bereaved person. It also offers a theoretical basis for the explanation of the ameliorative function of support. However, his theory has little to say about the psychological function of grief.

Behavioural perspectives on grief come from depression theory.

Central to this theory is that marital partners derive a sizeable proportion of their rewards from activities, which are mutually interdependent. The loss, through death of a partner, therefore leads to a reduction in the rate of positive response contingent reinforcement in the surviving partner. Moreover, this model suggests that the experience of grief is likely to be associated with an increase in aversive events. The behavioural theory of (depression) grief offers a credible explanation for a number of grief symptoms. It also accounts for a number of factors which modify the grief response. However, by limiting itself to the idea that behaviour is solely a function of schedules of reinforcement, and that identical changes in these schedules should lead to identical consequences, it disregards the importance of expectations in the equation.

According to the theory of learned helplessness, grief is
the response to a feeling of loss of control, due to the experience of noncontingency between responses and outcomes. The generality and chronicity of the grief response will depend, according to the reformulated theory of learned helplessness, on the globality and stability of the characteristics seen as responsible for the loss of control. It can explain, unlike the behaviour model, the differential behaviour of individuals faced with permanent rather than transient loss. However it fails to account for example, for atypical grief responses such as delayed or avoided grief.

**Stress Models**

Stress models of grief view bereavement as a stressful life event, that is an experience which overtaxes the coping resources of the individual. The analysis of grief as a stressful life event integrates it into the body of research which has linked psychosocial stress to a number of health consequences and has isolated various physiological processes assumed to mediate these relationships.

Early stress research carried out by Selye (1936, 1976) focused on bodily responses to stressors. Later retrospective studies by Lindemann (1942, 1950) and Brown and Harris (1978) linked the role of cumulative life stress to the aetiology of depression.

The psychological approach to stress has attempted to ascertain why certain psychological experiences are stressful, how the organism recognises stressful events, and distinguishes these from positive ones, and how
interindividual differences in relation to stress can be explained. These issues have been addressed by Lararus & Folkes (1984) in their Cognitive Model of Stress.

According to this model psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing, or exceeding his or her resources, and endangering his or her well being. This model underlines the relationship between demands and resources. However it also affirms that certain situations are likely to be experienced as universally stressful, but always in relation to the person's resources.

Thus Lazarus et al (1984) present cognitive appraisal of stress as an evaluation process which determines why and to what extent a particular situation is perceived as stressful to the individual. It involves; (1) primary appraisal, where the individual categorises a given situation with respect to its significance for their wellbeing, and decides whether the situation is relevant, benign positive or stressful; (2) secondary appraisal where the individual makes an assessment of their coping resources and options in relation to the situation; and (3) reappraisal where the individual, in light of new information about the situation, or about the impact of one's behaviour, results in a reappraisal of the situation.

Once the situation has been appraised, the individual has to do something to respond and master the situation, and to control their emotional reactions to it. The processes of responding to stressful demands are known as coping
processes, and may be problem focused or emotion focused. The former involves the management of the problem, for example, ensuring that there has been thorough preparation for an examination; the latter involves dealing with the emotional distress involved, such as dealing with anxiety that may accompany the examination experience.

How well an individual copes with stressful situations will also depend upon their coping resources, both personal (eg. physical and psychological health) and environmental resources (eg. social support).

Thus Lazarus' (1984) model to bereavement, may help predict the characteristics of those who are likely to run a high risk of poor bereavement outcome, and to relate these characteristics to strategies of coping that are maladaptive. However as Stroebe & Stroebe (1987) point out to answer questions about risk group's bereavement, researchers must identify the aspects of loss that are stressful, the coping resources of the individual which are relevant to these situational demands, and the coping processes that are typically employed by bereaved individuals. Moreover research should be guided by different coping strategies to good or poor adjustment and health outcome. The Deficit Model (Stroebe & Stroebe 1980, 1982, 1986) attempts to address these issues.

**Deficit Model of Partner Loss**

This model applies the general psychological stress model to the situation of conjugal bereavement. It offers an
analysis of the situational demand characteristics of widowhood, and of the coping resources required to deal with these demands. It accounts, to some extent, for individual differences in psychological and physical reactions to loss, and places bereavement in an interpersonal as well as an intrapersonal perspective.

**Demands of the Situation**

Since married couples may be conceptualised as a social unit, who mutually depend upon each other and who fulfil for each other a wide range of functions, the experience of bereavement will result in a number of deficits.

**Loss of Instrumental Support:** Marital couples may be said to have group resources in terms of task demands. Loss of a partner may reduce some of these demands but will also reduce resources. Difficulties which emerge as a result (taking over task functions previously undertaken by the spouse) may be lessened by the help of an extensive social support system (Korbrin et al., 1977) but may also add to emotional aspects of the loss.

**Loss of Validation:** Marital partners often serve as a mutual reference person for comparisons of assessments of one’s abilities and for a reliable evaluation of environmental demands. This is lost in bereavement. Social comparison processes also play an important role in the evaluation of one’s emotional reactions, particularly in novel emotion arousing situations. (Schachter, 1959) For most people, death of a spouse is an unprecedented situation, which is highly
emotionally arousing. Thus the bereaved may be unsure about how to act or what to feel and whether their reactions are normal.

**Loss of Emotional Support:** A partner's expression of care is likely to augment a person's feeling of self worth, and thus serve as an important function in the maintenance of psychological health. Deficits in emotional support as a result of bereavement may therefore be partly responsible for the lowering of self esteem often observed within the bereaved.

**Loss of Social Identity:** The loss of a partner is likely to have a direct effect on the surviving partner's self definition. As Tajfel (1978) emphasised, the social groups to which we belong are important determinants of our definition of self and form the basis for our social identity. The fact that the widow may be uncertain about acceptance by others as a single person, is likely to contribute further to this loss of self esteem.

**Coping Resources**

According to the interactional definition of stress upon which the Deficit Model is based, stress is experienced when the person perceives a situation as presenting a demand which exceeds their coping resources. In an analysis of resources which are likely to affect the individual's ability to cope with bereavement, Stroebe et al, distinguish between the intrapersonal and interpersonal resources.
**Intrapersonal resources:** According to the authors, personality traits are probably the most important resources which enable a person to cope with bereavement. Thus personality traits such as emotional stability (Eysenck & Eysenck 1964) and ego strength (Cattell, Eber & Tatsuoka, 1970) are likely to contribute positively to coping ability. Support for this view is strengthened by results from Smith, Johnson & Saracen, 1978).

**Interpersonal resources:** these include, for example, financial resources and social support, with the latter being of particular importance. Since this model implies that stress of bereavement can only be moderated by the availability of coping resources that respond to the deficit, Stroebe et al make distinctions between instrumental, validational and emotional support.

**Coping Processes:** Like Lazarus (1984) the authors distinguish two forms of coping, namely problem control and emotional control. The former relates for example, to taking over tasks previously done by the deceased partner, while emotion coping and control consists of the cognitive and behaviour strategies (eg. increased alcohol intake) directed at diminishing or suppressing distress. Denial is of course the most extreme form of emotion control, and may be exemplified in the widow who continues to set the dinner table for two.

Among bereavement researchers, there is a general agreement that grief work is the only strategy of emotion control which leads to a healthy resolution of the emotional distress reaction to loss. However it has been demonstrated that
(Silver, 1986) merely ruminating about a spouse's death does not resolve emotional distress. Taylor (1983) purports that there are a number of ways in which grief work, as an active coping strategy might differ from passive rumination. His view is rooted in the theory of cognitive adaptation to threatening events. He states that in order to be an effective coping strategy, grief work must involve: (a) a search for meaning in the experience; (b) an attempt to regain mastery over one's life; and (c) an effort to enhance one's self esteem.

Drawing on the cognitive model of stress, expounded by Lazarus et al., (1984) Stroebe et al., (1987) present a deficit model of grief. This model applies the general psychological model of stress to the situation of conjugal bereavement. It provides a framework for the analysis of the demands of the same situation which face a bereaved a marital partner: it identifies those at risk of poor bereavement outcome.

Having considered the various conceptual models of grief a review of empirical work relating to bereavement and the experience of grief now follows. Once again most studies refer to conjugal bereavement.

**Empirical Studies**

The earliest systematic research into the emotional and physical responses to bereavement was undertaken by Lindemann (1944) in the wake of the Coconut Grove disaster in the USA. Indeed the symptomatology presented by him forms a large part
of the generally accepted grief symptoms held today. These include somatic distress, guilt feelings, hostility and loss of patterns of activity.

Since that time a number of researchers, (Parkes, 1965; Clayton et al, 1965) have confirmed his work, but have also expanded upon it. The symptomatology of grief may be classified as follows:

1. **affective components** comprising: depression, feeling of sadness; anxiety; guilt; anger and hostility; anhedonia; and feelings of loneliness.
2. **behavioural manifestations** comprising: tenseness; overactivity without completing tasks; fatigue; and crying.
3. **Attitudes towards the deceased, and the environment** comprising: low esteem, hopelessness and helplessness; sense of unreality; suspiciousness; interpersonal problems; attitudes towards the deceased including waves of yearning, idealization, ambivalence, preoccupation with the memory of the deceased sometimes to the exclusion of anything else.
4. **Cognitive impairment and physiological changes and bodily complaints** comprising: slowed thinking; poor concentration; weight loss; sleep disturbances; energy loss; headaches; muscle cramp; indigestion; tightness in the throat; appearance of symptoms similar to those of the deceased; increased use of psychotropic drugs, alcohol intake and smoking; infections; susceptibility to illness and disease.

Research also suggests that different symptoms manifest themselves at differing times. This has led most authors to view the process of grief in terms of phases. (eg. Bowlby, 1981; Clayton et al, 1968; Parkes, 1965). Although there
are some differences of opinion in terms of how many phases bereaved people pass through, there is general agreement about the duration and succession of phases of bereavement. These have been identified as numbness; yearning/protest; despair; recovery and restitution.

During differing phases different symptoms may predominate. During the **numbness** phase which emerges as the initial response and which may last from a few hours to several weeks, the bereaved person may manifest temper outbursts, somatic symptoms, denial, feelings of disorganisation and helplessness.

During the **yearning and protest phase** the numbness gives way to a period of potent emotions, extreme psychological and physiological distress. The bereaved person experiences an intense longing for the lost person, and goes through uncontrollable sobbing. There is also an overriding urge to search for the deceased. In spite of the knowledge that the person is dead, there exists a desire to try to recover the person, which is impossible to overcome during this period. They are constantly preoccupied with thoughts of the deceased. Anger may be directed towards self but more often is directed to those who are nearby. These psychological symptoms are accompanied by physical symptoms including weight loss, sleep disturbance and somatic pain symptoms.

**Despair** is experienced normally as the first year comes to a close and may continue for months longer. It is during this period that the person is overwhelmed by depression. They withdraw from people and activities and somatic symptoms
Recovery and Restitution: At this period the person gives up all hope that the deceased will ever come back. Therefore the bereaved person begins to fulfil roles and acquire skills normally exercised by their partner. Independence and initiative return and the person moves towards building new relationships. This process of recovery and restitution is demanding and stressful, and it is not uncommon for symptom recurrences to emerge, especially at significant times such as anniversaries.

Parkes (1965) draws attention to the danger of perceiving grief merely as a set of symptoms which start after a loss and then fade away. Individual differences do exist and oscillation between the phases is usual.

Parkes, (1965a) and others have presented empirical evidence to substantiate the view that bereavement has deleterious effects on physical and mental health.

The most convincing evidence for physical deterioration may be seen in the increase in morbidity, in the form of various physical illnesses, including T.B. and cardiovascular disease, but also in the increased mortality in the months following a bereavement. Rees and Lutkins (1967) reveal increased mortality rates among parents who have lost a child and Rashkin (1984) showed a significant increase in mortality among bereaved grandparents; Mellstrom et al, (1982) found a highly significant increase in the death rate among widows in the first three months and among the widowers in the first
year. However there are a number of alternative explanations which question the notion that widowhood is (a) associated with increase in mortality or (b) that the increase is a consequence of the loss experience.

Firstly, there is the notion of differential selection which proposes that those who remain widowed have lower health status in contrast to those who remarry. Thus health is viewed, not as a consequence of marital status, but as a determinant. According to this interpretation, the widowed mortality rate is higher than their married counterparts because the healthier widows are "continually drained from the widowed and reselected into the married category". With remarriage rates being higher among the younger age band, and higher for widowers than for widows, differential selection could account for the higher mortality of the younger widowed, especially males.

Secondly, statistical artifacts and biases may exaggerate differences in the mortality rates of the widowed as compared to married people. This may be exemplified in the practice of collapsing age groups into large broad categories. Close analysis, for example reveals that in many cases the average age of the widowed is one year older than the married populations with which they are compared. Since it known that there is a relationship between age and mortality, the higher average age of widows within these categories may contribute to their higher mortality rate.

Thirdly, homogamy, would suggest that the death of a partner raises the probability of the death of the surviving partner.
Thus one might expect the healthy to marry the healthy and the sick to marry the sick. Moreover there would be similarity in attitudes and behaviours such as smoking and drinking and so on which are health risk factors.

Fourthly, joint unfavourable environments may also contribute to a person’s lifespan. Those experiencing high degrees of stress as a result of poverty, for example, might be expected to die more rapidly than those not sharing such experiences. Although the individual influence of these factors may be minor, in combination they may be a potent contributing factor to the finding from cross sectional studies, that there is a married to widowed differential in mortality risk.

Suicide accounts for only a small proportion of the overall difference in the mortality of widowed in comparison to those who are married. However it reflects in the strongest and clearest way, the depth of anguish and despair inherent in grief. It is a behavioural indicator of despair and is greatest for the period immediately following the loss. This has been demonstrated in a number of studies (eg. Bojanovsky, 1977, 1980; Kaprio & Koskenvuo, 1983). The latter study, for example, compared the suicide rates with the sex and age adjusted rates for the general population. The authors reported a peak in suicide rates for the first week after bereavement. The excess was sixty six fold for men and almost ten fold for women.

The frequency and intensity of depression following bereavement has been the focus of much research (eg. Clayton et al, 1973; Glick, 1974; Stroebe & Stroebe, 1985; Carey,
Carey (1977) for example, studied widows and widowers using Adjustment Scale which elicited self reports of loneliness, depression, and unhappiness. The results indicated a highly significant difference in depression between the bereaved and married group. Not unlike other studies of bereavement and depression however, Carey’s use of a newly constructed measure which somewhat arbitrarily defined depression, makes the results less than robust. However since the vast majority of studies do indicate a depression response to bereavement, it does have some apparent validity.

In a longitudinal study of bereavement, Stroebe et al, (1985) used Beck’s Depression Inventory. In terms of Beck’s criteria forty two per cent of the widowed sample in comparison to ten per cent of the married sample fell into the range mild to severe depression. The even more stringent criteria for moderate to severe depression were met by fourteen per cent of the bereaved sample, but only by five per cent of the married sample.

Although depression and grief have been closely associated in the literature there has been little attempt to differentiate the phenomena as many of the symptoms overlap. Recently however, some attempts have been made to address this important issue. Clayton (1990) for example claims that symptoms present in typical depression but not found in bereavement are: hopelessness, worthlessness and a loss of interest in friends. She identifies retardation as rare in bereavement and concludes that it should be considered...
pathological if present.
Low self esteem has also been suggested as differentiating depression and grief. This relates to findings presented by Fleming (1989) and Horowitz et al., (1980) who identify negative cognitions of self and negative latent self images respectively.
Thus depressive disorders may be best differentiated from normal grief by the presence of negative views of the self and the world, including low self esteem and hopelessness, ruminative and preoccupying guilt, suicidal ruminations and fantasies of reunion with the lost person. (Stroebe & Stroebe, 1993).

Literature comparing 'psychiatric illness' / psychological disorder of married and widowed samples has presented consistent evidence that bereavement is a powerful predictor or 'psychiatric illness' / psychological disorder. Gove (1972a) in a review of studies of marital status and incidence of mental disorder, found that the widowed were over-represented relative to the married sample, in nine out of ten studies and this was true regardless of the severity of the disorder. Moreover the literature on stressful life events has consistently confirmed loss as a powerful predictor of mental illness.

However not everyone responds in the same way to a bereavement. The pattern of grief manifested and the adjustment to the situation of loss may be affected by a number of factors. It is to these factors that we now turn.
Determinants Of Grief

**Antecedent factors**, especially those involving the marital relationship, influence adjustment to bereavement. In particular, dependency and ambivalence in marital relations do not bode well for the bereaved spouse. Parkes & Weiss (1983) for example, found that survivors of ambivalent marriages, initially seemed to adjust better to loss than those widowed after a happy marriage. However, follow up studies at two to four years after bereavement revealed that survivors of ambivalent marriages, showed greater signs of maladjustment and poor recovery from grief.

Lopata, (1973a, 1979) found disorganisation in widowhood to be related to previous marital roles. People who were more psychologically and socially dependent upon their spouse showed greater disorganisation. In keeping with predictions from behaviour theory and the Deficit Model, (presented earlier), spouses whose lives were completely devoted to marriage, and who were socially and psychologically dependent upon their spouses, are likely to have greater problems in adjusting to bereavement.

Partners whose relationships were not characterised by either conflict and ambivalence, or overdependence, but which were described as happy and loving, have better bereavement adjustment. Although intuitively challenging, Parkes (1975a) points out that viewed from a development perspective it makes sense: Children who are securely attached to their mothers do not cling to them. On the contrary they tolerate separation well. (Bowlby, 1975)
Mode of Death: Evidence from the Harvard Study, (Glick et al, 1974; Parkes & Weiss, 1983) found sudden and unexpected death to be one of the major predictive factors of bereavement outcome. Later Lundin, (1984a) compared health outcomes among a sample of a matched control group whose deaths had been expected. An increase in the frequency of sickness was found among those who has suffered sudden and unexpected bereavement in comparison to the matched control group. Moreover the rate of 'psychiatric illness' was particularly high among these individuals.

However results from a study by Sanders, (1983) suggests that the usefulness of preparation time is erased if the terminal illness is very protracted. For those bereaved individuals bereavement may prove as difficult as for the sudden and unexpected death survivors.

Age: Evidence reveals that the younger bereaved person is more likely to suffer health deterioration than an older person. (Ball, 1979; Maddison & Walker, 1967). Although reasons for this are unclear, it may be interpreted in terms of age related differences, in the expectedness of the loss. Since research shows that unexpected death generally carries a greater risk for someone than an unexpected death, a negative correlation between age and expectedness of loss could account for the greater health risk experienced by younger people.

Gender: There is still a lack of reliable information on sex differences and the impact on bereavement outcome, due in large part to the greater number of widows in comparison to
widowers. However the evidence to date does support in large part the hypothesis, that men fare worse in bereavement. Stroebe & Stroebe (1986) found that widowers were at greater risk. When widows and widowers were compared with the same sex, non bereaved comparison persons, widowers were found to suffer greater health problems in comparison to married men, than widows compared to married women. In terms of depression, Radloff (1975) showed that men adjust less well to bereavement than women. His study revealed that while married women were more depressed than married men, widowed men were more depressed than widows.

The most unequivocal support for sex differences in bereavement outcome comes from cross sectional mortality data. (eg. Kraus & Lilienfeld, 1959; M. Stroebe et al.,1981) which show that widowers have greater excessive mortality rates from all causes taken together, than do widows compared with married women.

Religiosity; There is some empirical evidence that religious beliefs help bereaved persons to overcome their loss. (Eliot, 1946;Gorer, 1965; Krupp & Kligfeld, 1962). However many of these are self report studies and do not investigate the relationship specifically between religiosity and outcome. Clayton et al, (1973) for example, found a significance between depressed and non depressed groups in church attendance. However since religion is multifaceted, encompassing personal spirituality, religious ritual and membership of a specific social network it is difficult to ascertain which components are critical.
Summary

Evidence from a number of empirical studies reveals the range of physical and psychological consequences of bereavement. Specific factors relating to conjugal bereavement outcome have been identified. These include marital relationship, mode of death, age, sex and religiosity.

Bereavement in Adults with learning difficulties

Although there has been a plethora of grief studies in the last thirty years relating to the general population, the same cannot be said of research related to the effects of bereavement on adults with learning difficulties. Indeed Strachan (1981) reveals that a search of the Index Medicus (1966 - 1980) has only one work specifically related to the reactions of mentally handicapped people to death. Furthermore a search of the Exerpta Medicus (1989) revealed no studies at all. It is only very recently that any attempt has been made to recognise and investigate the implications of loss for this population.

The reason for this may be two fold. Firstly Western society still approaches the experience of death as if it were a taboo. The use of euphemistic language such as "passed away" helps to maintain a safe distance between us and the bereaved. Also in contrast to the early part of this century when the experience of death was seen by young and old alike, nowadays most deaths take place within the clinical and somewhat 'safer' hospital environment. If we add to bereavement the double taboo of being "mentally handicapped
and bereaved" we are potentially doubly sure to ignore the plight of this population.

Much of the published work relating to bereaved adults with learning difficulties is in the form of anecdotal descriptions or case studies. Although methodologically these are somewhat limited they do serve a useful purpose in alerting us to the experiences of this group when bereaved. Moreover they reveal the need for more comprehensive and systematic studies of bereavement in adults with learning difficulties. It is therefore worthwhile spending some time presenting an outline of a case study which gives insight into the experience of bereavement and the response of staff to such individuals.

Kitching, (1987) presents the case of forty year old JB, a woman with moderate/mild learning difficulties who was admitted to hospital as a 'crisis intervention' when her widowed mother was admitted to hospital suffering from terminal cancer. In the months that followed, JB did not see her sisters, and visited her mother on two occasions only. The reason given by staff was that the hospital was too far away and secondly, there was feeling that JB did not understand the nature of her mother’s illness. When her mother died JB did not attend the funeral, nor was she informed of the date. After news of her mother’s death had been broken to her, neither the staff nor JB refer to it again. Some ten months later JB started to show signs of anxiety and unhappiness and she was admitted to a more secure unit as a result of temper outbursts which culminated in JB savagely attacking a member of staff. Medication was
prescribed, and at some later date a psychologist became involved, and helped JB work through her delayed grief reaction which, until this time, had not been considered as a precipitating factor in JB's behaviour.

Oswin, (1981) states that there is no reason why mentally handicapped people will not suffer any of the normal reactions to bereavement. She does identify that additional difficulties may be experienced by this group as a result of: (a) Poor intellect and multiple disabilities eg. social, verbal, visual opportunities; (b) failure of professionals and others to recognise their normal grief; (c) the inappropriate way in which services are organised.

She contends that having a mental handicap will not preclude anyone from the wide range of 'normal bereavement reactions' but may put them at risk of suffering additional problems. These may arise, for example, if someone, who has severe problems physically, is barred from the burial or getting to the hospital bedside, or attending the funeral. Moreover Oswin reports that not all professionals who work with people who have learning difficulties are familiar with normal effects of bereavement. Among the grief reactions illustrated by case studies Oswin includes loss of previous abilities including speech.

Wadsworth & Harper (1991) in a review of the literature, suggest that persons with mental handicap are as likely to experience the same type of emotional reactions to loss as their non mentally handicapped counterparts. However like other researchers, they underline that people with mental
handicap may display feelings differently. Moreover many caregivers neither recognise nor respect these signs of grief, because they lack information about the process of normal grieving. They may simply adduce that people with mental handicap are unable to display normal grief. Caregivers may also be unsure about how to show their concern, compassion and support.

Reactions to grief displayed by people with learning disabilities have not been well studied. (Wadsworth et al, 1991). Therefore it is uncertain whether they do suffer from the same physical and psychological consequences outlined earlier for the general population.

Mcloughlin, (1986) emphasises that the term "mentally handicapped" does not refer to an homogeneous group. Indeed there is a wide range of abilities, experience and background differences within this group. If, suggests Mcloughlin, this is accepted then it is to be expected that reactions to bereavement in the learning disabled population should not be markedly dissimilar to that encountered in the general population. Reflecting this Oswin states that many of the difficulties and problems arise because people with learning difficulties are treated as a race apart, so that their needs very often go unrecognised and unmet.

Day (1985) suggests that since it has been shown for the generic population that a correlation exists between bereavement and psychiatric illness, then for those bereaved adults with learning difficulties a higher rate of psychiatric disorder may be expected. He therefore examined
the pattern of psychiatric disorder in patients admitted to the acute psychiatric ward of a mental handicap hospital. He reported that thirty three per cent of patients over forty years of age were found to be suffering from neurotic disorders on first admission, compared with thirteen per cent of non mentally handicapped individuals, admitted to psychiatric wards for the first time suffering from neurosis. In all the mentally handicapped people admitted for neuroses there was a precipitant cause, and in approximately fifty per cent of cases this was identified as the death or serious illness of a relative/care giver and could be regarded as a bereavement.

More recent work by Conboy Hill (1992) describes the kinds of interventions offered to people with learning disabilities. She identifies these as medication or behaviour modification. Where behaviour has been identified as troublesome, the person has been "either sedated or trained out of it, often without any reference to any possible emotional cause". Of late there has been some change as the principles of Normalisation (Wolfensberger, 1972) have been introduced and adopted widely.

This has resulted in a more humane approach to people with learning difficulties, and to an acknowledgement that they too often have emotional needs and emotional lives. However Crick (1988) observes, many clients are still treated behaviourally or with drugs, following a bereavement. In addition many are forced to move home and day care, within days of bereavement.
Mansdorf et al, (1986) state that "cognitive response patterns in bereavement can be said to be related to changes in cognitive schemata. Since expression of cognitive change is verbal, adults with learning difficulties who have verbal deficits may express grief in ways which may significantly differ from the behavioural responses observed elsewhere, eg. Kubler Ross. (1969)

Emerson, (1977) has observed that approximately fifty percent of people with learning difficulties, who had been referred for behavioural or new challenging behaviours, had experienced a significant loss in recent times.

Conboy Hill (1992) also cites her grief work with people who have learning disabilities. She states that bereavement is often associated with a range of behavioural problems: voluntary mutism, self injurious behaviour, anorexia, loss of continence skills and aggression.

Kennedy (1989) states that following a death in the family, people with learning difficulties find themselves in a similar position as children, that is, they are 'sheltered from the event as much as possible. Rather than helping the bereaved person, this strategy merely compounds the problem and makes even more difficult the road to accepting and coming to terms with the loss.

This sheltering and shielding, according to Strachan, (1981) also exists in the professional community. He identifies the reluctance of the ward staff to include residents in the grieving process. The rationale given by the staff: either
they (residents) will not understand, or it will be too upsetting for them.

Thus people with learning difficulties are often infantalised. They are considered unable to understand the meaning of death, and are excluded from the normal processes and rituals of mourning in society. However, as Kitching (1987) rightly states, even if their situation is parallel to a child's understanding of death it is still not sufficient justification for the conspiracy of silence. Many researchers have shown that children can have a surprising grasp of death and its meaning. An exploration of the research into the concept of death in the child population now follows.

**Concepts Of Death**

Much work has been carried out with children in attempts to ascertain what conceptual insights they hold regarding death. Interestingly very little has been done using the adult population: perhaps because it is assumed that such concepts have become fixed by early adolescence and that they remain static thereafter. (Kastenbaum et al., 1977) Even less research has been carried out into the concepts of death held by adults who have learning difficulties. What studies there have been owe much to investigations carried out on the child population. It is to these studies that we now turn.
Children's Concepts of Death

Evidence suggests that children under the age of five years of age are aware of death. Kastenbaum, (1974) for example, reported that a sixteen month old child was observed to watch in alarm as an adult trod on a caterpillar and responded by saying 'no more'. Kane (1979) reported that all three year old children she interviewed were able to distinguish a picture of a dead rabbit from a picture of one merely sleeping.

Anthony (1971) reports that an understanding of animism and the notion of life in general is assumed, if not to precede that of death, to go hand in hand with it.

Stages of acquisition have been related to Piagetian stages. Up to seven years of age, life and will are attributed to inanimate objects. During the second stage children perceive that anything that moves has life. In the third stage, life is reserved for anything that appears to move of its own volition. The idea of stages has been applied to children’s understanding of death too. Nagy (1948) suggests the following: stage one (3-5 years) at this point there is a denial of death as a 'regular and final process' Death is viewed as a departure: a further existence in changed circumstances; stage two (5-9 Years) death is personified: one is carried off by the 'death man'; stage three (9-10 years) there is the recognition of death as the inevitable dissolution of bodily life.

Spreece and Brent (1984) in a review of the literature outline three major elements which are present in a mature
understanding of death. They are: (1) **Irreversibility**, which refers to the understanding that once a living thing has died its physical body cannot be made alive again. (2) **Nonfunctionality** which refers to the understanding that all defining functions cease after death. (3) **Universality** which refers to the understanding that all living things die.

As with the area of bereavement and adults with learning difficulties, there is a paucity of research into learning disabled adults' concepts of death. Bihm & Elliot (1982) however, investigated the concepts of death held by a group of mentally handicapped adults. They discovered that Piagetian cognitive levels were significantly related to a more realistic comprehension of death, on the three measures of a mature concept of death, indicating that cognitive development is related to an increasingly complex understanding of death by the mentally handicapped.

Mc Evoy (1989) actively sought the views of learning disabled adults on death. He adopted a cognitive developmental approach similar to Kane (1979) and others and focused on the most widely accepted components of a mature concept of death discussed in the developmental literature. These components were: causality, irreversibility, universality, nonfunctionality and what happens after death. This information was elicited by a structured interview. Results indicated no significant differences between sex, or reported experience of death and adults understanding of the concepts of death. However, those with higher scores in communication, self care and community skills, held better developed concepts of irreversibility and nonfunctionality. In addition those who
affirmed that they would die one day had a more mature concept of death.

Depending on the degree of handicap, there is varying impairment in the ability to formulate abstract ideas and concepts. It therefore seems likely, suggest McLoughlin (1986) that the ability to understand the concepts of death will affect the grieving process.

The question remains "How does cognitive ability relate to the ability to work through a normal mourning process?" Research carried out on the child population suggests that the most vulnerable group to produce maladaptive reactions and anxiety is the pre adolescent (ten to twelve years old); to a lesser degree Latency (six to nine years old) and the least vulnerable is the adolescent. (Rosenheim & Reicher, 1985)

The rationale behind this hypothesis is that pre-adolescents, while conceiving the full meaning of death, are not equipped with the ego strength to cope with it. This model may relate to the learning disabled population in that those with a more sophisticated concept of death may be better able to work through the normal grieving process, and those with a more vague concept may be more vulnerable and less able to resolve their grief.

Numerous case reports discussing the responses of people of very varied ability levels state that reactions are highly variable although they do often take the form of regressed or aggressive behaviour (Thirm, 1989; Kitching, 1987).

Conboy-Hill (1991) cautions against the assumption that people
whose developmental levels are below the level of concrete operations, remaining at the preoperational stage, are unable to perceive and be distressed by loss. Kitching (1987) also alerts us to this by stating that:

"Some people with mental handicap will be unable to grasp the concept of finality but this does not mean that they cannot grieve for someone who is no longer there. Such views can result in a self fulfilling prophecy."

However, Brelstaff (1984) in a study of eleven mentally handicapped individuals who had been bereaved found that they simply did not seem to suffer at all from the experience of losing someone. However this may be an illustration of the self fulfilling prophecy in action. Some people with learning difficulties cannot make their feelings known, but changes in mood or behaviour might supply clues to feelings, but equally these may go unnoticed.
Bereavement Counselling in the Learning Disabled Population.

Wadsworth et al. (1991) in a review of the literature, drew attention to the notable lack of individual therapeutic interventions for bereaved persons with a learning disability who are experiencing behaviour outbursts or other reactions to bereavement that lead to severe social consequences. They draw attention to the role that caregivers may play in providing immediate social support to the bereaved person. This assistance may range from breaking the bad news, to helping them acknowledge and accept the changed reality, facilitate emotional release and generally provide extra support.

Kennedy (1989) in a case study presentation of therapeutic intervention with a bereaved person with learning difficulties illustrates differing ways in which the person may be assisted to grieve. These include the use of (a) a life book, which is a summary, usually pictorial, of the important events and experiences relating to the deceased and the client, (b) a compare and contrast set, which comprises ordinary photographs of people of whom the client is particularly fond. Some photographs are of the living and the dead. The aim is to promote practice at withdrawing and then investing emotional energy in the living, (c) a formal diary. It's aim is to promote the reality of the loss and to help him/her deal with pain as it arises. Kennedy suggests that such methods should be chosen carefully and appropriately for each individual client.
Conboy-Hill (1992) draws attention to the difficulties inherent in bereavement counselling with people who have learning difficulties. In particular she addresses the question of emotional vocabulary and illustrates the point by stating that many people use the same word for a range of feelings. This suggests that before much is done in the way of counselling, active listening or therapy, many people need to learn a vocabulary to describe their feelings. She also highlights the pertinent issue of concentration span. In this respect Conboy-Hill suggests that therapists work, not on the fifty minute session, but on the principle of "Quit while you're winning". Thus the therapist must attempt to assess the client's ability to use the session profitably and to adjust the counselling clock to meet the needs and abilities of client, not the fifty minute therapy session.

Kitching (1987) in the case of JB used a guided mourning technique to help resolve a delayed grief reaction to her mother's death. The process allowed the client to express her anger and encouraged her to talk about her experiences, recalling painful memories as well as good ones. The use of treasured objects from home enabled the client to talk more fully about her mother. Referrals to the drama and art departments, where she was able to express feelings helped JB to work through some of her emotions about the loss and complemented the work of the psychologist. Finally, JB was taken to the hospital where her mother had died, and to the grave where she said a symbolic goodbye.

Kitching reports that JB's aggressive behaviour disappeared, and she was moved to a hostel shortly after the therapy.
Deutsch (1985) asserts that grief counselling is necessary for people with a mental handicap who suffer a bereavement or loss of any kind. The reason for this is that they have poor adaptive skills which generally make it more difficult for them to deal with everyday stresses. He suggests that erroneous reasons exist for not providing such counselling, and that these are related to making life easier for the care staff, and not for the client.

When counselling is used it should, according to Deutsch, encompass the tasks of mourning which include: the acceptance of the reality of the loss; the experience of the pain of grief; the adjustment to an environment from which the deceased is missing; and the withdrawal of emotional energy and its reinvestment in another relationship. Therapeutic interventions employed by Deutsch include death and dying education; speaking about the concepts of death; relaxation techniques; imagery, role playing and cognitive techniques.

The lack of published literature on bereavement counselling techniques highlights that grief counselling and therapy are in their infancy when applied to the learning disabled population. A number of difficulties particular to this population present themselves. These include, the ability of the client in terms of receptive and expressive language, concentration span, and conceptual understandings of death. However, single case studies presented by various authors (eg. Kitching, 1987) suggest that this is a fruitful and worthwhile area for research and development, with obvious
benefits for this client group.

The aims and hypotheses of the present study will be in the following chapter.
Introduction to Chapter Two

As is evident from this literature review, research into bereavement in adults with learning difficulties is an area which offers considerable scope for the interested researcher. This study attempts to investigate a number of areas which are conspicuous by their absence from the literature. These areas include the development of an objective measure of grief symptoms; empirical evidence for the hypothesis that learning disabled people grieve; systematic study and measurement of the effects of bereavement counselling and an exploration into learning disabled peoples’ concept of death.

Research Aims

1. To construct an observer rated grief inventory.
2. To discover if primary carers observe a difference in their clients after a bereavement as measured on the grief inventory.
3. To collect, by means of questionnaire, relevant sociodemographic data and to explore the relationships between these data and grief ratings.
4. To engage in bereavement counselling with up to six learning disabled adults who have: (a) moderate or mild learning difficulties; (b) verbal ability; (c) suffered a significant bereavement within the previous six months.
5. To compare ratings of clients on the grief inventory.
before, during and after bereavement counselling intervention.

6. To describe in greater depth, themes and phases of bereavement which emerge during bereavement counselling.

7. To construct a structured interview on the concept of death.

8. To measure client concept of death before and after bereavement counselling.

**Research Hypotheses**

1. The grief inventory will show temporal stability and internal consistency and be valid.

2. Carers will perceive a difference in clients after bereavement as measured by the grief inventory.

3. The following items on the grief inventory will be related to higher grief scores: (a) poor expressive and receptive language skills and (b) high dependency upon the deceased. Higher ratings on the grief inventory will be observed for (c) men; (d) unexpected death; (e) non attendance at funeral; (f) change of residence as a result of bereavement; and (g) absence of religious beliefs/life philosophy.

4. Clients' ratings on the grief inventory will show a downward trend throughout counselling intervention.

5. Clients will have a non zero score on the concept of death structured interview prior to counselling intervention.

6. Clients' score on the concept of death will be greater at the cessation of counselling.

7. Grief inventory and concept of death scores will be negatively correlated before and after intervention.
CHAPTER Two : Method

This chapter describes the design, methodology, research sample and data analyses for Study One and Study Two.

STUDY ONE

Research Design

(1) A likert style observer rated grief inventory was developed based upon relevant literature and piloted together with a sociodemographic questionnaire on twenty primary carers of learning disabled adults who had been bereaved within the previous two years.

(2) The amended versions of the grief inventory and the sociodemographic questionnaire were completed by almost sixty primary carers of learning disabled adults who had been bereaved within the previous two years. A repeated measures design was used to assess one aspect of reliability.

Research Sample

Research participants were learning disabled adults who had suffered a bereavement within the previous two years. The sample included adults with mild, moderate and severe learning difficulties, with and without verbal skills. They were identified by Local Service Coordinators. All participants were recipients of the services provided by the Cornwall Mental Handicap Trust.

Sociodemographic questionnaires provided the following information:
Sex: Of the total sample, 23 (44.2%) were male, and 29 (55.8%) were female.

Age: Of the overall sample, 41 (71%) were between the ages of 21-60; 7 (15%) fell within the 61-70 year old category and 4 (7.6%) fell within the age range 71-80 years of age. The mean age was 47.13; Range 21-80;

Learning Difficulties: There were 13 (25%) clients who had mild learning difficulties, 12 (23.076%) who had moderate learning difficulties and 27 (51.19%) who had severe learning difficulties.

Residence: Clients lived in a variety of settings. These included; Familial Home 8 (15.38%) Staffed Domestic Home 13 (25%); Respite Home 4 (7.69%); Hospital 20 (38.4%); Mencap Home 2; Supported Lodgings 2; Social Services Hostel 1; Private Residential setting 2 (13.4%)

Expectancy of Death: According to the carers' ratings five clients expected the death: forty seven did not expect the death even although in some cases the deceased had been ill.

Language Skills: Of the total sample, 41 (78%) had varying degrees of verbal competence, whereas 11 (22%) had no verbal skills at all.
### Table 1: Sociodemographic detail: sex, age, degree of learning disability and relationship to deceased.

<table>
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<th>Mild</th>
<th>Mod.</th>
<th>Severe</th>
<th>Parent</th>
<th>G'parent</th>
<th>Resident</th>
<th>Friend</th>
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<td>0</td>
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<td>2</td>
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</tr>
<tr>
<td>71-80</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td></td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
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<td>5</td>
<td>8</td>
<td></td>
<td>13</td>
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<td>3</td>
<td>7</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SEX</th>
<th>Male</th>
<th>Mild</th>
<th>Mod.</th>
<th>Severe</th>
<th>Parent</th>
<th>G'parent</th>
<th>Resident</th>
<th>Friend</th>
<th>Uncle</th>
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<tr>
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<td></td>
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<td>1</td>
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<td>0</td>
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<tr>
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<td>1</td>
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<td>5</td>
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<td>1</td>
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<td>3</td>
<td></td>
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</tr>
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<td>0</td>
</tr>
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<td>4</td>
<td></td>
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<td>1</td>
<td>0</td>
</tr>
<tr>
<td>71-80</td>
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<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>7</td>
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<td></td>
<td>6</td>
<td>2</td>
<td>11</td>
<td>9</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2: Participants' Residences.

<table>
<thead>
<tr>
<th>Family</th>
<th>SDH</th>
<th>Respite</th>
<th>Hospital</th>
<th>Supported Lodgings</th>
<th>Mencap</th>
<th>Hostel</th>
<th>Other Home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8</td>
<td>13</td>
<td>4</td>
<td>20</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3: Time since bereavement.

<table>
<thead>
<tr>
<th>Time in months</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-06</td>
<td>16</td>
<td>6</td>
</tr>
<tr>
<td>7-12</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>13-18</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>19-24</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 1: Sociodemographic detail: sex, age, degree of learning disability and relationship to deceased.
Procedure

The initial task was to construct and produce an observer rated sociodemographic questionnaire and a reliable and valid observer rated Grief Inventory.

Questionnaires were piloted, amended and finally sent to care staff with a covering letter. (cf. Appendices) They were completed by the client's primarily carer. All client information obtained remained confidential. There was however a system of coding so that a sample for the researcher could be readily identified. A list of names was retained by the researcher with the appropriate matched code so that this reliability procedure could be carried out. After completion of data collection this list was destroyed. The information elicited by means of these questionnaires identified perceived changes in clients since bereavement.

Initial contact with Clinical Psychologists was made several months prior to data collection and the Top grade Clinical Psychologist/Executive Member of the Mental Handicap Trust alerted professionals to the research. A list of all Local Service Coordinators and Managers of Adult Training Centres in Cornwall was obtained via the Clinical Psychology department. Subsequently each 'manager' was contacted by telephone and introduced to the research aims and rationale. In addition a letter was sent to each of the managers with a short outline of the research proposals. (cf.appendix 1) Thereafter a list of carers who had contact with bereaved clients was obtained. Each carer was then contacted by telephone and was sent a copy of the questionnaires for
completion. Local Service Coordinators also alerted staff at team managers and/or circulated a memo about the research.

All carers who were contacted, indicated interest in the research and those who had clients who fulfilled the criteria for inclusion in the research agreed to complete questionnaires. Seven of the fifty nine questionnaires originally sent out with stamped addressed envelopes were not returned according to the timeline. Thus the researcher made follow up telephone calls to these carers. In three of the seven cases carers had mistakenly identified clients who did not fulfil the research criteria. The remaining four were recontacted and encouraged to return the questionnaires but failed to do so. Others who had not fully completed the questionnaires were recontacted resulting in full completion of the questionnaires. Reliability checks by test retest were made one week after original questionnaire completion.

Research Materials

Sociodemographic Questionnaire

This questionnaire focused on elements normally found in sociodemographic questionnaires eg. age, sex and so on. In addition it incorporated items of particular interest to the researcher and which related directly to the hypotheses proposed. It was made up of both quantitative and qualitative items. The first draft of the questionnaire was circulated to a lay population for comment and then to second year Clinical Psychology trainees. Moreover they were piloted among health professionals working with bereaved learning
disabled adults. (N=20)

Amendments were made to the questionnaire in the light of feedback and comments from each of these sources. (cf. Appendix 2)

**Grief Inventory**

The first major research task was to construct a reliable and valid grief inventory. This was necessitated by the dearth of research in the area. Although some grief inventories do exist, for example, The Texas Grief Inventory (Zisook, 1977, 1982), it was considered inappropriate because it relies exclusively on self reports. This was deemed an inappropriate method to use because (a) Many learning disabled adults have little or no speech; (b) the time necessary to orient to clients who do have verbal skills would be impossible within the time available to the researcher; and (c) the researcher was alert to the possible added distress and pain experienced by clients within the context of a face to face encounter. Since follow up counselling could not be guaranteed it was considered ethically inappropriate.

A review of the 'grief literature' for the general population was completed and the emotional and behavioural symptoms commonly cited and generally agreed upon by a number of authors (eg. Bowlby, 1981; Parkes, 1965; Stroebe & Stroebe, 1987) comprised the items in the Inventory.

A number of formats for the grief inventory were discussed. These included; (a) An Analogue Format and (b) presentation of
two inventories, one pertaining to the client before bereavement and the other pertaining to the client after bereavement. The latter was decided against as it might be considered too long a task and fairly time consuming.

The format of the Inventory decided upon was a Likert-type questionnaire. The item total was 24 and the range of response choices was as follows:

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Much</td>
<td>A Little</td>
<td>Same</td>
<td>A little</td>
<td>Much</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>Less</td>
<td>Less</td>
<td>As before</td>
<td>More</td>
<td>More</td>
<td></td>
</tr>
</tbody>
</table>

Respondents were asked to tick the box they thought best described their client.

(cf. Appendix 3)

Pilot Phase of Grief Inventory

Phase One

A number of non professional/non Health Workers were asked to read the Inventory and asked to make comments about the readability of the items and their suitability. Subsequently a group of seven Clinical Psychology Trainees were asked to carry out two tasks. Firstly they were asked to generate a list of items which they would expect to observe in a bereaved person. This task was undertaken independently by each trainee and written responses were obtained. Secondly, they were asked to read the Grief Inventory and make comments about style, readability and face validity.
Phase Two

The Clinical Psychology Department in a neighbouring Health district provided the researcher with a list of health care workers who work with learning disabled adults. Initial contact was made by telephone and the researcher explained the nature and aims of the project. Carers were then asked if they would be willing to participate in the piloting of the questionnaire and Inventory. All of those contacted showed great interest in the research but many reported that they did not know of any bereaved clients.

Questionnaires were sent by post and a total of twenty comprised the pilot sample.

**Reliability** was assessed at the pilot stage, on a small sample of the returned questionnaires. Test-Retest using the Pearson Product Moment Correlation coefficient revealed the following scores on a sample of four clients: 0.838; 0.836; 0.466; 0.704.

**Content Validity** (during the pilot stage)

The content validity of the Inventory was supported in the following ways:

(1) The items selected were those commonly cited in the literature.

(2) The items corresponded well with the lists generated by the Clinical Psychology Trainees.

(3) The feedback from Health Professionals working with the
learning disabled population was confirmatory and favourable. (4) Clinical Psychologists specialising in the field of learning disabilities read the inventory and made minor suggestions regarding content and format.

**Readability**

The readability of the questionnaire was assessed using the formula devised by Flesch (1948). This provides normative data for the user of the formula to estimate the percentage of the population likely to understand a piece of reading material with a given score.

The score range is 0 - 100. The lower the score the more difficult the reading text is to read. The initial draft of the Inventory produced a Reading Ease Score of 61.9 which means that 75% of the population would be able to access the text.

See Appendix 3.

**Reliability and Validity For The Research Sample**

**Test Retest Reliability** coefficient is the correlation between the obtained scores of the same group, or a sample of the same group, taking the same test on two different occasions: the closeness of the coefficient to = 1.00 indicates the reliability of the test.

If the time interval between the two administrations is very short, individuals may produce an unduly high reliability coefficient. In general, the value of the test retest...
reliability coefficient falls as the interval increases, indicating the greater likelihood that error variation is contributing to the difference in scores.

For the purpose of this study test retest was carried out one week after the original completion and results yielded the following:

Pearson Product Moment Correlation Coefficient = 0.9304
Thus indicating ** .001 level of significance (one tailed test)

**Internal Consistency**

Another test of reliability is Cronbach's Alpha. This analysis is frequently used to indicate internal consistency reliability.

The use Cronbach's Alpha serves to overcome memory and practice effects by focusing on consistency among items rather than consistency in scores over time.

Reliability analysis from this test yielded the following result:

Alpha = . 9436

Thus there is very good evidence to support the view that the Grief Inventory is internally consistent.

**Validity**

**Face Validity** refers to how appropriate a test appears to be, to the potential user or to someone actually taking the test.
During the pilot stage, responses from Clinical Psychologists, Clinical Psychology Trainees and Health Professionals all supported the Face Validity of the Grief Inventory.

**Content Validity** for the Grief Inventory is purported by the researcher on the grounds that: (a) The items used in the Inventory are those commonly cited in the literature as outlined in Chapter One and (b) The list of items generated by Clinical Psychology Trainees, when asked to include those items they would expect in a Grief Inventory of this sort corresponded well to the instrument constructed by the researcher.

**Criterion Related Validity**

This type of validity illustrates the extent to which a test relates to a direct and independent measure of that which the instrument purports to measure. The researcher encountered difficulty with this aspect of validity. For the general population, one may argue that a test such as the Hamilton Rating Scale (1960) for example, might be an instrument with which to compare a grief inventory. However the researcher decided against using such an instrument for criterion related validity or the following reasons:

(1) The value of the results gained from the scale depends entirely on the skill of the interviewer in eliciting the relevant information. The researcher has not had experience using this scale nor could she commit the time necessary to conducting the interviews.

(2) The scale rests upon verbal feedback from clients during
interview Many clients with learning difficulties have impaired or no speech at all. Moreover attempts by the researcher to adapt the interview would undoubtedly put a question mark over its validity.

(3) The researcher was aware of potential distress for participants undertaking such interviews. Therefore on ethical grounds alone, the use of such an instrument which necessitates direct client contact was rejected. Indeed this was a major reason why an interview was not used in Study One at all.

**Analysis of Data**

(1) Reliability of the grief inventory was analysed using correlational statistics. Test Retest reliability was carried out on a sample (20%) of participants. A test of internal consistency was undertaken using Cronbach’s Alpha.

(2) Carers perceived differences in clients after bereavement were analyses by the One sample t Test.

(3) The relationship between grief inventory ratings and selected sociodemographic variables, as indicated by the hypotheses, were analysed using Pearson Product Moment Correlation Coefficient. Perceived differences between groups were analysed by Independent t-Test.

**STUDY TWO**

**Design**

A repeated measures design was used for two dependent
variables:

1. Clients' concepts of death ratings.
2. Observer ratings of clients on the grief inventory.

A time sampling procedure was used for themes which emerged during counselling and a content analysis procedure was undertaken.

Participants

This group was made up of four learning disabled adults who had experienced a significant bereavement within the previous six months. Written and verbal consent was obtained from each person before counselling intervention was undertaken. (cf. Appendix 4)

The three men and one woman who participated were aged 24, 33, 43 and 54 years old. Two had mild learning difficulties and the other two had moderate learning difficulties. The woman lived in a social services hostel, one man lived in supported lodgings and the other two resided in the family home. All of these clients were referred by a Principal Clinical Psychologist who considered that these clients would benefit from bereavement counselling. He was aware of the inclusion criteria which were:

(a) Clients' will have a moderate or mild learning disability.
(b) Clients will have been bereaved within the previous six months.
(c) Clients will have verbal skills.
Method

Participants were approached in the first instance by day workers/carers to ascertain whether they wished to have counselling. The sociodemographic questionnaire and the grief inventory were completed by the primary carer before the intervention commenced. Completion of the Concept of Death interview was also undertaken by the researcher prior to the first counselling session and again at the end of the intervention. Counselling intervention followed at weekly intervals over a ten week period, either in the client's home or a counselling room made available by the Mental Handicap Trust. Grief inventory ratings were collected at two weekly intervals for the duration of the intervention and on one occasion afterwards.

To keep the completion of the grief inventory as simple as possible the items were retained in the original form but the headings reflected the two week timescale at which they were to be completed. For this study the inventory was amended thus:

During the last two weeks my client has:

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item</td>
<td>[]</td>
<td>[]</td>
<td>[]</td>
<td>[]</td>
</tr>
</tbody>
</table>

The researcher also employed a Concept of Death Structured interview based upon McEvoy (1989) who simply employed materials used in the child population and outlined in the literature. (eg. Spreece & Brent, 1984).
The structured interview had three main focal points around which appropriate questions and verbal prompts were used. These focal points were based around the concepts of (1) universality, (2) irreversibility, (3) and non functionality as related to people's understanding of death and as identified in the literature (Spreece et al.; 1984, McEvoy 1989).

In addition questions investigating perceived causes of death and what happens to the person after death were asked. (cf. Appendix 5).

Answers pertaining to the three focal points mentioned above were rated according to the following criteria: 3 = good understanding; 2 = some understanding; 1 = no understanding. Total scores were calculated for each participant.

**Pilot Phase**

This interview technique was piloted on nine adults with learning difficulties all of whom had been bereaved six months previously. The interviews were completed over a two day period with the researcher giving a "group introduction" to the research and, allowing ample time and opportunity for clients to ask questions. The length of the interviews ranged from twenty minutes to thirty five minutes. The researcher exercised flexibility in this and insofar as one can "went with the client" in terms of terminating the interview. Participants were clearly informed that if they wished to stop the interview at any stage they could do so without giving any explanation. However the researcher also
underlined the importance of the contribution they were making. All nine individuals agreed to participate; although not all from the outset.

Participants were asked if they wished all the information which emerged during interview to remain exclusive to the interview situation, or if it might it be shared with their team leader. This was to ensure that any distress which emerged as a result of the interview could in some way be followed up if necessary. Some agreed the sharing of information and others refused.

The pilot phase offered invaluable insight to the researcher and the following general information was elicited:
1. Many clients reported that it "was hard but good" to talk about death. Many of the group mentioned the loss of 'X' the member of their day centre group who had died. They identified feelings of sadness and loss at losing 'such a good friend'. Others mentioned parents and grandparents who had died and feelings related to these bereavements.
2. One client quite articulately demonstrated the importance of ensuring that participants fully understood the meaning of the questions. When asked, "Once someone has died can they come back to life?", he responded by saying "yes", and then outlined in some detail artificial resuscitation. Thus the researcher was alerted to the need to both probe and prompt until the answer given by the participant is truly the most accurate he/she can give.
3. While some clients apparently took the interview 'in their stride' there was quite obvious distress for two clients. Permission was sought from these clients to inform their
their group leader of their distress and they agreed. This was done and a follow up telephone call was made by the researcher to the team leader some time later to ascertain whether any follow up support was necessary. This distress further highlighted the need for sensitivity. It seemed to give credence to the researchers view that this area was undoubtedly one worthy of research.

**Counselling Intervention**

Undertaking counselling with clients who have a learning difficulty is a challenging and new approach with this population. The counselling interventions with all clients necessitated:

(1) Ensuring that the clients wished to engage in counselling and that they freely gave their consent.

(2) Alerting them to the possible distress involved in such a situation.

(3) Using skills developed in adult mental health to enable clients to work through their grief according to the individual situation of the client and being sensitive to the speed with which clients may progress.

(4) Assisting clients to uncover and express their emotions by means of recalling: the initial stages of grief, the scenario of when they were made aware of death, the funeral and burial of the deceased if attended. According to the needs of the client and in conjunction with guidance from the Clinical Supervisor techniques such as the use of photographs, the (Gestalt) empty chair technique and visits to the graveside were used.

(5) Since this client group, not unlike children, are often
shielded from death, the researcher, according to individual circumstances attempted to facilitate communication between the client and family members. This involved in one case, a formal joint counselling session with a client and his eighty six year old mother. However all domiciliary counselling sessions necessarily involved a willingness to listen to the distress of bereaved spouses. Thus domiciliary visits were both time consuming in terms of travel and of client and family contact. Time spent in weekly client/family contact was often in excess of two hours per session.

**Analysis of Data**

(1) Data from the bereavement inventory ratings before, during and after intervention were analysed by Manova Trend Test.

(2) Data from concept of death scores before and after were analyses by t Test.

(3) The Pearson Product Moment Correlation Coefficient was used to analyse the relationship between Concept of Death ratings and Grief Inventory scores before and after interventions.

(4) Since all counselling sessions were tape recorded, the researcher selected sessions four, five and six and subjected the content to a time sampling procedure in an attempt to identify themes and characteristics of grief as they emerged in the counselling context. Other methods of analyses were considered including discourse analysis. However this procedure is both complex and extremely time consuming.
Content Analysis

Content analysis involves the identification of important and coherent examples of themes and patterns in data and the organisation of these data into meaningful and manageable themes.

Content analysis procedures followed in this study were those outlined by Guba (1978). Inductive analysis was used to organise the data into patterns and themes. These categories included a combination of those articulated by clients and those which were labelled by the researcher. Categories were not predetermined. Efforts were made to combine and follow the rules of convergence and divergence. This task involves categorising data according to (a) those elements which fit together and (b) those which have clear distinctions.

Ethical Considerations

The researcher approached the Top Grade Clinical Psychologist in the Mental Handicap Trust, to seek guidance about ethical issues. The researcher was informed that the considerations outlined in the initial research proposal were acceptable and the need to go through the Ethics committee formally was deemed unnecessary.

The following procedures were carried out to ensure the ethical integrity of the research:

(1) All counselling sessions were tape recorded and the researcher received supervision for each client for the
duration of the counselling intervention. The supervisor was a Principal Clinical Psychologist who worked with the learning disabled.

(2) The number of counselling sessions were extended for those clients who required further counselling. Decisions regarding termination of counselling sessions were made in conjunction with the Clinical Supervisor.

(3) Clients who agreed to engage in counselling were asked to give written consent. Therefore a simple consent form was drawn up which incorporated an explanation of the aims of the research. (cf. Appendices).

(4) Clients were informed verbally and by means of the consent form that they could withdraw from the research at any point without giving any explanation.

(5) All client referring agents were informed at the beginning and at the end of the counselling intervention.

(6) Counselling sessions took place in settings selected or agreed by the client.
The first section of this chapter presents quantitative and qualitative results from Study One. All analysis were completed using SPSS/PC.

Hypothesis One

The grief inventory will show temporal stability and internal consistency and be valid.

Analyses presented in Chapter Two demonstrated high Test retest reliability with a one week interval between questionnaire completion.

Pearson Product Moment Correlation $r = 0.9304$.

The reliability coefficient is therefore significant at the $** .001$ level.

Test of Internal Consistency, using Cronbach's Alpha also indicated a high degree of intercorrelation of the items within the Grief Inventory.

Alpha = .9436

Therefore there is good evidence to support the hypothesis that the Grief Inventory is internally consistent.

Chapter Two outlined the degree to which the Grief Inventory may be considered valid. To reiterate briefly,
(a) Face Validity: refers to how appropriate a test appears to be, either to a potential user or to someone actually completing the test or inventory. Support for the face validity of the Grief Inventory comes from responses of Clinical Psychologists, Clinical Psychology Trainees, other health professionals and a lay population during the pilot stage of Study One.

(b) Content Validity for the Grief Inventory is purported by the researcher on the grounds that: (i) The items used in the Bereavement Inventory are those commonly cited in the literature and outlined in Chapter One; (ii) The list of items generated by the Clinical Psychology Trainees, when asked to include those items they would expect to see in a Bereavement Inventory of this sort, corresponded well to the inventory constructed by the researcher.

Hypothesis Two

Grief Inventory scores will indicate a difference in carers' perceptions of clients after bereavement.

Analysis: Clients' total scores over the whole scale were analyzed by the One Sample t-Test.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number of Cases</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totscore</td>
<td>52</td>
<td>75.9231</td>
<td>9.778</td>
<td>1.356</td>
</tr>
<tr>
<td>Mean</td>
<td>52</td>
<td>72.000</td>
<td>.000</td>
<td>.000</td>
</tr>
</tbody>
</table>

Table 4: Results of one sample t-test: perceived changes in clients after bereavement.

t = 2.89; df.51; p<.05

76
Results therefore demonstrate a statistically significant difference in carers' perceptions of clients after bereavement on behavioural, emotional and psychological components as measured by the grief inventory.

**Hypothesis Three**

The following items from the Sociodemographic Questionnaire will be related to higher scores on the Grief Inventory:
(a) Poor expressive and receptive language skills; (b) High dependency upon the deceased.

Higher ratings on the grief inventory will be observed for (c) men; unexpected death; (e) non attendance at funeral; (f) change of residence as a result of bereavement; (g) absence of religious beliefs/life philosophy.

(a) Poor Receptive and Expressive Language skills.

**Analysis: Pearson Product Moment Correlation Coefficient.**
(Taking totals for all items pertaining to expressive and receptive language.)

**Results:** $r = .0388; p > .05$

This is a non significant result, with no evidence for a relationship between ratings on expressive and receptive language skills and scores on the Grief Inventory.

(b) Dependency upon the deceased.

**Analysis: Pearson Product Moment Correlation Coefficient.**

**Results:** $r = .0255; p > .05$

This indicates no relationship between degree of dependency and overall grief inventory scores.
Group 1 = Males

<table>
<thead>
<tr>
<th></th>
<th>Number of Cases</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>23</td>
<td>74.3913</td>
<td>10.022</td>
<td>2.090</td>
</tr>
<tr>
<td>Group 2</td>
<td>29</td>
<td>77.1379</td>
<td>9.579</td>
<td>1.779</td>
</tr>
</tbody>
</table>

(c) Table 5: Results of independent t-test: differences in grief inventory ratings for men and women.

\[ t = 1.01; \ df.50; \ p > .05 \]

Therefore there are no gender differences on Grief Inventory ratings. Consequently, this part of Hypothesis 3 is not substantiated.

Group 1 = Death Expected  

<table>
<thead>
<tr>
<th></th>
<th>Number of Cases</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>5</td>
<td>79.000</td>
<td>7.810</td>
<td>3.493</td>
</tr>
<tr>
<td>Group 2</td>
<td>47</td>
<td>75.5957</td>
<td>9.977</td>
<td>1.455</td>
</tr>
</tbody>
</table>

(d) Table 6: Results of independent t-test: differences in grief inventory ratings for those clients who did/did not expect the death.

\[ t = .90; \ df. 50 \ p > .05 \]

Results therefore indicate no significant difference in Grief Inventory ratings between those who did/did not expect the death to occur.

Group 1 = Funeral Attended  

<table>
<thead>
<tr>
<th></th>
<th>Number of Cases</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Standard Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>20</td>
<td>78.5000</td>
<td>9.512</td>
<td>2.127</td>
</tr>
<tr>
<td>Group 2</td>
<td>32</td>
<td>74.3129</td>
<td>9.740</td>
<td>1.722</td>
</tr>
</tbody>
</table>

(e) Table 7: Results of independent t-test: differences in grief scores for clients who did/did not attend funeral.

\[ t = 1.53; \ df.50; \ p > .05 \]
Although not significant at the .05 level, the outcome statistic indicates a trend in a direction opposite to the hypothesis. Thus carers gave higher ratings to those who attended funeral services in comparison to those who did not.

<table>
<thead>
<tr>
<th>Group 1 Moved Residence</th>
<th>Group 2 Remained at Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of Cases</td>
</tr>
<tr>
<td>Group 1</td>
<td>6</td>
</tr>
<tr>
<td>Group 2</td>
<td>46</td>
</tr>
</tbody>
</table>

(f) Table 8: Results of independent t-test: differences in grief inventory ratings for those clients who did/did not change residence as a result of bereavement.

\[ t = .82; \text{df}.50, p>.05 \]

Therefore there is no statistically significant difference in the Grief Inventory scores for those who move/do not move residence as a result of bereavement.

<table>
<thead>
<tr>
<th>Group 1 Clients with identified 'beliefs'</th>
<th>Group 2 Clients with no identified 'beliefs'</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Cases</td>
<td>Mean</td>
</tr>
<tr>
<td>Group 1</td>
<td>21</td>
</tr>
<tr>
<td>Group 2</td>
<td>31</td>
</tr>
</tbody>
</table>

(g) Table 9: Results of Independent T-Test. Differences in grief inventory ratings of for clients with/without religious beliefs/life philosophy.

\[ t = .51; \text{df}.50; p>.05 \]

Therefore there is no significant difference in Bereavement Inventory scores between those with/without religious or other ideas about life and death and those with none.
Qualitative Data Analysis

Carers were asked to identify and describe, changes in their clients' (a) mood, (b) behaviour, (c) sociability, (d) physical health and (e) sleep, following bereavement.

Carers descriptions were collated into categories using a simple inductive content analysis as outlined by Guba (1978). Of the total sample, twenty six carers (50%) identified mood changes.

<table>
<thead>
<tr>
<th>Mood Change</th>
<th>n</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sad/Tearful</td>
<td>12</td>
<td>23.07</td>
</tr>
<tr>
<td>Quiet</td>
<td>6</td>
<td>11.53</td>
</tr>
<tr>
<td>Mood Swings</td>
<td>6</td>
<td>11.53</td>
</tr>
<tr>
<td>Withdrawn</td>
<td>2</td>
<td>3.84</td>
</tr>
</tbody>
</table>

Table: 10 Perceived changes in clients' mood since bereavement.

Twenty five carers (48%) indicated perceived changes in their clients' behaviour since bereavement.

<table>
<thead>
<tr>
<th>Behaviour Change</th>
<th>n</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aggressive</td>
<td>8</td>
<td>15.38</td>
</tr>
<tr>
<td>Hyperactive</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Stereotyped Movements</td>
<td>3</td>
<td>5.76</td>
</tr>
<tr>
<td>Lethargic/Listless</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Attention Seeking</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Uncooperative</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Normalized</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Agitated</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Incontinent</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Unpredictable</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Anxious</td>
<td>2</td>
<td>3.84</td>
</tr>
</tbody>
</table>

Table 11: Perceived changes in clients' behaviour since bereavement.
Of the total sample, thirteen carers (25%) identified changes in sociability since bereavement.

<table>
<thead>
<tr>
<th></th>
<th>n=</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Withdrawn</td>
<td>8</td>
<td>15.38</td>
</tr>
<tr>
<td>Uneasiness with people</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Clingy</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>More Sociable</td>
<td>2</td>
<td>3.84</td>
</tr>
</tbody>
</table>

Table 12: Perceived changes in clients' sociability since bereavement.

Of the total sample, thirteen carers (25%) reported changes in their clients' physical health since bereavement.

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight Loss</td>
<td>6</td>
<td>11.53</td>
</tr>
<tr>
<td>Psychosomatic Pains</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>General Decline</td>
<td>3</td>
<td>5.76</td>
</tr>
<tr>
<td>Psoriasis</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Improved Health</td>
<td>1</td>
<td>1.92</td>
</tr>
</tbody>
</table>

Table 13: Perceived changes in clients' physical health since bereavement.

Of the total sample, only four carers (7.69%) reported any change in sleep since bereavement and in each instance described it as 'disturbed'.

Carers were also asked to identify and describe any new
challenging behaviours which their clients manifested post bereavement. Of the total sample, thirteen (25%) reported new challenging behaviours.

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>n</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Aggression</td>
<td>4</td>
<td>7.69</td>
</tr>
<tr>
<td>Anti-Social Behaviour</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Constantly clingy</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Excitable/Noisy</td>
<td>3</td>
<td>5.76</td>
</tr>
<tr>
<td>Verbally Abusive</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Constant Attention Seeking Behaviour</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Continual Questions</td>
<td>1</td>
<td>1.92</td>
</tr>
</tbody>
</table>

Table 14: Clients' new challenging behaviours since bereavement.

In response to Item:

Describe ways in which your client communicated verbally about the death of 'X', the following statements were made by twenty one (40.38%) carers.

<table>
<thead>
<tr>
<th>Verbal Communication</th>
<th>n</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repeatedly saying the name of the deceased.</td>
<td>4</td>
<td>7.692</td>
</tr>
<tr>
<td>Reiterating 'X' is gone /dead</td>
<td>4</td>
<td>7.692</td>
</tr>
<tr>
<td>Asking where and why the person has gone</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Recalling 'when mother was live'.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Stating 'I want to die too'</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Asking for some of the deceased's belongings.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Stating it was 'a relief'.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Expressing feelings of sadness.</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Discussing circumstances surrounding the death.</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Often bringing 'mother' into the conversation.</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Continually asking if people knew that his father was dead.</td>
<td>1</td>
<td>1.92</td>
</tr>
</tbody>
</table>

Table 15: Clients' verbal communications about bereavement.
In response to Item:

Describe non verbal ways in which your client communicated, or you think tried to communicate about the death of 'X'.

The following observations were reported by thirteen (25%) carers.

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking at photographs of the deceased over &amp; over.</td>
<td>3</td>
<td>5.76</td>
</tr>
<tr>
<td>Following female members of staff around.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Psychosomatic pains.</td>
<td>2</td>
<td>3.84</td>
</tr>
<tr>
<td>Agitation at times client normally visited the deceased.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Looking out of window at times when deceased normally visited.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Avoidance of places normally visited with deceased.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Refusal to eat.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Tearful when deceased is mentioned.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Crying incessantly.</td>
<td>1</td>
<td>1.92</td>
</tr>
<tr>
<td>Ripped up all photographs of mother.</td>
<td>1</td>
<td>1.92</td>
</tr>
</tbody>
</table>

Table 16: Clients' non verbal communications about bereavement.
Summary of Results: Study One.

1. Statistical analyses indicate that the grief inventory has high test-retest reliability and high internal consistency. Face validity and content validity are considered adequate. However no other type of validity has been confirmed.

2. Carers' ratings on the grief inventory demonstrate that they perceived a difference in their clients post bereavement.

3. No correlation between expressive and receptive language skills or level of dependency and grief inventory ratings was identified.

Grief inventory ratings failed to establish any statistical differences on the basis of: gender, expected/unexpected death; attendance/non attendance at funerals; change or maintenance of residence as a result of bereavement and presence or absence of religious beliefs/life philosophy.

4. Qualitative data analysis elicited by open ended questions illustrates the ways in which carers perceive changes in their clients since bereavement. Fluctuations in response to items range from 50% of carers who cited behavioural changes in clients to only 7.69% who described changes in clients' sleep since bereavement. 40.38% of carers described verbal communications regarding bereavement, and 25% of carers cited a variety of ways in which they thought their clients were communicating or trying to communicate about bereavement. Finally 25% of sample were identified as presenting with new challenging behaviours.
Study Two

Quantitative and qualitative data results from Study Two are presented in this section.

Hypothesis Four

Client ratings on the Grief Inventory will show a downward trend throughout the counselling intervention.

N=4

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Std. Dev.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline 1</td>
<td>61.250</td>
<td>17.251</td>
</tr>
<tr>
<td>Baseline 2</td>
<td>61.500</td>
<td>15.460</td>
</tr>
<tr>
<td>Intervention 1</td>
<td>55.500</td>
<td>14.821</td>
</tr>
<tr>
<td>Intervention 2</td>
<td>64.500</td>
<td>18.877</td>
</tr>
<tr>
<td>Intervention 3</td>
<td>56.250</td>
<td>18.980</td>
</tr>
<tr>
<td>Intervention 4</td>
<td>59.500</td>
<td>13.000</td>
</tr>
<tr>
<td>Intervention 5</td>
<td>63.000</td>
<td>16.391</td>
</tr>
<tr>
<td>Post Intervention</td>
<td>64.250</td>
<td>15.671</td>
</tr>
</tbody>
</table>

Table 17: Clients’ mean scores on the grief inventory, before during and after counselling intervention.

Manova Linear Trend Test: F = 5.12121; df,3; p > 0.05

Results indicate no downward trend in clients’ Grief Inventory scores before, during or after the intervention period.

Hypothesis Five

Clients will have a non zero score on the Concept of Death Structured Interview prior to the counselling Intervention.

Four participants engaged in bereavement counselling and completed the Concept of Death structured interview before
and after intervention. Results from the former completion of the structured interview are as follows:

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Irreversibility</td>
<td>3</td>
</tr>
<tr>
<td>Universality</td>
<td>3</td>
</tr>
<tr>
<td>Non Functionality</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 18: Clients' ratings on Concepts of Death.

Thus hypothesis five is upheld. However between participant differences are marked.

Participants' understanding of the causes of death and about what happened afterwards were also elicited. The following themes emerged: each client response is presented verbatim.

<table>
<thead>
<tr>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
</tr>
<tr>
<td>Car crashes</td>
</tr>
<tr>
<td>Heart attacks</td>
</tr>
<tr>
<td>Cancer</td>
</tr>
<tr>
<td>Serious illnesses</td>
</tr>
</tbody>
</table>

Table 19: Clients' response to: What causes people to die?

Thus of the three participants who offered responses to the question, all presented explanations relating to internal biological determinants; two also specified external events or causes.
Participant 1
Person goes up to Heaven
Meet other dead people in Heaven
Family grieve
People cry and all sorts

Participant 2
People are sad
It hurts everyone

Participant 3
Don't know

Participant 4
They stay in the pit (grave)

Table 20: Clients' response to: What happens to people afterwards?

Hypothesis Six

Clients' scores on the Concept of Death structured interview will be greater at the end of the counselling intervention.

A related t-test was carried out yielding the following result: $t = 1.57; df; 3; p > 0.05$
Therefore there is no significant increase in scores post intervention. Consequently hypothesis six is not supported.

Hypothesis Seven

Grief Inventory scores and Concept of Death scores will be negatively correlated before and after intervention.

Analysis before intervention: Pearson's correlation coefficient

Results: $r = 0.2887; p > 0.05$

Analysis after intervention: Pearson's correlation coefficient.

Results: $r = 0.1010; p > 0.05$
Thus hypothesis seven is not supported by the results. There is no significant correlation, either positive or negative, between clients' scores on the concept of death and grief inventory ratings.

Qualitative Data Analysis

In order to:

describe in greater depth, themes and phases of bereavement which emerged during bereavement counselling

alternate periods of one minute duration were transcribed from counselling tapes. The first and last ten minutes of each session were excluded from this procedure because the former normally consisted of counsellor-client greetings, and the latter was used by the counsellor to summarise the session. Subsequent to transcriptions, the researcher carried out a content analysis of the data. Results of the content analysis are presented in Figures 1, 2, 3 & 4 (overleaf)
Figure 1: Bereavement Counselling Participant 1.

Sessions 4, 5, & 6.

Key

Emergent Themes

- Crying
- Recall of Illness
- Negative Affect
- Questioning Death
- Own Mortality
- Memories of Deceased
- Deceased's Presence

Frequency
Figure 2: Bereavement Counselling: Participant 2. Sessions 4, 5 & 6.

Emergent Themes

Key
- Questioning Death
- Memories of Deceased
- Own Mortality
- Deceased's Presence
- Negative Affect
- Recall of Illness
- Crying

Frequency
Figure 3: Bereavement Counselling Participant 3
Sessions 4, 5, & 6

Key
- Questioning Death
- Memories of Deceased
- Own Mortality
- Deceased's Presence
- Negative Affect
- Recall of Illness
- Crying

Emergent Themes

Frequency
0 1 2 3 4 5 6 7 8
Figure 4: Bereavement Counselling. Participant 4.
Sessions 4, 5 & 6.

Emergent Themes

Frequency

Key
- Questioning Death
- Memories of Deceased
- Own Mortality
- Deceased's Presence
- Negative Affect
- Recall of Illness
- Crying
In order to illustrate the content of themes more fully, verbatim examples of each theme presented in the graphs are given below.

Questioning Death:
"Why my daddy die?"
"I keep on asking myself why he died...no answers."
"I want my daddy back."

Memories of Deceased:
"He was the best dad in the world."
"We did everything together.."
"He terrified me.."
"He never hugged me.."

Own Mortality:
"Death terrifies me."
"I don’t go out on my bike anymore, I’d rather be safe than sorry."
"AIDS worries me."
"If I died mum would be all alone."

Deceased's Presence:
"I can hear him talking to me."
"I can see my mother at night."
Negative Affect (expressed verbally):
"I wish I could have done something to help her..."
"I feel guilty saying nasty things about him."
"If he had taken more care, he'd still be here."
"I miss my dad."
"Christmas won't be the same without him."

Recall Of Illness:
"We went to see dad in hospital..."
"He fell out of bed...we had to help him."
"My poor mummy was in agony..."

Although not all themes were present across all participants, there were commonalities.

(a) Questioning Death: This relates to participants' understanding of death and their non acceptance of the finality and irreversibility of death.

(b) Negative Affect: This pertains to the range of negative emotions verbally expressed by clients in both a direct and indirect fashion. They relate to the deceased and include, anger, guilt, regret, fear and anxiety.

(c) Recall Of Illness: Of the four clients who engaged in bereavement counselling, two had parents with longstanding illnesses. Although neither expected their parent to die, each recalled the deceased's illness. In both instances, the illnesses cited were the cause of death.

(d) Memories of Deceased: This theme figured largely across participants. Those related during counselling tended to be of a repetitive and positive nature. However the movement towards expressing negative memories also occurred.

(e) Deceased's Presence: Two clients expressed the belief
that they could either hear or see the deceased. Both were of
the firm conviction that this was real.

(f) **Own Mortality**: Two clients referred to their own mortality and fear of death.

**Summary of Results: Study Two**

1. A manova trend analysis failed to establish a downward trend in carers' ratings of clients on the grief inventory before, during and after intervention.
2. All clients had some understanding of the concepts of death as rated by structured interview. There were however, conspicuous differences between clients scores.
3. There was no statistical difference in clients' concept of death scores before and after intervention.
4. No association was established between clients' concepts of death scores and their ratings on the grief inventory either before or after the counselling intervention.
5. Content analysis of counselling transcriptions revealed common themes which emerged across clients.

These results will be discussed in the next chapter.
Chapter Four

Discussion of Results

In this chapter the results from Study One and Study two are discussed in terms of the aims of research and the proposed hypotheses.

Research Aim: To construct an observer rated grief inventory.

Hypothesis One: The grief inventory will show temporal stability and internal consistency and be valid.

Any researcher attempting to construct a new psychometric instrument must accept that such a task involves a process, where refinement re content, format and language is essential. Consequently, the present form of the Grief Inventory is in its initial stages. Nonetheless realistic efforts to produce acceptable statistical reliability and validity, which are crucial to any psychometric instrument, have been made in the present construction of the Grief Inventory. Indeed results indicate that (a) the reading age of the questionnaire is such that seventy percent of the population can read and understand it easily; (b) reliability is high and that (c) some aspects of validity have been demonstrated.

Although it may be argued that the high test retest reliability may have been influenced by the short interval between both completions, it may equally be argued that the high internal consistency demonstrated using Cronbach's Alpha
overcomes the potential problems of memory and practice on results. Future research strategies concerned with the development of the inventory might include: (a) individual interviews with bereaved learning disabled adults to ascertain first hand their experience of bereavement. This would have to be undertaken only in a context where follow up support could be guaranteed and (b) interviews with experienced counsellors/psychologists who have expertise in bereavement counselling with this client group.

However, since the inventory was constructed primarily as a research instrument for a much underresearched but significant area of human experience, it may be said that it has fulfilled a useful purpose. It has alerted carers to the issues involved in caring for bereaved adults with learning difficulties and has provided the researcher with information which may be employed in developing further the Grief Inventory.

The researcher therefore presents the Grief Inventory as having served a useful purpose as a research tool and contends that outcome data on reliability and efforts at validity suggest that it has some acceptable psychometric properties.

The use of open ended questions pertaining to the grief experience elicited in the sociodemographic questionnaire also adds useful qualitative information which may aid further evolution of the grief inventory.

Undoubtedly a number of refinements with respect to format,
and particularly with respect to validity are necessary. The researcher acknowledges that the format of the Inventory could be improved upon. One or two items may have been inappropriately phrased, for example: "Since bereavement my client has: experienced tiredness" would be better phrased: appeared tired or showed signs of fatigue. Moreover although all items were expressed in the negative the literature suggests that some phrase reversal may help ensure more thoughtful/true responses.

There are also merits and limitations related to employing a questionnaire as a measuring instrument. Interviews have been assessed as being more accurate, they maintain the interest and motivation of the person completing the task. More positively, questionnaires enabled the researcher to cover a large population. In the initial stages of research this appears a useful way of collecting a broad pool of information. Moreover in this research project, the opportunity encountered in Study Two with those clients engaged in counselling enables the researcher to gain self report information from clients themselves in an unthreatening way. This adds another dimension to the information gathered. However retrospective data may fall prey to distortions of recall through the active reorganisation of memory (Bartlett, 1932).

Finally measures of grief are for the most part designed to characterise symptomatology rather than the grieving process or adaptive behaviours. Like other grief inventories this researcher constructed inventory focuses on negative emotional states and social and behavioural manifestations.
which accompany such states. It does not address the grieving process per se.

**Research Aim:** To discover if primary carers observe a difference in their clients after bereavement.

**Hypothesis Two:** Grief inventory scores will indicate a difference in carers' perceptions of clients after bereavement.

The result indicated that carers perceived a difference on a number of psychological and behavioural components after bereavement. Thus the hypothesis was supported and it may be concluded that carers are open to and accept that clients with differing degrees of mental handicap do experience grief after bereavement.

However, the grief inventory is an observer rated instrument. Thus the results which have been elicited pertain not to the clients experience of bereavement and grief, but rather to the perceptions of the carers. Consequently the perceptions of carers are open to the influence of expectations. One carer, for example, recorded on the questionnaire that he had worked with learning disabled people for thirty years and that he held to the firm conviction that this client group never grieve. Therefore the findings of previous researchers (Oswin, 1981; Strachan, 1981) who suggest that carers assume that learning disabled people do not grieve is undoubtedly still recognisable. Such assumptions also have a direct impact on the care such learning disabled people will receive post bereavement.
Some carers reported that while they accept that their clients do grieve, they felt impotent to offer any constructive support and found broaching the subject with their clients/family member difficult and threatening. Thus moving from recognising and accepting grief in clients to intervening constructively and confidently as appropriate appears to be problematic for some carers. Again this reflects Oswin’s (1992) views that many carers are neither familiar nor comfortable with the process of grief and are uninformed and about how and when to offer appropriate supportive interventions.

Another confounding factor in carers ratings of clients may include their own feelings regarding bereavement and their own emotional state. Thus for those parents / family members who completed the questionnaire the ratings may in some way reflect their own stage of grieving .

Finally the research sample included a wide variety of people with varying degrees of ability. Consequently, the terms mental handicap or learning difficulties should not lead the reader to assume that this is a homogeneous group. Rather it comprises people with a wide variety and range of abilities and personality traits. Thus although the results demonstrate that carers perceived a difference in clients after bereavement, further research into differences between those with mild, moderate and severe learning difficulties would enrich data analysis.
Research Aim: To collect, by means of questionnaire, relevant sociodemographic data and to explore the relationship between these data and grief ratings.

Hypothesis Three: The following items will be related to higher grief inventory scores: (a) poor expressive and receptive language skills and (b) high dependency upon the deceased.

Higher ratings on the grief inventory will be observed for: (c) men, (d) unexpected death; (e) non attendance at funerals; (f) change of residence as a result of bereavement; (g) absence of religious beliefs/life philosophy.

(a) Correlational analysis did not support this part of the hypothesis. It may be proposed that no relationship emerged because although some clients have superior expressive and receptive skills in relation to others for the tasks of daily living, they may need to learn vocabulary pertinent to their emotional lives. A parallel may be drawn with the child population who may understand death in the abstract, but have very little way of talking about the experience of bereavement.

(b) Dependency on the deceased was assessed by asking how close the client was to the deceased. Again this item may have been unclear. Does closeness really underlie the concept of dependency? Literature (Leick & Neilson, 1987) indicates that a person's response to bereavement will be affected by the meaning the deceased had for the surviving person. Perhaps some indication of the meaning the deceased held for the client may have been a more appropriate assessment of dependency.
Results showed no significant difference between the Grief Inventory scores of men and women. This outcome in some way reflects the findings on conjugal bereavement which are still equivocal on the impact of sex differences on conjugal bereavement. (Stroebe and Stroebe, 1983)

It may be proposed that conventional sex differences are not as clearly delineated in adults with learning difficulties. Consequently it may be argued that there is less emphasis on conventional gender roles and expectations and this may go some way to explaining why no gender differences emerged from the data.

One may also argue that although there are indications that men are less motivated to seek social support and that this may have a direct bearing on adjustment after bereavement, the availability of social support for most learning disabled people does not depend on self motivation or the active seeking of services. Most learning disabled people find themselves in the position of being monitored for need and are actively offered or encouraged to accept support.

No statistical difference emerged on the grief inventory scores for those who expected and those who did not expect the death of the deceased. However various points should be considered. Firstly, research has shown that initially clients/patients often do not internalise traumatic news. It is difficult to assess just how the carers judged that their clients expected the death, since no further information was elicited. Communication of such news should always be verified by the carer eliciting from the client, an
understanding of what was communicated. This must surely be
doubly true in the case of adults with learning difficulties.
Moreover since discussion of death is often softened by the
use of euphemistic language the way in which it was
communicated and how often it was communicated is crucial in
any assessment of the effect of expected or non expected
bereavement. Finally, clients understanding of the concepts
of death may have confounded carers assessment of the
situation.

Interestingly, some carers did indicate that the death was
expected but that the client was excluded from sharing such
information because families did not wish them to know. This
indicates that the conspiracy of silence described by
Strachan (1981) and others is still alive and well.

(e) It was hypothesised that non attendance at funeral would
increase clients scores on the grief inventory. However
results indicated no statistical difference between those who
did or did not attend funerals. Attendance at funerals has
been shown to help the bereaved person realise the death,
with the support and help of others (Goldberg, 1981). It also
provides the opportunity to talk openly about the person and
to express feelings. However in the case of people with
learning difficulties the funeral may in fact have the
opposite effect. Verbal reports from carers indicated that
the funeral experience for their clients was particularly
distressing because (a) some were not told about the death or
funeral until the day it was due to take place and (b) some
families instructed carers to sit with the client at the back
of the church, because they might in some way disrupt the
service or become too distressed. Thus in this context the
funeral provides neither the opportunity for leavetaking, nor
a supportive setting for the client to express grief. More
information about the experience of the funeral for all
clients would help the researcher to assess its impact on the
grieving process. It also does not explain why almost half of
the sample did not attend the funeral services.

(f) Results did not support this part of hypothesis three. It
may be suggested that clients were well prepared for
bereavement or that a change from the previous residence
resulted in a more enriching and secure environment. This
suggestion is based upon verbal communication from a carer
who participated in the pilot phase of the research. He
recounted a situation where the client had been kept indoors
for a number of years by his carer and that his living
situation was characterised by a lack of stimulation and
emotional warmth. However this possible explanation remains
unverifiable and speculative. However it may be interpreted as
a hopeful sign that such a small number of bereaved people
were obliged to move residence after bereavement.

(g) Results indicate that those with known belief systems
were rated no differently on the grief inventory. A number of
points may be made. Firstly all clients with identified
belief systems, or ideas about life and death, were described
in terms of religious beliefs. It is not known however
whether such information was elicited from case notes or
direct conversation or knowledge gained from client. Thus
someone may be identified as having a religious faith solely
on the grounds that they come from a family who hold

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religious beliefs. Secondly, literature on the influence of religious beliefs and bereavement outcome is not straightforward since religion is a multifaceted concept/experience. Glick et al., (1974), for example, reported that religion was of great comfort to bereaved widows and Heyman & Gianturco (1973) found that church affiliation provided emotional strength for widows. Since these are subjective reports they do not actually investigate specific relationship between religiosity and bereavement outcome. Clayton, Halikas, et al., (1973) however did find an association between depressed and nondepressed groups in church attendance. Therefore it may be that religious beliefs per se help bereaved people or that the social support network of the religious community protects the individual from the adverse effects of life stress, including bereavement. Unfortunately since no data on church attendance and church related networks was elicited in the study it is difficult to assess this factor further.

Qualitative Data

Qualitative data gained via the questionnaire and reported in the previous chapter provides additional insight into client changes perceived by carers. In summary, carers perceived differences in behaviour, sociability, mood, physical health and sleep patterns of their clients. However the numbers of carers reporting each of these items varied considerably. The largest number of perceived changes related to mood, with 50% of carers describing a variety of change, closely followed by changes in behaviour (48%). Sleep disturbance on the other hand was
reported by only seven percent of all carers. It may be argued that changes in mood and behaviour are more obvious and apparent in day to day living, whilst sleep disturbance may only be noted if either the person reports it or carers themselves are disturbed during the night by the client. Moreover the categories chosen by the researcher, although important to the study of bereavement, may be said to overlap. Thus changes in sociability may be described under behavioural changes by some carers. The unclear delineation between categories may have contributed to lack of response by carers. Moreover the disparity of responses may also be related to the type of residence in which the client was living. People living in family homes or staffed domestic houses may be monitored less during the night than people in hostels or hospitals. Additionally professional carers and family members may report in different ways, with professionals being more able or more often asked to report in such fashion.

Data describing ways in which clients communicated or were perceived to communicate about bereavement included verbal and non verbal media. Verbal communications were concrete in nature. They indicated to some extent the preoccupation with the deceased that has been identified in bereaved people, and revealed something of clients emotional responses to bereavement.

While learning disabled people undoubtedly experience powerful emotions they may be less well adept at expressing them clearly. It is crucial therefore that carers become skilled in listening to and addressing underlying issues and
emotions communicated in statements such as, "I want to die too." For many adults with learning disabilities one of the tasks of bereavement will be to develop a language that gives them the tools to talk about death and their grief. This is not a task which they can successfully undertake alone.

A variety of behaviours were interpreted by carers to be communications about loss. Although the descriptions pertain to a small number of clients only, they do seem to reflect some of the known ways in which people in the general population express their grief.

While acknowledging some methodological limitations of the present study, the qualitative data elicited is useful and indicates that at least a number the components of grief identified in the general population are observed in bereaved learning disabled adults. Most notably these include: sadness/tearfulness, aggression, social and emotional withdrawal and changes in physical health. Moreover the emergence of a variety of new challenging behaviours identified in twenty five percent of participants in this study, suggests that this may be one way in which learning disabled people may manifest their grief. This data supports previous research findings (Emerson, 1977) and re-emphasises the need to educate carers in the understanding and recognition of possible grief reactions. If such education is not routinely offered to care staff, interventions offered to bereaved learning disabled people may be limited solely to "medication or modification". (Crick, 1988; Conboy-Hill, 1992). Such intervention may retard if not thwart the normal grieving process.
Study Two

Research Aim: To compare clients' ratings on the bereavement inventory before, during and after bereavement counselling intervention.

Hypothesis Four: Clients' ratings on the grief inventory will show a downward trend throughout the counselling intervention.

Results do not support the above hypothesis. However a number of important points are worth making.

1. Clients expressed a need to continue with counselling and all reported finding it useful. At various stages they were asked if they wished to continue or terminate the intervention. All affirmed their desire to continue. Indeed termination of counselling intervention for two clients was a difficult issue to contemplate.

Termination of client-counsellor contact is a crucial stage in any therapeutic intervention but more so in bereavement counselling. It may be proposed that such a leavetaking reflects in some way the experience of bereavement itself. Consequently it may result in clients reexperiencing painful aspects of grief. For those who have not resolved grief issues it may potentiate an upsurge in grief symptomatology. Conversely it may be used to therapeutic advantage as an inroad to pertinent grief issues for the client.

In this research study clients were informed at the beginning of the counselling intervention that there would be ten sessions. They were reminded about termination three weeks before the end of the intervention and on each subsequent week. They were also encouraged to disclose how they felt
about the forthcoming termination and the final leavetaking was clearly structured and communicated.

(2) The experience helped to define counselling approaches which would be of use in the future. There is a need to clearly structure counselling sessions since many learning disabled people are unused to counselling as an intervention and find difficulty using the therapeutic session to address issues. The use of art and other creative ways of gaining inroads into psychological processes especially the identification of emotions would be helpful. Moreover Conboy-Hill's (1992) maxim of quitting while you’re ahead is invaluable. The attention span of clients vary and the counselling clock should be flexible enough to accommodate this.

(3) The surviving parents of two of the bereaved clients had particular difficulties adjusting to bereavement. This necessitated individual support sessions, although it was made explicit that such discussions were not formal, contracted counselling sessions. In one instance the distress experienced by the client and his surviving parent was so great that one joint formal counselling session was undertaken. Insight gained at this joint session was invaluable. One point will illustrated. The client would often speak in whispers when referring to the deceased. During the joint session it was observed that the surviving parent also did this. Therefore the counsellor explored with both individuals why they were doing so. It was apparent that this was a strategy of protection undertaken by the mother and subsequently adopted by the client. It underlined
difficulties in communication re the death and fears that the mother had discussing her feelings with her son.

The researcher modelled open clear discussion regarding grief and subsequently mother and son both reported more open discussion about the deceased.

This episode exemplifies that family systems have implicit and explicit rules (Ford, 1993), including rules that deal with emotional expression. Thus because of the functioning of family rules, a family may or may not be helpful in dealing with grief. Consequently those who undertaking bereavement counselling with people who have learning disabilities may wish routinely to employ family therapy/counselling sessions as part of intervention plan. This approach may be equally useful to those clients living in residential settings, where there will also be sets of implicit and explicit rules at work.

(4) Related to the issue above was the decision to include carers in the pre counselling interview pertaining to the clients concept of death. Carers reported that this was the first time they heard the client say many things about what they understood and how they felt about death. Whilst potentially distressing for carers, it may be viewed as a necessary step in ascertaining styles of communication or lack of communication within the family context and may subsequently facilitate communication between family members/carers.

(4) It may have been overambitious to suggest that over the
intervention period there would be a downward trend in grief ratings. It may have inadvertently given tacit support to the idea that people in the initial stages of bereavement should be counselled or 'therapised' out of grief. Finally, long term benefits of early supportive intervention with this client group may be an area worthy of future research.

Hypothesis Five

Clients will have a non zero score on the Concept of Death structured interview prior to the counselling intervention.

Results indicate that all clients had an understanding of some of the concepts of death. Ratings however varied markedly across clients. For the sake of clarity, clients will be referred to as K, N, J and C.

Irreversibility: K and C demonstrated at interview that they had a clear and mature understanding of the concept of irreversibility. That is they identified that once a person has died they cannot be brought back to life. Clients N and J both reported that it was possible to bring a dead person back to life. Although questioned about how this might be achieved one client said he did not know, while the other contended that if you "just love them" they could come back to life.

Universality pertains to the view that only things which are alive die, and that we will all die one day. The question relating to the former idea was: Do things die? In all
instances the researcher further clarified the question by listing a set of inanimate objects. Clients K and C reported that things do not die but further explanation was not given by either. N and J expressed the view that things did die. With respect to the concept that all people die K and J asserted that this was their belief. However N and C protested vehemently that this was not so.

The researcher also investigated clients' concept of their own mortality. Client K and C asserted that they would die. However K, stated that this thought terrified him, and qualified his response by stating that he thought it would happen when he was about one hundred. This may simply be an indication of the difficulties that learning disabled people have with the concept of time. However it may also be explained, in psychoanalytic terms, as a defence. That is the contemplation of one's own mortality is one which is difficult to embrace. Clients N and J clearly and vigorously reported that they would not die. However, as Rochlin (1967) states:

"What is remarkable is not that children arrive at the adult view of the cessation of life, but rather how tenaciously throughout life adults hold to the child's beliefs and how readily they revert to them"

In this way N and J's vigorous defence of their immortality may be explained. Also Anthony's (1971) suggestion that the notion of animism is assumed to precede or go hand in hand with the notion of death, is borne out by N and J's response.

Non Functionality: Clients K and C clearly expressed their
understanding of the concept and confirmed that they knew that death meant the cessation of life defining functions. On the other hand N and J both stated that all life defining functions were retained. This view was maintained although the researcher was at pains to explore and question clients thoroughly. Thus it can been seen that clients varied greatly in their understanding of death.

The researcher also explored two other related areas. Firstly, clients were asked: **What causes people to die?**

Results reported in Chapter Three, demonstrate that: One client (J) reported that he did not know; N cited illness/disease, whereas K and C included both disease/illness and external factors, ("car crashes" and "air pollution"). The finding that illness predominates as the perceived cause of death suggests that these clients do not see death as an internal biological process which operates according to natural laws.

Comparisons may be drawn with the literature on children’s concepts of death. It has been demonstrated, for example, that between the ages of 7-11, children move from believing death to be externally caused to believing that illness is the result of internal biological dysfunction. Although older children also cite illness and external causes, they demonstrate an appreciation of the biological inevitability of death. This was not established by clients in the present study and is consistent with McEvoy’s (1989) findings.

Finally clients were asked: **What happens to the person**
afterwards?

Interestingly only two clients (K) and (N) gave relevant answers. The former related to life after death whereas the latter was funeral associated. These clients also mentioned emotional content, for example, "Family grieve", "people cry and all sorts"; "It hurts everyone...people are sad".

The distress involved in asking such direct questions about death to recently bereaved adults was apparent. Moreover, since they were conducted during the first client/counsellor encounter, one may also submit that use of inappropriate language may have contributed in some way to results. There was insufficient time, for example, to attune to the clients emotional vocabulary which may have affected communications and thus researcher ratings of clients concepts of death. As Conboy-Hill (1992) suggests, it is essential to help learning disabled clients to learn a vocabulary to describe their feelings. One might also suggest that client/counsellor rapport is a prerequisite to undertaking such an interview and that this may have an effect on client response and ratings.

**Research Aim:** To examine the relationship between clients' concepts of death and grief inventory ratings before and after intervention.

**Hypothesis Six**

Clients' scores on the Concept of Death structured interview will be greater at the end of the counselling intervention.

Results show no difference in scores pre and post
intervention. It is difficult to explain just why no differences emerged in client concept of death ratings after intervention. However one client who had a mature understanding of death, scored the highest possible rating prior to counselling and another could only have increased his score by one. Therefore this undoubtedly affected ratings comparisons as there was a ceiling effect.

Another client, N disclosed that she ‘saw’ her mother every evening. She was convinced that this experience reflected reality. ‘Seeing’ her mother every night conflicted with the reality presented to her by the counsellor, namely that dead people don’t come back to life and that they cannot walk, talk and so on. Consequently the concepts of irreversibility, nonfunctionality, and universality were incompatible with her experience.

**Hypothesis Seven**

Grief inventory scores and concept of death scores will be negatively correlated before and after intervention.

Results did not support this final hypothesis and therefore suggest that level of conceptual understanding of death does not necessarily affect the distress experienced by people with learning difficulties. Moreover it is difficult to assess how much this result was affected by the emotional defence of denial. Some participants seemed to fluctuate during the counselling intervention from a clear understanding and articulation of, for example the concept of irreversibility, to a vigorous assertion that the deceased
would come back. This in some way reflects what Parkes (1965a) refers to as the oscillation between phases of bereavement. Indeed during the yearning and protest phase the person has an overriding urge to search for the deceased. Thus in spite of the knowledge that the person is dead there exists a desire to try to recover the person, which is impossible to overcome during this period. It may be that client scores on the concept of death interview and their carers ratings simply reflect this process.

Qualitative Data

Content analysis of counselling transcripts yielded some significant information about the themes and phases of grief experienced by learning disabled adults. It is acknowledged however that content analysis as a procedure is part science, part art, and that since the researcher was also the counsellor, there may be a possible bias effect. Moreover the transcripts relate to a sample of only three counselling sessions per client.

Nevertheless a number of recurring themes and ideas did emerge which were categorised and classified across clients and presented in Figures 6, 7, 8, and 9.

All themes presented in this study have been identified in the grieving process for the general population. Preoccupation with memories of the deceased, for example, is referred to in the literature as being a characteristic of the yearning and protest phase of grief. Such preoccupation was evident during the counselling sessions for three of the
four clients.

Questioning death pertains to clients non acceptance of the death. This theme emerged across all clients. Again the literature on grieving in the general population identifies the desire on peoples' part to try to recover the person, as a result of intense longing, and in spite of the knowledge that the person is dead. It is most apparent in the early stages of grieving. The Gestalt empty chair technique was used with two of the four counselling clients in an attempt to effect leavetaking.

Two clients reported seeing or hearing the deceased. Such images are almost hallucinatory and leave people with the firm conviction that they have in fact seen or heard the deceased. However while hallucinations are normally viewed as a psychotic feature, they may be present at the beginning of an otherwise normal grief reaction and are not unheard of in the general population. (Leick et al., 1991)

A variety of expressions of negative affect, including, guilt and anger were unmistakable across all clients. These painful emotions were addressed during counselling primarily through a process of normalisation, by indicating and reassuring clients that such emotions were neither out of place nor unusual in people who were grieving. Consequently clients were actively encouraged to express such emotion. Such an approach has already been demonstrated to be effective in addressing negative affect in grieving people.

In conclusion it is proposed that the limited data presented
in this study regarding the grieving process experienced by learning disabled adults gives weight to the view that this population grieve in similar fashion to the general population. Individual differences are to be expected since not all people grieve in the same way at the same time. Stages of grieving are not rigid and sequential. Also it should not be assumed, as the literature indicates, that all people go through every stage of grief.
Implications For Service Delivery

Results from this study provide a firm foundation from which to proceed in the much underresearched area of bereavement in adults with learning difficulties.

Moreover a number of implications for service delivery may be delineated:

All carers of learning disabled people should be aware of the normal grieving process and additional potential difficulties which may be encountered by bereaved learning disabled people. Consequently, a number of recommendations are made:

1. Induction courses for new care staff should include workshops on bereavement and grief. This may give carers the opportunity to express doubts and anxieties about dealing with such a potent issue. Additionally it will hopefully address the self fulfilling prophecy that people with learning difficulties do not grieve.

2. If a relative of a learning disabled person is known to have a terminal illness, relevant professionals should initiate and maintain contact at an appropriate level for the duration of the course of illness and in the initial stages of bereavement. This will facilitate communication between client and family about crucial issues such as the right of the learning disabled person to make his/her own decision about saying goodbye to the person and about attendance at funerals. It may also proffer the opportunity for
counsellors/psychologists to assist the client to develop a vocabulary to express emotional content. This will have implications for the efficacy of post bereavement counselling which ideally should be undertaken with the same counsellor.

(3) Any counselling intervention undertaken with bereaved learning disabled adults who are resident in the familial home, should routinely include family counselling. This will enable identification of any systemic maladaptive ways of coping with bereavement which may affect the learning disabled individual in the resolution of grief.

(4) The systemic context for learning disabled people also includes small staffed domestic houses, hostels, supported lodgings and hospitals. Like families, those employed in residential care settings should also be assisted to identify their coping mechanisms both facilitative and maladaptive as these impact the bereaved person's resolution of grief.
Dear

I am a final year Postgraduate Clinical Psychologist in Training at the University of Plymouth and I am conducting a research project on bereavement and adults with learning difficulties.

I am sure you know that this is an area where very little useful research has been done, yet it is a painful area which at one time or another will undoubtedly affect the lives of some of your clients.

In order to carry out this research I need the assistance of your staff who work directly with learning disabled clients who have been bereaved. I hope that you feel able to help me in this work by supplying a list of the names of those clients who have been bereaved within the last two years.

Attached to this letter you will find a short outline of the
Appendix 1. cont'd.

research proposal, the names and telephone numbers of my supervisors, the questionnaire your staff will be asked to complete, and the covering letter I will send to all those carers involved in the study.

Please do not hesitate to contact me at the above address or on *telephone number* after 6pm. Alternatively you may wish to contact any one of my supervisors.

I look forward to hearing from you soon.

Yours sincerely,

Maureen T. Fitzpatrick.

Clinical Psychologist in Training.
BEREAVEMENT IN ADULTS WITH LEARNING DIFFICULTIES.

Part One

Primary carers of learning disabled adults who have been bereaved within the previous two years will be asked to complete a grief inventory and a questionnaire pertaining to sociodemographic information.

The aim of this part of the study is to identify if there are any perceived changes in the clients since bereavement.

Part Two

Carers involved in this part of the study will be asked to complete the grief inventory at specified intervals while the clients receive grief counselling. They will also be asked to complete a sociodemographic questionnaire.

Up to six learning disabled adults bereaved within the previous six months will be offered up to ten counselling sessions by the researcher. The aim of this is to offer support to clients and to identify themes and phases of bereavement as experienced by these clients.
Appendix 1. cont’d

Only those with verbal skills and moderate or mild learning difficulties will be offered counselling. Written consent will be obtained from clients prior to counselling.

FIELD SUPERVISORS

Mr. Frank Baker, Principal Clinical Psychologist.
Tel. 0209 219251

Mr. Kevin Simpson, Principal Clinical Psychologist.
Tel. 0208 73281

Dr. A.T. Carr, Academic Supervisor, Clinical Teaching Unit

University of Plymouth. Tel. 0752 600600
Appendix 2.

Confidential

Client: Male / Female

Age:

Relationship to deceased..........................

How many months ago was your client bereaved?.............

Did your client expect the death? Yes / No.

How often did your client see this person?

Every day [ ]

Once a week. [ ]

Once a fortnight [ ]

Once a month [ ]

Other [ ] Please detail.................................

Did your client attend the funeral / cremation? Yes / No.
Appendix 2 cont'd.

Did your client live with the deceased? Yes / No.
If 'Yes' please detail...........................................

Did you client move residence at the time of bereavement? Yes / No.
If 'Yes', please detail...........................................

Where does your client now live?
SDH [ ]
Family Home [ ]
Mencap Home [ ]
Respite Home [ ]
Hospital [ ]
Other [ ] Please detail.................................

Did your client receive any help for problems linked to bereavement? Yes/ No.
If 'Yes' what type ( eg. behaviour programme, new home, medical, social, counselling)

........................................................................
........................................................................
........................................................................
........................................................................
........................................................................
Appendix 2 cont'd.

Can you describe your client's ideas about life and death. Yes / No.
If 'Yes' please give details (eg. religious beliefs)

How would you describe your client's relationship with the deceased?
Very     Quite     Quite     Very
Close    Close     Detached  Detached

Are your client's learning difficulties:
Severe     Moderate     Mild
[ ]        [ ]         [ ]

Do you have any test results which back this up? Yes / No.
(eg. WAIS score)
If 'Yes', please detail

How does your client express her/himself?
Appendix 2 cont'd.

<table>
<thead>
<tr>
<th>Mainly Verbally &amp; Gesture</th>
<th>Verbally by gesture</th>
<th>No effective Communication</th>
<th>Other</th>
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</table>

If you client communicates verbally, does he/she use:

<table>
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<tr>
<th>Mainly Sentences</th>
<th>Short Phrases</th>
<th>Single Words</th>
</tr>
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</table>

How would you describe your client's understanding of the spoken word?

<table>
<thead>
<tr>
<th>Very</th>
<th>Good</th>
<th>Poor</th>
<th>Very</th>
<th>No understanding</th>
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</table>

Has your client shown any new challenging behaviours since bereavement?  Yes / No.

If 'Yes', please detail:

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Appendix 2 cont'd.

Please write down any way in which your client communicated or you think tried to communicate about their loss. (e.g. saying person's name over & over: looking out of window at the time the person normally visited)


In your own words please describe the effects that this death has had on your client.

Changes in Mood.


Changes in Behaviour


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Appendix 2 cont'd.

Changes in Physical Health

Changes in Sociability

Changes in Sleep

Please add any other comments you think may be useful.
Appendix 2 cont'd.

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE.
YOUR HELP IS GREATLY APPRECIATED.
Appendix 3

I am interested in any changes which you have noticed since your client was bereaved.

Please rate your client on each of the items below by placing an 'X' in the box which you think best describes your client.

1 = Much Less  2 = A Little Less  3 = Same as Before
4 = A little More  5 = Much More  N/A = Not Applicable.

Since bereavement my client has:

<table>
<thead>
<tr>
<th></th>
<th>1=Much Less</th>
<th>2=A Little Less</th>
<th>3=Same as Before</th>
<th>4=A Little More</th>
<th>5=Much More</th>
<th>N/A=Not Applicable</th>
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<tbody>
<tr>
<td>Appeared Depressed</td>
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<tr>
<td>Shown Poor concentration</td>
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<tr>
<td>Been Irritable</td>
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<tr>
<td>Had Temper Outbursts</td>
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<td></td>
<td></td>
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<tr>
<td>Smoked Cigarettes</td>
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<tr>
<td>Needed Medication</td>
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<tr>
<td>Had Poor Appetite</td>
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<tr>
<td>Been Socially Withdrawn</td>
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<tr>
<td>Cried</td>
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<tr>
<td>Appeared Restless</td>
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<tr>
<td>Had Minor Illnesses</td>
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<tr>
<td>Appeared Nervous</td>
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Appendix 3 cont'd.

1 = Much Less  2 = A Little Less  3 = Same as Before  4 = A little More/  5 = Much More  N/A = Not Applicable.

Since bereavement my client has:

<table>
<thead>
<tr>
<th>Disorder</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>N/A</th>
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<tbody>
<tr>
<td>Been Unable to Enjoy herself</td>
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<tr>
<td>Experienced Tiredness</td>
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<td>Had Memory Problems</td>
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<td>Looked Sad</td>
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<td>Withdrawn from Hobbies</td>
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<tr>
<td>Appeared Agitated</td>
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<tr>
<td>Complained about Physical Wellbeing</td>
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<tr>
<td>Shown Fearful reactions</td>
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<tr>
<td>Had Sleep Difficulties</td>
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<tr>
<td>Had Major Illness</td>
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<td>Been Clingy</td>
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<td>Shown a Loss of Skills</td>
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</table>
Appendix 4

Consent Form

I wish to spend some time talking with Maureen T. Fitzpatrick about the feelings and thoughts I have about the death of ____________________________.

I know Maureen can offer me ten sessions and that if I want to stop seeing Maureen at any time I am completely free to say so. I do not need to say why I don't want to see her any more.

I know that Maureen is going to ask ____________________________ some questions about how I have been feeling recently.

I also know that Maureen is going to be writing a research paper about how people with learning difficulties feel and think after someone we love dies. I know that in the paper she will write about me and some of the things we will talk about, but my name will not be mentioned and no-one reading the paper will know it's about me. I will not be the only person Maureen writes about.

I sign this paper to say that I give my permission to Maureen to include me in her research.

Client signature________________________________________

Date______________________________________________________
Concepts of Death Structured Interview

I am going to ask you some questions about what you think about death and dying. There are no right or wrong answers. I just want to find out what you think about it. Some of the questions might make you feel a bit upset. If they do let me know.

1. Irreversibility
   Can you make dead people come back to life?

2. Universality
   Do things die?
   Does everybody die?
   Do you think you will die?

3. Non Functionality
   When someone dies can they still breathe, hear, see?

4. What causes people to die?

5. What happens afterwards?
REFERENCES


