

GRIEF AND LOSS FOLLOWING TRAUMATIC BRAIN INJURY

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By

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DECLARATION

**This work has not been submitted to any other institution
or for any other qualification.**

SUMMARY

Literature Review: The literature review summarises the main theoretical models of grief and illustrates how these have developed from intra- to inter-personal models and from clinical to psychosocial models of bereavement. The paper explores the concepts of pathological, anticipatory, and disenfranchised grief, and attempts to identify aspects that are relevant to grief in contexts other than bereavement. Finally an attempt is made to integrate themes from the literature that are applicable to the experience of loss amongst relatives of traumatically brain-injured patients. Some useful concepts are identified, but there is not yet an adequate description in the literature of the characteristics and time course of the experience of grief in this population.

Research Paper: - This research paper seeks to contribute to our understanding of grief and loss in the relatives of brain injured people. The study investigated the utility of a modified form of the Inventory of Complicated Grief as an appropriate measure of grief, and explored the hypothesis that unresolved grief was associated with poor family adjustment following traumatic brain injury. The study found that the Inventory of Complicated Grief had potential to be a useful assessment tool, with some further modifications, but in this small study, it was not possible to identify a component of grief distinct from anxiety and depression that predicted family adjustment.

Critical Appraisal: - The process of identifying and carrying out the research study is discussed. The direction of the study was influenced both by clinical questions and practical issues. Factors that assisted the process or made it more difficult are described. Finally, consideration is given to the question of future research in the light of the experience of carrying out this particular project.

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THE CONCEPT OF LOSS FOLLOWING TRAUMATIC BRAIN INJURY

“The spouse cannot mourn decently. Although he has lost his mate as surely and permanently as if by death, since the familiar body remains, society neither recognises the spouse’s grief nor provides support and comfort that surrounds the bereaved by death” (Lezak 1987)

SUMMARY

The first part of this review summarises the main theoretical models of grief and illustrates how these have developed from intra- to interpersonal and from clinical to psychosocial models of bereavement. It offers a general critique of the research in this area. The second part of the paper explores the concept of pathological grief and its relationship to normal grief, and the concepts of anticipatory grief and disenfranchised grief. These concepts are examined in detail to identify aspects that are relevant to grief in contexts other than bereavement. The third part attempts to integrate themes from the literature review that are relevant to the experience of loss amongst relatives of traumatically brain injured patients. The normal models of grief, which are predominantly bereavement –focused, have little to contribute in these cases. There are similarities between the risk factors for pathological grief and for the pattern of occurrence of traumatic brain injury, but it is not clear that the concept of pathological grief is helpful in these cases. The difficulty of grieving whilst caring is illustrated in the literature concerning anticipatory grief, but the lack of a defined endpoint for relatives following traumatic brain injury alters the pattern of response. It is the concept of psychosocial death that is most directly relevant to the experience of loss amongst these family members, but as yet there is little research in the literature that adequately describes the characteristics and timecourse of this concept for this group of people.

INTRODUCTION

The sense of loss experienced by relatives of brain injured individuals is different from normal bereavement or from sudden death in that the loved one is still present. Little is known about the process by which individuals or families grieve or cope with this type of loss.

This paper will begin by defining the terms used in the literature to describe grief, mourning and bereavement. The major models of normal grief described in the literature are then reviewed and the methodological problems inherent in research in this area are discussed. Secondly, the paper will review the literature concerning pathological and atypical grief reactions and identify aspects that are relevant to grief in contexts other than bereavement, and in particular, in relation to grief in caregivers. Finally the paper will attempt to identify themes from the literature that are relevant to the experience of loss amongst relatives where they continue to provide care and support to a family member who has sustained a traumatic brain injury. With traumatic brain injury the initial damage is caused by an external event such as an assault, fall, or road traffic accident, as distinct from an internal event such as a stroke or brain infection.

Definitions

The terms bereavement, grief, and mourning are often used interchangeably. For the purpose of this paper *bereavement* is defined as the objective situation of recent loss of someone significant through that person's death. *Grief* is the emotional or affective response to loss. *Mourning* is the action(s) expressive of grief.

Normal grief has been the subject of an extensive literature since Freud's (1917) paper "Mourning and Melancholia". A brief review of the models of grief is given below. Although the models provide different explanations and interpretations, there is common agreement about the symptoms of grief (see Table 1) and that *normal grief* can be described in a number of 'phases' or 'stages' (variously defined in the different models, see Kubler Ross 1969, Bowlby 1981, Parkes 1970), beginning with numbness that may last for hours or days, moving through a period of yearning and protest, which alternates with despair, until there is recovery and restitution, although the assumption that a state of resolution is attained following normal grief was challenged by Wortman and Silver (1989). They reported evidence that suggested that for some people such a state of resolution is not achieved.

The concept of *pathological grief* was first introduced by Freud (1917) who saw it as the basis of clinical depression. It includes variants such as *absent grief*, *chronic grief* and *distorted grief*. The concept has undergone a number of refinements and reformulations which are discussed in more detail later in the paper.

Atypical grief is a blanket term that has been used to cover all forms of non-normal grief, including pathological grief. In this paper it has been used to encompass the concepts of *anticipatory grief*, which is a term originally introduced by Lindemann (1944) and refers to a grief reaction that is experienced prior to an actual death, and *disenfranchised grief* which was a term used by Doka (1989) to describe the position of someone who experiences a sense of loss but does not have a socially recognised right, role, or capacity to grieve.

Table 1: List of Grief Symptoms

Affective	Depression Anxiety Guilt Anger and hostility Anhedonia Loneliness
Behavioural manifestations	Agitation Fatigue Crying
Attitudes toward self, the deceased, and the environment	Self reproach Low self esteem Helplessness, hopelessness Sense of unreality Suspiciousness Interpersonal problems (withdrawal from social functions) Attitudes toward the deceased (yearning, idealisation, ambivalence, preoccupation)
Cognitive impairment	Retardation of thought and concentration
Physiological changes and bodily complaints	Loss of appetite Sleep disturbances Energy loss Somatic complaints Changes in drug taking Susceptibility to illness and disease

(Adapted from Stroebe & Stroebe (1987))

MODELS OF NORMAL GRIEF

There is an extensive literature on models of grief which contains three broad approaches to understanding grief. 1) The first, and for many years most dominant, of these approaches followed Freud's (1917) paper which focused on grief and depression. In their various forms the depression models analyse grief as an emotional response to loss and seek to provide an understanding of many of the emotional symptoms of the grief reaction. Over the years the models have drawn on core themes in psychological theory including psychoanalytic theory, attachment theory, behavioural theory, and cognitive

theory and the contributions made by each of these models to our understanding of normal grief resolution are discussed in more detail below. 2) The second major approach has described grief in terms of a response to an overwhelming life event, and has drawn on the model of coping with stress developed by Lazarus and Folkman (1984). Stroebe & Stroebe (1987) in particular have developed an understanding of the emotional and physical consequences of partner loss by applying the general principles of the psychological stress model to conjugal bereavement and this is discussed below.

3) The third approach is one that seeks to integrate the various models and to provide a holistic framework that encompasses different forms of loss, and to place grief and loss in a broader socio-cultural domain. Two such approaches, that of Schneider (see Frears & Schneider 1981) and Jacobs (1993) are described below.

1. Depression models

a) Psychoanalytic theory

In his classic paper "Mourning and Melancholia" Freud (1917) sought to demonstrate that grief ('mourning') could serve as a model for clinical depression ('melancholia'). He described both as reactions to a loss, and that they were characterised by depressed mood, loss of interest, and inhibition of activities. Individuals are assumed to develop attachment or love toward those persons who are important for the satisfaction of their needs. In psychoanalytic theory love is conceptualised as the attachment (cathexis) of libidinal energy to the mental representation of the loved person (the object). The more important a person is, the greater the attachment. When a loved person is lost through death the survivor's libidinal energy remains attached to thoughts and memories of the deceased. Since the individual has only a limited pool of energy at his or her disposal, this attachment to the lost object has to be abandoned in order to regain the energy resources bound by the lost object. To sever these ties to the object requires the

investment of additional free energy, and the process therefore forces the grieving individual to turn his/her back on the real world.

For Freud therefore the psychological function of grief is to free the individual of his or her ties to the deceased, achieving gradual detachment by means of reviewing the past and dwelling on memories of the deceased. Failure to complete this process results in the development of pathological grief, which Freud saw as the basis of clinical depression. Where no loss experience could be identified in some of his own cases of depression he resolved this discrepancy by suggesting that the memory of the loss may sometimes be repressed. He believed that the major differences between the states of grief and depression were the absence in healthy grief of guilt, self-reproach, and lowered self-esteem.

Critique of Freud and the psychoanalytic approach to grief

Freud's analysis has not withstood more recent work that has found that self reproach and low self esteem, although more typical of pathological grief, are quite frequently encountered in healthy grieving (Parkes 1985). Although both grief and depression may involve guilt, in depression guilt tends to be associated with a general sense of culpability, whereas in bereavement the guilt feeling is usually connected to some aspect of the loss itself. Symptoms characteristic of grief but not depression include the yearning for the deceased, imitation of his/her behaviour, preoccupation with memories of the deceased, and feelings of "not being here" and of "watching from the outside" (Stroebe and Stroebe 1987).

Freud's work has had a major influence on subsequent theories and therapy programmes by his suggestion that grief is a process to be "worked through". However, the focus of

this work has been primarily on the intrapersonal analysis with less emphasis on the effects on social interaction and cultural expectations of recovery from grief. It does not provide an account of the bereaved individual's need to talk to others about their loss and to receive condolence and social support.

b) Attachment theory

The theory of attachment was developed by Bowlby (1969, 1973, 1981) and integrates ideas from psychoanalysis and ethology. It provides a functional interpretation of grief, with an emphasis on the biological rather than the psychological function. Central to Bowlby's theory is the assumption that attachment behaviour has survival value for many species and that grief as the negative aspect of attachment is a general response to separation. He argued that the protest-despair sequence of phases observed in bereavement is a characteristic response of many species to the disruption of strong affectional bonds.

One of the major functions served by an attachment object, particularly a mother, is that of providing a base of security from which the individual can explore the environment. Whenever an infant is confronted with a frightening stimulus, it not only withdraws, but it also retreats toward the attachment object. When the attachment object is gone, there is no longer any secure base to which to retreat in the presence of frightening stimuli. Under these conditions, being separated from one's attachment object can be terrifying, and according to Bowlby, this is the reason why distress is such a universal reaction to the separation from an attachment object.

Attachment theory conceptualises grief as a form of separation anxiety in adulthood that results from the disruption of an attachment bond through loss. It offers a plausible

explanation for the searching behaviour, for being angry about the neglectful behaviour of the lost attachment figure. Although this anger and searching is dysfunctional when a separation is permanent it can be understood as automatic reactions to separation. Bowlby argued "If the urges to recover and scold are automatic responses built into the organism, it follows that they will come into action in response to any and every loss and without discrimination between those that are really retrievable and those, statistically rare, that are not" (Bowlby 1973, p. 53).

Whether an individual reacts to loss with normal grief responses or develops a form of pathological grief depends, according to Bowlby (1981), on certain childhood experiences, in particular the pattern of parental attachment behaviour. He distinguished three disordered forms of attachment: anxious attachment, compulsive self-reliance, and compulsive care-giving. It is beyond the scope of this paper to review his theory in detail. However, Bowlby assumed that "pathogenic parenting" had a pervasive influence on an individual's later relationships, and on the way in which they reacted to the loss of an attachment figure. For example, adults whose childhoods were characterised by anxious attachments to their parents are likely to be insecurely attached to, and overdependent on, their marriage partners and in bereavement are liable to show a chronic grief reaction. There is some evidence to support this view from Parkes & Weiss (1983) study of a sample of Boston widows.

Critique of attachment theory and grief

Attachment theory offers a plausible theoretical interpretation of many aspects of normal and pathological grieving. It can explain the urge to search for the lost person and the anger at being deserted. The depressive phase of grieving can be identified as a special case of depression, arising as a result of the disorganisation of behaviour patterns that is

brought about by the loss of a significant object or goal. It allows one to identify the antecedents of various forms of pathological grief and also offers an explanation for the universality of core symptoms of grief. Bowlby's theory also moved the theory of grief from a purely individualistic focus to an interpersonal perspective and one of the implications of his theory is that the impact of loss can be lessened by forming substitute attachments. New behaviour patterns adapted to new objects can be built up as old ones are broken down, and this suggests an adaptive function to the behavioural processes of the depression. It also offers a theoretical basis for the explanation of the role of social support in bereavement.

c) Behavioural theory

Behavioural theory, like psychoanalytic theory, has focused on depression rather than grief. Depression is characterised by a reduced rate of behaviour, associated with negative affective states. It is therefore plausible for a behavioural theorist to view depression as the result of a reduction in the rate of response-contingent positive reinforcement.

For most people their everyday activities are closely connected with a relatively small number of significant others, and if one of these individuals is lost through death, then many of the usual responses will fail to elicit their customary rewards. This is particularly true for marital partners who are likely to gain a sizeable proportion of their rewards from activities which are mutually interdependent. It is plausible to assume that the extinction of a repertoire of responses which has been built up through years of common experience with a spouse, child or parent, will be a difficult experience. The analogy between bereavement and extinction does offer a plausible explanation for a number of symptoms which are characteristic of grief, such as the reduction of goal-

seeking behaviour, and the protest-despair response to separation and loss. However, the basic weakness of the behavioural theory is that it does not accommodate the role of cognitions. Identical changes in schedules of reinforcement should result in identical consequences, regardless of the reasons which led to the change. Thus in purely behavioural terms there should be no difference between death or absence in terms of the alterations to the schedule of reinforcement. It is difficult therefore to explain why individuals who are devastated when their partners die may have been able to cope successfully with extended absences of their marital partners, for example, absences caused by business trips or hospitalisation. In order to distinguish between the two situations it would be necessary to take account of the attributions made by the person left behind and how they interpret the meaning of the separation.

d) Cognitive theory

The major influence on cognitive models of depression and grief is the model of learned helplessness developed by Seligman and colleagues (e.g. Abramson, Seligman, & Teasdale, 1978; Seligman, 1975). In this model the basic assumption is that “when an animal or person is faced with an outcome that is independent of his responses, he learns that the outcome is independent of his responses” (Seligman, 1975, p.46). This learning results in motivational, cognitive, and emotional deficits. If persons or animals have learned that the escape from aversive stimulation occurs independent of responses, they will be less motivated to initiate a response, will have great difficulties in learning that responses can produce relief, and will react to traumatic experiences at first with fear and then depression. On the basis of the similarity of learned helplessness and depression Seligman proposed that learned helplessness and depression are parallel processes. This presented a number of problems as the original theory had emphasised that it was the uncontrollability rather than the aversiveness of the outcomes which was responsible for

the motivational and emotional deficits. It seemed implausible, however, that people would get depressed because uncontrollable good things tended to happen to them. In addition, it was difficult to reconcile the view that depressed individuals believe that outcomes occurred independently of their responses with their tendency towards self-blame and feeling responsible for these outcomes.

The reformulated model (Abramson et al 1978) attempted to address some of these problems by changing the model from a learning into an attribution theory. In the reformulated version, the depressed person learns that outcomes are uncontrollable but this in itself is insufficient for the motivational, cognitive and emotional deficits to occur. For helplessness to be induced, individuals must also expect that future outcomes are uncontrollable. Whether current uncontrollability will lead to the expectation of future uncontrollability depends on the attributions an individual makes about the causes of the uncontrollability. The authors argue that “when a person finds that he is helpless, he asks why he is helpless. The causal attribution he makes then determines the generality and chronicity of his helplessness deficits as well as his later self-esteem” (Abramson et al., 1978, p. 50). Abramson et al went on to suggest that these attributions could be classified along dimensions of personal-universal helplessness, stability, and globality. The reformulated model suggests that people become depressed when they believe that desired outcomes are unobtainable, that highly aversive events are unavoidable, and that they can do nothing to change this state of affairs. Whether or not they experience this as a blow to their self esteem will depend on whether they blame themselves for the bad outcome. The generality and chronicity of their depression as well as their loss of self-esteem will depend on the globality and stability of the factor seen as causal. The intensity of the motivational deficits will depend on the degree of certainty with which

uncontrollability is expected, while the emotional and self-esteem deficits will depend on the importance of the outcome.

The learned helplessness model, particularly in its reformulated model, has clear implications for a theory of grief. When an individual loses a spouse through death, a decreased sense of outcome control is likely to be generated, which in turn will be accompanied by depression and cognitive disorganisation. The duration of the depression and whether it will be accompanied by a lowering of self-esteem, will depend on the surviving spouse's interpretation of the loss. In the normal course of events, bereaved individuals are unlikely to blame themselves for the death in a global sense and the loss experience should result in a feeling of universal helplessness and depression, but not loss of self-esteem (similar to the pattern of grieving described by Freud 1917). Not infrequently, however, bereaved individuals do feel some responsibility for the loss, sometimes irrationally, and this self-blame is typically accompanied by intense guilt feelings. Parkes & Brown (1972) in their study of Boston widows and widowers identified a number of factors which are particularly likely to induce self blame. For example, after a loss due to suicide or sudden and unexpected loss, or where the loss was associated with ambivalent marital relationships.

Critique of the learned helplessness model

The learned helplessness model can account for many aspects of grief, including the different responses to permanent and temporary loss. It can also explain why the presence of ambivalence in the relationship to the deceased might increase the risk of pathological grief reactions (Parkes & Weiss, 1983), since the ambivalence might affect the attributions surrounding the death event. The model struggles however to account for other pathological developments such as delayed grief, or absent grief.

2. Stress models

Stress models view bereavement as a stressful life event, one that overtaxes the coping resources of an individual. The cognitive stress model of Lazarus & Folkman (1984) defined stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources" (p.19). It can be applied generally to all types of stress. Stroebe & Stroebe (1987) developed a model of partner loss which applies the stress theory specifically to bereavement.

According to Lazarus & Folkman's (1984) model, the extent of the stress experienced in a given situation does not depend solely on the demands of the situation or on the resources of the person, but on the relationship between demands and resources. Lazarus distinguishes three basic forms of appraisal, primary appraisal, secondary appraisal, and reappraisal. In *primary appraisal*, individuals categorise a given situation with respect to its significance for their well-being, and decided whether the situation is irrelevant, benign-positive, or stressful. Once a situation has been categorised as challenging or stressful, individuals have to evaluate their coping options to decide on the potential for coping and to decide which strategy will be most effective in a given situation in achieving the intended outcome. This assessment of coping resources and options is referred to as *secondary appraisal*. The extent of stress experienced in a given situation is the combined result of an interaction between primary appraisal of what is at stake and secondary appraisal of coping options. As the original appraisal of a situation may change as new information about the situation or about the impact of one's own behaviour is received, there may need to be a *reappraisal* of the situation.

When a situation has been appraised as stressful, individuals have to act to master the situation and/or to control their emotional reactions to the situation. These processes of

responding to stressful demands have been called coping processes and Lazarus & Folkman (1984) distinguished two basic forms of coping, problem-focused or emotion-focused. Problem-focused coping involves attempts by the individual to deal with stress by acting on the environment or the self. Emotion-focused coping involves a reappraisal of the stressful problem, entailing a change in the meaning of the problem. Problem-focused coping strategies tend to be highly variable across stressful encounters, whereas emotion-focused coping strategies tend to be more stable. In addition to the coping process, individuals draw upon their coping resources which can be personal (health, positive self-concept, good problem solving skills etc.) or environmental (material resources, social support etc.).

The *Deficit Model of Partner Loss* (Stroebe & Stroebe 1987) applies the general psychological stress model to the situation of conjugal bereavement. The appraisal process identifies aspects of loss that are stressful, which may include the loss of instrumental support e.g. with household tasks or income, loss of validation support i.e. someone to tell you that you are doing a good job, and loss of social identity or role. The coping resources of the individual include personality traits, abilities, skills and knowledge, as well as access to financial and social support.

Stroebe & Stroebe (1987) also distinguish between problem-oriented coping and emotion-oriented coping. In the bereavement literature there has been a limited amount of discussion of the role of emotional control strategies to reduce distress by repression e.g. through drinking, taking tranquillisers, or distraction. The general view of practitioners (e.g. Worden, 1982, Jacobs & Ostfeld, 1977) seems to be that distraction or repression, particularly in the early stages is unhelpful as it prevents the individual working through his or her grief. However, there do not seem to have been any

empirical studies to support this view. In spite of this lack of research there seems to be a general consensus among bereavement researchers (e.g. Bowlby, 1981; Freud, 1917; Lindemann, 1944; Parkes, 1972) that grief work is the only strategy that leads to a healthy resolution of the emotional reactions to loss. It is difficult to assess the validity of this claim since the concept of grief work has never been clearly defined.

Critique of the stress models

By drawing on the more general framework for the analysis of psychological stress, the cognitive stress model does extend beyond the focus of bereavement and depression, and encourage an analysis of both the intrapersonal and the interpersonal environment. By applying this more general model to conjugal bereavement Stroebe and Stroebe (1987) have developed a framework for the analysis of grief includes the demands of the situation that confront a person who has suffered the loss of a partner as well as the resources needed to cope with these demands. However, stress models focus mainly on the current situation of the individual, looking at whether the bereaved person has sufficient personal and interpersonal resources to cope with the demands. Although personal resources and coping processes may be influenced by past experience of loss, the model does not fully account for grief itself that arises from losses suffered in the past.

One of the strengths of the cognitive stress approach is that the model encourages the identification of individuals who are at high risk of poor bereavement outcome. In providing this potential framework for therapeutic intervention it is similar to the *adaptive* model described by Jacobs (1993) (see below).

3. Schneider's model of loss and grief

Frears & Schneider (1981) proposed a model which they argue is applicable not only to bereavement but different losses and different situations. Schneider (1984) claimed that the model was more holistic, in that it incorporated not only the biological, emotional, and behavioural aspects of the individual, but also the intellectual and spiritual aspects. It involves seven phases, from intense sadness to recovery: initial awareness, attempts to limit awareness, awareness of loss, gaining perspective, resolving loss, reformulating loss and transforming loss. Initial awareness occurs when an individual realises that he or she has experienced a loss. Attempts to limit awareness are a natural reaction to this initial awareness (e.g. "if I just work hard enough this will go away"). Awareness of loss occurs when one can no longer deny the significance of the loss, resulting in deep grieving and sadness. During this phase people fear for their own survival. The move towards healing occurs when one begins to gain perspective on and to accept the loss by examining what was lost and gained in the process. Resolving the loss requires some sort of restitution, a public acceptance of the loss. Reformulating the loss allows the grieving person to reframe his or her life in a new and expansive way. During this period persons are very self focused. During the final phase - transforming the loss - the person refocuses his or her attention on society.

In spite of its claim to inclusivity in its definition of loss, this model continues to focus primarily on the intrapersonal experience of loss. It does not extend to the broader socio-cultural expectations of how or when to grieve.

4. Jacobs' Adaptive Model

Jacobs (1993) attempts to integrate various elements from earlier models. His adaptive model takes into account the environmental context (e.g. social supports that influence an individual's response to a challenge), the nature of the loss itself, as well as the personal strengths and vulnerabilities of the individual. In the adaptive model the death of an intimate is a necessary but not sufficient cause of the clinical complications of bereavement. A loss, originating in the social environment and conceived of as a vector of potential disease, evokes grief in the survivor and, at the same time, causes a fundamental change in the environment. The changed environment is characterised by the irrevocable absence of the deceased individual and the empty situations caused by the loss. This view identifies a separation anxiety disorder in adults that probably occurs most often, but not exclusively, in the circumstances of bereavement and that probably has some relationship to separation anxiety disorder of childhood. By emphasising the social environment and the grieving tasks derived from it, such as the need to adjust to the status of being widowed, it partially resolves the controversy over how long grief endures.

The adaptive model provides a broader view of the complex process of adjusting to loss than does the specific deficit model proposed by Stroebe & Stroebe (1987). It has similar explanatory and predictive power, but as with all these models there is little empirical evidence to support them.

Summary of the review of models of normal grief.

The early work of Freud (1917) was important in establishing the idea that grieving serves an important psychological function, and in promoting the idea of grief work. However, the focus on the purely intrapersonal process of recovery from grief has had a very strong influence on subsequent analyses, and it is only more recently that broader multidimensional approaches have been considered. The work of Bowlby, drawing upon attachment theory provided a clear descriptive analysis of the yearning and searching behaviours characteristic of grief, and also began to include the elements of social interaction and need for and benefits of social support following a bereavement. Behavioural theory had only a limited contribution to our understanding of grief, but cognitive theory by incorporating attributional theory has provided a model that can explain the difference in psychological terms between separation and death, and which can incorporate the effect of ambivalent relationships in predicting some forms of pathological grief reactions. More helpful in terms of providing a framework that can guide therapeutic interventions is the analysis in terms of adjustment to a stressful life events, since this draws together the assessment of both the intrapersonal resources and the situational demands. Models such as that of Frears and Schneider (1981) and Jacobs (1993) have attempted to integrate these functional analyses of the coping process with the intrapsychic processes described in the depression-models.

The major difficulty in this field is that so few of the models have been subjected to rigorous empirical evaluation. The following section will examine difficulties in research in this field.

Critique of Methodological Issues in Grief Research

1. Measurement of Grief

In spite of the considerable body of work devoted to conceptualising and measuring the experience of bereavement, there is still no standard approach to bereavement assessment, in either the clinical or research settings. The validity of measures of grieving is unproven. So many variables seem to be involved, such as cognitive, emotional, physiological states, and to vary in importance over time. The ability of the measures to discriminate grief from other related constructs such as depression, physical health, or mood state, has not been demonstrated. Little attention has been paid to extending the scope of the measures beyond the individual to the affected family system, whose grief reaction may be interdependent.

2. Research Design Issues

Although bereavement is a universal phenomenon it is not straightforward to design a study to investigate it. Identifying and accessing a bereaved population can be difficult. The enormous number of factors thought to influence the grieving process need to be considered, including the age and gender of the griever, the psychological well-being of the griever prior to the bereavement, the nature of the loss (e.g. sudden, traumatic, or predicted), the extent of social support etc. It is difficult also to control for variables such as tranquilliser use or use of alcohol. Large scale studies that may measure only a limited number of variables have to be compared with smaller studies that can provide greater depth in assessment and analysis but which may have only limited generalisability to other groupings of bereaved individuals.

There are problems with defining normal and pathological grief. Although the symptoms of normal grief have been extensively described in the literature, the range of individual variation in responses is also apparent. Finally, there are socio-cultural expectations about appropriate grief reactions that can influence the way in which a griever responds to a researcher. The difficulties inherent in conducting research in such a sensitive area with so many variables to consider may explain why grief models have been subjected to limited empirical evaluation.

There have been more recent longitudinal in-depth studies with well-controlled designs that controlled for potential biasing factors in sampling, or social desirability bias of responses. For example, McCrae & Costa (1993) used a longitudinal data set with a large sample to examine the course of recovery among the bereaved. They were able to measure the long-term effects of widowhood by comparing a pre- and post-event assessment of certain key variables, in a repeated measures analysis that controlled for initial differences between groups on key biographical variables. They were also able to avoid bereavement “priming”, as respondents were not aware that widowhood was a variable of interest. However, most longitudinal studies suffer from high subject attrition rates, and have made only limited use of control groups.

There is also a tendency throughout the literature to make unjustified inferences of causality. For example, it is claimed that social support helps the bereaved get over loss on the basis of the finding that the better adjusted have higher levels of social support than the worse off. This is not necessarily a valid inference, since there may be other factors that jointly affect health outcome and the provision of support. Stylianos & Vachon (1993) explored the interaction of personality and social support and found that

certain personality types are associated with better coping styles and are easier to provide with social support.

PATHOLOGICAL AND ATYPICAL GRIEF REACTIONS

This section of the paper will examine pathological and atypical grief reactions and identify aspects of grief that are relevant in contexts other than bereavement. First it will consider the concept of pathological grief and what this contributes to our understanding of the grieving process. Secondly it will focus on grief in the context of caregiving and the concept of anticipatory grieving for the terminally ill. Finally it will explore the concept of disenfranchised grief, in particular the notion of psychosocial death where the death is not recognised but the griever nevertheless experiences a sense of loss.

1. Pathological Grief

The term pathological grief was first used by Freud, in reference to the depressive symptoms he felt were characteristic of melancholia rather than mourning. Deutsch (1937) first suggested that absent grief was a variant of pathological grief. Lindemann (1944) subsequently introduced a typology of morbid grief reactions that extended beyond depressive symptoms (Freud's 'melancholia') and absent grief. He proposed that 'delayed grief' was a major variation of morbid grief, and in addition he itemised nine clinical presentations of 'distorted grief' which if untreated would become unresolved, prolonged grief.

Bowlby (1981) identified two main variants of disordered mourning as chronic mourning, including severe and prolonged emotional response, and absent grief, which

described a pattern of persistent anger and self-reproach associated with depression in the prolonged absence of conscious sorrow. This formulation was based in his cognitive theory of attachment discussed earlier in which the patterns established in childhood influenced later relationships and responses to loss, including bereavement.

Parkes (1965) based his formulation of pathological grief on his direct observational studies and classified pathologic bereavement reactions as inhibited grief, delayed grief, and chronic grief. This typology provided the cornerstone of more recent attempts to develop descriptive criteria for the diagnosis of pathologic grief.

Subsequently Parkes and Weiss (1983) developed another typology that acknowledged the potential effects of the manner of the death and characteristics of the relationship to the deceased individual as part of the clinical syndrome. This included unanticipated grief, conflicted grief (described as similar to delayed or absent grief and thought to occur when the relationship was ambivalent) and chronic grief.

There have been some detailed and systematic studies of grief symptoms that have identified complications in the normal bereavement process. For example, Bornstein et al (1973) found that although 45% of acutely bereaved spouses developed depressive syndromes during the first year of bereavement that were transient and subsided spontaneously, 17% of the sample remained depressed throughout the whole first year of bereavement. Other studies have documented a risk of anxiety disorders during acute bereavement (Jacobs 1987; Jacobs et al 1990). What remains unclear is the relationship between normal mourning, depressive illness including anxiety disorders, and pathological grief. There is considerable overlap between the syndrome of pathological grief and other psychiatric syndromes, such as major depression and anxiety disorders.

There have been very few studies examining this area and those that have been published (e.g. Kim & Jacobs 1991) have been retrospective and based on small numbers of patients. Pathological variants of grief do not differ qualitatively from normal grief (with the exception of the syndrome of absent grief). In most instances the criteria for pathological grief are set in reference to the normal progression of grief (emotional numbing and disbelief, separation distress, mourning-depression, where these phases overlap but evolve over time). There are no empirical studies of the criteria for the diagnosis of pathological grief and no definitive consensus by clinicians

In spite of this lack of conceptual clarity the idea of a state of pathological grief has an intuitive appeal and has been recognised throughout history and described in art and literature.

2. Anticipatory Grief

Anticipatory grief is a term originally introduced by Lindemann (1944) and is applicable to all chronic illness. Some studies have shown that the opportunity to engage in anticipatory grief resulted in better adjustment to bereavement (Futterman, Hoffman & Sabshin, 1972; Parkes & Weiss, 1983; Vachon et al., 1982), suggesting that the warning of a death may give people time to prepare for the inevitable. Other studies have found that there was no relationship between the length of the anticipatory grief period and adjustment following the death (Maddison & Viola, 1968; Parkes, 1970). It is important to distinguish between forewarning of loss and anticipatory grieving. Individuals may be aware of the impending loss but not grieve in anticipation (Clayton et al, 1973). In part this may explain the somewhat contradictory findings about the value of having advanced warning, as not all studies have made this distinction.

The concept of anticipatory grief has survived, partly because Rando (1986) expanded the concept to include grief over past and current, as well as future losses. Although most studies have focused on the terminally ill, where the anticipated loss is imminent and certain, the concept has also been applied to the challenges faced by families of people with chronic illnesses such as Alzheimer's Disease or other dementias. The changes in the early stages of dementia may be gradual, but as the nature and extent of the changes and their implications become clear family members may start to prepare for a future without the loved one. Providing increasingly demanding care, while simultaneously managing their own grief, places additional demands on an already overloaded caregiver (Parks & Pilisuk, 1991). Some authors have discussed the expectation that the demands of caregiving impede the anticipatory grief process. For example Marples (1986) stated that "family members cannot properly mourn the loss of the person they once knew; they are too preoccupied with the activities necessary for providing care" (p.492).

Some authors have utilised what amounts to "stages" of grief when describing the response of caregivers to the diagnosis and ongoing care of an impaired family member. Cohen, Kennedy, and Eisdorfer (1984) suggested that during the terminal phase of the disease families experience a degree of "maturation" where caregivers accept a patient as being very different and as never returning to the earlier status of the person they knew and loved. Cole, Griffin, and Ruiz (1986) acknowledged that although the family may mourn the loss of their loved one, especially during the latter stages of Alzheimer's Disease, the fact that the patient is still living complicates the situation, and they suggest the family may need permission to grieve the loss of a relationship that no longer exists.

Much of the literature on anticipatory grief and caregivers of persons with Alzheimer's Disease and other dementia is largely suggestive and anecdotal. However, Ponder and Pomeroy (1996) systematically investigated the grief behaviours of 100 caregivers of person with dementia providing an average of just over forty hours of care each week to a patient who had received a medical diagnosis of Alzheimer's Disease or other dementia an average of almost three years earlier. They developed the Stage of Grief Inventory (SGI) to identify the extent to which caregivers expressed feelings and attitudes characteristic of five stages of anticipatory grief (denial, over-involvement, anger, guilt, and acceptance). They also adapted questions from the Parental Experience Assessment Form (PEAF; see Rando 1983) to identify the number of anticipatory grief behaviours the caregiver reported they had engaged in during the prior two months (e.g. discussing with someone the possibility that the care recipient would die; thinking what the future would be like without the care recipient), and questions from the Anticipatory Grief Inventory (Levy, 1991). Finally, they used the Despair Scale of the non-death loss version of the Grief Experience Inventory (Sanders, Mauger, & Strong, 1985). They found that the caregivers were simultaneously experiencing varied and even contradictory feelings. They describe a pattern of grief intensity and grief behaviour, whereby caregivers in the early stages of grief are either unable to acknowledge the losses that are occurring or are concentrating their efforts on forestalling the ravages of the illness. During the denial stage, caregivers may fail to recognise the importance of even gross deterioration of their loved one's cognitive functioning. Denial is often followed by "over involvement" which is characterised by an exaggerated concentration of the care recipient's needs at the expense of the caregiver's physical health and interpersonal relationships. Both the intensity of grief and the number of grief behaviours increased during the middle stages of grief. The ability of the caregiver to acknowledge anger towards the illness, the care recipient, health care professional, or

other family members, and their own inability to perform to their expectations signified their acknowledgement of the devastation brought about by the illness. Finally, both the intensity and number of grief behaviours declined as the caregiver reached acceptance.

The authors report that the majority of the sample (73%) scored most highly on the acceptance subscale of the SGI but go on to describe the impression of the researcher conducting the interviews who felt that caregivers in other stages were under identified due to the lack of sensitivity of the instrument used and the social desirability inherent in personal interviews. This highlights two of the major problems with bereavement research as noted earlier in the general critique of methodological issues. There are a growing number of measures being adapted in a variety of ways to meet the demands of specific populations or studies. The measures may prove to be insufficiently sensitive as in this study, and few studies are able to avoid the problems with social desirability bias.

3. Disenfranchised Grief

Where a person experiences a sense of loss but does not have a socially recognised right, role, or capacity to grieve, their grief is disenfranchised. The person suffers a loss but has little or no opportunity to mourn publicly (Doka 1989). The concept has been used to describe unique problems in grieving among different populations such as perinatal death (Raphael 1983), ex-spouses (Doka 1986), and pet loss (Kay et al., 1984). Other groups include families of Alzheimer's patients (Doka 1985) and adults with learning disabilities (Lipe-Goodson & Goebel, 1983; Edgerton, Bollinger, & Herr 1984)

The concept of disenfranchised grief recognises that societies have sets of norms or grieving rules that attempt to specify who, when, where, how, how long, and for whom people should grieve. These rules may be explicit, for example, codified in personnel

policies (e.g. a week off for the death of a spouse or child, three days for the loss of a parent or sibling) or implicit. In any given society these grieving rules may not correspond to the nature of attachments, the sense of loss or the feelings of survivors. Doka (1989) argued that there are three main reasons why people may be excluded from the normal grieving process.

a) The relationship itself is not recognised

In general society recognises kin-based relationships. The underlying assumption is made that closeness of relationship exists only among spouses and/or immediate kin (Folka and Deck 1976). Although relationships with stepchildren, caregivers, colleagues, roommates (e.g. in nursing homes) may be long-lasting and are recognised, mourners may be expected to support and assist family members rather than grieve publicly themselves. Other non-traditional relationships such as extramarital affairs or homosexual relationships have tenuous public acceptance and limited legal standing and grief at the death of a partner may not be acknowledged or socially supported. Ex-spouses or former friends may have limited contact but the death of the significant other can still cause a grief reaction because it brings finality to the earlier loss, ending any remaining contact or fantasy of reconciliation or reinvolvement. These feelings may also be shared by others in their world such as parents or children mourning the loss of “what might have been” or “what once was” (Doka, 1989).

b) The griever is not recognised

Here the person is not socially defined as capable of grief, therefore there is little or no social recognition of his or her sense of loss or need to mourn. It is the personal characteristics of the bereaved that in effect disenfranchise their grief. The very old and the very young are typically perceived by others as having little comprehension of or reaction to the death of a significant other. Similarly, mentally disabled persons may also

be disenfranchised in grief (Lipe-Goodson & Goebel, 1983; Edgerton, Bollinger, & Herr 1984).

c) The loss is not recognised

Some losses are not socially defined as significant. Perinatal death for example is still regarded by many as a relatively minor loss in spite of a rapidly growing literature detailing the strength of the grief reaction experienced by many women (Raphael 1983).

Abortion too can create a sense of loss that is hidden and confounded by the additional conflicts surrounding personal beliefs about the sanctity of life. Another loss that is often not perceived as significant is the loss of a pet. Nevertheless research does show strong ties between pets and humans and profound reactions to loss (Kay et al 1984).

Of more direct relevance to the traumatic brain injured population are losses resulting from what Sudnow (1967) describes as “social death”. Sudnow defined social death as being when “relevant attributes of the person begin permanently to cease to be operative as conditions for treating him” e.g. a person who is comatose or a highly disoriented and institutionalised Alzheimer’s patient”. Here the person is alive but treated as if dead. The main carer often cannot move on with their own life. Kalish (1966) added that perceptions of social death occur on a continuum: “A given person may be socially dead to one individual, to many individuals, or to virtually everyone”.

“Psychosocial death” is a term that has been used when the persona of someone has changed so significantly, through mental illness, organic brain syndromes, or even significant personal transformation (e.g. through addiction, conversion) that significant others perceive the person as he or she previously existed as dead. In all these cases spouses and others may experience a profound sense of loss, but that loss cannot be publicly acknowledged for the person is still biologically alive.

Mental illness, chronic brain disorders such as Alzheimer's disease, substance abuse, and of course, traumatic brain injury, can have a significant impact on the personality of an individual and can radically affect the lives of others around him or her. All relationships change over time as people grow and develop. Not all changes create problems, the differentiation being between sudden/dramatic changes in a relationship and the normal incremental changes over time. In some situations the changes in one party or dissimilar changes in both may lead to the dissolution of the relationship – “we've grown apart”. However when change is dramatic, and particularly when it is not perceived as intentional or as under the control of the person, options like divorce or separation may be effectively precluded.

It has long been recognised that relatives of people with Alzheimer's often experience deep feelings of loss. Cole, Griffin and Ruiz (1986) reviewed the issues that arise for families as they cope with caring for someone with a chronic degenerative condition. They note that “family members may also feel a profound sense of loss, as a loved one who was once a vital person gradually loses mental, physical and social abilities”. The qualities of the person to whom one was attached are no longer present. As one spouse of an Alzheimer's victim said “All you have is a shell mocking what once was.” The person is psychologically dead.

There has been work done in exploring the effects of psychosocial death in relation to Alzheimer's Disease (Wasow 1986, Liptzin, Grob and Eisen 1988, Quayhagen and Quayhagen 1988). One of the most pervasive reactions is guilt, either because of a belief that the relative could or should have responded to symptoms earlier that might have delayed or prevented subsequent difficulties, or because the relative feels that it was their own inability to be an effective parent or good spouse that contributed to the problem.

In addition to guilt about causation, there is often guilt about the ways in which the relatives are coping – where the condition is perceived as beyond the control of the victim the relative may feel it is inappropriate to respond angrily or to get irritated. The relative may also feel guilty about their own negative feelings toward the victim.

Although the intensity and nature of grief reactions to psychosocial losses are affected by all the same variables that affect any response to loss (such as the nature of the relationship, family and social support, and circumstances surrounding loss), Doka (1989) argues that two variables are unique to this form of loss, firstly, the extent to which knowledge of the level of disability or change in the person is shared and/or perceived by others, and secondly, the extent to which the underlying condition causing psychosocial death can be viewed along a continuum of reversibility to irreversibility. With irreversible conditions, the loss is certain, and although that knowledge may be resisted by defence mechanisms such as denial, there will often be a sense of hopelessness. The irreversibility of the loss may create high levels of ambivalence and subsequent guilt as one copes with the daily tasks of life. There may be deep, guilt provoking desires for the victim's institutionalisation or even death.

In situations that are perceived as reversible, there may also be increased impatience with the slow pace of recovery and intensified feeling of anger toward a victim who is perceived still to have some sense of control. Liptzin, Grob and Eisen (1988) found that over time relatives of depressed patients felt more burden than did relatives of dementia patients, since the latter often grew to accept the fact that the relative's decline was inevitable, irreversible, and thus beyond their control. Bennett and Bennett (1984) noted that hopelessness can help families experience less blame and measure accomplishments in terms of endurance and adaptation rather than cure.

The problem of disenfranchised grief lies in the paradox that the very nature of this type of grief exacerbates the problems of grief, whilst at the same time removing or minimising the usual sources of support. Disenfranchising grief can intensify the feelings of anger, guilt, or powerlessness that can form part of the normal grief experience. In addition, both ambivalent relationships and concurrent crises have been identified in the literature as conditions that complicate grief (Worden 1982, Raphael 1983, Rando 1984).

UNDERSTANDING GRIEF AND LOSS FOR RELATIVES IN RELATION TO TRAUMATIC BRAIN INJURY

This section of the paper will briefly review the relevance of models of normal grief in understanding the nature of the loss and grief experienced after traumatic brain injury. It will then consider the similarities between the risk factors for traumatic brain injury and for pathological grief. Finally it will explore aspects of psychosocial loss and the effects on caregivers of anticipatory grief in relation to the experiences of relatives of traumatically injured people.

The models of normal grief are not particularly helpful in understanding the sense of loss after traumatic brain injury as they focus primarily on bereavement. In particular the depression models, with their primary focus on the intrapersonal analysis, are inadequate to account for the complex set of demands and expectations placed on families after traumatic brain injury. The continued presence of the individual makes it difficult to go through the process of severing existing ties, as required both by psychoanalytic theory and attachment theory. Behavioural theory cannot explain the changes in the face of the

continued presence of the injured relative who may continue to exhibit many of the same behaviours. The life-stress models provide a framework for analysing the resources available to family members, and potentially of identifying who will need additional support. It is interesting to note that for many years support for families following traumatic brain injury has focused on the emotional coping process, particularly during the early stages. More recently there has been greater attention to the longer term support needs of family members and here the literature has described problem-focused approaches (Jacobs 1991). Others have argued that until the emotional task of grieving has begun the family cannot take steps to reorganise themselves (Perlesz & Mclachlan 1986). From work with people experiencing chronic stress over which they have no control comes evidence that suggests that under such conditions, problem-focused coping can be counter productive and emotion focused coping more likely to produce better outcomes (Collins, Baum, & Singer 1983). There is scope here for further work to understand the most appropriate timing and nature of any interventions.

Many of the defining characteristics of traumatic brain injury establish the risk factors for pathological or abnormal grief responses. It is by definition a sudden, traumatic, and unanticipated event. There is usually an element of liability to be established, which may result in blame being attached to the injured person, the relative directly (e.g. if they were driving the car but were unhurt), or indirectly (e.g. where the relative blames themselves for not preventing the accident), or to a third person who may or may not be criminally liable. In addition, more than two thirds of those who sustain traumatic brain injury are aged under 30 years and the ratio of males to females is approximately 2:1 (Jennett & MacMillan 1981). Thus in terms of vulnerability factors outlined in the literature, traumatic brain injury affects a young predominantly male population, and the griever are predominantly parents and partners. The nature of the loss is sudden and

unpredicted, and the cause of the injury may give rise to conflicting emotions of guilt and anger. Although there are obvious parallels in terms of vulnerability factors, there is no systematic descriptive data on the development of normal or pathological grief in the relatives of people who have sustained traumatic brain injury.

There is, nevertheless, widespread recognition that family members may go through a process of grieving for the losses that result from the head injury. In some cases the family members report that the fundamental aspects of the injured person's personality have changed such that the person they knew and loved is "dead". Since the recovery process is an uncertain one with extended periods of hope and despair, feelings about the changes may remain in turmoil for many months or years. This uncertainty and the concomitant disorganisation of the grieving process have resulted in the development of the term "mobile mourning" (Muir et al 1990). The experience of grieving can be put off, sometimes indefinitely, which has been termed "grieving in abeyance" (Perlesz and McLachlan 1986). There are parallels here with the concept of "delayed grief" as a pathological outcome following normal bereavement, and also with the concept of psychosocial death. In that the injured person is present and the sense of loss is not acknowledged. The need to provide care and support whilst living with the sense of loss has some similarities with the phenomenon of anticipatory grief, although the comparison is limited as there is no natural endpoint following traumatic brain injury.

Resolution of grief associated with psychosocial death may be difficult to achieve. Worden (1982) suggested that four tasks are necessary before grief can be resolved: accepting the reality of death, experiencing the pain of grief, adjusting to a life without the deceased, and withdrawing emotional energy from the deceased and reinvesting it in others. Following traumatic brain injury this may involve the prolonged process of

recognising the nature and extent of the personality change and experiencing fully the sense of loss, and here there is a parallel with the difference between anticipatory grief and forewarning of loss. Many family members may describe changes without acknowledging the losses these changes entail. The physical appearance and many of the mannerisms may stay the same, giving the illusion that nothing has changed and contributing to a situation in which the bereaved may continue to deny the reality of the loss. The emotional catharsis first described by Freud (1917) and which forms the core of most grief work involves a review of the relationship and a resolution of the feelings inherent in such a review. Although theoretically possible, social expectations and practical constraints mean that such a process is rarely observed in clinical practice following psychosocial loss.

The literature on anticipatory grief also suggests that the burden of caring may prevent or inhibit this process of review. Apart from the practical problem of lack of time when the griever is also a carer, there is no space for emotional detachment. The demands of time spent caring, supervising the individual, or in taking on roles that the injured person can no longer fulfil is likely to increase. Instead of becoming more detached the relationship will also develop in what are often less positive ways, involving as it does the growing demands of care, and the changed and often bizarre behaviour of the person which causes new stress, shame, guilt, anger, and helplessness. At a time when they need support from family or society, the changed behaviour of the person may result in increasing isolation. Societal and family pressures can make it difficult to withdraw from the situation either practically or emotionally let alone invest in a new relationship. There may be conflicting pressures where a partner has to consider the needs of the injured adult against the needs of dependent children. The spouse may become what Grossman and Grossman (1983) called a pseudowidow or a cryptowidow; he or she

remains legally, but not behaviourally, married. As Lezak (1987) said in the quotation given at the beginning of this paper: "The spouse cannot mourn decently. Although he has lost his mate as surely and permanently as if by death, since the familiar body remains, society neither recognises the spouse's grief nor provides support and comfort that surrounds the bereaved by death".

Very little is known about the effects on carers who decide to leave the situation. The divorce rate after traumatic brain injury is high and there is some evidence to suggest that parents provide care for longer than spouses. In spite of the parallels with elderly carers and their relatives with dementia, the main difference with the traumatic brain injured patients may lie in the relative youth of the population. Most people who sustain traumatic brain injury are aged between 18 and 30 years old and have a near normal life expectancy. There is evidence of the long-term burden on carers who remain in contact (Livingstone & Brooks 1988) but little information other than anecdotal on those who move on. For those who remain it is unclear if they have achieved some form of a partial resolution of feelings that allows them to maintain emotional equilibrium, recognising the losses experienced while continuing to give care. It is also unclear whether this is what constitutes 'adaptation' after brain injury, and if so whether it is a stable state or whether the grieving process is held in a state of partial suspension or abeyance. Further work on the process of family adaptation and the factors influencing it is required. The main research study seeks to contribute to this body of knowledge.

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**THE ROLE OF GRIEF IN FAMILY ADAPTATION FOLLOWING
TRAUMATIC BRAIN INJURY**

ABSTRACT

Previous research has shown that family members experience psychological distress and an increased caregiver burden following traumatic brain injury (Livingston & Brooks 1988). Relatively little research to date has considered the extent to which family members recognise and grieve for the loss of the person they used to know. This preliminary study examined the utility of a modified version of the Inventory of Complicated Grief (Prigerson et al 1995) as a measure of grief in 34 relatives of people who had sustained a traumatic brain injury at least 12 months previously, and the role of complicated grief in predicting family adjustment (Family Assessment Device, Epstein et al 1983). Severity of injury and socio-demographic factors were not predictive of family adjustment. High levels of anxiety and depression (Hospital Anxiety and Depression Scale, Snaith & Zigmond 1983) were identified in relatives up to four years post injury. In this small study it was not possible to identify a component of grief distinct from anxiety and depression that predicted adjustment. However, the assessment tool was comprehensible and acceptable to relatives and with further modification may provide a useful measure to test the hypothesis that unresolved grief prevents successful family adjustment.

INTRODUCTION

Most studies suggest that around 70% of traumatic brain injuries result from road traffic accidents. Other causes include cycling accidents, assaults, falls and sports injuries. It is difficult to obtain precise data regarding the incidence of traumatic brain injury, due to variations in definition and methods of data collection. Jennett and MacMillan (1981) cited estimates of the incidence of hospitalisation following head injury in Britain and the United States as between 200 and 300 per 100,000 of the population. They estimated that around one in five of those admitted to hospital had sustained moderate or severe head injuries. Many of those who sustain mild head injuries can suffer ongoing cognitive difficulties (Levin et al 1987a).

Males are more likely than females to sustain traumatic brain injury, with figures varying between ratios of two and three to one. More than two-thirds of those who sustain traumatic brain injury are aged under 30 years, the majority occurring in those 15-24 years of age (Jennett & MacMillan 1981). Studies focusing on other characteristics of the traumatic brain injured population suggest that a greater than average proportion have a history of psychopathology, substance abuse, particularly heavy alcohol consumption, and poor academic performance (Bond, 1984; Haas, Cope, & Hall, 1987; Rimel & Jane, 1984). Traumatic brain injury has also been shown to occur more commonly in the lower socio-economic classes and amongst those who are unemployed (Rimel & Jane, 1984). Improvements in acute care have resulted in reduced mortality rates in recent years. This, together with the relative youth of those who sustain traumatic brain injury, has led to a rapid growth in the number of survivors of traumatic brain injury in the community. The vast majority of these survivors return to living with

family members who are often ill equipped to respond to the changes in life style and caregiver burden imposed by the injury and its sequelae (Diehl 1983; Sbordone 1988).

The concept of 'burden' is as difficult to define as it is to measure. It involves a multiplicity of social, emotional and physical effects that the injury has on the caregiver, as well as on the perceptions of the caregiver and his or her capacity to cope. In addition, the concept of burden has to reflect the nature of the interaction between the injured person, the caregiver, and other family members. Most studies have made an operational decision to define burden e.g. as the psychosocial functioning of the caregiver. Following the model established in studies of family burden after discharge of long-stay psychiatric inpatients to the community (Grad & Sainsbury 1968) burden has been viewed as relatives' complaints (subjective burden) and/or the measurable effect of burden on the relative (objective burden). In practice this distinction becomes blurred, and most studies that attempt to assess objective burden appear in fact to measure relatives' perceptions of their burden, rather than objective change. Measures of caregiver psychological distress have often consisted of single questions or visual analogue scales, or questionnaires of unknown reliability and ambiguous meaning. The relationship between 'burden', 'strain' and 'psychological distress' (such as anxiety and depression) is usually unspecified.

Livingston & Brooks (1988) reviewed the literature on burden in families following traumatic brain injury. They found that the broad range of populations studied and problems with methodology made comparison between studies of family burden difficult. Livingston et al (1985a) reported high levels of distress that develop rapidly during the first three months post injury and persist for one, five and seven years post injury (Livingston et al 1985b, Brooks et al 1986, Brooks et al 1987). Rosenbaum & Najenson

(1976), studying a military population, found a high level of depression and irritability in the wives of head injury victims compared with partners of paraplegic patients and staff wives. This pattern was not found by Oddy et al (1978) at six months post injury, who found more family disturbance in single patients living with parents compared with married patients living with a spouse. Livingston et al (1985b) also looked at social adjustment and found that by six months post injury the relatives of the severely injured patients were beginning to show evidence of social malfunctioning and that this poorer functioning persisted at twelve months post injury. They argued that deterioration in the social functioning of relatives is slower to evolve than mood disturbance as decisions about whether to give up work or spend more time at home are often delayed for a time.

Several studies have looked at relatives' complaints about the patient's problems following head injury (Brooks et al 1986; Brooks et al 1987; Rosenbaum & Najenson 1976; Oddy et al 1978). Most relatives are concerned about tiredness, impatience, loss of temper, apathy, aggression, and lability of mood, together with more cognitive complaints of slowness of thinking and memory difficulties.

Some studies have used homogenous samples of only mild or only severe injuries, and subsequent measures of the patients' difficulties are often in the form of self report ratings by the patient or the caregiver rather than objective clinical rating systems or neuropsychological assessment. However, in spite of these reservations about comparability, the studies are consistent in highlighting a high incidence of mood disturbance in the relatives of the brain injured. Common sense suggests that patient descriptors, such as severity of injury or residual cognitive deficits, should be related to caregiver psychological distress, but empirical research has failed to find consistent patterns of association between the patients' level of disability and caregiver's

psychological distress. Livingston et al (1987) found that the major intrapersonal determinant of psychosocial adjustment for relatives was their previous psychiatric and physical health record. In their previous study (Livingston et al 1985b) they found that the major factor predicting relatives' psychosocial distress was the subjective complaints voiced by the patients. Age, social class, relationship to the patient, work experience, and medication were not strong predictors of relatives' distress.

Based on the model of depression outlined by Brown et al (1977), Livingston & Brooks (1988) suggested that relatives may be 'sensitised' by previous illness experience themselves and that the symptoms of the head injured person create stresses that provoke maladaptive coping strategies. More recently Kreutzer et al (1994a) compared the adaptation of families after traumatic brain injury with more general psychological models of stress and specifically models of coping with chronic illness such as Alzheimer's Disease (Vitaliano et al 1991). In this conceptualisation the problems experienced by the families with a chronically ill member are related more to their own resources, coping styles and organisation than to the injured person's limitations.

Moore et al (1989, 1991, 1993) published a series of studies examining the relationship between individual coping and system coping in individuals and families with TBI. They found that family coping and marital resources were overwhelmed by TBI, so that coping had only a minor role in eventual outcome. External circumstances, such as improved childcare, patient care services and increased social support seemed to be overriding factors in predicting outcome.

Leaf (1993) collected data from more than 75 families over a three year period asking the families what elements helped them cope and adjust to the tragedy. The range of

time post injury extended from 3 months to 25 years post injury. From 0 to 1.5 years families cited faith, family and friends, and services. From about 1.5 years onwards the main coping supports were family and friends, professional support and the availability of services, and information and education. The trend was such that the longer the period since the injury the more value families placed on understanding the nature of the deficits and becoming able to deal with changes in memory, behaviour and personality.

Researchers have attempted to measure the burden of family members as a function of traumatic brain injury using measurement scales developed in family system work. Frank et al (1990) found that individuals with traumatic brain injury relied extensively upon information seeking strategies as a way of coping, and families emphasised family cohesion as a way of coping. The increased passivity and dependency often reported following TBI required families to be more cohesive to manage the dependency. Kreutzer et al (1994a) extended the evaluation of individual psychological symptomatology and family functioning. He found that nearly half the caregivers of their sample of mild, moderate and severely injured individuals met the criteria for psychiatric “caseness” when measured between 1.5 months to 5 years post injury. Using the Family Assessment Device (Epstein et al 1983) to measure healthy family functioning, they found problems in a number of dimensions including family communication, affective involvement and roles. Spouses of individuals with brain injury were found to have less optimal adjustment than parents. Douglas & Spellacy (1996) found that the strongest predictor of long term family functioning was given by caregivers’ self report of depression, social support, and coping together with the caregivers’ perceptions of patient competency.

Over the past three decades increased knowledge of the effects of traumatic brain injury on survivors and their families has given rise to increased appreciation of its complexity. Research has looked at injury related factors, psychopathology of both the injured person and the relatives, stress and coping theory, and more recently models of loss and grief. There has been a recognition that family members may go through a process of grieving for the losses that result from the brain injury, although this process may be incomplete. Romano (1974) observed the responses of families and found relatively little progress beyond the initial stage of denial. Families had a strong tendency to maintain the fantasy that the patient would “wake up” and return to his or her previous level of functioning. Relatives would often deny or minimise the patient’s disabilities and hold unreasonable expectations regarding the patient’s ultimate level of functioning. This denial could extend over many years. Thomsen (1984) reported mothers of brain damaged patients who still denied the impact of the injury for up to ten or fifteen years. However, in some cases the family members report that the fundamental aspects of the injured person's personality have changed such that the person they knew and loved is "dead". Since the recovery process is an uncertain one, with many reasons for hope and despair, feelings about the changes may continue to be in turmoil for months and years. This uncertainty and the concomitant disorganisation of the grieving process have resulted in the development of the term "mobile mourning" (Muir et al 1990). The experience of grieving can be put off, sometimes indefinitely, which has been termed "grieving in abeyance" (Perlesz & McLachlan 1986). Perlesz and her colleagues have argued that until the emotional task of grieving has commenced the family cannot take steps to reorganise themselves from the crisis state brought about as a response to the initial trauma of the injury to a more adaptive organisation (Perlesz et al 1992) that can cope with the burden of long term care. However, the assumption that families of head injured patients inevitably reach a stage of acceptance during which roles and

relationships are redefined to promote optimal adjustment has not been empirically tested.

The assumption that following bereavement most people do achieve a state of resolution has been challenged (Wortman and Silver 1989). The long term complications associated with prolonged or otherwise abnormal symptoms of grief have not been systematically investigated, partly because no suitable scale has been available. Prigerson et al (1995) developed a scale to measure those symptoms of grief that have been shown to be distinct from bereavement-related depression and anxiety and to predict long term family functioning. They termed these symptoms “complicated grief” and developed the Inventory of Complicated Grief (ICG) to assess them. The principal aim of the present study is to investigate whether a modified version of the ICG could be a useful predictor of adjustment in a UK sample of relatives of brain injured individuals. Previous work suggests that the functioning of the primary caregiver is more likely to be associated with family adjustment than are measures of severity of injury or demographic variables. The relationship between the functioning of the primary caregiver and the presenting symptoms of the brain injured individual will also be explored.

AIMS AND HYPOTHESES

The purpose of the current study is to explore the relationship between grief and family adaptation following traumatic brain injury. The study has two broad aims. Firstly, to investigate the psychometric properties of the Inventory of Complicated Grief as a measure of a sense of loss for relatives of a brain injured population in a UK sample. The study will also look at the relationship between complicated grief and levels of anxiety and depression. Secondly, the study will explore whether complicated grief plays

a role in accounting for family adaptation following traumatic brain injury. It is hypothesised that:-

1. Socio-demographic factors relating to client and carer, and injury related factors such as severity of injury, or time since injury, will account for only a small proportion of the dependent measures of family functioning and psychological well-being.

2. Poor family functioning will be related to continuing impairments of behavioural and social control in the injured family member, measured by the Neurobehavioural Rating Scale, rather than to the original severity of the injury, as measured by length of post traumatic amnesia and length of coma.

3. Individual measures of family functioning, as measured by the subscales of the Family Assessment Device, will be explained by the level of grief resolution (measured by the modified Inventory of Complicated Grief) for each person, rather than by injury related factors.

METHOD

1) Participants

Participants were identified from a sample of 148 patients previously recruited from consecutive admissions to Leeds hospitals for an evaluation of the Leeds Head Injury Team between June 1993 and February 1995. Criteria for entry in that study were:-

- Aged 16-65 at the time of injury
- Normally resident in Leeds, Bradford or Harrogate

- Inpatient admission of 72 hours or more at either the Leeds General Infirmary (LGI) or St James University Hospital (SJUH)

44 patients were not eligible for the original study under the exclusion criteria of a premorbid history of psychotic illness, alcohol or drug abuse requiring treatment or causing significant life problems, other neurological conditions causing significant difficulty at the time of injury, or other serious mental health problems, with the exception of treatment for reactive depression.

The original study therefore followed up a total of 104 cases, all of which were initially considered as eligible for the current study (see Table 1). However, 16 were excluded as they had no identifiable carer, and 4 were not contacted because the relative lived beyond reasonable travelling distance. Three cases were known to the clinical service and were not contacted. In two cases this was because the team were in the process of negotiating a handover of care to other agencies and did not wish to make fresh contact with the families. The third case had recently been re-referred to the team in relation to charges of criminal assault and child protection and it was not felt appropriate to contact the family about research at this stage.

In six cases contact was made but this did not result in interview. One carer was in the process of moving house and another was ill when initially contacted. Neither responded when contacted again. A third case provided a telephone contact which was wrong, and did not respond to a further letter. Two relatives were not at home at the agreed appointment time and did not respond to subsequent letters. In the final case a mutually convenient interview time could not be identified in spite of a number of telephone calls.

Interviews were carried out with 15 primary carers (mother or partner) and in a further five cases both the primary (mother or partner) and secondary carer (4 fathers, 1 stepfather) were interviewed.

Table 1 : Breakdown of original sample of 104 cases at follow up.

Interviewed	20
Refused	20
No response to letters	35
Not contacted/no identified relative	16
Not contacted/relative lives beyond daily travelling distance	4
Not contacted/clinical grounds	3
Contact made/not interviewed	6
Total	104

Demographic data on cases where relatives declined to be interviewed or where no contact was made was obtained from the original study for comparison with the interview sample. These analyses are reported in the Results section.

In view of the small sample size achieved from the original target group, ethical permission was sought to contact cases on the existing clinical caseload of Leeds Head Injury Team (HINT). Cases were considered eligible if they met the original study criteria of being aged 16-65 at the time of injury, resident of Leeds (Bradford and Harrogate residents were not treated by the Leeds HINT), and with an inpatient stay of more than 72 hours at either the LGI or SJUH. An additional criteria of being at least 12 months post injury was set, in order to focus on longer term adaptation rather than acute distress.

Under these criteria there were 23 eligible cases, of which 9 cases formed part of the original sample group and had already been approached. Of the remaining 14 cases, 7

interviews were arranged with primary carers (mother or partner), and 1 interview with primary carer (mother) and secondary carer (sister).

Table 2: Breakdown of eligible HINT cases not part of original sample.

Interviewed	8
No response to letter	2
Not contacted/clinical grounds	3
Contact made/no interview	1
Total	14

Two relatives did not respond to the initial letter inviting them to take part. Three cases were not contacted. In two of these cases the family situation was particularly chaotic at the time and the team felt it was inappropriate to involve the families in a research study. In the third case the relative had not known the injured person pre-injury and would not have been able to complete key parts of the research questionnaires. One final case was willing to be interviewed but worked three part time jobs and a mutually convenient appointment could not be arranged within the timescale of the research.

2) Procedure

Approval was obtained from the research ethics committee in Leeds.

The named relative interviewed in the previous study where this was known, or the injured person if this was unclear, was contacted by letter including an information sheet explaining the purpose of the study and saying that the researcher would contact them within a few days. Telephone contact where possible was made to explain the nature of the study and what their involvement would be, and where appropriate a visit was arranged. If the relative declined at this stage no further attempt was made to contact them. Where no telephone contact was possible a second letter including a reply slip and

a stamped addressed envelope was sent. A third and final letter was sent, which also included a stamped addressed envelope.

Those that consented were visited at their homes. There was one exception where the parents of the injured person requested that the interview be held at the hospital site. At interview family members present were invited to ask questions about the research and were asked to sign a consent form before proceeding with the interview and questionnaires.

The interview and questionnaires covered:

- Current socio-demographic status of relative and injured person
- Current symptoms of the head injured person (NRS)
- Assessment of family functioning (FAD)
- Assessment of mood of the relative (HADS, WSRS)
- Assessment of loss/grief (ICG)

Where particular problems were identified and further help requested arrangements were made to refer the relatives and injured individual to the Leeds Head Injury Team. This was required in two cases.

3) Measures

Background Information

i) Severity of injury was measured in the original study in terms of Glasgow Coma Scale (GCS) scores (Teasdale & Jennett, 1974, 1976), duration of coma/unconsciousness and of post-traumatic amnesia (PTA). The information from the medical records at the two

acute hospitals did not always allow for an accurate assessment of GCS scores or duration of coma. In discussion with the previous researcher it was apparent that the most reliable measure was the retrospective estimate of the duration of PTA. This was gained by the researcher in all cases, using careful questioning at interview with the injured person and their relative about when the injured person's continuous day-to day memory returned. The classification of duration of PTA was that used by Jennett and Teasdale (1981):

- up to an hour (mild)
- 1-24 hours (moderate)
- 1-7 days (severe)
- more than 7 days (very severe)

For the 8 HINT cases post traumatic amnesia was estimated by the current researcher, using the same criteria.

ii) Educational achievements were recorded together with information about employment. For the original sample, premorbid intellectual functioning was estimated at six months post injury using the National Adult Reading Test or NART (Nelson 1991). The NART is widely used in clinical settings as a predictor of pre-injury intellectual functioning where there are no acquired reading difficulties. The NART consists of 50 irregular words which the subject is asked to read aloud. As irregular words they cannot be correctly read phonologically with the result that correct reading must be through the lexical route implying previous familiarity with the words. The NART has been shown to be resistant to neurological dysfunction (Crawford et al 1987). Preinjury IQ estimates were not available for the 8 HINT cases.

iii) The carer's emotional state had been assessed at each follow up interview using the Wimbledon Self-Report Scale WSRS (Coughlan & Storey 1988). The WSRS was developed as a self-rating scale to detect mood disturbances in the general population and people with neurological or major physical illnesses. It consists of thirty adjectives and phrases describing pleasant and unpleasant feelings. The respondent rates, on a four-point scale, how often in the last week they experienced each feeling. For unpleasant feelings the ratings are: (a) most of the time; (b) quite often; (c) only occasionally; (d) not at all; for pleasant feelings the order is reversed, i.e. (a) not at all; etc. Responses (a) and (b) score 1 and (c) and (d) score 0. The scoring on a 1,1,0,0 system effectively transforms the scale into a two point one. The scores are totalled and the overall response classified as normal (0-7), borderline (8-10) or case (11-30). 'Case' indicates a clinically significant mood disturbance requiring treatment.

Measures used at interview

Examples of all measures used are provided in the appendix.

a) Modified Inventory of Complicated Grief (Prigerson et al 1995) – see appendix 1

Prigerson and colleagues developed a scale that focuses on the symptoms of grief that are distinct from bereavement-related depression and anxiety and which predict long term functional impairment. Factor analysis has shown that the Inventory of Complicated Grief (ICG) measures a single underlying construct of complicated grief. The ICG total score is associated with severity of depressive symptoms and a general measure of grief indicating a valid but distinct assessment of emotional distress. Individuals with a total score greater than 25 have been found to have significantly worse general, mental and physical health, social functioning and bodily pain, as well as depression and this has therefore been suggested as the threshold score for determining syndromal levels of complicated grief.

For the purpose of this study the scale was modified by replacing the word 'death' with the word 'injury' and the phrase 'person who died' with the phrase 'person I knew before the injury'. Two items were omitted (item 4 and item 8) as the rewording was inappropriate. The questionnaire was administered towards the end of the interview after discussion with the relative about perceived changes in the injured person. Scoring was on a 5 point scale of never (0), rarely (1), sometimes (2), often (3), and always (4).

b) Wimbledon Self Rating Scale (Coughlan & Storey 1988) – see appendix 2

As this measure had been used in the previous study it was repeated in order to explore changes in mood over time for primary carers.

c) Hospital Anxiety and Depression Scale (Snaith and Zigmond 1983) – appendix 3

The Hospital Anxiety and Depression Scale (HADS) is widely used with patients with a physical illness because many of the somatic symptoms of depression are excluded. It was used in addition to the WSRS in this study as it is more widely used in clinical practice and in published research, thereby facilitating comparison with other studies.

d) Family Assessment Device (Epstein et al 1983) – see appendix 4

The Family Assessment Device (FAD) is based on the McMaster Model of Family Functioning and is made up of seven scales which measure Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement, Behaviour Control and General Functioning. The General Functioning scale assesses the overall health of the family and is made up of items that correlated highly with all six scale scores. The correlation between the six dimensions scales ranges between 0.4 and 0.6 but when the effects of the General Functioning Scale are removed the six scales are relatively independent. The FAD is moderately correlated with other self-report

measures of family functioning, and it differentiates significantly between clinician-rated healthy and unhealthy families. Cut off scores have been developed for identifying healthy and unhealthy families (Miller et al 1985). The authors found a fairly high association with the Beck Depression Inventory ($r = 0.67, p < 0.001$).

e) Neurobehavioural Rating Scale (Levin et al 1987b) – see appendix 5

The Neurobehavioural Rating Scale (NRS) was originally designed for administration within a hospital setting on the basis of interview and observation of the injured person. There are clear guidelines for administering and scoring the scale items. Although further work is needed to establish its validity and reliability in broader clinical settings there are few other scales which address the areas of behavioural and social control impairment that are widely reported to be predictive of family burden and family breakdown. It was used in this study as a way of recording the primary carers' perception of current symptomatology and not as an objective measure as originally designed.

RESULTS

1. Sample Characteristics

Response Rate

Of the 104 cases in the original study 20 were followed up for this study, together with an additional 8 cases not involved in the earlier study ($n=28$). A total of 34 relatives were interviewed, although in several cases the secondary carer did not complete a full data set.

Characteristics of the patients

Comparisons between the injured people identified from the original study and those from the HINT caseload showed that the two samples did not differ in terms of age at injury, or years of education. Data was not available from the HINT group to compare pre-injury IQ levels. The two samples differed in the number of months post injury ($n=20$ mean = 43.3 s.d.=5.6 range 33-52; $n=8$ mean = 26 s.d.= 13.3 range 14-56; $t = 4.9$ $p<0.001$). Visual inspection indicated that the sex ratio of the injured person was different in the two groups (male:female $n=20$ 4:1; $n=8$ 7:1) but chi-squared comparisons were not appropriate as the expected values for female gender were below 5 for both groups. Similarly, visual inspection indicated that the HINT caseload did not include any mild/moderate injuries (PTA < 24 hours), whereas 6/20 of the sample from the original study were categorised as mild/moderate injuries.

The total sample interviewed ($n=28$) was compared with all those not interviewed from the original sample ($n=84$) and did not differ on the demographic or injury related variables as shown in Table 3.

Table 3. Characteristics of brain injured individuals in current interview sample ($n=28$), compared with those not interviewed because they refused, did not reply, or were not contacted ($n=84$).

	Original Sample $n=104$	Interviewed sample $n=28$	Refusals $n=20$	No reply $n =40$	Not contacted $n=24$	Statistical test used $n=28$ vs. 84
Sex of injured person	78% male	82% male	70% male	78% male	83% male	Chi square n.s.
Age at injury (median)	32 (22,43)	32 (24,45)	38 (23,52)	30 (20,41)	32 (22,38)	T test n.s
Severity of injury %>24hrs PTA	64%	79%	45%	65%	71%	Chi square n.s
Education (median yrs. and range)	11 (10,11)	11 (10,11)	11 (10,11)	11 (10,11)	11 (10,15)	T test n.s

The comparison was also made between the pre-injury IQ range of the 20 cases interviewed and the 84 not interviewed (see Table 4). Pre injury IQ data was not available for the HINT cases.

Table 4: Comparison of estimated preinjury IQ ranges based on NART scores for the interviewed/not interviewed original sample

	Original Sample n=104	Interviewed sample n=20	Refusals n=20	No reply n =40	Not contacted n=24	Statistical test used n=20 vs. 84
Est. IQ <90	40%	24%	17%	34%	32%	Chi using
pre 90-110	45%	59%	66%	65%	46%	<90/ >90
injury >110	15%	18%	17%	9%	23%	n.s

The twenty cases contacted who refused to participate did not differ significantly from those interviewed, not contacted, or where there was no response although the data in Table 3 would suggest that a smaller proportion of this group may have been severely injured (45% with PTA > 24 hours). At least three relatives made comments when they declined to be interviewed which suggested there were no ongoing problems, for example, “there aren’t any changes.. it wasn’t a bad head injury.. it was his hands really” and “everything is alright now”. Two relatives declined saying “it’s all behind us now” and “I don’t want to be reminded”. Several relatives commented that they had been interviewed twice already and did not want to be involved again.

Characteristics of relatives

In the original sample of 104 head injured clients the identified primary carers were predominantly female (82%) and this was still the case at interview (85%). The proportion of partners remained the same (43%) but there was an increase in the percentage of parents interviewed (35 % in the original sample; 51% at interview). The age ranges of the relatives interviewed were not significantly different.

2. Psychometric investigation of the Inventory of Complicated Grief (ICG)

The first aim of the study was to investigate the utility of the Inventory of Complicated Grief for relatives of brain injured people in a UK sample. Table 5 shows the reliability of the modified scale used for this study and the data presented by the original authors (Prigerson et al 1995).

Table 5 Reliability of the modified Inventory of Complicated Grief.

	Cronbach's alpha	Mean	Standard deviation
Modified ICG n=34	0.91	19.7	17.3
ICG	0.94		

Table 6 (see below) shows the item-total correlations for the individual items with the total score. The correlations were at or above $r=0.50$ for all items except question 9, which assessed the extent to which the relative felt pain in the same area of their body or had some of the same symptoms as the injured person. The item assessing the sense of loneliness was most highly correlated with ICG total score ($r=0.91$), followed by the feeling that life is empty since this person was injured ($r=0.90$), preoccupation with thoughts about the injured person to the point of distraction ($r=0.88$), and not being able to accept the loss of the person as they were preinjury ($r=0.88$).

Table 6: Item correlations for Modified Inventory of Complicated Grief with total ICG score (n=34).

Item	Pearson	Mean	SD
1. I think about this person so much it's hard for me to do the things I normally do	.88**	1.27	1.33
2. Memories of the person I knew before the injury upset me	.78**	1.27	1.45
3. I feel I cannot accept the loss of the person I knew before the injury	.88**	1.35	1.63
4. I feel drawn to places and things associated with the person I knew before the injury	.79**	0.85	1.35
5. I can't help feeling angry about the injury	.82**	2.12	1.32
6. I feel disbelief over what happened	.73**	2.00	1.23
7. Ever since the injury it is hard for me to trust people	.67**	1.15	1.13
8. Ever since the injury I feel like I have lost the ability to care about other people or I feel distant from people I care about	.65**	0.53	0.90
9. I have pain in the same area of my body or have some of the same symptoms as the injured person	.38	0.91	3.79
10. I go out of my way to avoid reminders of the person I knew before the injury	.5*	0.47	0.83
11. I feel that life is empty since this person was injured.	.9**	1.03	1.45
12. I hear the voice of the person I knew before the injury speak to me	.72**	0.50	1.08
13. I see the person I knew before the injury stand before me	.5*	1.41	1.64
14. I feel that it is unfair that I'm OK when this person is injured	.87**	1.03	1.45
15. I feel bitter over this person's injury	.54**	1.79	1.34
16. I feel envious of others who have not lost someone close	.69**	0.88	1.12
17. I feel lonely a great deal of the time ever since he/she had their injury	.91**	1.15	1.44

* significant at P < 0.05. ** significant at P < 0.001 level

3. Psychometric properties of Family Assessment Device (FAD).

The sample size was too small to permit factor analysis of the FAD. Table 7 presents the number of items, reliability levels, means and standard deviations for each of the seven scales based on the responses of the 32 relatives who completed the scale at interview, and compares these with the figures available in the original validation study using the responses of 503 individuals (see Epstein et al 1983). Reliability coefficients were satisfactory for all scales except behaviour control (Cronbach's $\alpha = 0.41$). This scale was excluded from further analysis.

Table 7: Reliabilities, Means and Standard Deviations of the Seven Scales of the Family Assessment Device for the current sample (n=32) and for the original sample (n=503, Epstein et al 1983).

	Cronbach's <i>alpha</i>		Mean		Standard Deviation		Number of Items
	n=32	n=503	n=32	n=503	n=32	n=503	
Problem Solving	.71	.74	2.0	2.3	.25	.47	5
Communication	.60	.75	2.2	2.3	.2	.51	6
Roles	.82	.72	2.4	2.4	.27	.43	8
Affective Responsiveness	.73	.83	2.1	2.4	.23	.61	6
Affective Involvement	.64	.78	2.1	2.2	.24	.50	7
Behaviour Control	.41	.72	2.0	2.0	.19	.41	9
General Functioning	.87	.92	2.0	2.2	.68	.58	12

4. Psychometric properties of the Mood Questionnaires.

In all analyses the Wimbledon Self Report Scale (WSRS) and the Hospital Anxiety and Depression Scale (HADS) produced the same pattern of results. As the HADS is more widely recognised, only these results are given in this paper with the exception of the data on mood scores over time (see page 72).

Table 8: Reliabilities, Means and Standard Deviations of the Hospital Anxiety and Depression Scale (HADS) and Wimbledon Self Report Scale (WSRS).

	Reliability (Cronbach's <i>alpha</i>)	Mean	Standard Deviation	Number of Items
HADS anxiety n=33	0.93	8.09	5.58	7
HADS depression n=33	0.83	4.76	3.72	7
WSRS n=31	0.97	7.56	9.23	30

5. Hypotheses

Hypothesis 1: - Relationship of socio-demographic variables to family adjustment.

Correlations were performed between the Family Assessment Device scales (FAD) and relevant socio-demographic variables (see Table 9). Spearman's correlations were used for the gender of the injured person and relative. Pearson's correlations were used for the variables of age, pre-injury IQ, and income of the relatives at interview.

Significant correlations were found for gender of the head injured person with all FAD scales except Affective Involvement i.e. where the injured person was male the scores on the FAD scales were higher. Higher FAD scores are associated with poorer family adaptation. The other significant correlations were between income range and FAD-affective involvement and FAD-affective responsiveness. In both cases the negative correlation suggests that a higher income is associated with fewer family adjustment problems as measured by these two subscales.

Table 9. Pearson's correlations of socio-demographic variables of patient and relative with family adjustment.

FAD sub-scales ①	Age of tbi at injury n=28	Pre-injury IQ range n=20	Age at interview of relative n=32	Income per household at interview n=28
FAD-R	.12	-.27	-.06	-.37
FAD-PS	.15	-.14	-.24	-.18
FAD-GF	.20	-.20	-.07	-.33
FAD-C	.19	-.09	-.11	-.05
FAD-AR	.05	-.10	.05	-.42 *
FAD-AI	.26	.09	-.03	-.48 *

* significant at $p < 0.05$.

① Family Assessment Device subscales: Roles (FAD-R), Problem Solving (FAD-PS), General Functioning (FAD-GF), Communication (FAD-C), Affective Responsiveness (FAD-AR), Affective Involvement (FAD-AI).

T-tests were used to compare the mean scores for males and females for both the gender of the injured person and of the relative interviewed. No significant effects on family adjustment were found for the gender of the relative interviewed. Significant effects were found for the effect of gender of the injured person and family functioning (see Table 10). Further analysis of this effect was not possible because of the small number of female injured participants.

Table 10. Comparison of mean scores for male and female injured persons with family adjustment

FAD sub-scales①	FAD-AI mean score and s.d.	FAD-AR mean score and s.d.	FAD-C mean score and s.d.	FAD-GF mean score and s.d.	FAD-PS mean score and s.d.	FAD-GF mean score and s.d.
Female n=5	12.0 ± 1.9	12.2 ± 0.8	9.6 ± 3.4	17.4 ± 5.1	7.2 ± 2.1	13.2 ± 4.8
Male n=23	13.0 ± 2.7	14 ± 1.8	13.7 ± 2.0	25.1 ± 4.7	10.9 ± 1.4	17.6 ± 2.8
	n.s	t=-3.38 *	t=-3.66 **	t=-3.1 *	t=-4.89 **	t=-2.82 *

* significant at $p < 0.05$. ** significant at $p < 0.001$

① Family Assessment Device subscales: Roles (FAD-R), Problem Solving (FAD-PS), General Functioning (FAD-GF), Communication (FAD-C), Affective Responsiveness (FAD-AR), Affective Involvement (FAD-AI).

Hypothesis 2: - Level of impairment and family adjustment.

i) Severity of original injury

Correlations were calculated between the six FAD scales and the mood scales (Hospital Anxiety and Depression Scale and the Wimbledon Self Report Scale) and severity of original injury as measured by length of post traumatic amnesia (PTA) and worst Glasgow Coma Scale Score (GCS). All correlations were non significant i.e. neither PTA nor worst GCS score were correlated with any of the FAD scales or with current mood state (r s ranged from -0.08 – 0.28 , n.s.).

ii) Severity of current symptoms

The reliability of the Neurobehavioural Rating Scale (NRS) was calculated (Cronbach's $\alpha = 0.87$ mean 67.9 S.D. 38.2). Severity of current problems as measured by NRS was significantly correlated with FAD-Roles ($r=0.5$, $p<0.008$) and FAD-Affective Involvement ($r=0.5$, $p<0.009$) but not with the other FAD scales.

The NRS was also correlated with raised anxiety and depression on the Hospital Anxiety and Depression Scale (HADS-Anxiety $r=0.71$, $p<0.001$; HADS-Depression $r=0.80$, $p<0.001$). On examining the correlations with the HADS, it was apparent that HADS-Anxiety and HADS-Depression were associated with both NRS and FAD-Roles and FAD-Affective Involvement, raising the question as to whether the relatives' mood was affecting their perception of problems as identified using the NRS.

Table 11. Partial Correlations of Neurobehavioural Rating Scale total score (NRS) and FAD-roles (FAD-R) and FAD-affective involvement (FAD-AI) with Anxiety and Depression removed.

	Zero Order Correlations	Partial correlations controlling for HADS-Anxiety	Partial correlations controlling for HADS-Depression
NRS and FAD-R	0.50 *	0.24	-.06
NRS and FAD-AI	0.50 *	0.34	-.02

* significant at $p<0.05$

Partial correlations of NRS total score with FAD-Roles and with FAD-Affective Involvement were carried out to see the effect of controlling HADS-Anxiety and HADS-Depression. With the removal of HADS-Depression the correlations between NRS and FAD-Roles and FAD-Affective Involvement disappeared and with the removal of HADS-Anxiety the correlation was non-significant (see Table 10). This suggests that the association of NRS with the FAD scales was attributable to the effects of mood on both scores.

Hypothesis 3: - The role of complicated grief in accounting for family adjustment.

Bivariate correlations showed that total score on the Inventory of Complicated Grief was significantly associated with FAD-Roles ($r=0.53$ $p<0.05$), FAD-General Functioning ($r=0.37$ $p<0.05$) and FAD-Affective Involvement ($r=0.44$ $p<0.05$), but not with FAD-Problem Solving ($r=0.12$ $p=0.50$), FAD-Communication ($r=0.21$ $p=0.26$), FAD-Affective Responsiveness ($r=0.09$ $p=0.63$). However, the three FAD scales of Roles, General Functioning and Affective Involvement were also associated with Neurobehavioural Rating Scale (NRS), HADS-Anxiety and HADS-Depression, raising a question about the unique contribution that the ICG is making to variance in FAD scores. In Table 11 are shown the partial correlations for FAD-Roles, General Functioning and Affective Involvement with ICG when each of these variables is controlled for. Partial correlations indicate the degree of association between complicated grief and family adjustment after controlling for any portion of the variance which is shared with the control variable. However, when depression scores are removed the correlation between the FAD and the ICG disappears. The effect is not as dramatic with the removal of the anxiety scores but the correlations are not significant. One tailed tests were used, as it was hypothesised that any effect of mood would be

unidirectional. Interestingly, a significant association was obtained between ICG and FAD-Roles after controlling for NRS, suggesting perhaps that the behavioural problems of the injured person do not significantly affect the impact of grief on family-role functions.

Table 12. Zero Order and Partial Correlations between FAD scales and Inventory of Complicated Griefcontrolling for mood (HADS-anxiety and –depression), Neurobehavioural Rating Scale Score.

	ICG Zero order correlation	HADS-D	HADS-A	NRS total
FAD-R	.53**	.07 ns	.29 ns	.27*
FAD-GF	.37*	-.18 ns	.10 ns	.15 ns
FAD-AI	.44*	-.08 ns	.27 ns	.11 ns

*significant at $p < 0.05$

**significant at $p < 0.001$

6. Mood and Grief

A supplementary aim of the study was to examine the validity of the ICG as independent from mood. In their original paper Prigerson et al (1995) suggested that the ICG could identify a component of grief that was distinct from anxiety and depression. It has not proved possible in this study to separate the components of grief from those of anxiety and depression.

The Wimbledon Self Report Scale was used in the current study in order to explore the changes in mood over time in the original sample. Table 12 describes the emotional state of the relatives at six, twelve and eighteen months post injury and again at follow up (primary carers only). Data is not presented for the 8 cases where no previous interviews had taken place.

Table 13. Emotional state on the Wimbledon Self Report Scale for relatives at 6, 12, 18 months post injury and at follow up in current study, compared with a general population sample (data from Coughlan & Storey 1988).

Time since injury	N	Median raw score	Inter-quartile range	Borderline/case N (%)
6 months	96	3.5	1,10	31 (33%)
12 months	72	2.0	0,9	24 (34%)
18 months	37	3.0	0,10	13 (35%)
Follow up at mean 43.3 months (range 33-52)	20	1.0	0,8	6 (30%)
General population	274	-	-	33 (12%)

Approximately one third of relatives scored within the range that would warrant further investigation in clinical practice (scores of 8 or more) up to eighteen months post injury, and at follow up 30% of the relatives were scoring within this range. Only 12% of the general population would be expected to score in this range, indicating that these relatives continue to experience considerable mood disturbance at an average of over three and a half years post injury.

DISCUSSION AND CONCLUSIONS

The study's overall aim was to explore the relationship between grief and family adaptation following traumatic brain injury. Specifically, the study investigated whether complicated grief could be identified as having a particular role in accounting for family adaptation over and above factors such as severity of injury, socio-demographic variables and other mood related variables.

The first hypothesis was that socio-demographic variables relating to the injured person and the relative would account for only a small proportion of the dependent measures of family functioning and psychological well-being. The results support this hypothesis, in that there were few significant correlations. Gender of the injured person had an effect on five out of six FAD scales, suggesting that where the injured person is male, there are more problems of adjustment within the family. It was not possible to investigate the relationship between the variables separately for men and women because of the small sample size.

The lack of significant correlations between socio-demographic variables and psychological adjustment is consistent with previous studies which have also found demographic variables to be poor predictors of longer term psychological adjustment in relatives.

The second hypothesis related to the role of continuing impairments in the behaviour and social control of the injured person in contributing to poor family adjustment and psychological distress in relatives. A high level of continuing behavioural disturbance as measured by the Neurobehavioural Rating Scale was correlated with two subscales of the FAD, i.e. FAD–Roles and FAD–Affective Involvement. These are two of the three scales identified by Kreutzer et al (1994a) as being associated most closely with continuing problems in family functioning. However in the current study the correlations between the NRS and the FAD scales could be accounted for by the mood component measured by HADS-anxiety and HADS-depression, with the effect being more marked for the depression scale. The NRS was being used as a subjective measure of continuing behavioural problems, and it is not unreasonable to suggest that as such it was likely to be closely correlated with the relatives' mood state. This is consistent with previous

suggestions that indicate that relatives' perceptions of the injured person and their deficits is a better predictor of the adjustment of the relative. The lack of objective measurement of the current functioning of the injured person is a limitation in this study. However, Kreutzer et al (1994a, 1994b) found a similar relationship between the caregiver's report of their own and the patient's complaints, and in their study they had carried out a range of independent neuropsychological measures of the patient's functioning. They were therefore able to examine the hypothesis that caregivers were 'projecting' their own symptoms onto the patients. Further analysis of their data did not support the conclusion that the relationship between patient symptoms and caregiver distress was a direct result of the methodology of using self report by carers to assess patient symptoms. Thus, although it would have been helpful to have an objective measurement of the functioning of the injured person in the current study in order to disentangle the effect of the mood state of the carers, it is not clear that this in itself would have altered the overall interpretation of the results.

The main aim of the study was to explore the utility of the Inventory of Complicated Grief as a predictor of family adjustment with a sample of relatives of people who have sustained a traumatic brain injury. The inventory itself in its modified form did have good internal consistency, although one item was weakly correlated with the total scale score. The scores on the modified ICG were associated with some aspects of family adjustment, FAD-roles, FAD-affective involvement, and FAD-general functioning but these correlations became non significant when the effects of anxiety and depression were controlled for. Psychological distress in the relative did seem to be linked to family adaptation as predicted, but it was not possible to identify a factor of complicated grief over and above the effects of anxiety and depression to account for successful family adaptation. However, the items most highly correlated both with the total grief rating

and individually with measures of family functioning and mood were those that identified loneliness, emptiness and envy of those who have not lost someone. These are difficult emotions to elicit from relatives as they often perceive them as evidence of disloyalty or selfishness. The questionnaire, subject to further modifications, may provide a useful therapeutic tool whereby these emotions can be more easily acknowledged.

Although the Inventory of Complicated Grief did not identify a separate concept of complicated grief in this study, further investigation into its psychometric properties and its predictive value is required as it appears to have potential to be a useful measure. Provided they had already identified some changes in their relative earlier in the interview, relatives who completed the modified ICG found the concept of loss meaningful and most of the questions easy to respond to. For those who reported that their relative had made a full recovery, the questions were more difficult to complete and several relatives commented that it was as if they were being asked to talk about someone who had died. Specific items were confusing to relatives and could be amended in a future study, for example, item 13, 'I see the person I knew before the injury stand before me'.

This study represents one of the few attempts to explore the concept of loss in a UK sample of relatives of head injured people. It is limited by its small sample size. It would be valuable in further work to utilise an objective rating of either the Neurobehavioural Rating Scale, or one of the limited number of alternative scales designed to look at longer term social and behavioural functioning.

The aim of identifying a measure of loss is driven by the clinical need to work with family members to help them to adjust to the major change in their lifestyles following a

traumatic brain injury in a close family member. Many family members are counselled or prescribed medication for depression in the years following the injury to their relative but there is little evidence to suggest that this model of treatment is successful. The evidence actually suggests that relatives continue with high levels of depression and anxiety for many years after the injury. Beyond measuring the levels of emotional disturbance in family members there has been little theoretically driven work to understand the factors influencing the development and maintenance of these emotional states. One of the potential avenues to explore is the model of unresolved and unacknowledged grief. Lack of recognition of the loss by the broader family and social network is a common theme in clinical practice. The current study represents an attempt to acknowledge that clinical problem. The Inventory of Complicated Grief does allow carers to express difficult emotions, which in turn allows therapists an opportunity to work with relatives to help them understand the situation and move forward. In spite of its limitations the study has provided useful information to allow for a more systematic approach to investigating the possible role of complicated grief in family adaptation following traumatic brain injury.

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CRITICAL APPRAISAL

ORIGINS OF THE PROJECT

The idea for the project arose directly from my clinical role in the rehabilitation and support for people who have sustained traumatic brain injury. I work closely with families who are struggling to come to terms with the sustained trauma of living with someone who has suffered a brain injury. During the rehabilitation process, which might involve working with a family over a two or three year period, it happened quite frequently that a family member would say, at some point, "it would have been better if he'd died" or "I lost my son that day...even though he's sitting there looking the same..he's not the same person". For all these relatives the acknowledgement of this sense of loss felt like a defining moment in their adjustment, but it was difficult to predict whether the relative would then continue in their caring role, or whether they would decide to leave the situation.

The concept of loss in its broader sense e.g. loss of function, of ability, of role, and of the person you used to be or know, is an important theme in rehabilitation. For the relatives there seemed to be parallels with issues that arose with bereavement, but at the same time the continuing presence of the person made the comparison difficult. However, some colleagues attended a conference in Australia in 1996 which included a paper from the Family Therapy Centre in Melbourne (Douglas 1996) where there had been a study looking at grief in the families of traumatic brain injured individuals. The audiocassettes of the presentation discussed the concepts of 'grieving in abeyance' (Perlesz & McLachlan 1986) and 'mobile mourning' (Muir et al 1990), which seemed to describe some of the clinical features seen in my clients.

One of the factors discussed in the Australian presentation was the impact of different coping strategies and whether it was possible to help families adjust by exploring and developing their coping. When I explored the literature on coping strategies more generally, it was clear that there was a debate about when certain strategies were most appropriate. I was interested in this because of similar themes that had arisen in another review I had recently carried out of the literature on the role of families in the behavioural management of people with traumatic brain injury. Family education programmes were an important feature in the literature, and it was apparent that family education programmes were gradually shifting in emphasis from emotion-focused coping strategies towards problem-focused coping. In the American literature in particular, problem-focused training was being advocated as more appropriate for unresolvable situations. The Australian literature, however, seemed to suggest that unless the emotional state was addressed, if not first then in parallel with problem-focused training, then the relatives would not be able to make use of the practical advice. At this stage I considered using qualitative methodology to carry out an in-depth analysis of the coping processes used by relatives following traumatic brain injury. Although I was unfamiliar with the methodology, it felt like an opportunity and a challenge. However I was concerned about the identification of suitable participants. In particular I was concerned because I provided the major clinical service to families in the local area, and I felt it would be difficult to identify cases in which I had either not been involved or in which I would not feel obliged to become involved should the situation require intervention. Adding to an already overstretched caseload was not the object of the exercise.

At this point I found the number of ideas and possibilities somewhat overwhelming. It was difficult to focus down on a specific area and make it into a practical proposition. Faced on a daily basis with the clinical need, I wanted to solve it all instantly. The identification of a specific research question was one of the most challenging parts of the process for me. In the end the choice of project was guided by a combination of practical changes and further reading around the key areas of family adaptation and grief and loss.

1. Change of Job

The decision to change my job in the middle of the degree presented both opportunities and challenges. Inevitably the process of leaving one post and establishing myself in a new service within a different health region occupied my time and my thinking for a number of months. However, the change also provided me with access to an existing database of traumatically brain injured clients and carers, which made it easier to consider exploring adjustment issues over a longer follow-up period. In addition, by moving to a different health region I was confident that I would not have been involved in any previous interventions.

2. Identification of a measurement scale for family adaptation.

I had been interested for several years in the idea of measuring family functioning and had collected various measures as I came across them in clinical practice. However, I had not seriously investigated the literature. This project encouraged me to explore the literature more thoroughly. This highlighted several recent papers that had used a particular family assessment scale that I had come across several years previously but had been unsure about using with my particular client group. Reading the various

papers gave me greater confidence that this measure could potentially provide useful information.

3. Identification of a measurement scale for unresolved grief.

The information from the Australian conference had suggested that there were various measures to assess grief, some of which could be adapted for use with a brain injured population. I carried out another literature search of the areas of grief and loss in order to locate these measures and also to get a general sense of whether the notions of loss were in fact useful concepts with this client group. During this search I found a paper describing the measurement of complicated grief, including a scale that in my view had potential to be adapted to assess unresolved grief following traumatic brain injury.

With the combination of the practical job changes, and the identification of potentially useful measures, I was finally able to produce a more specific outline proposal. In the end this proposal was very different from what I had earlier envisaged. Instead of exploring coping strategies using qualitative methodology, I now planned to test the hypothesis that family members experience a grief reaction following traumatic brain injury, and that this reaction affects their adaptation to the situation.

TIMESCALE AND PROGRESS

Initial discussions with my supervisor about carers and coping strategies took place in summer 1996 i.e. six months into the course. At that stage I was thinking about a qualitative analysis of positive coping in family members. Due to serious family illness and the decision to change jobs, there was then a six month gap in the thinking process.

When I took up my new post in February 1997 I had negotiated dedicated study time. This, together with support from the new service for a follow-up study of the existing database, helped me to focus my ideas more rapidly. My own thinking had shifted in the intervening months with the feedback from the Australian Conference, and further discussions with colleagues about carers and loss. Once the ideas were clear the proposal was straightforward to write. It was submitted to the training course committee by April 1997, and also to the Ethics Committee in Leeds. Initial discussion had suggested that the project might receive Chair's approval, but in the end the full proposal had to be submitted. At the same time my employing Trust implemented a new Research and Development strategy which required that the proposal had to be submitted to their R&D Directorate in order to obtain the appropriate indemnity cover.

The University approval came through in July 1997 with just a few points of clarification. The R&D directorate in Leeds also agreed the proposal with no amendments. "In principle" agreement came through from the Ethics Committee subject to an additional letter to the general practitioner of all relatives interviewed. Full approval was granted in August 1997. I had been aware of the problems experienced by colleagues in gaining ethical permission, but for this particular project the process WAS relatively straightforward.

In August 1997 letters were sent to all potential participants as outlined in the research paper. These letters were followed by telephone calls wherever a number was available, but unfortunately many of the numbers on the original database were now unobtainable. When a second letter complete with reply slip and stamped addressed envelope had a very limited return rate I became concerned about the difficulty in actually making contact with sufficient numbers of people. The original database had identified 104

cases which had seemed sufficiently large to allow for a reasonable attrition rate. I had expected that there would be a significant number of refusals, both actively and through failure to respond, but the numbers interviewed were lower than anticipated. Although the low number was disappointing, it was not unexpected. Apart from issues specific to this client group (see below) I knew from previous work that one of the unwritten laws of research is that the seemingly endless stream of suitable participants dries up immediately you start the research project. After the second letter, I decided to approach families living beyond the Leeds border but within travelling distance, and I also re-contacted the Ethics Committee to gain permission to extend the project to include appropriate cases from the community head injury team service. This permission was granted rapidly by Chair's approval and without need to submit any further information.

Interviews were carried out between September and mid-November. A further disappointment was that the interviews were predominantly with the primary carers, and occasionally also with spouses of primary carers. The hope had been to get a number of members of the same family together in an attempt to look at issues for different family members and also because this would have increased substantially the number of participants.

Data analysis was more straightforward than anticipated. Before beginning the project I had been concerned about the analysis stage since my recollection of data analysis involved giving hand-written sheets to data processing technicians, sitting by the mainframe trying to remember the appropriate line of instruction to type, and then walking back to data processing to collect the results. The developments in technology

and in SPSS were a revelation and a delight, making the whole process so much quicker and easier.

It was only in the final stages of writing up of the project that the pressure of time became a major factor, and choices had to be made about how to allocate time between the demands of a full-time clinical job, the research, and having a life. However, with a short deadline it was easier to prioritise because there was a clear endpoint.

AIDS AND BARRIERS TO PROGRESS

1. Supervision

In the early stages when there were so many ideas and possibilities it was extremely helpful to discuss these with my supervisor, who was able to direct me towards useful starting points in the literature and eventually to help me to isolate the relevant ideas and tighten up on my thinking process. Good supervision was also important at this stage in order to ensure that the study was methodologically sound, and this had enormous benefits subsequently when it came to the analysis stage.

2. Participant numbers

I was aware from my own experience and that of friends and colleagues that it is always more difficult than anticipated to contact sufficient numbers of participants. I was not therefore surprised by the problems with the current study, although I was disappointed. Although I took steps to increase the response rate, in the end this had only a limited effect. With hindsight I feel that I could have been more aware of the potential problem, given my knowledge of the clinical population in question. I feel that closer

inspection of the original sample data might have predicted a low response rate for a number of reasons:

- a) A high proportion of mild/moderate injured people, who were more likely therefore to have made a full recovery and not to respond to yet another reminder of the injury.
- b) A high proportion of assault cases, which tend to occur in young unemployed men who form a transient population likely to be lost to follow up.
- c) The length of time since injury coupled with the fact that some families had already been interviewed on at least two occasions.

If I were carrying out a similar follow-up study in the future, particularly if I was again picking up on another researcher's data, I would place greater emphasis on exploring the characteristics of the suggested participant group before specifying the methodology.

In spite of these reservations and the benefits of hindsight there were strong reasons for using this sample which remain valid, including the fact that the follow-up data was directly relevant to arguments about service provision for people longer term after traumatic brain injury and to ongoing discussions about the funding of my clinical service.

3. Measurement problems.

The identification of appropriate measurement tools was a major part of the early discussions and thinking about this project. Having identified what seemed to be appropriate measures, it felt during the process of interview and analysis that each of the

tools was unsatisfactory in some way. The Inventory of Complicated Grief in its amended version was acceptable and comprehensible to family members but it actually needed more work to adapt it for use with this population. In this study it was being used as the dependent measure and as such was an important measurement tool, without its validity and reliability having been adequately established.

Similarly, the Neurobehavioural Rating Scale is one of the few published scales that look at social and behavioural changes after brain injury. As such it seemed appropriate for the study, but its reliability has been established in a limited number of settings, and usually more acutely. More importantly, in the current study it was being used as a subjective measure of the injured person's current functioning, as perceived by the relative, rather than an objective measure. This is one of the major limitations of the study in that it restricts the interpretation of the data. To have avoided this limitation would have necessitated an in-depth interview with each injured person, including psychometric assessment, which would have created an enormous additional time component to the study. It would probably have reduced the response rate still further as a number of relatives who agreed to be interviewed did so on the understanding that it would not involve the injured person who had already stated that they wanted no further follow-up.

The difficulty in identifying appropriate measures is not unique to this study. Throughout the literature different studies have used or amended different measures as I have done. This process, whilst understandable, has made it difficult to compare across studies.

4. Resources

a) access to library facilities and interlibrary loans

I was fortunate in that I was able to utilise my study time to visit the library to collect books and order articles. Very few of the specialist books and articles were directly available and it was essential therefore to make use of the interlibrary loan system. Unfortunately, articles with promising titles or abstracts frequently turned out to be irrelevant or unhelpful.

b) time

This was a crucial and valuable resource. Working full-time and attempting to complete the clinical doctorate, particularly the research thesis, was difficult. It became possible only when I negotiated and took dedicated study time. In the final few months, it was also necessary to invest some of my annual leave and personal time. This was particularly important as a way of timetabling sufficient 'chunks' of time. There were certain stages both in the data analysis and in the write-up which could not in my view be achieved through small snatches of time between other commitments.

c) computers

I would not have been able to juggle my work, research and home commitments without the benefit of my home computer. Again, this was particularly relevant for the analysis and write-up stages, as I was then able to work to my own schedule, and not have to negotiate access to buildings, equipment etc.

5. Professional isolation

I was fortunate in that my immediate team colleagues were generally supportive, especially in terms of accepting my time and intellectual commitment to the research during the final few months, even though this inevitably had repercussions for them in terms of workload and decision making. In spite of their tolerance and their support for me personally, they were unable to provide support in the form of understanding of the demands and stresses of research. Working in a community team with no other psychologists is professionally isolating at the best of times, but even more so when trying to carry out research. Senior psychologists, particularly those working in specialist posts in multidisciplinary teams often have little contact with other psychologists, and even less with those who regularly carry out research. One of the reasons for doing the D. Clin. Psych. was to gain confidence in my own ability to complete the research in spite of this isolation. What actually happened was that the isolation was highlighted, together with the practical problems this created. Even when I had agreed study time which I took, there was a major problem in juggling the demands of a full time clinical job with the need to access staff, equipment, libraries etc in a different city. Study leave time would be booked months ahead to prevent it being swallowed by clinical demands, but then would not fit in with the availability of staff, or university holiday periods.

REFLECTIONS AND CONCLUSIONS

1. Origins of project

I found the process of identifying the specifics of the research project particularly challenging. I felt there was a conflict between my 'clinical hat' which wanted to sort the problem and address directly the distress, versus the 'research hat' which was

looking to contribute to the greater understanding and body of knowledge. It may be that this is a particular problem for clinicians working with client populations with chronic problems and high levels of distress, where the complex questions and the messy lives that face you every day do not sit easily in the tight framework and methodology of research. I found it difficult to translate the theoretical justification for the research into a clinical justification, particularly when interviewing distressed clients.

2. Research administration

With the benefit of previous research experience I was aware of the length of time it could take to set up a research project, including potential difficulties with submissions to relevant bodies such as Ethics Committees. I was also aware of the need to keep clear records of the interview process, which is of course good clinical practice. However, the amount of time that it took to identify the project, and produce the relevant paperwork even for such a small-scale study was a luxury in a busy clinical post. I have been involved in submitting proposals for larger scale research bids and I am aware of how much time this takes. The recent developments in accounting for research time in the NHS may help to raise the profile of this issue by acknowledging the time spent in pre-protocol work. I have some concerns that the emphasis on formalising this work, and the various hurdles of submission and re-submission, may deter all but the dedicated and the experienced. However, on a personal note, I hope that the fact that the process was relatively straightforward for this particular project will encourage me to pursue further projects, even in the face of the paperwork.

3. Research process

It has been many years since I carried out clinical research rather than service or staff evaluations. The previous clinical study had been during my clinical training i.e. when I was relatively inexperienced in clinical interviewing. I was very aware in the current study of the difference between interviewing for the purposes of the research study and my normal clinical interviewing. As a clinician, when I visit a home or meet with a new client I am empowered to ask questions and to direct the conversation. Because of the nature of my client group I usually need to explain who I am, why I am there, what I do and often have to persuade or negotiate with clients and carers. However, I am there to offer something to the client or carer, and do not need to justify my presence. If clients or carers are angry or offensive I know how to handle the situation, and what groundrules to set. If they want to reject what is on offer I know the limitations of my powers of persuasion and how to leave them with a route back into the service at a later date. With the research interviewing I was without that set of justifications for being there, and asking something of them without being in a position to give anything. Once I had gained the relevant information I felt I had to engage in conversation or to make some form of social gesture. On the few occasions where the family was in crisis it was much easier for me to gain the data as I was also able to step back into the role of provider of a service rather than a supplicant searching for data. Throughout the process I was sustained by my clinical sense that this was a valuable exercise and that I could see its relevance if not to the person I was interviewing then to others. If I was to carry out further research it is this commitment to the purpose and value of the research question that would take a higher priority.

Future Research?

I feel strongly that the issues addressed in this research project are important and should be more widely disseminated. The forum for doing so is through publication. There is further work that needs to be done to identify the time course and contributing factors to family adaptation following traumatic brain injury and I am keen to carry out further research in this area. However, my experience of the current project has taught me that for future projects I need to ensure that:

- a) I identify colleagues with interests and experience in similar areas of research.
- b) I identify a research question that I feel is relevant to my clinical experience.
- c) I have access to adequate resources to complete the project.

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MODIFIED INVENTORY OF COMPLICATED GRIEF p. 1.

Sometimes months after a head injury people feel that the "old" person has gone and they miss him/her. The next set of questions asks you to think about your relative as they were before the injury.

I think about this person so much that it's hard for me to do the things I normally do.				
never	rarely	sometimes	often	always
Memories of the person I knew before the injury upset me				
never	rarely	sometimes	often	always
I feel I cannot accept the loss of the person I knew before the injury				
never	rarely	sometimes	often	always
I feel drawn to places and things associated with the person I knew before the injury				
never	rarely	sometimes	often	always
I can't help feeling angry about the injury				
never	rarely	sometimes	often	always
I feel disbelief over what happened				
never	rarely	sometimes	often	always
Ever since the injury it is hard for me to trust people				
never	rarely	sometimes	often	always
Ever since the injury I feel like I have lost the ability to care about other people or I feel distant from people I care about				
never	rarely	sometimes	often	always

I have pain in the same area of my body or have some of the same symptoms as the injured person.					
never	rarely	sometimes	often	always	
I go out of my way to avoid reminders of the person I knew before the injury					
never	rarely	sometimes	often	always	
I feel that life is empty since this person was injured					
never	rarely	sometimes	often	always	
I hear the voice of the person I knew before the injury speak to me					
never	rarely	sometimes	often	always	
I see the person I knew before the injury stand before me					
never	rarely	sometimes	often	always	
I feel that it is unfair that I'm OK when this person is injured					
never	rarely	sometimes	often	always	
I feel bitter over this person's injury					
never	rarely	sometimes	often	always	
I feel envious of others who have not lost someone close					
never	rarely	sometimes	often	always	
I feel lonely a great deal of the time ever since he/she had their injury					
never	rarely	sometimes	often	always	

THE WIMBLEDON SELF-REPORT SCALE

NAME DATE.....

Words in capital letters below describe how people sometimes feel. With each word there are four choices (a), (b), (c) or (d) - that can be used to show how often you have had that feeling. Please indicate how often you have had each feeling in the past 6-7 days by underlining one of these choices each time.

WORTHLESS

(a) most of the time (b) quite often (c) only occasionally (d) not at all

RELAXED

(a) not at all (b) only occasionally (c) quite often (d) most of the time

DESPERATE

(a) most of the time (b) quite often (c) only occasionally (d) not at all

PANICKY

(a) most of the time (b) quite often (c) only occasionally (d) not at all

HELPLESS

(a) most of the time (b) quite often (c) only occasionally (d) not at all

GUILTY

(a) most of the time (b) quite often (c) only occasionally (d) not at all

CONFIDENT

(a) not at all (b) only occasionally (c) quite often (d) most of the time

DISCOURAGED

(a) most of the time (b) quite often (c) only occasionally (d) not at all

MISERABLE

(a) most of the time (b) quite often (c) only occasionally (d) not at all

LONELY

(a) most of the time (b) quite often (c) only occasionally (d) not at all

IRRITABLE

(a) most of the time (b) quite often (c) only occasionally (d) not at all

GLOOMY

(a) most of the time (b) quite often (c) only occasionally (d) not at all

NERVOUS

(a) most of the time (b) quite often (c) only occasionally (d) not at all

HAPPY

(a) not at all (b) only occasionally (c) quite often (d) most of the time

ANNOYED

(a) most of the time (b) quite often (c) only occasionally (d) not at all

UNWANTED

(a) most of the time (b) quite often (c) only occasionally (d) not at all

Please turn over

17. **TENSE**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
18. **STUPID**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
19. **AS IF I AM BEING PUNISHED FOR SOMETHING**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
20. **IN GOOD SPIRITS**
 (a) not at all (b) only occasionally (c) quite often (d) most of the time
21. **FULL OF REGRETS**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
22. **FRIGHTENED**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
23. **AS IF MY LIFE HAS BEEN RUINED**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
24. **WORRIED ABOUT MY FUTURE**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
25. **CHEERFUL**
 (a) not at all (b) only occasionally (c) quite often (d) most of the time
26. **USELESS**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
27. **FED UP**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
28. **HOPELESS**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
29. **ANGRY**
 (a) most of the time (b) quite often (c) only occasionally (d) not at all
30. **CONTENT**
 (a) not at all (b) only occasionally (c) quite often (d) most of the time

Please check you have answered all the questions.

Thank you.

Hospital Anxiety and Depression Scale (HADS)



Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

FOLD HERE

FOLD HERE

A	D			A	D
3	0	I feel tense or 'wound up'	I feel as if I am slowed down	3	0
2	0	Most of the time	Nearly all the time	2	0
1	0	A lot of the time	Very often	1	0
0	0	From time to time, occasionally	Sometimes	0	0
0	0	Not at all	Not at all	0	0
0	0	I still enjoy the things I used to enjoy	I get a sort of frightened feeling like	0	0
1	0	Definitely as much	'butterflies' in the stomach	1	0
2	0	Not quite so much	Not at all	2	0
3	0	Only a little	Occasionally	3	0
3	0	Hardly at all	Quite often	3	0
3	0	I get a sort of frightened feeling as if	I have lost interest in my appearance	3	0
2	0	something awful is about to happen	Definitely	2	0
1	0	Very definitely and quite badly	I don't take as much care as I should	1	0
0	0	Yes, but not too badly	I may not take quite as much care	0	0
0	0	A little, but it doesn't worry me	I take just as much care as ever	0	0
0	0	Not at all	I feel restless as if I have to be on	0	0
0	0	I can laugh and see the funny side of things	the move	0	0
1	0	As much as I always could	Very much indeed	1	0
2	0	Not quite so much now	Quite a lot	2	0
3	0	Definitely not so much now	Not very much	3	0
3	0	Not at all	Not at all	3	0
3	0	Worrying thoughts go through my mind	I look forward with enjoyment to things	3	0
2	0	A great deal of the time	As much as I ever did	2	0
1	0	A lot of the time	Rather less than I used to	1	0
0	0	Not too often	Definitely less than I used to	0	0
0	0	Very little	Hardly at all	0	0
3	0	I feel cheerful	I get sudden feelings of panic	3	0
2	0	Never	Very often indeed	2	0
1	0	Not often	Quite often	1	0
0	0	Sometimes	Not very often	0	0
0	0	Most of the time	Not at all	0	0
0	0	I can sit at ease and feel relaxed	I can enjoy a good book or radio or	0	0
1	0	Definitely	television programme	1	0
2	0	Usually	Often	2	0
3	0	Not often	Sometimes	3	0
3	0	Not at all	Not often	3	0
3	0		Very seldom	3	0

Now check that you have answered all the questions

TOTAL

This form is printed in green. Any other colour is an unauthorized photocopy.

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FAMILY ASSESSMENT DEVICE p 1.

The following statements are things you could say about your family. Please rate how much you agree that each item describes your family by ticking one of the four alternative responses: strongly agree, agree, disagree, strongly disagree.

	strongly agree	agree	disagree	strongly disagree
1 We usually act on our decisions regarding problems.				
2 When someone is upset the others know why.				
3 When you ask someone to do something, you have to check that they did it.				
4 We are reluctant to show our affection for each other.				
5 If someone is in trouble, the others become too involved.				
6 We don't know what to do when an emergency comes up.				
7 Planning family activities is difficult because we misunderstand each other.				
8 After our family tries to solve a problem, we usually discuss whether it worked or not.				
9 You can't tell how a person is feeling from what they are saying.				
10 We make sure members meet their family responsibilities.				
11 Some of us just don't respond emotionally.				
12 You only get the interest of others when someone is important to them.				
13 You can easily get away with breaking the rules.				
14 In times of crisis we can turn to each other for support.				
15 People come right out and say things instead of hinting at them.				
16 Family tasks don't get spread around enough.				
17 We do not show our love for each other.				
18 We are too self-centred.				
19 We know what to do in an emergency				

FAMILY ASSESSMENT DEVICE p 2

		strongly agree	agree	disagree	strongly disagree
20	We cannot talk to each other about the sadness we feel.				
21	We have trouble meeting our bills.				
22	We get involved with each other only when something interests us.				
23	We have no clear expectations about toilet habits.				
24	Individuals are accepted for what they are.				
25	We resolve most emotional upsets that come up.				
26	We are frank with each other.				
27	There's little time to explore personal interests.				
28	Tenderness takes second place to other things in our family.				
29	We show interest in each other when we can get something out of it personally.				
30	We have rules about hitting people.				
31	We avoid discussing our fears and concerns.				
32	We discuss who is to do household jobs.				
33	We can express feelings to each other				
34	We confront problems involving feelings.				
35	We don't hold to any rules or standards.				
36	There are lots of bad feelings in the family.				
37	We express tenderness.				
38	We feel accepted for what we are.				
39	If the rules are broken, we don't know what to expect.				
40	We try to think of different ways to solve problems.				
41	We don't talk to each other when we are angry.				
42	If people are asked to do something, they need reminding.				

FAMILY ASSESSMENT DEVICE ?3.

	strongly agree	agree	disagree	strongly disagree
43 Making decisions is a problem for our family.				
44 Anything goes in our family.				
45 Our family shows interest in each other only when they can get something out of it.				
46 We are generally dissatisfied with the family duties assigned to us.				
47 We are able to make decisions about how to solve problems.				
48 We cry openly.				
49 There are rules about dangerous situations.				
50 Even though we mean well, we intrude too much into each other's lives.				
51 We don't get along well together.				
52 When we don't like what someone has done, we tell them.				
53 We confide in each other.				

NEUROBEHAVIORAL RATING SCALE

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DIRECTIONS: Place an X in the appropriate box to represent level of severity of each symptom.

E ___
M ___
V ___

PATIENT _____ Sex ___ M ___ F

INITIAL GCS _____

ID# _____ Age _____ Educ. _____ (yrs)

Coma Duration (days) _____

Date ____ / ____ / ____ Occup _____

CT Findings (≤ 7 days postinjury) _____

Date of injury ____ / ____ / ____

Primary Hospital _____

Rater _____

Hypoxia: Y ___ N ___

Shock: Y ___ N ___

	Not Present	Very Mild	Mild	Moderate	Mod. Severe	Severe	Extremely Severe
1. INATTENTION/REDUCED ALERTNESS —fails to sustain attention, easily distracted; fails to notice aspects of environment, difficulty directing attention, decreased alertness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. SOMATIC CONCERN —volunteers complaints or elaborates about somatic symptoms (e.g., headache, dizziness, blurred vision), and about physical health in general.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. DISORIENTATION —confusion or lack of proper association for person, place, or time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ANXIETY —worry, fear, overconcern for present or future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. EXPRESSIVE DEFICIT —word-finding disturbance, anomia, pauses in speech, effortful and agrammatic speech, circumlocution.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. EMOTIONAL WITHDRAWAL —lack of spontaneous interaction, isolation, deficiency in relating to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. CONCEPTUAL DISORGANIZATION —thought processes confused, disconnected, disorganized, disrupted; tangential social communication perseverative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. DISINHIBITION —socially inappropriate comments and/or actions, including aggressive/sexual content, or inappropriate to the situation, outbursts of temper.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. GUILT FEELINGS —self-blame, shame, remorse for past behavior.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. MEMORY DEFICIT —difficulty learning new information, rapidly forgets recent events, although immediate recall (forward digit span) may be intact.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. AGITATION —motor manifestations of overactivation (e.g., kicking, arm flailing, picking, roaming, restlessness, talkativeness.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. INACCURATE INSIGHT AND SELF-APPRAISAL —poor insight, exaggerated self-opinion, overrates level of ability and underrates personality change in comparison with evaluation of clinicians and family.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Not Present	Very Mild	Mild	Moderate	Mod. Severe	Severe
13. DEPRESSIVE MOOD —sorrow, sadness, despondency, pessimism.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. HOSTILITY UNCOOPERATIVENESS —animosity, irritability, belligerence, disdain for others, defiance of authority.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. DECREASED INITIATIVE/MOTIVATION —lacks normal initiative in work or leisure, fails to persist in tasks, is reluctant to accept new challenges.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. SUSPICIOUSNESS —mistrust, belief that others harbor malicious or discriminatory intent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. FATIGABILITY —rapidly fatigues on challenging cognitive tasks or complex activities, lethargic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. HALLUCINATORY BEHAVIOR —perceptions without normal external stimulus correspondence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. MOTOR RETARDATION —slowed movements or speech (excluding primary weakness).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. UNUSUAL THOUGHT CONTENT —unusual, odd, strange, bizarre thought content.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. BLUNTED AFFECT —reduced emotional tone, reduction in normal intensity of feelings, flatness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. EXCITEMENT —heightened emotional tone, increased reactivity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. POOR PLANNING —unrealistic goals, poorly formulated plans for the future, disregards prerequisites (e.g., training), fails to take disability into account.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. LABILITY OF MOOD —sudden change in mood which is disproportionate to the situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. TENSION —postural and facial expression of heightened tension, without the necessity of excessive activity involving the limbs or trunk.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. COMPREHENSION DEFICIT —difficulty in understanding oral instructions on single or multistage commands.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. SPEECH ARTICULATION DEFECT —misarticulation, slurring or substitution of sounds which affect intelligibility (rating is independent of linguistic content).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>