

**PARENTAL GRIEF AND TRAUMA:  
AN EXPOSURE COMPARISON STUDY OF INJURY  
VERSUS NON-INJURY CHILD DEATHS**

BY

SHELAGH MARCHENSKI

A Thesis  
Submitted to the Faculty of Graduate Studies  
In Partial Fulfillment of the Requirements for the Degree of

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*Dedicated to my children who have gone on ahead:*

*Tiffany Jean 1970-1993*

*Flint Peter John 1978-1995*

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## ABSTRACT

This thesis involves an exposure comparison study of the traumatic stress and grief experienced by a convenience sample of 40 parents in response to the death of their child. The sample consisted of parents (77.5% mothers) aged 30 - 62 years ( $M = 47.21$  years,  $SD = 8.25$  years) who, with one exception, were residents of Manitoba. Participants were drawn primarily from the city of Winnipeg (62.5%), an urban centre with a population of over 600,000. Thirty-five per cent were from rural, primarily agriculturally based Manitoba communities. Deceased children ranged in age from 0 - 35 years ( $M = 18.63$  years,  $SD = 9.14$  years) and 58% were male.

Using a double cohort epidemiological design, the exposure group consisted of 23 parents who had experienced the sudden unanticipated death of a child due to external causes (injury). The comparison group was composed of 17 parents who had experienced the death of a child due to a previously diagnosed life-threatening condition (non-injury). Parents bereaved from 6 to 24 months were contacted between October 2001 and April 2003. Data were gathered through quantitative questionnaires and personal interviews.

Both injury and non-injury bereaved parents experienced posttraumatic stress at higher levels than the general population. When controlling for the age of the child at death, injury death was a significant predictor of the intensity of posttraumatic stress symptoms. The groups did not vary significantly on measures of grief. The intensity of grief and trauma was not significantly reduced over two years, and patterns over time were sometimes linear and sometimes curvilinear, depending on the dependent measure. Child age at death was a significant predictor of the intensity of traumatic stress regardless of the cause of death. Some small significant negative correlations were found between measures of perceived social support and bereavement symptoms with family support related to measures of both grief and trauma and support from friends related to grief only. Parents expressed their need for validation, support and respite especially noting the important role of the workplace and non-professional bereavement support.

This research adds to the evidence that the death of a child is a traumatic experience for parents. It suggests the importance for practice of assessing posttraumatic stress in all bereaved parents especially parents of children who die at a young age or as a result of injury.

Members of the examining committee are: Sid Frankel, Ph.D., Faculty of Social Work; Sharon Taylor-Henley, MSW, Faculty of Social Work; John R. Walker, Ph.D., Department of Clinical Health Psychology, Faculty of Medicine, University of Manitoba.

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## CHAPTER 1

### RATIONALE AND SIGNIFICANCE

#### Research Questions

The death of a child creates a crisis for parents of monumental proportions. Every child death is a tragedy and each tragedy is colored by the circumstances of the death. The sudden unanticipated death of a child due to injury presents a specific set of challenges to survivors. One of these challenges may be dealing with symptoms of traumatic stress.

The sudden violent loss of a loved one has been shown to be predictive of traumatic stress or posttraumatic stress disorder (PTSD) symptoms across a wide variety of events (Green, 1993). Although traumatic parental bereavement has not been designated as one of those events, the injury death of a child appears to meet the criteria of a traumatic event as outlined for the diagnosis of posttraumatic stress disorder (PTSD) in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994). Do the parents of children who die as a result of injury experience symptoms of posttraumatic stress? Do their symptoms of traumatic stress differ in frequency or intensity from those of parents who anticipate the death of their child due natural causes? Do injury bereaved parents experience more intense grief than other bereaved parents? Is there any relationship between levels of traumatic stress or grief and the parents' perception of social support? What services do parents access? What do parents identify as their service needs? These are the questions to be addressed by this research.

## Significance

The number of parents who experience the death of a child due to injury is significant, as is the proportion of child deaths due to injury. An injury is defined as a "predictable and preventable event which causes bodily harm and results from an interaction between a host, an agent and the environment. Injuries may be intentional or unintentional in origin" (Injury Prevention and Control Coalition, 1994). Deaths from external causes are seen primarily as accidents, homicides and suicides. Current trends in the United States reveal that accidents are the leading cause of death among all persons aged one to thirty-seven and the fourth leading cause of death among persons of all ages (Rando, 1992). "Accident" is the term applied to most deaths that occur as a result of motor vehicle crashes, falls, poisoning, drowning, fire, suffocation, and firearms. "Technological advances simultaneously have both decreased the proportion of natural deaths that occur and increased the proportion of sudden and unanticipated traumatic deaths" (Rando, 1992, p. 50). Rando (1992) notes increasing rates of homicide and suicide also add to the increased proportion of traumatic deaths. Although mortality rates for children and youth in the United States have declined since 1900, the proportion of deaths from external causes - injuries, homicide and suicide - has risen sharply. In 1900, external causes accounted for about ten percent of deaths among children and youth. By 1985 that percentage had risen to 64 percent (Rando, 1992, p. 50). The final source of increase in parental bereavement is also related to technological advance. As adults live longer, their chance of being predeceased by one of their offspring increases. There is no indication that these trends will be reversed.

There is also no reason to believe that the Canadian experience is markedly different. Using Statistics Canada information for 1990-1992, Health Canada (1998) reported unintentional injury was the leading cause of death for children and youth. Almost one in three deaths of persons under 20 years of age was injury related. Although the overall number of deaths is decreasing, injuries remain the leading cause of death among children and youth. The mean number of injury deaths in this age group was 1,542 in the years 1990-1992 (Health Canada, 1998). The proportion of injuries as a cause of death increased with age. For children aged 10-14 more than 50% were attributed to injuries. Among youth 15-19 nearly 75% of fatalities were due to injuries. In 1995, the number of deaths due to injuries was 1,405 compared to 236 deaths attributed to cancer and 82 as a result of infectious diseases including 15 from AIDS (Health Canada, 1998).

In Manitoba, injuries - particularly car crashes - remain the most common cause of death for children (College of Physicians and Surgeons of Manitoba, 2000). The latest annual report of the Paediatric Death Review Committee (College of Physicians and Surgeons of Manitoba, 2003) records that in 2000 injuries were responsible for 29 or 38 percent of all deaths of children between 29 days and 14 years of age. Among adolescents 15 to 17 years of age the percentage of injury deaths rose sharply to 71 percent of deaths (22 of 31 deaths). Each year in this province, there are several hundred injury deaths. Manitoba Health (1998) reports that 579 Manitobans died from injuries in 1996. Forty-two percent of those deaths (a total of 243) occurred in individuals between

0 and 39 years of age, and 119 occurred in people under 25 years of age<sup>1</sup>. In 2000, there were 51 injury deaths of Manitobans under 18 years of age (College of Physicians and Surgeons of Manitoba, 2003).

For the city of Winnipeg, the 1996 death toll due to injury was 100 individuals between 0 and 39 years<sup>2</sup> of age. Of these, 36 persons died before they reached 25 years of age (Manitoba Health, 1998).

### **Relevance**

Understanding the impact on parents of the traumatic death of a child offers insight useful for theorists in the fields of both traumatology and thanatology and may provide an area for convergence of the expertise in both fields. Similarly, there are benefits for practitioners whose focus is on either those experiencing the effects of trauma or those suffering the grief of unanticipated loss. Policies that are intended to ameliorate or compensate victimization may be informed by enhanced awareness of the impact of specific occurrences. The following offers a brief synopsis of the relevance of this research to theory, practice, and policy.

### **Implications for theory**

Grief and mourning, the timeless responses to loss, appear to be as universal as death itself. However, the empirical underpinnings of our theories to explain these processes are relatively new. In studies of grief responses, bereaved parents have been

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<sup>1</sup> The largest percentage of injury deaths occurs among the elderly. In 1996, fifty-two percent of fatalities occurred in persons over 70 years of age (Manitoba Health, 1998, p. 16).

<sup>2</sup> The death of individuals over 39 may also create bereaved parents. This study will concentrate on the loss of individuals for whom parents are the next-of-kin.

largely ignored. Over a lifetime, adults can expect to experience many losses including the deaths of loved ones. Of these, the death of a child has been judged to be the most difficult death to face. For example, Middleton, Raphael, Burnett & Martinek (1998) found death of a child to be more difficult than either the death of a parent or the death of a spouse. In spite of this or perhaps because of it, parental bereavement has not received a great deal of empirical review. The majority of the empirical work in the study of bereavement has concentrated on the more prevalent experience of widows. Current theory is, therefore, based on a narrow although prevalent experience of bereavement.

In a general way, the experience of bereavement and mourning is a common one. However, there are a number of factors that complicate bereavement for parents in general and for traumatically bereaved parents in particular. Because of these factors, it has been suggested that the generic model of grief is inadequate to describe parental grief (Klass & Marwit, 1988-1989; Rando, 1986). Any study of bereaved parents adds to our understanding of their experience and the relevance of current models to that experience. As previously argued, traumatically bereaved parents represent a significant proportion of bereaved parents and their experience must be part of a parental bereavement model.

The process of grief in surviving family members of traumatic death victims must be understood with the benefit of the accumulated knowledge of both thanatology and traumatology. There is growing recognition that the fields of thanatology and traumatology each contribute to our understanding of the impact of sudden, violent loss (Figley, 1996; Green, 2000; Stroebe, 2001). The injury death of a child is an example of a bereavement that is also a traumatic event. The study of this event presents an

opportunity to increase the potency of both grief and trauma theory and models as our understanding of traumatic responses to bereavement is increased.

#### Implications for practice

The impact of traumatic stress on the individual has been shown to be significant physically, socially, emotionally, cognitively, psychologically, and neurobiologically (van der Kolk, 1996). Indeed a traumatic stressor is understood to be "a stimulus that provokes an overwhelming affective reaction that can jeopardize existing adaptive capacities and impair psychological and physiological functioning" (Sprang & McNeil, 1995, p. 56). The death of a child has been viewed as a traumatic stressor. The injury death of a child meets the criteria for a possible subsequent diagnosis of posttraumatic stress disorder (PTSD). There is some evidence of traumatic stress in bereaved parents (Stewart, 1999). Where traumatic stress responses have been found to be coincident with grief, they have been shown to interfere with or delay appropriate mourning processes (Rando, 1996; Raphael, Middleton, Martinek & Misso, 1993). It is therefore important to recognize the incidence and develop an awareness of the prevalence of traumatic stress in parental bereavement

In practice, theory and conceptual models constitute the standard used in the diagnosis of "normal" versus pathological grief. Because of the duration and intensity of parental grief responses, and the lack of empirical study of this experience, parents are at risk of being over-diagnosed with pathology based on a model that does not differentiate between losses. Information on parental bereavement is needed to clarify norms.

The importance of this understanding is emphasized by Videka-Sherman (1987) in her summary of research on the effect of parental bereavement. She suggests that the most important implication of parental bereavement research for clinical practice is the demonstrated need for social workers and health care professionals to adjust their expectations about the nature and effect of parental bereavement. In addition to modifying their own expectations about the nature and duration of parental bereavement, informed social workers "should play a key role in influencing the expectations of other professionals and family members and friends about parental bereavement" (Videka-Sherman, 1987, p. 110).

Further, the social worker has a role in maintaining and enhancing family solidarity (Videka-Sherman, 1987). Parental bereavement often occurs within the context of a nuclear family unit. The impact of the loss on the parents and the resultant impairment of their ability to function "as usual" may have devastating effects on the living children dependent on them. The loss of a child requires resolution on an individual, couple, and family basis. Any impairment of the functioning of parents may have detrimental effects on the functioning and development of surviving children. This adds to the importance of providing parents with accurate information and informed helpers as they struggle to understand their experience and navigate the journey from loss to recreation of themselves, their roles, and their family.

Numerous studies have noted the ameliorative effects of social support for both the bereaved and for victims of trauma (e.g. Klass & Marwit, 1988-89; Panzer, 1989; Sprang & McNeil, 1998; Sprang & McNeil, 1995). However, the availability of social support for bereaved parents has been problematic. Rando (1986) notes that it is



common for bereaved parents to experience feelings of "...abandonment, helplessness, and frustration as reactions to their experiences with other parents" (p. 38). As a result of social stigma, "...bereaved parents are often left without many of the social and emotional supports desirable for coping with the grief process" (Rando, 1986, p. 38). Ensuring that parents have access to adequate and appropriate support is another area for social work intervention.

The focus of social work practice is the interface of the individual and the environment. Clarifying the difficulties faced by individuals experiencing parental bereavement offers one aspect for social work study. Considering the effects of the social network is another person/environment interaction where intervention may be useful. However, there is a third area that has been largely ignored by the bereavement literature, which is generally written from a psychological perspective. That is, the needs of the bereaved as identified by the bereaved. The social work problem solving process begins with understanding the problem as it is seen by the individuals experiencing it (Compton & Galaway, 1994). The needs of bereaved parents have been implied by researchers and diagnosed by therapists. To ensure the reliability of information on the needs of parents, research must be directly informed by the parents themselves.

#### Implications for policy

Traumatically bereaved parents typically find themselves interacting with a number of social institutions, agencies, and organizations that may include: emergency services, hospitals, the police, Victim Services, the Medical Examiner's office, Crown Attorneys, the Court, and insurance providers including the Manitoba Public Insurance

Corporation (MPIC). Understanding the impact of traumatic loss is important for policy makers in all organizations dealing with victimization. Due to the lack of general recognition of traumatic stress as an element of parental bereavement, information and techniques known to assist in the amelioration of trauma are not readily available to parents.

The Victim Compensation program of Manitoba Justice provides financial compensation and counselling services to victims of crime. Manitoba Justice now recognizes surviving family members as victims where a death has resulted in criminal prosecution. MPIC also provides compensation to surviving family of car crash victims. The policies of these organizations with regard to what is necessary for victims can be informed by a more accurate understanding of victims' responses.

Where a death results in criminal prosecution, the bereaved have no standing in court except to offer a victim impact statement prior to sentencing. Increased recognition of the impact on survivors' may assist victim advocates in their efforts to provide more restorative options for the bereaved.

The service needs of bereaved parents have been minimally identified. Therapeutic approaches to bereavement have been outlined to some degree and include social support as previously discussed. However, there is little in the literature that would indicate what parents have identified as their service needs. What is recorded is incidental to researchers' studies or anecdotal in nature. Empowering service recipients to identify service needs is pivotal to the ideals of social work practice and policy.

### **Conclusion**

A study of traumatically bereaved parents adds to our understanding of parental bereavement, traumatic stress reactions and PTSD. The development of sound clinical intervention strategies, research programs, and social policy must be based on an inclusive theoretical framework. From a social work perspective, an inclusive theoretical framework is understood to have components that reflect knowledge of the individual, the environment and the person/environment interaction.

## CHAPTER 2

### LITERATURE REVIEW

Traumatic parental bereavement can be viewed through a bereavement lens or through a trauma lens. Each of these lenses clarifies portions of the experience. Accordingly, the literature of each of these approaches will be summarized as it affects our understanding of traumatic parental bereavement. Using both lenses provides a depth of vision that is not possible with either single lens.

#### **Defining constructs**

The focus of this research is the experience of parents who lose a child to sudden death as a result of physical injury. These are the parents that will be defined here as traumatically bereaved. They include parents who lose a child to accident, suicide, or homicide. The constructs of grief, trauma, and social support and the relationship among them are critical to our discussion of traumatic parental bereavement.

The terms bereavement, grief, and mourning are sometimes used interchangeably. For this discussion the following definitions have been adopted from the literature. Bereavement is the state of having experienced a loss. Grief refers to the reaction to the perception of loss. It includes psychological, social and somatic responses. Mourning is the culturally defined expression of grief (Stroebe & Stroebe, 1987). Grief and mourning are usually conceptualized as processes (e.g. grief work) that describe adjustment and adaptation to loss.

The definitions of trauma that are useful to this study are those that include the concept of loss. Although not all loss is traumatic, loss is an inherent component of trauma. Trauma can be understood within the conceptualization of stress. Stressful experiences are conceived as the experiences of an individual in relation to an event such that the elements of the event in combination with the characteristics of the individual result in stress and the disorganization and restructuring of the individual's beliefs (Stamm, 1999a). "The key differentiation between a stressful experience and a traumatically stressful experience is the *demand* for reorientation"(Stamm, 1999a, p. 5). The demand for reorientation is created by the violation of basic assumptions connected with survival as a member of a social group (Brewin, Dalgleish and Joseph as cited in Green, 2001), and by "the subjective assessment by the victims of how threatened and helpless they feel" (Van der Kolk and MacFarlane, 1996, p. 6).

Posttraumatic stress disorder (PTSD) is a stress reaction subsequent to a particular type of stressful event. PTSD is defined by the Diagnostic and Statistical Manual of Mental Disorders (4th Edition Text Revision) (DSM-IV TR) (American Psychiatric Association, 2000). Its diagnosis depends on exposure to a traumatic event involving death or serious injury or threat of death or serious injury to self or others. The person's response to the traumatic event must involve intense fear, helplessness or horror. Symptoms in response to the event must contain the following elements: the event must be persistently reexperienced; there must be persistent avoidance of stimuli reminiscent of the trauma; and there must be symptoms of increased arousal. These symptoms must persist for more than one month and must cause clinically significant distress or

impairment in social, occupational or other areas of functioning. For a more detailed review of symptoms see Appendix A.

The literature acknowledges the full-blown disorder but measures of PTSD are often made on a continuum that assesses the presence and intensity of symptoms not necessarily the presence of the disorder (Stevens-Guille, 1996). When authors speak of trauma responses (Rynearson & Geoffrey, 1999) posttraumatic stress (Bell, 1995) or traumatic stress (Stamm, 1999), this writer has assumed these responses are reflective of PTSD symptoms but may not meet the criteria for diagnosis.<sup>3</sup>

A discussion of definitions is not complete without drawing attention to the confusion in the literature around usage of the term "traumatic grief". Some writers use the term to mean grief in response to traumatic death (Sprang and McNeil, 1995; Stevens-Guille, 1999). However, Selby Jacobs (1999) (also Jacobs, Mazure & Prigerson, 2000) has proposed traumatic grief be the term used to describe a type of pathological grief reaction that arises from the trauma of separation from the deceased. This concept is unrelated to the mode of death and is grounded in separation anxiety theory. Because of this confusion, the term traumatic grief will be avoided in this study except where it may arise in quotation from other sources.

Social support, as used here, "refers to the clarity or certainty with which the individual experiences being loved, valued, and able to count on others as needed" (Sprang & McNeil, 1998, p. 50). It is the cognitive appraisal of support that is regarded as the central focus for consideration without regard for the social network as it exists or as it is accessed. Using an appraisal of an individual's social interactions or transactions

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<sup>3</sup> Rando (1993) adopted a similar position. She used the term posttraumatic stress to refer to both diagnosed PTSD and posttraumatic reactions that did not meet the criteria (p. 570).

would provide only an external frame of reference (Sprang & McNeil, 1998, p. 50). It would not give any indication of the individual's perception of his or her social network or of the availability of a reliable confidante.

## **Theoretical Approaches**

### Grief

The bereavement lens provides us with information on adaptation to loss. Loss is an integral part of the human condition. Every change encompasses both an ending and a beginning. Each ending is counted a loss. Often the new beginning compensates for any loss and grief is swiftly passed over. However, many changes are unwelcome and the losses they bring initiate a longer process of grief and mourning. Death presents the greatest loss that humans encounter. Dealing with the death of a loved one has been a focus of contemplation throughout the course of human history. To clarify the modern understanding of bereavement, a very brief review of the major contributors to twentieth century thought is in order.

Our understanding of grief and mourning has been shaped by a series of scholars most notably Freud (1957), Lindemann (1944) and Bowlby (1980). Each of these giants in the field offers a particular insight that has been the foundation for later theorists.

Freud's study of mourning was secondary to his psychoanalysis of depression. Interpreting his early twentieth century work, the purpose of mourning was to free the individual from attachment to the deceased (Klass, 1988). Freud described grief as a profoundly painful dejection. It was marked by a loss of interest in the outside world, a loss in the capacity to love and a withdrawal from any activity not connected with

thoughts of the lost person (Rando, 1984). Rando (1993) summarizes Freud's early insights. Freud theorized that in spite of the significant changes from normal attitudes that grief produced, it was neither pathological nor amenable to treatment. Time was regarded as the only thing necessary or helpful for resolution. He characterized mourning as painful and associated with both a loss of interest in the outside world and a loss in the capacity to love. The high energy required for the internal work of separating left nothing for other purposes or interests. He described pathological mourning as the failure of the withdrawal of the libido from the lost object and its subsequent displacement on to another. Instead, continued identification of the ego with the lost object resulted in pathological mourning.

Erich Lindemann, a pioneer in grief study, offered his conceptualization of grief in three stages; shock and disbelief; acute mourning; and resolution (Rando, 1988). As summarized by Rando (1984) Lindemann outlined three tasks that constitute "grief work". The first task was to detach oneself from the deceased, moving from a living relationship to one of memory. Second, the griever must adapt to a world that exists without the deceased. Finally, the griever must reinvest energy withdrawn from the previous relationship in someone or something else. After the Coconut Grove fire in Boston in 1942, Lindemann wrote about acute grief as a normal reaction to a distressing situation. Characteristics that marked the reaction syndrome included somatic distress, preoccupation with the image of the deceased, guilt, hostile reactions, and loss of patterns of conduct (Stroebe & Stroebe, 1987).

John Bowlby, writing in the 1960's, based his understanding of loss on attachment theory. He believed that attachment behaviour was instinctual and that both normal and



pathological development could be explained by the history of attachment between parent and child. His model, as described by Klass (1988), was based on data from the study of widows. Bowlby characterized the problem of dealing with the death of a loved one as a "state of disequilibrium brought about by a sudden change in the environment"(as cited by Klass, 1988, p. 198). A new equilibrium was formed when the individual ceased searching and striving to restore the lost object and formed attachments to other objects.

Two types of grief theories can be distinguished: depression models and stress models (Stroebe & Stroebe, 1987). Depression models based on the work of Freud analyze grief as an emotional reaction to loss and describe its symptoms in intrapersonal terms. Bowlby added an interpersonal perspective to the depression model. Stress models, such as Lindemann's, view bereavement as a stressful life event demanding coping resources. Each of these perspectives offers insight into the grief and mourning of traumatically bereaved parents.

Grief is broadly painted as consisting of three phases: avoidance, confrontation and accommodation (Rando, 1993). All the grief reactions can be housed in one or another of these categories. These phases are not necessarily linear or discrete. There is increasing discussion of the oscillation of avoidance and confrontation/ intrusion and the relative merits of each for an adaptive outcome (Stroebe, 2001). This discussion parallels the debate over the relative merits of separating from versus maintaining ties to the deceased (Bonanno, 2001).

The process of mourning has been conceptualized as a series of tasks, e.g. Rando's (1993) six "R" processes of mourning. The internal tasks of mourning include the intrapsychic work of decathexis and adaptation to loss (revision of assumptive world,

modification of roles, development of a new identity). The external focus is on adaptively moving into and investing in a new world without the deceased loved one. Both of these processes are made more difficult by stressors specific to the individual and the circumstances surrounding the death.

The Two-Track Model of Bereavement proposed by Rubin (1999) attempts to acknowledge and combine the two main approaches that have characterized the clinical and research bereavement literature. The first approach considered separation from the deceased as the critical response to loss. The second approach was more empirically directed and viewed the outcome of bereavement as a biological, behavioral, cognitive and emotional process that was similar to responses to stress or trauma. Rubin bases his model on the understanding that the bereavement response "occurs along two main axes, each of which is multidimensional. The first axis or Track I is reflected in how people function naturally and how this functioning is affected by the cataclysmic life experience that loss may entail. The second axis (Track II) is concerned with how people are involved in maintaining and changing their relationship to the deceased" (Rubin, 1999, p. 684-685). Rubin describes the basic thrust of the model as one of definition of a paradigm for the analysis of measurable behaviour and cognitive-affective responses to loss. He suggests that the multidimensional nature of his model enhances the opportunity to recognize areas of mutuality such as that between the fields of loss and trauma. For just this purpose the model is useful here. Although Rubin's primary intention in developing the model was to emphasize elements of the Track II dimension, relationship to the deceased, it will be used here to provide a context for examination of Track I, the functioning of traumatically bereaved parents. Using the Track I construct narrows the

focus on the sequelae to loss and facilitates concentration on those elements of response to loss that are parallel to established trauma responses.

### Trauma

Since the inception of war, literature has recorded the observation that exposure to overwhelming terror can lead to troubling memories, arousal and avoidance (van der Kolk, Weisaeth, & van der Hart, 1996, p. 47). Tomb (1994) draws our attention to descriptions by Homer, Cicero, Shakespeare, and Samuel Pepys. The study of trauma emerged from curiosity about the origin of the unexplainable physical symptoms seen in accident victims and hysterics. Were they the result of physical or psychic shocks to the system? (McFarlane & van der Kolk, 1996, p. 563). Psychiatry has had a troubled relationship with the idea that reality can profoundly and permanently alter people's psychology and biology. In the nineteenth century, attention turned to the connection between traumatic experience and the functioning of the mind. Charcot (as cited in van der Kolk, Weisaeth, & van der Hart, 1996, p. 52) first proposed that the symptoms of his hysterical patients had their origins in histories of trauma. Janet observed that his traumatized patients seemed to react to reminders of the trauma with responses that had been relevant to the original threat but that had no adaptive value in the present (as cited van der Kolk, Weisaeth, & van der Hart, 1996, p. 52). The First World War provided impetus for a resurgence of interest in traumatic effects (Tomb, 1994). In 1915, a British military psychiatrist was the first to use the term "shell-shock" in medical literature (van der Kolk, Weisaeth & van der Hart, 1996, p. 48). As described by Brett (1996), Abram Kardiner observed the persistence of profound conditioned biological responses while

working with traumatized U.S. veterans of World War I. The soldiers of World War II and survivors of the Holocaust provided a fertile field for further study of traumatic effects. Perhaps not too surprisingly, "... between 1895 and 1974, the study of trauma centered almost exclusively on its effects on white males" (van der Kolk, Weisaeth & van der Hart, 1996, p. 61). Most recently, the field of study has broadened to include abused children and battered women among other survivors. Throughout its modern history, the etiology of traumatic symptoms, whether organic or psychological, remained hotly debated (Horowitz, 1993). Van der Kolk, McFarlane & Weisaeth (1996) suggest that the debate has always been carried out in a sociopolitical context that has had a profound influence on the perspective of scientific review. "The history of PTSD has been intimately entwined with the ways legal systems have dealt with disability and pension entitlements. Legal systems have played a major role in defining how societies acknowledge the association between traumatic events and psychiatric symptomatology" (van der Kolk, McFarlane & Weisaeth, 1996, p. xv). It was also influenced by whatever the prevailing emphasis in the mind-body dichotomy was at the time.

As previously indicated, PTSD is defined by the American Psychiatric Association. First appearing in the DSM III (American Psychiatric Association, 1980), the criteria for diagnosis were adopted by a committee that relied heavily on Kardiner's observations (van der Kolk, 1996). The genuineness of traumatic distress has been repeatedly challenged and sufferers accused of malingering. "However, the exposure of many young psychiatrists and other future mental health professionals to combat led to changes in the way that clinicians thought about the effects of stress and trauma"

(McFarlane & de Girolamo, 1996, p. 133). PTSD has subsequently been confirmed in a vast literature as a relevant diagnostic construct.

### Grief and Trauma

Death is a central theme of both trauma and bereavement. However, the divergence of trauma and bereavement perspectives began with the 1980 revision of the DSM-III. "...death, grief and bereavement were missing from any discussion of what constitutes a traumatic event" (Figley, 1996, p. 92). The field of traumatology developed to focus on the impact of death and dying on the functioning of the survivors. Thanatology viewed death as a natural part of human experience and preferred to avoid a pathological interpretation of responses to death. The majority of trauma research has focused on veterans of combat and survivors of disasters. The history of trauma research has been one of movement from identification of particular responses to particular events (e.g. rape trauma, combat trauma) to recognition that trauma responses share more commonalities than differences.

At this point in time, there is growing recognition of bereavement-trauma links. The revision of criteria for PTSD diagnosis in the DSM-IV (American Psychiatric Association, 1994) and the widening definition of traumatic events have converged with the growing awareness of thanatologists that the mode of death is related to bereavement outcomes. The result is a growing literature of interest to both traumatology and thanatology. Figley (1996) observes no difference between the stress associated with the death of another and the stress associated with being scared to death. The violent/sudden loss of a loved one is listed among eight generic dimensions of trauma (Green, 1993) and

identified as a potent predictor of traumatic stress (Stamm, 1999b). In relation to other stressful events, death is more closely linked to events traditionally considered traumatic (e.g. rape, disaster) than to stressors of daily living (Stamm 1999b). As the field of thanatology has moved beyond a simple phase model for the grief process, there has been increasing awareness of the degree to which the traumatic circumstances of a death inform the process of mourning. There is also considerable overlap in the symptoms of acute grief and traumatic stress. Figley (1996) concludes, "Even the most cursory review of research provides considerable evidence of the overlap of symptoms between PTSD and bereavement; that the experience of surviving the death of a loved one - especially the death of a young child or a child as an adult - is extraordinarily traumatic" (p. 95). The symptoms that overlap include recurrent and intrusive recollections, recurrent distressing dreams and flashbacks, psychological distress at exposure to symbols of the event or the deceased, and physiological symptoms such as difficulties with sleep or concentration (Stamm, 1999a). While there is considered to be overlap in symptoms of these phenomena, Raphael and Martinek (1997) provide an excellent summary of the distinctions between grief and trauma reactions. While intrusions are symptomatic of both grief and trauma the content of intrusive recollections is different. In trauma, they are related to the event. The content in grief is the image of the deceased. Similarly, anxiety is common to both trauma and bereavement reactions. However, anxiety in trauma is general and generated by threat. In grief, anxiety is separation anxiety. In trauma reactions there is avoidance of reminders of the event. In grief, there may be avoidance of reminders of the absence of the lost person. This would be coincident with fond remembrances of the deceased. In trauma reactions, arousal is oriented to threat and

there is general scanning and alertness to danger. In bereavement, arousal is oriented to the lost person and may include searching behaviour and scanning for cues of the deceased.

The intersection of grief and trauma has been studied in a number of contexts. These include the relation of bereavement to other traumas. Green, Krupnick, Stockton, Goodman, Corcoran & Petit (2001) compared the responses of those who had experienced a traumatic bereavement with a no trauma control group and a physical assault group. They concluded that a traumatic loss was associated with traditional trauma reactions. Symptoms of intrusion, reexperiencing and acute stress occurred at a higher rate in the traumatic loss group than in the other groups. Stevens-Guille (1999), in a Canadian study, reported on coincident grief and posttraumatic stress reactions in the surviving family members of homicide victims. Similarly, grief and trauma have been noted in the survivors of car crash victims. Sprang & McNeil (1995), describing the response to a drunk driving fatality as a post-homicide reaction, suggested that grief and PTSD share common predictors. Stewart (1999) explored the relationship between grief, traumatic stress and death notification, noting the increased difficulty of coping with sudden, violent death. Amick-McMullan, Kilpatrick, Veronen and Smith (1989) in their study of family survivors of homicide, argue for a multidimensional approach to understanding grief that does not assign symptoms to either grief or PTSD formulations. Instead, all dimensions characteristic of the complexity of survivor reactions would be recognized.

Given the overlap in risk factors for complicated mourning and traumatic stress reactions (refer to Table 1, p. 50 for summary), it seems logical to expect at least some

degree of comorbidity. It also seems logical to assume that the parental role as child protector would predispose bereaved parents to an elevated level of helplessness and horror in response to child death. Certainly helplessness is characterized as a typical response in parental bereavement (Weiss, 1988). This would put parents at increased risk of traumatic stress reactions and PTSD.

In considering the construct of trauma and its application to the bereaved, it is important to assess the potential negative effects of diagnostic labelling. As discussed in this subsection, grief and trauma have diverged in part due to the desire to keep grief free from any labels of pathology. PTSD is a diagnosis of mental disorder and, therefore, a pathological reaction.

Labelling theorists posit that "negative societal conceptions of mental illness exist and are independent of, and prior to, a labeled persons actual behavior"(Socall & Holtgraves, 1992/2001, p. 435). Deviant behaviour does not simply violate norms but is behaviour that is successfully defined or labelled by others as deviant. Therefore, an act is not inherently deviant but becomes so because of the negative reaction of others to the act and to the person who performs it. Both are labelled as deviant. Labels are applied externally by others and internally by the self. Citing Thoits, Hayes (2000/2001) notes that it is not necessary for behaviour to be outwardly condemned for individuals to see themselves as deviant. "Taking the role of the generalized other enables the well-socialized individual to anticipate and respond to the reactions of others before they take place (or even if they never take place)" (Hayes, 2000, p. 2). The application of stigmatized labels by the formal social network (doctors, mental health professionals, agencies), by the informal social network (friends, relatives, associates) and/or by the self



is an interactional process that can affect a person's thoughts, feelings, and actions (Hayes, 2000). Labels can therefore induce stigmatization, and shame and serve as self-fulfilling prophecies.

This suggests the question: would applying the PTSD label to the bereaved lead to increased stigmatization and/or increased symptomatology?

The degree of stigma associated with PTSD is unclear. Stigma associated with PTSD has not been widely explored in the literature. Because it was initially defined as a normal reaction to abnormal events, PTSD may not be subject to the same stigma as other "mental illness" diagnoses.

The possibility of negative consequences must be weighed against the potential for increased understanding of parental grief to reduce the stigmatization of bereaved parents. Parental bereavement is already stigmatized. One of the difficulties for parents is the disparity between the length and intensity of parental grief and the social perception of acceptable limits for the length and intensity of grief. This stigma may be alleviated by further research into the parameters of parental grief.

It is certainly not the intention of this research to add to the labels that may be applied to grieving parents. Rather, the intent is to broaden recognition of the components of parental grief so that parents will *not* be labelled as deviant grievers but as normal parental grievers in general and, perhaps, as normal parental grievers of traumatic death in particular. For example, although reactions such as anxiety and depression might arouse clinical concern and diagnosis of pathology in other circumstances, in moderate degrees they are considered part of the normal response to significant loss.

Similarly, it is the intent here to evaluate the occurrence of traumatic stress symptoms in bereaved parents so that what is typical might be considered normal.

Murphy (2000/2001) suggests that "trauma theory needs to replace classic grief theory" (p. 8) in theory-driven research studies of persons bereaved by violent death. Clearly, knowledge of the incidence of traumatic stress in bereaved parents is essential for future research and program development.

The question posed cannot be answered definitively. However, it is the writer's opinion that the potential benefits of increased understanding outweigh the possible risks of labelling.

## **Empirical Research**

### Grief

The present understanding of grief is based on accumulated clinical observation and empirical research. The focus has been on developing a scientific understanding of the process of and successful adaptation to bereavement, and differentiating between normal and pathological responses to loss and their respective antecedents. If grief is conceptualized using Rubin's (1999) Two-Track model, it is possible to see one area of largely clinical exploration of the process of adaptation to loss. This is often a psychoanalytically oriented study of the development of a new relationship with the representation of the deceased. A more empirically focused approach (the one of interest to this study) examines the dimensions of Track 1, that is the functional changes to biological, behavioural, cognitive and emotional processes that are the result of the crisis of loss. Defining normal grief and distinguishing it from grief pathology and from other

disorders remains a persistent problem for grief investigators (Rando, 1993; Stroebe, 2001). In 1987, Faschingbauer, Zisook, and DeVaul noted that the construct of grief had not yet been fully operationalized or validated. In spite of progress, difficulties remain. This is in part due to the previous lack of clarity in separating the axes outlined by Rubin (1999). However, it is also due in part to the lack of psychometrically sound instruments available to study bereavement (Hansson, Carpenter & Fairchild, 1993; Hogan, Greenfield, Schmidt & Lee, 2001; Lev, Munro & McCorkle, 1993).

Understanding the normal trajectory of bereavement "has been hampered, in part, by the use of questionnaires designed to measure psychiatric dysfunction, such as depression and anxiety, rather than instruments specifically developed to measure grief" (Hogan et al., 2001, p. 2). Those instruments that have been developed to measure grief have usually been constructed using rational methods rather than the more psychometrically sound procedure of empirically deriving instrument items from data collected from bereaved adults. Rationally designed instruments typically rely on the experience of practitioners and researchers who choose items for instruments from existing instruments, from research findings, or from anecdotal clinical experience. Examples of this process include the Texas Revised Inventory of Grief (Faschingbauer, Zisook & DeVaul, 1987) and the Grief Experience Inventory (reviewed by J. Stake, 1985). Content validity of the instruments is also determined by a "panel of experts" rather than by empirical methods (Hogan et al., 2001).

Without a clear understanding of "normal" grief, pathology cannot be consistently determined. "In addition to imprecise and inconsistent terminology, objective criteria to determine just when grief and mourning become complicated are absent, primarily

because what may constitute pathology in one set of circumstances may not in another" (Rando, 1993, p. 11). It is not clear where pathological grief fits in a diagnostic system. There remains a pull between the desire to ensure adequate help for those enduring complicated forms of bereavement and the hesitation to establish grief as a pathological phenomenon. It is, however, generally accepted that what is identified as pathological or complicated grief is determined by measures of the intensity and/or duration of grief symptomatology (Stroebe & Stroebe, 1987). Delayed grief is also recognized as problematic.

Researchers have concentrated on examining aspects of the death event and aspects of individual mourners in their search for predictors of complicated grief. There are also empirical efforts at categorizing adaptive responses to bereavement. There is empirical evidence that a number of variables are associated with increased intensity or duration of grief.

The age of the decedent has been shown to be inversely related to and a robust predictor of the intensity of grief (Gamino, Sewell & Easterling, 1998; Gamino, Sewell & Easterling, 2000). Studies have shown that compared to other bereavements, the grief of parents is particularly severe (Rando, 1986). Death of a child has been found to be more difficult than either the death of a parent or a spouse (Middleton, Raphael, Burnett & Martinek 1998; Sanders, 1979-80; Sanders, 1986; Raphael & Dobson, 2000). Compared to other grievers bereaved parents showed more intense grief reactions of somatic types and greater depression, anger and guilt (Sanders, 1986).

The mode of death has been related to bereavement outcome. Deaths that are traumatic or seen as preventable are associated with higher subjective grief misery

(Gamino, Sewell & Easterling, 2000). Unanticipated loss is associated with increased symptoms. Sanders (1986) compared the effects of sudden and long-term illness death of a spouse. In sudden death, the survivors experienced significant feelings of loss of control, more intense anger and frustration, and a larger number of physical complaints especially 18 months to 2 years post death. She noted the shock phase of bereavement which usually lasts a few weeks was greatly extended by sudden loss at times lasting into the second year of grief. Although Sanders (1986) derived her findings from conjugal bereavement, Fish (1986) found in a comparison of parents bereaved by sudden versus anticipated death that more intense grief was only associated with sudden death for fathers.

Violent deaths whether through accident, homicide or suicide have been associated with anxiety, depression, hostility and cognitive disturbances in bereaved parents. In a sample of over 280 bereaved parents, Murphy, Das Gupta, Cain, Johnson, Lohan, Wu & Mekwa (1999) found that all types of mental distress measured by the Brief Symptom Inventory were present following violent death bereavement. Mothers reported scores on 10 measures of mental distress that were up to five times higher than those of women in the normative sample 4, 12, and 24 months post-death. Similarly, fathers reported scores for the same periods that were up to 4 times higher than those of men in the normative sample (Murphy et al., 1999). Mental distress was persistent. Two years after the violent deaths of their children, parents' overall distress levels were more than twice as high as measures of "typical" American men and women. Particular modes of death have also been investigated. Extreme grief is the experience of family survivors of homicide victims (Stevens-Guille, 1999).

Stamm (1999b) identified a significant distinction between the intrusion and avoidance of grief and those of trauma. A comparison of intrusion and avoidance scores across different types of death found similar intrusion scores. However, avoidance scores for deaths that were likely traumatic were significantly higher than "normal" bereavement scores. This suggests that reexperiencing (intrusion) is a normal part of bereavement but that in traumatic bereavement the intrusive images are unwelcome reminders of the trauma rather than the deceased and therefore avoided.

The intensity of grief has been shown to vary relative to a number of personal variables. A greater number of losses and a history of previous mental health treatment have been shown to be mourner liabilities (Gamino, Sewell & Easterling, 2000). In bereaved parents, gender differences are significant. Measures of grief consistently score mothers as more acutely bereaved than fathers (Fish, 1986; Schwab, 1996). Fish (1986) found that mothers experienced notably greater grief intensity than fathers in the loss of a daughter and in the loss of an infant. Fathers grieved for sons with much greater intensity than for daughters. The grief of mothers was found to be greater after two years than it was before. Age appears to influence the grief intensity of men with older fathers grieving more intensely than younger fathers do. Fish (1986) found the age of the child was positively related to the intensity of father's grief but this was not clear with mothers. (The coincident increase in the age of the child and the father makes this result difficult to interpret.) Social class was found to be inversely related to distress five years after child's death (Videka-Sherman, 1987).

Positive adjustment was predicted by constructive action to seek new fulfillment (Videka-Sherman, 1987; Gamino, Sewell & Easterling, 2000). It was also related to the

ability to see something good resulting from the death; by having a chance to say goodbye; by intrinsic spirituality and by spontaneous memories of the deceased (Gamino, Sewell & Easterling, 2000). The subsequent birth of a child was also found to be a robust predictor of positive grief adjustment (Murphy-Mancini, 1988-89).

### Trauma

Epidemiological studies have demonstrated that exposure to traumatic events is surprisingly widespread (McFarlane & de Girolamo, 1996, p. 136). Van der Kolk and McFarlane (1996) describe PTSD as "a very common disorder" (p. 5). Yehuda (1999) cites estimates that suggest as many as 14% of Americans will develop PTSD at some point in their lives. In the United States, the National Comorbidity Survey used an epidemiological sample of 8,098 persons to examine the current and lifetime prevalence of PTSD in the U.S. population. They found that 60.3% of the male sample and 50.3% of the female sample had experienced a trauma that met the DSM-IV (American Psychological Association, 1994) criteria. The capacity of these events to produce PTSD varied ranging from 48.4% of female rape victims to 10.7% of men witnessing death or serious injury (Kessler et al. as cited by McFarlane & de Girolamo, 1996). The most common trauma was tragic death (McFarlane & Girolamo, 1996). Ehlers, Mayou and Bryant (as cited in Blanchard & Hickling, 1998) in a prospective longitudinal study assessed 967 persons injured in motor vehicle accidents (MVA). The prevalence of PTSD was 23.1% at 3 months and 16.5% at one year after the accident.

By definition, PTSD follows exposure to a horrific event. However, as the prevalence indicates, not everyone exposed to traumatic events suffers from the

syndrome. Like grief intensity, posttraumatic stress is the result of the interaction of elements of the event and the unique characteristics of the individual. Having said that the objective characteristics of an event are not sufficient predictors of the condition, it is important to remember that one of the most salient predictors of PTSD remains the severity of the traumatic event (Yehuda, 1999). The type of trauma is also important to the incidence of PTSD. Epidemiological studies demonstrate that interpersonal victimizations are associated with the highest rates of chronic PTSD (Yehuda, 1999). The prominence of chronic PTSD symptoms is noted in studies of the survivors of homicide (Rynearson & Geoffrey, 1999). The degree of life threat and the extent of physical injury are positively correlated with both the occurrence and severity of PTSD (Stamm, 1999a). Violent death "is a potent risk factor for the development of traumatic stress disorders" (Stamm, 1999b, p. 32). Seeing another person disfigured, mutilated or dead is another possible precursor to PTSD (Green, 1993). Rynearson and Geoffrey (1999) list the degree of exposure and perceived responsibility as risk factors associated with the event. Also, if the trauma involves a family member, the risk is increased. Amick-McMullen, Kilpatrick, and Resnick (as cited by Green, 2000), in a nationally representative sample in the United States found 23% of family or friends of victims of criminal or vehicular homicide developed PTSD at some point after the death. Resnick, Kilpatrick, Dansky, Saunders and Best (1993) found a lifetime PTSD rate of 22% in female family members of homicide victims. This was lower than rates for victims of rape, other sexual assault and physical assault where rates ranged from 31-39%. It was higher than rates for directly experienced non-criminal trauma such as disasters and accidents where the rate was 9% (Green, 2000, p. 11). Applebaum and Burns (1991) investigated a sample of



twenty families who lost a child through accidental injury or murder. All siblings reported some PTSD symptoms and 45% met the DSM-III-R criteria for the disorder. Overall, 35% of the parents met the diagnostic criteria for PTSD (Applebaum & Burns, 1991). Rynearson and McCreery noted a high correlation between death of a child and posttraumatic symptoms (as cited in Rynearson & Geoffrey, 1999). It can be argued that the parental relationship predisposes parents to increased horror and helplessness in the face of child death and therefore increases their risk of developing PTSD.

A number of personal risk factors have been identified. Cumulative lifetime stress, particularly a history of exposure to trauma is an important risk factor (Yehuda, 1999). Childhood abuse has been noted as an especially potent predictor (Rynearson, 1999; Yehuda, 1999). Women are at greater risk than are men. Yehuda (1999) notes the prevalence for women (18%) is almost twice that of men (10%). It is unclear if this difference is the result of an inherent female susceptibility or simply a reflection of women's greater victimization. In family survivors of homicide, women were more affected by post-trauma reactions (Stevens-Guille, 1999). Risk is also elevated by a previous history of behavioural or psychological problems (Yehuda, 1999). Most recently, biological factors have been explored and there is some evidence of a possible genetic predisposition to PTSD (Yehuda, 1999).

#### Social Support

Bereaved parent and author Harriet Schiff notes the "need for support during all phases following the death of a child" (Schiff, 1977, p. 12). Social support has long been identified as an important resource for the bereaved (Klass, 1988). Its ameliorative

effects have been noted not only for grief but for traumatic stress responses as well (Sprang & McNeil, 1998). Both grief and trauma are stressors. Interactionist approaches to stress conceive of social support as a resource that helps people cope with the demands of their environment (Stroebe & Stroebe, 1987). Stroebe and Stroebe (1987) have summarized the person-environment interaction model of stress (citing the work of Lazarus and Folkman) and applied it to spousal bereavement. In that model, the extent of stress in any situation is described as depending on the *relationship* between the demands of the situation and the resources of the person. The degree of stress ascribed to a particular situation is the result of a three-step process of cognitive appraisal. In the primary appraisal, the significance of the situation is judged in respect to the well-being of the individual. When a situation is categorized as challenging, a secondary appraisal assesses the coping options and coping resources. Reappraisal continues on an ongoing basis as new information is received about changes in the situation and the impact of one's behaviour. If a situation is appraised as stressful, the individual must then act to master the situation and/or control his or her emotional response to the situation. The success of the individual in mastering the situation is dependent on the individual's coping resources. Coping resources are described as either personal or environmental (Lazarus and Folkman as cited in Stroebe & Stroebe, 1987). One of the environmental resources is social support. In the deficit model of bereavement proposed by Stroebe and Stroebe (1987) for spousal bereavement, loss of a spouse creates a loss of instrumental support, validation support and emotional support. These deficits must be moderated by coping resources. This moderation can occur in three ways. In the initial appraisal of the situation/resource balance, the presence of coping resources will determine the degree to

which stress is experienced. Second, coping resources can limit the degree of pathological response to the situation. Finally, coping resources can be used to alter the stressful nature of the environment. Social support especially emotional support is suggested to be a most important interpersonal resource (Stroebe & Stroebe, 1987). The protection afforded by the availability of social support is described as a buffering effect (Stroebe & Stroebe, 1987; Wethington & Kessler, 1986). As Stylianos and Vachon (1993) indicate, there is no objective way to determine the helpfulness of a specific support attempt. The helpfulness of any intervention is determined solely by the recipient. There has been a debate among social support researchers whether social support should be conceptualized as a perception of hypothetical resource availability or as the actual transfer of advice, aid and affect through interpersonal networks. However, the "stress-buffering effect is most consistently found when support is measured as a perception that one's network is ready to provide aid and assistance if needed" (Wethington & Kessler, 1986, p. 78).

While the majority of research in this area appears related to spousal bereavement, there is evidence that bereaved parents receive or perceive inadequate or less support than other bereaved individuals and that the support that is received is not sustained over time (Brabant, Forsyth & McFarlain, 1995; Rando, 1986).

#### Service Needs

If service is defined as support or assistance provided by the formal or informal social network, then describing the need for service expressed by bereaved parents is a useful area of inquiry for social work practice. Amick-McMullan, Kilpatrick, Veronen

and Smith (1989) found that the most striking characteristic of those who seek help was the "sheer magnitude of distress and the need to ventilate deeply rageful and fearful feelings" (p. 33). In spite of the intensity of the needs of some survivors of traumatic bereavement, this writer was unable to access any studies that directly measured the service needs of bereaved parents. Some evaluative studies report on what parents find helpful. Many authors, as a result of their research findings or clinical experience, infer needs of parents and/or offer recommendations for program development.

In reviewing what others have assessed as the needs of the bereaved, one or both of two dimensions are typically addressed: emotional needs and problem-solving needs (Murphy, 2000/2001). Problem solving requires accurate information and the information needs of parents have been documented in studies as summarized by Farrugia (1996/2000) and Rosenblatt (2000). Because parents are anxious, exhausted and have difficulty concentrating, Murphy (2000/2001), in her evaluation of an intervention program for traumatically bereaved parents, suggests that written materials be provided as a backup for verbal contact. She further emphasizes the importance of skill acquisition noting, for example, the areas of communication with spouse and understanding the legal system. She states that most bereavement programs are brief and affect focussed. Both those factors serve to limit their effectiveness.

Emotional needs of the bereaved have been more widely considered. Farrugia (1996/2000) has summarized studies exploring the helpfulness of professional intervention. Parents consistently noted the importance of a caring and compassionate attitude on the part of helpers. Being comfortable with the expression of grief (Farrugia, 1996/2000; Videka-Sherman, 1987) and using fundamental support skills such as active

listening and allowing people to discuss memories (Farrugia, 1996/2000) were seen as helpful.

In addition to these general comments, the literature outlines interventions to assist the bereaved in their journey to loss accommodation. As these interventions are presumed to meet a need, they will be used here to infer the service needs of the bereaved. Figley (1996, December) suggests that there are several points for meaningful intervention in traumatic loss and has proposed a "wave related" model of intervention for traumatic loss accommodation. In his model, the first wave involves crisis intervention. The second wave is trauma mastery and includes arousal reduction techniques. The third wave is directed at resolution of acute grief. The fourth wave supports healthy loss accommodation. This model will be used as a guide for organizing the interventions found in the literature.

#### Crisis Intervention

A number of very concrete suggestions are made for assisting parents at the time of death. These include allowing or facilitating contact between the body of the deceased and the bereaved (Farrugia, 1996/2000; Stewart, 1999/2000), offering parents assistance with the notification of others, and remaining with parents until the support system is in place (Stewart, 1999/2000). The death notification itself can exacerbate traumatic stress effects if it is not accurate and given in doses, that is, in small, incremental bites of information (Stewart, 1999/2000). Also there may be child care or transportation needs that are immediate.

Critical Incident Stress Debriefing (CISD) (Mitchell, 1983) has been used to assist emergency personnel cope with the stress of violence and death associated with disasters. It is also recommended for other trauma survivors (Bell, 1995/2000; Figley, 1996, December). An approach adapted for families, the Family Debriefing Model, is suggested for the bereaved family survivors of suicide (Juhnke & Shoffner, 1999/2000)

### Trauma mastery

A number of approaches are thought to be useful for trauma survivors. Harris-Lord (1996) indicates that survivors need to talk about the incident repeatedly and have their personal reactions accepted and believed. Horowitz (1993) emphasizes the importance of early intervention for stress reduction and the prevention of chronic or delayed responses. Reduced pathology is then amenable through brief therapy. Amick-McMullan, Kilpatrick, Veronen & Smith (1989) in their study of homicide survivors suggested the utility of stress management techniques such as relaxation, and guided self-dialogue. There are a number of other techniques useful for trauma reduction. These include Thought Field Therapy (THT) (Callahan, 1985), Traumatic Incident Reduction (TIR) (Gerbode, 1995), Eye Movement Desensitization and Reprocessing (EMDR) (Shapiro, 1995) and Visual/Kinesthetic Disassociation (Bandler & Grinder, 1979). Amick-McMullan et al. (1989) found that psychological symptoms were significantly related in a negative direction to satisfaction with the justice system. Almost 2/3 of the variance in measures of anxiety and depression could be accounted for by that single variable. Education for coping with the justice system was, therefore, strongly recommended.

### Grief resolution

The acute phase of grief is the painful interval characterized by the most intense reactions to the loss (Rando, 1993). Rosenblatt (2000) found bereaved parents valued good non-judgmental listening, constancy, asking good questions, witnessing important events related to the death, witnessing parent grieving and acknowledging parent realities. Videka-Sherman (1987), responding to the needs of mourners in sudden death bereavements, suggested the development of an outreach program that would provide follow-up between two and three months post-loss to assess mourner functioning and initiate services as necessary. Survivors reported feeling their loss most severely during the post funeral period between six weeks and three months post bereavement. The tendency of family members to isolate themselves and grieve individually has been noted. "Such isolation appears to have inhibited needed familial interpersonal support and family communications" (Juhnke & Shoffner, 1999/2000, p. 8). Family intervention was recommended.

### Loss accommodation

Gamino, Sewell and Easterling (1998/2001) in summarizing the responses of 74 mourners to the question "what has helped?" found that the common denominator was an involved coping style based on actively engaging others, oneself or the environment. This information is valuable to both the formal and informal support networks. They may then encourage "mourners to proactively address known grief tasks rather than reactively expect that the simple passage of time will be sufficient to assuage the painful affect of grieving" (Gamino, Sewell & Easterling, 1998/2000, p. 10).

## Methodology

Using the Two-Track Model (Rubin, 1999) to describe grief, it becomes clear that the empirical emphasis relevant to this study is that of the functioning of mourners and the variables that are associated with symptoms of traumatic stress. A number of instruments have been developed for measuring grief symptoms in general and comorbid conditions in particular. The validity and reliability and diagnostic utility of the instruments vary. Without offering a comprehensive review of each instrument, it is interesting to note that the Impact of Event Scale (IES) (Horowitz, Wilner & Alvarez, 1979), the Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982), and the Grief Experience Inventory (GEI) (Sanders, Mauger & Strong, 1985) are widely used measures of recent distress. The Beck Depression Index (Beck, 1976) and the Beck Anxiety Index (Beck, 1987) are also frequently used to assess grief sequelae (Horowitz & Milbrath, 1998). The Structured Clinical Interview (SCID) (Spitzer, Williams, Gibbon, & First, 1990) offers another measure of mental distress. This potpourri of instruments is indicative of the previously discussed difficulties encountered in consistently defining and operationalizing the construct of grief. It also demonstrates the tendency to assess dysfunction associated with bereavement rather than grief or mourning per se. Often several measures are used to develop a broad picture of mental distress. Some of the measures have been standardized. Typical methodology would involve a single-cohort correlation/regression design to test hypotheses concerning factors thought to complicate mourning. Some studies have added comparison with established norms or a comparison group.



The field of trauma relies on a wide variety of research methodologies.

Epidemiology, the study of the distribution and determinants of disorders in populations, has been important to understanding the etiology of PTSD. It is the methodology for investigating the relative contribution of exposure and individual vulnerability. Such information is obtained from studies of entire populations or representative samples. The role of the intensity of exposure for example, is demonstrated by increasing prevalence rates with coincident intensity of exposure (McFarlane & de Girolamo, 1996).

PTSD is assessed according to the symptom and duration criteria defined by the DSM-IV (American Psychiatric Association, 1994). A variety of techniques are used. Self-report questionnaires, structured and semi-structures interviews, empirically derived psychometric measures, psychophysiological approaches and collateral evaluations have been developed for use with a variety of populations. Research into particular aspects of traumatic response relies on inferences from animal investigation and brain imaging technologies (Van der Kolk, McFarlane, & Weisaeth, 1996). Psychophysiological measures typically include heart rate, blood pressure, muscle tension, skin conductance level and peripheral temperature (Newman, Kaloupek, & Keane, 1996). A multi-modal approach is recommended to increase diagnostic utility (Newman et al., 1996). Most PTSD measures were designed to assess combat trauma and validated for that population. There has been some development of measures for victims of accident and sexual assault. The Structured Clinical Interview for DSM-III-R (SCID) is the most widely used semi-structured interview across a range of trauma populations (Newman, Kaloupek, & Keane, 1996). Because survey data indicate that after an individual experiences one high-magnitude stressor, there is increased possibility that he/she will be exposed to two or

more stressors over the lifespan, it is recommended that any assessment of PTSD should include an exploration for evidence of previous traumatic stressors (Newman, Kaloupek, & Keane, 1996).

Methodologically, the study of death and trauma present some inherent difficulties. Studies related to parental bereavement are predominately retrospective rather than prospective. This means it is impossible to be entirely confident in the estimation of variables as they existed prior to the event. Understanding factors that predispose individuals to traumatic responses or difficult grief outcomes is therefore compromised. Murphy et al. (1999) describe the problems presented by sampling in studies of parental bereavement. Samples are usually small and drawn non-randomly. Bereavement support groups are a primary source of subjects. Data are collected at varying times post-loss. Often, the ages of decedents and causes of death have varied widely within a single sample. Each of these factors compromises the generalizability of the study's findings. Further most studies are cross-sectional giving no indication of parents' bereavement adjustment over time.

### **Gaps**

Thanatological research has not brought trauma and grief together. Although clinicians may recognize some degree of traumatization related to bereavement there are "few research studies dealing with the impact of traumatization on individuals and families, the interaction of trauma and grief responses, or the clinical implications of these factors" (Wolfe & Jordan, 2000, p. 577). Speaking from a clinician's viewpoint, Wolfe and Jordan (2000) note that better information about the impact of trauma on

mourners and the impact of grief/loss on the traumatized would enhance current understanding of the nature of the sequelae of trauma and loss. Effective intervention is dependent upon accurate understanding.

Grief is viewed as an individual journey and there is considerable evidence to support this view. However, bereavement is almost always a family affair. Parental bereavement is particularly so. The systemic impact of bereavement appears to lie outside the concern of thanatology. This gap does not appear to be filled by the family therapy field (Wolfe & Jordan, 2000).

The role of social support in successful adaptation to grief and trauma is also not clear. Many studies have associated provision of social support with significant benefits (Raphael, Middleton, Martinek, & Misso as cited in Zisook & Shuchter, 2001; Sprang & McNeil, 1998). But in other studies social support did not appear to provide any protective effects (Murphy et al., 1999; Stevens-Guille, 1999).

The service needs of bereaved parents have been inferred from research findings and from clinical practice. However, they have not been clearly postulated from a parent perspective.

The biological markers of acute grief and traumatic stress offer a research direction that may provide another avenue for clarifying the connection between grief and trauma. The relationship of the biological sequelae of trauma and bereavement to the compromised health outcomes noted for mourners is another area for fruitful inquiry.

It is unclear what the relationship is between traumatic stress symptoms, mode of death, and parent helplessness. Is it the sudden violent nature of a death that precipitates posttraumatic symptoms or the degree of helplessness felt by the parent or both? One

might expect similarities between the helplessness felt by parents in child injury deaths and in non-injury deaths. It seems clear that traumatic stress is associated with sudden violent death. There is some evidence to show that traumatic parental bereavement produces traumatic stress symptoms. However, the relationship between child death in general and traumatic stress has not been explored. Without that information, the predictive risk of parental bereavement and traumatic parental bereavement cannot be delineated.

The interface between trauma and grief and their respective manifestations requires a great deal more research. It remains to be determined whether these phenomena overlap or are distinct. Are traumatic responses to child death part of a pathological grief response that requires a diagnostic category or are they a typical response that is manifest in a significant portion of traumatically bereaved parents? If they are atypical, does that necessarily imply they are pathological? Can atypical responses be recognized and responded to without the label of a diagnostic category? What is the process of adjustment for these parents?

## CHAPTER 3

### METHODOLOGY

It is clear from the literature that grief and trauma are intertwined in cases of traumatic death. Studies have demonstrated that posttraumatic stress symptoms occur in survivors of specific traumatic losses across relationships. However, there has been little research on the occurrence of posttraumatic stress across events within a particular relationship. Parental grief has been found to be the most intense grief without consideration of the impact of the cause of death. Social support has been shown to ameliorate stress in a variety of settings including grief and trauma.

The focus of this study is the exploration of the relationship between the traumatic death of a child and posttraumatic symptomatology and grief in parents. Also the relationship between social support and the impact of bereavement will be examined.

This focus suggests the following questions:

- What degree of posttraumatic stress do bereaved parents experience?
- Do injury bereaved parents experience more symptoms of posttraumatic stress than parents bereaved by other causes?
- Do injury bereaved parents experience a greater intensity of grief than parents bereaved by other causes?
- Is parent perception of social support related to the grief intensity or trauma symptomatology that they experience?
- What are the service needs of bereaved parents?
- Do injury bereaved parents experience different service needs than parents bereaved by natural causes?

## Hypotheses

To study these questions, several hypotheses are advanced:

1. Parents bereaved by the injury death of a child for whom they are the next-of-kin will report more symptoms of posttraumatic stress than parents bereaved by non-injury child deaths.
2. Parents bereaved by the injury death of a child for whom they are the next-of-kin will score higher on a measure of grief intensity than parents bereaved by non-injury child deaths.
3. Bereaved parents' perception of social support will be negatively correlated with grief intensity.
4. Bereaved parents' perception of social support will be negatively correlated with posttraumatic stress symptoms.
5. Injury bereaved parents will experience service needs different from those experienced by non-injury bereaved parents.

## Research Design

Because the subject matter of this research precluded an experimental design, a double cohort cross-sectional design was used.

A cohort study of risk was proposed as the best available alternative to an experimental design. Cohort studies follow the same logic as clinical trials that answer the question: does disease follow exposure? (Fletcher, Fletcher & Wagner, 1996). For this study a double-cohort design was most desirable. Double-cohort studies have two distinct samples of subjects: one group with exposure to a potential risk factor and a

second group of controls that have no exposure or lower levels of exposure (Hulley & Cummings, 1988). This should not be confused with a case-control design where samples are chosen on the basis of outcome. In this cohort design, external or exposure control dictated that samples were chosen on the basis of exposure to a potential risk factor (Hulley & Cummings, 1988).

In the present study, the exposure group consisted of parents who had experienced the injury death of a child. In Canada, the International Classification of Disease - ninth revision (ICD-9) is used to classify deaths and hospitalization (World Health Organization, 1977). Events associated with injuries are classified using the codes for external cause of injury and poisoning (E-codes) (Health Canada 1997/2001). Parents, bereaved as a result of an event that could be classified using the E-code system, were considered the exposure group. As a further criterion, the E-code classifiable injury must have resulted in death within 72 hours of its occurrence. The non-exposure or comparison group consisted of parents bereaved by internal causes.

The double cohort design for exposure control introduces a comparison group that strengthens the study. However, it also creates the possibility of introducing variables for which there is no control. The comparison group in this study was hoped to approximate the exposure group on variables known to influence grief and trauma responses. However, the groups could not be matched perfectly. Differences might have confounded the findings in ways beyond current understanding of the phenomena under study. Therefore, differences were measured and the groups were compared. Where possible, the effects of potentially confounding variables were removed by statistical means.

This was a cross-sectional study gathering data from two groups during one period of time. Cross-sectional studies have the advantage of being of short duration. However, they provide only a snapshot view and do not provide information on progress over time.

### **Sampling**

Parents whose period of bereavement was between 6 and 24 months duration were contacted. This time period was chosen to avoid intruding on the newly bereaved. No one was approached before six months post-bereavement. Parents were included only up to two years post bereavement to allow for a balance in maximizing bereavement effects and minimizing memory distortion. Also, parents have indicated the greatest accommodation to traumatic loss occurs in the third year of bereavement (Murphy, 2000).

The groups in this study were designed to demonstrate the greatest polarity in bereavement circumstances. In the exposure group, three variables were characteristic of all deaths. They were all sudden, violent and unanticipated. These are injury deaths that might be categorized using an E-code classification as found in the International Code of Diseases accepted as standard in Canada (World Health Organization, 1977). The comparison group consisted of parents whose experience was much less sudden, non-violent and to some degree anticipated. To maximize the difference between groups, it was necessary to exclude parents of children who died suddenly from natural causes. That meant exclusion of Sudden Infant Death Syndrome (SIDS) deaths and any death from a natural cause that was not previously diagnosed as a life-threatening condition.



Also, it was necessary to exclude parents of children who died more than 72 hours after an injury.

Parents were contacted through a variety of channels. A request for subjects (Appendix B) was included in the quarterly newsletter of The Compassionate Friends, a self-help organization for bereaved parents. Information about the study and a request for subjects was provided at a sharing meeting of The Compassionate Friends (TCF), Winnipeg and at the 25<sup>th</sup> National TCF Conference in Salt Lake City, Utah in July 2002. Obituaries in the Winnipeg Free Press were searched. Potential volunteers were contacted by letter a minimum of six months post death and provided with information about the study and an invitation to participate (Appendix C). Letters were followed where possible with telephone contact to provide further information, answer questions and explain consent. An outline of the telephone contact interview and a copy of Consent Form are included in Appendices D and E respectively.

Although telephone contact may be considered intrusive, the telephone technology in a great many homes allows for screening of calls by selective use of any one or more of the following telephone features: answering machine, voice mail, and call display.

A further consideration was that people who are highly stressed might be willing to participate but unable to organize themselves to follow up on a written request. Assuming responsibility for follow-up is intended to relieve potential respondents of that burden. If interest in participating is expressed, potential respondents were offered the choice of receiving the consent form by mail or in person prior to an interview.

The sample was restricted to the parents of children who died subsequent to a live birth<sup>4</sup>. There was no maximum age boundary for decedents but recruitment was limited to parents who were the next-of-kin to the deceased. As next-of-kin all these parents shared similar early bereavement experiences such as death notification, body identification, responsibility for funeral arrangements. They also had primary responsibility for winding up the affairs of the deceased, for interface with the justice system and any consideration of litigation arising out of the circumstances of the death. Parents charged with contributing to the death of their child were excluded.

To maintain an independent sample, only one parent from each bereaved family was included. Parents were allowed to self-select for participation.

### Measures

A series of measures was administered individually to all participants. Scores were obtained on measures of trauma symptoms, grief and perception of social support. Service needs were summarized. To ascertain the comparability of the two groups, demographic information as well as data on variables that have been empirically linked to the intensity of grief or trauma (as summarized in Table 1) were collected. Demographic information included gender, marital status, age, and income level. Additionally, the participant's perception of his or her physical health, his or her past experience with trauma, previous history of mental health treatment, religiosity, and the subsequent birth of children was recorded. The gender of the decedent and his or her age at death was noted. Parent perception of the preventability of the death was obtained. Anticipation of

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<sup>4</sup> This limitation was not intended to minimize the grief of parents of stillborn children or those suffering loss through miscarriage or spontaneous abortion.

Table 1

Variables Effecting the Impact of Loss and Trauma

Grief	Trauma
<p>Factors related to the death event: Increase intensity of grief reaction</p> <ul style="list-style-type: none"> <li>• Sudden death versus natural death across relationships (Middleton, Raphael, Burnett &amp; Martinek, 1998).</li> <li>• Accidental death versus natural death across relationships (Middleton, Raphael, et al., 1998).</li> <li>• Traumatic death among strongest predictors of grief affect (Gamino, Sewell, &amp; Easterling, 2000).</li> <li>• Perception of preventability (Gamino, et al. 2000).</li> </ul> <p>Increase duration of grief reaction in parents:</p> <ul style="list-style-type: none"> <li>• Accident versus illness death of child (Murphy-Mancini, 1988).</li> <li>• Violent death (Murphy, Das Gupta, Cain, Johnson, Lohan, Wu &amp; Mekwa 1999).</li> </ul>	<p>Factors related to the death event</p> <ul style="list-style-type: none"> <li>• Generic dimensions of trauma <ul style="list-style-type: none"> <li>- Violent/sudden loss of a loved one (Green, 1993)</li> <li>- Witnessing or learning of violence to a loved one (Green, 1993)</li> <li>- Exposure to the grotesque (Green, (1993).</li> </ul> </li> <li>• Higher rates of stress disorders in stigmatized deaths and intentional deaths (Green, Krupnick, Stockton, Goodman, Corcoran &amp; Petit, 2001).</li> <li>• Degree of violence/ mutilation (Rynearson &amp; Geoffrey, 1999)</li> </ul>
<p>Factors related to the decedent</p> <ul style="list-style-type: none"> <li>• Intensity of grief for the loss of a child &gt; loss of a spouse &gt; loss of a parent (by adult child). ( Lev, Munro, McCorkle, 1993; Middleton, Raphael, Burnett &amp; Martinek 1998; Sanders, 1979-1980).</li> <li>• Age of decedent in inverse relationship to parent survivors' grief affect (Gamino, Sewell &amp; Easterling, 2000).</li> </ul>	<p>Factors related to the decedent</p> <ul style="list-style-type: none"> <li>• Death of a child (Rynearson &amp; Geoffrey, 1999)</li> </ul>
<p>Factors of individual vulnerability</p> <ul style="list-style-type: none"> <li>• Gender. Women show increased intensity of grief reaction (Schwab, 1996; Sidmore, 1999-2000; Sprang, McNeil &amp; Wright, 1992-1993).</li> <li>• Previous history of mental health problems associated with increased bereavement distress (Gamino, Sewell &amp; Easterling, 1998); co-morbidity (Zisook, Shuchter, 2001).</li> <li>• Income, religiosity and marital status inversely associated with level of grief (Sprang, McNeil &amp; Wright, 1992-1993).</li> </ul>	<p>Factors of individual vulnerability to PTSD</p> <ul style="list-style-type: none"> <li>• Associated with female gender (Yehuda, 1999) <ul style="list-style-type: none"> <li>- in drunk driving, fatality survivors (Sprang &amp; McNeil 1998)</li> <li>- in homicide survivors (Sprang &amp; McNeil &amp; Wright, 1992-93).</li> </ul> </li> <li>• History of depression associated with PTSD in motor vehicle accident victims (Blanchard, Hickling, Taylor &amp; Loos, 1995/1998).</li> <li>• History of earlier trauma and PTSD (Blanchard, Hickling, Taylor &amp; Loos, 1995/1998; Yehuda, 1999).</li> <li>• Religiosity and subjective measures of health inversely associated with PTSD (Sprang &amp; McNeil, 1998).</li> </ul>
<p>Post event factors related to grief response</p> <ul style="list-style-type: none"> <li>• Social support use and perception have been inversely associated with grief and mourning (Klass &amp; Marwit, 1988-1989; Sprang &amp; McNeil, 1998; Sprang, McNeil &amp; Wright 1992-1992).</li> <li>• Parental grief inversely associated with birth of a subsequent child (Murphy-Mancini, 1988/89).</li> </ul>	<p>Post event factors related to trauma response</p> <ul style="list-style-type: none"> <li>• Social support inversely associated with PTSD drunk driving fatalities (Sprang &amp; McNeil, 1998)</li> <li>• Associated with litigation following MVA (Blanchard &amp; Hickling, 1998).</li> </ul>

the death was also noted. Data were analyzed descriptively and for significant differences between groups.

### Instruments

#### Grief

Grief was measured using the Hogan Grief Reaction Checklist (HGRC) (Hogan, Greenfield, Schmidt & Lee, 2001). (Appendix F). This is a recently developed instrument designed to measure the multidimensional nature of bereavement. The HGRC consists of 61 statements reflecting six subscales. It is scored on a 5 point Likert scale that asks respondents to rate the degree to which the statements describe their experience ranging from 1 "does not describe me at all" to 5 "describes me very well"(Hogan et al., 2001). The six subscales provide measures of Despair, Panic Behavior, Blame and Anger, Detachment, Disorganization, and Personal Growth.

The internal consistency of the total instrument was .90 on a sample of 586 adults who had experienced the death of an immediate family member. Cronbach's alpha coefficient for the six subscales ranged from .79 - .90. This suggests that the subscales contain items that constitute relatively homogeneous response patterns.

Test-retest analysis of reliability provided evidence that the subscales are relatively stable over time. Test-retest of the HRGC subscales over a 4-week period resulted in correlation coefficients ranging from .77 to .85 with the exception of the Blame and Anger subscale at .56. All results were significant at the  $p < .001$  level. Gamino, Sewell and Easterling (2000) report comparable reliability estimates in their use of the instrument in a sample of 85 heterogeneous mourners.

The authors report that to determine convergent and divergent validity, the HGRC subscales were compared to subscale scores on the Texas Revised Inventory of Grief (TRIG), the Grief Experience Inventory (GEI), and the Impact of Event Scale (IES). The results indicate appropriate although modest correlation between HGRC subscales and subscales of the TRIG, GEI, and IES. The great majority of subscale correlations were significant at the  $p < .001$  level. The Personal Growth subscale was negatively correlated to each of the other HGRC subscales and all of the TRIG, GEI, and IES subscales. Negative correlations ranged from  $-.13$  to  $-.50$ . The range of correlations<sup>5</sup> between the subscales of the HGRC and those for the GEI, TRIG, and IES was  $.20$  to  $.63$ . While this may seem particularly modest, it should be noted that the range of correlations for subscales in the three comparison tests was  $.14$  to  $.46$  for positive correlations and  $-.13$  to  $-.47$  for negative correlations. The individual subscales showed a stronger relationship to other instrument subscales with similar content than to instruments with less related behaviours (Hogan, et al., 2001). Concurrent validity for the HGRC also appeared to be supported by strong and consistent correlation with the GEI in the study of Gamino, Sewell and Easterling (2000).

The authors also tested the ability of the scale to differentiate between intensity of grief in groups bereaved less than or more than three years. Significant group differences were found in the predicted directions. They also tested four groups of mothers differentiated by the cause of their child's death: illness, accident suicide or homicide. Significant findings were noted for the Panic Behaviour and the Blame and Anger subscales indicating the ability of the HGRC to differentiate between grief reactions subsequent to particular modes of death (Hogan, et al., 2001). Gamino, Sewell and

Easterling (2000) found the HGRC superior to the GEI in detecting subtle differences in grievers' self-reported negative affect.

The advantage of the empirical derivation of this scale is the resulting contribution to its potential validity. The items in the checklist were generated from interview and anecdotal data provided by bereaved adults. The wording of items mirrors the words and phrases used by bereaved adults and should be well accepted and understood by bereaved subjects. The initial set of items was analyzed through a series of focus groups organized according to either cause of death or relationship to the deceased. Both factors are important to this study. Of particular interest, the initial testing was done on a group of 586 adults, the majority of whom were bereaved parents (N=428). The revised instrument was tested and again samples consisted of bereaved parents. This concentration on bereaved parents in constructing the scale increases the applicability of the instrument to the sample proposed for this study. Further, the scale was developed on non-clinical samples that should assist in establishing "normal" grief reactions. The inclusion of Personal Growth, a measure of adaptation, provides an additional insight into the process of bereavement that is not typically offered by bereavement instruments.

As a self-report scale, it offers ease of administration, and a low time demand for both administration and scoring. The advantages and disadvantages of self-report measures are discussed in more detail in the Data Collection section of this chapter.

Unfortunately, the bereaved adults used to validate this scale were all recruited through mutual support groups except for a group of 47 nursing students who had experienced the death of a loved one. The nature of the bias that may have been

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<sup>5</sup> Correlations that were not significant were omitted from the ranges cited.

introduced by this factor is unclear. While the subscales were tested for discriminant validity against subscales of other measures of grief, a more portent result might have been achieved by comparison to other measures of related constructs such as anxiety or depression. Similarly, the authors do not report on the scale's ability to discriminate between bereaved and non-bereaved groups. Because it is a new instrument, it has not been widely used or critiqued. Its diagnostic utility has not yet been clearly established. It has not been validated with other groups and norms are not reported. A respondent reading level is not indicated. Initial test samples were predominately white, female and middle class raising the question of the scale's applicability to other groups.

#### Posttraumatic Stress

Traumatic stress symptoms were measured using the Clinician-Administered PTSD Scale (CAPS) (Blake, Weathers, Nagy, Kaloupek, Klauminzer, Charney & Keane, 1990). The CAPS (summarized in Appendix F) is a 30 item structured clinical interview designed to assess the occurrence of symptoms from each of the three clusters of symptoms characteristic of PTSD: intrusion, avoidance, and hyperarousal. It provides a means to evaluate self-reports of exposure to potential Criteria A events that are preliminary to PTSD assessment. CAPS assesses the frequency and intensity of each symptom using standard prompt questions and explicit behaviourally anchored rating scales. The impact of symptoms on social and occupational functioning is also assessed. An overall severity rating is determined. The CAPS-1 yields both continuous and dichotomous scores for current and lifetime PTSD symptoms (Blake, Weather, Nagy, Kaloupek, Gusman, Charney & Keane, 1995). The scale is first administered for current symptoms. If PTSD is not currently present, then a lifetime score is determined.

The reliability of diagnostic interviews is greatly concerned with level of the agreement between two interviewers conducting independent assessments, interrater reliability in addition to test-retest reliability. In a preliminary investigation by three clinicians on a sample of 60 Vietnam veterans, interrater reliability was reported in the range of .92 to .99 for each of the three symptom clusters (Weathers & Litz, 1994). Foa and Tolin (2000) also determined high interrater reliability. In a complex study of 123 Vietnam veterans and three unique rater pairs, Weathers and Litz (1994) report test-retest reliability coefficients ranging from .77 to .96 for frequency and intensity scores and .90 to .98 for total severity scores. Similar results are documented by Blake, Weathers, Nagy, Kaloupek, Klauminzer, Charney and Keane (1990) on a sample of seven veterans.

Diagnostic utility (Newman, Kaloupek & Keane, 1996) measures sensitivity, specificity and efficiency. Sensitivity is the probability that those with the diagnosis will be correctly identified. Specificity is the probability that those without the diagnosis will be correctly excluded from diagnosis and efficiency is the overall probability that true cases and non-cases will be categorized appropriately (p. 245). Based on the PTSD module of the Structured Clinical Interview for DSM-III-R (SCID), Weathers and Litz (1994) found the CAPS was highly predictive of PTSD diagnosis in their sample of 123 Vietnam veterans. Using a total severity score of 65, sensitivity was 84%, specificity was 95% and efficiency was 89%.

Internal consistency estimates were calculated for the three PTSD symptom dimensions. Weathers and Litz (1994) report on two tests with similar results. In the larger sample of 123 veterans alpha coefficients for the three symptom clusters ranged from .85 to .87 and the alpha coefficient for all 17 symptoms was .94. This indicates a



high degree of homogeneity among items at least in that particular population of combat veterans.

Regarding construct validity, in the sample of 123 Vietnam veterans CAPS demonstrated good convergent validity with standard measures of PTSD including the Mississippi Scale (.91), the PK subscale of the MMPI-2 (.77), and the SCID (.89). It was weakly (range .14-.34) correlated (divergent validity) with measures of antisocial personality (Weathers & Litz, 1994).

Because this scale was developed to address the limitations of other structured interviews it offered some distinct advantages. Measuring both frequency and intensity of symptoms allowed those with frequent but less intense symptoms and those with occasional but more severe symptoms to meet diagnostic criteria (Newman, et al. 1996).

A critical advantage for this study was the assessment of the "worst ever" one-month time period (lifetime assessment). This allowed the capture of symptoms that may no longer be present in their original intensity or frequency. Because the study encompassed mourners at various points post death, this was an important equalizing opportunity.

There are disadvantages to this measure. It was validated on veterans and has not been correspondingly validated on civilian populations. It is somewhat lengthy to administer requiring approximately an hour. There is also some uncertainty around rules for scoring (Weathers, Ruscio & Keane, 1999).

The interest in this study was to explore the possible presence of PTSD symptoms in bereaved parents. Diagnosis was based on two of the original rationally derived scoring rules described by Blake (1994). One rationally derived convention, the F1-I2

rule, for establishing the presence of a symptom counts a symptom when its frequency is rated as "1" (occurred at least once during the designated time period) or more and its intensity is rated as "2" (at least moderately intense or distressing) or greater. A more conservative strategy, the Severity = 4 rule, endorses a symptom when its frequency and intensity ratings sum to four or more. Both these scoring strategies have been criticized for overestimating PTSD status. Weathers and Litz (1994) compared the diagnostic utility of the various scoring rules for the CAPS with diagnosis provided by the PTSD module of the Structured Clinical Interview for DSM-III-R (SCID). Their results are reproduced in Table 2.

Table 2

Diagnostic Utility of CAPS Scoring Rules with SCID-Based Diagnosis as Criterion

<u>Scoring Rule</u>	<u>Sensitivity</u>	<u>Specificity</u>	<u>Efficiency</u>	<u>kappa</u>
F1-I2	.88	.73	.81	.62
Clinician ratings	.68	.98	.81	.64
Severity = 4	.87	.74	.81	.62
Diagnosis calibration rule*	.90	.82	.86	.72
Symptom calibration rule*	.91	.86	.89	.77

\*Using these rules, scores are based on the optimally efficient cut off score for predicting either the corresponding SCID PTSD symptom (symptom calibration rule) or the SCID PTSD diagnosis (diagnosis calibration rule). Thus each CAPS item has its own cutoff score (Weathers & Litz, 1994).

Table 2 indicates a somewhat lower specificity rate for the F1-I2 and Severity = 4 rules but adequate sensitivity and efficiency. Weathers, Ruscio and Keane (1999), citing Kraemer, identify types of tests that are optimal for different assessments. Optimally specific tests minimize false positives and are best for confirming diagnosis. Optimally sensitive tests minimize false negatives and are best for screening. Optimally efficient tests minimize the overall number of diagnostic errors giving equal weight to false

positives and false negatives. These tests are best for differential diagnosis. Weathers et al. (1999) suggest that it is unlikely that any single scoring rule would be optimal for all three assessment tasks. Further, they recommend using the F1-I2 rule for screening.

The decision to use the somewhat less stringent scoring conventions for this study was based on the exploratory nature of the research and the increased ease of scoring afforded by those conventions. The goals of this project were met by a test that offered optimal screening of participants rather than diagnosis. There was no intention to ascribe to individual bereaved parents a diagnosable mental condition. The intent was to examine parents' responses to loss in an effort to clarify links between grief and trauma. A potential increase in the probability of committing Type II error was felt to be justified.

However, given the possibility of false positives, the rates of diagnosis associated with various rules were examined. Blanchard, Hickling, Taylor, Forneris, Loos and Jaccard (1995) compared the prevalence of diagnosis for 100 victims of recent motor vehicle accidents using various CAPS scoring rules<sup>6</sup>. They found a range of diagnosis from 44% of the sample using the most liberal rule to 29% using the most conservative rule. Fleming and Difede (1999) in their study of PTSD in 69 burn victims found a range of prevalence from 32% to 25 % for the most liberal<sup>7</sup> to the most conservative scoring rules. Weathers, Ruscio and Keane (1999) compared the prevalence of diagnosis resulting from nine scoring rules. Prevalence in a non-clinical sample of 243 male Vietnam veterans ranged from 48% using the F1-I2 rule to 26% using the most stringent rule. Foa and Tolin (2000) compared the prevalence of PTSD using rules described by

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<sup>6</sup> Blanchard et al (1995) This study included a rule of 2 (Frequency +Intensity =2), rule of 3 (Frequency + Intensity =3) and rule of 4 (Severity = 4). Both the rule of 2 and the rule of 3 are more lenient than the F1-I2 rule.

<sup>7</sup> Followed Blanchard et al. (1995) as above.

both Blanchard et al. (1995) and Weathers et al. (1999). In their sample of 39 individuals with and without traumatic experiences, prevalence ranged from 51% to 32% using the rules described by Blanchard et al. Employing rules outlined by Weathers et al., prevalence was 35% using the liberal rule (F1-I2), 31% using the moderate rule and 17% using the most stringent rule<sup>8</sup>.

The potential in this study for increased prevalence of PTSD as a result of using the more lenient scoring rule was noted and considered in the interpretation of the results.

### Social Support

Social support was measured using a pair of self-report instruments (Appendix F). The Perceived Social Support - Friend Scale (PSS-Fr) and the Perceived Social Support -Family Scale (PSS-Fa) were developed by Procidano and Heller (1983) to measure the degree one perceives his or her needs for support fulfilled by family or friends. Items on each of the 20-item scales are scored "yes", "no", or "don't know". Higher scores reflect more perceived self-support.

In a sample of 222 Indiana University undergraduates, the internal consistency and one-month test-retest reliability of the scales were substantial. Alphas for the PSS-Fa ranged from .88 to .91 and the range for the PSS-Fr was .84 to .90. Good concurrent validity is reported for both scales. Scores correlated with measures of psychological distress and social competence. Clinical and nonclinical groups differed on both measures.

This is a brief measure that required little time to administer and score. The

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<sup>8</sup> The moderate rule as described by Weathers et al. (1995) was TSEV65. Frequency > 1 = Intensity > 2 = Severity > 65. The stringent rule was CR75. PTSD symptom was considered present if Frequency + Intensity for each item was rated as present by 75% of clinicians.

separate measures of support from family and friends were designed to contribute to our understanding of mourner's perceptions. Normative data were derived from a sample of undergraduate psychology students. The degree that the sample was representative of adult perceptions of social support may be questioned.

### Service Needs

Service Needs were measured using a short series of open-ended questions related to each of Figley's (1996, December) intervention waves and the dimensions of both problem solving and affect. The questions in this structured interview format were developed for this study (Appendix F). Because they had not been tried, a pretest was used to increase their utility. Initially two bereaved parents whose experience fell outside the time frame of this study were asked to participate in the interview as it was initially outlined. Using the retrospective technique suggested by Dillman (2000) for the construction of surveys, pretest participants were then debriefed. Questions were also subject to academic committee review. Some adjustment was made to the clarity and specificity of questions prior to their inclusion in the study.

Questions related to the use of services were also included in the Personal Information questionnaire. Those questions were patterned after those asked by Walker, el-Guebaly, Ross & Currie in Research Report No. 35 of the Winnipeg Area Study (Currie et al. 1981-1993). A comparison could then be made between the pattern of services used by bereaved parents and the pattern of services used by a normative group obtaining help with stress and anxiety.

### **Data Collection**

In this study, the personal nature of the data to be collected and the vulnerability of the respondents required a high degree of sensitivity from the researcher and the research process. Obtaining informed consent ensured that respondents were prepared for the type of information that was requested. If necessary, the researcher provided a comfortable and private setting for the interview. Confidentiality was ensured by assigning a number code to each participant. Measures from the same respondent could then be identified.

Much thought was given to the order in which the measures were administered. Conventional wisdom often prescribes that one should work up to more difficult questions. However, studies of "the effect of question order upon people's willingness to reveal sensitive information do not provide consistent support for the idea that threatening questions should come last"(Abrahamson, 1983, p.358). The guideline used here is that of a critical incident debriefing model. That model moves through several phases beginning with facts and thinking, moving to reactions and affect, then returning to a more cognitive level (Bell, 1995; Juhnke & Shoffner, 1999). In an effort to approximate that format, the Personal Information questionnaire was administered first followed by the Life Events Checklist, the CAPS, the HGRC, the PSS-Fr and PSS-Fa scales and finally the service needs assessment. The interview format is outlined in Appendix G.

Data were collected through standard self-report measures, structured interviews and survey questions. Each of these methods has advantages and disadvantages.

Self-report measures require little time to administer and score. In addition to being part of an interview, they may be completed as a mail-out or as homework following contact with the researcher. They are less intrusive than interviews. The privacy afforded by self-report scales may provide encouragement for increased candor on sensitive issues (Rubin & Babbie, 1997). There is greatly reduced potential for interviewer bias (Rubin & Babbie, 1997). However, they must be carefully constructed so that the language of items is understood and items are interpreted consistently by all respondents. Closed format questions limit the range of responses and, therefore, the information collected. However, the closed format results in fewer non-completions (Abrahamson, 1983). When the range of relevant responses is known they provide excellent specificity thus eliminating the difficulty of responses in non-comparable categories (Abrahamson, 1983). The typical disadvantages of self-report questionnaires are low response rates, lack of control over the conditions of completion and lack of visual observation of the respondents reactions to the questions (Neuman, 1991). Having the questionnaires completed in conjunction with the interviews helped to circumvent these disadvantages.

Interviews address the shortcomings of self-report measures. They gather a richness of data not otherwise obtainable. Interviewers can interpret questions that may be confusing to respondents and identify misunderstandings that may occur. The interview format allows for probes that may reduce "don't know" or "no answer" responses (Rubin & Babbie, 1997). They can also increase the amount of information given as a response. The interviewer is an observer as well as an inquisitor. This allows the process to be sensitive to the respondent's needs and comfort level. While structured

interviews limit the scope of information collected, they introduce a standardization that increases the comparability of the responses (Abrahamson, 1983). Standardization requires the interviewer to stringently comply with the protocol established for a structured interview measure in order to maintain the validity of the measure.

The cost of using interviews is measured in time, convenience and potential bias. Interviewer bias is greatest in face-to-face interviews (Neuman, 1991). The presence of an interviewer may reduce or increase the respondents' comfort and willingness to participate. The appearance, tone of voice, question wording of the interviewer may affect the respondent (Neuman, 1991). Further, expectancy effects have been shown to occur. This can result from the interviewer subtly communicating his/her expectation to the respondent or by the interviewer's interpretation of ambiguous responses within an expected framework (Abrahamson, 1983). Thus there is potential for researcher bias in both data collection and analysis.

When considering bias that might have been introduced by the researcher in this study, it was important to be aware of the researcher's personal perspective and the coincident implications for objective research. As a bereaved parent, the researcher had a personal understanding of the experience to be examined. The advantage of increased credibility with respondents proved to be especially important in the recruitment process. Awareness of some of the pitfalls in relating to the bereaved and the completion of personal work in the acceptance of childhood death were also useful. A potential disadvantage was the possibility of contaminating the data collection or analysis with the researcher's personal perspective rather than accurately reflecting the respondents' experiences. Also, there was the personal cost of resonance with the experience of



others. Arguably, this proved to be not more significant and possibly less troublesome than the compassion fatigue experienced by a non-bereaved researcher. The possibility of reacting to the respondent's story and contaminating the data collection process exists for every researcher. Personal experience with death and a comfort level in discussing the end of life served to reduce rather than heighten the researcher's reactivity.

## **Data Analysis**

### Preliminary Analysis

In an exposure control study, it is important to establish the similarity of the groups in every way except their exposure to the independent variable. Therefore, a preliminary analysis reviewed and described the characteristics of the groups and then determined any significant differences in the composition of the groups. Demographic characteristics were compared as well as the occurrence of variables related to the levels of traumatic stress and grief responses.

This involved data at various levels of measurement. Interval measure data were compared for significant differences using t tests. Ordinal data was compared using the Mann-Whitney U test. Chi-square was used to test for significance of differences in nominally measured data.

The comparison of variables related to the level of traumatic stress included:

- a) at the interval level - a comparison of the mean social support scores of each group
- b) at the ordinal level - a comparison of the groups' perception of health, and degree of religiosity

- c) at the nominal level - a comparison of gender, the experience of previous trauma, history of treatment for a diagnosed mental health disorder, and litigation subsequent to the death event

The comparison of variables related to grief intensity included:

- a) at the interval level - a comparison of the mean age of the respondent, age of the decedent, and duration of bereavement
- b) at the interval level - a comparison of income level
- c) at the nominal level - a comparison of the number who have experienced the subsequent birth of a child, the number married, the number of female decedents

#### Primary Analysis

The primary analysis addressed the hypotheses as follows:

1. Posttraumatic stress in the exposure and comparison groups was compared.
  - a. The dichotomous scores for the occurrence of PTSD in each group were compared using a two-way chi-square. Care was exercised to correct the general chi-square formula for continuity based on the total sample size and expected frequencies. Where the smallest expected frequency was less than 5, Fisher's exact test was used (Cramer, 1997, p. 131). Where possible, group differences were statistically controlled using logistic regression analyses.
  - b. The mean scores of each group were compared using an independent samples t test. The total symptom score from the highest measure (current or lifetime) recorded for each individual was used for comparison. Group differences were controlled using standard multiple regression analyses.

2. Grief in the exposure and comparison groups was compared.
  - a. The mean grief scores of each group on each dimensions of grief measured by the HGRC were compared using t tests. Each of the variables found to be significantly different between the injury and non-injury groups was controlled in a separate model using standard multiple regression.
3. Social support was correlated to grief and posttraumatic stress symptoms.
  - a. Normality of the distribution of social support scores was examined.
  - b. The relationship of social support to the level of PTSD and grief was determined using both parametric (Pearson's correlation coefficient  $r$ ) and non-parametric (Spearman's  $\rho$ ) correlations.
4. Service needs were categorized and frequencies determined using a combination of qualitative and quantitative techniques. The addition of qualitative methods to this analysis offered the particular advantage of qualitative techniques in recognizing and understanding the experiences of individuals without imposing preexisting expectations on the phenomenon under study. The qualitative process used for the needs assessment in this study was reflective of the approach to evaluative research described by Patton (1990).
  - a. The process notes were transcribed and organized. As described by Sandelowski (1995), the questions in the structured interview were used as an initial organizing framework. Data were segmented according to the questions that generated them

- b. A mixed methods approach was taken to the analysis of the data including summation of general survey information, content analysis and quantitative comparisons in addition to qualitative analysis.
- c. Using open coding the transcribed responses to each question were organized into units of meaning. Using the qualitative process of induction, units of meaning were then grouped around common themes to identify the central phenomena. Interpretation was based on the overriding themes that emerged.
- d. Once the central phenomena were established, the individual responses within each category were separated into injury or non-injury groups. The proportion of each groups' responses within a particular theme were compared using a  $z$  test for the difference of proportions. In this test, the  $z$  ratio was calculated by dividing the difference between proportions by the standard error of the difference (Levin & Fox, 2000, p. 233). The obtained  $z$  value was compared to the critical value. Scores for the  $z$  test were calculated and reported only for those comparisons where the proportion of one group at least approximated double the proportion of the other. Significant differences between groups were reported as they arose.
- e. Inter-rater reliability for the categorization of service needs was determined using Scott's  $P_i$  (1955) as recommended by Allen-Meares (1984). Interrater reliability is usually expressed as a ratio of the observed agreement between judgements and the expected agreement due to chance. The index proposed by Scott (1955) offered the advantage of correcting for the number of categories in the code and the frequency with which each was used. The

index results in a score that varies between 0 and 1. An agreement of .7 or better would be considered acceptable. In Scott's (1955) formulation:

$$p = \frac{P_o - P_e}{1 - P_e}$$

$P_o$  (observed percent agreement) represents the percentage of judgements on which two analysts agree when coding the same data independently.  $P_e$  is the percent agreement to be expected on the basis of chance.  $p$  is the ratio of the actual difference between obtained and chance agreement to the maximum difference between obtained and chance agreement. "The percent agreement which could be expected by chance depends not only on the number of categories in the dimension but also on the frequency with which each of them is used by coders" (Scott, 1955, p. 323). Therefore, total probability of chance agreement equals the sum of the probabilities of agreement on each of the categories taken individually (Scott, 1955). By determining the distribution of each response as a proportion of all responses,  $P_e$  (expected agreement) can be calculated as the sum of the squared proportions over all categories.

5. The effects of the duration of bereavement were assessed:
  - a. The correlation between the intensity of grief and trauma scores and the number of months since bereavement were assessed for the all respondents using Pearson's correlation  $r$ .
  - b. The sample was divided into three time groups and mean grief and traumatic stress scores for each time group were compared and plotted. One-way between-groups analyses of variance were conducted.

- c. The relationship between time and the injury and non-injury groups was explored using a standard multiple regression model that included a time/group interaction variable.
6. Other exploratory analyses were conducted:
- a. The effect of education on grief, trauma and social support measures was assessed by examining the degree of association between scores and parents' education level using Spearman's Rank Order Correlation Coefficient. To the writer's knowledge, none of the measures used have established a literacy level. [The tests of PSS were validated on undergraduate students (Procidano & Heller, 1983). Descriptive statistics for study samples validating the HGRC note income but not education levels (Hogan et al. 2001).]
  - b. The effect of Aboriginal ethnicity was assessed by dividing the total number of respondents into two groups based on Aboriginal or non-Aboriginal ethnicity. In this comparison, the categories of Aboriginal ethnicity were collapsed. The mean scores of each group on grief, trauma and social support measures were compared using independent samples *t* tests. The proportion of PTSD diagnosis in Aboriginal and non-Aboriginal groups was examined using Fisher's Exact Test.
  - c. The effect of the age of the child on measures of grief, trauma and social support was examined. The correlation between the age of the child at death and all measures was determined using Pearson's Product Moment Correlation Coefficient. The sample was divided into two groups by age of the child and mean scores were compared using *t* tests. Mean scores for each age range in

injury and non-injury groups were compared observationally. The sample was then divided into three age groups and injury and non-injury groups were compared using a child age and injury death interaction regression model and a two-way analysis of variance.

- d. The pattern of services used by parents was examined and, using the Chi square test, compared to the pattern of a normative group dealing with stress and anxiety. The proportion of injury and non-injury bereaved parents using each service type was also compared.

#### Statistical Significance

The usefulness of any data analysis for generalization is dependent on the degree of probability that the findings have occurred as a result of chance. Therefore the statistical significance level used in a study deserves consideration.

The probability of Type I error is partly controlled by the researcher's choice of the level of significance. The level of significance for a hypothesis test is predetermined on the basis of which type of error is more costly or damaging and, therefore, riskier (Levin & Fox, 2000).

In this study, the consequence of a Type II error was considered more harmful than a Type I error. That is, if some parents experienced traumatic stress and it was not recognized (Type II), the negative implications for practice and further research were greater than the cost of concluding parents had symptoms of traumatic stress when they in reality did not (Type I). There was more benefit to increasing the possibility of

research into findings that were tenuous, than to prematurely concluding parents did not experience posttraumatic stress.

As the probabilities of Type I and Type II error are inversely related, choosing a greater likelihood of Type I error or  $\alpha$  (alpha) reduces the probability of a Type II error or  $\beta$  (beta). In social research it has become customary to use a modest level of significance, usually  $\alpha = .05$  (Levin & Fox, 2000). Although  $\alpha = .05$  is customary, in order to increase statistical power as discussed below, a significance level of  $\alpha = 0.1$  was used.

#### Statistical Power

Statistical power is determined by calculation. Effect size<sup>9</sup> was calculated using the formula:

$$ES = \frac{(\text{exposure group mean}) - (\text{comparison group mean})}{\text{comparison group standard deviation.}}$$

Once an effect size is known, a statistical power analysis determines the probability of committing a Type II error. The probability of Type II error or  $\beta$  when subtracted from 1 is called power ( $1 - \beta$ ). Using statistical power analysis, the researcher can determine a sample size that will provide a selected  $\beta$  level. Alternatively, knowing a sample size and significance level allows the researcher to consult tables that provide a power level that corresponds to the known variables (Rubin & Babbie, 1997). The goal in this study was to collect data from 20 parents bereaved by injury within an 18-month period following the child death. This was doubled with a comparison group. The actual sample used for quantitative analysis consisted of 23 parents bereaved by the injury death of a child (injury group) and 17 parents bereaved by the non-injury death of a child (non-



injury group) for a total sample of 40 parents. With a sample of forty, assuming a medium effect size,<sup>10</sup> the statistical power would be .48 at .05 significance and .60 at .10 significance (Rubin & Babbie, 1997). In order to achieve the recommended maximum of .2 probability of Type II error, the power would have to be .80. (For that power, the sample size would need to be 90 at .05 and 70 at .10.) In results of one-tailed tests, the power figures at the .10 level approximate the power of two-tailed tests at the .05 level (Rubin & Babbie, 1997). Because the hypothesis allowed for a one-tailed test, a sample of forty with medium effect size ( $r = .30$ ) and .10 significance (equivalent to .05 significance in two-tailed tests) would have a power of .60. However, by increasing to  $\alpha = .10$  for one-tailed tests, a group of 40 would achieve a power of .80 when the effect size approaches .50 (Cohen, 1988, p.32). Cohen considers .5 a medium effect size, that is, one that is large enough to be visible to the naked eye. Rubin and Babbie (1997) describe .5 as a large effect size for social research. Therefore, in this study, the standard for statistical power was only met when the findings approached an effect size of .50.

Significant increases to the sample size were not possible within the scope of this research project. To modestly increase the pool of possible subjects, the age of decedent was eliminated as a criterion for inclusion. Instead, next-of-kin status was used. Continuing data collection over an extended time period successfully broadened the population of potential respondents without the confounding effect of extending the sample to include parents more than 2 years post death event.

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<sup>9</sup> The calculation of effect size in sets of frequencies or proportions requires an alternate formula that is outlined in Cohen (1988) p. 216.

<sup>10</sup> Medium effect size is considered typical of social work research outcomes (Rubin & Babbie, 1997).

Other researchers have argued for the conventional wisdom of targeting a ratio of 10 subjects to each predictor variable (Gamino, Sewell & Easterling, 1998). This study met that requirement.

## CHAPTER 4

### DATA ANALYSIS

The data analysis consisted of both qualitative and quantitative components. The following includes a description of sampling and preparation of the data set prior to analysis as well as an assessment of missing responses, the internal consistency of the instruments used and the equivalence of the exposure and comparison groups. It describes the quantitative analysis addressing each of the stated hypotheses. Also outlined are the results of exploratory analyses conducted to examine the effects of bereavement duration, of education, of Aboriginal ethnicity and of the age of the child at death on measures of grief, trauma and social support. Statistical analyses were undertaken with the Statistical Package for the Social Sciences (SPSS 11.0). Finally, a qualitative analysis is presented exploring elements of services parents found helpful in bereavement and comparing responses of exposure and control groups.

#### Sampling

The sample was drawn between October 2001 and April 2003. Contact with potential participants was initiated in one of the following ways. Information on the study was presented at a Sharing Meeting of the bereaved parent self-help group, The Compassionate Friends (TCF) Winnipeg, and interested parents invited to volunteer. A notice and invitation to participate was included in a 2002 issue of The Compassionate Friends Winnipeg Newsletter (Appendix B). A similar notice was posted at the 2002 National TCF Conference in Salt Lake City, Utah. In addition, letters were sent to Winnipeg and rural Manitoba parents who were more than 6 months and not more than

24 months post child death (Appendix C). Parent names were obtained from obituaries printed in the Winnipeg Free Press. Addresses and phone numbers were attached to those names, where possible, by searching Winnipeg, and Manitoba telephone directories and the Henderson Directory. The letter sent to parents outlined the purpose of the study and invited their participation. It included two options for declining to participate. Parents could return the enclosed postcard or leave a telephone message indicating their preference for no further contact. Personal letters were the most efficient method of contacting parents. Of 75 actual connections with parents by follow-up telephone call and/or letter, 40 or 53.3% resulted in a completed interview. Responses to the request to participate are summarized in Appendix H. Information was gathered from 43 participants. Questionnaires and structured interviews were completed in person with 40 respondents. Three respondents completed questionnaires at home and forwarded them by mail. One of these participants was personally interviewed. The two remaining structured interviews were conducted by telephone.

The database initially consisted of 43 cases. Files were inspected for errors and cleaned. One case was removed because it did not meet the injury or non-injury death criterion. In that instance, death was a result of a previously undiagnosed internal condition. Two cases were removed from the quantitative analysis because data inspection revealed that more than 5% of their responses were missing (Case 1 = 9 of 155 or 5.8% missing, Case 2 = 20 of 155 or 12.9% missing). The remaining 40 cases (23 injury and 17 non-injury) comprised the data set for analysis.

A description of the sample is outlined in Table 3. The participants were parents, both fathers and mothers, ranging in age from 30 to 62 years. Their education, income,

Table 3

## Description of Sample (N = 40)

Variable		Descriptor	Frequency	Percent
Characteristics of Parent Interviewee	Gender	Male	9	22.5
		Female	31	77.5
	Age in years at child death N = 39	Minimum 30	Mean 47.21	SD 8.25
		Maximum 62		
	Residence location	Urban Winnipeg	25	62.5
		Town or rural Manitoba	14	35.0
		Other <sup>11</sup>	1	2.5
	Marital status at death	Married	29	72.5
		Common-law	3	7.5
		Divorced	3	7.5
		Separated	1	2.5
		Widowed	1	2.5
		Single	2	5.0
		Missing	1	2.5
	Parent Educational Attainment	Incomplete elementary	2	5.0
		Junior high school	2	5.0
		High school	18	45.0
		Post-Secondary	3	7.5
		University diploma	7	17.5
		Bachelor Degree	5	12.5
Household income by rank N = 38	Minimum - \$6,000	Median \$50,000 - \$ 54,999		
	Maximum \$100,000+			
Aboriginal Ethnicity	Non-Aboriginal	33	82.5	
	North American Indian	2	5.0	
	Metis	4	10.0	
	Missing	1	2.5	
Importance of religion or spirituality	Very important	13	32.5	
	Moderately important	13	32.5	
	Somewhat important	11	27.5	
	Unimportant	3	7.5	
Regular religious involvement	Yes	14	35.0	
	No	26	65.0	
Physical health prior to death	Excellent	8	20.0	
	Good	25	62.5	
	Fair	6	15.0	
	Poor	1	2.5	
Mental health treatment prior to death	Yes	4	10.0	
	No	36	90.0	
Depression treatment prior to death	Yes	3	7.5	
	No	37	92.5	
Mental health treatment at time of death	Yes	2	5.0	
	No	38	95.0	

<sup>11</sup> One respondent was from a rural location in the United States.

Variable		Descriptor	Frequency	Percent
Characteristics of Deceased Child	Gender of deceased child	Male	23	57.5
		Female	17	42.5
	Child age at death in years N = 40	Minimum 0	Mean	SD
		Maximum 35	18.63	9.14
Child's living arrangement	Living with parents	16	40.0	
	Independent	14	35.0	
	Institution or group home	3	7.5	
	Long-term hospitalization	7	17.5	
Characteristics of Death	Cause of death	External or injury death	23	57.5
		Internal or non-injury death	17	42.5
	Suicide death	Yes	6	15.0
		No	34	85.0
	Death anticipated one month	Yes	8	20.0
		No	32	80.0
	Death anticipated one week	Yes	10	25.0
		No	29	72.5
Missing		1	2.5	
Death anticipated one day	Yes	15	37.5	
	No	25	62.5	
Preventability as rated by parent	Preventable	20	50.0	
	Not preventable	18	45.0	
	Unsure	1	2.5	
	Refused	1	2.5	
Legal action taken as a result of child death	Yes	4	10.0	
	No	36	90.0	
Sequelae to Death	Time since death in months N = 40	Minimum 7	Mean	SD
		Maximum 24	16.50	4.40
	Parent's current living arrangement	Married	28	70.0
		Common-law	4	10.0
		Divorced	2	5.0
		Separated	3	7.5
		Widowed	2	5.0
		Refused	1	2.5
	Compare health now to health prior to death	Improved	4	10.0
		About the same	19	47.5
Not as well		16	40.0	
Much worse		1	2.5	
Added a child subsequent to the death	Added child	4	10.0	
	No added child	36	90.0	
Coping- used professional services	Yes	26	65.0	
	No	14	35.0	
Coping - used reading	Yes	28	70.0	
	No	12	30.0	
Coping - attended a group	Yes	10	25.0	
	No	30	75.0	

residence, health, ethnicity and religiosity are described. Parents provided information on their deceased child's gender, age, and living arrangement prior to death. Information

was gathered on elements related to the death including the cause of death and a measure of the degree to which it was anticipated. The sample consisted of 23 parents of children who died from external causes or injury and 17 parents of children who died from internal causes or non-injury. Parents were asked whether they judged the death to have been preventable and whether legal action ensued as a result of circumstances of the death. The description of sequelae to the death included the length of bereavement, the parent's post-death living arrangements, health and coping strategies. The most common participant was a married, middle-aged, middle-class Winnipeg woman with some post-secondary education who valued religion and was in good health. However, the range of participants was broad across age, education, income, residence location, ethnicity, and religiosity. Although most lived in Winnipeg, participants included parents from a variety of Manitoba communities. Their experiences with death included suicide, murder, car crashes, freak accidents, congenital abnormalities and both lingering and quickly fatal diseases. Some children died at home in their own beds with family close by. Others perished alone. Some deaths occurred in other countries. The children who died ranged from infants to adults who left behind children of their own.

### **Preliminary Analysis**

#### Analysis of Missing Data

In an exposure control study, it is important to establish the similarity of the groups in every way except their exposure to the independent variable. To determine the comparability of the groups in this study a number of procedures was undertaken. The initial comparison involved the pattern of missing responses in each group. The demographic characteristics and the occurrence of variables related to the intensity of

traumatic stress and grief responses in each group were then compared. An analysis of the mean number of missing responses per case determined that there were no significant differences between groups (Table J 1). Two items had more than one missing. The income item on the Personal Information Instrument was missing two responses. Item 35 on the HGRC had 21 missing responses. This was the result of recording as "missing" the responses to 21 erroneously worded questionnaires. A Fisher's Exact Test was conducted on the missing income responses per group and yielded an Exact Significance of .499 (2 - sided). For the HGRC item, the  $X^2$  test with Yates' Correction for Continuity value was also not significant ( $X^2 = .000$ ,  $df = 1$  and  $p = 1.000$ ). Therefore, it can be concluded that there was no systematic pattern of differences in missing variables between the injury and non-injury groups in this sample.

To prepare the scale scores for further analysis, those individual scores containing missing items were prorated. The grief dimensions of Detachment, Blame & Anger, and Disorganization as well as the Perception of Social Support- Friends scale contained prorated scores.

To clarify any contaminating effects of the incorrectly worded item that was included in 21 of the HGRC scales, the scores of those who received the corrected (amended) item were compared with those who received the original incorrect (unamended) item. Comparison was made between scores on all instruments administered subsequent to presentation of the erroneous item (Table 4). As previously indicated, an alpha level of 0.10 was used throughout the analysis to reduce the probability of committing Type II errors. Using that alpha level, two dimensions were found to be significantly different for the amended and unamended groups: Despair ( $p =$



.063) and Blame & Anger ( $p = .060$ ). Because the amended item might have been a confounding variable for those dimensions, it was controlled in the analysis of Despair and Blame & Anger.

Table 4

Comparison<sup>12</sup> of Groups With and Without the Amended HGRC Item 35 (N = 40)

Scale Score		N	Mean	SD	t	df	p (2-tailed)
Despair - HGRC	Amended	19	27.84	8.85	-1.91*	36.42	.063
	Unamended	21	34.24	12.16			
Panic Behaviour - HGRC	Amended	19	28.79	10.39	-.900	38	.374
	Unamended	21	32.43	14.58			
Personal Growth - HGRC	Amended	19	39.95	10.28	.517	38	.608
	Unamended	21	38.33	9.46			
Blame & Anger - HGRC**	Amended	19	11.55	4.72	-1.935	38	.060
	Unamended	21	14.93	6.13			
Detachment -HGRC**	Amended	19	14.26	5.526	-1.025	38	.312
	Unamended	21	16.35	7.161			
Disorganization - HGRC**	Amended	19	17.46	7.694	.016	38	.987
	Unamended	1	17.43	6.562			
PSS-Fr**	Amended	19	12.78	4.630	-1.092	38	.282
	Unamended	21	14.19	3.487			
PSS-Fa	Amended	19	14.89	4.760	.519	38	.607
	Unamended	21	14.05	5.482			

\*Equal variances not assumed

\*\*Scores containing missing items were prorated.

<sup>12</sup> Comparison was made of scores determined by instruments used after the introduction of HGRC 35 in the interview process. Because the CAPS was administered entirely before the HGRC, CAPS scores were not compared.

To clarify any potential effects of using both actual and prorated scores in the analysis, the responses to HGRC35 of the 19 participants who received the correctly worded item were treated as missing and scores were prorated. The prorated scores were compared with actual scores using a Pearson Correlation Coefficient. There was a strong correlation between the actual and prorated scores of those who received the correctly worded HGRC 35 item ( $r = .978, n = 19, p = .000$ ). Therefore, it was judged to be acceptable to use the actual scores in further analysis.

#### Internal Consistency of Instruments

The reliability of the instruments for this sample was calculated and compared to that reported in the literature. Weathers and Litz (1994) report the CAPS had strong internal consistency with an alpha coefficient of .94 over all 17 symptoms ( $N = 123$ ). In the current study, the Cronbach's alpha coefficient was .80. Weathers and Litz (1994) reported alpha coefficients ranging from .85 to .87 for the symptom clusters. In this study, the symptoms cluster alpha coefficients were: Reexperiencing  $\alpha = .49$ , Avoidance & Numbing  $\alpha = .75$ , Hyperarousal  $\alpha = .55$ . Each of the Reexperiencing and Hyperarousal clusters consisted of five items. Low Cronbach's alpha values (e.g. .50 or less) are common with short scales (Pallant, 2001). In the report of Procidano and Heller (1983) the PSS-Fr and the PSS-Fa were homogenous measures with Cronbach's alpha of .88 and .90 respectively ( $N = 222$ ). In this sample, the corresponding Cronbach's alpha were .82 and .78. Hogan, Greenfield and Schmidt (2001) found the internal consistency for the total HGRC instrument was .90 ( $N = 586$ ). In the current study, the instrument demonstrated a Cronbach's alpha of .96. Comparison of the internal consistency reported by Hogan et al

(2001) on the six dimensions of the instrument and that found in the current study is outlined in Table 5. Alphas determined for instruments for this sample are adequate with the exception of two of the symptom clusters of the CAPS instrument.

The Pearson correlation of all measures is shown in Table 6. The correlations between the dimensions of the HGRC are generally medium to large and most were significant in this sample. The exception to this was the Personal Growth dimension. Correlations to Personal Growth tended to be small to medium in strength. In that instance the only significant relationships were negative correlations between Personal

Table 5

Internal Consistency of the Dimensions of the Hogan Grief Reaction Checklist

Dimension	As Reported	Current Study
Despair	.89	.90
Panic Behaviour	.90	.92
Personal Growth	.82	.86
Blame and Anger	.79	.86
Detachment	.87	.87
Disorganization	.84	.91

Growth and Detachment ( $r = -.422, p < .01$ ) and Personal Growth and Blame & Anger ( $r = -.391, p < .05$ ). All the Personal Growth correlations were in the expected negative direction. Correlations between CAPS symptom cluster scores were significant ( $p < 0.10$ ) and medium to large with the exception of the relationship between Reexperiencing and Avoidance & Numbing where the correlation was small ( $r = .286$ ). The correlations between the HGRC measures and the CAPS measures were also generally significant and

Table 6

Pearson Correlations of All Measures

Measure		1	2	3	4	5	6
1. HGRC - Despair	Pearson Correlation	1	.648**	-.234	.702**	.696**	.508**
	Sig. (2-tailed)	.	.000	.145	.000	.000	.001
2. HGRC - Panic Behaviour	Pearson Correlation	.648**	1	-.271*	.735**	.403**	.588**
	Sig. (2-tailed)	.000	.	.091	.000	.010	.000
3. HGRC - Personal Growth	Pearson Correlation	-.235	-.271*	1	-.422**	-.391**	-.210
	Sig. (2-tailed)	.145	.091	.	.007	.013	.193
4. HGRC - Detachment	Pearson Correlation	.702**	.735**	-.422**	1	.569**	.724**
	Sig. (2-tailed)	.000	.000	.007	.	.000	.000
5. HGRC - Blame & Anger	Pearson Correlation	.696**	.403**	-.391**	.569**	1	.311*
	Sig. (2-tailed)	.000	.010	.013	.000	.	.051
6. HGRC - Disorganization	Pearson Correlation	.508**	.588**	-.210	.724**	.311*	1
	Sig. (2-tailed)	.001	.000	.193	.000	.051	.
7. CAPS - Reexperiencing	Pearson Correlation	-.065	.076	-.059	.108	.265*	-.040
	Sig. (2-tailed)	.692	.642	.717	.506	.099	.808
8. CAPS - Avoidance/Numb.	Pearson Correlation	.417**	.482**	-.229	.573**	.393**	.366**
	Sig. (2-tailed)	.007	.002	.154	.000	.012	.020
9. CAPS - Hyperarousal	Pearson Correlation	.265	.465**	-.306*	.574**	.312**	.544**
	Sig. (2-tailed)	.099	.003	.055	.000	.050	.000
10. CAPS - Total Severity	Pearson Correlation	.303*	.457**	-.256	.557**	.416**	.384**
	Sig. (2-tailed)	.058	.003	.111	.000	.008	.014
11. PSS - Family	Pearson Correlation	-.256	-.050	.174	-.081	-.055	-.020
	Sig. (2-tailed)	.111	.761	.284	.619	.734	.901
12. PSS - Friends	Pearson Correlation	-.139	-.270*	.190	-.128	.010	-.131
	Sig. (2-tailed)	.391	.092	.241	.431	.952	.419

\*\* p = .05

\* p = .10

Table 4

## Pearson Correlation all Measures (cont'd)

Measure		7	8	9	10	11	12
1. HGRC - Despair	Pearson Correlation	-.065	.417**	.265*	.303*	-.256	-.139
	Sig. (2-tailed)	.692	.007	.099	.058	.111	.391
2. HGRC - Panic Behaviour	Pearson Correlation	.076	.482**	.465**	.457**	-.050	-.270*
	Sig. (2-tailed)	.642	.002	.003	.003	.761	.092
3. HGRC - Personal Growth	Pearson Correlation	-.059	-.229	-.306*	-.256	.174	.190
	Sig. (2-tailed)	.717	.154	.055	.111	.284	.241
4. HGRC - Detachment	Pearson Correlation	.108	.573**	.574**	.557**	-.081	-.128
	Sig. (2-tailed)	.506	.000	.000	.000	.619	.431
5. HGRC - Blame & Anger	Pearson Correlation	.265*	.393**	.312**	.416**	-.055	.010
	Sig. (2-tailed)	.099	.012	.050	.008	.734	.952
6. HGRC - Disorganization	Pearson Correlation	-.040	.366**	.544**	.384**	-.020	-.131
	Sig. (2-tailed)	.808	.020	.000	.014	.901	.419
7. CAPS - Reexperiencing	Pearson Correlation	1	.431**	.286*	.671**	-.020	.123
	Sig. (2-tailed)	.	.005	.073	.000	.900	.449
8. CAPS - Avoidance/Numb.	Pearson Correlation	.431**	1	.593**	.905**	-.273*	-.1511
	Sig. (2-tailed)	.005	.	.000	.000	.088	.353
9. CAPS - Hyperarousal	Pearson Correlation	.286*	.593**	1	.781**	-.045	-.025
	Sig. (2-tailed)	.073	.000	.	.000	.783	.878
10. CAPS - Total Severity	Pearson Correlation	.671**	.905**	.781**	1	-.173	-.051
	Sig. (2-tailed)	.000	.000	.000	.	.287	.755
11. PSS - Family	Pearson Correlation	-.020	-.273*	-.045	-.173	1	.537**
	Sig. (2-tailed)	.900	.088	.783	.287	.	.000
12. PSS - Friends	Pearson Correlation	.123	-.151	-.051	-.025	.537**	1
	Sig. (2-tailed)	.449	.353	.878	.755	.000	.

\*\* p = .05

\* p = .10

medium to large. The notable exception was the Reexperiencing cluster of CAPS where the correlations to HGRC dimensions were not significant. There was a large correlation between the Friends and Family measures of social support. However, there were only two significant correlations between social support and other measures, a small negative correlation between perceived support from friends and Panic Behaviour ( $r = -.270$ ,  $p < 0.10$ ) and a small negative correlation between family support and Avoidance & Numbing ( $r = -.273$ ,  $p < 0.10$ ).

### Equivalence of Groups

The demographic characteristics of groups were compared (Table J 2). The groups were also compared for variables noted in the literature to have an effect on grief or trauma. Non-parametric tests were used for nominal and ordinal data comparison and t-tests were conducted on interval data to determine the statistical significance of the differences between groups.

There were several significant differences between the groups on the variables examined. The groups were found to differ significantly on two variables related to grief: the age of the child at death and the addition of a child to the family subsequent to a child death. The mean age in years of the children at death in the injury group ( $M = 21.65$ ,  $SD = 4.74$ ) was significantly older than the non-injury group mean age ( $M = 14.53$ ,  $SD = 11.91$ ,  $t = 2.33$ ,  $p$  (two-tailed) = .030). None of the injury parents (0%) had added a child to the family subsequent to the death while four or 23.5% of the non-injury group had added a child (Exact Sig. = .026). The groups differed on one variable inversely related to grief and trauma: importance of religion. The non-injury group (Mean rank = 25.18, median = 3) ranked religion or spirituality significantly higher than it was ranked by the

injury group [Mean rank = 17.04, median = 2, Mann-Whitney  $U = 116.000$ ,  $Z = -2.279$  Asymp. Sig. = .023 (two-tailed)]. Two other variables were found to be significantly different. The injury group (20 of 23 or 87%) used reading as a method of coping significantly more often than the non-injury group [8 of 17 or 47%, Fisher's Exact Sig. = .013 (two-sided)]. Also, the groups were different in their residence location. In this sample, the proportion of injury parents living in rural Manitoba (12 of 23 or 52% of group) was significantly greater than the proportion of non-injury parents [3 of 17 or 18% of group, Fisher's Exact Sig. = .046 (two-sided)]. As these differences might confound the effects of injury or non-injury death, the influence of child age, the addition of a child, religiosity, urban residence and reading were separately controlled in the analysis of group differences. Standard multiple regression analysis was used to control for the effects of these variables. As expected, the groups differed significantly on the three variables measuring anticipation of the death. Because anticipation is implicit in the injury or non-injury group classification, no attempt was made to control for its effects. In fact, this difference serves to validate the classification.

### **Primary Analysis**

The primary analysis included a quantitative comparison of the trauma and grief symptoms and the perception of social support of parents in injury and non-injury groups. It included an exploratory assessment of the effects of the duration of bereavement, of Aboriginal ethnicity and of education on trauma, grief and perceived social support. Further exploratory analysis was conducted to examine the effects of the age of the child

at death. The qualitative component of the primary analysis examined parents' service needs and compared the needs of parents in each group.

### Quantitative Analysis

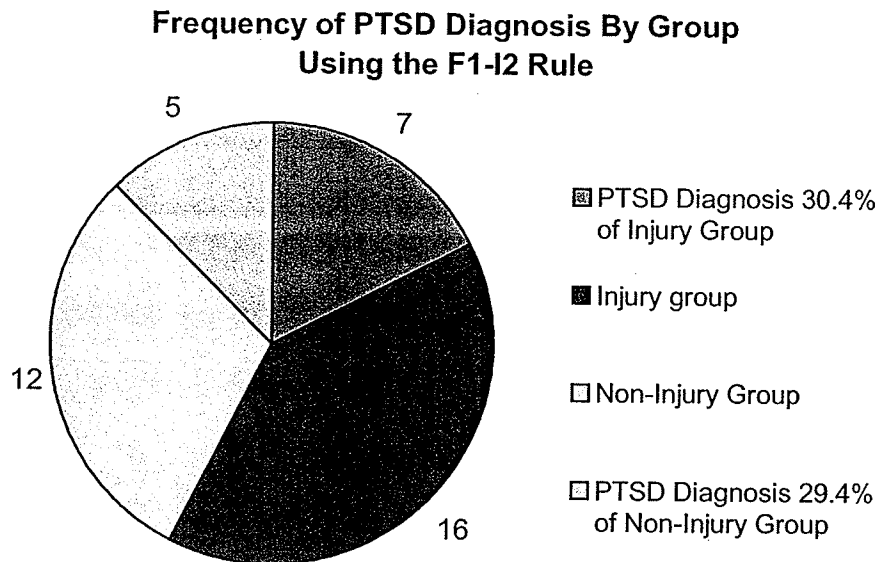
#### Comparison of Traumatic Stress

The initial hypothesis stated that parents bereaved by the injury death of a child for whom they are the next-of-kin would report more symptoms of posttraumatic stress than parents bereaved by non-injury child deaths. To test this hypothesis, posttraumatic stress in the injury and non-injury groups was compared using both dichotomous diagnosis scores and continuous total severity scores.

The dichotomous scores for the occurrence of PTSD in each group were compared using a two-way chi-square. Two rationally derived scoring rules were used: (a) the F1-I2 rule where a frequency =1 + intensity =2 constitutes presence of a symptom; (b) Severity =4 rule where a sum of frequency and intensity that is equal to or greater than 4 constitutes a symptom.

Using the F1-I2 rule, PTSD diagnosis criteria were met by 7 parents or 30.4% of the injury group and 5 parents or 29.4% of the non-injury group. As shown in Figure 1 this comprised respectively 18% and 13% of the entire sample. The Fisher's Exact Test demonstrated no significant difference in PTSD diagnosis between exposure and comparison groups,  $p = .612$  (one-sided). Using the Severity = 4 rule, 4 parents or 17.4% of the injury group and 2 parents or 11.8% of the non-injury group met diagnostic criteria. The Fisher's Exact Test for this scoring rule indicated that the difference between groups was again not significant,  $p = .489$  (one-sided).





**Figure 1.** Frequency of PTSD diagnosis in injury and non-injury groups using the F1-I2 diagnostic rule.

Because the groups were significantly different on some variables known to effect PTSD, it was necessary to evaluate the effects of those independent variables on the differences between groups. To control for the effects of the group differences unrelated to the circumstances of the death, logistic regression analyses were conducted. The dependent variables were the PTSD dichotomous scores derived using either the F1-I2 or the =4 scoring rule. Control variables were each of the variables unrelated to death that were found to be significantly different between the groups. Because of the small sample size, separate regression equations were calculated for each potentially confounding independent variable. Results are summarized in Tables J 3 and J 4. The differences between groups remained insignificant for the F1-I2 rule analysis. The small number of

parents diagnosed using the Severity =4 rule created additional difficulties in controlling for the effects of the five variables unrelated to death on which the groups differed. To control for religiosity, it was necessary to create a separate model for each individual category of response. When controlling for the "added child" variable, non-injury death became a significant predictor of PTSD diagnosis. However, the Wald parameter was high and a more detailed analysis of the test variable revealed that all four parents who were positive on the added child variable were in the Non-injury group. Two were positive for PTSD diagnosis and they constituted the total number of non-injury parents diagnosed. This distribution produced too many empty cells in the model to draw a reliable conclusion based on the results. It was not possible in this instance to use logistic regression to accurately remove the effects of an added child on the diagnosis of PTSD using the Severity =4 rule. Therefore, there was no statistically significant evidence of a difference between Injury and Non-injury groups in the frequency of diagnosis of PTSD using the Severity =4 rule.

The continuous (Total Severity) scores of each group were compared using an independent samples t-test. Total Severity scores represent the sum of frequency plus intensity scores for each item. The Total Severity score from the highest measure (current or lifetime) recorded for each individual was used for analysis. One of the advantages of the CAPS is that it provides a measure of symptoms in two time frames either "the one-month period preceding the interview (Current Diagnosis) or the most symptomatic one-month period following the traumatic event(s) (Lifetime Diagnosis)" (Blake, Weathers, Nagy, Kaloupek, Klauminzer, Charney & Keane, 1990, p. 2). This serves to reduce the difficulty of interviewing parents at varying lengths of time post

child death. As each of these time frames meets the requirements of the hypothesis being investigated, they have been combined here for analysis.

The independent samples t-test indicated no significant difference in mean Total Severity scores between the injury group ( $M = 26.70$ ,  $SD = 19.88$ ) and the non-injury group [ $M = 25.18$ ,  $SD = 14.84$ ,  $t = .265$ ,  $df = 38$ ,  $p = .397$  (1-tailed)]. (Summarized in Table 7). The magnitude of the differences in the means was very small (eta squared = .002). Further comparison of the scores for each symptom cluster of PTSD showed differences between the groups were similarly insignificant. On observation, the greatest difference in the scores of the injury (exposure) group and non-injury (comparison) group was in hyperarousal scores. It should be noted that the difference in re-experiencing scores was in the opposite direction to that predicted.

Table 7

Between Groups Comparison of Mean Scores: CAPS Total Severity and PTSD Symptom Cluster Scores

Dimension		Mean	SD	t (df =38)	p (one-tailed)
Total Severity (PTSD)*	Injury	26.70	1.88	.265	.397
	Non-injury	25.18	14.84		
Re-experiencing (PTSD)*	Injury	5.57	4.97	-.063	.275
	Non-injury	6.71	7.01		
Avoidance & Numbing * (PTSD)	Injury	11.09	11.32	.121	.452
	Non-injury	10.71	7.31		
Hyperarousal (PTSD)*	Injury	10.04	6.88	1.12	.136
	Non-injury	7.76	5.61		

\* equal variances assumed

Because the groups were significantly different on some variables known to effect PTSD, it was necessary to evaluate the effects of those independent variables on the

differences between groups. To control for the effects of the group differences unrelated to the circumstances of the death, standard multiple regression analyses of the PTSD Total Severity and dimension scores as the dependent variables and each of the unrelated differences as control variables were performed. Because of the small sample size, separate regression equations were calculated for each potentially confounding independent variable. Results are summarized in Tables J 5 - J 8.

When controlling for child age, injury death became a significant predictor of PTSD symptoms [ $B = 7.891$ ,  $SE B = 5.713$ ,  $t = 1.381$ ,  $p = .088$  (one-tailed)] in general and of Hyperarousal symptoms in particular [ $B = 3.922$ ,  $SE B = 2.136$ ,  $t = 1.8336$ ,  $p = .037$  (one-tailed)]. Analysis of the covariance of injury death and child age produced adjusted means for CAPS Total Severity scores (injury  $M = 29.40$ , Std. Error = 3.56, non-injury  $M = 21.51$ , Std. Error = 4.19). The Effect Size calculation using the adjusted means indicated a medium Effect Size ( $ES = .467$ ) where injury death explained about 6% of the variance in the CAPS total severity scores. Further analysis of the covariance of injury death and child age produced adjusted means for Hyperarousal severity scores (injury  $M = 10.74$ , Std. Error = 1.330, non-injury  $M = 6.82$ , Std. Error = 1.57). The corresponding Effect Size ( $ES = .606$ ) indicated that approximately 8% of the variance in CAPS Hyperarousal scores was explained by injury death.<sup>13</sup> Hyperarousal scores are included in Total Severity scores and a high correlation between these scores has been noted in Table 8 (Pearson's  $r = .781$ ,  $p = .000$ ). Therefore these results should not be viewed as independent findings. For all other control variables there was no significant difference in the severity of PTSD symptoms between groups.

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<sup>13</sup> Cohen's (1977) guidelines have been used to describe the strength of ES and the corresponding percentage of variation in the dependent variable.

In summary, parents of children who died from an injury appeared to experience more intense symptoms of posttraumatic stress than parents of children who died from internal causes. In this sample the difference in continuous scores became statistically significant when the effects of the age of the child were controlled. Therefore, the null hypothesis can be cautiously rejected. In a larger sample the differences between groups might be more obvious. It is important to note here that almost one-in-three parents who experienced the non-injury death of a child also reported traumatic stress symptoms at the PTSD diagnostic level. This indicates that symptoms of traumatic stress are also characteristic of non-injury bereavement.

#### Comparison of Grief

The second hypothesis stated that parents bereaved by the injury death of a child for whom they were the next-of-kin would score higher on a measure of grief intensity than parents bereaved by a non-injury child death. To test this hypothesis, the mean grief scores on each dimension of the HGRC for each group were compared using independent samples t-tests. No significant differences were found between the groups (Table 8.)

Using a standard multiple regression, each of the variables found to be significantly different between the injury and non-injury groups was controlled in a separate model. See Table J 9 through Table J 14 for a summary of the results. Controlling for each of these variables revealed only one significant difference between the injury and non-injury groups on one grief dimension. Removing the effects of adding a child to the family subsequent to bereavement resulted in a significant difference in Panic Behaviour between the injury and non-injury groups ( $B = -6.033$ ,  $SE B = 4.391$ ,  $t = -1.374$ ,  $p = .089$  one-tailed) with the non-injury group experiencing more Panic

Table 8

Between Groups Comparison of Mean Scores: HGRC Dimensions of Grief

Dimension		Mean	SD	t (df =38)	p (one-tailed)
HGRC - Despair*	Injury	31.26	12.12	.040	.968
	Non-injury	31.12	9.82		
HGRC -Panic Behaviour*	Injury	29.04	12.96	-.956	.345
	Non-Injury	32.94	9.82		
HGRC - Personal Growth*	Injury	39.74	10.66	.477	.636
	Non-Injury	38.24	8.64		
HGRC - Detachment*	Injury	15.80	7.13	.491	.626
	Non-Injury	14.77	5.54		
HGRC - Blame & Anger*	Injury	13.76	6.59	.558	.580
	Non-Injury	12.74	4.34		
HGRC - Disorganization *	Injury	17.73	6.43	.296	.769
	Non-Injury	17.06	7.96		

\*equal variances assumed

Behaviour than the injury group. This finding is in the opposite direction to the hypothesis. An analysis of covariance of injury death and the addition of a child produced adjusted means for the injury ( $M = 28.14$ , Std. Error = 2.74) and the non-injury groups ( $M = 34.17$ , Std. Error = 3.22). The adjusted means were used to calculate the effect size ( $ES = .53$ ). This finding suggests that injury death has a moderate negative effect on Panic Behaviour, that is, parents who experience the injury death of child develop less intense symptoms of panic behaviour than do parents who experience the non-injury death of a child. There are some difficulties in interpreting this result. First, the number of cases with added children was small (4 of 40 cases). Second, all the parents who had added a child to their family subsequent to the death of a child were in the Non-injury group. The low occurrence and skewed distribution of this variable within the sample may have compromised the validity of the result. However, replication

in a larger sample would suggest that panic behaviour is more closely related to non-injury death than injury death.

In summation, the null hypothesis cannot be rejected. There was in this sample no significant evidence of greater grief intensity, as measured by the Hogan Grief Reaction Checklist, in parents bereaved by injury death than in parents bereaved by non-injury death. The grief experience of bereaved parents was similar regardless of cause of death. The only possible exception was in Panic Behaviour which, in this sample, was found to be greater in non-injury bereaved parents.

#### Correlation of Perceived Social Support to Grief

The third hypothesis to be investigated stated that bereaved parents' perception of social support would be negatively correlated with the intensity of grief. The distribution of Perceived Social Support scores for both Family and Friends proved to be negatively skewed indicating a cluster of scores at the high end of the scale (PSS-Fr Skewness =  $-.408$ , PSS-Fa Skewness =  $-.746$ ). Kurtosis values were also negative indicating a relatively flat distribution (PSS-Fr Kurtosis =  $-.916$ , PSS-Fa Kurtosis =  $-.412$ ). The Kolmogorov-Smirnov test for the normality of results was significant for both the PSS-Fr and PSS-Fa scales indicating a violation of the assumption of normality (PSS-Fr  $p = .019$ ; PSS-Fa  $p = .052$ ). In view of difficulties with normality in distribution, non-parametric tests were included in the analysis of social support.

The relationship between perceived social support (as measured by the PSS-Fr and PSS-Fa) and grief (as measured by the dimensions of the HGRC) was investigated using Pearson product moment correlation coefficients. All the correlations of PSS-Fa to grief were in the expected direction. The small negative correlation of PSS-Fa to Despair

was significant at the  $p < .10$  level (one-tailed) indicating that higher levels of perceived support from family were associated with lower levels of despair. There was also a small<sup>14</sup> negative correlation between PSS-Fr and Panic Behaviour,  $p < .05$  (one-tailed) with higher levels of perceived support from friends associated with lower levels of panic behaviour (Table 9). None of the other variables examined had a statistically significant relationship with perceived social support.

Table 9

Pearson's Correlation of Measures of Perception of Social Support to Measures of Grief (N = 40)

		PSS-Fa	PSS-Fr	Despair	Panic Behav.	Personal Growth	Detach.	Blame Anger	Disorg.
PSS-Fa	Pearson Correlation	1	.537**	-.256*	-.050	.174	-.081	-.055	-.020
	Sig. (one-tailed)	.	.000	.055	.381	.142	.309	.367	.451
	N	40	40	40	40	40	40	40	40
PSS-Fr	Pearson Correlation	.537**	1	-.139	-.270*	.190	-.128	.020	-.131
	Sig. (one-tailed)	.000	.	.196	.046	.121	.216	.476	.209
	N	40	40	40	40	40	40	40	40

\*\* Correlation is significant at the .01 level (one-tailed)

\* Correlation is significant at the .10 level (one-tailed)

Because of the size of this sample and difficulty meeting the normality assumption required for parametric tests, these correlations were replicated using the non-parametric alternative, Spearman's Rank Order Correlation (Table 10). Directions and significance were replicated and an additional correlation was found to be significant. There was a significant positive correlation between PSS-Fr and Personal Growth,  $p = .072$  (one-tailed). The Personal Growth dimension is in the opposite direction of the

<sup>14</sup> Cohen's (1988) guidelines have been used to describe the strength of the relationship between variables.



other dimensions. Therefore a positive correlation between perception of social support and personal growth reflects the hypothesis.

Table 10

Spearman's Correlation of Measures of Perceived Social Support to Measures of Grief (N = 40)

Spearman's Rho		PSS-Fa	PSS-Fr	Desp.	Panic Behav.	Pers. Growth	Detach	Blame Anger	Disorg
PSS-Fa	Correlation Coefficient	1.000	.540**	-.213*	-.084	.139	-.028	-.032	-.041
	Sig. (one-tailed)	.	.000	.094	.304	.197	.431	.421	.401
PSS-Fr	Correlation Coefficient	.540**	1.000	-.141	-.235*	.225*	-.109	.052	-.088
	Sig. (one-tailed)	.000	.	.194	.072	.082	.251	.376	.295

\* Correlation is significant at the .10 level (one-tailed)

\*\*Correlation is significant at the .01 level

Both parametric and non-parametric tests indicated some negative correlation between parent's perception of social support and the intensity of symptoms of grief as measured by the Hogan Grief Reaction Checklist. In this sample there appeared to be differences in the correlation of perceived family social support and perceived support from friends with family support correlated to Despair and support from friends correlated to Panic Behaviour and Personal Growth. The correlations that were noted were not large but those that were significant all occurred in the predicted direction. Their presence precludes acceptance of the null hypothesis and makes a modest case for its rejection. In this sample, there was some negative correlation between perception of social support and the intensity of grief symptoms in bereaved parents. Similar results in a larger sample would allow for increased confidence in rejecting the null hypothesis.

### Correlation of Perceived Social Support to Posttraumatic Stress

It was also hypothesized that bereaved parents' perception of social support would be negatively correlated with symptoms of posttraumatic stress. Concerns about the normality of the distribution of social support scores described earlier also apply to these analyses. The relationship between perceived social support (as measured by the PSS-Fr and PSS-Fa) and posttraumatic stress (as measured by the dimensions and Total Severity score of the CAPS) was investigated using Pearson product moment correlation coefficient, Table 11.

Table 11

#### Pearson's Correlation of Measures of Perceived Social Support to Measures of Posttraumatic Stress

		PSS-Fa	PSS-Fr	Reexp	Avoid	Hyper	Total Severity Score
PSS-Fa	Pearson Correlation	1	.537**	-.020	-.273*	-.045	-.173
	Sig. (one-tailed)	.	.000	.450	.044	.391	.143
	N	40	40	40	40	40	40
PSS-Fr	Pearson Correlation	.537**	1	.123	-.151	-.025	-.051
	Sig. (one-tailed)	.000	.	.224	.176	.878	.377
	N	40	40	40	40	40	40

\*\* Correlation is significant at the .01 level (one-tailed)

\* Correlation is significant at the .05 level (one-tailed)

With one exception the relationships between perception of social support and measures of posttraumatic stress were in the predicted direction. The correlations were small or very small. There was a small significant negative relationship between Perception of Social Support - Family and Avoidance and Numbing symptoms [ $r = -.273$ ,  $N = 40$ ,  $p = .044$  (one-tailed)] indicating that as perception of support from family

increased, symptoms of avoidance and numbing decreased. No other relationships were statistically significant.

Because of the size of this sample and difficulty meeting the normality assumption required for parametric tests, these correlations were replicated using the non-parametric alternative, Spearman's Rank Order Correlation, Table 10. In addition to the relationship noted above, this test found a small significant negative correlation between the CAPS total severity score and the perceived social support from family as measured by the PSS-Fa [ $r_s = -.279$ ,  $N = 40$ ,  $p = .041$  (one-tailed)].

Table 12

Spearman's Correlation of Measures of Posttraumatic Stress Symptoms to Measures of Perceived Social Support (Non-Parametric)

Spearman's rho		PSS-Fa	PSS-Fr	Reexp	Avoid	Hyper	Total Severity Score
PSS-Fa	Correlation Coefficient	1.000	.540**	-.128	-.318*	-.128	-.279*
	Sig. (one-tailed)	.	.000	.216	.023	.215	.041
PSS-Fr	Correlation Coefficient	.540**	1.000	.125	-.090	-.017	-.028
	Sig. (one-tailed)	.000	.	.221	.291	.458	.432

\*\* Correlation is significant at the .01 level (one-tailed)

\* Correlation is significant at the .05 level (one-tailed)

Both parametric and non-parametric tests provide evidence of the existence of a negative relationship between perception of social support and symptoms of posttraumatic stress. In this sample, significant correlations were found between the perception of family support and elements of posttraumatic stress. There were no significant correlations between perceived support from friends and posttraumatic stress

symptoms. These results modestly support the hypothesis of a negative correlation between perceived social support and symptoms of posttraumatic stress. They further suggest that in this sample the perceived support of family had a greater relationship to traumatic stress than the perceived support of friends. Similar results in a larger sample would allow stronger endorsement of the hypothesis.

### Exploratory Analyses

Exploratory analyses were conducted to examine the effects of bereavement duration, of education and of Aboriginal ethnicity on measures of grief, trauma and social support. The pattern of service use was also examined.

#### Effects of duration of bereavement.

The effects of the duration of bereavement on grief and trauma scores for the entire sample were assessed using Pearson product moment correlation coefficient (Table J 15). There was a small positive correlation between the number of months since the child death and the Despair dimension of the HGRC [ $r = .28$ ,  $N = 40$ ,  $p = .08$  (two-tailed)] indicating that Despair increased somewhat over time in this sample. There was a medium positive correlation between the number of months since bereavement and scores on the Blame and Anger dimension of the HGRC [ $r = .31$ ,  $N = 40$ ,  $p = .05$  (two-tailed)] with increased elapsed time being associated with a moderate increase in blame and anger. These relationships are shown in scatterplots Figure 2. To examine the nature of the relationship between the passage of time and scores on all measures, the

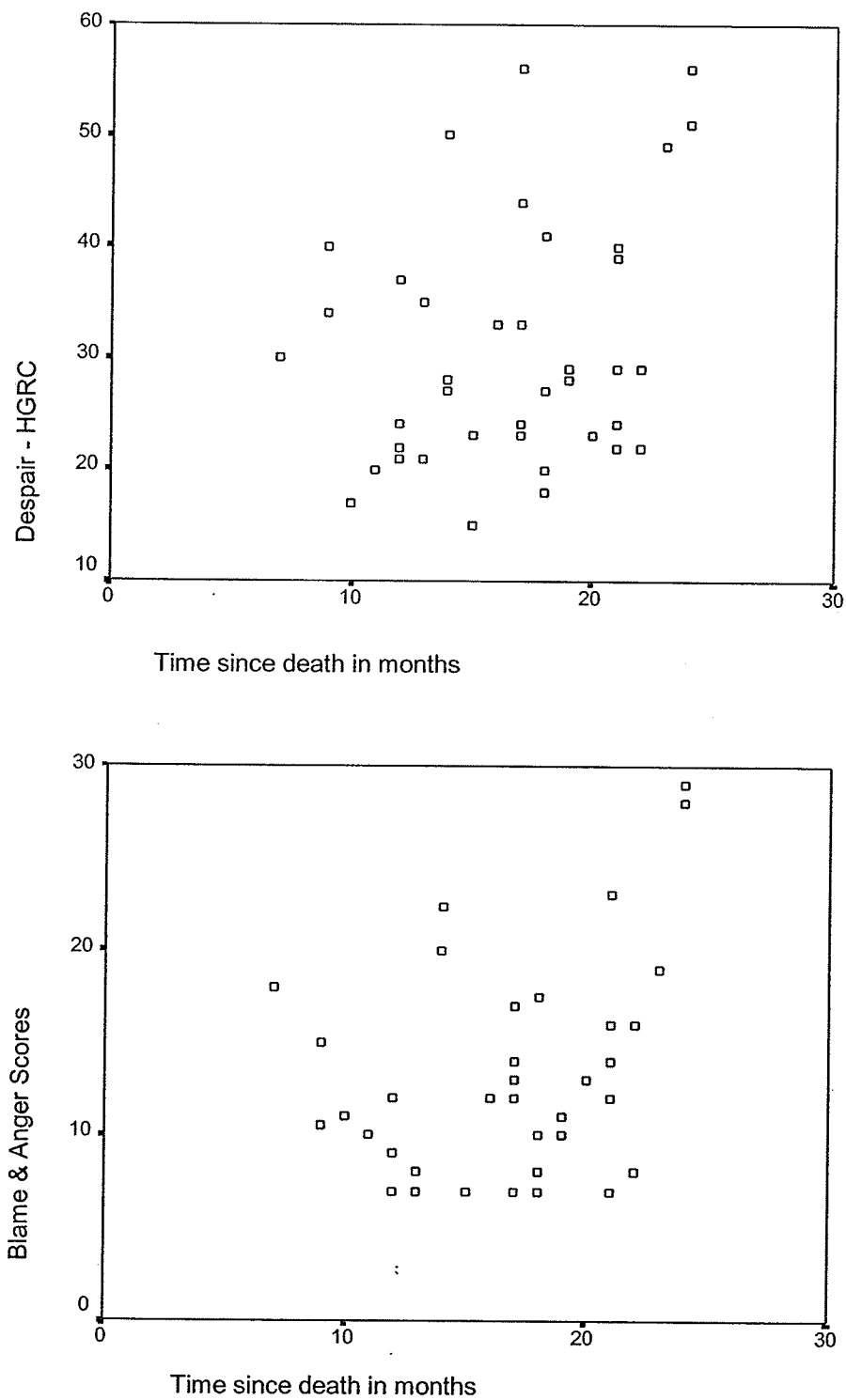
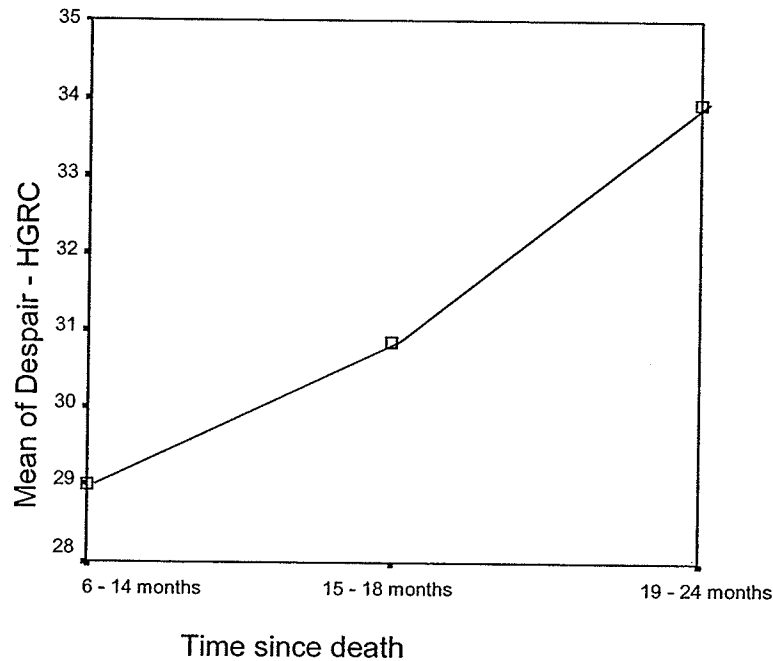


Figure 2. Scatterplots of Despair and Blame & Anger scores (two dimensions of the Hogan Grief Reaction Checklist) over time.

sample was divided into three groups by the number of months post child death (Group 1: 6-14 months post death, Group 2: 15-18 months post death and Group 3: 19-24 months post death). The means of each group on each measure were compared observationally (Table J 16) and plotted. On observation there was no general trend of reduced mean scores over time. On the contrary, with only two exceptions (Disorganization and Hyperarousal) the mean symptom scale scores at 19-24 months post death were higher than the mean scores at 6-14 months post death. Therefore, instead of time ameliorating negative symptoms it tended to exacerbate them in this sample. For Personal Growth, where an increase would be a positive indication of progress over time, the reverse occurred with the mean score at 19-24 months lower than at 6-14 months. The only positive direction was found in the measures of social support where perception of social support appeared to increase over time.

Plotting the means of the three time groups suggested that the nature of the relationship between time and symptomatology might not always be linear. Despair appeared to have a linear relationship with time as demonstrated in Figure 3. The plots of several other measures suggested that the relationship between time and symptoms might be curvilinear rather than linear. Panic Behaviour and Blame & Anger are examples of possibly curvilinear relationships demonstrated by a comparison of means (Fig. 4 & 5). In an effort to clarify the significance of these observations a one-way between-groups analysis of variance was conducted. There were no statistically significant differences at the  $p < .10$  level (J 17). The differences in Blame & Anger scores for the three groups approached significance [ $F(2, 37) = 2.36, p = .108$ ]. The effect size, calculated using eta squared, was small (.01). Post Hoc comparisons of Blame & Anger scores using the

Tukey HSD test indicate the mean score for parents 15-18 months post death ( $M = 11.19$ ,  $SD = 3.83$ ) was significantly different from the mean score of parents 19-24 months post death ( $M = 15.84$ ,  $SD = 7.10$ ,  $p = .093$ ). Parents 6-14 months post death ( $M = 12.96$ ,  $SD = 5.13$ ) did not differ significantly from the other two groups.



**Figure 3.** Plot of HGRC - Despair score means for parents divided into three groups by the number of months since death of child.

The assumption of homogeneity of variance was violated in the analysis of the CAPS Total Severity scores (Levene's test Sig. = .03). Therefore, the Kruskal-Wallis test was used to further analyze the variance in CAPS scores for the three time periods. Results of the Kruskal-Wallis ( $\chi^2 = 1.095$ ,  $df = 2$  and Asymp. Sig. = .578) indicated no significant difference in the intensity of PTSD symptoms in the three time periods. Mean ranks were 22.07, 17.73 and 21.58 respectively.

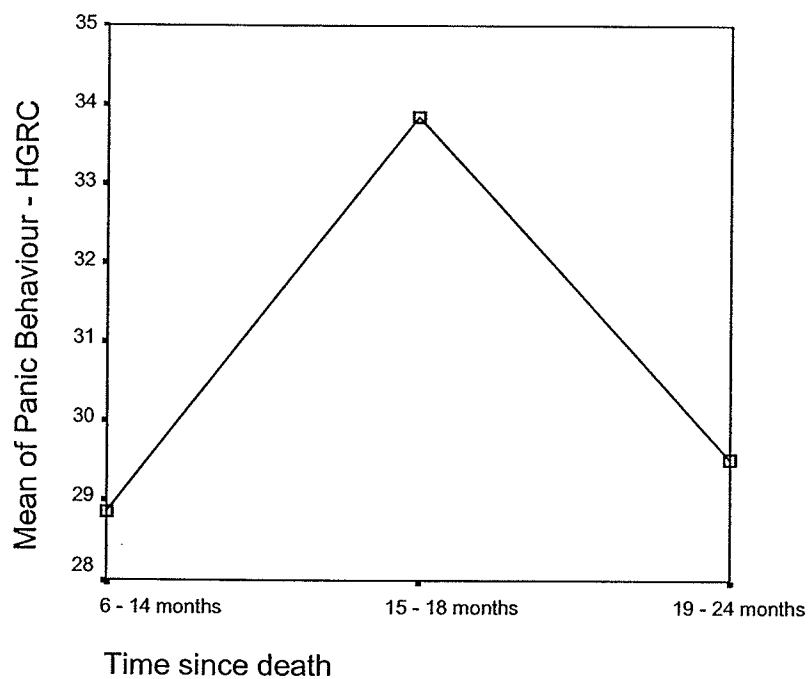


Figure 4. Plot of HGRC - Panic Behaviour mean scores for three groups of parents divided by the number of months since child death

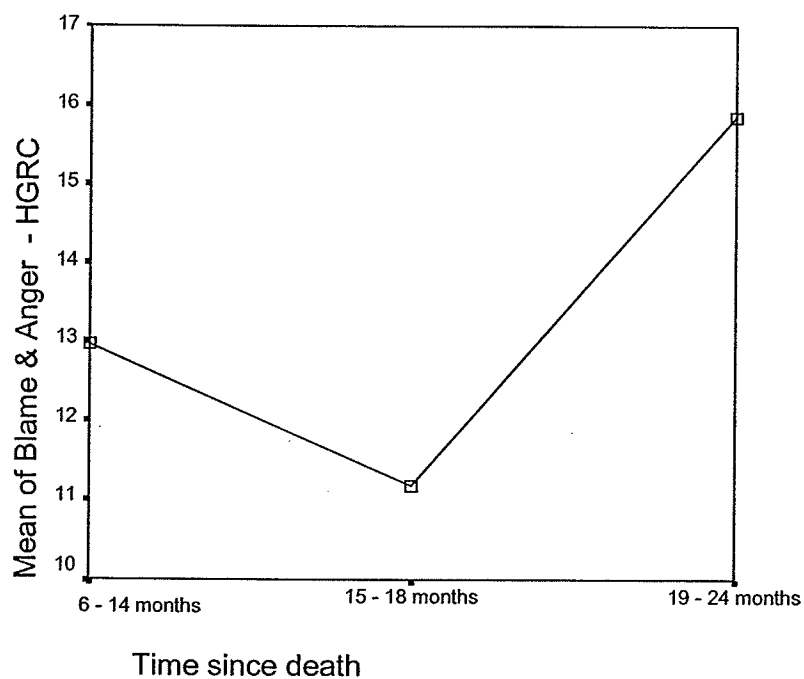


Figure 5. Plot of HGRC - Blame & Anger mean scores for three groups of parents divided according to the number of months since child death.



To explore the relationship between time and the dependent variables in the injury and non-injury groups a standard regression was formulated using a continuous time variable, a dummy group variable and an interaction variable. Separate regressions were calculated for each score (Table J 18). There was a significant interaction when controlling for time and group on the PSS-Fa score indicating that support increased significantly more over time for the non-injury group than the injury group. There were no other significant differences in the interaction of time and symptoms between the injury and non-injury groups.

In summary, time did not appear to lessen symptoms of grief or trauma and there was evidence that symptoms tended to increase over the first two years of bereavement. Although the mean scores of parents grouped by time since death differed observationally, the significance of those differences was not statistically substantiated in this sample. Injury and non-injury groups differed significantly on only one measure with parents bereaved by non-injury deaths reporting an increase in perceived social support from family over time. Given the size of the sample, its non-random nature and its limited statistical power it is not reasonable to apply these findings beyond this group of participants. However, similar findings though insignificant in this small group might be significant in a larger sample. Although inconclusive these findings raise questions about the nature of the relationship between time and symptoms. In a linear relationship one would expect to find the means moving in the same direction and the greatest difference in means occurring between the first time group and the last time group. The findings here cast doubt on measures of grief and trauma being in a linear relationship with the passage of time, at least as can be interpreted over the passage of two years. It

is clear, however, that for these parents the adage that "time heals all wounds" is a myth in the first two years following a child death.

#### Effects of education.

Because literacy levels for the measures used were not established, it was important to consider whether literacy would influence test scores. Although not a true measure of literacy, it was assumed that higher levels of education might increase participant's understanding, familiarity and comfort level in completing the survey instruments and correspondingly influence test scores. Therefore, the degree of association between education and measures of grief, trauma and social support was assessed using Spearman's Rank Order Correlation Coefficients (Table 13). For this correlation, to ensure a more accurate ranking, the categories of University were collapsed into undergraduate and graduate.

A significant negative relationship was found between level of education and the Panic Behaviour dimension of the HGRC where  $r = -.331$ ,  $p < .05$  (two-tailed). In this instance, higher levels of education were associated with lower levels of Panic Behaviour. No other significant relationships were found between education and measures of grief. Therefore the education level of participants did not appear to generally influence test scores.

#### Effects of Aboriginal ethnicity.

The effect of Aboriginal ethnicity was assessed by dividing the total number of respondents into two groups based on Aboriginal or non-Aboriginal ethnicity. In this comparison, the categories of Aboriginal ethnicity (North American Indian  $n = 2$ , Metis  $n = 4$ ) were collapsed (Table 14). On observation, the Aboriginal group mean for

Table 13

Spearman's Correlation of Education to Measures of Grief, Posttraumatic Stress & Social Support (N = 40)

Spearman's rho		Education
PSS-Family	Correlation Coefficient Sig. (2-tailed)	-.023 .888
PSS-Friends	Correlation Coefficient Sig. (2-tailed)	-.065 .690
Total Severity Score CAPS	Correlation Coefficient Sig. (2-tailed)	.016 .923
Despair - HGRC	Correlation Coefficient Sig. (2-tailed)	-.226 .160
Panic Behaviour - HGRC	Correlation Coefficient Sig. (2-tailed)	-.331* .037
Personal Growth -HGRC	Correlation Coefficient Sig. (2-tailed)	.161 .322
Blame & Anger - HGRC	Correlation Coefficient Sig. (2-tailed)	-.121 .456
Detachment -HGRC	Correlation Coefficient Sig. (2-tailed)	-.121 .457
Disorganization - HGRC	Correlation Coefficient Sig. (2-tailed)	-.209 .196

\* Correlation is significant at the .05 level (2-tailed)

intensity of PTSD symptoms appeared much larger than the non-Aboriginal group mean. On all measures of grief, the non-Aboriginal group had higher means than the Aboriginal group with the largest difference on measures of Despair. There was a wide variation within the groups on scores for both PTSD and Despair measures. Although mean scores of perceived support from friends were about equal between groups, there was a notable difference in the perceived support from family. Aboriginal parents reported less family support. The mean scores on measures of grief, trauma and social support were

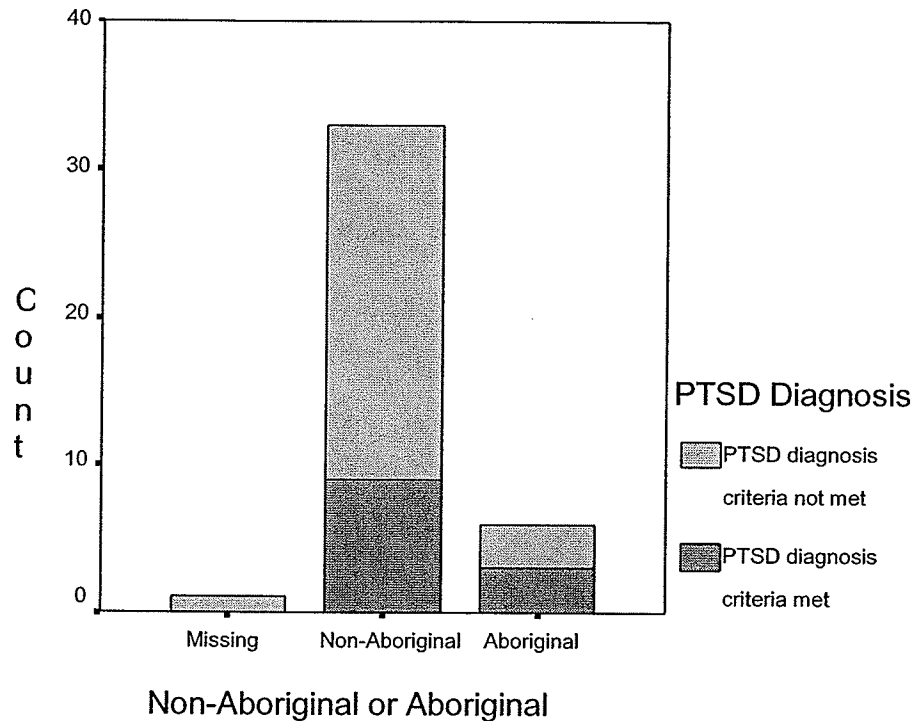
Table 14

Comparison of Aboriginal and Non-Aboriginal groups

Measure	Group	n	Mean	Std. Deviation	t	df	<i>p</i> (2-tailed)
Total Severity Score - CAPS	Non-Aboriginal	33	24.88	18.25	-.913	37	.367
	Aboriginal	6	32.17	16.15			
Disorganization - HGRC	Non-Aboriginal	33	17.36	7.29	.166	37	.869
	Aboriginal	6	16.83	6.05			
Blame & Anger - HGRC	Non-Aboriginal	33	13.67	6.02	.585	37	.562
	Aboriginal	6	12.17	3.97			
Detachment - HGRC	Non-Aboriginal	33	15.45	6.65	.178	37	.860
	Aboriginal	6	14.93	6.34			
Panic Behaviour - HGRC	Non-Aboriginal	33	31.33	13.60	.665	37	.510
	Aboriginal	6	27.50	8.12			
Despair - HGRC	Non-Aboriginal	33	32.39	11.45	1.274	37	.211
	Aboriginal	6	26.17	7.71			
Personal Growth - HGRC	Non-Aboriginal	33	39.21	10.10	.349	37	.729
	Aboriginal	6	37.67	9.09			
PSS-Friends	Non-Aboriginal	33	13.53	4.11	-.011	37	.991
	Aboriginal	6	13.55	4.67			
PSS-Family	Non-Aboriginal	33	14.76	5.03	1.22	37	.229
	Aboriginal	6	12.00	5.44			

compared using independent samples *t* tests. No significant differences were found in any measures (Aboriginal *n* = 6, Non-Aboriginal *n* = 33). The size of the Aboriginal group restricted this analysis to a low power. The large differences noted in the means of CAPS Total Severity scores and HGRC Despair scores might reach significance if replicated in a larger sample.

In this sample the proportion of Aboriginal parents diagnosed with PTSD using the F1-I2 rule was 50% of the sample (N = 6, PTSD = 3). The proportion of non-Aboriginal parents diagnosed with PTSD using the same rule was 27.3% (N= 33, PTSD = 9). Proportions are shown in Figure 6.



**Figure 6.** Proportion of PTSD diagnosis in Aboriginal and non-Aboriginal groups using the F1-I2 rule.

The significance of the difference of proportion of cases of PTSD in Aboriginal and non-Aboriginal groups as diagnosed using the F1-I2 rule was examined using a Fisher's Exact test. The Exact significance (2-sided) was  $p = .348$ . While the 22.7% difference in the percentage of cases diagnosed in each group appeared large (27.3% in non-Aboriginal participants and 50% in Aboriginal participants) there was not enough

power in a sample this size to find the difference significant. If these results remained consistent in a larger sample, significance would likely result. Using the more stringent =4 diagnostic rule, the proportion of Aboriginal parents receiving a diagnosis remained larger than the proportion of non-Aboriginal parents receiving a diagnosis. However, the difference in proportion was greatly reduced (Aboriginal parents diagnosed = 1 of 6 or 16.7% and non-Aboriginal parents diagnosed = 5 of 33 or 15.2%).

Aboriginal or non-Aboriginal ethnicity may influence grief and trauma responses. In this sample, Aboriginal parents experienced more intense symptoms of traumatic stress and a greater proportion of Aboriginal versus non-Aboriginal parents was diagnosed with posttraumatic stress. Non-Aboriginal parents experienced more intense symptoms of grief. None of these differences were statistically significant and they may only reflect an anomaly in this sample. If, however, these results were replicated in a larger sample significance would be the likely result. Differences might be the result of true differences in the populations or the result of culturally different ways of interpreting and/or responding to the instrument

#### Effects of the age of the child at death.

Further exploratory analysis was conducted to clarify the relationship between child age and measures of grief, trauma and social support. The correlation between child age and all measures was determined using Pearson's Product Moment Correlation Coefficient (Table 15). There was a significant medium negative relationship ( $r = -.375$ ,  $p = .017$ ) between child age and CAPS Total Severity score indicating that as the age of a child at death increased the intensity of PTSD symptoms decreased. This negative

Table 15

Pearson's Correlation of Child Age and All Measures (N = 40)

Measure	Pearson Correlation to Child Age	Significance (2-tailed)
CAPS -Total Severity Score	-.375**	.017
CAPS - Reexperiencing	-.446***	.004
CAPS - Avoidance & Numbing	-.276*	.085
CAPS - Hyperarousal	-.210	.194
PSS-Friends Score	.057	.725
PSS-Family Score	.207	.200
HGRC - Despair	.025	.878
HGRC - Personal Growth	.085	.601
HGRC - Panic Behaviour	-.064	.697
HGRC - Blame & Anger	-.138	.397
HGRC - Detachment	-.080	.624
HGRC - Disorganization	-.044	.786

\* $p < .10$ \*\* $p < .05$ \*\*\* $p < .01$ 

relationship was seen again between child age and the Reexperiencing ( $r = -.446, p = .004$ ) and the Avoidance & Numbing ( $r = -.276, p = .085$ ) symptom cluster of CAPS.

Because the significance of  $r$  is strongly influenced by the size of the sample (Pallant, 2001), it is difficult to establish significance in a small sample such as this. The finding of significance at this level is therefore a most interesting outcome. The shared variance of child age and PTSD as determined by the coefficient of determination (.141) was 14%.

That is, child age helped to explain 14% of the variance in the CAPS Total Severity scores.

The total sample was divided into two groups based on the median age (20 years, in this sample) of the child at death. On observation, the intensity of grief and trauma symptoms found in parents of children less than twenty years of age was in every instance greater than the intensity of symptoms found in parents of children more than twenty years of age (Table 16). Personal growth, a positive measure, was greater in parents of older children.

In the CAPS Reexperiencing symptom cluster, the death of a younger child ( $M = 7.57$ ,  $SD = 6.82$ ) was again related to more intense symptoms than the death of an older child [ $M = 4.37$ ,  $SD = 4.14$ ,  $t(33.43) = 1.81$ ,  $p = .079$  (two-tailed)]. Although not significant, the death of a younger child ( $M = 30.29$ ,  $SD = 13.30$ ) was related to more intense symptoms of traumatic stress as measured by the CAPS Total Severity score than the death of an older child ( $M = 21.97$ ,  $SD = 20.96$ ,  $t(38) = 1.62$ ,  $p = .113$  (two-tailed)). The magnitude of the difference in means was moderate (eta squared = .065), with 6.5% of the difference in means explained by the age of the child.

On one measure of grief (Personal Growth) differences between groups also approached significance with parents of younger children ( $M = 37.10$ ,  $SD = 9.40$ ) reporting less growth than parents of older children [ $M = 41.32$ ,  $SD = 9.92$ ,  $t(38) = -1.38$ ,  $p = .175$  (two-tailed)].

In the perception of social support from family, the difference in one pair of means was significant at the  $p < .05$  (two-tailed) level. Interestingly, there was greater perception of social support from family in parents of older children. In this instance,



Table 16

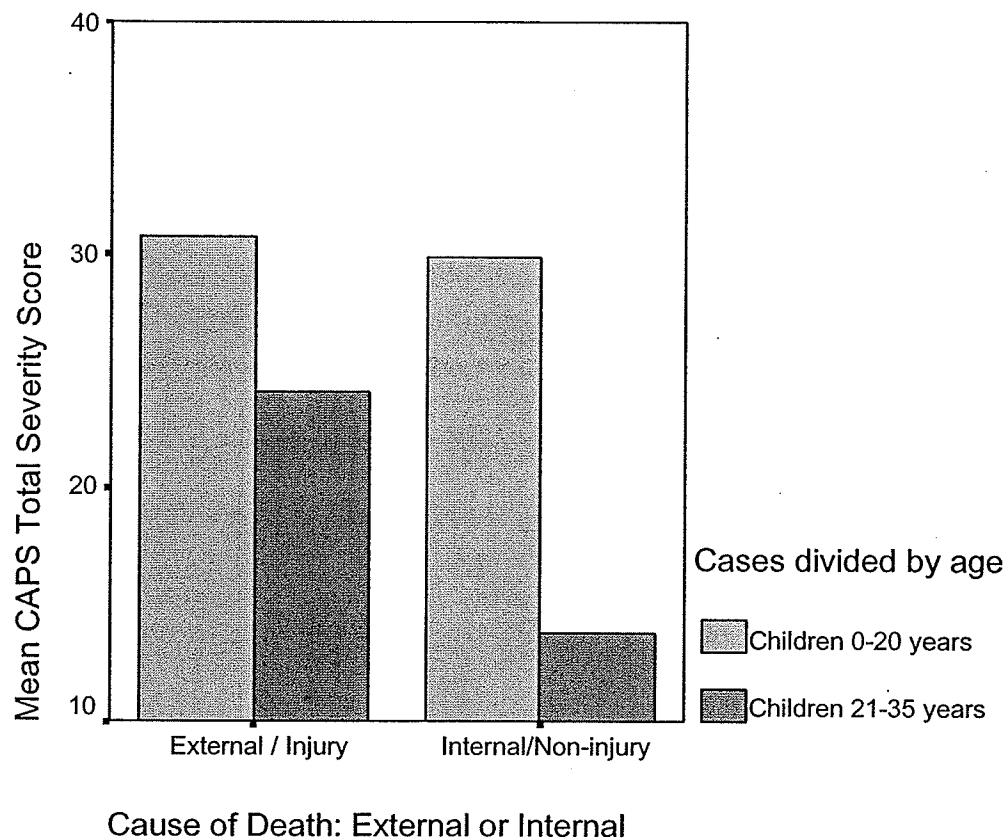
Comparison of Means on All Measures of Groups Divided by Age of Child  
(Child =20 years N = 21, Child >20 years N =19)

Dependent Variable		Mean	SD	<i>t</i>	df	<i>p</i> 2-tailed
PTSD Total Severity score	Child =20 years	30.29	13.30	1.62	38	.113
	Child >20 years	21.37	20.96			
Hyperarousal - CAPS	Child =20 years	10.33	5.16	1.32	38	.195
	Child >20 years	7.68	7.43			
Avoidance & Numbing - CAPS	Child =20 years	12.38	6.75	.98	38	.325
	Child >20 years	9.32	12.18			
Reexperiencing - CAPS (Equal var. not assumed)	Child =20 years	7.57	6.82	1.81	33.43	.079*
	Child >20 years	4.37	4.14			
Despair -HGRC	Child =20 years	32.52	10.24	.792	38	.433
	Child >20 years	29.74	12.02			
Panic Behaviour - HGRC	Child =20 years	32.19	10.77	.774	38	.444
	Child >20 years	29.05	14.73			
Personal Growth - HGRC	Child =20 years	37.10	9.40	-1.38	38	.175
	Child >20 years	41.32	9.92			
Detachment - HGRC	Child =20 years	16.61	6.13	1.30	38	.200
	Child >20 years	13.98	6.66			
Blame & Anger - HGRC	Child =20 years	14.05	5.65	.840	38	.406
	Child >20 years	12.53	5.80			
Disorganization - HGRC	Child =20 years	17.66	6.38	.199	38	.843
	Child >20 years	17.21	7.86			
PSS-Fr <sup>15</sup>	Child =20 years	13.59	4.10	.103	38	.918
	Child >20 years	13.45	4.16			
PSS-Fa <sup>15</sup>	Child =20 years	12.90	5.25	-2.10	38	.042**
	Child >20 years	16.16	4.46			

\*\*  $p < .05$  two-tailed

\*  $p < .10$  two-tailed

<sup>15</sup> Results of the comparison of mean PSS-Fr and PSS-Fa scores for two age groups were confirmed using the non-parametric Mann-Whitney U test. PSS-Fr  $z = -.041$ , Asymp. Sig. (two-tailed) = .967; PSS-Fa  $z = -2.070$ , Asymp. Sig. (two-tailed) = .038.



**Figure 7.** Mean CAPS Total Severity Score by group and child age

the parents of younger children reported significantly less perceived family support ( $M = 12.90$ ,  $SD = 5.25$ ) than the parents of older children [ $M = 16.16$ ,  $SD = 4.46$ ,  $t(38) = -2.10$ ,  $p = .042$  (two-tailed)].

Dividing the age groups by cause of death allowed an observational comparison of means. The means of Total Severity scores for parents of younger children were very similar regardless of the cause of death (younger child injury death  $M = 31$ , younger child non-injury death  $M = 30$ ) (Figure 7). In older children, injury death appeared associated with a higher mean CAPS Total Severity score.

To examine the relationship between child age and CAPS severity scores in the injury and non-injury groups a standard regression model was formulated using child age,

a dummy group variable and an interaction variable (Table J 19). The interaction variable was not significant indicating no difference in the effect of child age on the injury and non-injury groups [ $B = -.44$ ,  $SEB = .824$ ,  $t = -.512$ ,  $p = .306$  (one-tailed)].

However, to further explore the impact of child age and injury death on PTSD as measured by the CAPS Total Severity score, a two-way analysis of variance was also conducted. Participants were divided into three groups according to the age of their child at death (Group 1: 0-17 years, Group 2: 18-23 years, Group 3: 24-35 years). On observation the CAPS scores decreased as child age increased in both injury and non-injury groups. As demonstrated in Table 17, the decrease in the Non-injury group mean was much greater than in the Injury group mean.

Table 17

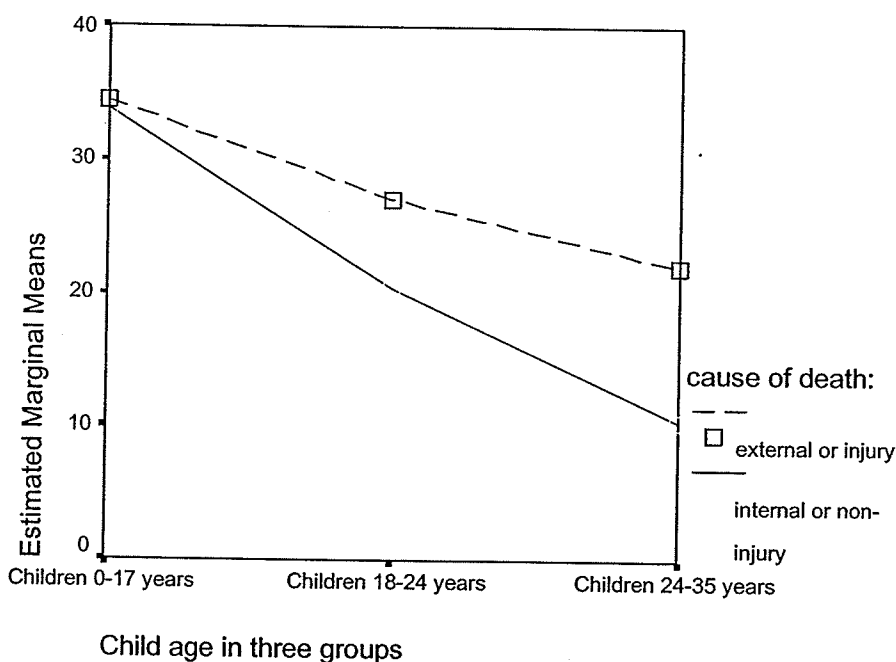
Mean CAPS Total Severity Scores for Age of Child Divided in Three Groups

Dependent Variable: Total severity score on all PTSD symptoms

cause of death:	Child age in three groups	Mean	Std. Deviation	N
external or injury	Children 0-17 years	34.4000	14.24079	5
	Children 18-24 years	27.1111	21.41521	9
	Children 24-35 years	22.0000	21.56386	9
	Total	26.6957	19.88246	23
internal or non-injury	Children 0-17 years	33.7778	13.47013	9
	Children 18-24 years	20.5000	10.66146	4
	Children 24-35 years	10.5000	6.19139	4
	Total	25.1765	14.83760	17
Total	Children 0-17 years	34.0000	13.19674	14
	Children 18-24 years	25.0769	18.55380	13
	Children 24-35 years	18.4615	18.71103	13
	Total	26.0500	17.71708	40

There was a statistically significant main effect for the age of the child at death [ $F(2, 40) = 3.24$ ,  $p = .05$ ]. The effect size was large ( $\eta^2 = .16$ ). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for the 0-17 years

age group ( $M = 34.00$ ,  $SD = 13.20$ ) was significantly different from the 24-35 years age from either of the other groups. The main effect for injury death [ $F(1, 34) = 1.142$ ,  $p = .293$ ] and the interaction effect [ $F(2, 34) = .299$ ,  $p = .744$ ] did not reach statistical significance. A plot of mean scores for each group (Figure 8) demonstrated again the similarity of PTSD scores in Injury and Non-injury group parents of younger children and the increased disparity between the groups as the age of the child at death increased.



**Figure 8.** Means of CAPS Total Severity PTSD Scores for Injury and Non-injury groups by the age of the child at death.

In this sample, the age of the child at death was a predictor of PTSD symptoms with the death of younger children associated with greater intensity in parent symptoms. Although not significant, symptoms of grief also appeared to be inversely related to the age of the child. Parents of younger children perceived significantly less social support from family than parents of older children.

### Use of Services

The pattern of services used by bereaved parents was compared with the pattern of services used by a normative group dealing with stress and anxiety as reported by Walker, el-Gruebaly, Ross & Currie in Research Report No. 35 of the Winnipeg Area Study (Currie, R. et al. 1981-1993). Table 18 demonstrates that on observation the bereaved parent group followed the pattern of the normative group. In every instance, women sought help more often than men. The most common source of help for both groups was reading, followed by seeing a professional and then attending a group. The proportion of respondents seeking help was much higher in every instance in the bereaved parent group. The z test for the significance of difference in proportions between the total bereaved parent group and the total Winnipeg Area Study group demonstrated the differences were significant for help seeking in general [ $z = 4.38, p < .001$  (two-tailed)], for seeing a professional [ $z = 5.13, p < .001$  (two-tailed)], for using reading [ $z = 4.27, p < .001$  (two-tailed)], and for attending a group ( $z = 3.0, p < .01$  (two-tailed)).

The help-seeking behaviour of the injury and non-injury groups was compared as shown in Table 19. Although the Injury group followed the previously established pattern, this comparison made it clear that in this sample the non-injury bereaved parents did not adhere to the pattern previously demonstrated. Parents in this group sought professional help more frequently than they used reading as a method of coping. The difference between the groups in the use of professional help was not significant.

Table 18

Comparison of Proportion of Respondents Utilizing Help in Three Common Practice Areas by Gender.

Type of Help	Bereaved Parent Male		Bereaved Parent Female		Bereaved Parent Total		Winnipeg Area Study Male		Winnipeg Area Study Female		Winnipeg Area Study Total	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Respondents N	9	(23)	31	(77)	40	(100)	257	(44)	322	(56)	579	(100)
Professional	4	(44)	22	(71)	26	(65)	45	(18)	107	(33)	152	(26)
Reading	4	(44)	24	(77)	28	(70)	76	(30)	135	(42)	211	(36)
Group	2	(22)	8	(26)	10	(25)	3	(09)	36	(11)	59	(10)
Any Method*	6	(67)	27	(87)	33	(83)	101	(39)	177	(55)	278	(48)

\* Number of respondents using any of the three types of help. Note that respondents often used more than one type of help.

Table 19

Comparison of Bereaved Parents' Help-Seeking Behaviour by Injury and Non-injury Groups

Group		Professional			Reading			Support Group		
		Yes	No	Total	Yes	No	Total	Yes	No	Total
Injury Group	N	16	7	23	20	3	23	7	16	23
	Percent	70	30	100	87	13	100	30	70	100
Non-injury Group	N	10	7	17	8	9	17	3	14	17
	Percent	59	41	100	47	53	100	18	82	100

However, the Injury group used reading as a method of coping significantly more often than the Non-injury group. The  $X^2$  test with Yates Correction for Continuity was significant ( $X^2 = 5.631$ ,  $df = 1$ , Asymp. Sig. = .018).

The help-seeking pattern of bereaved parents was similar to that of the general Winnipeg population in dealing with stress or anxiety. However, bereaved parents used help significantly more often than the comparison group. Injury bereaved parents used reading as a method of coping more often than non-injury bereaved parents.

### Summary

This analysis was based on data gathered from 40 parents who had experienced the death of a child within the past 24 months. The parents of children who had died as a result of an external cause (N=23) formed the exposure group and the parents of children who had died as a result of an internal cause (N = 17) formed the comparison group. The exposure or injury group was compared with the comparison or non-injury group on measures of traumatic stress, grief and perception of social support. The effects of the duration of bereavement, aboriginal ethnicity, education and age of the child were examined.

It was hypothesized that injury bereaved parents would experience more intense symptoms of traumatic stress than non-injury bereaved parents. Using the CAPS, groups were compared on dichotomous diagnosis scores and continuous symptom severity scores. There was very little difference between groups in the proportion of parents diagnosed with PTSD (Injury = 30.4% and Non-injury = 29.4%). On dichotomous indicators, there was no significant difference between groups. In the comparison of continuous symptom severity scores, when the age of the child was controlled, the injury group experienced significantly more intense symptoms of traumatic stress as measured by the CAPS Total Severity score and the CAPS Hyperarousal symptom cluster score. Therefore, the null hypothesis was rejected.

It was hypothesized that injury bereaved parents would experience more intense symptoms of grief than non-injury bereaved parents. As measured by the HGRC, the grief symptoms of injury bereaved parents were not significantly more intense than those of non-injury bereaved parents. There was one finding of significance and it was in the opposite direction to the hypothesis. When the effects of "adding a child to the family" were removed, the comparison group scored significantly higher than the exposure group on the HGRC measure of Panic Behaviour. The null hypothesis could not be rejected.

It was hypothesized that parents' perception of social support would be negatively related to the intensity of grief and traumatic stress symptoms. Perceived support from family (as measured by PSS-Fa) was negatively correlated to elements of grief (Despair dimension of the HGRC) and traumatic stress (CAPS Total Severity and Avoidance & Numbing symptom cluster). Perceived support from friends was negatively correlated to the HGRC - Panic Behaviour dimension of grief. The null hypothesis was rejected.

The relationship between time and all measures was examined. There was a significant negative correlation between time and two grief dimensions, Despair and Blame & Anger indicating that these measures of grief increased over time. There was no significant reduction in any grief or trauma score over time. Perception of family support increased over time for the non-injury group. The relationship between the passage of time and the intensity of grief and trauma symptoms may be curvilinear rather linear.

Although there was one significant correlation between education level and grief (Panic Behaviour  $r = -.331$ ,  $p = .037$ ), it was concluded that education did not generally influence scores.



In this sample, Aboriginal ethnicity appeared related to more intense symptoms of traumatic stress and less intense symptoms of grief. The Aboriginal group reported less perceived social support from family than the non-Aboriginal group. Differences were not significant.

Parents of younger children experienced more intense symptoms of grief and traumatic stress. This relationship was significant for the CAPS total severity score and the Reexperiencing score. Parents of younger children also perceived significantly less social support from family than parents of older children perceived.

The pattern of help-seeking of bereaved parents was similar to the pattern of a normative group but the portion of bereaved parents seeking help was significantly greater than the proportion of the normative sample seeking help. In this sample, injury bereaved parents used reading as a method of coping significantly more often than non-injury bereaved parents.

### Qualitative Analysis

This portion of the analysis was intended to add to present knowledge of bereaved parents' expressed need for services and address the hypothesis that injury and non-injury bereaved parents would express different service needs. Analysis was based on data collected from 42 injury or non-injury bereaved parents interviewed by the researcher between October 2001 and April 2003. Two respondents, omitted from the quantitative analysis due to missing items, were included in the database for the qualitative analysis.

In general, the assessment of service needs interview immediately followed the collection of quantitative data. Variation in this format occurred where there was a time

shortage (quantitative data collected separately) or where distance necessitated a telephone interview. Interviews occurred in the home (35 or 83%) or workplace (2 or 5%) of the respondent, over the telephone (2 or 5%), or in a neutral setting (3 or 7%).

Data were collected in the form of process notes written as parents answered a standard set of questions in a semi-structured interview format. The semi-structured interview included five questions with sub-questions and the analysis was structured to report on responses to each question in the order in which they were presented. Some of the questions were asking for specific information of a more quantitative than qualitative nature and those responses have been quantified within this analysis. As indicated, the interview was designed to elicit information related to each of the intervention stages described by Figley (1996, December). Figley outlined four points for meaningful intervention in traumatic loss. His intervention "waves" address crisis management, trauma mastery, acute grief resolution, and healthy loss accommodation. The preface to the questions defined formal services as the subject of the inquiry (Appendix G). Comments on informal services have also been reported.

Very few research interviews lasted less than two hours. Parents usually spent some time "telling their story" in the course of the quantitative data gathering. As a result of the length of time spent in data gathering and the high emotional content of the information given, parents were tired by the time these more qualitative questions were introduced. This fatigue limited, in some cases, the amount of information gathered

To clarify the reliability of this content analysis, a second coder was recruited to re-code the data from each question into the previously determined categories for that question. The agreement between coders was 79.7% (421 of 528 responses coded the

same). Using Scott's (1983) Index of Inter-coder Agreement, a comparison was made between the percentage of observed agreement and the percentage of expected agreement over data ascribed to the given number of categories. Using this calculation agreement varies from 0.00 to 1.00. A rating of .7 was viewed as acceptable. Inter-rater reliability was determined for each question. The mean inter-rater reliability for all questions was  $p = .755$ .

### Service Needs Related to the Time of Crisis

1.1 *At the time of crisis, those days immediately following your loss, was there anything provided to you that you remember as being helpful?* Number of responders 42 or 100% of the sample, Inter-rater reliability  $p = .69$ .

This question was intended to gather information related to parents' needs in the period of crisis immediately following the death of a child. Responses to this question offered the richest source of data in the service needs assessment. Responses were coded and grouped until two overarching themes emerged: control and validation. All the intermediate themes appeared to fall into one or the other of these broad statements of human need. Validation included recognition and acknowledgement of the magnitude of the death event, sharing in the loss and acts of compassion and caring. Control encompassed all the responses related to reducing the degree to which parents were overwhelmed by the event. These included anticipating and reacting to parents' needs, being flexible and adapting services to individual situations, and providing information, resources and referrals.

At the time of crisis, the most commonly cited need was for recognition and validation of the event. Parents (15 or 36%) wanted and appreciated having the actions

of those around them acknowledge awareness of the momentous nature of the death event (9 or 39% of injury parents & 6 or 32% of non-injury parents). "What was helpful from the homecare and the nurse from hospital was their acknowledgement that an incident of major importance has occurred" (N19<sup>16</sup>). "The school principal came to the house the next day. The school had a memorial service. One of the children wrote a song. They presented my child's artwork to me (mother)" (J18). "One nurse at the hospital was especially helpful. She saw progress to death as a preparation. Allowed time. Offered a lock of hair and hand print. This was very special and important" (N2). In addition, five comments related to negative experiences as a result of a lack of recognition from those involved in the crisis. "The social worker came to hospital the day of the death. Other than that no one did anything"(N9). "We were not allowed to go to the hospital to see the body. First saw him at the funeral. Didn't get all his clothes or pills back. All confusing at the time" (N10). "Death occurred days after the assault and nothing was offered at the hospital"(J4)

Sharing was important to 13 (31%) parents [Injury  $n = 5$  or 22% and Non-injury  $n = 8$  or 42%,  $z = -1.40$ ,  $p > 0.10$  (two-tailed)]. Parents valued those who indicated knowing the child and sharing their loss. "Nurses came and spoke to the family of the impact of (deceased) in their lives and the lives of the patients he touched"(J12). "Children at school shared remembrances of (deceased)"(J18). "The neonatal nurse has been a great support and even gave the eulogy" (N19).

Compassion and caring were referred to by 11 (26%) parents (Injury  $n = 6$  or 26% and Non-injury  $n = 5$  or 26%). Those who were able to provide service in a way that

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<sup>16</sup> Respondents have been assigned an individual numeric code in combination with a group designation, J = Injury group, N = Non-injury group.

emphasized their human connection to the bereaved families were especially appreciated. "RCMP relayed information in a very professional manner but you could see compassion" (J20). "Doctor at the hospital was very compassionate and related to the family without a professional veneer" (J12). "Doctors and nurses were the main supports. It was very helpful that they were always available. It was never more than a few minutes to get in touch with an oncologist. I had home phone numbers for nurses. The staff was very caring and sharing in good-bye" (N7).

Support provided to reduce the degree to which parents were overwhelmed by the event was grouped under the control theme. Many parents (15 or 36%) commented on the importance of having others anticipate their needs (Injury n = 8 or 35%, Non-injury n = 7 or 37%). They appreciated attention to practical physical needs as well emotional needs. "The nurse offered to call people, made the room private and offered chairs and drinks"(N3). "RCMP officer was very helpful. He still does follow-up. He phoned several times and offered information"(J15). In addition five parents referred to the importance of recognition and anticipation of their needs as a family. "A Klinik worker came to the house three days before the funeral and met with the entire family. They monitored for other suicide tendencies and presented information on services. The RCMP checked to ensure the connection to Klinik had happened" (J3). "On arrival at the hospital the Doctor spoke to everyone at the same time - that was helpful" (J16). "Pastor offered support for siblings"(J15).

Parents valued having their wishes recognized and accommodated. Often this required flexibility on the part of service providers. Nine (21%) parent responses (Injury

n = 6 or 26%, Non-injury n = 3 or 16%) were included in the flexibility theme. This sometimes related to flexibility in the hospital setting with visiting and viewing. "The family was allowed to come and go at the hospital at any time. At the end, we were given (deceased) for whatever time was left. No restrictions on the number of people present and unlimited access" (N14). More often flexibility was referred to in connection with the clergy or funeral home in planning and carrying out the funeral or memorial service. One injury bereaved parent described the flexibility of the funeral home in accommodating her need to meet the plane returning her child's body to Winnipeg and to have the hearse come by the house in a symbolic homecoming (J5). Another offered: "Clergy were flexible with the music and allowed the service the way we wanted" (N7). Also, "The Funeral home was very good. We had as much time as we wanted for viewing, no sales pitch. Whatever we wanted, they did: no coffin, rap music, teen section"(J9). In addition, this need was also stated negatively when parents felt there was a lack of flexibility "Priest not supportive at all, just rules"(N13).

Connecting to resources was noted as helpful by 9 (21%) parents [Injury n = 7 or 30% and Non-injury n = 2 or 11%,  $z = 1.51$ ,  $p > 0.10$  (two-tailed)]. Although not statistically significant, this appeared especially important to those in the injury group who were suddenly in a situation for which they had no preparation. The most often cited resource was literature related to the situation. "Funeral home provided literature to assist with explaining the process to (child of the deceased)" (J10). Referral to appropriate services was also noted including counsellors, lawyers and clergy.

Access to information was important to parents. It was important at the scene: "Hospital mortician was also kind and prepared us regarding his condition and answered

questions" (J8). It was important in dealing with questions after the event: "Information from the Medical Examiner that the death was fast and peaceful"(J2 injury). A parent was contacted 1-2 weeks after death by the Doctor who gave a verbal report.

"Information on the cause of death was helpful" (N13 non-injury).

Having a previous relationship with those involved at the time of death or in the arrangements that followed was recalled as being helpful by 9 (21%) parents (Injury n = 6 or 26% and Non-injury n = 3 or 16%). At the scene "knowing some of the people made it better" (J20). "Knowing the funeral director was helpful and increased trust" (J6). "Had many personal connections to the funeral home that made it easier" (N7).

The needs expressed by parents in response to this question appeared to fall into two categories, either validation or control. Parents most often cited their need for validation of the magnitude of their experience. This included actions demonstrating awareness of the momentous nature of the event, acts and attitudes of compassion and caring, and indications of having known the deceased child and sharing in the parent's loss. Helpful acts that tended to reduce the degree to which parents were overwhelmed by the event were grouped under the control heading. These included anticipating parents' needs by the offer or initiation of direct support or assistance, having the flexibility to adapt service provision to recognize and accommodate parents' wishes, and providing information as well as resources and referrals. No significant differences between groups were noted.

*1.2 Was there anything else that would have helped you deal with those immediate challenges?* Number of respondents 17 or 40% of sample, Injury n = 9 or 39% of group, Non-injury n = 8 or 42% of group, inter-rater reliability  $p = .626$ .

In describing what would have been helpful at the time of crisis, participants referred to three broad themes: practical concerns, regrets about decisions made and unmet expectations. They presented some practical, physical concerns [Injury  $n = 1$  or 11% of Injury respondents, Non-injury  $n = 3$  or 38 % of Non-injury respondents,  $z = -1.30$ ,  $p > 0.10$  (two-tailed)]: "The financial burden of the funeral was hard to bear" (N16); " A more comfortable place to wait for the night expecting his death" (N17).

Several parents [Injury  $n = 3$  or 33 %, Non-injury  $n = 1$  or 13%,  $z = .96$ ,  $p > 0.10$  (two-tailed)] cited regrets for decisions that had been made, for example: "Would have been helpful to have included more family members at the interment." (J10).

The majority of responses related to unmet expectations (Injury  $n = 4$  or 44 %, Non-injury  $n = 5$  or 63 %). Parents reported they did not receive the recognition, flexibility or respect they needed for themselves and their surviving family members. They felt let down by various service providers including the hospital, the funeral home, and the police, as well as by the media and by their informal support network. "Contact with the hospital social worker was supposed to happen but we never connected. The pediatrician did not speak at our level. I wished they had told us the possibilities and used our language. The first doctor told us our child would live. Why did he say that?" (N6). "The siblings felt left out or unacknowledged as grievors at the scene. Too many people interfered with family togetherness" (J20). "The funeral home was not pleasant, would never go back. They were not accommodating of siblings' wishes for viewing or musical choices. They were offended by gifts of friends and we were rushed by their schedule" (J2). The media made one family's experience more difficult by publishing unsubstantiated blaming reports (later proved unfounded) about the possible cause of the



fatality (J7). Two non-injury bereaved parents (Non-injury n = 2 or 25%) poignantly referred to the isolation they experienced. After the death "when you walk out of the hospital, you are on your own"(N7). "I wish that my friends had more interest in me and my feelings... I find the majority of people have no empathy and no sympathy" (N15)

No need for help was indicated by one parent (Injury n = 1 or 11%).

*1.3 In your experience in the hospital, was there anything that could have reduced the stressfulness of that situation?* Respondents N = 13 or 31% of the sample, Injury n = 5 or 22 % of group, Non-injury n = 8 or 42 % of group, Inter-rater reliability p = .730.

Most responses referred to improving or expanding services available through the hospital [Injury n = 2 or 40% of Injury respondents, Non-injury n = 6 or 75% of Non-injury respondents,  $z = -1.26$ ,  $p > 0.10$  (two-tailed)]. Two parents (Non-injury) wanted more involvement from the hospital social worker. The need for privacy was expressed: one parent (N14) appreciating what they received with another (N11) wishing that more had been available. One parent (N16) described questionable care with her child being belittled for incontinence and, in her final days, not receiving adequate medication to control pain. Echoing a previously cited parent's concern about lack of services on leaving the hospital (1.1), one parent (N19) compared services in Winnipeg with those in Toronto, noting that services here were dependent upon hospital admission. In Toronto there was post-stay follow-up. Also a bereavement counsellor was attached to the neonatal unit and was able to provide continued contact. The limited flexibility of the service provided in ICU or the medical ward compared to what parents were used to in Children's Hospital was noted by both an injury bereaved and non-injury bereaved parent. For one family, the injury death of a child coincided with a parental hospitalization (J19).

Parents felt that the nurses were reluctant to acknowledge their loss. Also, there was no sharing of the information on the parents' loss to successive nursing staff shifts over the course of parent treatment. Retelling or explaining was onerous and should have been unnecessary.

### Service Needs Related to Trauma Mastery

*2.1 After the funeral, when you were faced with the aftermath of the death, were there any services you received that were helpful at that time?* Number of responders N = 31 or 74% of sample, Injury n = 17 or 74% of group, Non-injury n = 14 or 74% of group, Inter-rater reliability  $p = .788$ .

This question was intended to assess what parents found helpful in the time period following the immediate crisis. As described by Figley (1996, December), intervention at this time could assist with trauma mastery. The responses to this question revealed a broad range of experience across the sample. Some parents could not recall receiving any services. "Can't think of anything. Just have to work through it."(J19). Others recalled the extreme difficulty of that time. "First 3-4 months found it really hard to maintain daily living"(N10). "I hit rock bottom... People noticed I wasn't myself. I was suicidal" (J16). Some were able to recount a variety of supports and services that were accessible or provided to them. In the broad sense, these services again addressed the themes of control and validation. However, they are not easily categorized as either primarily control or primarily validation. Counselling and special provisions in the workplace provide practical assistance with stress reduction and with coping that is, control. At the same time, they recognize the significance of the event in the parent's life and acknowledge the parent's needs thus providing validation.

Of 31 respondents, 10 reported receiving helpful services in this time frame (Injury  $n = 7$  or 41% Non-injury  $n = 3$  or 21%). Eight families (19%) were assisted by counsellors for parents or children or both [Injury  $n = 6$  or 35%, Non-injury  $n = 2$  or 14%,  $z = 1.33$ ,  $p > 0.10$  (two-tailed)]. The counsellors were from a variety of sources, ranging from employee assistance to those specific to the cause of death. Counselling provided parents with emotional and/or practical support. "I knew that I didn't have the knowledge to cope. Am I going insane? It was logical to seek help and advice. This is the same problem-solving approach that applies to the rest of life" (J3). The Children's Hospital memorial service was also cited as helpful. Follow-up with a physician or psychiatrist of the deceased was mentioned as helpful by two parents (Injury  $n = 1$  or 4%, Non-injury  $n = 1$  or 5%). Two parents (5%) cited psychotropic medication as important to their ability to cope at this time (Injury  $n = 1$  or 6%, Non-injury  $n = 1$  or 7%). Two parents found comfort in learning about some good that would result from the death through organ or other donations (Injury  $n = 1$ , Non-injury  $n = 1$ ).

The second most commonly cited source of assistance was the workplace [Injury  $n = 12$  or 71%, Non-injury  $n = 1$  or 7%,  $z = 3.60$ ,  $p < .001$  (two-tailed)]. This was cited significantly more often for injury-bereaved parents. Six parents credited a supportive employer or helpful co-workers with assisting them through this time (Injury  $n = 6$  or 35%, Non-injury  $n = 0$ ). The ability to take extended time off with a minimum of red tape was also greatly appreciated. Time off or time away was mentioned as important by 5 (29%) of injury bereaved parents (Non-injury  $n = 0$ ). Two parents employed without benefits reported the importance of financial support (Injury  $n = 1$  or 6%, Non-injury  $n = 1$  or 7%).

Several parents cited help they found themselves through literature or using the Internet [Injury 3 or 18%, Non-injury 1 or 7% of group,  $z = .70$ ,  $p > 0.10$  (two-tailed)]. Also noted were personal support network, other parents, or religious community.

In this time period, parents found counselling support and assistance in the workplace most helpful in meeting their need for control and validation. Injury bereaved parents reported the helpfulness of the workplace significantly more often than non-injury bereaved parents.

*2.2 Is there anything that could have been provided to help you?* Number of respondents = 14 or 33% of sample, Injury  $n = 5$  or 22% of group, Non-injury  $n = 9$  or 47% of group, Inter-rater reliability  $p = .806$ .

Responders (6 or 15% of sample) wanted follow-up (Injury  $n = 2$  or 40% of Injury respondents, Non-injury  $n = 4$  or 44% of Non-injury respondents). They expected follow-up and they wanted it to be initiated by the service provider. Parents felt let down by hospital social workers, nursing staff, police and spiritual advisors. "Parents need more help to see how they're dealing with things, more hands on. Don't wait for me to call you. I could have knocked on the hospital social worker's door, but why didn't she call us?" (N1). "Could have offered or referred us for counselling when ready. Had to push for counselling for (sibling) who was there when the body was discovered" (J18).

Three parents referred to their need for time off or more time off (Injury  $n = 1$  or 20%, Non-injury  $n = 2$  or 22%). "Just wanted some rest. A chance to get away and relax would have been good. Some isolation" (N16). "Wonder now if more time off would have been a benefit. Would I be as tired as I am now if I had taken time off?" (N17).

The third need expressed was for practical help with tasks of daily living (Injury n = 1 or 20%, Non-injury n = 2 or 22%). "Needed help with cooking and cleaning" (N6). During the interviews, the exhaustion of some parents was palpable. This was especially true of parents whose child's death was preceded by a lengthy period of intense care.

Three parents raised concern related to information sharing (Injury n = 1 or 20%, Non-injury 2 or 22%). These included obtaining information from the police, and doctors. One mother of a deceased infant was disturbed by calls from baby product telemarketers. She wondered "If information could have been shared within the child health care system so the baby systems could react appropriately" (N19).

In summary, parents expressed their frustration at not having services meet their expectations in terms of follow-up and initiative. They noted a need for respite from work and/or the tasks of daily living.

*2.3 Did you receive information from the Medical Examiners office? Was it timely? What would have been helpful for you?* Number of responders 30 or 71% of sample, Injury n = 23 or 100% of group, Non-injury n = 7 or 37% of group, Inter-rater reliability  $p = .774$ .

The Medical Examiner's representative attends all accidental deaths but not all deaths. This explains the disparity in the proportion of injury and non-injury responders to this question. Because this question did not apply equally to the groups no between groups statistical comparisons were made. For three of those responding to this question, information from the Medical Examiner's office was not important (Injury n = 3 or 13%). "Got the report but I didn't read it." (J11). "Didn't want to know anything" (J14). For the majority of parents the medical examiner's office played an important role in

providing information and answering questions. Five parents spoke positively about their experiences with the representatives of the ME's office (Injury n = 5 or 22%). "The ME was in charge at the scene and shared information from the start. Called the next day about the autopsy and toxicology to be performed. Called a couple of times. Especially helpful the talk about a peaceful death" (J2). Nine parents (39% of those responding) reported having to pursue information (Injury n = 6 or 26%, Non-injury n = 3 or 16% of group). Some were successful. "I phoned them and they did send the report and it was timely about two months after" (J21). "Got information but had to ask and pursue. It took too long" (J23). Others found it more difficult. "Called and called for report. Made a trip to the office. Timely? No" (J17). After describing receiving "very abrupt" answers to her questions, one mother asked: "Do you have to have no compassion to be a medical examiner?" (J15). Several parents expressed their opinion on the degree to which the ME's time frame for providing information met their needs. Of those who directly answered the question of the timeliness of the information, four reported being satisfied (Injury n = 3 or 13%, Non-injury n = 1 or 14%). These respondents reported receiving information between 1 and 6 months after the death. Seven respondents felt that information had taken too long (Injury n = 6 or 26%, Non-injury n = 1 or 14%) and referred to waiting periods of a year or more. One parent was still waiting for the report at the time of the interview 18 months after the injury death.

Where the death of a child involved the Medical Examiner's office, most parents were interested in receiving information from the ME. Approximately 20% of parents in this sample had positive experiences with the ME's office. About 40% indicated they had to pursue information. Of those reporting on the timeliness of information,

approximately twice as many said it took too long compared to those who found the information timely.

*2.4 If there were charges laid as a result of your child's death, what supports would have helped you deal with that situation in a way that was the least uncomfortable for you?* Number of respondents 5 or 12% of sample, Injury n = 5 or 22% of group.

A more speedy resolution was the desire of two parents, of the police investigation in one instance and of the court case in the other. Both cases experienced a significant time lapse between the death and the decision to lay charges (6 months - 1 year). One parent was disturbed by the lack of charges in their child's death. Another parent noted the value of support from a court worker and the Victim Assistance Program.

#### Service Needs Related to Acute Grief Resolution

*3.1 When you started to look at all you had lost, did you receive any services that were helpful at that time?* Number of responders 19 or 45% of the sample, Injury n = 13 or 57%, Non-injury n = 6 or 32% of group, Inter-rater reliability  $p = .823$ .

Once parents have been able to deal with any traumatic responses to their loss, they can begin to deal with their primary and secondary losses. The wide variation in the degree to which parents found the death of their child traumatic complicated the distinction between this wave (acute grief resolution) and the previous intervention wave (trauma mastery). For some an intervention aimed at reducing arousal and traumatic stress was not necessary. Those parents recognized only a period of crisis followed by a period of grief resolution.

Two respondents felt that they had no need of services at this time (Injury  $n = 2$  or 15% of Injury respondents, Non-injury  $n = 0$ ). Two others said they had received nothing in the way of services (Injury  $n = 0$ , Non-injury  $n = 2$  or 33% of Non-injury respondents). The remaining parents described counselling, reading and rituals as helpful. Six parents were receiving counselling (Injury  $n = 4$  or 31%, Non-injury 2 or 33%). Some parents were receiving formal grief counselling. Others were visiting physicians or psychiatrists with whom they had a previous relationship. "After 3 months I started grief counselling and went every week for 4-5 months" (N4). During this time period, more parents referred to reading as a source of help (Injury = 5 or 38%, Non-injury = 2 or 33%). "Reading material was very helpful; both stories of other survivors and reading about coping with loss"(J3). Memorials were mentioned as helpful (Injury = 1 or 8%, Non-injury = 2 or 33%). "I did a balloon release at the gravesite on her birthday" (N19). The workplace was still an important support and was mentioned by three parents (Injury = 2 or 15%, Non-injury = 1 or 17%). "...workplace was very good and allowed several months of leave and financial support" (J9). One parent found referral to The Compassionate Friends helpful. Three parents reported on individual coping strategies such as: "Keeping busy (J19), and "Started drinking quite a bit more" (J21).

In this third intervention wave, parents noted the helpfulness especially of counselling and reading. Also mentioned as helpful were rituals and a supportive workplace.

3.2 *Is there something else that would have helped you at that time?* Number of responders 12 or 29% of the sample, Injury = 9 or 39% of group, Non-injury 3 or 16% of the group, Inter-rater reliability  $p = .829$ .



Respondents to this question wanted more understanding from others and from social systems. Frustration was expressed with the way they, themselves, had done things, "If I did it over, I would have seen a grief counsellor right away" (J2) and the way others had responded to them, "I didn't want people to be sorry. It's better to hug somebody and say you can be there if they want" (J15). They especially expressed frustration with the systems with which they dealt (3 or 25% of responders, Injury = 2 or 22% of Injury responders, Non-injury n = 1 or 33% of Non-injury responders). "The taxation department was a real hassle" (J1). The insurance company requirements were a "real pain in the butt" (J23). They wanted people to understand their needs and respond appropriately (Injury n = 2 or 22%, Non-injury - 1 or 33%). "Literature provided by nurses was pretty basic and not very useful"(N7). "Need to have family reach out to me rather than expecting me to reach out to them"(J10). "Had to change psychiatrists to find someone more helpful...(second one) was empathetic and understood my feelings and the severity of my feelings...." (J18). The hospital "team and nurses had become friends and there was no further follow-up" after the death (N1). Two injury bereaved parents spoke of being alone, one by desire: needed "some solitude, some space" (J20) the other by ability: "too withdrawn to get involved in anything"(J11).

In reviewing their circumstances, parents noted regrets for decisions they had made and frustration with the way systems and individuals understood and responded to their needs.

*3.3 Did you have access to an employee assistance counsellor? Did you make use of this service? How did you access it?* Number of respondents 33 or 79% of sample,

Injury = 17 or 74% of group, Non-injury = 16 or 84% of group, Inter-rater reliability  $p = .901$ .

The responses to this question are summarized quantitatively in Table 20. This

Table 20

Summary of Use of Employee Assistance Counsellors (EA) by Bereaved Parents

Category	Injury group		Non-injury group		Total		Z
	n	Proportion of group	n	Proportion of group	N	Proportion of Total	
Don't know	1	6%	1	6%	2	6%	
No access to EA	5	29%	6	38%	11	33%	
EA Available but not used	8	47%	4	25%	12	36%	1.32
Used an alternative	6	35%	1	6%	7	21%	2.04*
Used EA positive experience	1	6%	2	13%	3	9%	.70
Used EA negative experience	2	12%	2	13%	4	12%	

\*  $p < .05$  two-tailed

summary provides strong evidence that Employee Assistance (EA) programs are not utilized as a resource by most bereaved parents. For 11 or 33% of responding parents, the program was not available. These parents were self-employed, unemployed or worked for organizations without an EA program. In 12 or 36% of cases, the program was available but not used. Some parents saw no need, "Think you have to work it through on your own" (N16). Others used an alternative counsellor, physician or psychiatrist of their choice. The proportion of injury-bereaved parents using an alternative was significantly greater than the proportion of non-injury bereaved parents. In two cases parents were required to see a Psychologist or Psychiatrist to determine their eligibility for disability. Some described the EA service as inappropriate "Was mainly concerned with workplace needs" (J2). Others were more critical "She was useless"

(N9). Three parents had good experiences with EA. "I had 15 one hour sessions. It was about enough. The first EA counsellor wasn't a good fit and I tried a second one successfully" (J23).

Bereaved parents did not generally access Employee Assistance counselling professionals. Only approximately 20% of the bereaved parents in this sample used EA for assistance in coping with their bereavement and of those only half reported a satisfactory experience. Significantly more injury than non-injury bereaved parents reported using an alternate source of counselling support.

*3.4 Would personal contact from a bereaved parent group have been welcome or helpful? When?* Number of respondents 40 or 93% of sample, Injury = 22 or 96 % of group, Non-injury = 18 or 95% of group, Inter-rater reliability  $p = .745$ .

At present, The Compassionate Friends Winnipeg indirectly contacts Manitoba parents of children whose obituary is published in the Winnipeg Free Press. An information package including a newsletter is sent to the funeral home for forwarding. There is routine personal contact only as a follow-up to attendance at a sharing meeting.

The majority of parents said they would have appreciated personal contact from a bereaved parent group (23 or 58% of respondents, Injury = 14 or 64% of Injury respondents, Non-injury = 9 or 50% of Non-injury respondents). Some responses were extremely positive. "It would be great, super to have had contact initiated by a bereaved group." (N5). "Yes. Thought I was going out of my mind. Didn't want to live" (J10). The need to connect to others with similar experience was expressed. "Would have liked someone to come to the house and talk about this is what you may experience, this is what I experienced. Need to know that others go through it and survive it. You feel so alone "

(N7). "Feel like you're the only one" (N5). The importance of an other-initiated contact was also emphasized. "Would have liked them to initiate contact and take the lead in getting me there. Had a feeling of detachment. Contact early and ask - can I call you? DO NOT ask me to call." (N6). "Figuring out and trying to find groups was beyond me" (N9).

A number of parents (Injury = 7 or 32%, Non-injury = 2 or 11%,  $z = 1.57$ ,  $p > 0.10$ ) referred to contact they had with bereaved parents who were already within their social network or who contacted them on an individual basis. Some felt that this negated any need for further contact. "Have 5 co-workers who have lost children in the past year. We have regular contact and therefore other contact is not necessary" (J15). "No, I don't think I would have liked that. Had a connection with other bereaved parents. We were offered connection to a couple who had experienced a similar death" (N19). Others used their experience as an example of the usefulness of contact from other bereaved parents. "Didn't need additional support. Had visits from other bereaved parents. It was helpful to hear their stories" (J12). "Had contact from a couple through a sympathy card. Family member arranged for a meeting. Have established a relationship that is ongoing." (J14). "Had friends who lost their son so had someone to talk to" (N17).

Some parents said "no" to contact (9 or 23% of respondents, Injury = 4 or 18%, Non-injury = 5 or 28%). Two of these indicated they had contact with other parents and their needs were met as noted above. Therefore, a total of 7 parents or (18% of respondents, Injury  $n = 4$  or 18%, Non-injury  $n = 3$  or 17%) indicated they did not want contact from other bereaved parents. For three of these, meeting with other parents did not fit with their view of effective problem solving. "Wanted to be alone" (J7).

"Probably not a help. Prefer to try not to think about it."(N10). "Groups are for people who cannot deal with it at home" (J9).

In addition to those rejecting contact from a parent group, other parents expressed concern about dwelling on the past in an unproductive way. Three parents questioned the helpfulness of parent group contact. (Injury  $n = 1$  or 5%, Non-injury  $n = 2$  or 11%,  $z = -.74, p > 0.10$ ). "Not the types to sit around and talk about it" (J22). "Didn't want to rehash and keep in the past. Wanted to move forward" (N16). Two parents who tried TCF raised the same concern. "Contacted TCF and attended three meetings. Did not feel there was progress and was concerned about the potential negative influence from other attendees" (J2). "Attended TCF and felt that people there were not moving forward" (J4).

Eighteen parents (45% of respondents to this question) suggested a time when they would have been ready for contact from a bereaved parent group. The majority (13 or 72% of respondents to this question) preferred early contact, that is, sometime in the first two months following child's death. Six parents suggested immediate contact within the first month following the death (Injury  $n = 3$  or 14%, Non-injury  $n = 3$  or 23%). "Right at the time of death" (J10). "Could have come to see me the next day" (N15). "I think anytime after the funeral" (J6). "Contact within the first month" (N7). Three parents (Injury  $n = 1$  or 5%, Non-injury  $n = 2$  or 11%) said contact should not occur before one month had passed. "Not during the first month" (N8). Four (Injury  $n = 1$  or 5%, Non-injury  $n = 3$  or 22%) thought that 1-2 months would be the best time. Six months was the best time frame for four parents (Injury  $n = 2$  or 9%, Non-injury  $n = 2$  or 11%) and one parent (J16) suggested about a year after the death was the right time.

Parents referred to three types of contact: newsletters (current method of TCF Winnipeg), other written contact and telephone calls. Written contact has the advantage of giving the parent increased control over her or his response. "Nice to be notified 2 or 3 times because you lose track. Mail is good. It allows you to pick a time to face it" (J20). "Received the TCF Newsletter. It was a good approach. More was more than I could cope with" (J23). Other parents would have preferred more direct contact. "A call from a bereaved parent would be good" (N5). "Would have liked someone to come to the house" (N7). "TCF sends newsletter. Contact might have helped" (J19).

In summary more than 80% of respondents were interested in or appreciated having contact with other bereaved parents. It was important that others take the lead in initiating contact. Of those expressing a preference, the majority preferred that contact be initiated in the first two months following the death.

*3.5 Would contact from a social worker have been helpful? When? What type of contact?* Number of respondents 39 or 93% of sample, Injury n = 21 or 91% of group, Non-injury n = 18 or 95% of group, Inter-rater reliability  $p = .740$ .

Ten parents (26% of respondents) did not view contact from a social worker as potentially helpful (Injury = 7 or 33%, Non-injury = 4 or 22%). Parents who elaborated on their answer either saw no need for help or did not see value in what a social worker might offer. "Don't really think so. Someone who has been in the same situation would be a better avenue" (N11). "Guess not. I prefer talking to friends" (J17). "Don't know what they would have to offer that would help. I wasn't looking for someone to talk to" (N16). One parent said no because her/his needs were met within the existing system. "No. Family as a whole met with police and Victim Services" (J4). Three parents (8% of

respondents) responded that they did not know if social work contact would be helpful (Injury = 3 or 14%, Non-injury = 0).

Eleven (28% of respondents) thought contact from a social worker would have been helpful [Injury = 4 or 19%, Non-injury = 7 or 39%,  $z = -1.39$ ,  $p > 0.10$  (two-tailed)]. They cited a need for support, information and normalization of their experience from a professional. "Yes, call just to listen. Maybe tell me what is normal. I missed professional help from both the social worker and the minister" (N7). "Yes to help me understand what was happening to me. I thought I was going to have a nervous breakdown - that I could lose it and not know it" (J11).

Six more parents (15%) thought a social worker might have been helpful. (Injury = 2 or 10%, Non-injury = 4 or 22%). "Don't know. Anything that might be good, do it. Might be a good idea to make sure there is something to eat in the house and maybe provide some information. .... For some, a social worker might be the only support" (N14). Having the contact initiated by the social worker was also important. "Maybe.... If somebody called and came out to listen and maybe gave a flier of groups, where, when etc. Figuring out and having energy to find groups was beyond me" (J8).

In addition, 10 or 21% of parents [Injury = 9 or 43%, Non-injury = 1 or 6%,  $z = 2.62$ ,  $p < .05$  (two-tailed)] reported having had contact from a social worker or other professional counsellor. The proportion of injury-bereaved parents reporting contact was significantly greater than the proportion of non-injury bereaved. (It was not clear that parents recognized any difference between a social worker and other counselling professional and therefore this analysis does not distinguish between them.) Some parents had opportunities for professional contact as a result of connections in their social

or occupational networks. "Had one at work who contacted me. To know it was available was helpful although I used it only once" (J15). "Probably had 8 social workers contact me, many with specialties in loss" (J23). Not all social work contacts were positive. "Saw a social worker once 1-2 months after. It was not very helpful." (J20). No systematic method of contact from a social worker was evident in the experience of parents in this sample. Although Non-injury parents might have received social work services in the hospital prior to child death, it was readily apparent that parents in the Non-injury group were no more closely allied to post-death social work service than parents in the Injury death group. In fact, the opposite appeared to be true in this sample.

Nineteen parents (Injury = 5 or 23%, Non-injury = 14 or 78%) offered opinions on the timing of social worker contact. One parent suggested anytime would be acceptable. Immediately or during the first month was the preference of eight parents (42% of respondents (Injury = 2, Non-injury = 6)). Four suggested 1-2 months and three felt that it should occur after two months. Three parents thought an initial contact and later follow-up should characterize contact. "A social worker who has knowledge of resources would be useful. Someone to come out, talk to them ...in the first month. If they refuse, try a month later" (J18). "Contact initially offering support and later follow-up after first few weeks" (N4). One non-injury parent suggested that follow-up of the social work assistance offered in the hospital would have been helpful (N13).

Eleven parents commented on the type of contact they would have preferred. (Injury = 6 or 29%, Non-injury = 5 or 28%). A phone call was the contact of choice for 7 parents (64% of respondents, Injury = 3 or 14%, Non-injury = 4 or 22%). Two parents



(18%) preferred contact by mail and two (18%) suggested a letter with telephone follow-up.

Three parents reiterated the importance of having the contact initiated by the social worker. "Probably more helpful to have them initiate contact" (J14). "I know I couldn't have done it myself. I was just existing. If someone called it would feel like proper care" (N5).

In this sample, approximately one-quarter of parents were not interested in contact from a social worker. The remaining three-quarters of bereaved parents were interested in or open to receiving the services of a social worker/counsellor who was aware of the needs of bereaved parents and the resources available to them. They indicated a general preference for having the social worker contact them by telephone within the first two months of a child's death.

#### Service Needs Related to Loss Accommodation

4. *Would you say that you have reached the point of starting to look toward the future?* Number of respondents N = 34 or 81% of the entire sample, Injury n = 19 or 83% of group, Non-injury n = 15 or 79 % of group, Inter-rater reliability  $p = .867$ .

This question was designed to allow respondents to identify themselves in the fourth wave of Figley's (1996, December) intervention model where the focus is healthy loss accommodation. Twenty (59%) of the respondents gave positive responses and the positives were balanced between injury (n = 11 or 58 % of the group) and non-injury groups (n = 9 or 60% of the group). Other responses were grouped as "partly" (N = 5, Injury n = 5 or 26%), "one day at a time" (N = 2, Injury n = 2 or 11%) or "no" (N = 7). There was a significant difference between the proportion of injury and non-injury

parents indicating they were not looking toward the future at the time of the interview. Of the seven "No" responses 6 were from non-injury parents and only one from an injury parent [Injury  $n = 1$  or 5% of group, Non-injury  $n = 6$  or 40% of group,  $z = 2.5$ ,  $p < .05$  (two-tailed)]. However, when all those who did not answer in the affirmative ( $N = 14$ , Injury  $n = 7$  or 37%, Non-injury  $n = 7$  or 47%) were grouped together, there was no significant difference between the group proportions. At this point in time some parents were continuing to feel acute grief reaction: "Nothing makes any sense anymore" (N1). Others were noting doing things they had been unable to do before. The difficulty in assigning oneself to a particular stage was characterized by the non-injury bereaved parent who described her life as a dichotomy between a functioning professional and a grieving parent. "It's like I'm living two lives - one is working and planning, the other is (deceased child)" (J17).

If participants answered "yes" or "partly" to question 4, they were asked; "Is there anything that would be helpful for you at this time?"

Twenty-six parents (62% of the entire sample) responded to this question (Injury  $n = 16$  or 70 % of group, Non-injury 10 or 53 % of group, Inter-rater reliability  $p = .577$ ). Seven parents offered no suggestion (Injury  $n = 4$  or 25% of Injury respondents, Non-injury  $n = 3$  or 30% of Non-injury respondents). Six parents cited a need for more time (Injury  $n = 3$  or 19 %, Non-injury  $n = 3$  or 30%). The need for more time was summed up most succinctly by the parent who said what would help her was "People not thinking that you should be done" (N14). This was reflected in the plans of parents to continue with professional services initiated with counsellors or psychiatrists and by the desire for ongoing recognition that respite from the responsibilities of "normal" life and work was

still required. "The understanding that you are still not up to par. I still need more time, more rest time, more breaks than I would have normally needed. I'm frustrated with myself" (N17). Six parents wanted continued acknowledgement and/or opportunities for sharing, especially with other bereaved parents (Injury  $n = 4$  or 25%, Non-injury = 2 or 20%). "Still would like something like the newsletter to hear from other parents what they went through. Someone to call and check every quarter - acknowledge my loss" (N6). Three parents said it would be helpful to continue with activities related to their loss such as following through on planned memorials (Injury  $n = 3$  or 19%, Non-injury  $n = 0$ ). Three parents were looking for new activity or direction. "I want to go to school, take a course, get more confidence"(J10). Three parents cited practical needs: money, resolution of legal issues related to the death, mending past family relationships.

Parents identifying themselves as beginning to look forward tended to report the need for more time and support to continue their journey to loss accommodation. The few parents who cited a readiness to tackle new things were the exception.

#### Service Recommendation

5. *If you were to recommend a service to be developed to help bereaved parents, what would it be?* Number of respondents 42 or 100% of sample, Injury = 23, Non-injury = 19, Inter-rater reliability  $p = .779$ .

This question produced many pregnant pauses. Other questions asked parents about their direct experience but this question asked them to consider the needs of bereaved parents more generally. Some felt they had little to offer in the way of suggestions. Others were very articulate. Many parents used this question as an opportunity to summarize their previous comments and provide an overview of their

experience. "We died as a family and are restarting as a new family" (J9). Most were able to share their perception of the needs of bereaved parents and how those needs might be met to help them deal with the task of becoming "new families".

Five parents (12% of sample) had no suggestion for service development (Injury = 4 or 17 % of Injury responders, Non-injury = 1 or 5% of Non-injury responders). One of those parents offered this advice: "Don't forget them but don't dwell on it. Don't make it your life, it will just eat you. A lot of people thrive on this. There is no need. Humor is the best therapy" (J1).

The balance of the sample presented a variety of needs and suggestions as to how they might be more adequately met. The most frequent responses were categorized within the boundaries of information and support. These reflect again the continuing themes of control and validation. Information assists parents in resuming control of their lives. Support recognizes and validates the parental grief experience.

Parents expressed a need for knowledge (11 or 26%, Injury = 6 or 23%, Non-injury = 5 or 26%). They wanted to know what to expect in the grief process (4 or 10% of respondents, Injury = 3 or 13%, Non-injury = 1 or 5%) and they wanted to deal with someone who had that knowledge (3 or 7% of responders, Injury = 1 or 4%, Non-injury = 2 or 11%). "You question what is normal. You need help getting familiar with grieving" (J23). You want to know: "What is an OK way of losing your mind versus a not OK way of losing your mind" (N14). "You have to talk to someone with some knowledge" (J2). Parents also wanted to know how to deal with the systems confronting them (4 or 10% of responders, Injury = 2 or 9%, Non-injury = 2 or 11%). One parent described her need for a service organized "to provide useful, factual information" and "to be a resource to guide

through what the system demands" (N19). This need was also clearly stated by an injury-bereaved parent. "In our situation, with a crime involved, something on (the) law and our rights and the legal system both criminal and civil... Criminal case, civil case, insurance, so much to deal with" (J8). Citing vulnerability to funeral homes described as the "biggest crooks on the face of the earth", one parent suggested a "need for help with what happens next after death" because "funeral homes will take every penny" (N1). Parents also wanted information on available resources. "Not enough information on services available" (N1). "I think many are not aware of resources... Feel like you're all on your own fighting the battle and you're not really" (J23).

In addition to information for themselves, three parents (7% or respondents, Injury 2 or 9%, Non-injury 1 or 5%) expressed the need for a more informed public. "More information for others on how to cope with bereaved - not to be scared of them and run away" (J14). "I wish there was more information for people to know what to say" (N7). One parent suggested educating the public was a role for social workers (N2).

Another main theme expressed by parents was their need for connection to others (9 or 21% of responders, Injury = 5 or 22%, Non-injury = 4 or 21%) especially others with similar experience. Connection was needed to counteract the isolation felt by parents. You need: "Access to a friendly ear. You think you're the only one" (J22); "Contact right away from bereaved parents themselves" (J5); "Outreach of volunteers acquainted with the situation who have been through it to give an ear" (N3). The opportunity to share their story was important. "Talking with other parents a big help" (J6). "Being able to talk freely to other people about them (deceased child) helps" (N8).

"A visit to talk about what is happening. This is what I've been wishing for since the day he died, someone to talk to" (N15).

Three parents (7%), all from the non-injury group (16%) expressed a need for rest and relief from the demands of work or daily living. As one parent put it "A chance to get away from everything" (N18). The difference in proportion of injury (0% of group) and non-injury bereaved parents [16% of group,  $z = -2.03$ ,  $p < .05$  (two-tailed)] who expressed this need was significant.

Parents suggested how their need for information, support and/or respite might be met. The majority of parents proposed either support groups or one-on-one relationships with someone knowledgeable. Other options included family support, faith connections, and literature.

Support groups were the most frequently suggested method of getting information and support (14 or 33% of respondents, Injury = 6 or 26%, Non-injury = 8 or 42%). "Any support group of people with like experience would be good" (J6). "Meet with others in need - be able to help another family" (N13). "A place for talking, reading, sharing listening, crying" (N14). "A place where people can tell their story within the company of a caring community that understands" (J12).

One-on-one meetings with a counsellor or experienced parent were the preference of (9 or 21% of respondents, Injury = 4 or 17%, Non-injury = 5 or 26%). Counsellors needed to be knowledgeable and empathetic. "It's critical that the counsellor be compassionate and understanding, a guide through unfamiliar territory" (J3). But it was not necessary for many that the support person be a professional. "Somebody to sit down and have a cup of coffee and find out if they could do anything for them" (J19). "I think

if another bereaved parent had come forward when he first passed away it would have helped" (J13). "...should have had someone phoning to talk, either a parent or a professional" (N10). Two parents (5% of respondents, Injury = 1 or 4%, Non-injury = 1 or 5%) mentioned the importance of services offered to the family unit. "Help the family cope, not just me" (J11).

An important element of contact was that it was other-initiated. Parents referred to "outreach" (N3), to "contact *from* bereaved parents<sup>17</sup>"(J5), "Needed someone to take the initiative" (N6), "a phone call or letter" (N13). "I know I needed pushing, someone to call and say, you need this and I'm coming to make sure you get it" (N6).

Follow-up was seen as important. Follow-up to an initial contact from a social worker was suggested: "Even if you don't want it today, keep offering" (N1). Follow-up to helping relationships established in the hospital was also seen as potentially helpful. One parent said that while her child was sick, it was nice to have someone to talk to, to help her prepare and know what to expect, how she might feel. Then she felt "totally cut off" when she walked out of the hospital after her child's death. She suggested it would be good to have someone at the hospital walk through the last days with you and then continue (N7).

Three parents (7% of respondents, Injury = 2 or 9%, Non-injury = 1 or 5%) suggested they would be able to initiate contact with resources. Options for this might be "Telephone numbers of a network of people" (J22) or a 1-800 line, "Even if it was as basic as a referral to services that are good, specific to the area and a listening ear" (J18). Two parents (5% of respondents, Injury  $n = 2$  or 9%,  $z = 1.32, p > .10$ ) referred to the importance of literature. "Reading is what worked for me" (J9).

Seven parents (17% of respondents, Injury = 4 or 17%, Non-injury = 3 or 16%) included a time frame for service provision. Three suggested immediate involvement of a service provider or connection to services. The other suggestions were 2-3 weeks after loss, two months after, three months after and nine months following loss.

The challenge of connecting people to resources was creatively addressed by two parents in particular. One suggested a service that would be available for parents immediately with information to guide them through the situations and systems associated with child death. In the process of information provision there would be opportunities for counselling or referral to counselling. In the same way that nurses make an assessment of the coping skills of a new mother, a professional could make an assessment "to recognize those who might benefit from different kinds of help. People can't necessarily identify what they need" (N19). Another parent suggested the possibility of "a bereavement team that moves about in the beginning" (J23). Such a team would provide a service similar to that previously described.

The final suggestion was related to the need to have time away from employment. "We have some leaves for health reasons, but I haven't seen them for grieving reasons. Six to eight weeks of Employment Insurance would be really helpful. Memory is affected, clarity of thinking, short term help would be very helpful and not put the whole onus on the employer" (N17).

In summary, when asked for their recommendation for service development, parents suggested ways to meet their need for information, support and relief. Parents wanted information on the process of grief and how to cope with their loss both practically and emotionally. They wanted support in the form of connection to support

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<sup>17</sup> Emphasis added.



groups or to other bereaved parents or issue specific counsellors. They wanted respite from the demands of daily living. Generally, parents did not want sole responsibility for initiating services.

### Summary

Using Figley's (1996, /December) model of intervention waves provided some insight into what parents found helpful during the process of adaptation to the loss of a child. Although there was much overlap from "wave" to "wave", some distinctions can be noted.

At the time of crisis, those first days immediately following the death, parents appreciated actions and attitudes that acknowledged a momentous event had occurred. They valued those who were able to provide service with compassion and those who shared in their loss. These themes provided validation for parents' experiences. In addition to validation, parents highly valued services provided to assist them in maintaining some control. This included systems and individuals anticipating and being organized to meet their needs. It included flexibility in organizations that allowed parents to have their particular needs addressed as well as information and resource provision. Dealing with those with whom they had a previous relationship was also valued. Many of the suggestions for improvement of services in this time frame were directed at increasing the ability of the systems in place to recognize and meet parents' needs. It was important for parents to have supports that would limit the degree to which they were overwhelmed by the event. At no other time in this model was control as important as it appeared in the crisis period.

Following the acute crisis phase, Figley (1996, December) suggests there is a period where emphasis is on trauma mastery. In the first weeks after the funeral, many parents were dealing with acute symptoms. Counselling and workplace support were cited most often as helpful interventions at this stage pointing again to the need for validation and control. A supportive workplace was noted significantly more often by injury bereaved parents. Parents also valued information. These interventions continued to address parents' needs for validation and control. There was a sense that at this stage many parents were struggling just to maintain daily living. Also at this time, a distinction became clear between parents who were looking for assistance and a small number whose values prohibited help seeking.

The third wave in this model addresses the acute grief phase. Reading was the most often cited source of help at this time. Also many parents were either looking for or welcomed support. They were striving to understand themselves (control) and be understood by others (validation). Specific kinds of assistance were surveyed. Reflecting their need for understanding, parents most often recognized other bereaved parents as a source of support. Knowledgeable counsellors were also considered important. The shift from dealing with trauma to dealing with grief is highlighted by parents' introduction of rituals and memorials as a helpful tool.

Healthy loss accommodation is the focus of the final wave. Although parents self-identified as having moved beyond acute grief, their responses here indicated their ongoing reliance on support and understanding. They described their need to continue with counselling, with contact with other parents, and with respite from the demands of a "normal" routine of work and other responsibilities. They reacted to what they perceived

as the general view that their grief should have been resolved by now. A very few were ready to move forward with new challenges.

The experiences of parents bereaved by an injury death and those bereaved by a non-injury death were more alike than different. There was very little evidence to support the hypothesis of different service needs for injury and non-injury bereaved parents. Parents from both groups appeared to share equally in their need for recognition of the catastrophic nature of their loss and their need to re-establish a sense of control in their lives. Both groups noted strengths and weaknesses in the systems with which they were dealing. Significant differences between the groups in proportions of responses were infrequent.

Common themes, changing only in emphasis, are evident for both groups at each intervention wave in this assessment of service needs. Throughout this description, the threads of validation and control can be traced as they are woven in the fabric that is the parental bereavement experience.

## CHAPTER 5

### DISCUSSION

This chapter is organized to present key findings and their relationship to the existing body of literature. Contributions to the empirical literature and implications for the theoretical literature will be discussed. Implications for future research, policy and practice will be outlined. Finally limitations of the research project will be examined.

#### **Contribution to Literature**

##### Trauma

A major purpose of the current analysis was to test whether there was empirical evidence of the presence of posttraumatic stress in parents who were bereaved by the injury death of a child. The initial assumption was that parents whose child's death was sudden, unanticipated, and from external causes would experience more symptoms of posttraumatic stress than parents whose child's death was the result of a previously diagnosed internal cause. The findings of this study modestly support the author's assumption.

The injury death of a child was significantly related to the intensity of posttraumatic stress in parents. Analysis of the continuous measure of PTSD provided evidence that injury bereaved parents experienced more intense symptoms of traumatic stress than non-injury bereaved parents when the effects of the age of the child at death were controlled. Injury deaths have previously been shown to produce PTSD symptoms in survivors across relationships (Blanchard & Hickling, 1998; Green, 2000; Harris-Lord, 1996; Resnick, Kilpatrick, Dansky, Saunders & Best, 1993; Stevens-Guille, 1999) and in

parents for particular causes of death (Applebaum & Burns, 1991). This finding would indicate that the death of a child from any injury cause predicts symptoms of traumatic stress in parents. The finding that PTSD symptoms were more intense in injury bereaved parents than non-injury bereaved parents supports the commonly held assumption that sudden violent death causes more stress than other types of death. This assumption is implicit in the DSM-IV TR (American Psychiatric Association, 2000) description of traumatic events that includes learning about a child's life threatening condition but does not include the child's death from that condition. The comparative stress effects of injury and non-injury child deaths have been demonstrated in the recently reported research of Li, Precht, Mortensen and Olsen (2003). They assert the greater impact of the injury death of a child is evident in the mortality rates of parents up to 18 years following the death of a child. In their nation-wide study in Denmark, "the unexpected death or death from unnatural causes of a child resulted in higher relative maternal mortality rates than did the expected death of a child" (p.366). The author is not aware of other studies comparing the traumatic effects of injury and non-injury child death.

The dichotomous diagnosis scores provided prevalence rates for comparison. Caution needs to be taken in interpreting the prevalence rates found in this study. The possibility of increased Type II error has been noted as a result of using the less stringent F1-I2 diagnostic scoring protocol. However, the finding of a 30.4% rate of diagnosis in injury bereaved parents was consistent with the rates of PTSD noted in the literature for other traumatic events. In summarizing the phenomenology of PTSD, Tomb (1994) indicated that with serious trauma, the "lifetime prevalence rate for PTSD from most causes tends to be about 30% of those exposed" (p.248) to the traumatic event.

The lifetime rates of PTSD<sup>18</sup> in family and friends of victims of criminal or vehicular homicide have been variously reported at 22.1% - 23.3% (Amick-McMullen, Kilpatrick & Resnick, 1991; Resnick, Kilpatrick, Dansky, Saunders & Best, 1993). Amick-McMullen Kilpatrick and Resnick (1991) based their finding of 23.3% prevalence upon an assessment of PTSD according to the DSM-III-R. No specific measure is described. Resnick, Kilpatrick, Dansky, Saunders and Best based their prevalence determination on a national sample of American women using the National Women's Study (NWS) PTSD Module, a modification of the Diagnostic Interview Schedule. Kappa coefficients of agreement between the NWS PTSD Module and the Structured Clinical Interview for DSM-III-R were .77 for lifetime PTSD and .71 for current PTSD. Differences in these rates and those found in the current study may be the result of different instruments. However, the author would argue that prevalence rates in a sample across relationships are not directly comparable to prevalence rates among parents.

Previous studies of parents have reported PTSD rates ranging from 12.5% for fathers and 27.7% for mothers at 5 years post-death (Murphy, Johnson & Lohan, 2002) to 35% in parents of children who died violently (Applebaum & Burns, 1991). (Both these studies used PTSD measures developed by the authors for their investigation. Specificity of the instruments was not reported.) Like the Murphy, Johnson and Lohan study (2002) this research combined all external causes of death rather than examining a particular cause such as vehicular crashes or homicides. Therefore, these results provide additional verification that the death of a child due to an external cause contributes to posttraumatic

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<sup>18</sup> It should be noted that these studies used different assessment tools and their rates are not directly comparable.

stress in injury-bereaved parents. Also, for the purpose of the diagnosis of PTSD, they support the inclusion of the injury death of a child as a traumatic event.

The unanticipated finding in this sample was the similarity between the traumatic sequelae to injury and non-injury deaths. In this study, more intense symptoms of traumatic stress did not lead to an increase in prevalence of diagnosis for the injury group. The PTSD rate for the entire sample (groups combined) was 30% consistent with Tomb's (1994) estimation. As a group, the Non-injury parents had a PTSD rate of 29.4%. Because this study did not include a cohort of parents who were not bereaved, it is necessary to consider other sources of normative data for comparison. Although not restricted to parents, the research of Stein, Walker, Hazen & Forde (1997) is instructive. In this study of a random sample of 1,000 adult residents of Winnipeg, the prevalence of full PTSD was 2.7% for women and 1.2% for men. Their analysis of the prevalence of partial PTSD (meeting many but not all of the requirements for diagnosis) was 3.4% for women and 0.3 % for men. Although the current findings were not gender-specific, it is apparent that the rates of PTSD diagnosis are considerably higher among the bereaved parents in this sample than the general population. Given that any significant differences between the groups on variables known to effect trauma responses were statistically controlled, it appears that the prevalence of PTSD in the non-injury group is a genuine finding in this sample. The writer is unaware of other research examining the traumatic impact of child death from internal causes. However similar results have been noted in another bereavement context. Green (2000) cites a 1991 study of conjugal bereavement reported by H. Schut, J. De Keijser, J. Van Den Bout and J. Dijkhuis. In that study the authors estimated the proportion of subjects who had "probable" PTSD at four time

points post-bereavement. They found that 20-31% of participants could be diagnosed with "probable" PTSD during at least one time period even though most of the spouses in their study had died of natural causes. Other comparisons in the literature are related to symptoms that follow different types of injury bereavements including suicide, homicide and accident (Dyregrov<sup>19</sup>, Nordanger & Dyregrov, 2003; Murphy, Johnson, Wu, Fan & Lohan, 2003).

These findings would support the description of the death of a child as a traumatic event. While there are references to the death of a child as a traumatic event (Rando, 1993; Figley, 1996) empirical evidence is not well reported. Witnessing or learning about the sudden unexpected death of a family member or learning that one's child has a life threatening disease are described in the DSM-IV TR (American Psychiatric Association, 2000) as potential precursors to PTSD. This research indicating that PTSD diagnosis and symptoms of traumatic stress are common in a sample of both injury and non-injury bereaved parents strongly supports the conceptualization of child death as a traumatic event without reference to the cause or circumstances of the death.

### Grief

Based on the literature, it was hypothesized that injury death would be associated with greater intensity in grief reactions. This was not the case in this sample. Closer scrutiny of the literature demonstrates some of the inherent difficulties in research in a field where the constructs are so variously defined and measured. For example, Murphy-Mancini (1988) in a study of 30 bereaved couples found better "grief resolution" in

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<sup>19</sup> Dyregrov et al. (2003) included SIDS in their comparisons but while SIDS is non-violent, it is also a sudden unanticipated death.



parents who had a child die from illness rather than accident. This is likely not comparable to grief as it is measured by the HGRC. Murphy, Gupta, Cain, Johnson, Lohan, Lang & Mekwa (1999) conclude that violent death of a child results in sustained mental distress but they offer no comparison to other child deaths. Using their 17 item Core Bereavement Items (CBI) scale on a sample of 120, Middleton, Raphael, Burnett and Martinek (1998) found sudden accidental deaths were related to higher scale scores. Comparing scores across relationships, their sample had most sudden accidental deaths in the parentally bereaved group thereby confounding that result. The research of Gamino, Sewell and Easterling (2000) also found accidental death to be a strong predictor of grief intensity as measured by the HGRC and the Grief Experience Inventory (GEI). However, their study (N = 85) was also done across relationships with only 11.8% of relatives being children. Again there was possible confounding of accidental death and parental bereavement. Indeed, they report that the strongest set of predictors were traumatic death, younger age of decedent, and perception of preventability. All three variables may be associated with parental bereavement. Sanders' (1982-83) study of 86 bereaved participants across relationships using the Grief Experience Inventory (GEI) and the MMPI found no significant differences between sudden death, long-term chronic illness death, and short-term illness death.

The present comparison of bereaved parents is by design a more accurate reflection of the impact of the mode of death on parental grief because it is made within the parental relationship. One study (Fish, 1986) compared the grief intensity of parents who experienced an unanticipated death of a child with parents who experienced an anticipated death. GEI scores of mothers were consistently higher in anticipated deaths

than in sudden deaths. For fathers the opposite was the case. These results reflect a gender incongruence that may influence a comparison of reactions to injury and non-injury death. However, as injury and non-injury groups in this study did not differ significantly in gender composition, it is assumed that this impact would be minimal.

The differences between groups in this study were, with one exception, very small and insignificant but consistent in that injury-bereaved parents' scores were slightly higher. These small differences might be significant in a large sample. The exception was the finding of a higher rate of Panic Behaviour in non-injury bereaved parents. This was an unexplained result for which the literature offers no suggestion. It may be that the somatic symptoms included in the Panic Behaviour dimension are actually measuring another dimension of stress. The Panic Behaviour dimension includes items that ask about headaches, backache, feeling tired, feeling ill, muscle tension and worry. Perhaps these symptoms are also applicable to the condition of fatigue and burnout that would be associated with parents who have endured the lengthy illness of their offspring. In assessing the discriminate validity of the HGRC, Hogan, Greenfield, and Schmidt (2001) noted that the Panic Behaviour scores were significantly higher for mothers whose child died by homicide than for mothers whose child died by illness or accident. This would indicate that the HGRC did not discriminate between illness and accidental deaths. This is consistent with the finding here of no significant difference between injury and non-injury bereaved groups.

Overall, the results of the comparison of grief intensity between groups in this sample challenge the view that grief intensity in bereaved parents is related to the mode

of child death. In this sample, the cause of death did not have a significant impact on grief intensity as measured by the HGRC.

### Social Support

There was no consistent correlation between measures of the perception of social support and the intensity of grief or traumatic stress. The hypotheses that perception of social support would be negatively correlated to grief and traumatic stress intensity were based on the premise that social support acts to ameliorate distress. In this sample, perceived social support did not have a large enough effect to be significantly noted. Although the null hypotheses could not be confidently rejected based on these results, there were indications that both grief and traumatic stress were negatively associated with perceived social support. Except for the very small and statistically insignificant positive relationship between PSS-Fr and Blame & Anger, all the correlations were in the predicted direction. Elements of both grief and traumatic stress demonstrated small significant relationships. Three grief dimensions (Despair, Panic Behaviour and Personal Growth) of the six tested demonstrated significant correlation to perceived social support. Two (Avoidance and Total Severity) of the four measures of posttraumatic stress were significantly correlated to perceived social support.

Defining the role of social support has been problematic across studies of grief and PTSD. Sprang & McNeil (1998), using Turner's Provision for Social Relations Scale, found it to be a robust predictor of reduced grief and PTSD. Murphy, Gupta, Cain, Johnson, Lohan, Wu & Mekwa (1999) found that social support, as measured by the Perceptions of Support Network Inventory of Orit, Paul and Behrman, did not provide

evidence of protective effects to injury bereaved parents. Stevens-Guille (1999) found no significant differences in levels of distress or past feelings of grief when comparing those who felt supported by family with those who did not feel supported by family. She did find a significant difference in PTSD between those groups. In her sample of family victims of homicide, family support was significantly related to higher levels of PTSD symptom intensity and stronger feelings of current grief. Her finding of the relationship between PTSD and family support is in the opposite direction to the finding in this study. [She describes the measure used as "rather weakly constructed" (p.64). It was based on the sum of five discrete items rated yes or no.] Comparing current findings with other studies introduces confusion as a result of variation in the constructs measured and the instruments used.

Social support is variously defined. Measures may be objectively constructed to quantify actual social interactions. They may reflect the action of the informal or formal network. They may also, as in this case, be constructed to measure support as an individual perceives it. A comparison of subjective and objective measurements is flawed. Correlation may exist between the two but they do not represent the same construct and cannot be considered equivalent. Differences in the effects reported in the literature may be the result of measuring different constructs. However, the studies cited (Murphy et al. 1999, Sprang & McNeil, 1998 and Stevens-Guille, 1999) like the present study attempted to measure social support subjectively. Even so, the inconsistency in the results suggests the possibility that different dimensions of social support are being examined. It should also be noted that Sprang and McNeil (1998) were examining post-homicide reactions across relationships. The participants in the studies of Murphy et al.

and Stevens-Guille were all bereaved parents. Differences in the correlation of social support to grief and trauma may also be a reflection of the participant's relationship to the deceased.

There appear to be differences in the pattern of relationships between perceived support from friends and from family and other measures in the present sample. The support of both family and friends was significantly related to elements of grief. Family support was negatively related to Despair and support from friends was negatively related to Panic Behaviour and positively related to Personal Growth. However, only perceived family support appeared related to PTSD. All these correlations were small. Other studies of grief and trauma have not differentiated between these potential sources of social support.

Interpreting the finding of a significant negative correlation between Avoidance & Numbing and perceived family support as an indication that perceived family support ameliorates PTSD symptoms raises questions for this writer. Can causality be assumed? If (as measured by CAPS) individuals are expending energy in avoiding thoughts and feelings associated with the death; if they are avoiding activities and people that arouse recollections of the death; if they have markedly diminished interest in significant activities, feel detached or estranged from others and have restricted affect; then it can surely be no surprise that they are not feeling the warmth of family support. (The actual presence or absence of family support may be largely irrelevant to perception.) Add to that the fact that their family members are co-bereaved and possibly suffering similar symptoms, and it is difficult to view the measure of perceived social support as an ameliorating intervening variable. It is more likely a secondary measure of the degree of

detachment and avoidance parents are experiencing. In effect, persons experiencing less intense trauma symptoms will, therefore, perceive greater social support. Because the Total Severity score includes the Avoidance & Numbing symptom cluster, it cannot be considered separately and must be challenged by the same argument.

This study corroborates, at least for particular elements of grief and trauma, the relationship between those measures and perceived social support. However, the nature of the relationship, i.e. whether social support acts to reduce the intensity of symptoms or whether it is merely a reflection of them, remains open to question. The relationship between social support and responses to the death of a child are not clearly illuminated by the current research.

#### Duration of Bereavement

The exploratory analysis of the effect of the passage of time on symptoms of grief and trauma clearly indicated that for this group two years was not enough time to significantly reduce the intensity of symptoms. Similar findings have been reported. In the Scott and White Grief Study, Gamino et al. (1998) calculated a correlation coefficient for time since death and GEI scores ( $N = 74$ ) across relationships of mourners from 1 month to 307 months post bereavement and found no statistically significant relationship. In the current study, an increase in symptoms was significant on measures of Despair and Blame & Anger and observed on most other measures from 6 to 24 months post bereavement. Other researchers have noted an increase over time in symptom intensity. Fish (1986) found grief intensity of mothers to be greater after two years. Rando as cited by Pine and Brauer (1986) found increased grief intensity three years after death of a

terminally ill child. Murphy, Johnson and Lohan (2002) compared mental distress and PTSD among 173 parents bereaved by accident, homicide or suicide prospectively 4, 12, 24 and 60 months post-death. Using the Brief Symptom Inventory (BSI) and the Traumatic Experiences Scale (TES) as measures, they found significant main effects for time in the reduction of both mental distress and PTSD. Their results generally supported their hypothesis that there would be significant main effects for time between 4 and 12 months but not between 12 and 60 months. They also found reexperiencing scores (PTSD) higher at 60 months than at any other time. The difference in the time frame examined in the current study (6 -24 months post death) and that used by Murphy et al. (2002) (4-60 months post death) is quite large. It is possible that the early differences noted by Murphy et al. were missed by the later start and the low numbers of early grievers in the current study. However, these results increasingly suggest the possibility of curvilinear relationships between time and at least some elements of grief and PTSD. Zisook, DeVaul and Click as cited by Gamino et al. (1998) reported a curvilinear relationship between time and grief affect and described the peak of acute grief occurring between 1 and 2 years post-death. Rubin (1993) describes the possibly curvilinear relationship of time and grief symptoms in Rando's study of parents bereaved by cancer. In that study, bereavement responses appeared to ease in the second year and become more pronounced in the third year. A curvilinear relationship would explain the increases found in the current study. Whatever the relationship, there is clear evidence that two years duration as examined in this research is an inadequate amount of time for amelioration of symptoms of grief and traumatic stress.

### Age of Child at Death

Because of the effects of child age at death on PTSD found in the regression analyses, further exploratory analyses were conducted. A significant negative correlation between the age of the child at death and PTSD was discovered in this sample. The younger age of the child at death was a significant predictor of increased intensity in posttraumatic stress symptoms in parents. This finding has not been generally reported. Typically, other studies have used "child" to define a person below the age of majority, usually 0-18 years of age. This study defined "child" in the context of relationship. The age of the deceased has not been reported as an important variable in the PTSD studies reviewed. For example, age of the decedent is not mentioned in the studies of Applebaum & Burns (1991), Stevens-Guille (1999), Sprang & McNeil (1998), Amick-McMullan, Kilpatrick, Veronen & Smith (2001). The effect of the age of the deceased child was examined in a national study of Danish bereaved parents. Child age at death (0-18 years) was found to have no effect on the risk of parental mortality (Li, Precht, Mortensen & Olsen, 2003). Dyregrov, Nordanger and Dyregrov (2003) expected to find a negative relationship between the age of the deceased and psychosocial distress but did not in their sample of parents (N = 232) bereaved by accident, suicide or SIDS. Like the present study, they defined child by relationship rather than legal status. They compared the correlation of age to measures of grief and trauma within categories of cause of death. Of course, the mean ages of these groups varied significantly (suicide M = 22 range = 11-29 years, accident M = 11 range 0-18years, SIDS M = 2.5 months range = 0-1year). No comparison was made of the effect of age across the causes of death. However, in spite of the difference in mean ages, no significant difference was found between survivors of



suicide and accidents and both groups evidenced significantly greater subjective distress than survivors of SIDS did. Only one correlation, a negative relationship between age and Inventory of Complicated Grief ( $r = -.29, p < .05$ ) for accident survivors was significant. Why these results differ from the present study is unclear. The difference may be due to the use of different measures. It may also be related to the differing age distribution in the two samples. The age range within groups in the Dyregrov et al. (2003) study was somewhat narrower than the current study. The age range in this study was 0-35 years ( $M = 18.63, SD = 9.14$ ). When the sample was divided into three groups for comparison, decedents between 24 and 35 years of age represented one third of the sample. The significant difference was between the youngest age group (0-17 years) and the oldest age group (24-35 years). The decedents in the Dyregrov et al. (2003) study tended to be younger; therefore, there was potentially less contrast between younger and older decedents.

It was interesting to note the difference in the rate of decline in PTSD mean scores of injury and non-injury parents as the age of the child increased. In this sample, the intensity of PTSD symptoms decreased for both injury and non-injury bereaved parents. However, from a similar starting point, the scores of non-injury bereaved parents declined much more rapidly than the scores of the injury group. This finding conjoins two areas that are largely unexplored in the literature: first, the relationship of non-injury death and symptoms of traumatic stress; and second, the relationship between the age of the child and symptoms of trauma.

The relationship between child age and the perception of social support in this study was unexpected. Parents of older children felt they had significantly more support

from family than parents of younger children did. Intuitively, one might conclude that the need for support from family would be greater among parents of younger children. If these needs were not met, parents might report that as a perception of less support. The work of Dyregrov et al. (2003) suggests another possibility. They found the best predictor of impaired psychosocial health was the "isolation of the survivor" variable. Half of the survivors in their study were found to "withdraw from others" to some or a large degree (p.157). They linked this tendency to factors common to parents who lose their children in sudden or traumatic deaths. Citing Jordan, Kraus and Ware, they describe "traumatic experiences as producing a kind of 'experience differential' in which the range of trauma-induced feelings and thoughts of the survivor are so different from the experiences of those who have not been victimized that the survivors become alienated from their social network" (p. 185). If the younger age of the child is associated with increased traumatic responses as found in the present research, then it might also be associated with increased withdrawal from others. (This assumption is supported by the significant negative correlation found here between perceived family support and the Avoidance & Numbing symptom cluster of the CAPS.) It might then be reflected as a perception of lack of support. If traumatic responses result in bereaved parents isolating themselves, then lack of perceived social support may be an outcome of trauma rather than an intervening variable.

#### Help-seeking

The rates of help-seeking among bereaved parents were much higher than those of the general population. It is interesting to compare those rates with the help-seeking

behaviour of those diagnosed with full or partial PTSD as reported by Stein, Walker, Hazen and Forde (1997). (Help-seeking in their study of 1,000 Winnipeg respondents was defined as going to see a physician, counsellor, or minister.) Rates for these groups ranged from 52.6% to 60.0%. The authors also note that help-seeking of persons with symptoms of posttraumatic stress (full or partial diagnosis) was significantly more common than in persons without symptoms. In the present study, 65% of bereaved parents (70% of the injury group and 59% of the non-injury group) reported seeking help from a professional. (In this study, a professional was described as a doctor, psychologist, counsellor, social worker or minister). Help-seeking can be viewed as an indication of the level of interference people experience with work, social and family functioning. It is further evidence of the level of difficulty experienced by bereaved parents.

#### Service Needs

In the previous discussion of the literature related to service needs, two dimensions were identified: emotional needs and problem-solving needs. In the qualitative analysis done here, the general themes of validation and control are parallel expressions of the emotional and problem-solving needs described. This analysis included recognition of the event, sharing, compassion and caring as elements of validation. The literature has described the importance of caring compassionate helpers who are comfortable with the expressions of grief (Farrugia, 1996-2000; Videka-Sherman, 1987). Problem-solving needs have been documented to include accurate information, written materials and skill acquisition (Farrugia, 1996-2000; Rosenblatt,

2000; Murphy, 2000/2001). This analysis grouped information and literature with recognition and anticipation of needs and flexibility that allowed systems to adapt to the wishes of parents. There were several new learnings suggested by this analysis. The importance of having previous relationships with those who provided service especially at the time of crisis was clearly stated by many parents. Parents indicated their need to have service provision initiated by service providers. It was very important that systems adapt to recognize and accommodate parents' needs. With 80% of parents reporting contact with or interest in contact with other bereaved parents, networking among the bereaved must also be recognized as an important need. The role of the workplace as a source of support was also emphasized.

Although the majority of parents expressed interest in contact with other bereaved parents, the use of support groups presents an interesting contradiction. In this analysis, 58% of parents responding expressed a desire for personal contact from a bereaved parent group, and 33% of parents suggested a support group was the best way to obtain information and support. In contrast, only 25% of respondents actually reported attending a group. It is unclear why parents have not used groups to the degree to which they appear to think they are useful. However, it may be a consequence of the need parents expressed to have support initiated by the support provider. It would be instructive to identify which support groups are most effective in connecting to parents: those which make personal contact or those which use other means. Support groups have been viewed as valuable in the literature. For example, Murphy, Johnson & Lohan (2003) found that parents who attended a bereavement support group were 4 times more likely to find meaning in their child's death than parents who did not attend. Dent,

Condon, Blair and Fleming (1996) found that more than one-third of families bereaved by sudden unexpected child death (N = 42) attended a grief support group and two-thirds of parents wanted to interact with other grieving parents. In their analysis of Finnish mothers' (N=91) experience of support following child death, Laasko and Paunonen-Ilmonen (2001) also found that mothers wanted to interact with parents with a similar experience. Given that connecting parents to other bereaved parents is important, the question of how to effectively make that connection needs to be addressed.

This study pursued comparison of injury and non-injury bereaved parents. However, the service needs assessment served to emphasize the overriding similarity in experience for these groups. While some small differences might be noted, the similarities are more striking than the differences. Dyregrov et al (2003) came to the same conclusion in their examination of parents bereaved by accidents, suicide and SIDS. Overall, the cause of death has some impact on bereavement processes but the experience of parents is defined by the death of a child not the manner in which the child died.

### **Implications for Further Research**

The present study raises questions about the nature of events that would predict traumatic stress in parents and about the prevalence of PTSD. It presents uncertainties about the measurement of grief, the role of social support in parental bereavement and the relationship between the passage of time and grief and trauma. It also exposes a need for further clarification of the impact of child age on symptoms of traumatic stress and grief.

### Posttraumatic stress

It can be reasonably concluded, based on these findings and the literature, that the injury death of a child is a traumatic event and a predictor of PTSD in a portion of those experiencing the event. However, the finding that PTSD symptoms are often sequelae to the non-injury death of a child needs further investigation. There is little empirical evidence for "natural" death as a precursor to PTSD. Further research is needed to clarify the definition of a traumatic event.

Determining the prevalence of PTSD diagnosis both full and partial has been done for a variety of populations. However, the instruments used and the criteria for determination of diagnosis are varied and not always reported in a manner specific enough for replication. There does not appear to be a "gold standard" screening instrument that is user friendly in terms of validity and ease of administration. Structured clinical interviews like the CAPS offer many advantages, especially to the clinician, but are lengthy to administer in the research context. Researchers have often chosen self-report and/or study specific measurement strategies. This makes comparison of prevalence rates complicated and unreliable. Recognition of a standard measurement strategy or an assessment of the relative diagnostic utility of various measures would serve to make comparisons more relevant.

### Grief

Although there are a number of comparisons of the impact on surviving family of ways of dying, conclusions remain mixed. One of the challenges to effective research is isolating constructs for comparison. Grief is a complex experience and its various components cannot be assumed to represent equivalent dimensions. The present findings

suggest that the biopsychosocial responses to loss among bereaved parents are similar regardless of the cause of child death. In this research, Rubin's Two-Track model (Rubin, 1999) proved to be an extremely useful tool for isolating the constructs to be explored. It appears that much of the confusion in the literature may result from comparison of components of the grief experience that are not equivalent and would lie on different trajectories of the Two-Track model.

Rubin (1993) has described loss as a double process event. "At one level, it is the attack on the relational bond to a particular individual that requires the bereaved to make major modifications in the internal relationship to the deceased. At another level, loss and its aftermath are a major traumatic stressor capable of affecting the bereaved at all levels of biopsychosocial functioning" (pp. 290-291). His two-track model is an attempt to isolate these related but not identical multidimensional aspects of loss along two main axes: functioning, identified as Track I; and relationship, identified as Track II. When grief is examined it must be clear which aspects are being studied and reported. The present study examined aspects of the functioning of bereaved parents. It did not address, for example, differences in injury and non-injury bereaved parents in the process of transforming and reorganizing their relationship to the deceased child or finding meaning in the death. Further research along both axes of Rubin's model would serve to clarify the grief process and allow more effective comparison of contributing variables.

A second challenge is finding or developing instruments that have the ability to discriminate between groups. Do the findings here indicate a fundamental similarity between the grief responses of injury and non-injury bereaved parents? Or are they simply a reflection of the inability of the HGRC to differentiate between those groups?

There may be differences between the functioning of injury and non-injury bereaved that are not reflected here. It is also possible that the differences between injury and non-injury groups cannot be seen in the functioning of parents (Track I) but are evident in relational aspects of coping with loss (Track II).

### Social Support

The role of social support also presents a fertile area for further research. This study has used a stress model to describe the bereavement experience. In spite of confusion in the empirical literature, social support is generally viewed as an ameliorating resource within that model. This finding of a few small significant correlations between perceived support and grief and trauma intensity does little to clarify the confused relationship found in the literature.

This study and others (Gamino, Sewell & Easterling, 2000) have been affected by problems that arise from the disproportionate representation of participants who acknowledge support, notably an increased risk of Type II error. A negatively skewed distribution is not unusual in life satisfaction measures (Pallant, 2001). Tabachnick and Fidell (1996) indicate that with reasonably large samples skewness does not substantively influence analysis. Research with larger samples may add to our knowledge of the relationship of social support to bereavement.

In addition, because of the nature of bereavement, there is usually no possible comparison of pre and post-bereavement measures. Studies are then cross-sectional and preclude determining causation. The literature has assumed a causal relationship between support and reduced symptoms of distress. The current exploration of perceived support



and both PTSD and child age raises a challenge to that causal assumption. In this sample, the lack of perceived support might have been the result of increased symptom intensity. Given the diversity of findings in the literature, a careful analysis of the relationship between social support and symptoms of grief and trauma is in order.

#### Bereavement Duration

Another area requiring further research is the nature of the relationship between symptoms of grief and trauma and the length of bereavement. More longitudinal studies including both injury and non-injury deaths are required. A minimum of five years would be needed with several test points to plot the path of symptom intensity. If, as has been suspected, this relationship or pieces of it are curvilinear then this information has significant implications for further research analyses, for policy and for practice.

#### Age of Child at Death

Finally, further research is necessary to clarify the effect of the age of the child at death. This study raises questions about the relationship between the age of the deceased child and both symptoms of trauma and perception of social support. It also suggests the effects may be different in injury and non-injury bereaved parents. Also, this sample was not large enough to examine any differences in age within the 0-18 age group. It is that group that is typically used in examining the death of a child. However, the parental bereavement experience is not confined to the death of a minor. To fully understand parental bereavement, its study cannot be limited by child age and any effects of child age should be understood.

### Implications for Theory

The present findings suggest that an accurate understanding of parental bereavement requires the marriage of grief and trauma theories. It might be argued that recognition already exists for posttraumatic stress symptoms in that the HGRC includes a panic behaviour dimension. Indeed, the links between trauma and loss have been outlined in the literature. Correlation between the CAPS total severity score and HGRC dimensions are noted and there are similarities in the items of both instruments addressing hyperarousal e.g. in areas of sleep loss, memory efficiency and some somatic symptoms. However, the symptoms associated with reexperiencing and avoidance characteristic of PTSD are not included in the HGRC items and appear unique to the assessment of PTSD. While determining the degree to which these instruments measure separate phenomena is beyond the scope of the present analysis, there is little reason to conclude they are measuring the same construct. Therefore, both grief and trauma must be seen as components of the parental bereavement experience. If these findings were replicated within a larger sample and could be generalized to the bereaved parent population, they would have important implications for our understanding of parental bereavement and for the characterization of a parental bereavement model.

This analysis tends to minimize differences between the bereavement experiences of injury and non-injury bereaved parents. It establishes that PTSD and/or traumatic stress can be expected to follow the death of a child in a portion of both injury and non-injury bereaved parents. This finding should not make it necessary to label or ascribe pathology to parents who have this experience. Rather, this phenomenon should be recognized as one of the expected potential responses to the death of a child. It should be

acknowledged as one of the components of the complicated grief that typically follows child death. Trauma mastery should be included among the normal tasks of parental grieving. While the intersection of grief and trauma has been recognized as a consequence of violent death (Steven-Guille, 1999), that same blending of grief and trauma is seen here to occur as a consequence of any death of a child death.

Rubin, Malkinson & Witztum (2003) in their recent examination of trauma and bereavement have argued that "the relation to the deceased is insufficiently acknowledged as a source of traumatic disruption following bereavement" (p. 667). One of the assumptions of their argument is that personal experience of a traumatizing proportion can occur in the case of bereavements that give no hint that external circumstances are particularly traumatic. They further suggest that bereavements that are the result of external trauma might be better described "...as bereavements occurring under conditions of additional external trauma" (p. 686). They posit that the relational aspect in bereavement can be central to what may be interpreted as a response to life-threat or trauma. "The location of trauma as basic to the experience of all bereavement for its impact on the reorganization vis á vis the representation of the loved one now deceased is considered as fundamental to the trauma of all bereavement" (p.667). The current study compared variables on Track I with the injury groups experiencing what would normally be considered a traumatic event. However, the findings of traumatic stress in injury and non-injury groups in this study would support Rubin et al. (2003) in their argument that an assault on Track II, i.e. on an existing relationship, in this case the parent child relationship, is equally important in creating a traumatic bereavement.

The association, in this study, of the younger age of a child with traumatic responses would further corroborate the view that there are relational factors in traumatic bereavement. Although the bonds of affection and commitment may be the same for parents of dependent children and parents of adult children, there is certainly not the same feeling of responsibility. Parents are responsible for the lives and well being of their dependent children. This sense of responsibility would contribute heavily to feelings of helplessness in the face of child death. Feelings of helplessness are by definition a predictor of PTSD (DSM-IV TR, American Psychiatric Association, 2000)). This may explain why the deaths of dependent children were associated with heightened levels of traumatic stress.

### **Implications for Policy**

Death of a child is a family issue. Where do families turn for assistance? There is no obvious resource choice for families. It is clear from the service needs assessment that families already associated with hospital services were not able to retain that resource after the death of their child. Employee Assistance programs (with modest exceptions) were generally unsuccessful in addressing parent needs. Finding helpful resources appeared to occur as much by chance as by design.

All families suffering the loss of a child have some association with a hospital. Almost all children receive hospital care preceding death and/or are pronounced dead in the hospital and/or are sent for autopsy. All deceased children have contact with a funeral home. It should be possible to coordinate family survivor services through one of these access points to bereaved families. But who would assume responsibility for the

cost of service provision? Death is usually included in the medical domain. Support services to families could be seen as intervention within the broad view of health care. This is especially true in the light of a recent Danish population study finding increased mortality rates for parents, especially mothers, of children who died (Li, Precht, Mortenson & Olsen, 2003). Many parents currently use their physician as a bereavement resource. Being able to offer the services of a competent hospital-based bereavement counsellor who could initiate early contact with parents and offer information and connection to resources based on assessment of need would make sense as a population health measure. So would post-death support to parents whose children have been undergoing medical care. Parents reported the benefit of receiving support from people with whom they were previously familiar. They also strongly expressed their preference for follow-up from hospital service providers. Those service providers are people who knew the child, cared for and cared about the child. Their previous experience with the child and the family makes their continued input particularly valuable according to the needs expressed by parents in this review. They have an important contribution to make to parents at their time of greatest need.

Other studies have noted parents' expectation that hospital workers continue to provide contact following child death (Dent, 1996; Laasko, 2001). Ward (1997) has described an Irish model of intervention with families experiencing SIDS. Procedures were developed based on discussion between nurses, chaplaincy, social services and pediatric staff with involvement from police and funeral directors. Specific responsibilities were given to each professional. An information booklet was prepared for parents. A senior pediatrician led the group. He/she saw parents immediately, shared

autopsy results two to three days later and saw parents again after six to eight weeks. Ongoing liaison was the responsibility of the casualty ward sister. The family physician and public health nurse were kept informed. An evaluation of the intervention demonstrated both short and long-term benefits to parents.

An inclusive approach to terminal illness would include follow-up family services in the event of child death. If this service could not be extended to all parents, it would remain useful to at least provide follow-up service to families who have experienced the death of a child following illness and hospital admission.

Parents in this study made it clear that an important characteristic of effective service provision was its outreach. Parents recognized their need to have others reach out to them. It was not enough to have services available; they needed to be directly offered. Parents clearly stated their need for reliable information compassionately relayed, for a listening ear and for connection to other parents with similar experience. The average time suggested for contact with them was 2.5 months post death. This description showed the foresight of Videka-Sherman who in 1987 proposed the development of an outreach program that would provide follow-up between two and three months post loss to assess mourner functioning and initiate services as necessary.

Extending services to the families of those who have died is not unknown in Manitoba. Hospice & Palliative Care Manitoba (2003), a non-profit charitable organization serving the dying, includes bereavement support among its services. Through staff and volunteers it provides care to individuals and families including one-to-one telephone support, information and referral, walking programs and written resources. Its approach treats the family system rather than just the dying individual. A

similar approach to the health of families who have experienced the death of a child is necessary.

Employment bereavement policies are inadequate. Many parents reflected on the importance of support (especially leave) provided in the workplace. Unfortunately, the financial help they received was dependent on either the goodwill of the employer or on the availability of sick leave. Some parents felt they returned to work too soon. Murphy, Johnson & Lohan (2002) reported that parents in their study of violent child death raised the same concerns. Paid bereavement leave would be of great assistance to parents. Adding bereavement leave to national Employment Insurance benefits would allow employers to respond more effectively to the needs of parents.

Employment Insurance initiatives recognizing the importance of family are already in place. Parents qualify for up to 50 weeks of combined maternity/parental leave upon the birth or adoption of a child into the family. Effective January 4, 2004, Human Resources Development Canada (2003) extended Employment Insurance to include Compassionate Care benefits. These benefits allow workers 6 weeks of paid leave to provide "psychological comfort or emotional support", or direct care to a gravely ill family member. The Government of Manitoba has recently enacted complementary legislation that entitles Manitoba workers to a maximum of eight weeks in unpaid compassionate care leave. This provincial leave harmonizes with the federal provisions and makes it possible for workers to apply for federal wage benefits. Given this recognition of family needs, it would be reasonable to add a parental bereavement leave to the existing family-based benefits.

When a child is born the community recognizes and welcomes the arrival with many supports for families as they adjust to include the newcomer. There are hospital and public health services, maternity/parental leaves, family, social and religious rituals. Similar supports would assist the family's adjustment to loss.

### **Implications for Practice**

The death of a child is a traumatic experience for parents. Effective clinical practice should therefore include an assessment of traumatic stress in all parents but especially in those whose child died at a young age or whose child's death resulted from injury. There are a number of assessment tools available and early assessment would enable clinicians to assist parents by providing information and techniques to support trauma mastery. If, as has been suggested (Rando, 1993), resolving trauma must precede the tasks of grief, then this is a vitally important intervention. Parents have expressed their need to establish some sense of control at a time when their lives are careening horribly out of control. Trauma mastery would enhance parents' ability to establish feelings of control.

The amount of time required by parents to adapt to loss is substantial and poorly recognized. Clinical practice supports must be available for the long term. Unfortunately intervention programs tend to be brief and affect focussed (Murphy, 2000/2001). Intervention programs for parents need to initially focus on the biopsychosocial responses of Track I including traumatic stress and then move to the cognitive tasks of meaning construction and adaptation to loss. Although, because this was not a longitudinal study, it is not possible to state that the intensity of symptoms increases on an individual basis, it



is clear that parents two years post death may be experiencing symptoms that are more intense than those experienced by the more newly bereaved. Recognizing the general duration and intensity of biopsychosocial symptoms would help clinicians avoid the pitfall of ascribing pathology to parents who are actually progressing normally through a most difficult experience.

Both the traumatic effect of parental bereavement and the duration of high intensity symptoms are necessary topics of education for the bereaved and for the public. Parents have noted the importance of information not only about available resources but also about what to expect as part of a typical parental bereavement experience. When parents wonder if they are "going crazy" it is not because they are missing their child but because of the intensity of biopsychosocial symptoms persisting over time. Practitioners need to be able to provide an accurate picture of parental grief and trauma.

This same accuracy is necessary in public education. Without an understanding of bereavement, those who would support bereaved parents are ill equipped. Providing public education is an important role for social work.

The service needs assessment provided some insight into parents' need for validation. Increased understanding of the nature of parental bereavement will allow those who are present at the time of crisis and those within the support network to respond with a greater awareness of the impact of the event.

### **Limitations**

A number of significant limitations in this study must be noted. These are related primarily to the to the nature of the phenomenon under study and the research design

necessitated by it. They have been grouped here as being related to the statistical analysis, the sampling protocol, the cross-sectional design or the measurements used.

### Statistical Analysis

A troubling aspect of the study was the lack of power in the statistical analysis. Because effect sizes tended not to be large, the sample size limited the power available and increased the probability of Type II error. To reduce the probability of Type II error, a less stringent alpha level ( $\alpha = .10$ ) was used. However, that choice increased the probability of Type I error. Using the .10 alpha level with one-tailed tests, an effect size approaching 0.5 was necessary to achieve a power of .80 in a sample of 40. The heightened probabilities of error necessitated the exercise of caution in interpreting the null findings.

### Sampling

Both the size of the sample and its voluntary nature presented challenges to the interpretation and generalization of the findings. The size of the sample was limited by both the rarity of the phenomenon under study and the potential bias in response measures due to the passage of time. Rarity refers to the relatively low incidence of bereaved parents in the general population. Because most bereaved persons show substantial recovery on mental and physical health measures within an approximate two-year interval (Hansson, Carpenter & Fairchild, 1993), measurement of responses needed to occur within months of the loss. This meant that the population from which a sample could be drawn at any one time was small and that it could not safely be made larger by increasing the number of months since the loss had occurred. It was necessary in this instance to increase the time period during which the sample was drawn (October 2001-

April 2003) so that the minimum sample size requirements could be met. Again the small sample size compromised the probability of avoiding Type II errors. This was especially noted in the analysis of social support where the distribution of scores was negatively skewed further increasing the probability of Type II error.

Another troubling aspect was the lack of random sampling. Effort was made to contact as wide a representation as possible of injury and non-injury bereaved parents in Winnipeg and the surrounding area during the stated time period. However, in an effort to include as many as possible in the sample, no one meeting the defined criteria was excluded.

Many factors both known and unknown influenced the composition of the final sample. The use of newspaper obituaries as a primary source of parent names excluded parents who did not publish an obituary in a Winnipeg newspaper. The process of attaching addresses and phone numbers to newspaper obituaries resulted in the exclusion of those with unlisted telephone numbers, those who had moved, those with common names, and those without telephone service listed in their name. Only 28% of the original sample (75 of 265) were actually contacted. Of those contacted 53% participated. The variables influencing the decision to participate are unknown.

Murphy, Baugher, Lohan, Scheideman, Heerwagen, Johnson, Tillery and Grover (1996) used death certificates from county medical examiner's offices and were able to contact 58% of potential study subjects. Of those contacted 62% agreed to participate in an intervention and evaluation program. Other studies have relied on samples drawn from the population of members of grief support groups (Schwab, 1996, Sprang & McNeil 1998) or clinical referrals and volunteers (Gamino, Sewell & Easterling, 2000).

Sprang & McNeil (1998) using randomly selected addresses from group membership lists had a 55% response rate for participation in a mail survey. The response rates of those contacted are generally comparable: 53% in this study, compared to 55% for Sprang & McNeil (1998) and 62% Murphy et al. (1996). The greater difference lies in the number of those contacted as a proportion of those who were potential contacts. Using the newspaper was less efficient and the implications of the resulting screening of participants are unknown.

This was a convenience sample and therefore neither random nor complete. Probability samples are not typical in bereavement studies and consequently comparative representativeness is difficult to assess. A sample of volunteers may easily be biased. This sample could be considered more representative than samples drawn from support group members or volunteers only. However, a limitation to the external validity of the findings remains and exerts a caution against generalizing beyond the sample studied.

### Design

Both the quasi-experimental and cross-sectional design of this study added to its limitations.

In this quasi-experimental design, participants could not be randomly assigned to comparison groups. Therefore the equivalence of the groups is open to question. Although multivariate statistical procedures allow researchers the opportunity to control for alternative variables as a means of ruling out rival hypotheses (Rubin & Babbie, 1997), it is impossible to control for all group differences. The groups may differ in ways that are not measured or perceived.

Cross-sectional studies are correlational studies. As such they are limited to describing relationships and cannot be used to determine causation (Rubin & Babbie, 1997). The use of a cross-sectional design meant that predictors and outcomes were measured at the same time. For example, in this study the measure of traumatic stress and social support occurred together. Coincident measurement may especially increase the inaccuracy of the determination of the predictors (Rubin & Babbie, 1997). Causal ordering is therefore problematic. Just as social support may effect the intensity of traumatic stress, the intensity of traumatic stress may impact both the nature and availability of social support.

#### Measurement

Other limitations to the study are related to measurement. Measurements of predictors in cross-sectional studies are often subjective and dependent on memory. For example, information collected on the most problematic period of posttraumatic symptomatology was influenced by memory. Many intervening factors may serve to bias pre-measurement recollection. In this instance, respondents reported on current grief/trauma symptoms that may have been ameliorated by variables intervening much earlier and not clearly recollected.

A weakness in the design of the service needs assessment was noted. Although the intention was to gather information related to Figley's (1996, December) traumatic stress model of intervention waves, no provision was made for those who were not experiencing traumatic stress. It would have been more informative to identify those who acknowledged traumatic stress and analyze their responses for an understanding of the

trauma mastery wave. Then all responses could have been more accurately analyzed in the grief resolution and loss accommodation waves.

Other limitations are related to potential weaknesses in the instruments as they were used here. Concern about the discriminatory function of the Hogan Grief Reaction Checklist has been mentioned. The CAPS was designed for use with veterans of armed conflict. Its transferability to civilian bereaved parents is uncertain. Difficulty in this transfer may be reflected in the low reliability of the Reexperiencing (Cronbach's  $\alpha = .49$ ) and Hyperarousal symptom clusters (Cronbach's  $\alpha = .55$ ). There were also concerns about the efficacy of the Life Events Checklist.

In a comparison model, it is necessary to assure the equality of the exposure and comparison groups on variables that may be confounding. This was especially important, in this instance, for those variables known to effect grief and trauma. Previous traumatic experience is thought to impact responses to subsequent traumatic events. Therefore, it was essential to document previous trauma and compare the groups on previous traumatic experience. In this study the Life Experience Checklist (LEC) portion of the CAPS was used. Within the context of the CAPS interview, the LEC is intended to be the starting point for a detailed review of the participant's previous experience. In this study, no lengthy review was intended. It would not have been appropriate in the context of the bereavement interview to ask parents to delve, for example, into a previous sexual assault. However, without exploration of the events recorded by participants, the nature and degree of previous trauma is unclear. Some parents appeared to record events that would not be considered life changing. Because there was no difference in the instructions or the responses of the groups, this did not appear to compromise the

between groups comparison. However, it is uncertain what previous trauma individuals in this study experienced and what impact those experiences may have had on the results.

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## Appendix A

### Diagnostic Criteria for Posttraumatic Stress Disorder

Diagnostic criteria for Posttraumatic Stress Disorder (309.81) as outlined by the American Psychiatric Association (2000):

- A. The person has been exposed to a traumatic event in which both of the following were present:
- (1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others
  - (2) the person's response involved intense fear, helplessness, or horror.
- B. The traumatic event is persistently reexperienced in one (or more) of the following ways:
- (1) recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.
  - (2) recurrent distressing dreams of the event.
  - (3) acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated).
  - (4) intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event
  - (5) physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event
- C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:
- (1) efforts to avoid thoughts, feelings, or conversations associated with the trauma
  - (2) efforts to avoid activities, places, or people that arouse recollections of the trauma
  - (3) inability to recall an important aspect of the trauma
  - (4) markedly diminished interest or participation in significant activities
  - (5) feeling of detachment or estrangement from others
  - (6) restricted range of affect (e.g., unable to have loving feelings)
  - (7) sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)
- D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:
- (1) difficulty falling or staying asleep
  - (2) irritability or outbursts of anger
  - (3) difficulty concentrating
  - (4) hypervigilance
  - (5) exaggerated startle response
- E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.
- F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Acute: if duration of symptoms is less than 3 months

Chronic: if duration of symptoms is 3 months or more

## **Appendix B**

### **Call for Subjects Notice**

#### **BEREAVED PARENTS**

**Volunteers who are willing to share their experience  
are needed for a research project.**

I am undertaking a study of parental bereavement. Participating in the study will involve an interview and completing three short questionnaires related to your experience with: grief, traumatic stress, and social support.

My interest in this area arises from my own experience as a bereaved parent.

The purpose of this study is to increase the accuracy of information available to bereaved parents and those wishing to support them. Only parents who have survived their child's death can provide this information.

Parents who were bereaved between September 1999 and March 2001 and lost a child due to injury or following diagnosis of a life-threatening condition are invited to call for further information.

Please contact:

**Shelagh Marchenski at (204) 885-7095**

Note: This research is undertaken as part of the requirement for a Master of Social Work degree. It has been approved by the University of Manitoba Research Ethics Board.



## Appendix C

### Initial Letter to Parents<sup>20</sup>

UNIVERSITY OF MANITOBA

CHILD AND FAMILY SERVICES RESEARCH GROUP  
Faculty of Social Work

Shelagh Marchenski  
Faculty of Social Work  
University of Manitoba

Winnipeg, Manitoba  
Canada R3T 2N2

Tel: (204) 474-6663

Fax: (204) 261-3283

E-Mail: Socwork\_Research@UManitoba.CA

Name

Address

Date

Dear \_\_\_\_\_

I am writing to ask that you consider sharing part of your experience as a bereaved parent.

Although the grief that results from the loss of a child is known to be more intense than grief from other losses, it is less well understood. It is important for bereaved parents to have information that can help them understand and cope with their loss. Accurate information about parental grief and about what parents find supportive is important for bereaved parents and for those who want to help bereaved parents. Only parents who have survived their child's death can provide this information.

As a bereaved parent, it was important for me to understand what was happening to me and to feel understood by others. As a result of my experience, I am undertaking a study of bereaved parents. The purpose of the study is to increase our understanding of the grief of parents.

I am attempting to contact all parents who are next-of-kin to a child of any age who died between October 1999 and March 2001. Your name was taken from a newspaper obituary [or other source if applicable]. To be included in the study, parents must have lost a child due to injury or due to a known condition. Injury deaths include children who are the victims of accidents, motor vehicle crashes, homicides and completed suicides. A known condition may include disease or genetic disorder. Excluded are the parents of children who have died suddenly of natural causes such as SIDS or an undiagnosed disease or genetic condition.

The study is limited to one parent from each family. Parents who volunteer will be interviewed for information about the circumstances of their loss and their reactions to the loss. The interview will include gathering information to assess the level of traumatic stress experienced by parents. In addition they will be asked to complete three short paper and pencil questionnaires. It will require a total time commitment of 1½ - 2 hours.

<sup>20</sup> This letter follows the general outline suggested by Dillman (2000) for survey cover letters.



The confidentiality of volunteers will be protected. Results will be grouped and no responses will be linked to identifying information.

This research will be used to meet one of the requirements for a Master of Social Work degree and will be conducted under the supervision of Dr. S. Frankel, University of Manitoba faculty advisor. It has received the approval of the University of Manitoba Research Ethics Board.

Research is an important way of adding to our knowledge. I hope that this project will increase the ability of our community to understand and support grieving parents. I will be contacting you by telephone to introduce myself and answer any questions. Alternatively, you may call me directly (204) 885-7095.

Thank you for your consideration of this request.

Sincerely

Contact card:

If you prefer no further contact:

1. please post this card in return mail

OR

2. call 889-1999 and leave a message declining contact.  
Please remember to leave your name so that you can be removed from the list.

## Appendix D

### Telephone Contact Outline

(This script is presented as a suggestion only. Actual conversation will follow the general outline and cover the contents of each paragraph. Scripted telephone contacts have not been found to be as effective as conversational ones in eliciting cooperation from respondents ((Houtkoop-Steenstra & Van Den Bergh, 2000/2001).

I am calling to introduce myself. I am the person who recently sent out letters to bereaved parents. My name is Shelagh Marchenski.

I am calling to follow up on the letter. First of all, just to clarify that my letter went to the right place, are you one of \_\_\_\_\_'s parents?

I'm so sorry for your loss. Do you feel up to talking to me today about the bereaved parent study? (Might I call you at a more convenient time?)

Do you have any questions about the study or may I refresh your memory?

Purpose - To add to the general knowledge of what it is like to lose a child. As a bereaved parent, I wanted to understand what was happening to me and I wanted to be understood by other people. I hope this study will eventually help other bereaved parents. To increase understanding of parental grief, I am approaching parents who have lost a child between 6 and 24 months ago, and asking them to help by sharing some of their experience.

I am hoping to talk to two kinds of bereaved parents: those whose child died suddenly as a result of an injury and those whose child died after being diagnosed with a life-threatening condition. That is, I am looking for parents who fall into one of two groups. One group will have experienced a sudden violent death. And another group will have experienced a death that was somewhat anticipated. This means that parents who lost a child unexpectedly without injury would be excluded. (That is SIDS deaths, some stillbirths, and unexpected deaths due to natural causes). Would your circumstances fall into one of the groups that we are studying?

This project is part of the requirement for my Master of Social Work degree. I am being supervised by a faculty advisor and have had the project approved by the ethics committee of the University of Manitoba.

Instruments - Those who are involved will be asked to complete three paper and pencil questionnaires and to participate in an interview. The questions will relate to your symptoms of grief and any symptoms of traumatic stress. There will also be questions

about the way you see the social support you are receiving. Some personal information describing such things as your age, marital status, health and previous life events will also be asked. Your name or individual circumstances will not be identifiable in any results. You may decline to answer any question at any time.

Time - It will take an hour and a half to two hours to complete. Participants will need to be able to make the necessary time commitment.

Place - You may choose the location for our meeting. It is important that you feel at ease so you may wish to meet in your home. I have an office location also available.

Do you have any questions?

Would you consider sharing part of your experience with me?

Schedule appointment - When would it be convenient to meet? I am available days or evenings during the week and on weekends.

I will call the day before to confirm our appointment.

Consent - A signed consent form will be necessary from each participant. The form acknowledges the information we have discussed today and your signature indicates your agreement to participate. I can mail you a copy or e-mail you so that you have time to consider it carefully.

Thank you for allowing me to talk to you today and for considering my request.



**Appendix E****Consent Form**

The overall purpose of this study is to increase our understanding of parental bereavement. In particular, this study will explore grief and stress reactions as well as social support and the service needs of bereaved parents. Participants will include parents who have lost a child due to injury and parents who have lost a child as a result of a known condition.

As a participant, you will be asked to complete three questionnaires. The questionnaires include one related to grief, one related to social support, and a third designed to collect information specific to your circumstances. In addition, participants will be interviewed using a standard measure of posttraumatic stress and also asked questions about service needs. The interview questions are all open-ended and there are no right or wrong answers.

Participants must be aware that answering questions about the circumstances that led to the death of their child will expose them once again to the pain of their most difficult loss. Discussing their responses to this crisis may also evoke painful memories and powerful emotions. However, sharing ones experience and having the opportunity to talk about the deceased have been noted to have beneficial effects for parents. Participants in other parental bereavement studies have reported on the benefits of participating (Dyregov & Dyregov, 1999/2001; Schwab, 1996).

Participation is completely voluntary and individuals are free to withdraw at any time. You may refrain from answering any question if you wish.

Questionnaires will be numbered so that responses may be assigned to the injury or non-injury group. Names will not appear on forms but will be recorded separately on a master list. The list will be destroyed following the completion of data collection.

The interview and questionnaires will take approximately an hour and a half to complete.

There is no compensation for participating in this study. A summary of the results will be provided to those participants who request it.

The study will be used to fulfill one of the requirements for a Master of Social Work degree. It has been approved by the Ethics Review Board of the University of Manitoba.

\*\*\*\*\*

I have read and understood the attached information and I agree to participate in this study.

Name.....  
(Please Print)

Signature.....

Date.....

Witness .....

## Appendix F

## Instruments

Personal Information

Identifier \_\_\_\_\_

A number of factors have been shown to be related to the way an individual responds to loss. Please provide the following information:

1. How would you describe your current physical health (check one)
  - Excellent
  - Good
  - Fair
  - Poor
  
2. If you were to compare your health today with your health before the death of your child would you say
  - Your health has improved
  - Your health is about the same
  - You are not as well as you were
  - Your health is much worse than it used to be
  
3. Prior to the death of your child, were you ever treated for a mental health condition?
  - Yes
  - No
  
4. If yes, were you treated for depression?
  - Yes
  - No
  
5. Were you under treatment for a mental health condition at the time of your child's death?
  - Yes
  - No
  
6. What was your child's age at their time of death \_\_\_\_\_ years?
  
7. What was your age in years at the time of your child's death? \_\_\_\_\_.
  
8. What was your child's gender
  - Male
  - Female

Identifier \_\_\_\_\_

9. What is your gender
- Male
  - Female
10. Since your child's death, have you added another child to your family?
- Yes
  - No
11. Did the circumstances of your child's death result in litigation?
- Yes
  - No
12. Do you think that your child's death could have been prevented?
- Yes
  - No
13. A month before your child's death, would you say that you "saw it coming"?
- Yes
  - No
14. A week before your child's death, would you say that you "saw it coming"?
- Yes
  - No
15. A day before your child's death, would you say that you "saw it coming"?
- Yes
  - No
16. Please describe the importance of religion or spirituality in your life
- Very important, a daily part of my life
  - Moderately important, regularly part of my life
  - Somewhat important, occasionally part of my life
  - Unimportant, not part of my life at all
17. Are you regularly involved with a religious or spiritual group?
- Yes
  - No

Identifier \_\_\_\_\_

18. Have you ever used any of the following kinds of help in coping with your bereavement:

a) Seen a professional person such as a doctor, psychologist, counsellor, social worker, or minister to discuss your loss?

- Yes
- No

b) Tried an approach to cope based on something you read?

- Yes
- No

c) Attended a group program for help in coping with loss?

- Yes
- No

19. What is your current living arrangement?

- Now married, living with spouse
- Common-law relationship or live-in partner
- Single, never married
- Divorced
- Separated
- Widowed

20. At the time of your child's death, what was your marital status?

- Married, living with spouse
- Common-law relationship or live-in partner
- Divorced
- Separated
- Widowed
- Single, never married

21. What is the highest level of education that you have completed?

- Incomplete elementary
- Complete elementary
- Junior high school
- High school
- Non-university ( vocational, technical, nursing)

University

- Diploma, certificate
- Bachelors degree
- Medical degree ( veterinarian, doctor, dentist)
- Masters degree
- Doctorate

Identifier \_\_\_\_\_

22. What is the total income of all members of your household for this past year before taxes and deductions?

- |  |                       |
|--|-----------------------|
| <input type="checkbox"/> Under \$6,000       | ? \$34,000 - \$35,999 |
| <input type="checkbox"/> \$6,000 - \$7,999   | ? \$36,000 - \$37,999 |
| <input type="checkbox"/> \$8,000 - \$9,999   | ? \$38,000 - \$39,999 |
| <input type="checkbox"/> \$10,000 - \$11,999 | ? \$40,000 - \$44,999 |
| <input type="checkbox"/> \$12,000 - \$13,999 | ? \$45,000 - \$49,999 |
| <input type="checkbox"/> \$14,000 - \$15,999 | ? \$50,000 - \$54,999 |
| <input type="checkbox"/> \$16,000 - \$17,999 | ? \$55,000 - \$59,999 |
| <input type="checkbox"/> \$18,000 - \$19,999 | ? \$60,000 - \$64,999 |
| <input type="checkbox"/> \$20,000 - \$21,999 | ? \$65,000 - \$69,999 |
| <input type="checkbox"/> \$22,000 - \$21,999 | ? \$70,000 - \$74,999 |
| <input type="checkbox"/> \$22,000 - \$23,999 | ? \$75,000 - \$79,999 |
| <input type="checkbox"/> \$24,000 - \$25,999 | ? \$80,000 - \$84,999 |
| <input type="checkbox"/> \$26,000 - \$27,999 | ? \$85,000 - \$89,999 |
| <input type="checkbox"/> \$28,000 - \$29,999 | ? \$90,000 - \$94,999 |
| <input type="checkbox"/> \$30,000 - \$31,999 | ? \$95,000 - \$99,999 |
| <input type="checkbox"/> \$32,000 - \$33,999 | ? \$100,000 +         |

Health #1 from Sprang & McNeil, 1998

Anticipation # 13-15 from Gamino, Sewell & Easterling, 1998

Service usage # 18, marital status # 19 and education # 21, Income # 22 from the Winnipeg Area Study Report

### Life Events Checklist

Blake, Weathers, Nagy, Kaloupek, Charney & Keane (1998)

Listed below are a number of difficult or stressful things that sometimes happen to people. For each event check one or more of the boxes to the right to indicate that: (a) it happened to you personally, (b) you witnessed it happen to someone else, (c) you learned about it happening to someone close to you, (d) you're not sure if it fits, or (e) it doesn't apply to you.

Be sure to consider your entire life (growing up as well as adulthood) as you go through the list of events.

Event	Happened to me	Witnessed it	Learned about it	Not sure	Doesn't apply
1. Natural disaster (for example, flood hurricane, tornado, earthquake)					
2. Fire or explosion					
3. Transportation accident (for example, car accident, boat accident, train wreck, plane crash)					
4. Serious accident at work, home, or during recreational activity					
5. Exposure to toxic substance (for example, dangerous chemicals, radiation)					
6. Physical assault (for example, being attacked, hit, slapped, kicked, beaten up)					
7. Assault with a weapon (for example being shot, stabbed, threatened with a knife, gun, bomb)					
8. Sexual assault (rape, attempted rape, made to perform any type of sexual act through force or threat of harm)					
9. Other unwanted or uncomfortable sexual experience					
10. Combat or exposure to a war-zone (in the military or as a civilian)					
11. Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war)					
12. Life-threatening illness or injury					
13. Severe human suffering					
14. Sudden violent death (for example homicide, suicide)					
15. Sudden, unexpected death of someone close to you					
16. Serious injury, harm, or death you caused to someone else					
17. Any other very stressful event or experience					

**National Center for PTSD**  
**CLINICIAN-ADMINISTERED PTSD SCALE FOR DSM-IV**

Name: \_\_\_\_\_ ID #: \_\_\_\_\_  
Interviewer: \_\_\_\_\_ Date: \_\_\_\_\_  
Study: \_\_\_\_\_

Dudley D. Blake, Frank W. Weathers, Linda M. Nagy,  
Danny G. Kaloupek, Dennis S. Charney, & Terence M. Keane

National Center for Posttraumatic Stress Disorder

Behavioral Science Division -- Boston VA Medical Center  
Neurosciences Division -- West Haven VA Medical Center

Revised July 1998



**Criterion A.** The person has been exposed to a traumatic event in which both of the following were present:  
 (1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others  
 (2) the person's response involved intense fear, helplessness, or horror. Note: In children, this may be expressed instead by disorganized or agitated behavior

I'm going to be asking you about some difficult or stressful things that sometimes happen to people. Some examples of this are being in some type of serious accident; being in a fire, a hurricane, or an earthquake; being mugged or beaten up or attacked with a weapon; or being forced to have sex when you didn't want to. I'll start by asking you to look over a list of experiences like this and check any that apply to you. Then, if any of them do apply to you, I'll ask you to briefly describe what happened and how you felt at the time.

Some of these experiences may be hard to remember or may bring back uncomfortable memories or feelings. People often find that talking about them can be helpful, but it's up to you to decide how much you want to tell me. As we go along, if you find yourself becoming upset, let me know and we can slow down and talk about it. Also, if you have any questions or you don't understand something, please let me know. Do you have any questions before we start?

ADMINISTER CHECKLIST, THEN REVIEW AND INQUIRE UP TO THREE EVENTS. IF MORE THAN THREE EVENTS ENDORSED, DETERMINE WHICH THREE EVENTS TO INQUIRE (E.G., FIRST, WORST, AND MOST RECENT EVENTS; THREE WORST EVENTS; TRAUMA OF INTEREST PLUS TWO OTHER WORST EVENTS, ETC.)

IF NO EVENTS ENDORSED ON CHECKLIST: *(Has there ever been a time when your life was in danger or you were seriously injured or harmed?)*

IF NO: *(What about a time when you were threatened with death or serious injury, even if you weren't actually injured or harmed?)*

IF NO: *(What about witnessing something like this happen to someone else or finding out that it happened to someone close to you?)*

IF NO: *(What would you say are some of the most stressful experiences you have had over your life?)*

**EVENT #1**

<p><b>What happened?</b> <i>(How old were you? Who else was involved? How many times did this happen? Life threat? Serious injury?)</i></p>	<p>Describe (e.g., event type, victim, perpetrator, age, frequency):</p>
<p><b>How did you respond emotionally?</b> <i>(Were you very anxious or frightened? Horrified? Helpless? How so? Were you stunned or in shock so that you didn't feel anything at all? What was that like? What did other people notice about your emotional response? What about after the event - how did you respond emotionally?)</i></p>	<p><u>A. (1)</u>          Life threat? NO YES [self ___ other ___]          Serious injury? NO YES [self ___ other ___]          Threat to physical integrity? NO YES [self ___ other ___]</p> <p><u>A. (2)</u>          Intense fear/help/horror? NO YES [during ___ after ___]          Criterion A met? NO PROBABLE YES</p>

**EVENT #2**

<p><b>What happened?</b> (How old were you? Who else was involved? How many times did this happen? Life threat? Serious injury?)</p>   <p><b>How did you respond emotionally?</b> (Were you very anxious or frightened? Horrified? Helpless? How so? Were you stunned or in shock so that you didn't feel anything at all? What was that like? What did other people notice about your emotional response? What about after the event - how did you respond emotionally?)</p>	<p>Describe (e.g., event type, victim, perpetrator, age, frequency):</p>   <p><u>A. (1)</u> Life threat? NO YES [self ___ other ___] Serious injury? NO YES [self ___ other ___] Threat to physical integrity? NO YES [self ___ other ___]</p> <p><u>A. (2)</u> Intense fear/help/horror? NO YES [during ___ after ___] Criterion A met? NO PROBABLE YES</p>
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**EVENT #3**

<p><b>What happened?</b> (How old were you? Who else was involved? How many times did this happen? Life threat? Serious injury?)</p>   <p><b>How did you respond emotionally?</b> (Were you very anxious or frightened? Horrified? Helpless? How so? Were you stunned or in shock so that you didn't feel anything at all? What was that like? What did other people notice about your emotional response? What about after the event - how did you respond emotionally?)</p>	<p>Describe (e.g., event type, victim, perpetrator, age, frequency):</p>   <p><u>A. (1)</u> Life threat? NO YES [self ___ other ___] Serious injury? NO YES [self ___ other ___] Threat to physical integrity? NO YES [self ___ other ___]</p> <p><u>A. (2)</u> Intense fear/help/horror? NO YES [during ___ after ___] Criterion A met? NO PROBABLE YES</p>
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For the rest of the interview, I want you to keep (EVENTS) in mind as I ask you some questions about how they may have affected you.

I'm going to ask you about twenty-five questions altogether. Most of them have two parts. First, I'll ask if you've ever had a particular problem, and if so, about how often in the past month (week). Then I'll ask you how much distress or discomfort that problem may have caused you.

**Criterion B. The traumatic event is persistently reexperienced in one (or more) of the following ways:**

1. (B-1) recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.  
 Note: In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.

<p><b>Frequency</b>                  Have you ever had unwanted memories of (EVENT)? What were they like? (What did you remember?) [IF NOT CLEAR:] (Did they ever occur while you were awake, or only in dreams?) [EXCLUDE IF MEMORIES OCCURRED ONLY DURING DREAMS] How often have you had these memories in the past month (week)?</p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How much distress or discomfort did these memories cause you? Were you able to put them out of your mind and think about something else? (How hard did you have to try?) How much did they interfere with your life?</p> <p>0 None                  1 Mild, minimal distress or disruption of activities                  2 Moderate, distress clearly present but still manageable, some disruption of activities                  3 Severe, considerable distress, difficulty dismissing memories, marked disruption of activities                  4 Extreme, incapacitating distress, cannot dismiss memories, unable to continue activities</p> <p><b>QV (specify)</b></p>	<p><u>Past week</u>                  F ___                  I ___</p> <p><u>Past month</u>                  F ___                  I ___                  Sx: Y N</p> <p><u>Lifetime</u>                  F ___                  I ___                  Sx: Y N</p>
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2. (B-2) recurrent distressing dreams of the event. Note: In children, there may be frightening dreams without recognizable content.

<p><b>Frequency</b>                  Have you ever had unpleasant dreams about (EVENT)? Describe a typical dream. (What happens in them?) How often have you had these dreams in the past month (week)?</p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How much distress or discomfort did these dreams cause you? Did they ever wake you up? [IF YES:] (What happened when you woke up? How long did it take you to get back to sleep?) [LISTEN FOR REPORT OF ANXIOUS AROUSAL, YELLING, ACTING OUT THE NIGHTMARE] (Did your dreams ever affect anyone else? How so?)</p> <p>0 None                  1 Mild, minimal distress, may not have awoken                  2 Moderate, awoke in distress but readily returned to sleep                  3 Severe, considerable distress, difficulty returning to sleep                  4 Extreme, incapacitating distress, did not return to sleep</p> <p><b>QV (specify)</b></p>	<p><u>Past week</u>                  F ___                  I ___</p> <p><u>Past month</u>                  F ___                  I ___                  Sx: Y N</p> <p><u>Lifetime</u>                  F ___                  I ___                  Sx: Y N</p>
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3. (B-3) acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated). **Note:** In young children, trauma-specific reenactment may occur.

<p><b>Frequency</b> Have you ever suddenly acted or felt as if (EVENT) were happening again? (Have you ever had flashbacks about [EVENT]?) [IF NOT CLEAR:] (Did this ever occur while you were awake, or only in dreams?) [EXCLUDE IF OCCURRED ONLY DURING DREAMS] Tell me more about that. How often has that happened in the past month (week)?</p> <p>0 Never 1 Once or twice 2 Once or twice a week 3 Several times a week 4 Daily or almost every day</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b> How much did it seem as if (EVENT) were happening again? (Were you confused about where you actually were or what you were doing at the time?) How long did it last? What did you do while this was happening? (Did other people notice your behavior? What did they say?)</p> <p>0 No reliving 1 Mild, somewhat more realistic than just thinking about event 2 Moderate, definite but transient dissociative quality, still very aware of surroundings, daydreaming quality 3 Severe, strongly dissociative (reports images, sounds, or smells) but retained some awareness of surroundings 4 Extreme, complete dissociation (flashback), no awareness of surroundings, may be unresponsive, possible amnesia for the episode (blackout)</p> <p>QV (specify)</p>	<p><b>Past week</b> F ____ I ____</p> <p><b>Past month</b> F ____ I ____ Sx: Y N</p> <p><b>Lifetime</b> F ____ I ____ Sx: Y N</p>
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4. (B-4) intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event

<p><b>Frequency</b> Have you ever gotten emotionally upset when something reminded you of (EVENT)? (Has anything ever triggered bad feelings related to [EVENT]?) What kinds of reminders made you upset? How often in the past month (week)?</p> <p>0 Never 1 Once or twice 2 Once or twice a week 3 Several times a week 4 Daily or almost every day</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b> How much distress or discomfort did (REMINDERS) cause you? How long did it last? How much did it interfere with your life?</p> <p>0 None 1 Mild, minimal distress or disruption of activities 2 Moderate, distress clearly present but still manageable, some disruption of activities 3 Severe, considerable distress, marked disruption of activities 4 Extreme, incapacitating distress, unable to continue activities</p> <p>QV (specify)</p>	<p><b>Past week</b> F ____ I ____</p> <p><b>Past month</b> F ____ I ____ Sx: Y N</p> <p><b>Lifetime</b> F ____ I ____ Sx: Y N</p>
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5. (B-5) physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event

<p><b>Frequency</b>                  Have you ever had any physical reactions when something reminded you of (EVENT)? (Did your body ever react in some way when something reminded you of [EVENT]?) Can you give me some examples? (Did your heart race or did your breathing change? What about sweating or feeling really tense or shaky?) What kinds of reminders triggered these reactions? How often in the past month (week)?</p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How strong were (PHYSICAL REACTIONS)? How long did they last? (Did they last even after you were out of the situation?)</p> <p>0 No physical reactivity                  1 Mild, minimal reactivity                  2 Moderate, physical reactivity clearly present, may be sustained if exposure continues                  3 Severe, marked physical reactivity, sustained throughout exposure                  4 Extreme, dramatic physical reactivity, sustained arousal even after exposure has ended</p> <p><u>QV (specify)</u></p>	<p><u>Past week</u>                  F ____                  I ____</p> <p><u>Past month</u>                  F ____                  I ____                  Sx: Y N</p> <p><u>Lifetime</u>                  F ____                  I ____                  Sx: Y N</p>
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Criterion C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:

6. (C-1) efforts to avoid thoughts, feelings, or conversations associated with the trauma

<p><b>Frequency</b>                  Have you ever tried to avoid thoughts or feelings about (EVENT)? (What kinds of thoughts or feelings did you try to avoid?) What about trying to avoid talking with other people about it? (Why is that?) How often in the past month (week)?</p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How much effort did you make to avoid (THOUGHTS/FEELINGS/CONVERSATIONS)? (What kinds of things did you do? What about drinking or using medication or street drugs?) [CONSIDER ALL ATTEMPTS AT AVOIDANCE, INCLUDING DISTRACTION, SUPPRESSION, AND USE OF ALCOHOL/DRUGS] How much did that interfere with your life?</p> <p>0 None                  1 Mild, minimal effort, little or no disruption of activities                  2 Moderate, some effort, avoidance definitely present, some disruption of activities                  3 Severe, considerable effort, marked avoidance, marked disruption of activities, or involvement in certain activities as avoidant strategy                  4 Extreme, drastic attempts at avoidance, unable to continue activities, or excessive involvement in certain activities as avoidant strategy</p> <p><u>QV (specify)</u></p>	<p><u>Past week</u>                  F ____                  I ____</p> <p><u>Past month</u>                  F ____                  I ____                  Sx: Y N</p> <p><u>Lifetime</u>                  F ____                  I ____                  Sx: Y N</p>
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7. (C-2) efforts to avoid activities, places, or people that arouse recollections of the trauma

<p><b>Frequency</b> Have you ever tried to avoid certain activities, places, or people that reminded you of (EVENT)? (What kinds of things did you avoid? Why is that?) How often in the past month (week)?</p> <p>0 Never 1 Once or twice 2 Once or twice a week 3 Several times a week 4 Daily or almost every day</p>	<p><b>Intensity</b> How much effort did you make to avoid (ACTIVITIES/PLACES/PEOPLE)? (What did you do instead?) How much did that interfere with your life?</p> <p>0 None 1 Mild, minimal effort, little or no disruption of activities 2 Moderate, some effort, avoidance definitely present, some disruption of activities 3 Severe, considerable effort, marked avoidance, marked disruption of activities or involvement in certain activities as avoidant strategy 4 Extreme, drastic attempts at avoidance, unable to continue activities, or excessive involvement in certain activities as avoidant strategy</p>	<p><b>Past week</b> F ____ I ____</p> <p><b>Past month</b> F ____ I ____ Sx: Y N</p> <p><b>Lifetime</b> F ____ I ____ Sx: Y N</p>
<p><b>Description/Examples</b></p>	<p><b>QV (specify)</b></p>	

8. (C-3) inability to recall an important aspect of the trauma

<p><b>Frequency</b> Have you had difficulty remembering some important parts of (EVENT)? Tell me more about that. (Do you feel you should be able to remember these things? Why do you think you can't?) In the past month (week), how much of the important parts of (EVENT) have you had difficulty remembering? (What parts do you still remember?)</p> <p>0 None, clear memory 1 Few aspects not remembered (less than 10%) 2 Some aspects not remembered (approx 20-30%) 3 Many aspects not remembered (approx 50-60%) 4 Most or all aspects not remembered (more than 80%)</p>	<p><b>Intensity</b> How much difficulty did you have recalling important parts of (EVENT)? (Were you able to recall more if you tried?)</p> <p>0 None 1 Mild, minimal difficulty 2 Moderate, some difficulty, could recall with effort 3 Severe, considerable difficulty, even with effort 4 Extreme, completely unable to recall important aspects of event</p>	<p><b>Past week</b> F ____ I ____</p> <p><b>Past month</b> F ____ I ____ Sx: Y N</p> <p><b>Lifetime</b> F ____ I ____ Sx: Y N</p>
<p><b>Description/Examples</b></p>	<p><b>QV (specify)</b></p>	

9. (C-4) markedly diminished interest or participation in significant activities

<p><b>Frequency</b>                  Have you been less interested in activities that you used to enjoy? (What kinds of things have you lost interest in? Are there some things you don't do at all anymore? Why is that?)                  [EXCLUDE IF NO OPPORTUNITY, IF PHYSICALLY UNABLE, OR IF DEVELOPMENTALLY APPROPRIATE CHANGE IN PREFERRED ACTIVITIES] In the past month (week), how many activities have you been less interested in? (What kinds of things do you still enjoy doing?) When did you first start to feel that way? (After the [EVENT]?)</p> <p>0 None                  1 Few activities (less than 10%)                  2 Some activities (approx 20-30%)                  3 Many activities (approx 50-60%)                  4 Most or all activities (more than 80%)</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b>                  How strong was your loss of interest? (Would you enjoy [ACTIVITIES] once you got started?)</p> <p>0 No loss of interest                  1 Mild, slight loss of interest, probably would enjoy after starting activities                  2 Moderate, definite loss of interest, but still has some enjoyment of activities                  3 Severe, marked loss of interest in activities                  4 Extreme, complete loss of interest, no longer participates in any activities</p> <p><b>QV (specify)</b></p> <p>_____</p> <p><b>Trauma-related?</b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b>Past week</b>                  F _____                  I _____</p> <p><b>Past month</b>                  F _____                  I _____                  Sx: Y N</p> <p><b>Lifetime</b>                  F _____                  I _____                  Sx: Y N</p>
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10. (C-5) feeling of detachment or estrangement from others

<p><b>Frequency</b>                  Have you felt distant or cut off from other people? What was that like? How much of the time in the past month (week) have you felt that way? When did you first start to feel that way? (After the [EVENT]?)</p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b>                  How strong were your feelings of being distant or cut off from others? (Who do you feel closest to? How many people do you feel comfortable talking with about personal things?)</p> <p>0 No feelings of detachment or estrangement                  1 Mild, may feel "out of synch" with others                  2 Moderate, feelings of detachment clearly present, but still feels some interpersonal connection                  3 Severe, marked feelings of detachment or estrangement from most people, may feel close to only one or two people                  4 Extreme, feels completely detached or estranged from others, not close with anyone</p> <p><b>QV (specify)</b></p> <p>_____</p> <p><b>Trauma-related?</b> 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b>Past week</b>                  F _____                  I _____</p> <p><b>Past month</b>                  F _____                  I _____                  Sx: Y N</p> <p><b>Lifetime</b>                  F _____                  I _____                  Sx: Y N</p>
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11. (C-6) restricted range of affect (e.g., unable to have loving feelings)

<p><b>Frequency</b>                  Have there been times when you felt emotionally numb or had trouble experiencing feelings like love or happiness? What was that like? (What feelings did you have trouble experiencing?) How much of the time in the past month (week) have you felt that way? When did you first start having trouble experiencing (EMOTIONS)? (After the [EVENT]?)</p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How much trouble did you have experiencing (EMOTIONS)? (What kinds of feelings were you still able to experience?) [INCLUDE OBSERVATIONS OF RANGE OF AFFECT DURING INTERVIEW]</p> <p>0 No reduction of emotional experience                  1 Mild, slight reduction of emotional experience                  2 Moderate, definite reduction of emotional experience, but still able to experience most emotions                  3 Severe, marked reduction of experience of at least two primary emotions (e.g., love, happiness)                  4 Extreme, completely lacking emotional experience</p> <p>QV (specify)                  _____</p> <p>Trauma-related? 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><u>Past week</u>                  F _____                  I _____</p> <p><u>Past month</u>                  F _____                  I _____                  Sx: Y N</p> <p><u>Lifetime</u>                  F _____                  I _____                  Sx: Y N</p>
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12. (C-7) sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)

<p><b>Frequency</b>                  Have there been times when you felt there is no need to plan for the future, that somehow your future will be cut short? Why is that? [RULE OUT REALISTIC RISKS SUCH AS LIFE-THREATENING MEDICAL CONDITIONS] How much of the time in the past month (week) have you felt that way? When did you first start to feel that way? (After the [EVENT]?)</p> <p>0 None of the time                  1 Very little of the time (less than 10%)                  2 Some of the time (approx 20-30%)                  3 Much of the time (approx 50-60%)                  4 Most or all of the time (more than 80%)</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How strong was this feeling that your future will be cut short? (How long do you think you will live? How convinced are you that you will die prematurely?)</p> <p>0 No sense of a foreshortened future                  1 Mild, slight sense of a foreshortened future                  2 Moderate, sense of a foreshortened future definitely present, but no specific prediction about longevity                  3 Severe, marked sense of a foreshortened future, may make specific prediction about longevity                  4 Extreme, overwhelming sense of a foreshortened future, completely convinced of premature death</p> <p>QV (specify)                  _____</p> <p>Trauma-related? 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><u>Past week</u>                  F _____                  I _____</p> <p><u>Past month</u>                  F _____                  I _____                  Sx: Y N</p> <p><u>Lifetime</u>                  F _____                  I _____                  Sx: Y N</p>
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**Criterion D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:**

**13. (D-1) difficulty falling or staying asleep**

<u>Frequency</u>	<u>Intensity</u>	<u>Past week</u>
<p>Have you had any problems falling or staying asleep? How often in the past month (week)? When did you first start having problems sleeping? (After the [EVENT]?)</p> <p>0 Never 1 Once or twice 2 Once or twice a week 3 Several times a week 4 Daily or almost every day</p> <p>Sleep onset problems? Y N Mid-sleep awakening? Y N Early a.m. awakening? Y N</p> <p>Total # hrs sleep/night _____ Desired # hrs sleep/night _____</p>	<p>How much of a problem did you have with your sleep? (How long did it take you to fall asleep? How often did you wake up in the night? Did you often wake up earlier than you wanted to? How many total hours did you sleep each night?)</p> <p>0 No sleep problems 1 Mild, slightly longer latency, or minimal difficulty staying asleep (up to 30 minutes loss of sleep) 2 Moderate, definite sleep disturbance, clearly longer latency, or clear difficulty staying asleep (30-90 minutes loss of sleep) 3 Severe, much longer latency, or marked difficulty staying asleep (90 min to 3 hrs loss of sleep) 4 Extreme, very long latency, or profound difficulty staying asleep (&gt; 3 hrs loss of sleep)</p> <p><b>QV (specify)</b> _____</p> <p>Trauma-related? 1 definite 2 probable 3 unlikely Current _____ Lifetime _____</p>	<p>F _____ I _____</p> <p><u>Past month</u> F _____ I _____ Sx: Y N</p> <p><u>Lifetime</u> F _____ I _____ Sx: Y N</p>

**14. (D-2) irritability or outbursts of anger**

<u>Frequency</u>	<u>Intensity</u>	<u>Past week</u>
<p>Have there been times when you felt especially irritable or showed strong feelings of anger? Can you give me some examples? How often in the past month (week)? When did you first start feeling that way? (After the [EVENT]?)</p> <p>0 Never 1 Once or twice 2 Once or twice a week 3 Several times a week 4 Daily or almost every day</p> <p><u>Description/Examples</u> _____</p>	<p>How strong was your anger? (How did you show it?) [IF REPORTS SUPPRESSION:] (How hard was it for you to keep from showing your anger?) How long did it take you to calm down? Did your anger cause you any problems?</p> <p>0 No irritability or anger 1 Mild, minimal irritability, may raise voice when angry 2 Moderate, definite irritability or attempts to suppress anger, but can recover quickly 3 Severe, marked irritability or marked attempts to suppress anger, may become verbally or physically aggressive when angry 4 Extreme, pervasive anger or drastic attempts to suppress anger, may have episodes of physical violence</p> <p><b>QV (specify)</b> _____</p> <p>Trauma-related? 1 definite 2 probable 3 unlikely Current _____ Lifetime _____</p>	<p>F _____ I _____</p> <p><u>Past month</u> F _____ I _____ Sx: Y N</p> <p><u>Lifetime</u> F _____ I _____ Sx: Y N</p>

15. (D-3) difficulty concentrating

<p><b>Frequency</b> Have you found it difficult to concentrate on what you were doing or on things going on around you? What was that like? How much of the time in the past month (week)? When did you first start having trouble concentrating? (After the [EVENT]?)</p> <p>0 None of the time 1 Very little of the time (less than 10%) 2 Some of the time (approx 20-30%) 3 Much of the time (approx 50-60%) 4 Most or all of the time (more than 80%)</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b> How difficult was it for you to concentrate? [INCLUDE OBSERVATIONS OF CONCENTRATION AND ATTENTION IN INTERVIEW] How much did that interfere with your life?</p> <p>0 No difficulty with concentration 1 Mild, only slight effort needed to concentrate, little or no disruption of activities 2 Moderate, definite loss of concentration but could concentrate with effort, some disruption of activities 3 Severe, marked loss of concentration even with effort, marked disruption of activities 4 Extreme, complete inability to concentrate, unable to engage in activities</p> <p><b>QV (specify)</b></p> <p>_____</p> <p>Trauma-related? 1 definite 2 probable 3 unlikely Current _____ Lifetime _____</p>	<p><b>Past week</b> F _____ I _____</p> <p><b>Past month</b> F _____ I _____ Sx: Y N</p> <p><b>Lifetime</b> F _____ I _____ Sx: Y N</p>
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16. (D-4) hypervigilance

<p><b>Frequency</b> Have you been especially alert or watchful, even when there was no real need to be? (Have you felt as if you were constantly on guard?) Why is that? How much of the time in the past month (week)? When did you first start acting that way? (After the [EVENT]?)</p> <p>0 None of the time 1 Very little of the time (less than 10%) 2 Some of the time (approx 20-30%) 3 Much of the time (approx 50-60%) 4 Most or all of the time (more than 80%)</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b> How hard did you try to be watchful of things going on around you? [INCLUDE OBSERVATIONS OF HYPERVIGILANCE IN INTERVIEW] Did your (HYPERVIGILANCE) cause you any problems?</p> <p>0 No hypervigilance 1 Mild, minimal hypervigilance, slight heightening of awareness 2 Moderate, hypervigilance clearly present, watchful in public (e.g., chooses safe place to sit in a restaurant or movie theater) 3 Severe, marked hypervigilance, very alert, scans environment for danger, exaggerated concern for safety of self/family/home 4 Extreme, excessive hypervigilance, efforts to ensure safety consume significant time and energy and may involve extensive safety/checking behaviors, marked watchfulness during interview</p> <p><b>QV (specify)</b></p> <p>_____</p> <p>Trauma-related? 1 definite 2 probable 3 unlikely Current _____ Lifetime _____</p>	<p><b>Past week</b> F _____ I _____</p> <p><b>Past month</b> F _____ I _____ Sx: Y N</p> <p><b>Lifetime</b> F _____ I _____ Sx: Y N</p>
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17. (D-5) exaggerated startle response

<p><b>Frequency</b>                  Have you had any strong startle reactions? When did that happen? (What kinds of things made you startle?) How often in the past month (week)? When did you first have these reactions? (After the [EVENT]?)</p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b>                  How strong were these startle reactions? (How strong were they compared to how most people would respond?) How long did they last?</p> <p>0 No startle reaction                  1 Mild, minimal reaction                  2 Moderate, definite startle reaction, feels "jumpy"                  3 Severe, marked startle reaction, sustained arousal following initial reaction                  4 Extreme, excessive startle reaction, overt coping behavior (e.g., combat veteran who "hits the dirt")</p> <p><b>QV (specify)</b></p> <p>_____</p> <p>Trauma-related? 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><b>Past week</b>                  F _____                  I _____</p> <p><b>Past month</b>                  F _____                  I _____                  Sx: Y N</p> <p><b>Lifetime</b>                  F _____                  I _____                  Sx: Y N</p>
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**Criterion E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.**

18. onset of symptoms

<p>[IF NOT ALREADY CLEAR:] When did you first start having (PTSD SYMPTOMS) you've told me about? (How long after the trauma did they start? More than six months?)</p>	<p>_____ total # months delay in onset                  With delayed onset (≥ 6 months)? NO                  YES</p>
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19. duration of symptoms

<p>[CURRENT] How long have these (PTSD SYMPTOMS) lasted altogether?</p> <p>[LIFETIME] How long did these (PTSD SYMPTOMS) last altogether?</p>	<p>Duration more than 1 month?                  Total # months duration                  Acute (&lt; 3 months) or chronic                  (≥ 3 months)?</p>	<p><b>Current</b>                  NO YES                  _____</p> <p><b>acute chronic</b></p>	<p><b>Lifetime</b>                  NO YES                  _____</p> <p><b>acute chronic</b></p>
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**Criterion F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.**

20. subjective distress

<p>[CURRENT] Overall, how much have you been bothered by these (PTSD SYMPTOMS) you've told me about? [CONSIDER DISTRESS REPORTED ON EARLIER ITEMS]</p> <p>[LIFETIME] Overall, how much were you bothered by these (PTSD SYMPTOMS) you've told me about? [CONSIDER DISTRESS REPORTED ON EARLIER ITEMS]</p>	<p>0 None                  1 Mild, minimal distress                  2 Moderate, distress clearly present but still manageable                  3 Severe, considerable distress                  4 Extreme, incapacitating distress</p>	<p><b>Past week</b>                  _____</p> <p><b>Past month</b>                  _____</p> <p><b>Lifetime</b>                  _____</p>
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21. impairment in social functioning

<p>[CURRENT] Have these (PTSD SYMPTOMS) affected your relationships with other people? How so? [CONSIDER IMPAIRMENT IN SOCIAL FUNCTIONING REPORTED ON EARLIER ITEMS]</p> <p>[LIFETIME] Did these (PTSD SYMPTOMS) affect your social life? How so? [CONSIDER IMPAIRMENT IN SOCIAL FUNCTIONING REPORTED ON EARLIER ITEMS]</p>	0	No adverse impact	<u>Past week</u>
	1	Mild impact, minimal impairment in social functioning	—
	2	Moderate impact, definite impairment, but many aspects of social functioning still intact	<u>Past month</u>
	3	Severe impact, marked impairment, few aspects of social functioning still intact	—
	4	Extreme impact, little or no social functioning	<u>Lifetime</u>

22. impairment in occupational or other important area of functioning

<p>[CURRENT -- IF NOT ALREADY CLEAR] Are you working now?</p> <p>IF YES: Have these (PTSD SYMPTOMS) affected your work or your ability to work? How so? [CONSIDER REPORTED WORK HISTORY, INCLUDING NUMBER AND DURATION OF JOBS, AS WELL AS THE QUALITY OF WORK RELATIONSHIPS. IF PREMORBID FUNCTIONING IS UNCLEAR, INQUIRE ABOUT WORK EXPERIENCES BEFORE THE TRAUMA. FOR CHILD/ADOLESCENT TRAUMAS, ASSESS PRE-TRAUMA SCHOOL PERFORMANCE AND POSSIBLE PRESENCE OF BEHAVIOR PROBLEMS]</p> <p>IF NO: Have these (PTSD SYMPTOMS) affected any other important part of your life? [AS APPROPRIATE, SUGGEST EXAMPLES SUCH AS PARENTING, HOUSEWORK, SCHOOLWORK, VOLUNTEER WORK, ETC.] How so?</p> <p>[LIFETIME -- IF NOT ALREADY CLEAR] Were you working then?</p> <p>IF YES: Did these (PTSD SYMPTOMS) affect your work or your ability to work? How so? [CONSIDER REPORTED WORK HISTORY, INCLUDING NUMBER AND DURATION OF JOBS, AS WELL AS THE QUALITY OF WORK RELATIONSHIPS. IF PREMORBID FUNCTIONING IS UNCLEAR, INQUIRE ABOUT WORK EXPERIENCES BEFORE THE TRAUMA. FOR CHILD/ADOLESCENT TRAUMAS, ASSESS PRE-TRAUMA SCHOOL PERFORMANCE AND POSSIBLE PRESENCE OF BEHAVIOR PROBLEMS]</p> <p>IF NO: Did these (PTSD SYMPTOMS) affect any other important part of your life? [AS APPROPRIATE, SUGGEST EXAMPLES SUCH AS PARENTING, HOUSEWORK, SCHOOLWORK, VOLUNTEER WORK, ETC.] How so?</p>	0	No adverse impact	<u>Past week</u>
	1	Mild impact, minimal impairment in occupational/other important functioning	—
	2	Moderate impact, definite impairment, but many aspects of occupational/other important functioning still intact	<u>Past month</u>
	3	Severe impact, marked impairment, few aspects of occupational/other important functioning still intact	—
	4	Extreme impact, little or no occupational/other important functioning	<u>Lifetime</u>

**Global Ratings**

23. global validity

ESTIMATE THE OVERALL VALIDITY OF RESPONSES. CONSIDER FACTORS SUCH AS COMPLIANCE WITH THE INTERVIEW, MENTAL STATUS (E.G., PROBLEMS WITH CONCENTRATION, COMPREHENSION OF ITEMS, DISSOCIATION), AND EVIDENCE OF EFFORTS TO EXAGGERATE OR MINIMIZE SYMPTOMS.	0	Excellent, no reason to suspect invalid responses
	1	Good, factors present that may adversely affect validity
	2	Fair, factors present that definitely reduce validity
	3	Poor, substantially reduced validity
	4	Invalid responses, severely impaired mental status or possible deliberate "faking bad" or "faking good"

24. global severity

ESTIMATE THE OVERALL SEVERITY OF PTSD SYMPTOMS. CONSIDER DEGREE OF SUBJECTIVE DISTRESS, DEGREE OF FUNCTIONAL IMPAIRMENT, OBSERVATIONS OF BEHAVIORS IN INTERVIEW, AND JUDGMENT REGARDING REPORTING STYLE.	0	No clinically significant symptoms, no distress and no functional impairment	<i>Past week</i>
	1	Mild, minimal distress or functional impairment	—
	2	Moderate, definite distress or functional impairment but functions satisfactorily with effort	<i>Past month</i>
	3	Severe, considerable distress or functional impairment, limited functioning even with effort	—
	4	Extreme, marked distress or marked impairment in two or more major areas of functioning	<i>Lifetime</i>

25. global improvement

RATE TOTAL OVERALL IMPROVEMENT PRESENT SINCE THE INITIAL RATING. IF NO EARLIER RATING, ASK HOW THE SYMPTOMS ENDORSED HAVE CHANGED OVER THE PAST 6 MONTHS. RATE THE DEGREE OF CHANGE, WHETHER OR NOT, IN YOUR JUDGMENT, IT IS DUE TO TREATMENT.	0	Asymptomatic
	1	Considerable improvement
	2	Moderate improvement
	3	Slight improvement
	4	No improvement
	5	Insufficient information

<b>Current PTSD Symptoms</b>
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Criterion A met (traumatic event)?	NO	YES
_____ # Criterion B sx ( $\geq 1$ )?	NO	YES
_____ # Criterion C sx ( $\geq 3$ )?	NO	YES
_____ # Criterion D sx ( $\geq 2$ )?	NO	YES
Criterion E met (duration $\geq 1$ month)?	NO	YES
Criterion F met (distress/impairment)?	NO	YES

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CURRENT PTSD (Criteria A-F met)?	NO	YES
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IF CURRENT PTSD CRITERIA ARE MET, SKIP TO ASSOCIATED FEATURES.

IF CURRENT CRITERIA ARE NOT MET, ASSESS FOR LIFETIME PTSD. IDENTIFY A PERIOD OF AT LEAST A MONTH SINCE THE TRAUMATIC EVENT IN WHICH SYMPTOMS WERE WORSE.

Since the (EVENT), has there been a time when these (PTSD SYMPTOMS) were a lot worse than they have been in the past month? When was that? How long did it last? (At least a month?)

IF MULTIPLE PERIODS IN THE PAST: When were you bothered the most by these (PTSD SYMPTOMS)?

IF AT LEAST ONE PERIOD, INQUIRE ITEMS 1-17, CHANGING FREQUENCY PROMPTS TO REFER TO WORST PERIOD: During that time, did you (EXPERIENCE SYMPTOM)? How often?

<b>Lifetime PTSD Symptoms</b>
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Criterion A met (traumatic event)?	NO	YES
_____ # Criterion B sx ( $\geq 1$ )?	NO	YES
_____ # Criterion C sx ( $\geq 3$ )?	NO	YES
_____ # Criterion D sx ( $\geq 2$ )?	NO	YES
Criterion E met (duration $\geq 1$ month)?	NO	YES
Criterion F met (distress/impairment)?	NO	YES

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LIFETIME PTSD (Criteria A-F met)?	NO	YES
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**Associated Features**

26. guilt over acts of commission or omission

<p><b>Frequency</b> Have you felt guilty about anything you did or didn't do during (EVENT)? Tell me more about that. (What do you feel guilty about?) How much of the time have you felt that way in the past month (week)?</p> <p>0 None of the time 1 Very little of the time (less than 10%) 2 Some of the time (approx 20-30%) 3 Much of the time (approx 50-60%) 4 Most or all of the time (more than 80%)</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b> How strong were these feelings of guilt? How much distress or discomfort did they cause?</p> <p>0 No feelings of guilt 1 Mild, slight feelings of guilt 2 Moderate, guilt feelings definitely present, some distress but still manageable 3 Severe, marked feelings of guilt, considerable distress 4 Extreme, pervasive feelings of guilt, self-condemnation regarding behavior, incapacitating distress</p> <p><b>QV (specify)</b></p>	<p><b>Past week</b> F ____ I ____</p> <p><b>Past month</b> F ____ I ____ Sx: Y N</p> <p><b>Lifetime</b> F ____ I ____ Sx: Y N</p>
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27. survivor guilt [APPLICABLE ONLY IF MULTIPLE VICTIMS]

<p><b>Frequency</b> Have you felt guilty about surviving (EVENT) when others did not? Tell me more about that. (What do you feel guilty about?) How much of the time have you felt that way in the past month (week)?</p> <p>0 None of the time 1 Very little of the time (less than 10%) 2 Some of the time (approx 20-30%) 3 Much of the time (approx 50-60%) 4 Most or all of the time (more than 80%) 8 N/A</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b> How strong were these feelings of guilt? How much distress or discomfort did they cause?</p> <p>0 No feelings of guilt 1 Mild, slight feelings of guilt 2 Moderate, guilt feelings definitely present, some distress but still manageable 3 Severe, marked feelings of guilt, considerable distress 4 Extreme, pervasive feelings of guilt, self-condemnation regarding survival, incapacitating distress</p> <p><b>QV (specify)</b></p>	<p><b>Past week</b> F ____ I ____</p> <p><b>Past month</b> F ____ I ____ Sx: Y N</p> <p><b>Lifetime</b> F ____ I ____ Sx: Y N</p>
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28. a reduction in awareness of his or her surroundings (e.g., "being in a daze")

<p><b>Frequency</b>                  Have there been times when you felt out of touch with things going on around you, like you were in a daze? What was that like? [DISTINGUISH FROM FLASHBACK EPISODES] How often has that happened in the past month (week)? [IF NOT CLEAR:] (Was it due to an illness or the effects of drugs or alcohol?) When did you first start feeling that way? (After the [EVENT]?)</p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How strong was this feeling of being out of touch or in a daze? (Were you confused about where you actually were or what you were doing at the time?) How long did it last? What did you do while this was happening? (Did other people notice your behavior? What did they say?)</p> <p>0 No reduction in awareness                  1 Mild, slight reduction in awareness                  2 Moderate, definite but transient reduction in awareness, may report feeling "spacy"                  3 Severe, marked reduction in awareness, may persist for several hours                  4 Extreme, complete loss of awareness of surroundings, may be unresponsive, possible amnesia for the episode (blackout)</p> <p><b>QV (specify)</b></p> <hr/> <p>Trauma-related? 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><u>Past week</u>                  F _____                  I _____</p> <p><u>Past month</u>                  F _____                  I _____                  Sx: Y N</p> <p><u>Lifetime</u>                  F _____                  I _____                  Sx: Y N</p>
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29. derealization

<p><b>Frequency</b>                  Have there been times when things going on around you seemed unreal or very strange and unfamiliar? [IF NO:] (What about times when people you knew suddenly seemed unfamiliar?) What was that like? How often has that happened in the past month (week)? [IF NOT CLEAR:] (Was it due to an illness or the effects of drugs or alcohol?) When did you first start feeling that way? (After the [EVENT]?)</p> <p>0 Never                  1 Once or twice                  2 Once or twice a week                  3 Several times a week                  4 Daily or almost every day</p> <p><u>Description/Examples</u></p>	<p><b>Intensity</b>                  How strong was (DEREALIZATION)? How long did it last? What did you do while this was happening? (Did other people notice your behavior? What did they say?)</p> <p>0 No derealization                  1 Mild, slight derealization                  2 Moderate, definite but transient derealization                  3 Severe, considerable derealization, marked confusion about what is real, may persist for several hours                  4 Extreme, profound derealization, dramatic loss of sense of reality or familiarity</p> <p><b>QV (specify)</b></p> <hr/> <p>Trauma-related? 1 definite 2 probable 3 unlikely                  Current _____ Lifetime _____</p>	<p><u>Past week</u>                  F _____                  I _____</p> <p><u>Past month</u>                  F _____                  I _____                  Sx: Y N</p> <p><u>Lifetime</u>                  F _____                  I _____                  Sx: Y N</p>
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30. depersonalization

<p><b>Frequency</b>          Have there been times when you felt as if you were outside of your body, watching yourself as if you were another person? [IF NO:] (What about times when your body felt strange or unfamiliar to you, as if it had changed in some way?) What was that like? How often has that happened in the past month (week)? [IF NOT CLEAR:] (Was it due to an illness or the effects of drugs or alcohol?) When did you first start feeling that way? (After the [EVENT]?)</p> <p>0 Never          1 Once or twice          2 Once or twice a week          3 Several times a week          4 Daily or almost every day</p> <p><b>Description/Examples</b></p>	<p><b>Intensity</b>          How strong was (DEPERSONALIZATION)? How long did it last? What did you do while this was happening? (Did other people notice your behavior? What did they say?)</p> <p>0 No depersonalization          1 Mild, slight depersonalization          2 Moderate, definite but transient depersonalization          3 Severe, considerable depersonalization, marked sense of detachment from self, may persist for several hours          4 Extreme, profound depersonalization, dramatic sense of detachment from self</p> <p><b>QV (specify)</b></p> <p>_____</p> <p><b>Trauma-related?</b> 1 definite 2 probable 3 unlikely          Current _____ Lifetime _____</p>	<p><b>Past week</b>          F _____          I _____</p> <p><b>Past month</b>          F _____          I _____          Sx: Y N</p> <p><b>Lifetime</b>          F _____          I _____          Sx: Y N</p>
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## CAPS SUMMARY SHEET

Name: \_\_\_\_\_ ID#: \_\_\_\_\_ Interviewer: \_\_\_\_\_ Study: \_\_\_\_\_ Date: \_\_\_\_\_

## A. Traumatic event:

B. Reexperiencing symptoms	PAST WEEK			PAST MONTH			LIFETIME		
	Freq	Int	F+I	Freq	Int	F+I	Freq	Int	F+I
(1) Intrusive recollections									
(2) distressing dreams									
(3) acting or feeling as if event were recurring									
(4) psychological distress at exposure to cues									
(5) physiological reactivity on exposure to cues									
<i>B subtotals</i>									
<i>Number of Criterion B symptoms (need 1)</i>									

C. Avoidance and numbing symptoms	PAST WEEK			PAST MONTH			LIFETIME		
	Freq	Int	F+I	Freq	Int	F+I	Freq	Int	F+I
(6) avoidance of thoughts or feelings									
(7) avoidance of activities, places, or people									
(8) inability to recall important aspect of trauma									
(9) diminished interest in activities									
(10) detachment or estrangement									
(11) restricted range of affect									
(12) sense of a foreshortened future									
<i>C subtotals</i>									
<i>Number of Criterion C symptoms (need 3)</i>									

D. Hyperarousal symptoms	PAST WEEK			PAST MONTH			LIFETIME		
	Freq	Int	F+I	Freq	Int	F+I	Freq	Int	F+I
(13) difficulty falling or staying asleep									
(14) irritability or outbursts of anger									
(15) difficulty concentrating									
(16) hypervigilance									
(17) exaggerated startle response									
<i>D subtotals</i>									
<i>Number of Criterion D symptoms (need 2)</i>									

Total Freq, Int, and Severity (F+I)	PAST WEEK			PAST MONTH			LIFETIME		
	Freq	Int	F+I	Freq	Int	F+I	Freq	Int	F+I
<i>Sum of subtotals (B+C+D)</i>									

E. Duration of disturbance	CURRENT		LIFETIME	
(19) duration of disturbance at least one month	NO	YES	NO	YES

F. Significant distress or Impairment in functioning	PAST WEEK		PAST MONTH		LIFETIME	
(20) subjective distress						
(21) impairment in social functioning						
(22) impairment in occupational functioning						
<i>AT LEAST ONE ≥ 2?</i>	NO	YES	NO	YES	NO	YES

PTSD diagnosis	PTSD PRESENT – ALL CRITERIA (A-F) MET?		CURRENT		LIFETIME	
Specify:	NO	YES	NO	YES	NO	YES
(18) with delayed onset (≥ 6 months delay)	NO	YES	NO	YES	NO	YES
(19) acute (< 3 months) or chronic (≥ 3 months)	acute	chronic	acute	chronic	acute	chronic

<i>Global ratings</i>				<i>PAST WEEK</i>			<i>PAST MONTH</i>			<i>LIFETIME</i>		
<b>(23) global validity</b>												
<b>(24) global severity</b>												
<b>(25) global improvement</b>												

<i>Associated features</i>	<i>PAST WEEK</i>			<i>PAST MONTH</i>			<i>LIFETIME</i>		
	<i>Freq</i>	<i>Int</i>	<i>F+I</i>	<i>Freq</i>	<i>Int</i>	<i>F+I</i>	<i>Freq</i>	<i>Int</i>	<i>F+I</i>
<b>(26) guilt over acts of commission or omission</b>									
<b>(27) survivor guilt</b>									
<b>(28) reduction in awareness of surroundings</b>									
<b>(29) derealization</b>									
<b>(30) depersonalization</b>									

**Hogan Grief Reaction Checklist**  
(Hogan, Greenfield & Schmidt, 2001)

This questionnaire consists of a list of thoughts and feelings that you may have had since your child died. Please read each statement carefully, and choose the number that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement that best describes you. Please do not skip any items.

- 1 - Does not describe me at all
- 2 - Does not quite describe me
- 3 - Describes me fairly well
- 4 - Describes me well
- 5 - Describes me very well

1. My hopes are shattered.	1	2	3	4	5
2. I have learned to cope better with life.	1	2	3	4	5
3. I have little control over my sadness.	1	2	3	4	5
4. I worry excessively.	1	2	3	4	5
5. I frequently feel bitter.	1	2	3	4	5
6. I feel like I am in shock.	1	2	3	4	5
7. Sometimes my heart beats faster than it normally does for no reason.	1	2	3	4	5
8. I am resentful.	1	2	3	4	5
9. I am preoccupied with feeling worthless.	1	2	3	4	5
10. I feel as though I am a better person.	1	2	3	4	5
11. I believe I should have died and she or he should have lived.	1	2	3	4	5
12. I have a better outlook on life.	1	2	3	4	5
13. I often have headaches.	1	2	3	4	5
14. I feel a heaviness in my heart.	1	2	3	4	5
15. I feel revengeful.	1	2	3	4	5
16. I have burning in my stomach.	1	2	3	4	5
17. I want to die to be with him or her.	1	2	3	4	5

18. I frequently have muscle tension.	1	2	3	4	5
19. I have more compassion for others.	1	2	3	4	5
20. I forget things easily, e.g. names, telephone numbers	1	2	3	4	5
21. I feel shaky.	1	2	3	4	5
22. I am confused about who I am.	1	2	3	4	5
23. I have lost my confidence.	1	2	3	4	5
24. I am stronger because of the grief I have experienced.	1	2	3	4	5
25. I don't believe I will ever be happy again.	1	2	3	4	5
26. I have difficulty remembering things from the past.	1	2	3	4	5
27. I frequently feel frightened.	1	2	3	4	5
28. I feel unable to cope.	1	2	3	4	5
29. I agonize over her or his death.	1	2	3	4	5
30. I am a more forgiving person.	1	2	3	4	5
31. I have panic attacks over nothing.	1	2	3	4	5
32. I have difficulty concentrating.	1	2	3	4	5
33. I feel like I am walking in my sleep.	1	2	3	4	5
34. I have shortness of breath.	1	2	3	4	5
35. I avoid tenderness.	1	2	3	4	5
36. I am more tolerant of myself.	1	2	3	4	5
37. I have hostile feelings.	1	2	3	4	5
38. I am experiencing periods of dizziness.	1	2	3	4	5
39. I have difficulty learning new things.	1	2	3	4	5
40. I have difficulty accepting the permanence of the death.	1	2	3	4	5
41. I am more tolerant of others.	1	2	3	4	5

42. I blame others.	1	2	3	4	5
43. I feel like I don't know myself.	1	2	3	4	5
44. I am frequently fatigued.	1	2	3	4	5
45. I have hope for the future	1	2	3	4	5
46. I have difficulty with abstract thinking.	1	2	3	4	5
47. I feel hopeless.	1	2	3	4	5
48. I want to harm others.	1	2	3	4	5
49. I have difficulty remembering new information.	1	2	3	4	5
50. I feel sick more often.	1	2	3	4	5
51. I reached a turning point where I began to let go of some of my grief.	1	2	3	4	5
52. I often have back pain	1	2	3	4	5
53. I am afraid that I will lose control	1	2	3	4	5
54. I feel detached from others.	1	2	3	4	5
55. I frequently cry.	1	2	3	4	5
56. I startle easily.	1	2	3	4	5
57. Tasks seem insurmountable.	1	2	3	4	5
58. I get angry often.	1	2	3	4	5
59. I ache with loneliness.	1	2	3	4	5
60. I am having more good days than bad	1	2	3	4	5
61. I care more deeply for others.	1	2	3	4	5

**Perception of Social Support -Friends**  
(Procidano and Heller, 1983)

*Directions:* the statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with friends. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answer you choose for each item.

- |  |     |    |            |
|--|-----|----|------------|
| 1. My friends give me the moral support I need.  | Yes | No | Don't know |
| 2. Most other people are closer to their friends than I am.                                      | Yes | No | Don't know |
| 3. My friends enjoy hearing about what I think.  | Yes | No | Don't know |
| 4. Certain friends come to me when they have problems or need advice.                            | Yes | No | Don't know |
| 5. I rely on my friends for emotional support.   | Yes | No | Don't know |
| 6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself.      | Yes | No | Don't know |
| 7. I feel that I'm on the fringe in my circle of friends.  | Yes | No | Don't know |
| 8. There is a friend I could go to if I were feeling down, without feeling funny about it later. | Yes | No | Don't know |
| 9. My friends and I are very open about what we think about things.                              | Yes | No | Don't know |
| 10. My friends are sensitive to my personal needs.   | Yes | No | Don't know |
| 11. My friends come to me for emotional support.   | Yes | No | Don't know |
| 12. My friends are good at helping me solve problems.  | Yes | No | Don't know |
| 13. I have a deep sharing relationship with a number of friends.                                 | Yes | No | Don't know |
| 14. My friends get good ideas about how to do things or make things from me.                     | Yes | No | Don't know |
| 15. When I confide in friends, it makes me feel uncomfortable.                                   | Yes | No | Don't know |
| 16. My friends seek me out for companionship.  | Yes | No | Don't know |

17. I think that my friends feel that I'm good at helping them solve problems. Yes No Don't know
18. I don't have a relationship with a friend that is as intimate as other people's relationships with friends. Yes No Don't know
19. I've recently gotten a good idea about how to do something from a friend. Yes No Don't know
20. I wish my friends were much different. Yes No Don't know

### Perception of Social Support-Family

**Directions:** The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with their families. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answer you choose for each item.

1. My family gives me the moral support I need. Yes No Don't know
2. I get good ideas about how to do things or make things from my family. Yes No Don't know
3. Most other people are closer to their family than I am. Yes No Don't know
4. When I confide in members of my family who are closest to me, I get the idea that it makes them uncomfortable. Yes No Don't know
5. My family enjoys hearing about what I think. Yes No Don't know
6. Members of my family share many of my interests. Yes No Don't know
7. Certain members of my family come to me when they have problems or need advice. Yes No Don't know
8. I rely on my family for emotional support. Yes No Don't know
9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later. Yes No Don't know



- |  |     |    |            |
|--|-----|----|------------|
| 10. My family and I are very open about what we think about things.  | Yes | No | Don't know |
| 11. My family is sensitive to my personal needs.   | Yes | No | Don't know |
| 12. Members of my family come to me for emotional support.   | Yes | No | Don't know |
| 13. Members of my family are good at helping me solve problems.  | Yes | No | Don't know |
| 14. I have a deep sharing relationship with a number of members of my family.  | Yes | No | Don't know |
| 15. Members of my family get good ideas about how to do things or make things from me.   | Yes | No | Don't know |
| 16. When I confide in members of my family, it makes me uncomfortable.   | Yes | No | Don't know |
| 17. Members of my family seek me out for companionship   | Yes | No | Don't know |
| 18. I think that my family feels that I'm good at helping them solve problems.   | Yes | No | Don't know |
| 19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members. | Yes | No | Don't know |
| 20. I wish my family were much different.  | Yes | No | Don't know |

### Service Needs Assessment

It is important that bereaved parents have the kinds of resources that they need. The following questions relate to the services that you received and the services you might have found helpful that were not available. We receive help from our family and friends in an informal way. I am particularly interested in finding out about help you may have received in a formal way from professionals, organizations or agencies. I would also like to know about any literature or other information that was available that was helpful to you.

1. At the time of crisis, those days immediately following your loss:
  - 1.1. Was there anything provided to you that you remember as being helpful?  
(Service providers at that time might include hospital staff, EMT's, police, victim services, spiritual advisors, funeral director)
  - 1.2. Was there anything else that would have helped you deal with those immediate challenges?  
Probes: Were there practical things that would have been useful?  
Was there anything that would have helped you with the emotions of that time?
  
2. After the funeral, when you were faced with the aftermath of the accident/suicide/homicide/death:
  - 2.1. Were there any services you received that were helpful at that time?
  - 2.2. Is there anything that that could have been provided to help you (with the trauma)?  
Probes: Were there practical things that would have helped?  
What would have helped you deal with your responses to the accident itself?
  
3. When you started to look at all you had lost:
  - 3.1. Did you receive any services that were helpful at that time?

3.2. Is there something else that would have helped you at that time?

Probes: Were there any practical things that would have helped?

Was/is there anything that might have helped you with the emotions of the time.

4. Would you say that you are at the point of starting to put together the pieces of your life?  
( If Yes continue)

4.1. Is there anything that would help you at this time?

Probes: Are there any practical things that would be useful to you?

Is there anything that would help you with the emotional aftermath of your loss?

5. If you were to recommend a service to be developed to help bereaved parents, what would it be?

## Appendix G

### Interview Format

Introductions - (Setting a tone of friendliness that suggests to the respondent that the interaction will be casual and intimate). Information provided:

- reason for interest in bereavement;
  - as a bereaved parent
  - desire for greater understanding of parental bereavement experience
- summary of purpose of study;
  - majority of research on widows
  - unclear model of parental bereavement
  - to increase knowledge about the experience of bereaved parents
- outline of the format for the interview
  - self-report measures and interview
  - order will be personal information, life events checklist, CAPS interview, grief reaction checklist, social support measure, service needs survey
- advise of refusal option;
- desire to move at a pace comfortable for the respondent
- housekeeping issues: water, tissue, washroom, smoking

This format will be prepared as an outline rather than a script. Scripted introductions have been found to be less successful than conversational introductions. A conversational introduction is more likely to evoke cooperative behaviour (Houtkoop-Steenstra & Van Den Bergh, 2000/2001).

Consent - Obtain informed consent if not already completed.

Feedback - Does respondent wish to receive a summary of findings?

Measures - The questions that will be asked in these measures will probe a sensitive and painful part of the volunteer's experience. Much thought has been given to the order in which they should be presented. Conventional wisdom often prescribes that one should work up to more difficult questions. However, studies of "the effect of question order upon people's willingness to reveal sensitive information do not provide consistent support for the idea that threatening questions should come last"(Abrahamson, 1983, p.358). The guideline used here is that of a critical incident debriefing model. That model moves through several phases beginning with facts and thinking, moving to reactions and affect, then returning to a more cognitive level (Bell, 1995; Juhnke & Shoffner, 1999). In an effort to approximate that format, the order of measures will be:

1. Personal information
2. Life events checklist
3. CAPS
4. HGRC
5. PSS-Fa and PSS-Fr
6. Service needs

Conclusion - Provide thanks for participation

Discuss impact of interview

Provide support group referral if respondent wishes further support

## Appendix H

### Sampling Summary

Contact through TCF Winnipeg Sharing Meeting	2
Contact through National TCF Conference	1
Contact through letter distribution	<u>40</u>
Total Interviews	43

The response rate for the mail-out contacts can be calculated as follows:

Year of Search	Names taken from obituaries <sup>21</sup>	Contact information found for:
Jan - Dec 2000	105	43
Jan - Dec 2001	112	54
Jan - June 2002	48	20
Total	265	117

Names researched 265

Letters sent 117

NO CONTACT		CONTACT	
Post Office Returns	12	Parents returned cards	11
Wrong information	19	Parents phone message	10
Unable to connect	11	Refused	10
		Ineligible <sup>22</sup>	4
		Interviewed	<u>40</u>
SUBTOTAL	<u>42</u>		<u>75</u>

Response rate as a percentage of total contacts made:  
40 of 75 or 53.3%

Response rate of parents approached verbally:  
40 of 54 or 74.0%

<sup>21</sup> Eliminated those with obvious SIDS deaths (if recorded) also eliminated stillbirths and neonatal deaths where indicated. Rural parents from the 2000 list were not contacted.

<sup>22</sup> Two parents had experienced the sudden non-violent death of a child. One parent had died following their child's death. One parent was unable to participate in an interview.

## Appendix J

Table J1

Mean Number of Missing Items per Case on Instruments or Scale by Group  
N = 40 (Injury = 23, Non-injury = 17)

Instrument (Scale)		Mean	SD	t	p (2-tailed)
Personal Information	Injury	.22	.67	.208	.836
	Non-injury	.18	.53		
HGRC - All dimensions	Injury	.65	.65	.315	.755
	Non-injury	.59	.62		
HGRC - Blame & Anger	Injury	.04	.21	-.215	.831
	Non-injury	.06	.24		
HGRC - Detachment	Injury	.52	.51	-.047	.963
	Non-injury	.53	.51		
HGRC - Disorganization	Injury	.04	.21	.857	.397
	Non-injury	.00	.00		
PSS - Friends	Injury	.09	.29	1.447	.162 <sup>23</sup>
	Non-injury	.00	.00		
Total missing all Instruments	Injury	.96	.77	.698	.489
	Non-injury	.76	.97		

Table J2

Comparison of Injury and Non-Injury Groups (N = 40)

Variable		Injury death	Non- injury death	Statistical test	Significance	Related to: <sup>24</sup>	
Related to Death	Time since (months)	Mean SD	16.61 4.73	16.35 4.06	Ind. Samples t- test	t = .179 p = .859 (2-tailed)	Grief
	Subsequent Legal action	Yes No	4 19	0 17	Fisher's Exact test	Exact Sig. = .123 (2-sided)	Trauma
	Prevent- ability	Yes No	14 8	6 10	Fisher's Exact test	Exact Sig. = .188 (2-sided)	Grief

<sup>23</sup> Equal variances not assumed.

<sup>24</sup> Variables related to grief or trauma as reported in the literature.

Variable			Injury death	Non-injury death	Statistical test	Significance	Related to. <sup>24</sup>
Death Anticipated	One month	Yes No	1 22	7 10	Fisher's Exact test	Exact Sig. = .006 (2-sided)	Grief
	One week	Yes No	1 21	9 8	Fisher's Exact test	Exact Sig. = .001 (2-sided)	Grief
	One day	Yes No	1 22	14 3	Fisher's Exact test	Exact Sig. = .000 (2-sided)	Grief
Child	Gender	Male Female	16 7	7 10	Fisher's Exact test	Exact Sig. = .108 (2-sided)	Grief
	Age	Mean SD	21.65 4.74	14.53 11.91	Ind. Samples t-test	$t = 2.33^*$ $p = .030$ (2-tailed)	Grief
	Living arrangement	At home Away	11 12	5 12	Fisher's Exact test	Exact Sig. = .332 (2-sided)	
Parent Descriptors	Gender	Male Female	5 18	4 13	Fisher's Exact test	Exact Sig. = 1.000 (2-sided)	Trauma & Grief
	Age	Mean SD	48.91 6.67	44.75 9.82	Ind. Samples t-test	$t = 1.48^*$ $p = .153$ (2-tailed)	Grief
	Residence Location	Urban Rural	11 12	14 3	Fisher's Exact test	Exact Sig. = .046 (2-sided)	
	Aboriginal ancestry	Yes No	20 3	13 3	Fisher's Exact test	Exact Sig. = .674 (2-sided)	
	Living with partner at death	Yes No	17 5	15 2	Fisher's Exact test	Exact Sig. = .438 (2-sided)	Grief
	Currently living with partner	Yes No	17 5	15 2	Fisher's Exact test	Exact Sig. = .438 (2-sided)	Grief
	Added child subsequent to death	Yes No	0 23	4 13	Fisher's Exact test	Exact Sig. = .026 (2-sided)	Grief
	Level of education	Mean Rank Median	20.48 4	20.53 4	Mann-Whitney test	Asymp. Sig. = .989 (2-tailed)	
	Household income	Mean rank Median	20.83 22	17.85 22	Mann-Whitney test	Asymp. Sig. = .410 (2-tailed)	Grief



Parent Health	Current physical health	Mean Rank Median	20.11 2	21.03 2	Mann-Whitney test	Asymp. Sig. = .775 (2-tailed)	Trauma
	Compare with health before death	Mean Rank Median	20.11 2	21.03 2	Mann-Whitney test	Asymp. Sig. = .787 (2-tailed)	Trauma
	Mental health treatment	Yes No	3 20	1 16	Fisher's Exact test	Exact Sig. = .624 (2-sided)	Trauma
	Treatment - depression	Yes No	3 20	0 17	Fisher's Exact test	Exact Sig. = .248 (2-sided)	Trauma
	Undergoing treatment at death	Yes No	2 21	0 17	Fisher's Exact test	Exact Sig. = .499 (2-sided)	Trauma
Religion	Importance	Mean Rank Median	17.04 2	25.18 3	Mann-Whitney test	Asymp. Sig. = .023 (2-tailed)	Trauma
	Regular involvement	Yes No	10 13	4 13	Fisher's Exact test	Exact Sig. = .315 (2-sided)	Trauma
Coping	Used Professional Services	Yes No	16 7	10 7	Fisher's Exact test	Exact Sig. = .521 (2-sided)	
	Used reading	Yes No	20 3	8 9	Fisher's Exact test	Exact Sig. = .013 (2-sided)	
	Attended group	Yes No	7 16	3 14	Fisher's Exact test	Exact Sig. = .471 (2-sided)	
Life Events Checklist	Happened to me	Mean SD	2.35 2.31	2.88 2.35	Ind. Samples t-test	$t = -.598$ $p = .554$ (2-tailed)	Trauma
	Learned about it	Mean SD	1.61 1.64	2.53 3.41	Ind. Samples t-test	$t = .265$ $p = .265$ (2-tailed)	Trauma
	Witnessed it	Mean SD	1.48 1.56	1.24 1.09	Ind. Samples t-test	$t = .549$ $p = .586$ (2-tailed)	Trauma
	Total	Mean SD	5.43 2.95	6.65 4.47	Ind. Samples t-test	$t = -1.033$ $p = .308$ (2-tailed)	Trauma
Social Support	PSS-Fr	Mean SD	14.26 4.24	12.53 3.74	Ind. Samples t-test	$t = 1.337$ $p = .189$ (2-tailed)	Grief & Trauma
	PSS-Fa	Mean SD	14.30 4.97	14.65 5.43	Ind. Samples t-test	$t = -.207$ $p = .837$ (2-tailed)	Grief & Trauma

\* Equal variances not assumed

Table J3

Summary of Logistic Regression Analysis for Variables Predicting PTSDDiagnosis Using the F1 - I2 Rule (N=40)

Controlled Variable	-2 Log Likelihood of Model Including Group Membership	Chi-Square	df	Sig (one-tailed)
Child Age	35.333	1.160	1	.141
Added child	8.681	1.059	1	.152
Urban Residence	10.094	.229	1	.316
Religiosity	13.622	.306	1	.290
Cope- Reading	9.578	.254	1	.307

\*For group: Injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 4

Summary of Logistic Regression Analysis for Variables Predicting PTSDDiagnosis Using the = 4 Rule (N=40)

Controlled Variable	-2 Log Likelihood of Model Including Group Membership	Chi-Square	df	Sig (one-tailed)
Child Age	25.252	1.344	1	.123
Added child	8.900	3.862	1	.025**
Urban Residence	8.165	.896	1	.172
Cope- Reading	8.044	.440	1	.254
Religiosity***				
Very important	9.463	.246	1	.310
Moderately NB	7.846	.291	1	.295
Somewhat NB	5.431	.019	1	.446

\*For group: Injury = 1, non-injury = 0

\*\* Alpha < .10 High Wald parameter (260.954) indicates this analysis is not reliable.

\*\*\*Because small numbers produced empty cells, the religiosity variable could not be controlled in one equation and a separate logistic regression was formulated for three categories of the variable.

Table J 5

Summary of Standard Multiple Regression Analysis for Variables Predicting  
PTSD Scores - Total Severity Score (N = 40)

Controlled Variable	B*	SE B	t	p**(one-tailed)
Child age	7.891	5.713	1.381	.088***
Added Child	6.157	5.991	1.028	.156
Urban Residence	-4.374	6.067	-.721	.238
Religiosity	-2.373	7.118	-.333	.371
Cope -Reading	-3.184	6.184	-.515	.305

\*For group: Injury = 1, non-injury = 0

\*\* Alpha = .10

\*\*\* $p < .1$  (one-tailed)

Table J 6

Summary of Standard Multiple Regression Analysis for Variables Predicting  
PTSD Scores - Reexperiencing Dimension (N = 40)

Controlled Variable	B*	SE B	t	p**(one-tailed)
Child age	1.060	1.864	.569	.287
Added Child	.796	1.911	.417	.340
Urban Residence	-.977	2.047	-.477	.318
Religiosity	-1.864	2.370	-.779	.221
Cope -Reading	-2.368	2.071	-1.143	.130

\*For group: Injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 7

Summary of Standard Multiple Regression Analysis for Variables Predicting  
PTSD Scores - Avoidance & Numbing Dimension (N = 40)

Controlled Variable	B*	SE B	t	p**(one-tailed)
Child age	2.909	3.292	.883	.192
Added Child	2.856	3.294	.867	.186
Urban Residence	2.785	3.216	.866	.186
Religiosity	-1.393	3.849	-.362	.360
Cope -Reading	-2.161	3.394	-.637	.264

\*For group: Injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 8

Summary of Standard Multiple Regression Analysis for Variables Predicting  
PTSD Scores - Hyperarousal Dimension (N = 40)

Controlled Variable	B*	SE B	t	p**(one-tailed)
Child age	3.922	2.136	1.836	.037***
Added Child	2.505	2.241	1.118	.136
Urban Residence	2.565	2.205	1.163	.126
Religiosity	.865	2.630	.329	.372
Cope -Reading	1.345	2.263	.595	.278

\*For group: Injury = 1, non-injury = 0

\*\* Alpha = .10

\*\*\*  $p < .1$  (one-tailed)

Table J 9

Summary of Standard Multiple Regression Analysis for Variables Predicting GriefScores - *Despair Dimension* (N = 40)

Controlled Variable	B*	SE B	t	p (one-tailed)
Child Age	2.224	3.759	-.022	.492
Added Child	-.431	3.934	-.110	.457
Urban Residence	2.224	3.759	.592	.279
Religiosity	.614	4.594	.134	.447
Cope -Reading	-1.188	3.993	-.298	.384

\* For group injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 10

Summary of Standard Multiple Regression Analysis for Variables Predicting GriefScores - *Panic Behaviour Dimension* (N = 40)

Controlled Variable	B*	SE B	t	p (one-tailed)
Child Age	-3.854	4.488	-.859	.188
Added Child	-6.033	4.391	-1.374	.089
Urban Residence	-1.864	4.313	-.432	.334
Religiosity	-4.416	5.214	-.847	.202
Cope -Reading	-3.816	4.578	-.834	.205

\* For group injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 11

Summary of Standard Multiple Regression Analysis for Variables Predicting GriefScores - Personal Growth Dimension (N = 40)

Controlled Variable	B*	SE B	t	p (one-tailed)
Child Age	1.009	3.464	.291	.386
Added Child	.124	3.417	.036	.486
Urban Residence	2.117	3.403	.622	.269
Religiosity	-.550	3.980	-.138	.446
Cope -Reading	-.323	3.471	-.093	.463

\* For group injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 12

Summary of Standard Multiple Regression Analysis for Variables Predicting GriefScores - Blame and Anger Dimension (N = 40)

Controlled Variable	B*	SE B	t	p (one-tailed)
Child Age	1.930	1.988	.971	.164
Added Child	2.261	1.953	1.157	.128
Urban Residence	1.271	1.989	.639	.264
Religiosity	.614	2.375	.259	.399
Cope -Reading	.419	2.052	.204	.419

\* For group injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 13

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief Scores - Detachment Dimension (N = 40)

Controlled Variable	B*	SE B	t	p (one-tailed)
Child Age	1.679	2.274	.738	.233
Added Child	.147	2.258	.065	.475
Urban Residence	1.316	2.250	.585	.281
Religiosity	-.085	2.638	-.032	.468
Cope -Reading	.044	2.306	.019	.493

\* For group injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 14

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief Scores - Disorganization Dimension (N = 40)

Controlled Variable	B*	SE B	t	p (one-tailed)
Child Age	1.080	2.498	.432	.334
Added Child	-.807	2.421	-.333	.375
Urban Residence	.005	2.444	.002	.499
Religiosity	-3.277	2.590	-1.265	.107
Cope -Reading	-.885	2.484	-.356	.362

\* For group injury = 1, non-injury = 0

\*\* Alpha = .10

Table J 15

Pearson's Correlation of Duration of Bereavement to All Measures

Measure		Time since death in months
HGRC - Despair	Pearson Correlation	.278*
	Sig. (2-tailed)	.083
HGRC - Panic Behaviour	Pearson correlation	.091
	Sig. (2-tailed)	.578
HGRC - Personal Growth	Pearson correlation	-.066
	Sig. (2-tailed)	.687
HGRC - Detachment	Pearson correlation	.130
	Sig. (2-tailed)	.423
HGRC - Blame & Anger	Pearson correlation	.311*
	Sig. (2-tailed)	.051
Disorganization - HGRC	Pearson Correlation	-.088
	Sig. (2-tailed)	.587
CAPS - Total Severity PTSD Symptoms	Pearson Correlation	.041
	Sig. (2-tailed)	.803
CAPS - Reexperiencing	Pearson Correlation	.035
	Sig. (2-tailed)	.831
CAPS - Avoidance & Numbing	Pearson Correlation	.045
	Sig. (2-tailed)	.784
CAPS - Hyperarousal	Pearson Correlation	.013
	Sig. (2-tailed)	.936
PSS-Family	Pearson Correlation	.192
	Sig. (2-tailed)	.236
PSS-Friends	Pearson Correlation	.174
	Sig. (2-tailed)	.284

\* p&lt;.10



Table J 16

Comparison of Means of Groups Divided According to Time Since Death

Measure	Group	N	M	SD	Min	Max
HGRC - Despair	6-14 months post death	14	29.00	9.28	17	50
	15-18 months post death	13	30.85	12.28	15	56
	19-24 months post death	13	33.92	11.83	22	56
	Total	40	31.20	11.06	15	56
HGRC - Panic Behaviour	6-14 months post death	14	28.85	10.27	19	55
	15-18 months post death	13	33.85	15.17	14	61
	19-24 months post death	13	29.54	12.90	15	52
	Total	40	30.70	12.73	14	61
HGRC - Personal Growth	6-14 months post death	14	38.21	10.12	20	55
	15-18 months post death	13	42.77	9.87	26	56
	19-24 months post death	13	36.38	8.82	23	51
	Total	40	39.10	9.76	20	56
HGRC - Blame & Anger	6-14 months post death	14	12.96	5.13	7	22
	15-18 months post death	13	11.19	3.83	7	18
	19-24 months post death	13	15.85	7.10	7	29
	Total	40	13.33	5.70	7	29
HGRC - Detachment	6-14 months post death	14	15.27	5.35	8	25
	15-18 months post death	13	14.78	7.06	8	30
	19-24 months post death	13	16.04	7.30	8	31
	Total	40	15.36	6.44	8	31
HGRC - Disorganization	6-14 months post death	14	18.49	7.15	8	31
	15-18 months post death	13	16.85	7.69	7	30
	19-24 months post death	13	16.92	6.63	8	31
	Total	40	17.45	7.03	7	31

Measure	Group	N	M	SD	Min	Max
CAPS Total Severity Score	6-14 months post death	14	27.79	12.94	0	54
	15-18 months post death	13	21.38	15.66	3	52
	19-24 months post death	13	28.85	23.62	2	76
	Total	40	26.05	17.72	0	76
CAPS Reexperiencing	6-14 months post death	14	6.29	5.99	0	15
	15-18 months post death	13	5.38	5.88	0	22
	19-24 months post death	13	6.46	6.13	0	21
	Total	40	6.05	5.87	0	22
CAPS Avoidance & Numbing	6-14 months post death	14	11.36	6.22	0	23
	15-18 months post death	13	8.85	9.39	0	33
	19-24 months post death	13	12.54	12.98	0	40
	Total	40	10.93	9.71	0	40
CAPS Hyperarousal	6-14 months post death	14	10.14	5.91	0	19
	15-18 months post death	13	7.15	5.90	0	20
	19-24 months post death	13	9.85	7.38	0	23
	Total	40	9.08	6.40	0	23
PSS - Friends	6-14 months post death	14	12.78	4.95	5	19
	15-18 months post death	13	13.85	3.87	7	19
	19-24 months post death	13	14.00	3.39	8	19
	Total	40	13.52	4.08	5	19
PSS - Family	6-14 months post death	14	13.57	5.49	3	19
	15-18 months post death	13	15.00	4.58	8	20
	19-24 months post death	13	14.85	5.44	4	20
	Total	40	14.45	5.10	3	20

Table J 17

Analysis of Variance for Time since Death and All Measures

## ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
Despair - HGRC	Between Groups	165.785	2	82.892	.665	.520
	Within Groups	4608.615	37	124.557		
	Total	4774.400	39			
Panic Behaviour - HGRC	Between Groups	193.763	2	96.881	.585	.562
	Within Groups	6130.637	37	165.693		
	Total	6324.400	39			
Personal Growth - HGRC	Between Groups	281.858	2	140.929	1.519	.232
	Within Groups	3433.742	37	92.804		
	Total	3715.600	39			
Detachment - HGRC	Between Groups	10.577	2	5.288	.122	.886
	Within Groups	1608.321	37	43.468		
	Total	1618.897	39			
Blame & Anger - HGRC	Between Groups	143.581	2	71.791	2.364	.108
	Within Groups	1123.694	37	30.370		
	Total	1267.275	39			
Disorganization - HGRC	Between Groups	23.436	2	11.718	.228	.797
	Within Groups	1903.308	37	51.441		
	Total	1926.744	39			
Total Severity - CAPS	Between Groups	426.774	2	213.387	.668	.519
	Within Groups	11815.126	37	319.328		
	Total	12241.900	39			
Reexperiencing - CAPS	Between Groups	8.735	2	4.368	.121	.886
	Within Groups	1333.165	37	36.031		
	Total	1341.900	39			
Avoidance & Numbing - CAPS	Between Groups	92.638	2	46.319	.478	.624
	Within Groups	3582.137	37	96.815		
	Total	3674.775	39			
Hyperarousal - CAPS	Between Groups	71.676	2	35.838	.869	.428
	Within Groups	1525.099	37	41.219		
	Total	1596.775	39			
Perception of Social Support - Family score	Between Groups	16.779	2	8.390	.311	.735
	Within Groups	999.121	37	27.003		
	Total	1015.900	39			
Perception of Social Support -Friends score	Between Groups	12.082	2	6.041	.351	.706
	Within Groups	636.702	37	17.208		
	Total	648.783	39			

Table J 18

Standard Regression Analyses for Time and Group as Predictors of Scale Scores.

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief Scores - *Despair Dimension* ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-16.989	14.026	-1.211	.234
Interaction variable	1.031	.827	1.247	.220
Time since death	.028	.667	.041	.967

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief Scores - *Panic Behaviour Dimension* ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-16.726	16.740	-1.211	.234
Interaction variable	.776	.987	.787	.437
Time since death	-.230	.796	-.289	.774

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief Scores - *Personal Growth Dimension* ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-1.107	13.078	-.085	.933
Interaction variable	.161	.771	.209	.836
Time since death	-.255	.622	-.411	.684

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief

Scores - Detachment Dimension ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-2.919	8.559	-.341	.735
Interaction variable	.237	.504	.469	.642
Time since death	.033	.407	.082	.935

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief

Scores - Blame & Anger Dimension ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-7.189	7.142	-1.007	.321
Interaction variable	.493	.421	1.172	.249
Time since death	.078	.339	.230	.820

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Grief

Scores - Disorganization Dimension ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-10.157	9.237	-1.100	.279
Interaction variable	.661	.544	1.214	.233
Time since death	-.574	.439	-1.306	.200

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting

Traumatic Stress Scores - CAPS Total Severity ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-7.241	23.792	-.304	.763
Interaction variable	.530	1.402	.378	.707
Time since death	-.186	1.131	-.164	.870

\*For group injury = 1, non-injury = 0

Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting

Traumatic Stress Scores - CAPS Reexperiencing ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	8.475	7.687	1.103	.278
Interaction variable	-.586	.453	-1.293	.204
Time since death	.431	.365	1.180	.246

\*For group injury = 1, non-injury = 0

Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting

Traumatic Stress Scores - CAPS Avoidance & Numbing ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	-16.108	12.758	-1.263	.215
Interaction variable	1.001	.752	1.332	.191
Time since death	-.554	.606	-.914	.367

\*For group injury = 1, non-injury = 0

Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Traumatic Stress Scores - CAPS Hyperarousal ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	.393	8.480	.046	.963
Interaction variable	.115	.500	.229	.820
Time since death	-.063	.403	-.156	.877

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Perception of Social Support - Family Scores ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	13.402	6.315	2.122	.041
Interaction variable	-.839	.372	-2.256	.030
Time since death	.770	.300	2.564	.015

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Summary of Standard Multiple Regression Analysis for Variables Predicting Perception of Social Support - Friends Scores ( N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	9.238	5.131	1.800	.080
Interaction variable	-.459	.302	-1.519	.138
Time since death	.454	.244	1.862	.071

\*For group injury = 1, non-injury = 0  
Interaction variable = time in months x injury group

Table J19

Summary of Standard Multiple Regression Analysis for Variables PredictingCAPS Total Severity Scores (N = 40)

Independent Variable	B*	SE B	t	p (one-tailed)
Injury death	16.485	17.754	.929	.179
Interaction variable	-.422	.824	-.512	.306
Child age in years	-.819	.349	-2.348	.013

\*For group injury = 1, non-injury = 0

Interaction variable = Child age in years x injury group





UNIVERSITY  
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Office of the President

Office of Research Services  
244 Engineering Building  
Winnipeg, MB R3T 5V6  
Canada  
Tele:  
Fax:

### APPROVAL CERTIFICATE

25 September 2001

**TO:** Shelagh Marchenski (Advisor S. Frankel)  
Principal Investigator

**FROM:** Wayne Taylor, Chair  
Joint-Faculty Research Ethics Board (JFREB)

**Re:** Protocol #J2001:078  
"Parental Bereavement: An Investigation of the Traumatic Impact of  
Child Death"

---

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.



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RESEARCH SERVICES &  
PROGRAMS  
Office of the Vice-President (Research)

244 Engineering Bldg.  
Winnipeg, MB R3T 5V6  
T:  
F:  
W:

## RENEWAL APPROVAL

16 January 2004

**TO:** Shelagh Marchenski  
Principal Investigator

**FROM:** Karen Duncan, Interim Chair  
Joint-Faculty Research Ethics Board (PSREB)

**Re:** Protocol #J2001:078  
"Parental Bereavement: An Investigation of the Traumatic Impact of  
Child Death"

---

Please be advised that your above-referenced protocol has received approval for renewal by the **Joint-Faculty Research Ethics Board**. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.