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Professional Interventions with Parents at the Time of the Sudden Death of a Child

By

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Abstract

The sudden death of a child is likely the most traumatizing event a parent can experience. Traumatic death, and particularly the death of a child, increases the risk of a complicated grieving process in mourners. Little has been written with respect to the interventions of professionals with parents at the time of a sudden death of a child. The present study examines the experiences of parents with a variety of professionals from the time of death notification through the funeral.

Twenty parents who were involved in Bereaved Families of Ontario participated in this study. The purpose was to examine the impact of professional interventions on the grieving process of the parents. Qualitative inquiry was utilized with the heuristic aspect of the phenomenological approach using semi-structured, open-ended interviews. Thematic analysis was completed at two levels. The first identified three key themes in helping: the provision of instrumental assistance, compassion and information. The themes in grieving were the reconstruction of the death scene, issues of control and the assumptive world, saying goodbye, making sense of the death, and carrying the deceased child forward in a new world. The integration of these themes produced concrete ways of helping parents through the trauma, and facilitating a healthy grieving process. The conclusion of the study outlines the clinical implications of these significant findings.

Dedication

This dissertation is dedicated to our Angels Remembered

Caroline

Christina

Frank

Ian

Jamie

Jason

Jason's Baby Sister

Jay

Kaitlyn

Kayla

Kevin

Luke

Marion

Melanie

Stephen

Tammy

Timmy

Trevor

and to my own Angel

Jeremy

Acknowledgements

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I would like to express my deep gratitude to the parents who participated in this study. I am sure that they, like myself, would give everything they own to not qualify for participation in this research. Their courage and openness in sharing their experiences made it all happen. I feel that I really got to know about who their children are in this process, and I am honored that they let me into their lives in the way that they did.

Last but not least, a big thank you goes to my family for all of their support: my parents, Marjorie and Eric; my partner David without whose love and support this work would have been even more difficult; and my wonderful daughter Jodie, my beautiful granddaughter Marissa (Mimi), my soon to be born grandson, and of course my son-in-law Peter, who are the lights of my life and my living angels. Jeremy's death led me to this work, but his life showed me the way. Now finally Dad, in answer to your constant question, "Is it done yet?" the answer is YES, IT'S DONE!

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Chapter One

Introduction

> Parents who lose a child are multiply victimized. We are victimized by the realistic loss of the child we love, we are victimized by the loss of dreams and hopes we had invested in that child and we are victimized by the loss of our own self-esteem. Not unlike the survivors of the concentration camps, we cannot comprehend why we did not die instead. (Kliman, 1977)

Rationale and Focus

The sudden death of a child is, for parents, likely the single most catastrophic event imaginable. The DSM IV (Diagnostic and Statistical Manual IV, 1997) categorizes the death of a child as a catastrophic stressor. Figley (1985) defines a catastrophe as "an event or series of events which is sudden, overwhelming and often dangerous to one's self or others" (p.xviii) and leads to such stress-related reactions as panic, hysteria, acute grief and outcry. Trauma related to death is defined by Rando (1996, p.60) as

> the disruption or breakdown that occurs when an event - either external or internal - presents a person with stimuli that are too powerful to be dealt with or assimilated in the usual way. This gives rise to sudden, intense anxiety that exceeds the person's ability to manage and defend against, causing the individual to be overwhelmed and unable to cope, eventuating in a state of helplessness and other flooding affects (e.g., shock, horror, anxiety, and vulnerability) in response.

Sudden death circumstances highlight the randomness of the trauma, increasing the overwhelming nature of the catastrophe and diminishing the bereaved person's ability to cope in the crisis of the moment (Rando, 1996). Both Figley (1985) and Rando (1996) identify that such traumatic deaths can lead to post traumatic stress disorders and complicated grief reactions. These reactions may be manifested through such behaviors

and experiences as reliving the trauma, and numbing of responsiveness to life stimuli. Other symptoms may include: depression, anxiety, hyper-vigilance, sleep disturbances, eating disturbances, guilt, anger, helplessness and powerlessness.

Over the last two centuries cultural understandings of death have changed dramatically. Interest in specific groups of bereaved individuals has grown during that time. Although there were studies completed on widows, there has been little written with respect to parental loss of a child until the late 1900's (Horacek, 1995). In addition, in the 1960's changing social values redefined the way in which professionals began to deal with mourning clients, placing a high value on emotional expression of the loss and the right of the client to do so (Davidson & Foster, 1995). Further interest on the part of social scientists in death and it's rituals led to the development of self-help literature (Smart, 1994).

While the sudden death of a child is not a rare occurrence, an interest in research and literature on the effects of the loss of a child on parents is relatively recent. Theories of grief and mourning in the field of thanatology were originally derived primarily from research with widows, who are an easily accessible group among the bereaved (Rando, 1986). This is readily observable through any review of the literature on grief and mourning. Further developments in thanatological research have focused on the differing natures of other types of losses, and the issues associated with them. More recently, articles have been written on the treatment of parental loss by authors such as Rando (1984; 1986; 1991; & 1994); Rosof (1995); Gyulay (1989); Videka-Sherman & Lieberman (1985); Weiss (1989); Brabant, Forsyth, & McFarlain (1994 a & b, 1995); Cook (1983, 1988); deVries, Lana & Falck (1994); Drenovsky (1995); and, Lehman,

et.al. (1989). These authors primarily address the ongoing treatment issues of parental loss. There are, however, only brief references to dealing with parents in the crisis of a sudden death.

As previously stated, the sudden death of a child is not a rare occurrence, even in western society. Rando (1992-1993), notes that in the United States the mortality rates for children and youth have been reduced since 1900, however, external causes of death in that age group have risen from approximately ten percent of those deaths in 1900, to sixty-four percent in 1985. Accidents in the United States are the leading cause of death in children and youths. Rando cites increasing exposure in today's society to elements that place individuals at higher risk for accidental deaths, such as technology, transportation modes, weapons systems and chemistry. According to Rando, the technological and medical developments in these areas have decreased the proportion of natural deaths and increased the proportion of accidental deaths. In addition, mutilation is common in such deaths. Rando (1992-1993), also cites the escalation of violence and pathology in society, combined with an

> ...increasing number of individuals with impaired psychological development, characterized by an often absent conscience, low frustration tolerance, poor impulse control, inability to delay gratification or modulate aggression, a sense of deprivation and entitlement, and notably poor attachment bonds and pathological patterns of relationships" (p.51)

as additional causes of increasing numbers of traumatic deaths. These features of society are seen across North America.

Within the Canadian context it is difficult to determine the complete extent of sudden death in children and youths from ages birth to twenty-four. Two categories of sudden or unexpected deaths are delineated in statistical data, while other types are not. In Canada, sudden death by external causes is identified in the Statistics Canada Mortality Tables. These include death by transport accidents, poisonings, falls, fires, lightening, drowning, suffocation, choking, firearms, explosives, electrocution, and various other accidents, as well as suicide, homicide, and a particularly disturbing category labeled 'medical misadventures'. Sudden deaths in this age group also result from acute myocardial infarctions, acute asthma attacks, obstetrical complications, and sudden perinatal deaths including Sudden Infant Death Syndrome. All of these are identified separately in the Mortality Tables, as well as a host of unexpected deaths from illnesses and surgeries that are not specified in those Tables.

In 1995 in Canada, for example, 2,425 children and youths between the ages of birth and twenty-four died from external causes (Statistic Canada Mortality Tables, 1995). These external causes include 646 deaths by suicide, 132 murders and 1,647 accidents. An additional 1,025 children and youths died suddenly of the illness- related causes referred to above. The number of sudden deaths in that age group in 1995 individually cataloged in the Mortality Tables totals 3,450 children and youths. Again, this does not include sudden deaths not separately listed. Clearly, many parents are faced with this type of catastrophic loss. The management of the trauma of such a catastrophe has a dramatic impact on both bereaved parents, and society as well. These personal and social costs are incurred from treating the complications in the grieving process that can flow from inept or inadequate professional interventions, or lack of any intervention at all, and

are quite high. Wheeler (1994) points out that the crisis precipitated by the death of a child threatens the very basic assumptions of a parent's beliefs, and the way in which this crisis is dealt with has significant implications for the grief process. Bowlby (1980) confirms that a great deal of psychiatric illness experienced in North America results from pathological grief processes. Videka-Sherman (1987) emphasizes the need for constructive interventions following the child's death as such interventions predict improved adaptation over time. Rees and Lutkins (1967) discuss the higher mortality rate among parents whose children have died sudden, violent or destructive deaths. Reilly (1978) supports the need for increased thought, sensitivity, and understanding on the part of professionals involved with parents at this time. Therefore, the importance of educated interventions on the part of the professionals involved with parents at the death of a child cannot be underestimated in terms of both personal cost to mourners, and social costs, in a multitude of aspects, not the least of which are medical and mental health issues. Raphael (1983) has stated that one in three bereavements result in a complicated grieving process. Rando (1993) estimates that in the United States there is a potential, at minimum, for six million new cases of complicated mourning each year. As Rando so aptly remarks:

> The costs of complicated mourning not only relate to personal suffering, they also extend economically, socially, politically, and philosophically into the family, social network, workplace, community, and society as a whole. Persons who believe that the losses suffered by others do not concern them should probably not examine too closely the realities of increased health insurance premiums; the financial and social costs of worker drug abuse, absenteeism, accidents and lowered productivity and product quality; the effects of escalating social violence; and so forth – all of which are among the many sequelae of complicated mourning. (1993, p. 5)

I have developed a particular interest in the professional interventions directed at parents at the time of the sudden death of a child, and the impact of those interventions on the parents' ability to process and accept the death, and begin the work of grieving. This interest was initiated by my personal experiences in the loss of my own son in a drowning accident, and the subsequent interventions by professionals that I experienced. In walking through the journey of grief, and helping to establish a support group for parents who had lost a child to death, I became involved with many other parents who had been through similar experiences. The sharing by these parents of interventions by professionals, which they identified as having interfered with their ability to cope and grieve, as well as identification of interventions that assisted them in their grieving process, further intensified my interest in this area. My own experiences, and those of the many parents who shared their own stories with me, highlighted the need for increased sensitivity, awareness and understanding of the needs of parents by professionals.

An Overview of the Paper

This dissertation is constructed in eight chapters. Chapter One: Introduction discusses in general terms the nature of the problem, the cultural context, statistics on sudden death of children and the social costs of mismanagement of the trauma experienced by parents at the time of the sudden death of their child. The chapter provides a focus and rationale for this dissertation. The chapter then provides an overview of the paper, outlining briefly the contents of each chapter.

Chapter Two: A Theoretical Perspective On Grief and Trauma begins with an in depth look at the models of grief currently espoused by therapists, such as those of Worden (1991), Rando (1993), and Kubler-Ross (1969). The trauma literature is reviewed. A

brief history of the development of our understanding of trauma is presented. The incidence and key features of PTSD as well as issues of causality are addressed. The three primary features of PTSD, intrusion, hyper-arousal and avoidance are reviewed. The linkage between trauma and grief in terms of the similar features in grieving a traumatic death and PTSD are discussed. The most noted work in this area is that of Figley (1984; 1985: & 1997); Janoff-Bulman (1985); Rando (1993); Simpson (1997); and Nader (1997). Traumatic death as a precipitant of complicated mourning is discussed, including parental loss as a predisposing factor. The purpose of this chapter is to develop a theoretical framework joining grief theory and trauma theory, and to relate that conceptual framework to the lack of literature with respect to intervening at the time of a traumatic death.

A review of the literature demonstrated limited information relevant to helping parents at the time of the death of their child. The literature review in this dissertation examines grief theories, and demonstrates the lack of a conceptual framework to inform the interventions of professionals with parents at the time of a sudden and/or unexpected death of a child. Finally, Crisis Theory is briefly reviewed. This theory is significant to the findings of this dissertation. The themes of professional assistance in the areas of information, compassion and instrumental assistance are highly related to the type of interventions described in Crisis Theory.

Chapter Three: Parental Loss, provides an examination of the literature on parental loss, specifically highlighting the limited literature with respect to the difficulties encountered by parents in the initial period following the sudden death of children. The chapter will identify the issues parents face when their child dies from any cause,

proposing that any death of a child is experienced as a trauma by the parents. It then explores the particular issues associated with sudden, traumatic death of a child. The chapter reviews the literature available on helping parents to deal with the sudden loss of a child at the time of the death, and demonstrates the limited research in this area. This chapter concludes with an examination of the literature available to professionals dealing with parents at such a time with respect to models of intervention.

The primary professionals involved from the time of a sudden death through to the end of the funeral most often include police, emergency room doctors and nurses, coroners, clergy, and funeral directors. In many situations social workers are not available in the immediate crisis of the death. In fact, today in most parts of Ontario, such is the case. In this particular study only two families had social workers involved with them at the time of the child's death. It is my position that the field of social work must take a professional stance in educating those involved with parents at the time of such a death, as some social workers are best trained to deal with emotional trauma and crises.

Chapter Four: Methodology, details the nature of the research study I have undertaken. It examines the design of the study, the sampling procedure, data collection and data analysis procedures. Issues of trustworthiness in this research are discussed, specifically credibility, transferability, dependability, and confirmability. There is a discussion of the ethical considerations involved in this highly sensitive research, and finally limitations and challenges experienced in the research are addressed.

Chapter Five: Losing a Child: The Parents Speak, begins with the telling of the stories of each child's death. There are thirteen stories in all, representing the details of the

deaths of the children of twenty parent participants. The stories are told as they were told to me, and partially in the direct words of the parents. The chapter describes the emotional experience of the loss for each of the parents involved. At the end of the chapter, some of the parents describe how their grief has changed over time, and the effect the loss of their child has had on their lives.

Chapter Six: Interventions Experienced, examines the actual experiences of parents with police, hospital personnel, coroners, chaplains, clergy, funeral directors, and in two situations, social workers. The parents describe their experiences, and the effects they felt these interventions have had on their grief. These are then linked to the grieving process using Rando's Six R Processes of Grief. The themes of the need for information, the need for instrumental assistance and the need for compassion are developed in this chapter.

Chapter Seven: The Analysis of the Data, develops the five themes that emerged from the research. The themes: reconstruction of the death scene, loss of control, the need to say goodbye, making sense of the death, and developing a new relationship with the deceased child are examined in detail and linked to the grief process. These themes are related to the themes developed in the previous chapter with respect to information, instrumental assistance and compassion.

In the final chapter, Conclusions, the research question is restated, and a synopsis of the themes is given. The clinical implications are outlined with specific detail from parents with respect to what professionals can do. Ways to facilitate reduction of trauma and beginning the grief process are identified. My own process in conducting this research is discussed. Areas for further research are identified. Finally, some comments

from the parents who participated in this research are offered as a conclusion to the paper. This is a work of the parents who participated. It is a work in progress and will always be, as they learn to carry on their lives without their children. It seemed fitting that they should have the final words.

Engaging in High Voltage Research

I would like to comment on the process of engaging in research that is both intensely personal in nature, and highly emotionally charged. I have already stated that my interest in the experiences of parents when children die suddenly and the impact of those experiences on the grief process stems from the sudden death of my own child. In the selection of a heuristic methodology, I have in this research, plunged myself into the very depths of the experience of parents who have lost a child suddenly. Because of my own loss, and at times in spite of it, I have been able to go to where those parents are in an effort to understand their experiences. I approached this research with an intense need to understand the experiences of parents and their impact on the grieving process, partially because I had worked so hard and for so long to understand those things about myself. In making the decision to proceed, I was very aware that to stand with the participants would bring me directly back to the pain of my son's death. This is what I call high voltage research. Immersion in interviews, transcriptions, and analysis meant living in a space beyond the compassion that we extend to our clients or our research participants. It meant being in the darkest places of my soul at times.

This process was an incredibly powerful one. I have learned an incredible amount about how parents survive the death of a child from the participants. I have also experienced considerable personal growth through this process. As with the death of my

son, I have again been changed through the sharing of the parents who participated, and through the personal struggle involved in doing this research. I believe that through sharing in and understanding their stories, I have reached a greater integration of the meaning of the life of my son in my own life. Both myself, and the parents who participated in this research wanted to do something that would help reduce the chance that other parents would lack support in their time of need. The highly charged meaning of this work to both the participating parents and to myself as parent and as researcher is what has brought this work to completion. It is our combined hope that this document will be of assistance to those who help parents whose children die suddenly, and therefore to the parents themselves.

Chapter Two

A Theoretical Perspective on Grief and Trauma

> ... you're going along in your life, quietly, with a little awareness of the dark side but doing okay. Then something can come along and climb through your window and rip the heart right out of you and destroy you utterly, sweep away all the signposts you know and leave you gibbering, on a rock, in the rain. (Neil Munro)

Models of Grief and Mourning: The State of the Art

Culture and religion have heavily influenced models of grief and mourning throughout history. Social values have played a large role in defining what was considered 'normal' in terms of grieving. Changing social values in the 1960's in North American culture, led to the encouragement of emotional openness in general, which influenced the way in which appropriate grieving was perceived (Davidson, & Foster, 1995). This has led to an unprecedented era of examining the grief process and writing about it.

The general trend in grief theory in the 1970's was the conceptualization of grieving as a series of stages, which ultimately resulted in the severing of ties with the deceased loved one, and moving forward in a world without that person (Fleming, 1998). Most models of grief treatment were based on the five-stage model proposed by Elizabeth Kubler-Ross (1969). The current thinking in grief theory is that grief is a process and involves the development of some form of new relationship with the deceased, as in Worden's (1991) emotional relocation of the deceased in one's life, and Rando's (1993) maintenance of a healthy relationship with the deceased. Further thinking involves the development of a 'personal healing theory' (Figley, 1984), and the idea of 'transcending'

the loss (Rando, 1998).

The state of the art, however, has been the very recent examination of the interconnections and overlays between trauma and grief. Rando (1993; 1994; & 1998) and Figley (1997), along with Simpson (1997), Nader (1997 a &b), Reed (1991), Wells (1993), Baker (1997) and Horowitz (1997) are currently working with models of grief and trauma which they are developing, as well as with treatment models based on this new conceptual framework. This current movement in thanatology draws heavily on the earlier work of Raphael (1983), as well as on the work of Figley (1984; & 1985) and Rando (1986; 1992-3; & 1994). There is agreement among these thanatologists that while there is a certain amount of trauma in every death, that certain types of deaths are more traumatic, and that traumatic death is a precipitant of complicated mourning.. The loss of a child is always viewed as a traumatic death.

Fowlkes' (1991) discusses the social morality of loss with respect to societal expectations in assigning differential merit to the various types of relationship losses one can sustain. Societal influence places an unrealistic expectation on mourners with respect to their responses to these losses. The meaning of a loss is derived from the social value placed on the relationship. For example the loss of a friend may be devalued by society, when in point of fact that friendship may have been more significant in the mourner's life than the relationship with a sibling or parent, which would likely be ascribed a higher social value. Thus the mourner's responses may be viewed by society as pathological.

Fowlkes' (1991) discussion of the morality of loss is interesting in the context of parental loss. Seldom in life is one likely to experience such an intense loss (Rosof, 1995; Rando, 1993; 1991; 1986; Gyulay, 1989; Klass, 1992-3; Schiff, 1977; Videka-

Sherman, 1987). Given that social expectations of mourners in general are based on theories developed from research that was primarily focussed on widows (Rando, 1986) it is small wonder that although there is agreement that the loss of a child is traumatic, the responses of bereaved parents, which are different than those of widows are often viewed as pathological. Commonly held myths with respect to the duration, intensity and outcome of the mourning process reinforce the view that the loss of any close individual should result in a set period of mourning, of a diminishing intensity over time. The mourner should then return to his or her previous "self" (Rando, 1991). The socially ascribed definition of what constitutes a 'close individual' is based on white, euro-centric dominant culture values.

Although Fowlkes (1991) raises an important concern with respect to mourners not having social acknowledgement for their loss and thus being subjected to unrealistic expectations in their grieving, it is of equal concern that there is insufficient social recognition of the differing effects of specific types of losses. Doka (1989) describes many issues arising when there is a lack of recognition regarding the nature of the relationship, the loss, or the mourner. He refers to this as disenfranchised grief.

The fact that bereaved individuals have differing issues according to the nature of their relationship with the deceased is supported by the proliferation of relationship specific bereavement support and treatment groups found in western culture. In North America, there are relationship specific bereavement groups such as those for widows and widowers, those for individuals who have lost someone to violence (for example CAVEAT in Canada), those for mothers who lost children as a result of accidents caused by impaired drivers (such as MADD), and those for bereaved parents (such as Bereaved

Families of Ontario and Compassionate Friends).

Even within the bereaved parent support community, groups are provided that are relationship specific, such as mothers' groups, fathers' groups, sibling groups, perinatal-infant loss groups, groups for the loss of older children, and groups for the loss of younger children. On the Internet, a variety of bereavement support user groups have developed, such as alt.support.grief, which is further subdivided into such groups as griefparents-accidents.

Fowlke's (1991) has presented an important view that ascribing value to a loss based on the social perception of the meaning of a specific relationship may pose difficulties for mourners when they mourn differently than what is expected for that specific loss. However, certain losses raise unique issues due to the social expectation placed on that relationship, irrespective of whether an individual had a strong attachment to the person or not. For example, in the loss of a parent or child there are specific roles and values that are inherent in the relationship. This creates issues specific to that particular loss. Even if a mourner has a poor attachment to the deceased, there are many complex issues that arise as a result of the mourner's owns expectations of, and the socially ascribed expectations inherent in, the relationship. The social acknowledgement of the significance of that loss is important to the healing process. Alternatively, the full impact of a loss may not be acknowledged socially when the relationship is not understood, as in the case of a particularly close friendship which one might describe as having the quality of a close sibling relationship. This supports the position that each loss must be assessed on the basis of the relationship that the mourner and the deceased had, and there should be acknowledgement that some losses are much more complex and

intense than others.

Five Stages

The current understanding of the process of grief is very much derived from Elizabeth Kubler-Ross's stages of grieving model, which proposes that one accomplishes the task of grieving in stages, more specifically in five stages. These are: shock, denial, and isolation; anger; bargaining; depression; and, finally, acceptance (1969).

Kubler-Ross proposes that when an individual is confronted with death or dying, a "temporary state of shock" (p. 37) occurs. Shock, and the subsequent denial the individual engages in, serves the purpose of protecting the individual from the pain of the loss. Kubler-Ross (p.7) identifies, in a definitive manner, the propensity for humans to flee from death. She cites the rituals in which our society engages with respect to death, such as making the dead look as if they were sleeping, and hiding death itself, or an imminent death from children, as part of the denial process. Furthermore Kubler-Ross attributes this denial to what she describes as "more gruesome" (p.7) modes of death that currently occur and are now frequently depersonalized and dehumanized through modern medicine. She views denial as a healthy process that allows the individual time to process the death and develop adaptive responses to their altered life situation.

Lindemann (1944) is one of the earliest authors of the theory that the first response to loss is a state of shock and disbelief. He describes this phase as being "...recognizable by the mourner's inability to accept the loss and occasionally the absolute denial that the loss has occurred" (p.142). Similarly, Engel (1964) proposed shock and disbelief as initial responses to loss. Engel described mourners as 'stunned' and 'incredulous' as a result of their loss, and subsequently shock and denial assist in protecting the individual

from the overwhelmingly painful feelings engendered by the death.

More recently, Worden (1991), in his four tasks of mourning describes the denial process, identifying that "denying the facts of the loss can vary in degree from a slight distortion to a full blown delusion" (p.11). Figley, as early as 1984, identified denial as an aspect of the mourner's inability to make the connection between a catastrophic loss and Post Traumatic Stress Disorder (PTSD) symptoms (p.8). Rando (1993; 1994) discusses the denial process as part of a natural desire on the part of the mourner to resist acknowledging that the loss has occurred. She describes this as a "natural urge to deny death's reality and avoid confronting it" (1993, p.44).

The withdrawal process engaged in by mourners provides a buffer against society. Kubler-Ross (1969) describes this process of isolating the self from the living as buffering the individual against the loss. Interaction with society brings constant reminders of the loss, whether that occurs as a result of emotional reminders of the loss, or by way of the comments and responses of others in the mourner's environment.

The second stage proposed by Kubler-Ross is anger. She describes this as occurring when an individual is no longer able to maintain the denial. Anger can then be displaced anywhere in the mourner's environment. Worden (1991) also describes anger as a normal feature of grieving, stemming from the frustration that the mourner experiences in not being able to prevent the death, or from the natural regression experienced by anyone suffering a significant loss. Rando (1993), Nader (1997), Leff (1987), Brabant, Forsyth, & McFarlain, (1994), deVries, Lana, & Falck, (1994), Glick, Weiss, & Parkes, (1974), Janoff-Bulman (1985) as well as many other authors categorize anger as a normal characteristic of loss.

Kubler-Ross' (1969) third stage, bargaining, is described as a stage wherein the mourner attempts to bargain, primarily with God, and in secret. While this behavior may be present in mourning there are not any significant writings with respect to such a behavior in the grief literature. Perhaps the most related response observed might be that presented by Bowlby's (1980) discussion of the pining and yearning a mourner often experiences subsequent to the disruption of a primary attachment created by the death. In pining after a lost loved one, a mourner may engage in some form of secretive bargaining thoughts. This pining, or even counter-factual thinking (Fleming, 1998) is more likely to be associated with feelings of guilt.

Kubler-Ross's theory appears more suited to the issue from which it was developed; the adaptation to approaching death by the terminal patient. Kubler-Ross's volume (1969) is the result of much of her work with terminally ill patients. While there are many similarities between facing one's own demise and dealing with the death of a loved one, there are some departures. Bargaining is more likely to occur among the terminally ill and among those watching a loved one die, than among those whose loved one is suddenly deceased. The process described by Kubler-Ross (1969) is something that takes time. In a sudden death of a child, the parent is faced with a "fait accompli" and must then come to terms with it. The bargaining that occurs in parental loss is more often a pleading, usually with God, that this nightmare not be happening. This is more likely to be an attempt to deny that the event has occurred, rather than an active bargaining process. The subtle difference lies in one's understanding that something has happened and consequently one is attempting to deny the truth of that fact, as opposed to making a conscious effort to avert an imminent event.

A common element that does present itself in Kubler-Ross' work on the experiences of terminally ill patients and mourners is the fourth stage: depression (1969). Virtually all mourners experience a form of depression as described by any author in the field of thanatology (Brabant, Forsyth and McFarlain, 1995; Cook, 1983; Engel, 1964; Figley, 1997; Glick et al., 1974; Hewitt, 1980; Horacek, 1995; Parkes, 1972; 1975; Parkes & Weiss, 1983; Rando, 1984; 1986; 1991; 1993; & 1996; Videka-Sherman, 1987; Videka-Sherman & Lieberman, 1985; & Worden, 1991). Kubler-Ross describes the function of the depression experienced by mourners as a facilitation of acceptance of the loss.

Worden (1991) points out that grief may appear as depression and that grief may also lead to a state of depression. As early as 1917, Freud identified depression as a form of grief, which he viewed to be pathological. More recently authors in the field of thanatology such as Rando (1993), Stroebe & Stroebe, (1987), and Raphael (1983), identify the presence of depression in grief, as well as the need to distinguish between normal grief symptoms which may appear as depression, and the development of a clinical depression that significantly impairs the mourner's ongoing functioning. Furthermore, Rando identifies the overlap of depressive symptoms with symptoms of anxiety in normal grief (1993), and describes anxiety as high when the mourner has not completed the steps of recognizing and reacting to the loss and depression occurring subsequent to that phase of mourning (1998).

Kubler-Ross (1969) identifies the fifth and final stage of grieving as "acceptance" (p.99). This is described as having come to terms with the loss and moving forward with life. More currently, acceptance is seen as a part of facing the reality of the death (Rando, 1993), a beginning process, rather than an outcome of the entire grief process.

When defining acceptance, Worden (1991) writes of emotional relocation of the deceased. This task involves finding a place in the life of the mourner for past memories and experiences with the deceased. Rando (1993) speaks of readjustment and reinvestment, having a different relationship with the deceased, and transcendence of the loss. Fleming & Robinson (1991) describe the grief process as moving from losing what the mourner has, to having what was lost.

Although the context in which 'acceptance' as a stage was developed was with terminally ill patients, coming to terms with the fact that death is inevitable is substantially different than learning to live with the loss of a significant attachment figure, particularly a child. The subtle implications of the term 'acceptance' may therefore be experienced as offensive. Bereaved parents may react at many levels to the use of that word, and the expectation of that outcome from grief. Use of language is emotionally charged in the helping professions and it is gratifying to see the shift in terminology developing in thanatology.

Four Tasks

In the nineties, grief therapists began to rely heavily on the work of Worden (1991), Figley (1997), and Rando (1986; 1992-3; 1993; 1994; 1996; & 1998). Worden moved from the five-stage model, to viewing grief as a process that requires the accomplishment of four tasks (1991). Worden supports Engel's (1964) view of grief as a healing process that may or may not be pathological in nature. He sees mourning as a necessary process in which certain tasks must be accomplished in order to achieve the reestablishment of equilibrium.

The first task identified is the acceptance of the reality of the death. Acceptance here is defined as "to come full face with the reality that the person is dead, that the person is gone and will not return" (p.10). Worden's use of acceptance as a concept, while it is vulnerable because of the linguistic and historical implications of the term, is much more palatable in the context in which he employs it. His acknowledgement that the task of acceptance is a continuing process throughout grieving is significant.

Worden views denial as the opposite of accepting the reality of the loss. Denial may be comprised of any or all of the three following dimensions: denying the fact that the loss has occurred (as in believing that the deceased has not died); denying the meaning of the loss (as in negating the significance of the deceased in one's life); and, denying the irreversibility of the death. Although the hope for reunion in some form of afterlife is normal and helpful to many mourners, the chronic search for reunion on this earth is not functional. Parkes (1972), in his research, describes one form that this denial may take:

> Spiritualism claims to help bereaved persons in their search for the dead, and seven of the people who were included in my various studies described visits to séances or spiritualist churches. Their reactions were mixed: some felt that they had obtained some sort of contact with the dead and a few had been frightened by this. (p. 52)

Worden's work supports the concept that mourners move in and out of denial, that acceptance takes time and that certain rituals and processes support the individual as they accomplish this task. In Worden's work, acceptance is viewed as understanding the reality that the deceased is permanently gone, similar to Rando's (1993) acknowledgement of the death and understanding of it. Acceptance is not seen as the goal of grieving, but rather the first task in a process that must be completed to function in a healthy manner.

Worden's second task of mourning is the task of working through the pain of the loss. He identifies the physical, emotional and behavioral aspects of the pain mourners suffer in the loss of a loved one. In working through the pain of the loss, the second task identified by Worden, mourners may use denial as a coping mechanism. Furthermore, society contributes to the mourner's natural impulse to deny the death and avoid the pain through overt and covert messages in which the mourner is directed away from the expression of grief. Even within the rituals that assist mourners in facing the death are messages related to control of emotion, finding goodness in the loss, and keeping one's emotions under control (Hockey, 1993).

The third task of grieving is for the mourner to adjust to an environment in which the deceased no longer lives. Worden acknowledges that such an adjustment means a variety of different things to different people, however, he states that "the survivor is usually not aware of all the roles played by the deceased for some time after the loss occurs" (1991, p. 15). Further to this adjustment is the necessity for the mourner to adjust to their loss of a sense of self, as well as their view of the world. The experience of questioning one's values and philosophy in life is common to mourners as they search for meaning and purpose in life subsequent to the shattering of the assumptive world that results from the death. (Worden, 1991; Wheeler, 1994; Gover, 1965; Janoff-Bulman, 1985; Klass, 1992-1993; Lerner, 1980). If this adjustment is not completed, the mourner fails to adapt to the loss (Worden, 1991), and may withdraw from society. As a result the mourner may fail to develop the necessary skills to survive in a redefined world. In the case of the loss of a child, adaptation requires adjustment to the loss of significant roles as opposed to assuming new ones.

The final task of mourning according to Worden is to emotionally relocate the deceased and move on with life. This is a clear movement away from the historical thinking that dictates that a mourner must put the deceased behind him or herself and move on. Worden is talking about finding a new way of relating to the deceased, which is a notion very much supported in the current thanatological literature (Rando, 1993; & 1998; Klass, 1992-1993; & Wheeler, 1994). In relation to parental loss, Worden states:

> Bereaved parents often have difficulty understanding the notion of emotional withdrawal. If we think of relocation, then the task for the bereaved parent is to evolve some ongoing relationship with the thoughts and memories that they associate with their child, but to do this in a way that would allow them to continue on with their lives after such a loss. (1991, p.17).

Successful completion of this task allows the mourner to 'reinvest' (Rando, 1993), and engage in new attachments. Worden identifies this as perhaps the most difficult task to accomplish, but essential to healthy grieving.

Six Processes

Rando's Six R Processes of Mourning (1993) are well known and accepted in the field of thanatology. They are: to recognize the loss, to react to the separation, to recollect and reexperience the deceased and the relationship, to relinquish the old attachments to the deceased and the old assumptive world, to readjust to move adaptively into the new world without forgetting the old, and to reinvest. These processes incorporate current thinking in grief theory and models of mourning, and while acknowledging commonalities in grief, the individuality of the mourner is recognized, and the concurrent nature of the processes is reinforced. The Six Rs are grouped into three general phases that identify the basic range of reactions experienced by mourners.

The first phase, avoidance, is the struggle to recognize the loss; that is, to acknowledge and understand the death. It is generally experienced in the period of time from the receipt of notification of the death and for a short time thereafter. Rando states:

> It is marked by the understandable desire to avoid the terrible acknowledgment that the loved one is lost. The world is shaken, and the mourner may be overwhelmed. Like the physical shock that occurs with trauma to the body, the human psyche goes into shock with the traumatic assault of the death of the loved one (p.33).

Herein lies the trauma of death. The mourners must both intellectually and emotionally grasp that a death has occurred. This phase is more pronounced in situations of traumatic death, such as sudden, unanticipated deaths, and the death of a child (Rando, 1996.

The next phase, confrontation, consists of the processes of reacting to the separation, recollecting and re-experiencing the deceased and the mourner's relationship with the deceased, and relinquishing old attachments to the deceased and to the old assumptive world. During this phase, grief is experienced most intensely. Separation anxiety is demonstrated through pining and yearning emotions and behaviors (Bowlby, 1980). There is an ongoing re-experiencing of the loss as the mourner comes face to face with the reality of living without the deceased (Rando, 1993). It is as if the mourner is newly confronted with the loss on an ongoing basis. Rando (1993) states:

> This phase is a painful interval when the mourner confronts the reality of the loss and gradually absorbs what it means. It is a time in which a most excruciating learning process takes place...(p.34).

The third phase described in Rando's Six Rs of Mourning is the accommodation phase. Rando describes this as a phase where "a gradual decline of the symptoms of

acute grief and the beginning of reentry into the everyday world" (p.40) takes place. The processes associated with this phase are: readjusting to move adaptively into the new world without forgetting the old, and reinvesting in life. The past and the present are integrated. There is recognition of the changed self, and a different attitude toward life. Rando conceptualizes the grieving process as including the incorporation into the mourner's life of a relationship with the deceased. This process is best described in the following statement:

> And, in the end, this moving forward with that scar is the very best that we could hope for... And then as you continue to invest emotionally in other people, goals, and pursuits, appropriately take your loved one with you, along with your new sense of self and new way of relating to the world, to enrich your present and future life without forgetting your important past. (Rando, 1988, p. 287)

Rando's conceptualization of a model of grief incorporates all of the current thinking in thanatology. It is broad enough to address all of the varied grief responses experienced by mourners. This conceptualization is respectful of the mourners' experiences, normalizing and validating them. It assists the clinician in the assessment of the mourner's grief response, and aids in identifying situations where an individual may be experiencing a complicated mourning process. Rando further provides a framework in which to understand and assist the mourner to move toward the ultimate goal of a new relationship with the deceased, and a reinvestment in life and relationships. Her identification of the issues and the emotions, cognitions, and behaviors of the mourner in the avoidance phase help us to understand the need for intervention at that time, as well as give some insight into what intervention(s) should occur. Her primary focus is on the treatment of complicated mourning and therefore on how to assist a mourner to go

through the avoidance phase when that has not been accomplished.

Healing Theories and Transcendence

The trend in the conceptualization of grief and mourning has moved from Kubler-Ross's five stages, through Worden's four tasks to Rando's six processes/three phases. Kubler-Ross presents a model that works well in describing the processes that terminally ill patients experience as death approaches. While mourners also experience many of the processes and emotions identified by Kubler-Ross, the model is quite restrictive. It places an expectation on mourners to proceed through five distinct stages of grief, and does not fully address the multitudinous and complex issues in mourning, nor does it recognize the interaction of the various processes that a mourner may experience. The oversimplification inherent in such a conceptual framework could easily lead to erroneous identification of pathological grief responses, and places a heavy burden on the mourner to meet the expectations of moving through defined stages. In short, I would say that Kubler-Ross made a good start in our conceptualization of grieving, however it was only a beginning. We have gained an important understanding of such processes as denial from Kubler-Ross. Fortunately for the mourning populace, we have moved forward in our knowledge and understanding of grief.

Worden's concept of tasks in grieving is helpful. It moves us away from the view that grief can be categorized and defined in specific stages through which the mourner must pass to gain acceptance. The notion of tasks acknowledges that there is active work on the part of the mourner, which is ongoing, and that these tasks can be occurring simultaneously. The idea of reinvestment in life as an outcome of healthy mourning, leaving room for some ongoing relationship with the deceased, normalizes the grief

experience and the need to retain some remnants of the relationship with the deceased. The conceptualization of the first task, that of accepting the reality of the loss, helps us to understand the significance of the initial response to loss. Worden's conceptualization of grieving very much complements Rando's, however Rando presents a much more comprehensive understanding of the grief process, it's relationship to trauma, and the need to intervene in the trauma. Both Rando and Worden have presented a model consistent with Fleming's identification of the process of grieving as that of moving from losing what one has, to having what one lost. That truly is the state of the art in grief models.

What is not present in these conceptualizations is a model for intervention at the time of the death, although Rando and Figley's conceptual frameworks lay the groundwork for one. Understanding that certain types of death are always experienced as a trauma, to one degree or another, ultimately leads us to the need for a model that informs interventions at the time of a traumatic death. The goal of such a model would be to reduce the incidence of complications in mourning. The focus of my work is to examine the need for such a model, and to contribute to the development of one.

The Trauma Connection

There is a new movement in thanatology, which is currently formulating a conceptual framework linking grief and trauma. The two major theorists in the area Figley (1997) and Rando (1996) have linked traumatic stress and/or Post Traumatic Stress Disorder with grief and mourning. Other theorists such as Simpson (1997), Gilbert (1997), Horowitz (1997), and Nader (1997) have all applied this framework to specific areas of grief treatment. The connections between trauma and grief are significant when applied

to sudden death, and to the loss of a child.

A Brief History of the Development of Knowledge in Trauma Outcome

Traumatic events, or extreme stressors have always been present in society as we know it. The history of wars, natural disasters, and public and private attacks of violence on individuals: bombings, mass shootings, plane hijackings, domestic violence, rape, sexual abuse, child abuse, and the experiences of everyday losses are often devastating to individuals, for example the death of a spouse or child. Trauma is experienced and integrated by individuals on an almost daily basis. One hears about traumatic events around the world that often give people pause to shudder and be grateful it is not happening to them. When the traumatic event comes closer to home, it may stir in individuals uncomfortable feelings that quickly settle. When the event or stressor directly affects a person, some individuals will develop symptoms that may be short lived, or may continue for a long time. Post Traumatic Stress disorder as defined by the DSM IV is a set of symptoms resulting from exposure to an identifiable traumatic event. The loss of a child is certainly a traumatic event and can lead to PTSD (Rando, 1998; Murphy et. al., 1999). It is therefore important to understand the trauma literature in terms of what it can offer to our understanding of grief.

The study of the effects of trauma on individual's psychological functioning began as early as 1887. Charcot (1887), first described the effects of trauma on his patients by attributing their hysteria to their traumatic histories. Janet (1904) made a significant contribution to our current understanding of the effects of trauma, recognizing that experiences that are overwhelming to individuals may be split off and not integrated into their cognitive schemas, resulting in an inability to provide a narrative to the experience,

yet having intrusive recurring memories of the traumatic event. This in effect is a partial description of what we currently call PTSD – the intrusion of unbidden memories of an overwhelming event. Kardiner (1941), who treated war veterans in the United States added to the understanding of PTSD by identifying the hyper vigilance that accompanies symptoms in war veterans. He looked at this process as both physiological and psychological and noted the enduring nature of the difficulties. Later Kardiner and Spiegel (1947) also examined protective factors in combat soldiers, specifically in terms of emotional attachments. They found that the stronger the relationship between the soldier, his comrades and leaders, the less likely there was to be psychological breakdown as a result of the trauma of war. The combined understanding of the effects of trauma at that time was that patients appeared to be stuck in the trauma, unable to resolve it and constantly experiencing new situations as though they were the original trauma (being triggered), and that there is a biological connection to the psychological state of the patients.

After World War II, further studies on war-related trauma began to focus largely on Holocaust Survivors and there is a great body of literature on the effects of the Holocaust on it's survivors. Many of these studies were in fact conducted by concentration camp survivors themselves (Krystal, 1968; Klein, 1974; Davidson, 1984). Krystal (1968) added to our understanding of PTSD by noting the evolution of the hyper-vigilant state to the blocking of affective states and inhibited behaviour that occurs for many PTSD patients.

More recently, Horowitz (1978) developed a model for psychotherapy with trauma survivors and incorporated the notion of alternating modes of intrusion and numbing into

the understanding of PTSD. Van der Kolk and McFarlane (1996) note that these states do not necessarily alternate, but rather co-exist. Figley's (1978) work with Viet Nam Veterans added to the development of the definition of PTSD in the DSM IV. Since the late 1980's numerous studies on groups of trauma survivors have been conducted and will be reviewed later in this chapter in terms of their contribution to our understanding of the impact of traumatic death on survivors.

A Working Definition of Trauma

Trauma is defined by Figley (1985) as: "an extraordinary event or series of events which is sudden, overwhelming, and often dangerous, either to oneself or significant other(s)" p.xviii). Rando (1998) defines trauma as "the wounding cause of traumatic stress". A trauma results from a stimulus too strong to be assimilated in the usual way. The stimulus barrier is breached and the ego loses its mediating function. As a result, the individual feels overwhelmed, and experiences feelings of loss of control and helplessness. Rando (1998) points out that every individual has his or her own tolerance level, and thus different levels of stress will be experienced as traumatic in different individuals. When people experience trauma, their defence mechanisms are influenced by their developmental stage, temperament and the context of the trauma (Van der Kolk & McFarlane, 1996). PTSD is seen as a lack of integration of the trauma into the individual's past or "person schema" (Horwitz, 1991), which then can become dissociated. . Herman, in her work on trauma states:

> Traumatic reactions occur when action is of no avail. When neither resistance nor escape is possible, the human system of self-defence becomes overwhelmed and disorganized. Each component of the ordinary response to danger, having lost it's utility, tends to persist in an altered and exaggerated state long after the actual danger is over. Traumatic events

> produce profound and lasting changes in physiological arousal, emotion, cognition and memory. Moreover, traumatic events may sever these normally integrated functions from one another. The traumatized person may experience intense emotions but without clear memory of the event, or may remember everything in detail but without emotion. She may find herself in a constant state of vigilance and irritability without knowing why. Traumatic symptoms have a tendency to become disconnected from their source and to take on a life of their own (1992, p. 34).

Traumatic stress is the effect of trauma (Rando, 1998), and: "is the clinical manifestation of problems associated with trauma induced during the catastrophe and represented by post traumatic stress reactions" (p. xix). With respect to grief, Figley describes this as the re-experiencing of the trauma, numbing of responsiveness, reduced involvement with life activities, hyper-vigilance, sleep disturbances, guilt, impairment of concentration, and other emotional reactions (1985). To that list Rando (1998) would add significant anxiety. A comparison of the symptoms of PTSD with the symptoms of grief demonstrates shared symptoms, such as shock, numbing, depression, avoidance, intrusive memories, sleep difficulties etc. (Figley, 1997; Rando, 1994, 1998; Raphael, 1983; and Stroebe & Stroebe, 1987). Rando describes the connection in this way:

> This catastrophic information implying permanent separation from the loved one gives rise to anxiety that is so intense and intolerable that it temporarily disables the person's adaptive capacities, causing a frightening state of helplessness. This, in turn, brings further anxiety, severe violations of the assumptive world, and the terrifying experience of the unknown, intense, disorganizing, out-of-control emotions that come surging up, overpowering the mourner who cannot master the feelings in the situation of acute posttraumatic stress. (Rando, 1996, p. 60)

The Psychological Characteristics of Trauma

The DSM IV sets out a series of criteria for the diagnosis of PTSD as a potential outcome of trauma. In summary these may include the experiencing of a traumatic event

which is then re-experienced through recurrent, intrusive, distressing memories and dreams, a sense of reliving the experience, intense psychological distress arising from exposure to environmental cues, or triggers, physiological reactions to cues, persistent avoidance of stimuli, numbness of responsiveness and increased arousal; all of which occur for at least one month and cause impairment in the patient's functioning.

Van der Kolk and McFarlane (1996) suggest that the diagnosis according to the DSM IV does not capture the breadth of the experience of PTSD although it has served a significant purpose in the recognition of psychological trauma as a legitimate condition and opened up the disorder to systematic investigation.

> The development of posttraumatic stress disorder (PTSD) as a diagnosis has created an organized framework for understanding how people's biology, conceptions of the world, and personalities are inextricably intertwined and shaped by experience (p.4).

Significant to the determination of an event as traumatic is the individual's subjective experience of the event (van der Kolk & McFarlane, 1996; Caruth, 1995). Central to the experience of trauma is the sense of helplessness and powerlessness and the subjective experience of threat that accompanies the event, as well as the meaning that the individual attributes to the event. The meaning attributed to the event by the individual has such a significant impact that studies have demonstrated that even subsequent to the trauma, additional relevant information can alter the individual's perceptions about the traumatic nature of the event (Kilpatrick et. al., 1989).

Van der Kolk and McFarlane propose that there are six critical aspects of how PTSD affects individuals: intrusion of memories that interfere with attention to current stimuli, compulsive exposure to situations that remind the individual of the trauma (reenactment),

avoidance of triggering situations, which becomes more generalized over time and leads to a numbing of responsiveness to life experiences in general, an inability to manage the physiological responses to any kind of stress, difficulties with attention, distractibility and an inability to discriminate stimuli, as well as changes in psychological defense mechanisms, and in their personal identity (p.9). The elements of intrusion, hyper-vigilance/hyper-arousal, numbing and avoidance and withdrawal from everyday activity are well documented in the trauma literature.

Hyper-arousal, intrusion, avoidance and constriction (numbing) are viewed to be the hallmark descriptors of functioning for individuals with PTSD (van der Kolk, Weisaeth, & van der Hart, 1996). These states have been observed in studies of combat survivors (Kardiner, 1941; Myers, 1915), holocaust survivors (Krystal, 1968; Eitinger, 1964), women and child victims of violence (Herman, 1992), and child abuse survivors (Cohen, Berliner & Mannarino, 2000), as well as numerous other groups of people exposed to trauma.). PTSD symptoms (intrusion, hyper-arousal, numbing and dissociation) have been demonstrated in studies of rape victims by Burgess and Holmstrom, (1972) who identified Rape Trauma Syndrome and Walker (1979) with Battered Woman Syndrome. These symptoms were noted to be similar to those found in combat survivors.

The pattern of intrusion, avoidance and hyper-arousal results in the diagnostic category of PTSD, which affects all aspects of functioning of the individual; biological, psychological, social and spiritual (Shalev, 1996). This paper will discuss the three primary features of PTSD, intrusion, hyper-arousal, and avoidance.

Intrusion

The usual response to trauma for most individuals is an intrusive remembering of the event alternating with avoidance. This intrusive remembering allows the individual to learn from the event (accommodate to it), and accept the event and readjust their expectations (assimilate the experience) (Lindemann, 1944). The initial repeated replaying of the event actually modifies the level of affect associated with it. Eventually the event is stored as a memory, which changes in intensity and detail over time. For those individuals who cannot assimilate the memory of the event, the stimuli which precipitate an intrusive memory become more generalized over time, and the trauma memories take on a life of their own, thus increasing the trauma and decreasing positive life experiences (van der Kolk & McFarlane, 1996). Traumatic memory is stored as feelings states that do not initially have a narrative attached (van der Kolk & Fisler, 1995; Herman, 1992). The trauma is not processed on a symbolic level, and this failure to process the narrative is significant to the development of PTSD (van der Kolk & Fisler, 1995). Intrusive memories come back in the form of dreams or flashbacks. These memories are frozen as they are stored, and do not change over time.

Intrusive recollections of the trauma leave people in a constant state of arousal. They are unable to integrate the traumatic event into their life experience and consequently remain a victim to the trauma. Studies have noted that in PTSD, the victim's story of the trauma remains static over time, whereas in those who do not experience PTSD, the story itself changes as it is integrated into ongoing life experiences. In the "Grant Study" (Lee, Vaillant, Torrey & Elder, 1995) of 200 World War II combat survivors followed longitudinally, those who did not suffer from PTSD had changed the stories of their

experiences over time, and the horrific nature of events were remembered with much less intensity. On the other hand, those few participants who had suffered from PTSD carried almost identical memories to the event that they had experienced; that is to say there was no change in memory over time. Van der Kolk and McFarlane (1996) suggest that this is the result of biological changes occurring as a result of the constant replaying of the trauma in the intrusion phase, which creates changes in the brain that affects memory. In this sense, then, traumatic memories do take on a life of their own, and become frozen in time, reinserting themselves into the present of the individual and overtaking the emotional self. The impact of this on current functioning reduces the individual's ability to engage in present activities and alters information processing in the present (van der Kolk & McFarlane, 1996).

The compulsive re-exposure to traumatizing events that occurs in intrusion is observed in three general outcomes. One is self-destructive behaviours. There are strong linkages between childhood abuse and self-harm in later life, for example suicide attempts, anorexia and self-mutilation (Van der Kolk, Perry & Herman, 1991). Another form of re-exposure occurs in re-victimization for example the victims of childhood sexual abuse who become prostitutes (Finklehor & Browne, 1984). The third outcome is in the victim becoming the victimizer. There are strongly established links between having been abused as a child and becoming an abuser or engaging in criminal behaviour (Groth, 1979; Lewis & Balla, 1976).

Avoidance

Avoidance or numbing is the individual's attempt to deal with chronic hyper-arousal (van der Kolk & McFarlane, 1996). It may be viewed as a form of surrender (Herman, 1992). Surrender is a result of the experience of complete powerlessness. It is the "frozen" state of the trauma victim. Individuals may employ various methods to achieve avoidance, such as the use of drugs and alcohol, or dissociation.

Hyper-arousal

Hyper-arousal in trauma survivors has been noted by various researchers (for example Herman, 1992; van der Kolk & McFarlane, 1996; Kardiner & Spiegel, 1947; Murphy et al., 1999). Chronic hyper-arousal and the inability to modulate it is seen in behaviours such as hyper-vigilance, an exaggerated startle response, and the sense of ever present threat, which over time becomes triggered by an expanding range of stimuli. People in this situation begin to react to situations with emotion rather than thought, and enter the fight, flight or freeze mode. The high level of physiological arousal is a self-preservation activity of the body (Herman, 1992). These patterns are thought to be biologically influenced through the development of pathways in the brain (van der Kolk & McFarlane, 1996). Individuals become easily over stimulated by the generalization of triggers, and become unable to sort out relevant stimuli. This strengthens the fixation on the trauma and reduces the adaptive capacity of the individual. All of these factors are significant to our understanding of the effects of trauma and the recovery process.

PTSD: The Debate over Causation

Yehuda (1999) suggests that while only 14% of people in the United States will experience PTSD symptoms at some point in their lives, a significantly higher percentage

of the population will experience a traumatic event. The view that trauma does not necessarily lead to PTSD is supported by Bowman (1999); Yehuda and McFarlane, (1995) and; Shalev, (1996) as well as by many other studies in the literature. Yehuda and McFarlane (1995) argue that PTSD is the exception rather than the rule after a traumatic event. They indicate that the nature and severity of the traumatic event has some effect on PTSD but state that the severity and chronicity of symptoms are not always proportional to the event, thus indicating that the nature and severity of the event itself is not predictive of PTSD outcome. They believe that the emerging data from co-morbidity studies demonstrates that underlying psychiatric conditions influence the development of PTSD, and believe that chronic symptomatology is more predicted by biological and physiological features of the immediate response to the traumatic event. A recent study by Murphy et al. (1999) of PTSD symptoms in parents following the violent death of a child indicate that after four months, 40% of mothers and 14% of fathers met the DSM IV criteria for PTSD, indicating that while mothers may be at risk for PTSD, the majority still do not develop it. Another recent study by Thompson, Norris and Ruback (1998) of family members of homicide victims found that 26% of the sample scored positively for PTSD symptoms. Fifty-five percent of the sample was parents of the homicide victim. This may suggest that the nature of the trauma is more relevant than some theorists may believe.

The fact that more people generally do not develop PTSD as an outcome of a traumatic event suggests that there are factors other than the event itself that may precipitate the trauma response seen in PTSD. Yehuda and McFarlane (1995) suggest that there may be biological and genetic risk factors for PTSD and that personal

vulnerability factors may be involved. They caution that the difficulty with looking for personal vulnerability factors is that this may lead to blaming the victim for their legitimate reactions to severely adverse events.

Personal Vulnerability/Pre-event Factors vs Event Characteristics

Bowman (1999) proposes that reactions to trauma are more affected by pre-event individual differences, as well as by the individual's perception of the event than they are by the nature and severity of the event itself. Pre-event differences identified by Bowman are: mental health diagnoses, prior exposure to violence (other traumas), cognitive ability (which can be protective), emotionality (optimism and emotional expressiveness), beliefs respecting one's own resilience or helplessness, errors in reasoning and attributions of meaning. This has also been demonstrated in family members of homicide victims, where prior traumatization was correlated with higher levels of distress (Thompson, Norris & Ruback, 1998).

Various studies have examined the predictors of PTSD in various traumatized groups. Some studies have found the nature and severity of the event as well as the duration of the event to be predictive of PTSD in survivors, particularly in combat survivors. Goldberg et al. (1990) studied twins who had experienced combat trauma and found the severity of the violence was a predictor of PTSD. Gallers et al (1988) and McFall, MacKay and Donovan (1991) also found the level of violence was a predictor. Other studies of combat survivors suggest that both the event (ie the level of violence and the duration of exposure were predictive (Green et al., 1990; Green & Berlin, 1987; Solkoff, Gray & Keill, 1986), however pre-event factors such as prior trauma and post-event factors such as social support were also predictive factors.

Gidycz & Koss's 1991 study of sexual assault survivors found that both the severity of the event and the prior mental health and belief systems of the victims were predictive of PTSD. Those who held optimistic beliefs fared better than those whose view of life was more pessimistic overall. Hickling et al. (1999) studied motor vehicle accident survivors and found that attribution of fault was a significant predictor of chronic PTSD. Those who blamed themselves for the accidents recovered from their psychological distress more readily than those who blamed others. However, Regehr, Cadell, and Jansen (1999) found no significant correlation between attributions of causality and PTSD. Their study did find that beliefs about level of control affected PTSD outcomes. These studies do suggest, then, that an individual's beliefs about self and the world affect the development of chronic PTSD.

Other studies have found pre-event vulnerability to contribute to chronic PTSD. North and Smith's 1992 study of the homeless found histories of abuse and family violence were significant predictors. Smith et al (1990) found prior psychiatric histories predictive of PTSD in plane crash survivors. McFarlane's studies on firefighters (1988 & 1989) suggested that while event characteristics may play a role in the outcome of chronic PTSD, histories of neurosis in the firefighters and family histories of psychiatric issues were significantly relevant. Davidson et al. (1991) identified that 66% of chronic PTSD sufferers also had past psychiatric issues and familial histories of psychopathology.

Post Event Factors

Post-event factors have been noted to impact on the psychological adjustment of individuals to trauma. Winje's 1998 study of families who had a family member die or sustain injuries in a tour bus crash in Norway in 1988, demonstrated that a strong need

for information about the event and feeling adequately informed was correlated with better psychological adjustment. Additionally, a strong need to know was associated with poor adjustment long term (at 5 years) which the author of the study believes to be related to emotional cognition as opposed to factual cognition and that "it may be that lack of definitive answers about facts, but particularly about emotional topics, contributes to the symptomatic rumination" (p. 640). Winje also found that attempts to understand what happened are part of a normal adjustment process.

Cognitive Factors

A trauma can lead to the shattering of the assumptive world (Janoff-Bulman 1985; Parkes, 1971; Epstein, 1980; Figley, 1984). The assumptive world is a theory of reality that allows individuals to bring order into an otherwise chaotic world (Epstein, 1980). Assumptions allow individuals to set goals, plan activities, and order their behavior to make sense of the world (Parkes, 1971). Major catastrophic events cannot be readily assimilated by the victim's assumptive world, and therefore the assumptive world is shattered.

When an individual is traumatized, feelings of anxiety and helplessness are elicited. There is a sense of loss of control, which jeopardizes the individual's feelings of safety and security (Janoff-Bulman, 1985). There is an inherent assumption that the world is just and orderly (Lerner, 1980), and that we are to some extent invulnerable (Perloff, 1983; Weinstein, 1980). A trauma shatters that sense of invulnerability and leaves the individual feeling a loss of control and powerlessness (Janoff-Bulman, 1985). The trauma is senseless to the individual, and the need to make sense, or experience order in

life leads to an intense search to understand the trauma (Rando, 1993; Winje, 1998) and a questioning of the meaning and purpose of life (Wheeler, 1994)

Van der Kolk and McFarlane (1996) also identify the changes in personal identity that occur as a result of trauma. These changes require a reconstruction of the individual's view of self that Janoff-Bulman (1985) identified. The process of incorporating the trauma into the individual's personal identity requires an integration of the experience with past knowledge and experiences (van der Kolk & McFarlane, 1996). This process is affected by the individual's prior view of the world (Janoff-Bulman, 1985) and previous life experiences (van der Kolk & McFarlane, 1996). Van der Kolk and McFarlane suggest that an internal locus of control reduces helplessness among trauma survivors. A study of rape victims by Regehr, Cadell and Jansen (1999) demonstrates that women who perceived themselves to have a higher degree of control over the outcome of events in their lives experienced lower rates of PTSD symptomology six months subsequent to the rape. This finding is also supported by Silver, Wortman & Klos (1982) who noted a positive association between internal locus of control and reduced emotional distress in individuals who had experienced traumatic events. The difficulty that an internal locus of control presents is that it can be manifested in self-blame, which may be engaged in to obtain a sense of control. Self-blame occurs in counterfactual thinking (Fleming, 1998) which may serve to enhance the individual's feelings of safety on the one hand, but may in fact increase other negative feelings that become treatment issues.

The violation of the assumptive world, and the ensuing posttraumatic stress is particularly intense in parental loss. The depth of the parent-child bond exacerbates the

trauma created by its' disruption, frequently resulting in severe post traumatic stress symptomatology (Rando, 1998). The issue of shattered assumptions in parental loss will also be discussed in the next chapter.

A feature of traumatic stress is anxiety. Anxiety forms a connecting bridge between trauma and traumatic stress (Rando, 1998). It is a normal reaction to threat or separation, and results from the loss of safety and security, and the arousal of the fight or flight response. Rando (1998) identifies the following factors which create anxiety in loss: facing the unknown; separation from a loved one; managing intensely labile emotions; helplessness; the sense of victimization; the shattering of the assumptive world; and, the experiencing of intrusive thoughts, feelings, and behaviors. Additional factors in loss creating anxiety are: loss of effectiveness of usual coping strategies; being unable to make sense of the loss; sustaining secondary losses; coping with survivor guilt, and the experiencing of fight or flight symptoms. In these factors we see the presence of the core symptoms of trauma: intrusion, hyper-arousal, and numbing or constriction previously discussed.

Summary

This debate over whether PTSD is a normal response by an individual to an abnormal event that is so far from the norm that it shakes the individual's beliefs (Janoff-Bulman, 1985) vs the position that PTSD is an abnormal response arising from the individual's experience of the confirmation of a belief that was held but previously avoided (van der Kolk & McFarlane, 1996) continues in the literature. Is the event the sole cause of the traumatic reaction, or do personal vulnerability factors account for the differing responses of individuals? The above studies demonstrate findings that support the position that

both event characteristics and personal vulnerability factors influence the development of chronic PTSD. There is common acknowledgement that the event alone cannot predict PTSD, owing to the low incidence in trauma survivors, and that the pre-event characteristics and the meaning attributed to the event impact on the development of PTSD and must be understood in order to provide appropriate treatment (Bowman, 1999). Prior traumatization, particularly in childhood is felt to be a strong factor (Davidson et. al., 1991; Resnick, Kilpatrick & Best, 1992). Mental health history in the victim is another significant factor (Breslau, Kessler & Chilcoat, 1998), as well as in the victim's family (McFarlane, 1988).

Traumatic Bereavement: Trauma and Grief

> The woman in the audience was nodding her head vigorously. It was one of those agreements with my words as a speaker that I long ago learned signals the person's having "been there, done that". On this occasion, I was talking about what tends to get lost when a traumatic death is approached either exclusively as a trauma, or solely as a loss. At the midmorning break in the conference, she approached me with her personal story. When she was six years old, she had discovered her father's body hanging in their garage after a successful suicide attempt. Concerned about the impact upon the little girl, her family immediately brought her for psychological assistance. For the next half century, the woman saw a succession of therapists who, in varying degrees and fashions, addressed with her the psychological impacts of growing up fatherless. However, it would be fully fifty years after her father's death before one therapist finally asked her the crucial question to start her on the road to healing: "Exactly what did you see when you found your father?" At long last, someone had begun to tap into her experience of the horrific event that had stimulated the unresolved posttraumatic stress preventing her from achieving closure on the loss.
> (Rando, 1997, p. xv)

Figley and Rando are strong advocates that both trauma and grief issues must be recognized and addressed in traumatic loss. Rando (1998) identifies three main tasks in working through traumatic loss: trauma resolution, grief resolution, and, loss

accommodation. Grief and trauma both involve loss. The individual experiences feelings of loss of control, and there is the subjective experience of the loss of ability to mediate, i.e. coping mechanisms become ineffective (Rando, 1993; 1998). Furthermore, Rando (1998) identifies six broad areas of similarity in trauma and in grief. The first is that both trauma and death are experienced as a 'personal disaster' and create similar symptomatology (Raphael, 1983). Features shared by disasters, both personal and societal, are: shock and denial; distress, the experience of helplessness; death and destruction; and, recurring images of the trauma (intrusion).

Shared Issues in Trauma and Grief

There are several shared fundamental issues in acute grief and trauma: disorganization or disruption, helplessness and loss of control, the severing of an important attachment, concerns with annihilation, and the experience of victimization. In both grief and trauma, intrusion, hyper-arousal and numbing are experienced. There are alternating modes of regulating exposure to the stressful and traumatizing experience. For example, the individual may vacillate between denial states, and intrusive recollections of the trauma, which continue until there is a functional revision of the assumptive world. In both acute grief and trauma, there is a need for trauma resolution, and for healthy mourning processes.

Rando (1998) identifies three levels of association of trauma and grief, which are supported in the work of Figley (1997) and Simpson (1997). The first level occurs in 'normal' deaths, such as in the anticipated passing of an elderly person. With such a death, some symptoms of trauma may be present, however they have little impact on daily functioning. In the second level of association, there are increased symptoms of

PTSD due to the presence of one or more elements of traumatic death. In the third level, the death involves a high number of traumatic elements, and the mourner experiences most of the clinical symptoms of PTSD.

The correlation of grief and trauma is very important. Rando's work in developing the conceptualization of levels of association is extremely helpful, as it points us in the direction of identifying and assessing the level of trauma experienced by the mourner in order to determine the appropriate use of trauma resolution techniques and grief resolution techniques. This entire aspect of grief has not been adequately addressed in previous conceptual models of mourning. There is disagreement regarding the need to address trauma issues first in treatment. Rynearson and McCreen (1993) identify the need for trauma reduction before initiating grief work. On the other hand Murphy et al. (1999) identify a strong correlation between trauma symptoms, mental distress and grief symptoms, suggesting not enough is known about the treatment of those who have experienced violent deaths and identifying the need for further research into theoretical models for this type of treatment. Furthermore, the issue of the treatment of the trauma at the time it occurs requires further research.

Factors Associated With Traumatic Death

Rando (1998) has identified six factors that can make the loss of a loved one traumatic. The first is suddenness and lack of anticipation. A sudden, unanticipated death is a massive violation to the mourner, which changes his or her world. There is a diminished capacity to cope, a violent shattering of the assumptive world, a loss of security, and an inability to make sense of what happened. All of these aspects of sudden death can lead to the development of PTSD in the mourner. The issues which arise for

the mourner include: the lack of opportunity to say goodbye; the shadow of unfinished business between the mourner and the deceased; disbelief, obsessive reconstruction of the circumstances of the loss in order to make sense of it; the lack of preparation for the death, resulting in secondary losses; and, the need to determine responsibility for the death and/or affix blame. Sudden death may also involve other high risk factors such as preventability, and violence, as well as complications with the judicial system.

This is a significant issue in death. When the death is expected, the mourner can make some attempt to prepare for it. When the death is sudden, the mourner has first to figure out, quite literally, what hit him or her, before he or she can acknowledge the death. The suddenness and lack of anticipation leaves the mourner stunned, and that must be dealt with first. The significant trauma associated with sudden death highlights the need for appropriate interventions at the time of the death, in order to avert complications in the mourning process and avoid having to assess and treat such complications at a later time.

A second set of factors associated with traumatic bereavement, as identified by Rando (1998), is violence, mutilation, and destruction. Deaths that include these features usually arouse feelings of shock, fear, and vulnerability. The mourner experiences a loss of control over his or her personal environment. A violent death may stimulate in the mourner generalized aggression and hostility, which may in turn exacerbate feelings of guilt and shame. Furthermore, such a death may elicit memories of previous aggressive wishes with respect to the deceased, stirring additional feelings of guilt.

A violent death leaves the mourner imagining what the deceased may have experienced at the time of death, thus constantly re-traumatizing the mourner. With such a death, the mourner is forced to confront the destructive capacities of man and nature.

Most significantly, this type of death breaches personal invulnerability, and violates the assumptive world. This violation constitutes a trauma for the mourner (Janoff-Bulman, 1985; Lerner, 1980; Perloff, 1983; Weinstein, 1980; Rando, 1993, 1998).

A third factor identified is preventability and randomness. If the mourner believes that the death did not have to happen, that the death was preventable, the mourner may begin to engage in counterfactual thinking (Fleming, 1998), which adds to self-blame. A death that is viewed as random leaves the mourner feeling unable to protect him or herself from such a death. It becomes imperative to the mourner to identify a cause that can then be controlled, and restore the mourner's sense of safety and security. Such a death may raise obsessive thinking, and rage. The mourner's experience of such emotions may lead to further traumatization.

Another factor associated with traumatic death is multiplicity. If there are multiple deaths, the mourner may well be faced with a loss of some of their usual supports, as they may be among the deceased, or are themselves mourning. Separating and working through the losses may become complex. In addition, multiple deaths usually involve violence and/or mutilation.

The fifth factor that may create trauma in death is the mourner's personal encounter with death. In combination with other high risk factors, death may precipitate a massive shock. The mourner may experience a significant threat to personal survival. As a result, the mourner may experience a high degree of anxiety.

While Figley (1997), Simpson (1997), Nader (1997) and others all support this view of factors associated with traumatic death, there is clear agreement among researchers in the area of traumatic death that the loss of a child is always seen as traumatic. The death

of a child is the most complex loss to contend with due to the nature of the loss and the number of associated issues; such as the intensity of the parent-child bond, the unnaturalness of a child predeceasing it's parents, and the many secondary losses associated with the loss of the child (Cook, 1983; deVries, Lana, and Falck, 1994; Drenovsky, 1995; Gilbert, 1988; 1997; Klass, 1992-1993; Rosof, 1995; Brabant, Forsyth and McFarlain, 1994, 1995; Smart, 1993-1994; Videka-Sherman, 1987; Wheeler, 1994; & Rando, 1986; 1988; 1993; & 1998). When the loss of that child is sudden and unanticipated, is viewed by the parents as preventable or random, and involves violence or mutilation and destruction as sudden deaths often do, the loss is a prescription for complicated mourning.

Rando highlights the lack of integration of trauma theory with grief theory, stating that:

> ...the vast majority of authors, researchers, and practitioners in both fields [thanatology and traumatology] have insufficiently integrated treatment of posttraumatic stress and loss when working with such survivors. (p. xvi)

Crisis Theory

Another area of literature that is helpful in understanding the needs of mourners is Crisis Theory. Crisis Theory provides a conceptual framework for understanding stressful situations and informing interventions. A body of knowledge was developed in two areas: the nature and process of crisis, and the use of this understanding to assist in working with people in a variety of crisis situations.

Selye (1956) studied responses to stressful situations, and identified three stages in these responses. These are: alarm reaction, resistance, and finally exhaustion. In the

alarm reaction the individual experiences the shock of the crisis. During resistance, there is an attempt at adaptation. In exhaustion, the usual coping mechanisms fail. Lazarus (1966) identified the need to assess threatening situations (crises) and potential solutions to facilitate what was termed as "mastery". Lindemann (1944) noted that certain life events arise for individuals that can either be mastered or become crises. He believed that personal vulnerability factors were contributory. Golan (1979) identified a model of crisis resolution to be utilized after assessing the individual's subjective condition.

The objectives of crisis intervention identified by Golan are: relief of symptoms, restoration of the individual to their pre-crisis level of functioning, developing an understanding of the precipitating factors, identifying remedial measures available through the community for the client, connecting the understanding of the current crisis with past life experiences with the client, and helping clients identify new ways of perceiving the crisis and new coping mechanisms that will help in future situations. She viewed the task of the caregiver to be assisting the client to carry out certain tasks, and cautioned against the caregiver owning the problem(s).

In the crisis, the client, according to Crisis Theory, must explore available options, solutions and so forth. He or she must then select a solution and/or role, utilize this and move through a period of adaptation and development of increasing competence. As the client achieves these tasks, he or she begins to function at an acceptable level. It is the role of the caregiver to facilitate this process.

The utility of this theory is in its' emphasis on assisting the individual to establish some manner of coping in the crisis. As suggested in the trauma literature, a sense of control is helpful to individuals during a trauma and decreases psychological stress

(Regehr, Cadell & Jansen, 1999; van der Kolk & McFarlane, 1996). Furthermore, the importance of listening to and allowing the individual to make choices and actively move towards resolution of the crisis is significant for trauma victims (Golan, 1979). The findings of this dissertation certainly support the importance of these two aspects of Crisis Theory.

Integration of Trauma, Grief and Crisis Theory

The current understanding of trauma and the factors that can contribute to PTSD are important in the understanding of the impact of the death of a child on parents. While most parents will not develop PTSD, many more than the norm may. In two studies, 26 – 40 % of parents were found to develop PTSD (Murphy et. al., 1999; Thompson, Norris & Ruback, 1998). The norm would appear to be approximately 14% (Yehuda, 1999). Certain types of losses, ie violent, sudden, random, unanticipated deaths are understood to be traumatic. (Rando, 1998). The death of a child is viewed to be the worst loss (Rosof. 1995; Schiff, 1977; Brabant, Forsyth & McFarlain, 1994a). According to Rando (1986; 1993) the death of a child places a parent at higher risk of complicated mourning. This is because the death of a child is seen as a severely traumatic event (Rando, 1986). The nature and severity of the event is to some extent predictive of PTSD in survivors, particularly the aspect of violence (Goldberg et. al., 1990; Gallers et. al., 1988). Violence is often an aspect of sudden death through the cause of the death, ie murder, suicide, accidents. Pre-event factors will likely affect outcomes in those bereaved by such losses. Prior histories of psychopathology (Davidson et al., 1985), and belief systems (Gidycz & Koss, 1991) may affect outcome. Post-event factors such as access to information (Winje, 1998) and social support (Solkoff, Gray & Keill, 1986) may have an impact.

The assault on the assumptive world that the sudden death of a child constitutes leaves the bereaved parent experiencing the feelings of loss of control and powerlessness described by Janoff-Bulman, (1985). Understanding the potential impact of this on future psychological adjustment as demonstrated in the trauma literature reviewed speaks to the need to facilitate the restoration of functioning, sense of control, and attribution of meaning during the crisis. The next step then, is to look at interventions at the time of the death with an understanding of the effects of trauma. Models of treatment for the bereaved have not previously addressed issues of trauma in the loss (eg. Kubler-Ross, 1969; Worden, 1991). The various models of grief theory presented in this paper represent an overview of how mourning has been and is perceived, both from a grief perspective as well as from a trauma perspective.

Rando's work in the identification of the factors seen in traumatic deaths reinforces the need to look at management of the initial period following the sudden death of a child, and develop a model for professionals dealing with these situations. While the current work of Rando (1998), Figley (1997), Gilbert (1997) and others represents a fundamental shift in thinking with respect to intervention in loss, the work of the various professionals involved with the bereaved at the time of the trauma itself is in need of a broader understanding of the presently developing paradigms. Current thinking is incorporating the understanding of trauma as a part of certain types of death.

Crisis Theory is a significant linkage in the work with parents at the time of the death of a child. The importance of the professional as facilitator, as opposed to problem solver, has been stressed by Golan (1979). Understanding the needs of individuals to

restore a sense of self-efficacy to assist in the restoration of functioning is relevant to work with bereaved individuals at the time of the death. The trauma literature has addressed the need of individuals to feel some sense of control (Regehr, Cadell & Jansen, 1999; Silver, Wortman & Kloss, 1982). Further, the importance of information has been demonstrated by Winje (1998). In Crisis Theory, the individual would be assisted to determine their own needs and meet them (Golan, 1979). Good crisis intervention skills fit well with assisting traumatized individuals in an effort to reduce psychological distress. This reduced psychological distress may reduce the likelihood of PTSD and/or complicated mourning later for the individual.

Summary

Throughout this chapter the changing models of grief have been presented. There has been an evolution in thinking about grief that has shifted from the work of Kubler-Ross (1969) through Worden (1991) and Rando (1993) and many others. The literature respecting the nature of trauma and the development of PTSD has been examined. The current thinking in thanatology linking grief and trauma, as described in the work of Rando (1994, 1998), Figley (1997), Gilbert (1997), Nader (1997) and others has been reviewed. The death of a child is always seen to be a traumatic loss, and many believe, the most traumatic (Rosof, 1995). The need for basic crisis intervention has been identified and the use of Crisis Theory applied. The next chapter will look at what makes the loss of a child such a traumatic event.

Chapter Three

Parental Loss

The finest years I ever knew
were all the years I had with you.
Nobody else could ever know
the part of me that can't let go.
And I would give anything I own,
I'd give up my life, my heart, my home.
I would give everything I own
just to have you back again,
just to touch you, once again.
(Bread, 1972)

The death of a child is considered to be the most devastating loss, the most traumatic death, the most difficult bereavement, the most intense loss and the least natural type of death to occur (Brabant, Forsyth & McFarlain, 1994, a; Wheeler, 1994; Lindemann, 1944; de Vries, .Lana & Falck, 1994; Clayton, Desmarais, Winokier, 1968; Klass, 1992-1993; Rando, 1986, 1988, 1993; Rollins, 1988; & Smart, 1993). A deceased child is never forgotten (Raphael, 1983; Rando, 1986; 1993; & 1998; Rosof, 1995; & Schiff, 1977). Such a loss is viewed, in our society, as provoking more intense grief reactions than the loss of an older individual (Rando, 1986; Clayton, Desmarais, Winokier 1968). Romanoff (1993) concurs that the death of a child is particularly intense, with little diminishment of the intensity of grief over time. The resulting significant disabilities for parents who lose children, and the consequent social costs, are very much supported in the literature as previously discussed. Neidig and Dalgas-Pelish's (1991) research demonstrates higher scores on intensity of grief, even twenty years after the loss, on the

inventories of parents. The prior review of the trauma literature demonstrates that mothers are at risk of developing PTSD (Murphy et. al., 1999). In this study 40% of mothers continued to have PTSD at four months post death of the child. Thompson and others (1998) also found that families of homicide victims at higher risk than the general population for developing PTSD. Of the family member in this study, 55% were parents.

The nature of the parent-child bond is presented as a significant factor in the complex grief experience of parents (Rosof, 1995; Rando, 1986; 1993; Raphael, 1983). In our society, parents are expected to nurture and protect their children. This expectation is reinforced in our legal system through legislation such as the Child and Family Services Act, 2000. The child is a part of the parent, a piece of the parent's genetic code that will carry on, a link between the past and future. "The ties of love and hope that bind parent and child are the most powerful in human relationships" (Rosof, 1995, p. 6). Consequently, the death of a child is seen as an existential wound to the parents (deVries, Lana & Falck, 1994).

Factors Impacting on the Traumatic Nature of the Death of a Child

There are specific factors associated with the loss of a child that places parents at high risk of complicated mourning due to the traumatic nature of the death (Rando, 1993). Many thanatologists are currently developing models of intervention for survivors of traumatic deaths, and even for parental loss (for example, Gilbert, 1997). Rando has developed a comprehensive conceptual framework within which to understand the impact and implications of the loss of a child. This conceptualization has developed from theories of grief and mourning, and the integration of trauma response theories into them. This concept is supported by the work of others such as Rollins (1988); Romanoff,

(1993); Seguin, Lesage, & Kiely (1995); Schwartz, (1977); Wheeler, (1994); Brabant, Forsyth & McFarlain (1994 & 1995); Dyregrov & Matthiesen, (1987); & Rosof, (1995), who all identified the traumatic nature of the death of a child. Horowitz (1991) has added to our development of the understanding of the process of mourning through his work in trauma within the framework of self schemas.

The specific factors include: age of the child, the psychological relationship between the parent and the child, specific issues arising from the loss of a child, marital issues, family system issues, and social issues. Rando's work is extremely comprehensive in this area, and valuable in understanding the issues that must be addressed in the immediate crisis of the death. To understand the issues parents may face can assist professionals in helping parents identify their needs during the crisis, utilizing good crisis intervention skills.

Age of the Child

Regardless of the child's age at the time of death, that child fills particular roles in the parent's life. In fact, a child fulfills many roles within a family, for example child, sibling, babysitter, household helper, companion, friend etc. Each family's unique structure and organization, and the various relationships among family members will determine which roles any given child may play within the family system, and in the lives of the parent. The loss of the child then creates a unique void in the lives of each family member.

The death of that child violates certain beliefs about the natural order of things (deVries, Lana & Falck, 1994; Sanders, 1979-1980; Parkes, 1985; Rando, 1984; 1986; & 1993). Children are supposed to bury their parents, not the reverse. This constitutes one

of the many violations of the assumptive world of the parents caused by the death of the child. Another violation may be the shattering of the parent's belief in the safety and security of their world, caused by the violence that comes with sudden death, or the mutilation that may be part of a terminal illness, and by their inability to protect their child from harm. Dyregrov & Matthiesen (1987) found increased anxiety in mothers and fears related to the safety of their surviving children, as well as to the security of the family. Although common belief is that the age of the child is irrelevant, there are specific issues for parents that arise out of the developmental stage of the child, and therefore the family, at the time of death. The treatment issues are addressed by Rando (1986 & 1993), and Gilbert (1997).

There are particular difficulties encountered by parents in the loss of children who are either very young, or well into adulthood. These parents may become disenfranchised mourners (Doka, 1989), due to lack of social acknowledgement of their loss (Rando, 1993). When the death is a stillbirth, or infant death, social response is often to remind the parents that they can have more children, as if the one that died were replaceable. The in-utero bonding is often unacknowledged and the loss minimized, and the building of hopes and dreams for that child, as well as the developing reality of the parental role, are unrecognized. Social support may be lacking as a result of the parents' social supports having had no real relationship with the child. Social discomfort with the loss of a child also impacts on the supports available to the parents. The myriad secondary losses are often not identified (Rando, 1986; 1988; & Leff, 1987).

Another such disenfranchised loss is the loss of an adult child. Parents of an adult child who dies may often be unacknowledged grievers. The primary focus of social

support tends to be centered on spouse and/or children of the deceased. Decision-making responsibilities are often out of the hands of these parents. Rando (1986; 1993) has identified issues related specifically to the loss of an adult child which compromise parental bereavement. Some of these are: the changed relationship the parent and child have in adult life; the unfairness of the adult child not being able to experience the rewards from the work he has done; having to watch the children of their adult child suffer; and, the possible disruption in the grandparenting relationship with them which may result from the now changed life circumstances.

The Psychological Relationship

Various factors within the relationship between parent and child can intensify grief following the death of a child, creating the appearance of abnormal grieving patterns. The varying structures of families and the past histories that each mourner brings to the loss further exacerbate these factors.

The parent-child relationship is thought to reflect the most complex projections of hopes, wishes, dreams, expectations, assumptions, beliefs and meanings of any relationship (Rando, 1986; & 1993; deVries, Lana & Falck, 1994; Klass, 1992-1993). The child is an extension of the parent, a piece of himself or herself, and thus feelings about the child are interconnected with feelings about the self. The child usually is a symbolic representation of the self (Klass, 1992-1993), a significator of purpose and meaning in life (Rando, 1986), and is both a person to love and to be loved by. The child may represent the future, a hope for future fulfillment, the continuation of the parents' genetic code, or possibly a chance for immortality. The child may provide parents with feelings of worthiness, status, and competence, and may represent other significant

relationships in the parents' lives.

The heavy investment of self which parents have in their children, as both a biological and psychological extension of the self, makes the issues arising from the death of the child both highly individual in nature, and extremely complex. The relationship a parent has with a child has significant meaning to the parent. The meaning attributed to the trauma impacts on psychological adjustment (van der Kolk & McFarlane, 1996; Caruth, 1995). The parent-child relationship may not have been what was desired. At certain developmental stages, children are separating from parents, and this is generally acknowledged as a difficult period in the parent-child relationship. Particularly in adolescence, the relationship may not be as the parent has always wished for. The disparity between the desired and the actual relationship is highlighted at the time of a child's death, and can create serious complications in mourning.

It is generally acknowledged in the literature that there are more inherently assumed responsibilities, and socially assigned ones, in the parent-child relationship, than in any other relationship (Rando, 1986; & 1993; Gilbert, 1997; & Rosof, 1995). The burden of protecting one's child is considerable, and although often not acknowledged, the death of a child represents to the parents their failure in this respect. The literature identifies guilt as a normal reaction to loss (Rando, 1993). In the case of parental loss, the unrealistic expectations that parents frequently hold of themselves predisposes them to extreme feelings of guilt, and thus to complications in mourning (Rando, 1986). Guilt is one of the primary driving affects in the bereaved where a death is seen as preventable, and where the mourner feels responsible for the safety of the deceased (Rando, 1998).

Incorporating parenthood into one's identity radically changes the view of self one

has. Over time, the parental role becomes a primary role in life and a major part of one's identity. The loss of a child thus can threaten one's sense of self in a way that no other loss can. In addition, the closeness and intensity of the relationship between parent and child is seldom seen in other relationship because of the previously outlined factors (Rando, 1986; 1988; &1993; & Rosof, 1995). The extreme loss of role and possible change in identity the death of the child represents, the reconstruction of the person's view of self (Janoff-Bulman, 1985) and the incorporation of the trauma into personal identity through processing of the narrative (van der Kolk & Fisler, 1995, Herman, 1992)) represent significantly difficult accomplishments that are required to move through mourning and resolve trauma.

Rando's conceptualization of the impact of the psychological relationship between parent and child on the parent's experience of loss is well informed. It synthesizes what is known about attachment, separation, identity, social expectations of parents, the nature of the parent child bond, and many other factors, thus demonstrating the level of trauma experienced in the death of a child and the shattering of the assumptive world. Currently thanatologists are developing an increasing understanding of how to process these issues in therapy, however, there is no focus on how to assist parents at the time of the death and potentially avoid complications in mourning. Crisis Theory (Golan, 1979) would propose that such assistance should take the form of facilitation, by tuning in to the needs of the parents and helping them identify and meet these needs.

Difficulties for Parents in the Loss of a Child

There are several factors that exacerbate mourning for a child, are traumatizing to the parents, and place them at higher risk of a complicated, prolonged, or otherwise difficult

mourning process. These are often identified in the literature as 'secondary losses' (Rando, 1986; 1988; & 1993; Brabant, Forsyth & McFarlain, 1994; Klass, 1992-1993; Sanders, 1979-1980; Rosof, 1995). These factors arise from the level of intimacy and the unique nature of the parent child relationship.

One of the primary factors that create dilemmas for parents is the loss of the parenting role with the child. As previously mentioned, the primary function of the parent is to nurture and protect the child. The death of the child represents, at a very basic level, the failure to do so. This failure, as perceived by the parents, creates severe guilt reactions. If the child is an only child, the parent completely loses his or her role as a parent. This creates an immense loss in the life of the parent. Not only does he or she have to deal with the death of the child, but additionally, he or she has to face life without the function of one of the major roles that he or she has assumed (deVries, Lana & Falck, 1994; Kliman, 1977; & Rando, 1993).

The loss of the child represents a major assault on parental identity. The experience of powerlessness and failure and the sense of violation create a diminished sense of self. Basic beliefs about the self and one's ability as a parent are changed, and require a profound shift in the parent's assumptive world.

As previously noted, the death of a child destroys a good part of a parent's future. Our children, to some extent, represent our chance for immortality. When a child dies, that part of the parent, which the parents had expected would carry on in this world subsequent to their own death, also dies. The parent's future is gone (Rosof, 1995; Videka-Sherman, 1985; Rando, 1986; 1988; & 1993).

The shattering of the assumptive world that results from the death of a child is viewed

as the worst violation of the assumptive world that an individual can experience (Rando, 1993). The immensity of the violation stems from the undermining of the orderliness of the universe (Gorer, 1965). Many thanatologists have written of the significance of the violation of the laws of nature in which is the inherent expectation that the young will care for and bury the old, not the parent bury their child (Rando, 1986; 1988; & 1993; Rosof, 1995; & Schwartz, 1977). The ensuing survivor guilt, combined with the guilt of failing to fulfill the parent role by successfully raising one's child cannot be underestimated

Intimately connected to this violation of the assumptive world is the loss of the child as a future caretaker. The general understanding of this issue is the view of the child, in later life, as a provider of emotional and perhaps even physical and financial support for parents. Most current thanatologists would agree that this is a treatment issue for parents, in looking at secondary losses. What may go unrecognized, which Rando (1993) does indeed speak to, is the loss of the child as an emotional support in the present life of the bereaved parent. It is often the case in a single parent home, or in many other family situations, that children fulfill some sort of role as emotional supporters of their parents. While this is recognized in family therapy (for example the concept of the parentified child), it is often an unacknowledged loss for a bereaved parent. When the deceased child is one of the few, if not only, emotional supports a parent has, that parent is even further traumatized by the death.

Many of the typically experienced grief responses are particularly intense in bereaved parents, certain aspects of grief, because of their intensity, do increase the risk for parents to experience a more complex mourning process. Some of these are the severity of the

anger, the level of pain of separation due to the nature of the parent-child bond, and, the enormous guilt experienced. Furthermore, the number and nature of secondary losses is much greater than in other bereavements, and the assault on the assumptive world more severe. Despair is magnified, and yearning and searching are intense.

Parents experience numerous difficulties in social support, and all of the unrealistic expectations society holds for mourners make bereaved parents appear pathological in their grief. The ongoing nature of the loss, which is never resolved because of the relationship issues, creates what Rando (1993) refers to as sudden temporary upsurges of grief (STUG) reactions. Rando aptly points out that parents literally grow up with the loss, as parents are often painfully reminded of their loss at times when the child would have graduated, married etc.

Family System Issues

The loss of a child has a major impact on the family system. Roles must be adjusted, and this is not an easy process (Figley, 1984; Gilbert, 1997; Rando, 1993). Often the bereaved parents must, despite the severity of their own pain, continue in the role of parents to other children. In doing so, they are continually reminded of their loss. Furthermore, parents are usually painfully aware of their failure to meet the needs of their other grieving children, who have lost a sibling. They fear losing their other children, as they are acutely aware of how tenuous life really is. They may become overprotective with surviving children, which may create difficulty in the relationship with the other children (Leff, 1987; Horowitz, 1997; Lehman et. al., 1989; & Rando, 1993).

At times, parents may tend to idealize the deceased child, and create resentment among the remaining children who cannot live up to the image of the dead child. The

parents may even resent the living children for being alive and making demands on them at a time when all that they can think of is the lost child (Rando, 1986; 1993). Finally, surviving children may resemble the deceased child physically or in terms of personality, and this can create difficulties for parents in the day-to-day parenting of that child. This is particularly unfortunate if the parents are remembering only the best qualities of the deceased child, and forgetting their humanness. A very unhealthy dynamic can be set up. The remaining child who resembles the deceased in some way may feel some responsibility to 'replace' the deceased child. This aspect of the changed family dynamic is not well attended to in the literature and certainly offers fertile ground for future research.

Marital Issues

A number of issues arise for a couple in the loss of their child. There are gender differences in grief which impact on the parents as a couple (Lehman et al., 1989; Rosof, 1995; Gilbert, 1997 & Rando, 1993). Individual grieving needs may further complicate mourning among couples. Role expectations within the marriage may place additional, and possibly unmanageable, demands on couples at such a time (Cook, 1988; Rando, 1986; 1993; & Gilbert, 1997).

Cook (1988) identifies the perception that fathers may grieve with less intensity than mothers. This perception is based on the gender-related societal expectations of men and women, particularly with respect to the demonstration of emotion. Cook questions this perception of a less intense grief and identifies that this belief may be borne out of conceptualization of grief from a female perspective. Fathers, in general, are expected to protect and shield their families, and, according to Cook, the cultural norm of less

familial involvement reduces fathers' emotional expressiveness. The question of whether or not men grieve less intensely after the death of a child is one that certainly requires further research. Currently, many fathers are much more involved in hands on care of their children, and that may be reflected in more open expressions of grief when children die than has been historically observed. Certainly over the last ten years, the development of father's groups within Bereaved Families of Ontario has grown (Bereaved Families of Ontario Annual Report, 1996).

It is unfortunately true that, in general, mothers receive more support for their loss. In general, men are expected to comfort their wives, and in crises there is a tendency to question fathers with respect to how the mothers are 'doing', while failing to ask the same question with regard to the father's own status (Cook, 1988). It is likely that these gender differences in grieving, differences in individual needs, and social expectations may complicate the marital relationship at a time when the couple is the least able to deal with additional stressors (Rosof, 1995, Rando, 1986).

Rando (1986; 1993), Gilbert (1997) and Brabant, Forsyth & McFarlain (1994) have all identified difficulties in communication, sexual expression, disparate images of appropriate mourning, and the entire issue of blame for the child's death that may create significant difficulties for parents. The kinds of responses elicited in the trauma of their child's death may present a different, and not always acceptable, view of the other partner.

Differing needs in grieving can present serious problems for the couple. One parent, for example, may wish to remove all traces of the child in order to control the intrusive feelings experienced as a result of seeing their belongings/pictures/etc. At the same time,

the other parent may find great comfort in the presence of these reminders. The resolution of such emotionally charged issues is difficult, if not impossible, at a time when couples are overwhelmed with the initial stages of grief.

Marriages, and parenting, are complex relationships. The overwhelming burden imposed by the loss of a child can contribute to the downfall of an already struggling marriage. Rando (1986) identifies the popular conception that the death of a child will often lead to divorce. She further proposes that this is erroneous, and that early studies in this area, which are not supported by current research, failed to look at the normal divorce rate.

Clinically, changes in the marital relationship are often seen. These may occur as a direct result of the trauma, from the need to 'pull together' as a couple to survive the loss. Additionally, it would not be unreasonable to expect to see changes in the relationship arise from the altered assumptive world created by the trauma. Further research in this area could provide reassurance to the many parents who believe that the loss of a child will be automatically followed by a divorce.

Issues Created by Social Attitudes

In her work, Rando (1996; 1988; 1993) has clearly identified the stigma attached to parental loss, and the failure of society, despite the strong value placed on the parent-child relationship, to support parents. The death of a child represents every parent's worst nightmare.

The rejection and abandonment that many parents experience socially, reinforces their isolation, and reduces the amount of support available to them individually and as a couple. Although there is often initial support in the loss, the social messages given at

that time, as previously discussed in this paper, reinforce the isolation and contribute to denial. As a society, we do not do well in dealing with trauma, or supporting those around us who threaten our basic assumptions. Other parents are often frightened, not so much by the bereaved parents themselves, but more by the realization that they could just as easily be in their place. Furthermore, the discomfort of facing their own fears of child loss, vulnerability, and uncertainty as to how to respond, may prevent others from providing social support to the bereaved parents (Rosof, 1995; Schiff, 1977).

Sudden Death: Helping Parents Cope

Although the current trend in understanding the loss of a child is greatly benefiting from the joining of traumatology and thanatology, there is not a great deal of literature on helping parents at the time of a sudden death of a child. The work of Gyulay (1989) is the most comprehensive material I was able to access. In her work, Gyulay walks professionals through the sudden death of a child, highlighting for caregivers the experiences and needs of parents at that time.

Gyulay identifies the feelings of parents as they proceed through the death notification, identification of the body, various decision-making processes, and preparation for the funeral. Suggestions from families with respect to what they felt was helpful were identified. Gyulay identifies specific guidelines in working with families at such a time.

One of the most significant issues identified by Gyulay is the need for information at the time of the death. Notification of the death and information with respect to the cause of the death and condition of the body must be addressed in such a way that is respectful of the parents' needs. Furthermore, Gyulay points out that in the crisis of the death,

parents' memories will be affected and writing down information, or having someone (a family friend for example) with the family may be helpful. Gyulay also recognizes the need for information is different at different times, and for different individuals, and this should be taken into account when sharing information. Giving the parents time to process information is viewed to be vital.

Gyulay clearly identifies the over-protective attitude professionals often have toward parents at such a time, and reinforces the necessity to help the family identify and meet their own needs. An interesting comment Gyulay makes with respect to seeing the child's body even when it has been severely traumatized, is that in twenty years of work with these situations, she has only had two families express regret at seeing their child's body. This certainly reinforces the need to look at professional decision making on behalf of and 'for the protection of' parents.

Gyulay discusses organ donation, autopsies, funeral decisions, and the need to encourage participation of the whole family in these areas. Gyulay goes on to address specific issues with respect to these areas, identifying the traumatic effects of the loss and the need for ongoing support to families. The significance of dressing the child for the funeral, positioning the body, farewell messages, and burial decisions are addressed with some guidelines for assisting parents. Although based on her personal experiences as a health care professional, Gyulay's article is extremely valuable, and reflects the need to deal with the trauma, the grief, and to provide sensitive, immediate intervention that assists the family through the trauma.

Other literature for professionals involved with parents at the time of the death of a child is extremely limited. Leff (1987) identifies health care workers' own feelings of

powerlessness that may pose a barrier in communicating with parents, and proposes that issues of bereavement need to be more fully explored in medical and nursing schools. This is supported by the work of Davidson & Foster (1995).

Neidig and Dalgas-Pelish (1991), in their study of parents' perceptions regarding the interventions of health care workers at the time of the death of a child, found that health care workers need to understand the differing issues arising in parental loss that makes such a loss unique and traumatic. They must further be prepared to facilitate the parents' grief experiences. Their study has produced specific helpful interventions that health care professionals can provide. It also identifies what parents experienced as unhelpful interventions. In reviewing their findings, the interventions could be organized according to the themes of instrumental assistance, compassion and information. Their work is reflective of the views of Rando and others in the field.

Weaver (1993) identifies the lack of published literature on the role of the clergy and lack of training in the effects of trauma on individuals and families. He reinforces the need for further training of clergy in this area. Weaver. Koenig & Ochberg (1996) again identified the need for training in the clergy's work with traumatized parishioners. They identified that clergy are greatly involved but underutilized in this regard. Hockey (1993) discusses the clergy's role in funerals and refers to 'managing' emotional expression. She identifies the conflict between the view supporting the need to express emotions openly, and the structured western funeral rituals. Frantz , Trolley, and Johll (1996) also view the clergy as having a limited role in the bereavement process. These various authors demonstrate the difficulty posed in social expectations from parents, and one can certainly see how they feed in to the denial process identified in the second chapter of this

paper.

Bradfield and Myers (1980) identify the resentment between clergy and funeral directors with respect to their roles: that is, whose territory is what. They identify that often there are conflicts regarding roles with parents with respect to both support and funeral planning. They clearly view this dispute as having a major impact on bereaved parents. Parry (1994) highlights the importance of immediate death review, the need to talk about and process the death during funeral arranging and visitation, and the need for funeral directors to be aware of this. Weaver, Koenig & Ochberg (1996) also identified the issue of mistrust between clergy and mental health professionals, and proposed that traumatized individuals with whom they are involved would benefit by these two groups engaging in training, collaboration and research together.

The most significant article with respect to funeral directors dealing with parental loss is Kalkofen (1989), which reinforces the need for the funeral director to act as a grief facilitator. Kalkofen offers suggestions to assist families through the funeral, such as permitting them to dress their child's body, providing open and honest information, holding a deceased infant, and providing support. Kalkofen suggests that funeral directors are emotionally affected more by a child's death than any other. He identifies the emotionally draining nature of this work and the need for personal support in order to accomplish this important work.

Clark (1981) identifies the need for police to perform a helping function in suicides and accidental deaths, as well as reinforcing the need for death education for police officers. He also identifies the need for mental health professionals who provide death education and consultation to the police to also provide consultation for police with

respect to their own feelings about the death. Clark emphasizes that police are subjected to traumatic deaths frequently and therefore rely heavily on psychological defenses. These defenses are likely to affect their responses to parents in a death of a child. Psychological support for police can reduce the effects of the ongoing exposure to trauma.

Charmaz (1975), also reports the self-protection engaged in by coroner's deputies in reporting deaths. Charmaz compares the management of death notification in two counties, and finds that central assumptions about human nature and the meaning of grief affect the manner in which deputies announce death, and the expectations they have about dealing with families, as well as families' responses. These assumptions clearly have a significant impact on the work of deputies. She identifies the amount of control deputies have as a result of their access to information and ability to manipulate the flow of vital information to the bereaved individual. As demonstrated in Winje's (1998) study, understanding what happened in a traumatic event is part of the normal adjustment process, and feeling adequately informed about events is associated with less psychological distress.

Summary

The professional literature available on helping parents through the crisis of a sudden death of a child is limited. What does exist clearly supports the need for appropriate intervention, and an understanding of the needs of parents at the time of the death. Furthermore, the literature identifies the lack of support for professionals with respect to the impact of this type of traumatic work on their own lives. Clearly, further research must be done with regard to the needs of parents at the time of a sudden death of a child.

A variety of other areas need further investigation, such as professional training on the issue, and professional training with respect to the personal management of vicarious traumatization. Most importantly, none of this research is based upon the advice of the parents themselves who have experienced the sudden death of a child. The research that follows is intended to bridge this gap in our knowledge by hearing what parents have to say.

Chapter Four

Methodology

> The heuristic research approach offers a systematic form of investigating human experience that draws on the researcher's internal frame of reference, self-searching and intuition, as well as that of others, with the aim of discovering and understanding the underlying meanings of the experience...Engaging in a dialectical process of self-searching while simultaneousiy searching with others creates a fusion of participants' frames of reference, and provides the opportunity to see, know, and understand in a different way (Carlin, 1997).

Theoretical Framework

Models of grief and mourning have developed significantly since the work of Elizabeth Kubler-Ross (1969) in the late sixties. The trend in the conceptualization of grief and mourning has moved from Kubler-Ross's five stages, through Worden's (1991) four tasks to Rando's (1993) six processes/three phases. More recently these models have incorporated the acknowledgement of trauma as an aspect of grief, and the significance of assessing the level of trauma in any loss.

Rando's work in the identification of high risk factors reinforces the need to look at management of the initial period following the sudden death of a child, and develop a model for professionals dealing with these situations. While the current work of Rando, Figley and others represents a fundamental shift in thinking with respect to intervention in loss, the work of the various professionals involved with the bereaved at the time of the trauma itself is poorly informed and can certainly benefit from an adaptation of the presently developing paradigms.

The field of thanatology has made great strides in the last twenty years. Moving along

a continuum of conceptualizing grief in a "stage" model, through "tasks" and into "phases" and "processes" has been extremely helpful in developing a more comprehensive understanding of the issues that bereaved individuals face in their lives. From a systems perspective, this understanding is imperative. As many thanatologists have reiterated, marital, family, and social issues affect the mourner intensely. Within this context, thanatologists have been able to understand the commonalities and differences in specific losses. This has led to a comprehensive understanding of the issues in parental loss, with much credit due to Rando, whose work has been extensive in this area.

The concept of the disenfranchised mourner is also helpful in that it raises the awareness of those in the helping professions. The understanding that many people grieve deeply over the loss of a significant other, when society may not have recognized the meaning of that loss, is important. Further, the bereaved parent may, in fact, be viewed to some extent as a disenfranchised mourner. This disenfranchisement results in the isolation that may stem from the stigma of losing a child.

The development of a conceptual framework relating traumatology to thanatology by such authors as Figley (1997), Simpson (1997), Gilbert (1997), and Rando (1988; 1998), is a great stride forward in death studies. The continuing work in this area is a significant contribution to the field. The difficulties mourners have faced as a result of the lack of understanding of the impact of trauma on loss have been numerous and painful. Particularly in the area of parental loss, these difficulties have been significant.

The trauma and loss connection has provided a particularly helpful framework for understanding parental loss. The conceptualization of the death of a child constituting a

trauma to the parents allows grief therapists to not only understand the depth of the loss, but also gives them tools to work with bereaved parents. The availability of techniques for trauma resolution can add significantly to the present treatment techniques utilized with bereaved parents. Failure to incorporate this new knowledge in the assessment and treatment of bereaved parents will inevitably result in inappropriate and highly unrealistic expectations of the parents as mourners, and ultimately create a situation ripe for complicated mourning processes.

The significant changes in thanatology have had a positive impact on the assessment and treatment of parental loss. If one views parental loss as a trauma, as current thanatology suggests, then inevitably the question must be asked: what can we do at the time of the trauma to prevent or reduce the incidence of complicated mourning and the resulting need for trauma resolution and grief management? Trauma reduction needs to be a major concern *at the time of the trauma.*

At this time there is no model for intervention at the time of the trauma of the sudden death of a child, although currently developing models for treatment certainly lay the groundwork. It is my view that a great deal more research must be done with respect to how professionals can best assist parents to reduce the trauma at the time of the child's death, rather than having to assess and treat the trauma months or years later. The goal of such a model would be to reduce the incidence of complications in mourning. The focus of my work is to examine the need for such a model, and to contribute to the development of one.

The Research Question

The purpose of the research question is to establish insights to begin to build a model

of intervention to utilize with parents by the various professionals involved at the time of the sudden death of a child; that is, from the death notification through the funeral. This model requires a thorough understanding of the impact of the traumatic death of a child on parents, which is currently not well formulated in the thanatological literature, as well as in-depth insight into the parents' own experiences and self-identified needs at such a time.

The 'grand tour' research question (Cresswell, 1994) is then formulated as: *what can involved professionals do to assist parents through the initial period of the sudden death of a child in order to help facilitate the most healthy grieving process possible in the given circumstances*? The 'mini tour' questions that flow from the primary research question then focus on the in-depth experiences of individual parents with each professional that they encountered; the impact of those various experiences, i.e., what was helpful, what was not, and why; and, in retrospect what could have been done/not done that would have been more useful to them in getting through that period of time.

The Methodology

This research is conducted with a phenomenological approach within a qualitative inquiry. The qualitative inquiry is designed to be consistent with certain basic assumptions. "This study is defined as an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants and conducted in a natural setting" (Creswell, 1994, pp. 1-2). Qualitative inquiry fits with problems which require exploratory research, have unknown variables, are context important, and/or may lack a theory base (Creswell, 1994). The proposed research is extremely context important, is exploratory in nature,

and requires assessment to determine the 'fit' of the theory base developed within current thanatological models. In qualitative inquiry "rules and procedures are not fixed, but rather are open and emerging" (Creswell, 1994, pp. 9-10). The researcher becomes the primary instrument, the fieldwork is of primary importance, and theory is built from inductive reasoning based on descriptive findings.

Qualitative inquiry lends itself well to a phenomenological approach "in which human experiences are examined through the detailed descriptions of the people being studied" (Creswell, 1994, p. 12). The phenomenological approach examines the structure of the experience or phenomenon. In a phenomenological approach, one has a:

> ...focus on how we put together the phenomenon we experience in such a way as to make sense of the world, and in so doing, develop a world view. There is no separate (or objective) reality for people. There is only what they know their experience is and means. The subjective experience incorporates the objective thing and a person's reality (Patton, 1990, p. 69).

To fully understand the experiences of bereaved parents, a phenomenological approach is necessary. In this type of research, the researcher can examine in-depth the subjective experiences of parents.

The primary implications of the phenomenological approach are twofold: first, that it is most important to understand what people experience and how they interpret their world, and second, that the researcher can only really understand a phenomenon if they experience it themselves through participant observation, or heuristic inquiry. The central meaning of any experience is mutually understood through the common experience of the phenomenon by the researcher and the participants. Heuristic inquiry then, stems from the phenomenological design by bringing the researcher's personal

experience to the forefront.

The following list highlights the significant characteristics of the heuristic aspects of the phenomenological approach (Patton, 1990):

Heuristic Approach

1. Connectedness & relationship are emphasized.
2. Essential meaning & personal significance are valued.
3. Creative synthesis includes the researcher's understanding of the experience.
4. The essence of the person in the experience is retained.

Heuristic research, then, "epitomizes the phenomenological emphasis on meanings and knowledge through person experience; it exemplifies and places at the fore the way in which the researcher is the primary instrument in qualitative inquiry, and it challenges the extreme traditional scientific concerns about the researcher's objectivity and detachment" (Patton, 1990, p. 73). This is an ideal approach for my research, given that I have personally experienced the loss of a child, and it is this loss that has prompted my desire to understand this particular phenomenon.

The heuristic approach requires that the researcher have personal experience with the subject under study (Moustakas, 1990). This personal experience provides the researcher with the ability to develop 'tacit knowing' (Douglass & Moustakas, 1985), the ability to sense the wholeness of a phenomenon from developing an understanding of the various aspects of it. Through this tacit knowing the researcher guides the research process, using intuition to shift the design to facilitate a greater process of discovery and depth of meaning (Moustakas, 1990). The use of the researcher's intuition helps to develop the

necessary 'sense of connectedness' (Patton, 1990) that helps research participants engage in a meaningful exploration of their own experience.

In the first stage of the research, the researcher immerses him/herself into the full quality of the experience of the participants. The researcher becomes fully involved with all of his/her senses in the experience of the phenomenon. Self-awareness and insights developed from the researcher's own personal experience with the phenomenon direct the research questions and process. The researcher seeks to develop intuitive or tacit knowing through a deepening understanding of his or her personal experience. This process is facilitated through self-searching, exploration of the literature, and observations of others directed at understanding the deepest meaning of the question.

The next stage, incubation, allows the awareness and understanding of the researcher to develop at a profound level. Incubation, or percolation, occurs as the researcher moves away from the intensive experience of the interviews and allows time for the absorption and integration of the experiences to occur. This stage is repeated throughout the research process as new data is accumulated, and deeper levels of meaning are attained.

In the illuminatory stage, the expanding awareness and deepening meaning brings a new level of knowing, and reveals the very fabric of the phenomenon studied. The researcher's awareness of the emerging meanings and themes expands to incorporate a richer and deeper understanding of the phenomenon.

During explication there is a "refining of emergent patterns and discovered relationships (Patton, 1990, p. 410). Further data is generated from the researcher's intuitive understanding of what is needed to direct and refine the research process. Data is then organized, patterns clarified, and concrete subjective experiences conceptualized

and refined (Craig, 1978). The researcher is then immersed in the data, developing an intimate knowledge of the material and the researcher's tacit knowing.

In creative synthesis, the total experience reveals patterns and relationships. The insights and experiences of the researcher are primary. Throughout the research process the researcher moves in and out of the various phases in a non-sequential fashion.

Sampling Procedure

In keeping with the heuristic aspects of the phenomenological approach, a purposeful sampling approach was utilized. Information-rich cases were sought for in-depth inquiry into the issues of central importance in this research (Patton, 1990). This purposive sample provided the opportunity to discover categories and their relationships (Glaser & Strauss, 1967) relevant to my grand tour research question.

The sample consisted of 20 individuals, who provided the "point of redundancy" criteria (Lincoln & Guba, 1985, p.202) in core themes, or the theoretical saturation point described by Glaser and Strauss (1967). The 20 parents were identified through three Bereaved Families of Ontario affiliates: Kitchener/Waterloo, Halton/Peel, and Hamilton/Wentworth/Burlington.

The sample was a convenience sample and was comprised of 4 couples 11 mothers and 1 single father. The couples, except for one, were interviewed individually. They were all of the white euro-centric dominant culture, Christian and middle class. The participants ranged in age from early thirties to early sixties. They were all 11 months to 7 years post bereavement. Some of the parents had experienced other losses since t he death of the child, for example the loss of a parent or sibling, and were able to draw comparisons between the experiences. Some of the parents were involved in continuing

litigation resulting from the death at the time of the interview. All were eager participants, willing to share their stories in the hope that it would help future bereaved parents. This is a philosophy central to the Bereaved Families operation.

This purposive sampling allowed for appropriate case examples to be identified, providing cases rich in experience but not so extreme as to compromise the research with pathological examples that are not reflective of the general population. Participants were intended to have lost a child, ages birth to 24, to sudden, unexpected death. Age 24 is the upper range of the late adolescent category in Statistics Canada data. As well, young people are usually out of their parents' homes and no longer dependent at that stage of life. In the course of interviewing, several parents offered to participate whose children were above the stated age group. While I had originally not intended to incorporate these interviews into the data in this study, it became clear that these three parents were raising several similar issues. These interviews were transcribed and analyzed, and in the analysis of the data, the themes that emerged were the same as in the target population. Therefore the data from these interviews was included in the study. The oldest child in the study was thirty-eight years old. The fact that the themes were the same bears out Rando's (1986) research that the age of the child is only relevant to the developmental issues that arise.

In this study I wanted sufficient time to have elapsed since the death to enable the parent to look back reflectively on the interventions that occurred, with some ability to identify what was helpful and what was not. The minimal time since the death of the child was identified as one year. The staff of Bereaved Families who assisted in identifying potential participants were given this time frame as a guideline and asked to

approach parents they felt had reached a stage in their grief where they could be reflective with respect to their experiences. Part of the interview process was to assess how well the parents could reflectively examine their experiences, irrespective of the time that had passed since their child's death. The time from death of the child to the interview ranged from 11 months to 7 years. All of the participants were able to reflect on their experiences in a manner helpful to this research.

Data Collection: Sources and Methods

Various sources of data have been identified that are within the purview of qualitative inquiry, such as, artifacts, documents, archival records, objective observation of research participants, participant observation, questionnaires, in-depth interviews, and focus groups (Yin, 1984; Lincoln & Guba, 1985). However, within a heuristic approach, a necessary "sense of connectedness develops between researcher and research participants in their mutual efforts to elucidate the nature, meaning, and essence of a significant human experience" (Patton, 1990, p.72). This requires a "systematic observation of and dialogues with self and others" (p.72) which flows from a face-to-face interview of the 'immersion' variety described by Patton (1990).

This study utilized in-depth individual face-to-face interviews between myself as researcher and the research participants wherein their understandings and experiences of interventions at the time of the death of their child could be processed intensively. All interviews were held in the homes of the participants, where the participants had privacy, and felt comfortable. Participants were offered other options such as the offices of the Bereaved Families affiliates to which they belonged. The participants chose their own homes, often for the convenience. Such natural settings best support open exploration of

the participants' construction of reality and the researcher's understanding of this phenomenon (Lincoln & Guba, 1985). Further, conducting the interviews in participants' homes afforded the parents opportunities to show me pictures and at times belongings of their child, or things their child had made. Following the interviews, they did not have to drive anywhere and could enjoy the comfort and emotional support of their own homes and families if they experienced any difficult feelings as a result of this area of inquiry.

The interviews were unstructured and open-ended, with an emphasis on the individual's experience of the phenomenon (Lincoln & Guba, 1985). An interview guideline was developed (see Appendix I) from my understanding of the literature, as well as from my professional and personal experience with this issue. Before beginning the formal interviews, I used the guidelines as a pre-test to interview three other bereaved parents who did not belong to a Bereaved Families affiliate. This assisted in developing my own comfort with the interviews, aided in developing probes, and helped me to identify where I might experience personal difficulty in the interviews.

Each participant was contacted by telephone by the sponsoring Bereaved Families of Ontario affiliate and asked if they would be interested in participating. I was given the telephone numbers of those who agreed. At that time I contacted the potential participant, reviewed the purpose and process of the research, issues of confidentiality and privacy, and their rights in participating. The participants were then offered an option of being interviewed in their home or at the office. A mutually agreeable date and time was established and the participants were given a means to contact me in the event that they changed their minds, had any other questions, or needed to cancel the interview. Each participant had been made aware by Bereaved Families of the purpose of the

research, and of the fact that I was also a bereaved parent.

At the beginning of each interview, I reviewed the purpose and process of the research, the rights of the participants, and the letter of consent (see Appendix II), which was then signed. Participants were asked for permission to tape the interviews, and the use of the tapes and transcripts was explained. They were reminded that they could stop the interview at any time or decline to answer any specific question should they so desire. The participants appeared comfortable and open, and I believe that their knowledge that I had also experienced the loss of a child was helpful in establishing relationships with them and in promoting an atmosphere of trust and openness. At the end of each interview, participants were able to share what the process of the interview had been like for them if they wished, and they were asked if there was anything they felt was important that they had not discussed. The research process was then reviewed and I gave them information regarding how they could access the findings of the dissertation. Some participants expressed an interest in reviewing the findings as they were written, and I indicated that I would contact them at the appropriate time.

As I interviewed further participants, the interviews became increasingly focussed, and additional areas were explored. One area that emerged in the early transcriptions was an indirect description of the experience of the loss of a child. As I recognized this and the value of these descriptions, I asked specifically what it had been like for the parents to have their child die. Another area of discussion that emerged as the interviews progressed was how the participants were themselves changed through the experience of their child's death, as well as how their grief had changed over time. As the data accumulated and I became immersed in it, themes began to emerge. I then incorporated

discussions relevant to some of those themes in the later interviews, and in follow up conversations with participants. These discussions assisted with the incubation of the data and with the development of themes.

When I began to approach the writing of the dissertation, it became clear to me that the children's stories needed to be told. I then contacted the parents for verbal consent to specifically tell each story, and in these conversations with parents, additional data was generated. More data came from five parents who voluntarily read drafts of the findings. I had originally hoped to hold two focus groups to serve as a member check, however this was not feasible as participants were spread out geographically and it would have been difficult to find a mutually suitable time and location for such a meeting. The conversations with parents in follow up regarding the children's stories and with those who reviewed draft chapters served as an effective member check in addition to generating additional data.

Other data came from my own field notes made subsequent to each interview, my personal reflections on the interviews that helped integrate the experiences of each interview with my understanding of the phenomenon being studied, both at a personal level as well as a professional level. Illumination, explication and creative synthesis (Patton, 1990) were greatly aided by the process of reconnecting with participants and engaging in discussions of the findings.

Trustworthiness Criteria

There are several potential design problems in qualitative inquiry. Purposive sampling leaves the researcher open to a 'stacked' sample. Negotiating the sampling process with the host agency can reduce the effect of this problem. Since the design is

emergent, time is not as controllable as in laboratory research. This must be factored into the work plan. Furthermore premature closure can be said to be an issue.

Of primary concern is to ensure the 'trustworthiness' of the research. In other words "How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of?" (Lincoln & Guba, 1985, p. 290). There are four issues of primary concern in this type of research, which all fall under the general rubric of trustworthiness: truth-value, or credibility; applicability, or transferability; consistency, or dependability; and, neutrality, or confirmability. I will address each of these issues and how they were be dealt with in this particular research individually.

Credibility

Truth-value, or credibility, is the ability to establish confidence in the truth of the findings of one's research. In principal it is impossible to do this, as in order to be able to prove the findings, a precise nature of reality, or objective reality must exist in order to compare the findings to it. Thus in qualitative inquiry, the concept of subjective reality must be taken into account. The concept of the multiple construction of reality is the foundation of qualitative inquiry and therefore of the heuristic approach. It is the very multiplicity of reality that the researcher seeks to understand in this type of research. The core question that has to be asked with respect to truth value in multiply constructed realities, then, is: are the findings credible? The research must thus be conducted in a manner that demonstrates the probability that the findings are credible and additionally seek from the participants in the research, confirmation that the findings verify their constructs.

There are three methods I was able to employ to establish the credibility of this research (Lincoln & Guba, 1985): through activities that increase the probability of credibility, through peer debriefing, through referential adequacy, and by member check. Activities that increase the likelihood of trustworthiness are prolonged engagement, persistent observation, and, to the extent possible, triangulation.

A prolonged engagement allows the researcher to learn the culture, build trust and detect distortions. The process of lengthy or repeated interviews was not carried out in this study. Another way to address trustworthiness issues is through membership in the group under study. Many researchers feel that one can only overcome distortions if one is an accepted member of the group under study (Lincoln & Guba, 1985). In the heuristic approach, the researcher's personal experience of the phenomenon often gives him or her instant credibility in the participant group. It is certainly the case that many bereaved parents feel that only another bereaved parent can truly understand the enormity of the loss experienced in the death of a child. My experience as a bereaved parent has resulted in other bereaved parents responding to me with a degree of openness that is not usually achieved as quickly or completely when the therapist has not lost a child. The participants in this research related openly to me as a bereaved parent. At times I would ask them to pretend I was not in order that they would explain fully what they felt about a particular issue. Many participants referenced my loss in explaining their specific issues.

Persistent observation through immersing oneself in the group being studied provides a depth of understanding of the culture. This is consistent with the immersion aspect of the heuristic approach. Persistent observation also permits the researcher to be more open to the multiple influences of the culture and thus focus on the important aspects of

the culture. My "membership" in this group, as a bereaved parent for seven years has provided me with the opportunity over time for persistent observation. Having had personal involvement with Bereaved Families of Ontario, as a bereaved mother, a volunteer and a professional consultant over the past six years has heightened my understanding of the issues bereaved parents face.

Triangulation or using multiple sources is quite important. When several sources report the same data, one can have greater confidence in the credibility of the data. The emergent themes of this research were evident among other bereaved parents from my clinical practice. Colleagues have also noted the themes presented by the participants in clinical practice. A parent who participated in this research and is also the Director of a Bereaved Families affiliate confirmed that the themes identified in this research are reflective of the themes parents in Bereaved Families identify in group:

> *I have reviewed your chapters once more...The diversity of situations allows for a fuller perspective into the issues faced by bereaved parents. This of course is of assistance to fellow bereaved parents and it is also of enlightenment for non-bereaved parents. The personal dialogue from each of the families certainly makes it real – the emotion and the connection is instant.*

> *The format, which you use to disclose the various situations, resemble the format used in support groups. As you mention in the beginning, sharing the story is the beginning to the process of grief work. As you break down and section off the categories of information shared by all you also resemble the topics covered in the group. In other words describing the many dynamics associated with parental grief allows for an understanding of the interventions needed – I appreciate that.*

As well, the themes were thoroughly supported by the small amount of relevant literature available, which was cited in the literature review chapters of this dissertation (Guylay, 1989; Kalkofin, 1989). Winje (1998) clearly supports the "need to know" experience by

parents in this research. The most notable study that clearly supports the findings of this research was that of Neidig and Dalgas-Pelish (1991). These other sources of similar information, that is the literature and the observations of other professionals may not be the usual form of triangulation, as all actual data for the study was collected from bereaved parents, however these sources support the data collected.

In peer debriefing, or the "process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind" (Lincoln & Guba, 1985, p. 308), the researcher's biases are challenged and there are opportunities to test emerging hypotheses. I was able to review the content of the interviews with colleagues who were interested in my work, and this debriefing helped broaden my own thinking and keep me aware of my own issues that arose throughout this research. The materials discussed were non-identifying to protect the confidentiality of my participants.

To provide referential adequacy, I recorded all interviews, transcribed them myself, and reviewed them constantly as I immersed myself in the data and the emerging themes. Since member checks could not be done through the focus groups proposed for the conclusion of the data collection phase, I reconnected with each participant as previously described and discussed the emerging findings, and had five participants review the draft findings chapters. All of these techniques assisted in boosting credibility.

Transferability

In qualitative research, the researcher must address issues of applicability or transferability by setting out a working hypothesis with a description of the time and context and by using thick description; example-rich, relevant data which can provide a

basis for transferability. In this manner, the similarity of future research contexts addresses the degree to which the findings are transferable. Similarly with consistency, or dependability, demonstrating the dependability of the process of the study as well as that of the findings occurs through the availability of thick data, which can form the basis for future replication of the research. Throughout the findings chapters in this study, rich, relevant quotes have been offered to support the themes identified and the conclusions elucidated.

Dependability

Lincoln and Guba (1985) discuss the concept of dependability as a substitute for reliability. Reliability is typically established through the act of replication. If the data is replicable, it is reliable. Lincoln and Guba point out that the construct of replicability is predicated on a belief in a "naïve realism" (p.299). Naïve realism poses that the phenomenon under study is concrete and unchanging. One can then re-examine the phenomenon in exactly the same way and obtain the same results.

Qualitative inquiry is predicated on the notion that reality is not unchanging, but rather fluid. Humans are changing beings and one can never find exactly the same set of circumstances twice in order to apply the same measure. The researcher then understands that there are differences that occur as a result of the phenomenon studied changing, as well as the design changing through it's emergent nature. Both of these factors must then be accounted for in the design of the research.

Lincoln and Guba suggest that in demonstrating credibility, one demonstrates dependability as they are interconnected and cannot exist without the other. They recognize that this is not a strong argument and suggest techniques to address

dependability. One is triangulation, which is addressed in credibility and insufficient alone to ensure dependability. Another is stepwise replication, which requires two teams of researchers. This is not feasible in my study. The other technique is the inquiry audit. While I have not engaged anyone to conduct an inquiry audit in this research, I have established an audit trail.

The audit trail consists of several things. The first is the raw data, which are the actual tapes of the recorded interviews, and written comments from participants. Next is the data reduction and analysis product. In this case, I have field notes, summaries, and working notes of my intuitions and ideas about the data. My study demonstrates data reduction and synthesis products through working drafts of findings and thematic relationships. These are incorporated into the dissertation and connected to the literature as Lincoln and Guba (1985) suggest. Process notes have been kept with respect to the developing methodology, the proposal has been retained, and the drafts of the interview guidelines have been kept (please see Appendix 1).

Availability of the raw data and the process by which the analysis occurred would enable an auditor to examine the research and determine the dependability of the findings.

Confirmability

Neutrality or confirmability is the ability to be sure that the findings are determined by the participants, rather than being the subjective views of the researcher. Intersubjective agreement by the participants is an excellent indicator of neutrality (Scriven, 1971) and is extremely important for the researcher to attend to. In discussing the findings with participants and obtaining their comments on the findings I have found a high degree of

intersubjective agreement. Equally helpful in this regard is the reflexive journal, which I refer to as field notes, and which records the data about myself as researcher, the process of the research, methodological decisions made and the reasoning behind them. These features of my research add to the confirmability of the findings.

Analysis

The heuristic approach lends itself well to phenomenological analysis, which is highly personal in nature. Moustakas (1990) and Patton (1990) support the model of immersion, incubation, illumination, explication and creative synthesis found in phenomenological analysis. These stages describe a process wherein the researcher processes and analyzes the data together with his/her own experience of the phenomenon.

Data analysis in this study consisted of transcription of tapes, identification of themes, further discussions with participants, and considerable processing of my own emotional response to the content of the data as well as the processing of my own grief response. Since it was necessary for me to make decisions as to what was significant to this research and what was not in the themes, it was important to process the personal aspects of the research in order to ensure as much as possible that the personal did not direct the analysis. Being able to discuss emerging themes with participants, other bereaved parents, and several colleagues in a peer debriefing process was extremely helpful to the process. To the interview transcriptions were added my field notes. A preliminary set of coding categories was identified from the literature and reading the initial interviews provided a final set of codes and sub code categories. Bogden and Bicklen's (1982, p. 166) "folder" approach was utilized with coded materials placed in folders according to categories for analysis. Themes and patterns were identified (Schatzman & Strauss,

1983) and analyzed within the conceptual framework of trauma and grief currently espoused in bereavement assessment and treatment theories.

Initial Analysis.

The first level of analysis of the data began by pulling from the interviews the experiences of participants with each type of professional and categorizing these experiences as helpful or unhelpful. Folders were set up for each professional and each category and quotes were identified from the transcripts that supported each set of data. The data from field notes and discussions with participants subsequent to the interviews was added to these folders.

During the interviews several participants expressed interest in the developing findings. At this stage, through telephone discussion with five participants, their views regarding the emerging themes were noted and added to the data.

Within each folder, commonalties in the helpful and not helpful intervention categories were identified. A description of what was helpful and what was not, as well as the effects of these interventions was drafted. The commonalties from each professional's interventions were compared across folders, and three themes emerged: the need for information, the need for instrumental assistance, and the need for compassion. All of the data was then coded across folders according to these themes. The themes were then incorporated into the discussion of the above data.

Second Stage Analysis

After completing the analysis of the interventions above and receiving feedback from participants with respect to that, the next step was to move back from the detail of the data, and look at the data globally. In percolating or incubating the data, five themes

emerged: the reconstruction of the death scene, issues of control and the assumptive world, saying goodbye, making sense of the death, and carrying the deceased child forward in the parents' lives. Folders were created for these themes. The data was then coded according to this set of themes and placed in the folders, along with rich examples of each theme. An analysis of the data in each folder was completed.

At that time I had begun the process of re-contacting each participant. Many of those contacted expressed an interest in discussing the themes, although some did not have sufficient time, and those who did contributed their points of view with respect to my analysis. I found this very helpful in keeping the work honest in terms of the voice of the parents. At this stage five parents had expressed an interest in the findings and were willing to read the draft chapters to provide feedback. This feedback was obtained through telephone and email contact contributed to the analysis. In addition, a group of four parents participated in a focus group, which provided additional data and served as a member check.

Synthesis

Synthesis occurred as the process of analysis and feedback from participants continued. Some of the parents provided me with written feedback.

During this phase of the research I also had the opportunity to present preliminary findings of the research on several occasions. The process of preparing the presentations and the discussions generated at the presentations were also helpful in the synthesis of the data analysis. The core themes and main elements have been summarized in a chart in Chapter Seven connecting the three themes from the actual interventions of professionals that emerged in the first level of analysis, with the five global themes connected to

grieving a traumatic loss that emerged in the second level.

As the methodology emerged through the unfolding of this research, I found my own understanding of the issue to deepen significantly and shift from a perspective wherein I was looking for answers to my own questions, to a perspective where I became in a sense, the voice of the participants. This process of shifting occurred as I thought about how to organize and present the two sets of emerging themes and their inter-relationships. I felt that I could not do justice to the data without presenting the stories upon which they were based. As I worked through the drafting of the stories and spoke with the parents regarding them, parents shared with me how their lives were changing and moving forward. In the work of re-telling the children's stories and relating the data, a parallel process occurred in my own grief process. By the end of the writing I felt that I had personally transcended my own loss, and a transformation had occurred. The work was no longer mine alone: it was the shared voice of the participants. The parents who became involved in this research had a message to give to professionals, and they are hopeful that their message will be heard by those who read this study. It has been my privilege to share their stories and their messages in this work.

Ethical Considerations

Two primary issues, which arise in research that involves human participants, are free and informed consent, and privacy or confidentiality. These issues were addressed through the research design that was approved by the University's Ethics Committee, and will be expanded upon here. Please see the Consent to Participate (Appendix 11) and the Letter to Participants (Appendix 111)

Free and Informed Consent

All of the participants in this research were approached through their local Bereaved Families of Ontario affiliate. The participants were informed of the nature of the research and that their affiliate had approved the study. The participants were offered the opportunity to participate or to speak to me for further details of the study before deciding. Those who chose to speak with me or to participate were asked permission to pass on their phone numbers to me to contact.

In my first contact with participants, I reviewed the nature and purpose of the study, their rights to confidentiality and privacy, and their right to decline to participate in any part or the entire interview should they find it too distressing. Due to the emotional nature of the material being shared in interviews, I reminded the participants that participating might raise some emotional distress for them. The risks of the research were addressed in that manner as well as the benefits, the most significant one to the parents being the contribution they felt they could make to the professional understanding of the issues that arise when a child dies suddenly. I indicated clearly to each participant that the data would be used in a general manner and would not be identifying to anyone unless it was someone who knew them and knew their story. I assured the parents that should I wish to use any quotation that may be identifying in some way, I would contact them first to clarify what may be used and be sure that they felt comfortable with the material.

All of the above information was reviewed again with parents at the time of the interviews when the consents were signed. By that point many of the parents said that I could use anything that would be helpful. Because these parents had all been a part of the

Bereaved Families organization, they were used to openly telling their stories. Some of the parents were continuing to be involved in inquests or some form of litigation and their only concerns rested with the impact of statements made on those processes. I assured these parents that nothing identifying would be used without their specific consent and that they would have final say as to whether their statements were used in the data.

Privacy and Confidentiality

Most likely due to their participation in Bereaved Families, privacy and confidentiality were often less of an issue than one might have expected. The assurances with respect to privacy made above were readily accepted, and often parents indicated that they had no concerns about their stories being told. As I began the process of writing the findings, it occurred to me that the data would be much more useful if grounded in the human stories of tragedy and transcendence that the parents had shared with me. Because I had not requested permission to describe each child's story or even to use the child's first name, I re-contacted the parents to describe how I wanted to write the chapter. I indicated to them that they did not in any way have to have their child's story told, as it was not necessary to tell all of them, however every parent gave consent.

Some parents were concerned about the confidentiality issue because of certain circumstances about their child's case, and in those situations, I reviewed the exact wording of the stories with the parents. In obtaining this specific verbal consent, I also reminded parents that others might easily recognize their stories, especially those from their own affiliate, or people who had seen media coverage of the stories. Parents expressed the desire to have their child's story be part of the dissertation and felt that it was an important part of professionals' development to hear them. They were assured

that no names other than their child's first name would be used, nor would any other identifying information be used such as towns, hospitals, doctors names and so forth.

Researching Sensitive Issues

I think it is important to acknowledge that a major ethical issue in research of this nature is the respect for the rights of and sensitivity to the needs of participants. As a bereaved parent myself, and through my affiliation in Bereaved Families of Ontario, I felt that it was essential to be sensitive to the needs of participants both during and after interviews. I spent extra time with participants at the end of interviews to ensure that they were not left in a state of distress. Options for assistance were available to parents had they felt the need, however none of the participants appeared unduly distressed by the process of the interviews. That is not to say that the interviews were not painful for them, but rather that they did not feel significant negative effects from them.

In this regard I felt it was particularly important to ensure that the data analysis and the use of quotations were accurately reflecting what the participants were saying. It was important to be sure each child's name was spelled correctly and their preferred name was used to refer to them in the stories. It was also important to have details such as age correct. I was often privileged to be shown pictures and so forth of the children. The stories then were not just stories, but the sharing of the lives and deaths of very important individuals who made a contribution to the lives of many people on this earth in the short time they were here. Demonstrating respect for this was clearly important for the parents, and was of great significance to me. Having parents review the stories and review and discuss the data was an important way to demonstrate this respect.

In sensitive research, the sensitivity should not end with the binding of the dissertation. To that end, the affiliates have been given the offer to have me attend a Family Support Night and review the findings. They will each receive a bound copy prior to my attendance. Furthermore, some of the parents who have moved away have asked for a copy, which will be sent to them, and I have offered to meet with and discuss the dissertation with any parents who wish to do so but cannot attend a session at Bereaved Families.

Limitations and Challenges in the Research Study

The primary limitation of this research is in the sampling process. It was difficult to find a sample size sufficient to meet the criteria of saturation from the general population of bereaved parents. I attempted in many ways to find a sample of people from outside of Bereaved Families of Ontario to no avail. While many people who wished to participate contacted me, they did not meet the criteria, even with an expanded age group. Primarily they did not meet the criteria either because their child had died from an extended disease process, or because the child had only very recently passed away. I found a number of parents responded to ads who were still so fresh in their grief that they were often still in shock over the death. It would have been unethical to interview them and they clearly were not ready yet to be able to reflect on the interventions they received. They were more in need of someone to hear their stories, or at times perhaps, of therapy.

Through Bereaved Families of Ontario I found many willing participants. This is likely because those who continue involvement with Bereaved Families often do so to help others, and this dissertation was seen as an opportunity to do just that. The participants were used to telling their stories, and clearly saw me as part of their culture.

These features assisted in the openness of the research. The sample being entirely from Bereaved Families, however, leaves the possibility that the groups have influenced the thinking of members in a common way that may not be found among non-group members. I believe it was helpful to have interviewed from several affiliates and people who were former members as well as present members, however that does not mitigate entirely the potential effects of organizational membership.

The largest challenge I experienced in conducting this research was in the process of my own grief. It was, for myself an incredible journey of understanding my own grief process in a way that I had not previously understood it, and in knowing and understanding my loss in a deeper and richer way. My grief journey in essence mirrored the development of the methodology. I re-grieved my own loss and expanded my 'tacit knowing' in a significant way. My personal loss incubated and percolated, was analyzed, and came to synthesis along with the research material. This was an emotionally draining experience that required me to be responsible to myself in the timing of each process and ensure that immersion was not unhealthy to myself as a researcher. As a result I feel that I have not only grown professionally from this work, but personally also.

The final challenge I will mention was encountered in re-contacting the parents who participated. I was unable to locate one parent, and sadly it may be that he has passed away. He had been very ill at the time of the interview, and left the area shortly afterward. It was heartwarming to hear the updates from the parents I did contact for permission to write the stories. They have all contributed to my journey, and are continuing on their own in many meaningful ways.

Conclusion

This research has been conducted within the naturalistic paradigm. It examines in-depth the subjective experiences of bereaved parents. It utilizes my own 'tacit understanding' born of being a bereaved parent myself to connect with the participants and understand their unique experiences. The thick and rich data that has been produced has led to a deeper understanding of the experiences and needs of parents in these circumstances.

Trustworthiness criteria have been addressed in the methodology through multiple and overlapping techniques. The use of member checking has been particularly invaluable in the analysis of the data. This has been achieved through discussions with some of the participants regarding the emerging themes and by having some of the participants read and comment on the drafts of the findings.

The analysis process has been detailed, as have been the ethical considerations in this research. The difficulty of researching extremely sensitive issues was discussed as one of the ethical considerations. Additionally, limitations and challenges have been addressed. The findings of this research study are clear. The next three chapters will present the discussion of the data and analysis and it's relationship to the literature.

Chapter Five

Losing a Child: The Parents Speak

Who ran from the fields screaming
when the blue dropped from the sky
and the swallows painted the sun black?
Did you feel the vibrations
as the earth tore open it's façade
and exhaled the smell of death,
oppressive, nauseous, acrid,
cocooning the scream in an eerie fog?
Where were you when time stopped,
the earth's axis froze,
and unparalleled silence challenged all knowledge
that the sun always rises.

The Process of Sharing

The loss of a child is commonly held in the literature to be the most devastating, intense, traumatizing and difficult to process loss of all (Brabant et al., 1994; Lindemann, 1944; Klass, 1992-3; Rando, 1986, 1993, & 1998; Rosof, 1985; & Smart, 1993-94). The purpose of this research was not to examine the emotional experience of the actual loss of the child, but rather the impact of professional interventions during the crisis period. During the interviews, however, an emerging picture of the painful experience of having a child die, and burying him or her produced some rich data. About half way through the interviews it became clear to me that this data should be recorded, as the opportunity for this kind of data collection is not often available.

As participants reconstructed the death of their child, the horrendous experience of their pain began to emerge. For myself as researcher, it became a challenge to focus on the interviews and to contain my own emotional reaction to their losses as well as the

emerging feelings stemming from the death of my own child. As I became more comfortable with this process, and developed a better ability to confront their pain in the interviews, I began to ask more specific questions with respect to their feelings about the death. What in the first several interviews emerged indirectly as participants reconstructed the death scene of their child, later was elicited by direct questions regarding that experience.

As the interviews progressed, increasingly open questioning regarding the experience of the loss led to direct statements of their experiences. These discussions progressed to participants sharing with me the change in their grief over time, and ideas and thoughts regarding the emerging themes were shared and discussed. Within this context the issues, problems and challenges created by the traumatic nature of their losses emerged and the impact of the professional interventions they had experienced were described.

In the process of sitting with the data from the interviews and digesting the themes that emerged, a framework for presenting the data began to develop. At that point it occurred to me that a remarkable opportunity was open to me to share these experiences in the written dissertation. This chapter presents the parents' descriptions, direct and indirect, of their unique experience of the loss of their child. To present each participant's entire story of the loss of their child in their own words would require an entire book itself. This chapter will therefore introduce briefly the participants and their children, and then report the participants expressed experience of the loss.

The Stories: Our Angels Remembered

Within the organization of Bereaved Families of Ontario, telling about the death of one's child is generally referred to as telling one's "story". In each affiliate's monthly

newsletter there is a section for 'Our Angels Remembered', where children are remembered on the anniversary of their death. In keeping with the model Bereaved Families uses, I will begin the findings with the stories of the participants.

Marion

At the time that I interviewed Marion' s mother it had been seven years since her death. Marion was a bright but troubled 38 year old woman who had been living on her own for some time, and was closely connected to her mother. Her life ended by suicide: she jumped from an 18th story apartment window at 5 am one morning. Marion was the second oldest of four children. Marion' s mother lived alone, having been divorced for some time. After her death, Marion' s mother discovered that she had been suffering from manic-depressive illness. Looking back over Marion' s life, her mother can now see the pattern of behaviours that resulted from her illness. She spoke of the guilt she still carries for not having known what the problem was.

Marion was living independently in a city some distance from her home, and working at the time of her death. Her mother heard the news from Marion' s brother:

> *My son phoned at 7 o' clock and said " Could I come over?" I said, " What' s happening?" And he said " I' m coming over". And I knew right then what had happened – that it was Marion, and that she was dead. My world just stopped right then for a moment.*

Initially Marion's mother understood that her daughter had died from a prescription drug overdose, as a bottle of pills was found in her room. It was not until the next morning when they went to the funeral home to make arrangements that she was told that Marion had fallen from the 18th floor.

Today, Marion's mother is comforted by the knowledge that in her lifetime her

daughter helped many people. Marion sponsored a foster child, and her mother continues to sponsor this little girl in memory of Marion.

Stephen

Almost two years after his death I interviewed Stephen's mother. She was continuing to have difficulty in understanding how the accident that ended his life had happened. Stephen was 29, married, and the father of an eight-month-old baby girl at the time of his death. Stephen wanted to remove a tree from his front yard that was interfering with his weeping beds. He and a friend decided to take the tree down themselves. In the process of cutting a branch, Stephen lost his footing and fell. Somehow the branch fell onto him, crushing him:

> *And his wife, like, Stephen had a baby. She was eight months old at the time, and she had her on her back. And she was watching out a window upstairs. And she had seen Stephen fall, but she didn't see the branch...My daughter talked to the next door neighbour who was outside at the time and had seen it also. And she had also told us that she had seen Stephen slip. She thought that Stephen knew it was going to happen because she could see the expressions on his face changing – that you knew that he knew the branch was going to hit him.*

A neighbour came running, as did Stephen's wife who had been watching the branch removal from a window in the house. His wife phoned for help while the friend tried to do CPR on Stephen. Stephen was alive when the ambulance arrived. After a frantic rush to the hospital to save him, resuscitation efforts failed and Stephen died.

Stephen's mother was at home preparing a birthday dinner for her daughter when the call came from a nurse at the hospital:

> *And she just said, " Stephen's had an accident. Could you come right away?" So, uh, I just dropped everything and said " Stephen's been hurt – I've got to go". And so [his brother] drove me up because the lady asked me " Have you got somebody to drive you up?" And I said, "Yes."*

I prayed all the way up, but when I got there they took us into a room and said that Stephen was going to die.

When she arrived at the hospital, Stephen's mother was taken in to see him, however she was not able to spend any time alone with him. His wife and friend were present the whole time, standing on each side of the hospital gurney, too shocked and frightened to move aside to let his mother in:

And so when the nurse brought me in, she said. "Let Stephen's mom in." . But nobody moved. I guess everybody was really in shock and didn't know what they were really doing. But they just kept talking to him and holding his hand and I couldn't get really in – I couldn't get near him. And so I went around and so [his wife] says " Come on over this side." Because I couldn't get to him on one side cause [his friend] was there with his leg strung around and holding his hand. So I went over to the other side but that wasn't any good either because she was there hovering over him so then I just held his one hand. But I would like to have been able to talk to him in my own way.

Stephen was taken to have a CT scan, however he died before the scan could be done. Many of Stephen' s mother' s questions about how the accident happened remain unanswered.

Melanie

Three weeks before Melanie' s third birthday she and her mother and brother were out on a morning outing to the market and grocery store. On the way home, while passing an intersection, a driver coming the other way failed to stop and broadsided the car they were travelling in. Melanie's mother has no memory of the accident. The last clear memory she has is of purchasing cheese at the market with her children:

That's the last clear memory I have. So, from what I understand, after the market I went to A&P to do some grocery shopping because they found bags from the A&P in my trunk. But I don't remember that. I proceeded

to go home, um, and about five minutes away from where my home is there is this intersection – and this is highway driving – this is country roads, which a truck failed to stop at the stop sign and drove right into my car. So my car hit the side of his truck. His truck split in two pieces and landed in the front yard of the school. And my car then hit - because my car hit the side of his truck, mine was a front-end collision. With that front-end collision, it meant that the steering wheel basically came onto me, and my two children received facial and head injuries from their faces coming forward. They also received seat belt injuries. Because of the force, the back seat came right off and the dash in the front came right out...Because the seat came undone in the back, Melanie's head ploughed into the front of the front seat and apparently she had what looked like it was a broken nose, and she had severe seatbelt injuries affecting her bladder. Um, from that point we were taken, rushed to, um, actually, before that a farmer is the one that came out and called the services. So the volunteer fire department came out, the ambulances, the police. We were all rushed to the [area] hospital. At which point it was decided that we all needed special care with the exception of my son. He stayed at [the area] hospital. Melanie was transferred to [a city hospital's] trauma unit, and I was transferred to [another city hospital's] trauma unit. So we all went in different directions.

The local hospital nurse notified Melanie's father. Melanie's mother was barely clinging to life, having sustained head injuries, broken bones and severe internal injuries, including such a severely damaged liver that she was actually placed on a liver transplant list immediately. Melanie's father stayed with his wife while the grandmothers each stayed with a child. Melanie's brother was discharged the following day, somewhat traumatized but not seriously injured.

Melanie was held over night for observation following a CT scan that was apparently clear. In the morning, she woke up screaming, and shortly after, lapsed into a non-communicative state. A second CT scan was read and determined to be clear. However blood tests indicated toxins in her blood:

That, that she was deteriorating quite quickly, so CT scan number three finally revealed that she had hemorrhaging from the impact of the car accident, and the blood pooled in the brain stem. And as the blood pooled

and, and hardened, so that slowly, once that began to happen, it cut off all living possibility. [All of her organs] started to break down and not function. So within six hours she went from barely being able to communicate to no communication. They put her on life support and from what I understand the nurse said to [Melanie" s father] " You know she'll continue to live like this possibly for the next 24 hours. But her little heart is working so hard to be able to live even on life support. Then you need to make some decisions."

Within hours Melanie had gone from apparently fine, to brain dead. Melanie" s mother was in critical condition in another hospital and her father had to make the decisions regarding her treatment alone:

They were just – he was saying that something is just not right and they were doing all the tests possible – they, they noticed that there's a great deal of pressure in her head...they asked me if, um, if they could take her to the emergency operating – they wanted – they wanted to operate on her head... And apparently that didn't work either... Um, I was scared. I was really scared. I didn't – I didn't want to believe that you know – that she was going to die.

Further complicating matters was the fact that Melanie's mother's head injuries affected her cognitive abilities, to the extent that she was unable to retain information. Family members constantly had to explain to her that Melanie had died:

So my family would have to repeat over and over that she's dead because I would forget. They would tell me and I would just completely lose it until they would calm me down with medication and they would tell me again.

Another aspect of Melanie's death that was particularly difficult was that had the doctor reading the first CT scan seen the hemorrhage, she likely would have lived. At one point a lawyer who read about the accident and Melanie's death in the paper showed up at the hospital offering to file a lawsuit. This was distressing for the family. Criminal charges were laid, however the driver only received a $54.00 fine for failing to stop.

Melanie's mother still finds it difficult that she was not there with her daughter when

she died. Her father is thankful for the opportunity to have held her when she was removed from life support. Today, Melanie's mother works with bereaved parents. The couple has since had another child.

Kevin

I interviewed Kevin's mother two years after his death. She described Kevin as being very close to her. Kevin was very mechanically inclined, an interest that he and his mother shared. Kevin would help her with car repairs and she would help him. At one point they even worked together for the same company for a year and a half. In the evenings they often worked on cars together in the driveway:

> *And then there were many, many hours, months went by where he would help repair my car... All the time he had cars, until he died, we would work out on the driveway at night. I sometimes would be his gopher – gopher this, gopher that, hold the trouble light, help him bleed the brake lines. He taught me so much as he was working. And this has been a big loss for me, this companionship. And yet I always knew that this was special, that not many moms got to spend this kind of time with an adult son.*

One evening Kevin was at work while his mother was out with a friend. On the way home she was approaching the company Kevin worked for when she saw a fire truck in the parking lot. At that point she had to pull over for a passing ambulance. Thinking there was a fire, she followed the ambulance into the parking lot to see what was happening. Another friend approached her and she said to him:

> *" I saw the fire trucks and I thought there was a fire. Is Kevin all right?" And until the day I die that silence that I swore lasted forever. Then [the friend] said " Ah, no". And at that I said He' s not dead is he?" But the owner's son came up and said " No, no, no. You've got to get back, you can't come here." Then [the friend] got me in his arms and he got me into one of the bays. I never saw Kevin at all. ' m glad I didn't.*

The police offered to take Kevin's mother to the hospital, however after waiting a long time without them taking her, another employee and a friend drove her in a company van. When they let her into the room Kevin was in they were doing CPR, however they allowed her to stand at his feet:

> *I just remember seeing his foot, and I remember holding on to his foot. And I started praying " Please dear God, help these people help my son. ". That's what I kept saying.*

Kevin's mother was then taken to the quiet room. When she was allowed to return to Kevin's room, the doctor ordered that CPR be stopped and Kevin was pronounced dead. Kevin had been driving a forklift that was known by the company to be mechanically unsound. Kevin went into a turn too fast, and because of these two factors, the forklift started to tip over. Because he had no training, and did not know that he should ride the forklift down in a tip over situation, Kevin jumped. The forklift tipped over and landed on him, crushing him. Kevin died at 21 ½ years old. He left behind a brother, two sisters, and was pre-deceased by his brother Timmy.

Timmy

Timmy was stillborn almost eight years before Kevin died. At 22 weeks gestation, Timmy died in utero. His mother carried him for a week, dead inside of her before she went in to labour and delivered him:

> *The day I had Timmy was a terrible, stormy day. They could not suction me because I was so big. They said it would kill me... The moment they took his body and laid it up on the table, the sun broke through the window. It shone on his body. Three things happened. My ex-husband – he was to be named Alden Dwight after his father, and himself, and he said, " You're not burying the name." ... I named him Timothy Mark. It was a Tuesday, our church bulletin goes to print Wednesday noon. Wednesday when I got home from the hospital the minister came out to the house, 4 o'clock, and he said, " What have you named the child?" I said*

" Timothy Mark". He pulls out his paper: the service for Sunday coming up was in print already. The first lesson was from Timothy, and the second lesson was from Mark. And the other last thing, the day of the funeral was to be a terrible February storm, the 12th of February. The storm held off. We finished at the cemetary, we got into the funeral car, and as we turned to pull out, it clouded over and it started. And to me our God was not talking, he was screaming... Maybe the purpose of this little child's life, he was only known to me, was to give me the faith that I have. That I didn't have that faith before this child, to help me through the loss of this one. Was there a reason and purpose? I think things are directed in a way.

Kevin and Timmy's mother has experienced the loss of two children; one adult, and one at birth. She feels that her belief in God was greatly strengthened through those three events surrounding Timmy's delivery and funeral, and that has been helpful in dealing with Kevin's death. In a follow up interview, she described the well meaning but callous things that people said when she lost Timmy. She was told she was still young enough to have more children, at least she had the other children, and that well, he was only a baby. None of these comments were helpful. She could not replace Timmy. Each child is irreplaceable. As she told me: " *The death of an unborn child is the death of a dream.* "

Kaitlyn

Kaitlyn's mother was 8 ½ months pregnant with her when the motor vehicle accident that changed her life forever occurred. Her mother was driving to visit family one day, when a young boy drove through a stop sign and hit her car. Kaitlyn's mother was airlifted to a Toronto trauma centre because of the severity of her injuries. Lying in intensive care, and on life support, Kaitlyn's mother was told that Kaitlyn was dead in utero. Her oxygen supply had been cut off in the accident and she had sustained head injuries resulting in her death. The driver of the other vehicle was not hurt.

After two days, Kaitlyn's mother was stable enough to have the birth induced. She gave birth to Kaitlyn who was in breech position, while on life support. She says of the birth:

> *I think both my husband and I would have probably liked it a lot better if we would have felt like we had a baby, not a dead baby. There's a big difference, um, in the sense that you get a lot of different treatment and the treatment you do get is sort of a lesser grade that you would have if you had a healthy baby. We didn't, um, the pictures we wanted taken properly. We didn't get, you know, any clothes on her. They just kind of wrapped her in a towel and gave her to us. Didn't get a lot of the things that you would normally get at a hospital – either baby footprints, or, um. I did get a lock of hair, although I had to ask for it.*

Kaitlyn received her name in a naming ceremony. She had been taken to the morgue, however, when it was time for the ceremony, the nurses warmed her little body under a heat lamp so that the parents could hold their child without feeling the cold.

Kaitlyn was her parents' first child and only daughter. Although the loss would have been equally as painful had Kaitlyn been a boy, her mother says there is the added dimension of having lost their only daughter. They have subsequently had three sons, one of whom was born after I interviewed her mother. The interview took place five years after Kaitlyn's death. At that time ongoing litigation was bringing up painful memories, however in a recent conversation I had with Kaitlyn's mother she told me that the continuing surgeries she is having as a result of the accident stir up the memories each time. She has had eighteen surgeries. The young boy who is responsible for Kaitlyn's death and her mother's injuries received a $78.00 fine.

Caroline

Caroline, whom family and friends knew as " Buzzy" or " Buzz" , was living away from home in another city where she had gone to university. Her parents describe her as

being well loved by everyone – her students, her colleagues, as well as her family and friends. She died at 24 years of age in a motor vehicle accident. Her mother described the accident:

> *She had lived a beautiful life, and everything that happened, it was – it was so comforting if you – I mean if you can think a death can be comforting. And just the whole circumstances of her – of the accident were just extremely comforting. She didn't have a mark on her. She, um, she – I actually believe that, um, she was lifted from the car before it even hit, which is really strange I know. But a little boy – she lost control on this S curve, and she managed to swerve out of the way of one car. And it was very fortunate because there was a little nine-year-old boy in the back seat who didn't have a seat belt on. She missed him, but she wasn't able to get out of the way of the other car that hit her on the side. And the little boy in the – in the car that she missed, said in the police report that the lady in the gray car put her arms up in the air, and then the other car hit her. So it's very interesting isn't it? So why would she put her arms up in the air you know? It – it was to me, you know, I – I believe that she – she was lifted out – out of the car before she even – that's why I believe she was killed instantly... I remember writing on her 21st birthday on her birthday card, I said, " May life always" – and it was a prayer. I remember saying this because I wanted to put something really from my heart. And I wrote, " May life always treat you as gently as you are." And I just felt that my prayer was answered... And that was my prayer answered. A mother's prayer. Because mother's prayers go up to heaven like homogenous big moonbeams I've been told. Moonbeams, they just – mother's prayers because they're so – they're so deep. They're so much, um, power there that they – when – when a mother prays for something you know; it just goes up on a big moonbeam. So I felt that her – that was an – my prayer was answered and she was treated gently.*

Their son told Buzzy's mother and father of the accident. By the time they arrived at the hospital, emergency room staff was attempting to stabilize Buzzy. However, their efforts failed and Buzzy died before the family could see her. After her death, her parents and brother and sister were able to spend some time with her in the hospital room. There was not a mark on her. Buzzy died of head injuries.

Jamie

17-month-old Jamie was living with his parents and two sisters when one day his mother noticed his arm was bothering him:

> *I noticed when he was in his playpen that he was starting his arm – his left arm. And I thought, well maybe a bug or a bee sting or something. And I couldn't see anything obvious. And he was just on guard. Like he was holding it in a strange way. And so we went to the park and he looked – leaning really peculiarly in the tire swing which has a back, and has the sides and the bar you pull up, couldn't fall out. But I was – I was getting afraid. I was getting very concerned because he wasn't himself.*

Jamie's mother took him home, where she discovered that he had a fever. As the fever mounted and he didn't respond to Tylenol, his mother's alarm mounted. She took him to a local hospital. Jamie's older sister had been similarly ill at a year old, and was diagnosed as a carrier of niceria meningitis. Because of that, his mother questioned the doctor as to whether he had checked for this condition and was told that he had. Jamie was sent home with a fever that continued to mount. Within five days, Jamie was dead of niceria meningitis.

As his illness worsened, Jamie's mother returned to hospital with him. He was transported to a major medical facility:

> *...They said he's only got a 1% chance and um, we went out for lunch and we were gone for about two hours. We came back and noticed from that two hours that we were gone that his skull had started to swell even more and we –we kind of knew it was coming. The first day we were at [the medical centre] – the first full day we were there, the doctor, the pediatrician, specialist came in and he was surprised that Jamie was doing so well in regards to his heart. And, said that the next 24 hours would tell whether he would live or die. Well, he hung on for a few days but of course he had total life support. His, err, liver, his kidneys first failed, then his liver, then his heart. And, um – so we – we were very, very hopeful. We thought he was going to make it but it was toying with the idea we knew that his extremities were all black and they were very cold and large and stiff.*

When they arrived at the medical facility to which Jamie was transferred, one of the nurses made a comment that they (the parents) had a lot of major questions to ask the first hospital. This suggested to Jamie's mother that there might have been some negligence. A friend recommended that they keep a record of everything that happened, which they did, including photographing Jamie as he lay dying. This was a very painful process for the parents, who were struggling with facing his death, while at the same time suspecting that the treatment he received had not been appropriate.

I interviewed Jamie's mother 19 months after his death. At that point they were about to begin discoveries for the medical malpractice suit that has resulted from Jamie's death. The process was very painful for Jamie's mother, however she felt it was very important:

> *I'd like to – I would like to have all of this completed so that there is some closure - I do get my answers. And I find it important to protect other people too. Medical malpractice shouldn't be kept under the table. I mean – it does protect other people. And my story has – made other young parents aware of – ask questions in emergency department no matter how dumb you think they are – ask them. I mean had I done it, it might have protected Jamie.*

Jamie's mother found comfort and support from other bereaved mothers. Knowing that Jamie's life had meaning also comforts her. She is hopeful that by sharing her story, she will help others.

Jason and His Baby Sister.

Jason was thirteen months old when he was involved in a motor vehicle accident in the middle of the day. His young mother was driving home with him when a drunk driver broadsided them in their car. By the time Jason's father was found and brought to the hospital, his mother was in a coma, and Jason was in intensive care. Within hours, he

was in surgery for a ruptured spleen. The surgery appeared to be successful. Two days later Jason's mother died as a result of her injuries. Jason was released from hospital, but shortly afterward he became so ill that he was re-admitted to hospital. He went into surgery with only a fifty percent chance of survival. In the interview eight years later, his father told me:

> *His liver, he had got infected into his liver. There was so much internal bleeding into his spleen still that they couldn't fix it at Sick Kids. But, um, they were trying to repair his liver, and he died on the operating table. And that was a big shock, because, well, the doctors had warned me he had a 50/50 chance going into the operation. But it was just, hard. The last time I saw him he was going into the operating room, and I didn't see him come back out.*

Jason died after four hours of surgery. His father was unable to attend the criminal trial, as his employer would not allow him time off work to do so. Although Jason's father worked hard to put his life back together without his wife and child, at the time of the interview he continued to be outraged over the sentence that the drunk driver received: two years less a day.

Four years later, Jason's father remarried, and his wife prematurely gave birth to a stillborn baby girl. The couple did not discover the pregnancy until she was five months along because of medical issues the mother was experiencing. Within a month of knowing they were expecting, the baby girl was stillborn. Initially they were told that no funeral arrangements need be made. They did not see the child, nor did they name her. Three months later, they were contacted by the hospital to claim the body. They found this to add substantially to their trauma. By that time the couple felt that they had put the loss of this baby behind them. They could not understand the need for the disposition of the baby's body. Until that point they had tried not to think of her as a baby, but to

consider it a miscarriage, which carried different meaning to them than a stillbirth. The marriage did not survive the loss of this infant. Sadly, Jason's father was then diagnosed with Hodgkin's disease and shortly after the interview experienced a recurrence of the disease.

Trevor

Three-month-old Trevor's parents had left him in the care of an adult babysitter while they went out to help a friend. Shortly after leaving, they received an urgent call to return to the sitter's home. Trevor had been transported to the hospital, and was dead on arrival. Two years later I interviewed his mother about her experiences surrounding his death:

> *The police met us at the door of the babysitter's house and told us that we should go to the hospital. And they offered to give us a ride but we didn't take it. They just told us that, um, I' m sure they told us it was the baby, um. They told us we should get to the hospital right away... And then they took us into the room where the baby was and let us, you know, hold him and stuff. And, and I felt like we weren't there for very long and it didn't seem like – the – the doctor was there and I guess someone from the hospital – a chaplain or something, she was there.*

A friend who was an on-duty police officer and had heard the emergency call on his radio, and came to the hospital to assist them. He went to tell the friends whom they had been helping to move what had happened, and offered other assistance. Trevor's parents left the hospital in shock to break the news to the family.

At the time of the interview, Trevor's older brother as well as a brother born after his death was present. Trevor's mother shared with me a keepsake box she has made to hold some of his things:

> *I have a whole box of his stuff that he had. I've made a box, a special box for all his stuff. The sleeper that I took off of him that morning, his shoes, his blanket.*

Trevor's mother had many issues with the funeral home, which will be addressed later in Chapter Six. These issues continued to cause distress at the time of the interview, and she shared with me the letter she sent to the funeral home outlining her concerns. In addition, there was an interview with the police; however, unlike some of the parents in this research, Trevor's mother did not find this experience unpleasant. Criminal charges were laid against the babysitter for having too many children in her care. Trevor's parents had not been aware of the number of children present that day at the home of the babysitter. They were aware that there were two adults providing childcare and thus assumed he would be safe. Trevor's death was not caused by any negligence on the part of his caregivers. He died of Sudden Infant Death Syndrome.

Trevor's mother spoke of the continuing impact of his death, particularly with respect to church:

> *We had the service in the church, and it was a good thing. Although it makes me not like to go to church anymore because he - I can still – I can still envision the little white casket there in front of the church every time I'm there. It really bothers me. So for that reason I wish we hadn't had it at the church you know.*

Trevor's parents held a funeral for him with an open casket. They had visitation despite the funeral director's discouragement of that. Trevor's mother felt it was beneficial:

> *You know, for those 175 people who actually showed up at the funeral, we would have had to all meet those people at some other point, you know. And then you know, in the course of time in the next year, you know, year that you run into these 200 people. You're going over it every time, and every time, whereas this way, you know, you get it all – you can get the brunt of it over with. You know, they've already seen you so they can now say " How are you doing?" as opposed to " Oh I'm really sorry to hear about your son."*

Trevor's mother and father struggled with the issue of whether or not to bring his 22-month-old brother to the funeral home to say goodbye. Unable to reach anyone who could give them some direction, they decided to bring him:

> *So we took him in the funeral home, and we took all our coats off, and we walked up there. And I picked him up and he looked at his brother and – oh – his face just lit up like he was happy. And he reached out his arms like " Oh, there's my baby brother!" Like he – he missed him for the three days, you know what I mean, and he was just – just the look on his face was just made it. You know it was very important that we did that you know – that- and we said, " No, no you can't pick him up, and just came to say goodbye." And um, and that he was going to heaven or whatever, and give him a Dinky car and that was it.*

Trevor's mother, as have many other parents, found comfort in helping other bereaved parents. Trevor's life was short, however his memory lives on.

Frank

Seven-year-old Frank's father came to Canada about a month before his family arrived. Approximately one month after the family arrived to join him, they were preparing to move out of their motel and into an apartment. Frank's father had just worked a night shift and was returning home. His mother had decided to visit a sister-in-law with the four children so that his father could sleep. Frank, his mother, sister and two brothers crossed at the lights and waited on an island for the next light to change. It was a rainy Monday morning, and although the rain had stopped, the road was wet. Frank's mother described the accident in an interview five years later:

> *We walked across and were standing on the island when I saw the truck brake very hard and I knew. He was coming for us, was the back part of the truck. And it was a tractor-trailer without the trailer part. And that reversed over us. Witnesses say I pushed two of my kids out of the way, otherwise they would have been more injured than they were, which I don't remember. Um, Frank was killed. He was actually pulled under the wheel of the cab, and his head smashed open, and the, the cab stopped on*

his leg, and I saw that.

Frank's father was on a bus on his way back from work. Because of the accident the bus was re-routed. By the time he got to the motel, the other children had been taken to two different hospitals. A Victims' Services worker assisted the parents in transporting them between hospitals and provided calm assistance in the chaos. One of the children had a sprained knee, another had injured his mouth and lost teeth, and the third had so severely injured both legs that a double amputation was possible. Thankfully, the boy's legs were saved, and the three children recovered from their injuries. Sadly, Frank had been killed instantly.

Frank's parents also had the media to contend with, right from the beginning. Immediately after the accident, while everyone was still at the scene the media arrived and began taking pictures. Frank's mother described her reaction:

> *I was furious. I was furious that they could take photographs of somebody's pain like that. And I found it very intrusive. They were on the other end of the road where I was sitting and waiting for [her husband], and um, I asked them to – first of all I said, " What are you doing?" And then they said they were just taking photographs. And I said " Why don't you* ***zoom in*** *and take it* ***properly*** *so everybody can see the gory details of it?" And then they said no they couldn't do that because that's news. And so I said, " Please just go." I was furious.*

Frank's parents felt that although the media brought many well-wishers to their aid, the media were excessively intrusive, and intensified their pain. The media tried to get on to the hospital ward and actually got into their motel room where they took a photograph of the family, which they put in the paper. The family had to get into their motel through the back way to avoid the press. In an effort to get the press to leave them

alone, the parents finally agreed to a news conference. They found that to be a difficult experience as the reporters asked many personal questions unrelated to Frank' s death.

At the time of the interview, five years after Frank's death, his parents were still facing the civil case, having completed the criminal trial in the interim. Frank's parents spoke gratefully of how the South African community came together to provide them with instrumental supports, arranging their apartment and setting up the furniture. The outpouring of community support that came after Frank's death helped this family carry on, as did their strong faith. Today Frank's mother is looking for ways to help other bereaved parents.

Luke

I interviewed Luke's parents almost a year after his death in their new home. Luke was the youngest of three children, having two older sisters. His parents had difficulty conceiving him, and his father described how hard they had tried to have Luke. They had been to fertility clinics. Luke's father had given up his full time job in order to stay home and care for him after he was born. Luke was only 21 months old when he died.

The night before Luke died, his sisters had not been feeling well, and Luke's father, concerned that Luke might come down with what they had, gave him a bit of Tylenol before putting him to bed. One of the girls was not well and the parents took shifts staying up with her. Eventually everyone settled into bed for the night. In the interview, Luke's mother described getting up, following her usual routine, and going in to Luke's room to wake him up. When she saw him, she knew that he was dead. He was cold. She remembered picking him up and running around screaming. Luke's father heard the

screams and ran in to the room to find his wife clutching Luke and running around screaming. He frantically dialed 911 and shortly thereafter the police arrived:

> *And they basically had to wrestle Luke away (from his mother). They took him downstairs on the couch. They were, I was behind the couch. The couch was kind of in the middle of the room. They were trying to give him CPR on the couch. And I' m thinking "You moron, do it on the floor". And finally they grabbed him and put him on the floor, because when they pressed on the couch the couch gave. You know, so then they put him on the floor when they realized. But I knew he wasn't – they tried. I mean they tried to.*

Luke was taken by ambulance to hospital where he was pronounced dead. While the doctors performed an autopsy to determine the cause of death, the police sealed off the house and began collecting "evidence". While the coroner was expressing concern for the possibility of viral meningitis, the police began an investigation. Luke's mother spoke of feeling accused:

> *...They (police) took everything. They came in when we weren't there. They* took *all his things. They took his bottles. What else would you think? They were not, they were not, I have the transcripts and when you look at the transcripts they said " you are not under suspicion" . There has got to be a better way. Because in the state that I was in what else would you think? Who sits you in a room for two hours and practically makes you feel like – (whispering) you killed your son.*

The girls were given precautionary treatment at the hospital and released. The entire experience was terrifying for them. Luke's parents were able to access help for their daughters, and later for themselves. At the time of the interview, they were working on putting their lives back together.

Kayla-Marie

Little Kayla-Marie was only 23 months old when she died. I interviewed her mother almost a year later:

I got the phone call from, at work. Actually it was my fiancé who phoned me and said Kayla, our daughter who was going to be – this was October and she was going to be two in November. She was 23 months. So he phoned me at work and said that she had choked on something, and that it wasn't good, and that she was at the hospital, and he didn't know anything. It was a message on my voice mail. I was at lunch at the time. So when I came back I checked the message, had phoned him on his cellular, and he told me just to go to the hospital. So I phoned the hospital, and they told me – they put me through to the crisis unit, so I knew it wasn't good. And they just told me to come and that they were trying to revive her. So when I went, so what happened was, she was at my mother-in-law's. She watched her during the day when I was at work. And she was sleeping in her playpen in his mother's room, and she had gotten out, and his mom was downstairs doing the laundry. She had gotten out and got hold of chocolate covered almonds that were on top of the t.v. I don't know what happened. I guess she put them in her mouth. I don't know whether she came down the stairs, or what happened. But when (Kayla's father's) mom had seen her, she was lying there. Didn't think anything of it, but saw on her face that she had chocolate, and noticed she had chocolate in her mouth, and tried to take it out. And she wasn't breathing a couple of minutes after that. And (Kayla's father) wasn't there when the situation was going on. All's I knew was that she choked on the chocolate covered almond and died. And I don't think there was much time in between that, and her lungs collapsed. And that's basically how she passed away.

At the time of Kayla's death, her father, who was a truck driver, was quite far away and had a six-hour drive to get back. Kayla's mother arrived at the hospital where she met some family members. Hospital staff encouraged her to see Kayla, however she wanted to wait until Kayla's father returned. This became a significant issue, and ultimately she felt forced to see Kayla before he arrived in case she would not be able to at all before the autopsy. Because of the police investigation, Kayla's mother and brother, and later her father could only see her in the presence of a police officer. As it turned out, the hospital agreed to allow Kayla to remain in the room until her father was able to arrive and see her. The police had also sealed off the house where she had died, and the family was not able to return to it for several hours.

When I interviewed Kayla's mother she had just begun the process of putting away Kayla's clothing about a month prior. She had not been able to give any of it away. She was also expecting her third child, and when I subsequently contacted her during the writing of this paper, she had given birth to a healthy little girl.

Christina

Fourteen-year-old Christina was living with her mother, stepfather and brother when she died. Six years after her death I interviewed her mother. Christina's mother described her daughter:

> *I look back at her life for the fourteen years that she lived, how much she jam packed in that fourteen years. I didn't do anywhere half of what she did in fourteen years as I have as an adult. Smile! Oh, everybody talked about her smile. One of her nicknames was Smiley. She smiled so good...And she, she loved animals. She was very handy with her hands. Volunteer, she loved to volunteer, help others, you know. Don't expect anything back – help others. She was very much like that.*

The night before Christina died, she argued with her mother; a typical adolescent-parent disagreement. The day of her death, when she did not return home from school on time, Christina's mother's first thought was that she had phoned her father to go and stay with him. The family waited for her to arrive home. Christina's mother had been feeling uneasy even before returning home from work. She began calling everyone she could think of, however no one knew where Christina was. Finally the police arrived at their door:

> *And so just before 6 o'clock, a couple of minutes to 6, my son was outside waiting for us to come outside and go for a walk. And he comes running in the house and he said there was policemen in our driveway. And I knew. The minute my son told me there was a policeman in our driveway, I knew she had died... And the two officers took my husband and seated him down in the kitchen. They had asked me to sit, and I said no – I was standing in the kitchen and I said no. And they each stood on each side,*

like one stood holding my husband's shoulder and the other one was standing in the kitchen doorway, my son right beside him, right at his legs, and then they proceeded to tell my husband – asked again "Are you the father of Christina?" And my husband's going "Yes" and I says "No, I'm the mother, I'm the mother of Christina". Because my husband wasn't the father. And they totally ignored me. Then they proceeded to tell my husband that there were a bunch of kids trying to cross the (highway), a group of 5 teenagers trying to cross the (highway), and that there was a fatality, and that Christina was the fatality. My husband didn't know what fatality meant. My son knew what it meant. He went running down the hall to his bedroom, just screaming. And in the meantime, I'm just standing in the kitchen and um, I hear one police officer say "you stay with them. I'll chase the kid". And he went running down the hall after my son, and the police officer's comforting my husband.

The police asked Christina's mother to arrange to visit the hospital that she had been taken to in order to identify her body. The family's priest drove her mother and stepfather to the hospital where they were taken to see her body and make the legal identification. Because the police tried to talk her out of going in to see her daughter's body, Christina's mother drew an incorrect conclusion as to how she had died:

...All of a sudden it dawned on me – oh my God, a transport truck hit her. And then I started to go wrangy. I says "Why didn't someone tell me that a transport truck hit her?" My priest took off out of there saying, " I will find out". He comes back with a nurse that had not come in. She sat me down and she explained to me exactly. She said, "It was not a transport truck that hit her. It was a car."

Christina sustained a massive skull fracture in the accident. Following the autopsy her family was told that the fracture was the cause of death, and that she died instantly. Christina's mother has worked hard in processing her grief. Her continuing volunteer work with bereaved parents helps her to honour Christina's memory.

Jay

Jay was a happy 23-year-old young man, working full time when he died. He had planned to go home to his mother's house after his shift and was carrying a knapsack

packed with belongings, as well as some liquor he planned to take to a party back home that evening. Driving on his motorcycle in the parking lot of his place of employment, Jay was involved in a collision. When his knapsack flew from the motorcycle, the bottles broke. Jay died from his injuries in full view of many of his colleagues. Initially the police were concerned that Jay had been drinking, because of the smell of alcohol, however the autopsy showed that he was not. Jay's mother recalls going to the police station for information about the accident, and how difficult that was. She recalls even her hearing being affected: it was as if sound was echoing, and it had an unreal effect to it. She described feeling numb and how difficult it was to believe it was really happening to her.

I asked Jay's mother where she found her strength to go on:

> *I' m a very determined person. If I make up my mind about something – I always have been. Maybe you call it stubborn. I think that in the beginning I really didn't care about things. But then I realized that I get some of my strength from Jay. I mean there isn't anything he didn't do. He lived so much in that 23 years. So I draw some strength from him.*

As are so many others, Jay's mother is very active in her organization helping other bereaved parents. In a way, this helps her to carry Jay on in the world. It is also a place that she can share her feelings openly:

> *I find a connection with other bereaved mothers that I can't get with anyone else. I think I feel comfortable with them because I can say what's on my mind without somebody looking at me and thinking "Oh, can't she get off that". So I've made, I have more friends now that are bereaved moms. I've been very selective about friends that I've kept from the past. I only keep people around me that I feel comfortable with. So I've lost a few friends along the way. But I'm very comfortable with my fellow moms, colleagues, whatever. I'm very comfortable with them because I can be whatever I feel at the time. And I don't have to feel, are they looking at me and thinking, "Will she ever get on", or "Does she, does she have to talk about it". So I think you take a new direction too. You*

know, you seek out people you are comfortable with. And I think since I've been through so much, I'm a little more selfish now than I used to be. I used to think I had to do everything and now I – I think, really think about things I do, and who I want to be friendly with. I'm careful not to upset myself... I find a lot of help in trying to help other moms. Like doing group and stuff. At first it brings old stuff back up again. But after you get further along with the group, it's nice knowing that they know they have somebody to talk to. And they always say, "Oh, did you feel that?" They're not really going crazy.

Jay left behind an older brother, who is now a parent himself. Jay's mother enjoys being a grandmother; however there continue to be times, five years after his death that she thinks about him and the heartache returns.

Tammy

Tammy, the youngest of three children was 25 years old when she died. Tammy was a diabetic, and had been having difficulties with the diabetes and with managing it. She was living with her boyfriend at the time of her death. One evening, after an argument, Tammy left the house and did not return. Her boyfriend called her parents to tell them that she had left on foot to go and call her parents. When they did not hear from her, they called the police. An extensive search was mounted for her, which then extended to incorporate civilian volunteers. The search lasted two days, and finally her body was found in a wooded area. According to the autopsy report, Tammy had given herself insulin. In the interview four years later, Tammy's mother said:

What we don't know was what was her state of mind. We know from (her boyfriend) that she was angry and upset. She knew how to manage her diabetes...so it probably was a suicide, and I came to terms with that. But I think the difference is, it wasn't a premeditated thing. I think her state of mind was somewhat befuddled. I feel sure of that.

Tammy's mother felt that the police were very responsive and put a large team of searchers together. The police and park rangers tried to keep their hopes up throughout

the search. The media picked up the story quickly, and that helped to make people aware and brought out many volunteers to help search. At the same time, having the media all around was quite intrusive, and often distressing. As with Frank's parents, Tammy's mother felt that the media was a double-edged sword. On the one hand, it brought out people to help find Tammy. On the other hand:

> *I think that was the worst, the press. It was a violation of my privacy. I didn't want it in the press anyway. I didn't want the whole world to know that Tammy was missing. I felt they weren't coming from an angle where if they put it in the press they might help find her. It was more "Let's get the guts of the story". That's how I interpreted it. It was like some scandal or something not quite right here. I never got the sense that they were thinking that in any way they would help, ever. It was highly publicized. But they were definitely shoving the microphone and trying to get whatever they could. So that didn't feel good at all. There's two things here. You're too distraught to answer these questions on the one hand, and on the other hand I just wanted her to come back and it would all be over.*

Tammy's mother has come to terms with her daughter's death, and now volunteers helping other bereaved parents, as do many of the parents that I interviewed. As did many of the parents in this research, Tammy's mother shared with me a little about her daughter:

> *I'm sure that most mothers of dead children say this, but I do say it sincerely: she was a very loving person. She gave of herself far more than she got. She just gave and she actually worked with severely handicapped teenagers. And she took me there one day, and I was just blown away by how she handled that. They were very severely handicapped. And she just was so gentle with them, and talked to them like she'd talk to you. And I was very touched by that. So she was a very loving, lovely young woman. But she had this disease, which was destroying her.*

Ian

Ian was 19-years-old when he died. One night, after work he went out to socialize with some of his friends. One of his friends was driving. The roads were wet and

slippery, and the driver was speeding. He lost control of the car, hydroplaned, and hit a hydro pole. Two of the friends died at the scene, and Ian was rushed to hospital where he later died of his injuries.

Ian's mother awoke early the next morning and felt uneasy. Her husband and youngest son were asleep. Her older son was living away from home on his own. When she went downstairs, she saw that Ian's coat was not there and he had not returned home that night. At 6:30 am, two police officers arrived at her front door:

> *They asked if I was – and I confirmed that. And they asked if I had a son called Ian, and I confirmed that. And then they said that there had been a horrific accident. I thought it was a little strange at the time that they didn't ask to come in. They were standing on my front porch, and I was standing holding the front door open in my nightgown, and we were talking at the door. And when they said that there had been a terrible accident, I invited them inside. I'm not sure whether they had to wait to be invited, but it seemed odd to me that they didn't ask if they could step inside before they told me that. I think if you're going to tell somebody something horrible, maybe coming inside and sitting them down somewhere would be a good idea. At about that point my husband started to come down the stairs. And I just, because of the feelings I had during the night of something being wrong and two officers at my doorstep at 6:30 in the morning, I just knew that it had to be the worst possible thing. And so I said to them Is he dead?" And they said, "Yes, he is". At that point (her husband) almost collapsed and sort of let out this wail, it's sort of the only thing I can describe it as. It was a sound that I've never heard before, and certainly wouldn't want to hear again. It was this anguished wail came out of him, and he – his knees just buckled and he almost went to the floor. And the officers each grabbed one side of him and half carried, half walked him into the living room and sat him on the couch. And at that point my main concern was I was worried about him.*

The officers talked to her about going to the hospital, which was in another city, to identify Ian. At that point her son awoke and was told the news, and then the police went to tell her other son. The officers left them to be driven to the hospital by their 22-year-

old son, however, Ian's parents contacted friends who came and got them and took them to the hospital.

Ian's mother described identifying his body as being traumatic. At the hospital they were taken to the quiet room where another police officer explained the identification process to them. After they saw Ian, their friends drove them home. Ian's mother said the friends described them as " two walking zombies with gray, pale faces".

I interviewed Ian's mother two years after his death. One of the things she spoke of was regarding the police taking Ian's license. As with many parents she had wanted to keep all of Ian's possessions, but was told the police had to take the license to inform the Ministry of Transportation:

> *...And it's an affront to me that they wanted to take it, but what's even worse, Linda, was that this year we got a letter from the Ministry of Transportation that was addressed to Ian. And it was telling him that he had to do his exit test, for graduated licensing. So I had to then phone the Ministry and tell them that he was deceased. And I told the person that I talked to that his driver's license was kept, and I was told it was kept so the Ministry would be informed.*

One can only imagine the pain of having mail sent to your deceased child two years later. Ian's mother, as do all of the parents, continues to work through her grief, and is also active in helping other bereaved parents.

The following is a summary of the demographic information regarding the children:

The Angels Remembered

Name of Child	Age at Death	Gender	Mode of Death
Marion	38 years	female	suicide
Stephen	29 years	male	fall
Melanie	35 months	female	MVA

Kevin	21 years	male	industrial accident
Timmy	0	male	stillbirth
Kaitlyn	0	female	stillbirth
Buzzy	24 years	female	MVA
Jamie	17 months	male	meningitis
Jason	13 months	male	MVA
Jason's sister	0	female	stillbirth
Trevor	3 months	male	SIDS
Frank	7 years	male	MVA/pedestrian
Luke	21 months	male	meningitis
Kayla	23 months	female	choking
Christina	14 years	female	MVA/pedestrian
Jay	23 years	male	MVA/motorcycle
Tammy	25 years	female	suicide
Ian	19 years	male	MVA

A Comment on the Stories

For this dissertation I interviewed five fathers and fifteen mothers. Collectively they had lost eighteen children in sudden deaths. The deceased children left behind them twenty-six surviving siblings. I have outlined the facts of their deaths as their parents have shared those facts with me. It is virtually impossible to describe the amount of pain and anguish shared by these families. The balance of this chapter is devoted to the parents' own description of their experience of the loss of their child.

The Worst Loss

The subjective experience of a traumatic event and the sense of powerlessness and perceived threat are central to a trauma (van der Kolk & McFarlane, 1996; Caruth, 1995). In the parents' own words, the loss of their child was the worst loss they had ever

experienced. Many parents felt that those who had not lost a child could not fully understand what it is like. One father said:

> *...People can sit there and can't imagine what it's like to lose a child. They have no idea. You wouldn't wish it on anyone.*

Another father cried as he expressed the pain of the loss of his child in relation to the loss of his parents:

> *...You know, I can't think of anything more devastating in my life. I mean, I've lost my father. I lost my mother. And it's nothing like that...not even close.*

Another mother described losing her child and then her mother:

> *I think for me there's nothing that could be any worse for a parent than to lose a child. It robs you of your future. A child that you've raised and nurtured, and you have great expectations for them. For the families their going to have. That's all taken away from you and I think it leaves you with a void that I don't think ever goes away. ... I can't imagine anything more... I just can't. Because I lost my mother a year afterwards and I couldn't even cry. I just, I was so full of grief still that I – it was just such a different feeling.*

One of the mothers spoke of her fear of losing another child. This fear is not uncommon in the initial stages of bereavement and is reflective of the experience of loss of control and powerlessness described in the trauma literature.

> *I think it's the worst thing that's ever happened to me. In fact I'm sure it's the worst thing that's ever happened to me. I think in my case the tragedy, the drama and the suddenness of it all. Like, the day before she disappeared we were all at the zoo together, and then she was gone forever. It's indescribable to lose a child isn't it? And for a while I was fearful I was going to lose my other ones. If it happened to one, why couldn't it happen to them? And I just couldn't live if that happened again. And I don't think anyone has a clue at all unless it's happened to them – I really don't.*

Another mother described her physical and emotional pain at the loss of her child:

I laboured 8 ½ hours to deliver a dead child. It was a terrible day.... At that point I cried and cried and cried. " Why dear God? Why my child? You know I wanted this child. I had surgery to have this child."

Other parents agreed it was the worst loss possible and that others could not truly understand the pain unless they had experienced it themselves. They also described the pain in terms of a broken heart:

It's the worst possible thing that could happen to you. It's worse than anything you could ever imagine. I know before Ian died, I kind of thought I would understand that sort of thing. I have a friend whose child died at 9 days old and I thought I understood how she felt and I thought I was compassionate. But until you experience it yourself, I don't think anyone can imagine what it feels like. It feels as though a part of yourself is gone. I felt for months like I had this hole in my chest. And it, it's interesting because you hear about people who have a broken heart, and they talk about heartache. And I had that. I had this pain in my chest that would not go away. And it was like somebody had driven a stake right through me. And it was like this open wound in the middle of my chest. Like someone had opened up my chest and ripped my heart right out. That's what it felt like.

And from another parent:

Part of me died. That night part of me died. And that part will never come back. I remember going to my doctor...I said, "My heart is broken. I have broken four bones in my body in my lifetime." I says " You know you put Plaster of Paris on them, six weeks, take it off, and it's mended. Can you do that with my heart? I want my heart mended".

Many other bereaved parents I have met in clinical practice share these descriptions of loss. Many parents say that a part of themselves died with their child. Many speak of a broken heart. And all agree that it is the worst kind of loss they have ever experienced.

The Death of the Child

For several of the parents who participated in this research there was a brief period of time in which the possibility that their child might die was made known to them. Others were simply informed of the death with no prior notice. For those who waited in quiet

rooms in hospitals, sat by the bedside of a dying child, or made that frantic drive to hospital not knowing what they would find, minutes became hours and hours, days. Jason's father described the agony of waiting for information about his son during surgery after an automobile accident:

> *All three of us were sitting there. The operation was only supposed to go for 2 ½ hours and we never saw anybody for 4. I guess 4 hours and 15 minutes or so. And we were getting worried and asking the nurses. And it seemed like they were doing the run around and not answering any questions. I guess because they are not allowed to say anything until it's official, I guess. I don't know...I just wish somebody would do it right away instead of waiting longer. They should be able to find out, and somebody should come out and tell you what's going on at least. If there's complications or something. Like...not leave you sitting there hanging and not knowing what is going on. And that was probably the worst feeling of the whole time.*

Tammy's mother described the experience of waiting through the search and attending at the search site:

> *It was horrible. I arrived and the helicopter was flying over. And these people. It was just an absolute nightmare.... They were asking all of these questions, you know, all these questions: who could she be with, who does she see, where are her friends, all these questions all the time and you know your mind, it just wanders. You think, " I don't really care. I just want – where is she, just get on with it" ...It was just like we were living in a movie. You know all these people coming and I don't think you – well you know yourself, you're just on a different planet, aren't you?*

Caroline's father spoke of being called to the hospital and feeling the presence of his deceased mother and grandmother with him on the trip:

> *(His son) say, "Buzz's been in an accident", right, and you go to the hospital right away. Well you jump in your car and you're driving over to the hospital. And my grandmother, who we named my daughter after sort of was with me. My mother was with me...But my grandmother seemed to be a very special person. And she was right there with me. My mother was there with me on my trip to the hospital, right. So you're almost sitting there and saying, you're almost preparing yourself even before you get there.*

Melanie's father described receiving the call from a nurse saying that Melanie, her mother and brother had been in an accident. He rushed to the hospital, uncertain of the condition of his family:

> *They had phoned and they had told me there had been an accident and that I should come down right away but I shouldn't drive myself. So immediately I thought, "Ok, this is major." So I basically ignored what they said and I just drove myself and I wondered if I'd know what the heck was going on. And it was, she... well she told me on the phone that there was a motor vehicle accident, so that what I did – I took off. Well, everything just...my...my heart just dropped. Everything, - you know wondering what the heck's going on? Right? A lot of anguish, anxiety and a lot of that 'til I obviously, I, I thought of the worst. And I – then I didn't want to...it can't be the worst, you know. You're clinging with your own mind...and I'm saying to myself " this can't., this can't be right".*

For those who had some small amount of time to prepare as their child lay dying, the fact of their dying seemed inconceivable. The process of denial and the struggle to face the death of their children was evident in many of their stories:

> *I honestly didn't think he was going to die. I knew he would lose his limbs. I knew he would be...they would be amputated and you know also many strange hurtful feelings going through that. Like knowing I don't care – I'll take him without his limbs as long as he's able to look me in the eye and exchange " I love you", or plant a kiss on my cheek. That was... I would have taken him. And we couldn't stay...I, myself and my husband couldn't stay in the room that long. Because you could say " I love you Jamie. Get well. (his sisters) need you. We need you." And all these things that you're saying over and over again. And all the tears are left on his face...umm, just have to leave the room, go get a breath of fresh air, have a cigarette, have a coffee. And then you feel so uneasy you go back you know. Back and forth, back and forth.*

And from Kevin's mother:

> *I remember being upset and going up to the girl. She's checking someone in – that did not matter – I interrupted "Where is my son? Where is my son?" And then they come and get, and say "We're going to the quiet room". And I go "No, no, no, no!" I know what that quiet room – I*

trained at St. Mary's. That's where they tell you your friend is dead.... Reality was just not sinking in – no Kevin. Just a few hours before (he) thanked me for a meal, said goodbye, thanked me for the phone call...no this can't be. I looked up and I said, "This is a pretty sick joke".

Many parents shared their memories of the physical and emotional shock they experienced when their child died. Some of these descriptions demonstrated the storing of traumatic memories in feeling states, which are difficult to attach a narrative to (van der Kolk & Fisler, 1995; Herman, 1992). Luke's mother described finding him dead in his crib, picking him up, clutching him to her chest and running around screaming. Her husband, in the next room heard her:

...And she walked out the door, and then I heard the scream. And you, it was like I could see right through that wall like it wasn't even there. And I knew what was wrong. I don't know why I knew – it just – the way she screamed. And then I ran in there, and he was, he was cold. And I ran out and dialed 911. And it was one of those stupid, crappy phones – one of those pulse phones – you have to kind of wait. And I kept dialing up real fast and wasn't getting – finally I dialed a little slower and got through. I can't really remember what they asked me on the phone or whatever. I think I was told to stay on the phone or something. And I remember...Gees, it's supposed to get better isn't it? I think it seems – and uh, I remember Teresa carrying him, and she reminded me like of a person in a burning building and just didn't know where to go. She was just running everywhere screaming. I remember feeling shocked, and that, that feeling that you just, somebody hit you with a sledgehammer, kind of feeling. Like, I just, my whole life just came crashing down on me.... And everything was really – my vision was really – because all I could see was like shadow. I remember seeing just shadows. Just like I said they were silhouettes, and with this policeman and Luke, standing beside her and...I had the strangest...sight

Some parents described feelings of panic and hysteria:

It was like – why couldn't I just – they don't have a clue. They just wanted me to calm down, and I didn't want to calm down

Many parents described the experience of the shattering of their worlds (Janoff-Bulman, 1985; Parkes, 1971), as did Christina's mother:

And my first instinct was to run outside and yell "Why God, why!" You know, my first thought was "Why couldn't God have saved her?" You know that was my first thought. I wanted to run outside. That was my first thought – to run outside and scream " Why God, why!"....And um the feeling...I was frozen. I literally couldn't move. I could hear my son screaming down the –running down the hall screaming. I could not move to chase him. I couldn't. I was literally frozen there...I couldn't believe I couldn't chase him. I thought was why couldn't I get and run after him? Why couldn't I chase my own son? And my reaction was to run outside and yell at God – " Why did you allow this to happen?". And that goes against every grain in my body, you know. That's not what my faith teaches me. And I guess that was more of a shock too, you know. Why am I yelling at God?

Frank's mother described alternating between panic and despair:

I remember...asking one of the witnesses whether they could just check if my son was really dead. I didn't want to live with the fear that he wasn't and I'd left him. I remember asking one guy if he could just check if Frank was dead. And he came to me and said that he's sorry that he is. And I asked him for a hug. That I can remember. But then they just tried to calm me down more than anything else, because I was just, between the pain of knowing that your child is dead and then trying to comfort, I was sort of swinging between hysteria and calmness. It was, it was that hard...Because I would say I was on the verge of panic the whole day, um, or I would just go into this deep despair. And then I would come out of it because I knew I would have to carry on. Actually, I was going up and down all day.

Frank's father also experienced the shattering of his world:

I couldn't understand all this commotion. I mean I'm standing on the bus. The bus took another route, you know what I mean. I – it just didn't make sense to me...There was a lot of congestion and it took forever (for the bus) and eventually I decided I was going to get off the bus in case, and that was like, I had to walk back. And I came to an intersection and I noticed this truck parked on the island there and a blanket at the back. So I knew somebody had been killed. But I thought " ok, just not get involved, and do my thing". And um, I walked back to the motel, and as I got close I saw her opening the door, and I just knew. The kids weren't around, and I just knew something had happened. And then it hit me, right, like it hit me. Just, my whole world came apart.

Caroline's mother talked about her experience of a presence and help from outside of herself, as well as having had a sense that her daughter's life was completed according to some plan:

> *My son was the first one to get the call from the police... and when he came to work he went up to the hospital to see her and then he came to work to see me, get me. And I think I knew from the minute he told me that – that she was – she, you know he told me she was very badly hurt. And I said, I think I knew right then that she was- she was gone. I felt her with me, and I just felt I was just sort of picked up and carried, you know, from that point on. Just, you know, there was a great amount of – of love and – and protection around me. ... I think I always knew at some level that I would lose Buzzy. And when it happened it was like, this is as it should be. It was like it had come full circle, her life, and it was complete. And, I just felt that as, as terrible as it all was – I felt that this was ok. You know, she was ok. She was with God and she was – I'd never have to worry about her again, and that she would be looked after forever and that she was happy and that she didn't want to come home – back here. And she, you know, only sadness that she had was her sadness for us. And I just felt that when she was born, they brought her in to me and she cried. She cried like no other baby had ever cried. She sobbed like her heart was broken. And I thought this is the strangest cry for a newborn. They scream, they don't sob. And she broke my heart. She just broke my heart. I thought, you know, this sad sobbing. And when she died I felt – I heard the same sobbing, it was me. And I just felt that everything had come –she died –she was born at 8:35 at St. Mary'sHospital and she died at 8:35 and even though she didn't die at St. Mary" s Hospital, that's where her place of death is marked. But it was exactly the same time in the morning. Her watch had stopped. I nearly died when I looked at the watch, because it was 8:35 and that was when she was born. But I just felt everything was as it should be. As sad as it is.*

The need for parents to be present at the moment of death or to have some understanding of that moment was evident in the interviews. The mystical bond between parent and child was ever present in the interviews. For Melanie's father, the opportunity to be present and hold his child at the moment of her death was a great comfort:

> *I um, had to make a decision... whether or not to keep her hooked up to the machine, or –or to just, you know, disconnect. And I had, and then, and actually Melanie's godfather, me and him... I confided in him and we*

went down in the garage and we talked for a while. And the decision was to – actually he made me make the decision. He didn't say disconnect, you know. Just the way he talked about it, and probably the best thing is to disconnect I guess. I should, I shouldn't say I guess I know that was the best thing. That's very hard. I was nervous about that for a long time. But, I asked – I came upstairs and, and that's basically what I told the doctor, right? And – and I asked her, I said, "Is it ok if I hold Melanie until you know... while you disconnect her?" Because she still had a little faint heartbeat. But I just wanted to hold her, you know. I held her when she came into the world, and I'd like to hold her when she goes out. And they were more than willing. Very helpful. No problem whatsoever. And that's the last I seen of my little girl.

The Changing Face of Grief

If one defines the process of grieving as a process in which one moves from losing what one had, to having what one lost (Fleming & Robinson, 1991), the parents in this research were at varying stages along the journey. Some were struggling with their anger, guilt and pain, while others had reached a place where they had come to terms with the death as well as they felt they ever would. They were all continuing to integrate the trauma into their lives. All would agree that mourning and a sense of loss is triggered at various times throughout the life span of the mourner. Marion's mother, seven years later, continued to struggle with feelings of guilt and the pain of her death:

I think in retrospect the feeling that remains is the guilt – that I should have recognized that it was a mental illness she was suffering from. And I think of all the little things I did that caused her grief. I – I didn't go to bed for a year after she died. I just put a blanket there on the floor and left the television on and dozed off. I was still working at that point, and I would get up in the morning and go back to work. I've been retired for years, but I still leave the lights on in the bedroom. I just have this mental picture of her in the dark jumping. It's a picture I can't get out of my head. I've read everything I can get my hands on and it seems like a text book example...I feel as if I'm just going through the motions of living – a broken heart that will never heal.

Jamie's mother, after 1 ½ years spoke of her anger towards the doctor who treated

him, her anxiety, the struggle of grieving while preparing to sue the doctor, how much emotion talking about it evoked in her, and her longing for him:

> *I'm shaking! I tremble when I talk about it. I don't cry much anymore, but I still tremble. It's still very, very real...I hate him. I have a newspaper clipping (of the doctor who treated Jamie) attached to a dart board...I've made photocopies and I throw darts at it...You know some people might think I'm weird for throwing darts at the stupid doctor's face... because when I think of Jamie, and I often do, we have many pictures and angels and everything. I find it very helpful to see his picture. I can, I can look at his picture but you know it – it's – I can look at his picture and smile and just be oh so cute, you know. I can almost feel him. I can almost feel him in my arms – but then that stops short and I get angry and I think of how it happened you know, and what is yet to come... I am grieving. I'm a very active griever and I have read a lot of books and I am coming along in my grief. I'm trying to integrate myself into quote "a normal life" but I still have this to attend to.*

Grieving is exhausting work. Caroline's father spoke of how it had taken three years to get the energy together to engage in legal action against her insurance company who were refusing to pay on her policy:

> *...The insurance company sort of said "Sue us if you want the money", you know, that type of thing. So that was three years ago, and I'm just getting ready, enough energy to get up and do that.*

Jason's father described his anger following the death of his son and his wife. He talked about how helpful the police were in calming him down at the hospital after they had informed him of his wife's death and the extent of his son's injuries. As he spoke, he reconnected with that anger and the pain:

> *...And they calmed me down because at that time I probably would have gone to look for the guy that killed them. At that time I didn't know that he (Jason) was dead yet, but I – but I probably would have found him and done something stupid...I went into a drunken stupor for I guess a month. I got drunk almost every day. I didn't want to do anything. I didn't even want to go back to work at the time...Ya, I was young, but I was happy, and some asshole had to take them both away from me.*

Melanie's father had to cope with his injured wife as well as handling funeral arrangements and managing things at home. This made the process of grieving difficult and complex:

> *...So I basically grieved by myself here at home, right? And – up until she (his wife) came home and that wasn't long enough. I thought I was healed, right, but that wasn't long enough. And then she came home. Then I thought that I have to be the strong guy, and I have to help her grieve, right? And it took a long time. She was grieving a lot, and you know, and I thought I should always be strong for her. So actually I kind of felt that I wasn't grieving properly. It – it took about two years and then things kind of blew up a little bit with me. You know, you don't put your finger on it until after the fact. All this stuff was inside of me. I thought I'd dealt with it and I thought I could handle it. It took a lot of time.*

Melanie's mother described the struggle she experienced in coming to terms with Melanie's death and where she had come to in the process of her grief:

> *I'm at a level of acceptance. I have finally accepted my life the way it is rather than to fight it. I fought it for a really long time. Fought the fact that I couldn't bear the pain, fought the fact that Melanie was no longer going to be a part of my life from this point on. And I have a lot of anger, a lot of anger.*

Christina's mother talked about how close she and her daughter were and the difficult journey grief has been. After six years, Christina's mother has found her way through the pain, and is able to reflect on the changes in her thinking and her life:

> *Christina – the daughter I always wanted. Joy of my life. Joy of my life. That's all there was. It sounds awful, but I was much more connected with my daughter than I was with my son... Part of me died that night. And that part will never come back. I don't see it ever coming back. Because I, for fourteen years, I was living my childhood through her. And when she died, my childhood died. I'm not the same person. I will never be the same person...I changed my views, my outlook, everything has changed. A 360-degree turn around. And I think for the better. I think I'm a much more loving and compassionate person than I used to be. My priorities. So much stuff, like I say, don't sweat the small things...But it didn't*

happen overnight. It was a gradual process.... My heart has mended... And I" m also enjoying life. And just because I'm enjoying life doesn't mean I miss my daughter less. So I see there is a future. Where in the beginning stages I never saw a future. I couldn't see past that pain... And I think I appreciate life more. Where before I didn't care for life after she died. I didn't care. Now I'm taking the time to enjoy it. I'm doing things for me. Just because I'm going on with life doesn't mean I don't have the pain... You have those times, but they're not as long. Or maybe you're down but not so depressed for days, like, weeks. Where now, maybe a day or half a day. It's, the pain comes, but maybe the intensity isn't as bad. You" re not in total shock... But it doesn't last for months like it used to...But the pain does come up pretty bad sometimes, but it's not as often. I guess as the phrase goes, time has a way of healing. You don't believe it at the time. I think time helps and it's also what you do in that time. If you are willing to help yourself. Where I was, I went looking. I read everything. I went off to self-help groups. I went, you know, I went looking for help to help myself. So I think that helps in your grieving and healing process, is if you're willing to help yourself. Huge difference

Tammy's mother also shared her journey:

I have a pain in my heart that goes away now, but it's always there. It's like a little bit of me is gone, a little bit. I'm not the same as I was before, and I'm a different person because a part of me that I loved dearly is not with me anymore. And it's out of order. Like my mother died first, and my father died, and I grieved. I grieved their loss. But I always knew that that would happen. Or you assume that that's going to happen. And, you know it's just devastating. And I think the grief is very difficult to keep a family together. I think to keep the rest of the family together after such a tragedy. Because each one of us was grieving in a different way. And handling our grief in a different way...But, I still cry – it's four years next month and I still cry. But I, I, probably have my life in proportion. It, it doesn't overwhelm my being, my every action. It did at first. Absolutely, totally. I was not able to do anything but grieve. I don't remember how long that went on. But now I've got it in – I know part of me's missing but you have to go on with that part missing because there aren't any choices.

Ian's mother shared the pain and the changes in herself and her priorities since his death:

It feels as though a part of yourself is gone. I felt for months like I had this hole in my chest. And it – it's interesting because you hear about people who have a broken heart, and they talk about heartache. And I had that, I had this pain in my chest that would not go away. And it was like

somebody had driven a stake through me. And it was like this open wound in the middle of my chest, like someone had opened up my chest and ripped my heart right out. That's what it felt like. And I still get it once in a while. Like now, when I'm talking to you. But It's not there all the time anymore, but in the beginning it was. But I think it's like your whole life has changed. It will never be like it was before. I'm a different person – I'm not the same person I was on Feb. 21/97. I'm a totally different person now. Some parts of that person are still here, but lots of what you see in front of you now is a re-created version of the former person, because I think you re-evaluate everything, and change your perspective on a lot of stuff. So, now I" m different. Things that I didn't feel were important before are a lot more meaningful now. And it's a pain that there is no cure for. Any other pain I've ever had, you knew you could do something about it. If you had some kind of an injury or some kind of an illness there was something that could be done that would improve that situation. Or something that you could do that would heal that condition. You knew that if you were sick, you would get better. But this, this pain, there isn't – there's nothing you can do to rectify it. Something that you just have to learn to live with, and that's a pretty hard job.

Jay's mother shared many similar feelings regarding her own journey:

I was just, just so numb. I don't know if you feel it. It's so unbelievable. It's so hard to believe that it's really happening to you. I think you always think it's somebody else, and you feel bad about it. And then it happens to you, and it's like this utter disbelief. How could this possibly have happened to you – to us? How could this possibly have happened? And it takes a long time to, and like I said to somebody one day "When did I start waking up and he wasn't the first thing on my mind?" Because for so long every time you opened your eyes, that was the first thing you think. And when you go to bed at night you can't get to sleep because of it. And then all of a sudden you start, you think one day "Oh, when did that happen?". You don't really know when it happened. It's just like a gradual feeling. But at the beginning it's very, very, hard, very, very, hard. It takes a long time to come to some sort of terms with it where you're not constantly crying and life does start taking on some meaning again. I think for a long time you push yourself. And then somewhere along the line I think you come to a point where you do things because you want to do them. You're not constantly doing – kicking yourself in the butt to get going. It's hard at the beginning. It's just total disbelief and anger and looking for some blame, looking for a reason. And there aren't any. You have to learn to accept the fact that it's happened. I know what people, I know what people, what they talk about a broken heart. Because there is a pain in your chest and it's so severe. I mean, you think you could be actually having a heart attack. And that lasts a long time, that,

that horrendous heartache. It's no wonder our bodies are in such bad shape for a long time. Just what it does to you physically... I can't imagine that it ever stops hurting. It doesn't hurt as bad. Sometimes it" s good. Maybe we just learn to deal with it better and it doesn't seem to be in our face quite as much. I mean it's the most unnatural thing to bury your child.

Caroline's mother expressed a feeling shared by most of the parents in this research:

We're still healing. We will always be healing as long as we're alive.

Virtually every parent described the death of his or her child as a trauma. Using Rando's (1993) model of the grief process, the parents in this research were in varying phases of the process of grieving, and some were continuing to actively deal with their trauma. The interviews, for many parents, brought back intense feelings associated with the memories, and at times I felt that I was witnessing many of them re-living or re-experiencing the death of their child. Each and every interview was a compelling experience for myself, both as researcher, and as bereaved parent. These parents willingly and openly admitted me into one of the most intimate experiences of their lives. They touched me deeply, and I am grateful to have had the privilege of hearing their stories and learning from them.

The focus of this research was on the interventions of professionals, and the balance of the findings will present the data and analysis of these. In the next chapter, I will identify the interventions and impacts of them that these parents have shared with me.

Chapter Six

Interventions Experienced: The Parents' Perspectives

I heard their sorrow like a witness
to a violent crush of cars
hears the scream of tires,
the crushing thud of metal collapsing,
the shattering crash of falling glass.
(K. Beatch, 1999)

Introduction

The parents in this research were involved with a variety of professionals from the time of death notification through the funeral. These included: police, doctors, nurses, social workers and crisis counselors, chaplains and various other clergy, coroners and funeral directors. Their experiences with each of these professional groups were varied, and impacted on them in many different ways. Some of the experiences were very positive, some neutral, and some quite negative. Where the intervention of the professional in question was experienced as very positive, or alternatively, very negative, the parents' memories of those interventions were very clear. Often parents recollected exact words that were spoken to them, demonstrating the continuing intensity of the memories. Parents in this research were able to identify clearly what was helpful and what was not.

In addition to the above-mentioned professionals, some of the parents experienced the involvement of other systems, most notably the criminal justice system, inquests, and the media. Those parents who were involved with inquests and trials, and/or had to deal with the media had similar things to say about each of these.

Some of the parents tried to understand the perspective of the professionals, and many

commented on how difficult their jobs were. There was frequent recognition of how painful dealing with the death of children and with the surviving parents must be for professionals. This sentiment, which was shared by many parents, was expressed by one parent this way:

> *But again you've got to take into consideration professionals are people too. They are people with their own feelings and everything. Maybe this was very traumatic for her. Yes, as a professional she must – it's part of her job. But let's give her the fact that she's a person too, and obviously they – she must have known from a professional point of view this is - this isn't just a – we write up a report and it's done. This is a business. This is a workplace. Death, there is a lot.*

Another parent, while expressing his anger at how the police had managed the situation at the time of his child's death, also expressed empathy for one particular officer at the scene. His empathy, though, was enfolded in anger at the officer's superiors:

> *I remember at that point talking about the police officer with the teardrop, and that's when they told me that – he had a – son – the same age. His name was [also] Luke, and he was sad...And he was the one I think – I think that they made him do the CPR. You know, they are a bunch of heartless – they should have taken him right out of there. You know I find out that – that – because one of our things that we didn't like that the police officer did. We find out after that one of the sergeants or whoever asked him if he wanted to be relieved. Well, don't you think he should have just said, you know, "Joe, or Nick or whatever your name is – I think you need to leave. You need to leave." You know, he is not going to say "I can't do this" in front of all his guys.*

These statements support Clarke's 1981 recommendations that police could benefit from psychological support when dealing with the death of a child, as well as Leff's (1987) findings regarding health care workers feelings of powerlessness in the face of the death of a child.

This chapter will report the findings with respect to parents' involvement with specific professionals as listed above, as well as briefly outline the findings regarding

involvement in inquests, trials and with the media.

Common Themes in Helping

The parents in this research reported a multitude of interventions that they had experienced as either helpful, or as unhelpful and adding to their trauma. Each of these specific interventions varied according to the particular professional group involved and the role of that professional group. Many of these interventions were similar in nature, but had unique aspects that were the result of the role of the professional, the amount of involvement with the family, and the sensitivity of the particular professional involved.

In examining the interventions that were helpful, three categories emerged. The first was the provision of instrumental assistance in a way that was respectful of the parents' needs. In the overwhelming trauma of the death of their child, parents experienced offers of instrumental assistance as helpful both in terms of the practical aspects of functioning after the death, and in terms of supportiveness. The second category was compassion. Compassion was seen to be demonstrated in many different ways. It was experienced as emotional support, having their wishes respected, being listened to and having the value of their child acknowledged. Finally, the provision of information in a timely fashion stood out as extremely helpful in the interventions of most professionals.

In Crisis Theory, the role of the professional is to facilitate the restoration of functioning, in part through assisting clients to carry out tasks and to identify and implement solutions or roles (Golan, 1979). The offering of compassion, instrumental assistance and information are functions that fit within the purview of Crisis Theory. Further, the trauma literature identifies the need for information as a part of normal adjustment and significant in the reduction of psychological distress (Winje, 1998). The

categories of helpful interventions therefore are consistent with good Crisis Theory practice.

Conversely the interventions that were experienced as unhelpful, or adding to the parents' trauma could be categorized in the same manner. The lack of instrumental assistance with the various processes parents had to engage in was unhelpful. Failure to demonstrate compassion often added to the trauma of the parents. Failing to provide information, or minimizing information, or providing information without sensitivity to the parents' needs around timing and amount were viewed as greatly distressing by the parents in this research study.

The following sections examine helpful interventions categorized as the provision of instrumental assistance, compassion, and information. These categories are applied to each professional group studied. Specific examples of each are reported. Unhelpful and/or traumatizing interventions are then discussed and examples given. The professional groups are discussed in the following order: police, nurses, doctors, coroners, social workers/crisis counselors, funeral directors, and chaplains and clergy.

Police

Sixteen of the twenty parents interviewed had involvement with police that stood out in their minds. Six of the parents noted significantly helpful involvement with the police, while eight had very difficult experiences. Two parents had mixed experiences with the police.

Interventions by police that were experienced as positive by parents were generally described as instrumentally helpful in a number of different ways such as helping to find relatives, transporting parents to hospital, and trying to ensure their physical comfort.

Compassion was seen in ways such as being empathetic or supportive, caring enough to be thorough in their work, and respecting the parents wishes where possible. The provision of information was highly valued with parents. The police were often at the scene of the death and able to fill in significant pieces of information for parents. Where they took the time to do so, it was experienced as very helpful.

Instrumental help was given to several parents. This instrumental help was also viewed as being supportive or compassionate. For one mother, the police questioning that occurred at the hospital subsequent to the death of her child was minimal and she felt that the questioning had no effect on her. The police officer quickly and quietly did his job, which she appreciated. However, another police force was instrumental in getting her fiancé, who was some distance away, to the hospital to join her and the family. She felt that they went to a great deal of effort to assist her fiancé, which made the situation much better for him. On the other hand, after the funeral, her experience with another officer was very upsetting to her, and will be described later in this section.

One mother felt that the police were very good in attending to their job at the scene of the accident and not being intrusive while she sat by watching, as well as in providing instrumental assistance to her. Most important to her was that she was supported in the way that she requested to be:

> *Then the police came...They just did little things like, kept asking me if I was ok, if I needed anything. I remember because I hadn't eaten that morning, I asked for a coke and they brought me a coke. And they basically left me alone, which I appreciated. The, the one policeman – every now and then he would just come and check that I was ok, and go away...So at the time that the media arrived, there were police there...they, they asked them to leave. [It was] appreciated because he supported me when I desired.*

Another mother described how helpful the police were when she and her husband were called home because their child was found without vital signs by the babysitter. The police directed them to the hospital and offered them a ride. The officer further offered assistance by going to tell the friend they were to have been helping that day. He also asked if they would like him to call others, however they didn't need him to do that. The offer of instrumental assistance, which they felt free to accept or decline, was experienced as very helpful to them in their crisis.

The demonstration of compassion was helpful for parents. For at least one of the parents in this research, his prior relationship with the officer in charge was helpful. They had gone to high school together, and this father felt supported by the officer:

> *He was very sympathetic, which I thought at the time was very good. You know, very professional and the whole thing. And I thought that it felt good to know somebody there, you know. So I believe that they know a little bit of warmth or whatever the heck you call it, and he was pretty good at that.*

Another mother commented on how "*The police were thorough and they were gentle*". She felt that these were very important behaviours in assisting her at the time.

The provision of information was a critical component in the support of parents during the trauma of their child's death. A mother who met with police some time after the accident talked about how important it was to her that the officer was willing to provide information to her:

> *And he finally sat down with us and he got out the file. And he showed us the pictures of the accident that he had. And he showed us the pictures of the roadway. Uh, I remember looking at the pictures of the roadway and saying "That's where my coffee cup was.", and "That's where the other pillow was.", and I couldn't remember what I had in the car. And he had a description of the groceries that they found in the trunk and who they had given them to, and, uh, that kind of information helped me to fit some*

of the pieces of the puzzle.

This mother went on to describe how the officer went through his investigation in detail, which was important information for her to hear.

One father described how much the police helped him at the hospital subsequent to the accident that claimed his child's life, particularly by providing information and support:

> *They took me into a room and told me what had happened, cause they had the full detailed report, because they were the ones that were on the scene. And, and they were there to comfort me, and they gave me a whole pile of lists of organizations I could contact if I wanted to at the time... You see it made it easier because they explained exactly what happened. And they also calmed me down.*

Searching for information is a normal part of the adjustment process in a trauma (Winje, 1998). The parents' need for information was a common theme throughout the interviews. This theme will be discussed in the following chapter as a significant element in the reconstruction of the death scene. The police are often in a position to assist parents by providing details when asked. Many of the parents in this research had unhelpful, and at times additionally traumatizing experiences with police. The issues of thoroughness, empathy or compassion, and provision of information were key themes.

The need for information was a key sensitive area. For many, there were serious difficulties encountered in obtaining information. One parent's experience, however, highlights the importance of the timing of intervention and the importance of identifying and respecting individual needs:

> *...The police kept wanting to see me, and wanting a report. And I said, "No, I don't want to see you". I didn't want to talk to them because I didn't know what had happened at that point. I hadn't known the circumstances of the – accident. I didn't want to know any more than what I had to absorb, which was that she was dead. I didn't want to know if it was her fault. I didn't want to know any details because I couldn't*

have handled it. And I thought they were ominous to me in their black, you know, uniforms. And they just seemed to be part of the whole accident, and I couldn't bear seeing them. I just didn't want to talk to them. They were frightening to me at that time. It was – I was dealing with something that was spiritual, not physical at that point, and I didn't want any of the physical details or anything around me...As it turned out, I didn't want to know if she was struggling. I didn't – didn't want to know if she was alive for a while. You know, I didn't want to know any – any – that she had any pain, or she had – you know. I preferred not to know at that time, so I couldn't probably handle it...They kept coming back and coming back and finally I think I told my son – I said "Tell them to go away please. I don't want to talk to them. I'm not going to talk to them". So I found them very, you know, they – very persistent. I – I was annoyed that they kept coming back, but they finally disappeared and I thought, well fine, good, you know. That's where – I felt I had – you know, was right in my decision.

Winje's 1998 study reports that feeling adequately informed is correlated with better psychological adjustment after a trauma. What was equally unhelpful for parents was feeling that they had to struggle to get information from the police. Many parents felt a personal visit to answer their questions would have been helpful:

...Even a personal visit might have been better and to explain the situation. In our case um, I mean there was an accident, and the situation, and we had like to pull teeth to find out information that I thought he should have been able to sort of come and visit with us on a one to one basis. And explain the situation, and how he came to what he did and the decisions he made. Because ultimately – in the sense of what the other person was charged with and all that kind of stuff as well.

One parent was able to get information, but with difficulty. She described going to the police station to learn about the details of the accident, wanting to know specific things such as who turned where and so forth, in order to fully understand what had happened. They did draw a diagram of the accident for her, however she could not make sense of what they were drawing. The police officers kept telling her how distraught the other driver had been over the accident, and appeared to be more concerned about defending

the other driver to her than in giving her information:

> *They seemed more concerned with how upset the guy who hit him was. Looking back now I think they were very concerned that I might seek him out and give him some grief.*

For others, who wanted police reports in the hope that the reports would give them more information, or where they might have been needed for other purposes, further difficulties were sometimes encountered:

> *I had to get the police report. Um, just to go and pick it up. It took them a while to get it. I don't know why. This is after the fact. They said that it would take them a couple of weeks for them to get it together...And then you had to pay a fee, which I thought was pathetic. You'd think that would be one of the things that would be covered, you know. Um, I had to pay a fee and I had to sign something. Then they only give you part of it. They can't give you the whole thing. It says right on the thing. Half of it isn't for you, kind of thing. So they leave parts out.*

Another parent's experience of asking for information from and paying for the police report was even more distressing:

> *And I'd gone to the police station. No I went to the police station to talk to him. And when I asked to see the police report, all he did was cover it up and hide and shield it and everything else. Wouldn't let me see a lot of stuff. And I asked, "what are you trying to hide from me?" And he says "nothing. Well you're not allowed to see the witness reports. You're not allowed to see this." I said, "All I want to know is what were the chain of events. That's all I need to know." And they wouldn't do it. They says, "You have to see a lawyer." I paid $600. to get the police report. And they sent pictures. And the pictures cost $20. For the 4 x 6 pictures...They had pictures of the signs. Pictures of the area. Pictures of the car that she hit, like the dent on the hood, and the windshield and stuff like that. $20. a picture! Now you tell me where's the justification in $20. a picture. And then I got three pictures that weren't even her accident scene! They were someone else's!*

Other concerns were identified with respect to police interventions. Lack of compassion was demonstrated in several ways. For example, one parent felt that the police were judgmental in their attitude. She described a distinct change in attitude on

their part toward her after the toxicology reports came back showing that her son had not been drinking prior to the accident. Once that report was in, the police became very co-operative in providing information and releasing reports. Prior to that she had made many calls to them to no avail. She felt that initially, when the police thought her son had been drinking, she was treated with a lack of respect that immediately changed when the proof came in that he was not.

One parent had two police officers come to her door. The family's experience of each of those officers was very different. One appeared to be very calming, while the other's attitude was very upsetting to both herself and her husband in that he appeared to lack empathy for the parents and was experienced as judgmental:

> *I thought that they were – one officer seemed to be more in charge and I felt that he was very compassionate. His approach to things was very calming and kind. And I – sure it's a very hard thing for them to do. The younger officer I found – he was the person who was asking if [her husband] would do anything rash. And there was – he also kept, several times, said to [her husband] that he should get a grip on himself and told him to "pull yourself together sir" and that sort of thing. And at one point I needed to have a cup of tea, and I didn't know it at the time but [my husband] told me later. When I left the room the fellow said to [her husband] "You've got to get your, get a grip on yourself. Your family needs you and you can't behave like this". And you know, like, kind of "shape up" attitude. Which if I'd been there in the room and heard him say that I would have been upset with him. Because I don't – I – I've heard other people describing their responses when told their child was dead, and certainly what [my husband] was doing was not unusual or different... and this particular fellow was saying to me – you know patting me on the shoulder and saying "You're doing very well, ma'am. You're doing very well ma'am", like I had to pass some kind of a – you know – evaluation or something.*

The lack of experience and discomfort shown by some officers speaks to the need for training in death notification. One parent specifically commented on the inexperience of the officer who greeted her at the hospital and how that clearly showed in his approach.

This officer was not experienced as unkind in any way, however his lack of experience kept him focussed on the information he needed, as opposed to being sensitive to the needs of the family and demonstrating compassion. Another family's encounter with an inexperienced officer was more distressing:

> *And the other officer was quite young. I think we were his first family that he had to come and tell. You could tell. Just the uneasiness. And like they were trying to make chit chat. We had already had supper by this time. Her plate was the only one left on the table with food on. And the police officer goes "Who didn't eat their supper?". And I just looked at him. I says "Who didn't come home?"*

Looking back, this parent was able to understand the way the officer behaved:

> *But I understand they're nervous too. This is not an easy task for them to do, is to come in and tell somebody that they've just lost a loved one. And especially a child I think. It doesn't matter. It's still hard to tell somebody they've lost a loved one. And I think they were trying to make chit chat.*

Other situations may have been the result of inexperience or lack of training also. One mother was told by a police officer that the officer would take her to the hospital when the ambulance had left with her child. The police officer got involved in other things, and the mother eventually had to have a friend take her. Another mother was told to get dressed to go to the hospital by the police, however she was in such distress that she felt someone should have offered assistance. This particular family felt that there was a lack of sensitivity on the part of the police in not sending a female officer, given the circumstances of the death and that there were small female children in the household. Probably the most difficult incident of this nature for me to hear as a researcher and as a parent came from this mother:

> *And I told them they could leave. And they wouldn't leave. The police officers wouldn't leave. They said we had to find somebody to come into*

the home before they could leave. It was their policy. I just wanted them out of my house. The main reason – this sounds awful – but the main reason why I wanted the one officer out of my home, he had my daughter's blood all over the knees of his pants and down. That's it...Because you could tell blood. You know blood when you see it...And he said he was there and he's the one that knelt down with Christina. And that's why he had blood. She had lost basically half her blood right there at the scene of the accident.

Another area identified as difficult was when police officers attempted to talk parents out of seeing their child's body:

And they said, "why don't you just let the men go and identify her. You know, you've got your ex-husband and your husband to identify her." And I said, "No, I have to do it". And they still try to talk me out of it.

It was usually mothers who police or other emergency personnel tried to talk out of seeing the body. Certainly in my clinical practice and encounters with other bereaved parents, this is not unusual. Another example came up in the interviews:

He asked, he suggested that my husband go without me, and I said no I was going in too. And he said to me "It's not a pretty sight."

While parents understand that the police or others are trying to spare the mother additional distress, it is important that professionals, including police, understand the significance of seeing the child's body. This issue was raised with respect to nurses and funeral directors as well in this study. This will be addressed in the discussion in Chapter Seven.

Three of the parents expressed specific concerns that their child's death had not been thoroughly investigated. The parents' perceptions of thoroughness were significant to them. One parent felt that the police had not investigated thoroughly enough to determine the sequence of events leading to the child's death, and indicated that the police would not explain their investigation to her. For another parent who experienced

an investigation of the death of his child, serious concerns arose when evidence was misplaced and the police, although refusing to return the child's blanket to them for burial, did not keep the child's sleeper that he was in when he died:

> *I think it was the Monday or Tuesday after the funeral, the funeral home phones and said to me that they had something of [the child's] that – we forgot. And I didn't want to go back there so I sent my brother-in-law. He went over there. He came back and here it's the pajamas he died in. And right away when I saw that, I thought, you know, "You won't give us the blanket because that's evidence, yet the pajamas he died in isn't? Are you guys a bunch of bumbling buffoons?" You know, I felt like this is how things got screwed up, this is how a jerk like – like the guy in California got off murdering his wife – O.J. Simpson. You know, all these little technicalities. If we had of did something, we probably would have got off. I mean I was just so...*

Even worse, was when parents felt interrogated or accused. In one situation, while the siblings of the dead child were being treated by the medical community for possible meningitis, the police sealed off the house and began collecting evidence. The parents were interviewed that day and again separately for hours a couple of days later.

> *They took everything. They came in when we weren't here (without the parents' knowledge) They took all his things, they took his bottles. What else would you think? There has got to be a better way, because in the state that I was in what else would you think? Who sits you in a room for two hours and practically – makes you feel like you – (in a whisper) you killed your son.*

This child's father described how intimidating he felt the police were during the interviews, and how he felt that he was being interrogated. Even when he tried to ask questions and state their concerns, this father felt intimidated:

> *...My wife and I talked about it a lot after this. They were terrified, were my daughters. I mean, I went to get my one daughter and she was under the covers – she'd grabbed them like this. I couldn't even move her fingers...They were scared, and I'm thinking, you know, you've got these big cops, you know, bigger than me. That's intimidating to a little tiny girl this big, you know. And at one point we were questioning the police – this*

is I couldn't even tell you how long after. But two police officers came – the main detective, he was a jerk! He was really – he needs a little bit of work that guy. I mean, I'm in retail business, I'm a meat cutter. And I've got more tact with customers than this guy did. We just lost our son! Anyway, I'm talking to him and I mentioned that to him: "Why couldn't you guys have had a police officer that was a woman there at least?" And I said, I said something about "Wouldn't you send a woman to a rape situation?" And then he stepped two steps right in front of my face – he got right in my face and said, "I'm fully trained for this" and went on. I can't remember all the – I wanted to hit him. You are in my house and you are threatening me. That's what I felt anyway. I felt threatened and I wanted to hit him. You don't do that to me in my house. Like, who the hell do you think you are? You're a policeman! You respect me in my house...I like I say, I've got no respect for them.

The mother in this case expressed her concerns about the effects of the police interventions on her young daughters:

And there were times when I thought...have you ever had a girlfriend, or your mother, or you know – think of what those things would do to you. Just think for two seconds, that could put, and I don't wish this on anybody, but if you could just have experienced it for two minutes, what it does to a person, or what it does to your family. Or what it did to the girls. And I remember writing in the letter – and I said "Who's going to take care of the psychological welfare of my children when they are 20 and they think daddy did something? Who is responsible for that?" What is wrong with these people. Do they think past their nose? This is not just an investigation – this is a family...

These parents felt intimidated and threatened throughout their involvement with police, and were not able to resolve these feelings. Unfortunately this added to their trauma, and was not helpful in their grief process. They became stuck in their anger and were unable to move forward in their grief. Remembering these encounters during the interviews evoked intense emotion, and the parents' descriptions at times had the quality of the frozen traumatic memories described by Herman (1992) and van der Kolk and McFarlane (1996).

The findings of the interviews with police would suggest that some officers do well

with parents, while others, perhaps in trying to be helpful, intensify the trauma. While parents were often prepared to try to understand the reasoning behind police interventions that they perceived as lacking sensitivity and compassion, they felt strongly about the impact of those interventions.

Nurses

Fourteen parents had involvement that they recalled as significant with nursing staff at the time of or subsequent to their child's death. Nine felt the nurses were very helpful, while three did not find them to be so, and two had mixed experiences.

Parents described the following interventions as being most helpful to them: providing instrumental assistance such as helping to prepare them for what was to come, and preparing them for seeing the child's body, providing items for them such as blankets, beds, and even a pager, helping with a naming ceremony and providing Tylenol; providing compassion by taking the time to talk to them, being comforting to the dying child, being comforting to other children, providing privacy during viewing of the deceased child's body, and, providing information by explaining various processes and procedures to them, and updating them on the condition of their child.

Several parents identified how grateful they were for the instrumental assistance provided to them by nurses. One mother remarked on a nurse's efforts to get people to move aside in order for her to see her son. Another parent told me about a nurse at one hospital who gave her the telephone number for the direct line so that she could call her without going through the hospital switchboard. Another parent received help in being able to stay with his child:

One nurse was good. She just got me anything I wanted. She made sure I

was completely comfortable. The doctor told me I wasn't allowed to stay. The nurse said, "Don't worry about it", I could stay as long as I wanted.

In terms of helpful interventions, one of the most significant aspects was the demonstration of empathy and compassion to the parents. Two parents describe how nurses were helpful by comforting their dying children:

She was – she was very good. and the nurse would you know. just do conversations with her – asked her about if she had any pets or just conversation...they knew how to treat Melanie. They were talking to her like just to give her comfort and warmth.

Another parent spoke of how the nurses tried to play with her child, bringing in a stuffed animal. Providing comfort to the dying child was comforting to the parents.

Parents who had other children at a hospital at the time of their child's death remarked on the importance to them that their living children were being compassionately cared for. In addition, at least one parent found the nurse for his other children to be supportive to him:

I mean. I think – when I think back, the most compassionate people were the nurses [for his daughters]. Well I talked to one nurse for a very long time. It must have been – felt like two or three hours.

Another parent spoke of how a nurse's actions made her feel that someone was caring, showing a little compassion:

...I had a very bad headache...but I said, you know, could I have a Tylenol. And she said "Oh we're not allowed to give, to err – give out medication". And I said "O.k.". And – then she kind of – didn't say anything more. And then she came back and she handed me the couple of Tylenol. So I think she, you know, sort of just said that maybe for if anybody had been listening or anything – but then she came back to the room.

Sometimes even the acknowledgement of the strain parents were under while waiting for their child to die was enough to be helpful:

Because a couple of nurses at a time just said – said, "I don't know how you're doing this running from hospital to hospital. You need to relax, right?"...The nurses were great there at the ICU. The nurses were just very good, very supportive.

The combined careful treatment of their child and compassion for themselves as parents was often appreciated and remembered long after the child's death:

That was important. The treatment he got at [the hospital] was top notch. Um, we were really pleased. They – they took the time that was needed. They never – I mean there wasn't much room with all the drips and the machines and the cords on the floor to be at his bedside. And when, err, a machine beeped, you know the nurses would come in and um – you know of course I'm trying to scramble to get out of the way. "No, no, no, just stay there. I can work around you". They – they were so good.

As with the police, information was important to parents, and nurses were often in a position to provide that. Parents whose children died in hospital remarked on how helpful it was to have nurses keep them up to date and explain what was happening to their child. Parents who came to the hospital to see or identify their child's body felt that nurses were in a position to be very helpful, by preparing them for what they would see. One parent described a particularly helpful experience with a nurse:

She explained in great detail what my daughter looked like. She told me what to expect when I went in there. She not once tried to talk me out of going in there...But she told me that my daughter would be pale, very pale. She had a mouthpiece in for CPR. She had a collar on. And that she'd be white, very white. And she explained all that – that's how she looked. And before everybody left I asked her "Can I hold Christina's hand?" I don't know why I had this desire. I needed to hold that hand of hers. And, um, Karen explained to me. She says, "She's going to be very cold". And again while we were there she told me, she says "Yes, you're more than welcome to hold Christina's hand. And she says "She will be very cold and she will be stiff".

One parent who had experienced the stillbirth of her child had mixed experiences with the nurses. She felt that she received a "lesser grade of treatment" as the parent of a baby

born dead. On the other hand, the nurses were very helpful in preparing the infant for the naming ceremony:

> *Two nurses in particular. And um, they actually – she had to go back to the morgue for a while – they couldn't have her out all day...And then when we had our naming service later that day they warmed her up. They put her under a heat lamp, which was really kind of nice, because everybody wanted to hold her then, and then they weren't holding this baby that was really cold. And so that was kind of a nice thing the nurses did.*

One parent who had been critically injured in the accident that killed her child had mixed experiences with the nursing staff. Some were very empathetic. This mother described an incident where a nurse was rather hard on her, and the compassionate responses of the other nurses to that situation:

> *Another time I remember I was in traction, and there was a nurse who came in and she said, "You've got to do more things on your own. You've got to get up – you don't need the nurses help for this and this". She was kind of being bossy with me. I just cried and cried and cried. I remember that incident, because I had three nurses who came immediately after that just profoundly apologizing for her behaviour and saying that this nurse would not be allowed even anywhere near me. So it kind of makes me think that as a unit they were compassionate.*

One mother had a very difficult experience at the hospital subsequent to the death of her child. The nursing staff there forced medication down her throat after she declined to accept the offered tranquilizing pills. Her husband recalls seeing nurses holding her and forcing pills into her mouth. Although the nurses were attempting to calm this mother down, neither she nor her husband felt that calming her down was the appropriate thing to do in that moment, particularly not by force. This was experienced as additional trauma for both of these parents: the mother who had the pills forced into her, and her husband who had to watch helplessly as they did it. This experience also reinforced their own

feelings of loss of control.

The parents who experienced negative interventions from nurses felt that they had received little if any preparation for seeing their dying or dead child. The parents felt that the nurses could have been very helpful in doing so. The experiences of those who had nurses inform them and prepare them demonstrates the importance of this to parents at this time.

Nurses are often in a position to assist parents through some very traumatic events associated with the loss of their child. They often have considerable impact on how parents manage the trauma and if not careful can certainly add to the already intolerable pain and suffering parents are experiencing. The findings regarding nurses reflect the work of Guylay (1989) and Neidig and Dalgas-Pelish (1991), and highlight the importance of assisting parents to identify and meet their own needs, rather than making decisions for parents.

Doctors

Eleven of the parents in this research study had some kind of involvement with doctors, other than coroners, with respect to the death of their child. Three parents had mixed experiences with the doctors they encountered, three parents found the doctor they saw very helpful, and five parents had experiences that ranged from an uncaring disregard for their pain, all the way to misdiagnosis or mistakes that cost the life of their child.

Doctors had surprisingly limited involvement with parents in this research. Even in accident situations, the doctor in charge of the treatment of the child was seldom available to the parents by the time they arrived at the hospital. Often nurses and

chaplains dealt with the parents. In some of the situations, doctors were involved with the parents for follow up of their own injuries. For other parents the only contact they had with a doctor was with their family doctor after the death, for personal or family member's health care. Again, doctors played a surprisingly small role with follow up, which was an issue for some of the parents.

Parents who had helpful experiences with physicians identified that meeting instrumental needs, providing some kind of follow up, showing compassion, and giving information to have been the interventions that assisted them in their trauma.

One example of instrumental assistance that was helpful came from a mother who told of how she had such a violent headache at the house after her daughter died that she was unable to get to sleep. At 11:30 at night, the family priest contacted the family's physician who came out to the house and stayed with her until he was able to get her enough medication to reduce the headache and allow her to sleep. The following morning she was so severely ill that the doctor returned to her home and gave her a shot of gravol so that she would stop vomiting and be able to function to make funeral arrangements.

Compassion was identified as a key need from doctors. For one father, finding someone who would listen to him with compassion was crucial, and he found that from a source that surprised him:

> *And I talked to one doctor. I'm not sure what nationality he was – East Indian, or Pakistani, or one of – uh – and I'm thinking this kid – I mean kid – and he looks like he's right out of medical school, has got more compassion than these people who've got ten years on him, or 15 years, or 30. It's pathetic. How can one man like that...have more compassion at their age than the older people. They've got nothing. Like the police. And I'm thinking there's something wrong here.*

Another parent found her family doctor very helpful shortly after the death when the doctor contacted her:

> *In fact she was really nice. She phoned me and she said, "I just heard about Tammy dying" she said. "I was away and I wanted to phone you". And I thought that was really nice...So she was good. And [Tammy's doctor] phoned and said, "I'm really sorry to hear". I think that was really good because it's not easy to reach out. A few minute phone call is all it takes to show that people care and they're acknowledging it you know.*

One father who was experiencing difficulties with the physician treating his dying son and wife found comfort from his family doctor, who arrived at the hospital and spent some time with him at the bedside of his dying wife while his son was in surgery. He felt that his doctor's compassionate presence greatly assisted him in getting through that time.

A parent who had been injured at the time of her child's death, found her primary physician to be very protective of her. His compassion and caring were extremely helpful to her during a very traumatic time. He had been the physician who had to make the decision as to whether she could be transferred to the hospital her daughter lay dying in, and had not been able to let her be moved. In spite of this decision, this mother clearly felt his caring:

> *I don't know if he felt emotionally tied because of that. Because he ultimately had to make the decision that he couldn't let a mother go to see the daughter and that must have been a very difficult decision for him to make. He was so much involved that a year and a half later [he saw her in the hospital while treating another family member] and he spotted me...and he yelled across the hall, he said "There's my living miracle!" And he just embraced me. So he really was a wonderful man, and he really cared.*

Compassion and information were described as the most important things doctors could give parents. The mother in the situation above went to see the doctor who had

treated her daughter after she had sufficiently recovered to do so. She and her husband went to see the room her daughter had been in, and met with the doctor. She asked him to explain why her daughter had died. He did that and told her that as a result of the child" death, he would be treating patients differently.

Information was again a critical theme in helpful interventions by doctors. For one father who had experienced a stillbirth of a child, the doctor's presence was comforting but his information was extremely important for himself and his wife to understand what had happened. This doctor took some time with the parents explaining why the infant had been still born.

For one of the parents, the doctor who took over her child's case just before he died was very helpful. He made himself available at any time to her and her husband. He provided them with thorough information, and patiently answered all of their questions. This was very helpful to them. This mother had other issues with a different doctor, which will be addressed in the next section.

Distressing issues with doctors included a lack of follow up or contact by long term family physicians following the sudden death of the child, and having a cold, impersonal attitude towards the surviving parents. For at least one parent, the physician's attitude caused considerable distress. A more serious concern was the lack of information coming from doctors with respect to the child's death, a theme that was present with both police and nurses as well. Most distressing of all was that two parents had to deal with doctors whose misdiagnosis or treatment errors caused the death of their child.

One parent described the impersonal attitude of the doctor in charge following her daughter's accident, and how she felt he might have been more helpful.

I found him to be terribly impersonal. Just came into the room and – told me that – the condition was very, very, very bad. And they couldn't stabilize her in any way. And of course I asked if I could see her, and he said, "Ok." And we were walking down the hall and then as we were about ½ way there – err. I don't know what happened, but, um, we were told to go back to the [quiet] room. And shortly after that he came in and said that she was gone... [He] just related the facts as they were... But he didn't seem – you know he wasn't supportive or – he didn't seem compassionate. [He could have] maybe held my hand, you know. Showed some kind of compassion in his face. I don't think, you know, you accept a lot, but you expect something more than, you know, just the facts and just walk out.

One parent had a more difficult experience resulting from the attitude of a doctor treating her subsequent to the death of her child. This doctor was treating her for injuries she sustained in the fatal accident. She had gone for a follow up appointment:

He said, "I think it's time for you to go back to work."... And I said " You don't understand [Dr. __]. I've just lost my child and I can't go to work". And he said, and this is a room where it's divided by curtains, so there are about three other patients in the room. So he said, " Your daughter is dead. It's time for you to get on with your life. There is nothing you can do about bringing her back. It is time for you to stop this self pity and get back to work." And I was shocked...I said – I said "But I can't even function!" And he said "I have no time to be standing here watching you cry. I have a waiting room full of people. I want you back to work".

This mother was then subject to assessment by a panel of six psychiatrists trying to understand why she was so profoundly grieving the death of her daughter. In clinical practice, clients sometimes report this lack of understanding. Heavy use of medication and lack of understanding of the grieving process is much more common than one would hope.

Other parents had experiences where doctors were inconsiderate in other ways. One parent's family physician of twenty years duration did not even call the family or remark on the child's death to a sibling of the child who attended the office for treatment. This

was painful for the parent who felt that after this length of time as a patient, one might expect some outreach from one's own physician. Another parent attempted to speak with her child's psychiatrist after the child's death. The parent experienced the doctor as brusque, and although she realized his professional limitations in discussing her daughter felt that he pushed her aside, telling her to get on with her life and forget all of this.

Failing to provide information was another significant issue for parents. More than one parent said that the physician on duty at the time of their child's death was unavailable by the time they had reached the hospital. Another doctor reading the chart then provided information, which lacked the detail parents wanted. Another parent described the doctor as distant, and not explaining things to him. Another parent commented that the Chaplain at the hospital actually provided more information than one of the doctors did.

Two families experienced the most painful issue of misdiagnosis and malpractice. One family did not find out about the doctor's error that cost their child's life until much later, and had been feeling until that time, that the doctor was supportive:

> *I guess the bottom line is – he messed up. The doctor screwed up. They had people there that weren't qualified to read the CT scan properly, and the whole thing wasn't that solid. You know, a big screw up is what it ended up being...until that point I thought the doctor – not knowing what the doctor was doing – [I thought he was] doing not a bad job.*

Another couple who had a doctor misdiagnose their child similarly spoke of being relieved by the doctor's reassurances and exchanging nice thoughts about him on their way home from their first trip to the hospital. This mother, later in the interview, described how her energy was very much directed into anger toward the doctor and took away from her time to grieve over her son. She spoke of seeing an article in a local paper

about his involvement in a charity and clipped the picture of him from it:

> *And, I throw darts at that. I've made photocopies, other people have given me their newspapers, and I throw darts at it... Some people might think I'm weird for throwing darts at the stupid doctor's face. You know, well he put his picture in there, so it – it's important to me, you know, and I – I feel so much anger.*

Overall in the interviews, doctors had less involvement than one might expect. Where they did it was clear that providing information (a continuing theme in this research), listening, showing compassion and reaching out in a follow up call were all significant ways of helping.

Coroners

Eight of the parents interviewed described involvement with coroners. Given that most of these deaths would have been coroners' cases, it is surprising that such a low number of parents had direct dealings with the coroner in their case. Of the eight, one parent described their dealings as neutral. That parent indicated that the coroner behaved in ways typical of a government bureaucracy however did not elaborate. Of the others, four had positive involvement with coroners and three felt their involvement increased their trauma.

For those who felt the coroner impacted positively on the situation for them, the keys were a compassionate approach and the provision of information. All four parents indicated that the coroner had been respectful, compassionate, and most importantly had answered their questions regarding the death of their child. Where the coroner was able to say that death was instantaneous, parents felt relief. The issue of whether the child suffered was put to rest for the parents. For others the detail the coroner was able to provide helped them in their efforts to re-construct the death scene and make sense of the

death. One parent expressed appreciation for a coroner who apparently was removed from her child's case:

> *...The first coroner who got removed from the case because he spoke to the media and said it wasn't fair to the family – all these delays [the case had had several adjournments]...And I talked to the coroner, and I found out, yes, in fact I needed to know three questions: did he die instantly; did he suffer at all, and I got the answers. It was instantaneous. He never knew what hit him. There was no suffering.*

Unfortunately for three of the parents in this research, their encounters with the coroner were significantly distressing to them. For one parent, the time the family had alone with their child's body after the death was rushed because the coroner wanted to receive the body immediately. This parent felt it would have been helpful to have had more time with the child. The parent said, *"I just think he could have waited ten more minutes"*.

Another parent was pressured to see her child, as the coroner wanted to take possession of the child's body. When the coroner finally came to see this mother, she experienced his attitude as extremely cold. The child had choked to death in the care of her paternal grandmother, who was present when the coroner entered the room. He indicated that an autopsy had to be done, and when asked why an autopsy had to be done if he already knew what had happened, the tone of his response was distressing to the family:

> *And he turned around and he said in this evil kind of response "We don't know what happened. We don't really know." You know, like, very cold...and I said to him, I thought that was inappropriate. He could have turned around and said, "It's just formality. We have to do it for the records". That sort of thing. But he said, "We don't know what happened. Nobody knows what happened". Just very cold.*

The natural guilt feelings the grandmother experienced were greatly exacerbated by

the coroner's attitude, and some more complicated family dynamics were stirred up as a result of what they felt was an implication of foul play. This parent was able to call and confront the coroner with her feelings on the matter later. She said:

> *And I told him, I said "Just to let you know what we went through at the hospital. I think that maybe you could have come across in a different tone. And you know, more sympathetic. And said, "This is just a formality. This is what I have to do." ... And he said, um, "I'm sorry you feel that way. It's not my job to comfort you."*

In addition to this experience of the coroner, this mother was further distressed by delays in getting the report, having to pay a fee for it, and having her child's name spelled incorrectly on the autopsy report. She felt that the coroner could have been more respectful and demonstrated a little human warmth. She felt that these difficulties with the coroner, which were still distressing to her at the time of our interview had a negative impact on her grief:

> *I think you go through time periods where it's something to be upset about instead of the actual occurrence. And it just makes it worse. Instead of concentrating on what's happening and dealing with it, your grief, you're dealing with these people. And thinking "How can they be that way" and "Why are they thinking this way" and "How can somebody be that ignorant", instead of concentrating on healing and your loss.*

This expression of how interventions that added to the trauma took away from the parent's ability to grieve and to heal were common to many parents, not only with respect to coroners, but to all of the professionals in this research.

Another parent felt similarly traumatized in dealing with the coroner. After begging the coroner not to do an autopsy, this mother was told that she would benefit from one, as she would learn whether or not her daughter had some such condition as cervical cancer. This made no sense to her as her daughter had died in a pedestrian accident at the age of

14. She experienced the coroner as cold and unfeeling. She felt that he should have simply explained the need and only carried out as much of an autopsy as was necessary to determine the cause of death. When she and her husband went to see the coroner later to discuss the autopsy and receive a copy of it the experience worsened. First they were charged a fee for the autopsy report of approximately $25. for six pages. When they went through the report it contained a multitude of errors. This parent attempted to point out the errors and was even more distressed by the discussion that ensued:

> *On the report they said there wasn't any visible scars whatsoever. When I questioned him "What about the long one on her arm?" [he replied] "I said there was no visible scars". When they had her listed as age 16, I said that my daughter was 14. Then they had her autopsy report, it was performed April 5. My daughter died April 6...And finally the coroner looked at me and he goes to me, he says "Ma'am, are you trying to tell me this is not your daughter? Your daughter did not die?". I says "Sir, this is not what I am trying to tell you. I'm just telling you why is there so many mistakes?" And, I almost came back out and said, because this was at the time of Paul Bernardo and Holmolka. I almost felt like saying, because they had just dug up Tammy Holmolka's body to do another autopsy. I almost told him "Now I know why they had to re- you know, to dig up Tammy Holmolka to do another autopsy because of the shoddy workmanship in this office...The first page had I think six mistakes on it...You have to resolve those issues before you can carry on with your grief. For me. That's particularly with me. I found a lot of the issues I had to deal with, to get past, in order to get on with my grief.*

For the parents who experienced coldness and disrespect from coroners, this added to their trauma. The errors on autopsy reports discussed by two of the parents in this research have been reported to me in clinical practice by many other parents, and all find them distressing. Not only do these things add to the parents' trauma, but as described by the parents, become obstacles to the grieving process. Errors on the autopsy also relate to the parents' experience of the social value of their child and social recognition of the extent of the personal loss the child's death represents, a theme that came up in different

ways in this research. As a point of interest with respect to parents being charged a fee for the autopsy reports, which I have also noted in clinical practice, the Chief Coroner of Ontario did inform me that only reasonable photocopying costs may be charged. The Chief Coroner agreed that $25. for six pages was not reasonable.

Social Workers/Crisis Counselors

Social workers in the form of Victim's Services workers or hospital social workers were only encountered by five of the parents (four families) in this research. Because the focus of the research is on the traumatic period of the loss through the funeral for the most part, I did not ask parents about their post funeral counseling experiences. One parent had what may be called a neutral experience with a hospital social worker, from which we might take a lesson as professionals in the field. This mother was hospitalized due to her injuries in the accident that killed her child. A hospital social worker came to see her, but indicated that she would be transferring from the hospital shortly. While the mother felt that the social worker was probably compassionate, she did not want to invest in a relationship with someone who was preparing to leave as they spoke:

> *I do remember her saying she was going to have a transfer, and possibly that's why I tuned her out. Because I thought "Well you're not here long term and I can't give myself to something that's just going to go".*

This highlights the importance of being able to follow through during the crisis.

The other four parents had very positive experiences with social workers, which they felt were helpful in making it through the trauma. Again, these experiences were focused around the provision of instrumental support, compassion, and information. Compassion, or the provision of support was the key in social work interventions. Some parents said that if such a person were to have been available to them, they believed it would have

been helpful. One parent said that the hospital social worker was compassionate, and helpful in referring them to community organizations to assist them later. Another parent felt supported by the hospital social worker, particularly when she experienced difficulty with the coroner. The support of this social worker helped her to feel that she could confront the coroner with her experiences. The social worker did this by validating the parent's experience and confirming her recollection of it. The social worker was additionally helpful in deciding whether her other child should see the deceased child's body at the hospital, and was comforting to her.

Frank's parents experienced the most striking work by a social worker and a Victims' Services worker. Shortly after the accident occurred a Victims' Services worker arrived to assist them. This worker drove them around to hospitals, listened to them, reassured them, provided them with information, was calm, reassuring, empathetic, broke things down into manageable steps and helped them organize themselves in the midst of what felt like chaos. The worker provided them with information and choices about the things that had to be done. At the hospital, the social worker there added to their support network in many of the same ways:

> *First impression was "Right, What have we got here? You're fine. We'll take care of you". Just this firmness of knowing that everything was going to be ok. And not panicking at the whole situation. That gave me comfort. Because I would say I was on the verge of panic the whole day. Or, I would just go into this deep despair, and then I would come out of it because I knew I would have to carry on. Actually, I was going up and down all day. With [the Victims" Services worker and the hospital social worker] there, I could just let go for a while. That's the feeling I got from both of them, that you know, you can cry, that's fine. It was as if "don't worry about the external things. They will be taken care of". She was just there. She didn't push herself on to us... She was just like a block that was there...They were there, although they were not there all the time. They supported us. It was very helpful in dealing with – now, and what might be*

coming in the future.

These workers also normalized and validated some of the experiences and feelings that the parents were having. Through the provision of instrumental assistance, compassion and information they greatly assisted the parents to get through their crisis. Together with the chaplain of the hospital they formed a strong support system for the family that significantly helped with the trauma.

Although few parents had the support of social workers available, the usefulness of such support argues strongly for social work presence in emergency rooms in hospitals, as well as in Victims' Services organizations. Providing instrumental assistance as requested, partializing problems for parents, and advocating for them are all helpful. Showing compassion and strength, respecting the parents wishes, helping to get them thinking about things they needed to do, and providing information are key roles social workers can play.

Funeral Directors

Of the twenty parents in this research, seventeen had specific comments to make with respect to the funeral directors with which they dealt. Seven felt their experiences with funeral directors were very positive and helpful, seven felt that their experiences were negative, and three had mixed experiences. Among the positive interventions funeral directors provided were: providing instrumental assistance through such activities as allowing parents freedom to participate in setting up the visitation room, allowing parents access to the child's body to touch, and running interference during visitation when parents felt overwhelmed; demonstrating compassion by acting in a professional yet empathetic manner, providing support, and providing follow up after the funeral; and,

providing information through helping to guide parents through the process, and making helpful suggestions about the process while demonstrating respect for the parents' wishes.

Instrumental assistance in guiding parents through the protocols and processes of visitation and the funeral was very helpful to these seven parents. When compared to the other seven parents' experiences, one can see the importance of support at this time. Most parents commented on how ill prepared they were to have to plan a funeral for their child. For many of the parents, this was the first funeral they had to plan. It was also a funeral they never expected to have to plan. The funeral directors who provided guidance, but respected parents wishes were seen to be helpful to the grieving process.

> *They were very professional. When they see that you don't need help they were laying back, right? So it wasn't that difficult you know.*

Not making things more difficult was important to parents who did experience difficulty, as will be addressed later in this section. Instrumental assistance that was given sensitively was also viewed as compassionate by the parents. One of the parents in this study described how the funeral home helped her to make the visitation rooms personal, which was very helpful to her in her grief:

> *So we gathered up all his life books, his football sweater, his hockey things. Everything we could find and we set up three rooms of Kevin's life...so it really made it nice for everyone to have that at the funeral home...they've been really great. They did a good job.*

Another parent also commented on how significant it was to her in her grief to be able to make the visitation room into a room that reflected her child, although the funeral director was quite surprised by the family's work in decorating the room.

Funeral Directors have a significant opportunity to be of instrumental assistance and

emotional support throughout the visitation and funeral processes. One parent talked about the role of the funeral director in assisting him to make it through the visitations, both physically and emotionally:

> *They were helpful and quite good. Like during the viewing they would make sure I was there for the viewing. And after a viewing they made sure I knew when the next one was and that I knew what was going on. They had a private room for me to go to when I didn't have – when I couldn't stand being in the viewing anymore with too many people around. They would act as a buffer so that when I had people come in, they would ask me if I wanted to talk to them. And if I didn't want to talk to them they would send them off.*

While many parents commented on how the funeral directors were willing to make changes to the appearance of their child's body if it was not to their liking, one parent described how helpful it was to her in getting through the trauma of the death and funeral to be able to be supported by the funeral director in participating in preparing her daughter for viewing:

> *When we were at the funeral home, I remember seeing Kayla and her hair was all hair sprayed and it just wasn't her. It was usually a mess and they had it all straight. And not curly. And I remember saying "What are you doing? This doesn't even look like her". And she [the funeral director] was very nice. She went and got me something so I could fix her hair. She went and got me water. She said, "You can do her hair. You can do whatever you want." And I remember putting nail polish on her. Like, she was very inviting with everything. She was very supportive.*

Sensitively offered instrumental assistance was perceived as empathetic and supportive as described above. Other compassionate interventions were identified with respect to follow up or outreach. Two parents indicated that the follow up phone call or visit from the funeral director was very helpful in the days immediately following the funeral. Others mentioned that the openness of the funeral director to be contacted afterwards was supportive. The professional, competent yet compassionate manner of

many funeral directors was seen to be very helpful in getting through the difficulty of the funeral. These findings are supported by Kalkofen's 1998 recommendations for funeral directors, which identified the need to offer information, support and access to the child's body as well as the to offer the opportunity for participation in the preparations and planning for visitation. While some parents' experience of the funeral directors was that many of them were very young they did feel that these young people made an effort to help them.

The negative experiences of parents in this research included a lack of instrumental assistance, for example failing to assist in guiding the process, and making assumptions on behalf of the parents without asking about their wishes. Failure to act in what was perceived as a compassionate manner included the apparent inexperience of many youthful funeral directors to which parents often attributed a lack of compassion. Lack of assistance in providing information was demonstrated by not giving suggestions or assistance in negotiating issues (particularly in divorced families), and not listening to the needs of parents. The information provided in what was experienced as the blatant "sales" side of the funeral business was at times perceived as a lack of compassion Even those parents who had positive experiences often commented on the business aspect of the funeral production:

> *Now we just have to pick out the coffin, right? So they take you into the coffin room...and they've got like 25 or 30, err, things in there, and you almost get into a state of, err. It's almost that same feeling when you go to Macdonald's and they say, "Do you want fries with that?" That kind of thing.*

Another parent expressed a frequent theme regarding the business aspect of the funeral industry, as well as the youthfulness of the funeral directors often encountered:

But I had this young guy. I felt like he was a kid. And he was. I don't know if he would have been 24, 23. He didn't look very old, boy. I don't know, maybe I'm not seeing things right. And I – there was one point I got up and left, because he, um, gave off that salesman air or something. That salesman pitch. And I just left. I had to; not so much calm down or anything like that. Just try to gather my thoughts. Well I guess he tried. I mean he's got a job to do too. I think maybe he was too young. That he didn't know. I had the feeling after, and even now when I think about it, I think he was overwhelmed. I think so. I think he was – I mean I cried through that whole thing. That was the hardest job I had to do in my life...I mean it was basically, I felt like – you know how you're arranging your wedding and you're flipping through a book? That's what it felt like. I hated it. It was kind of business-salesman-like. And yet at the same time it was "Could you hurry up. This is starting to touch me."

One parent expressed concern over the way the funeral director dealt with making funeral arrangements for her infant. She described the experience as being "nickelled and dimed" with respect to every item's cost. The funeral directors focus appeared to be on money, rather than ensuring they had a positive experience. He also did not inform them of the SIDS Foundation when they were trying to decide where they would request donations go to. Their child died of SIDS. The negotiation of arrangements was a terrible experience for the family. Fortunately for them, the particular funeral director went on vacation in the midst of their time at the funeral home, and the director who assumed responsibility for their child was much more open to their wishes. This parent wrote a letter of concern to the funeral home in the hope of improving the situation for other parents to come.

Another parent had a similar experience regarding the emphasis on financial aspects of the funeral home arrangements:

So the funeral people came over. We didn't know what to do. So the young guy said "You could put her in a box that cost $45." [This parent's daughter was being cremated.] And I just went berserk. And I ran, I ran, I just simply ran away. My daughter dead in a $45. box. It was so

inappropriate. In fact a good friend was there and she wrote the funeral home about it. She said it was totally – I mean I ran, I ran in the house and then I ran around. I was just frantic. To me it was saying "Is that all she's worth?", you know. And why put a price on it at this point? I mean no matter how rich or how poor you are, when you are burying your child price is not an issue. It's to do the right thing. And to mention the box cost $45. was, I just went totally berserk. For some reason it was the money thing that hit me. That was my experience of it. In fact it does stay with me. Because I was at a funeral in April and he was there...and I saw him walking down. And my friend who was with me felt me take my breath. And I still haven't gotten over that – that box thing and the money. I guess I'm still really tender...the whole issue of putting your child in a box, your dead child in a box, is so very, very sick to me.

Another parent also detailed the horror she experienced when the funeral director made an assumption that social assistance would be paying for her daughter's funeral, without ever having discussed it with her. While parents expressed their understanding that funeral homes are a business, and that finances must be dealt with, they generally felt that funeral directors need to recognize that they are burying a child, and therefore need to be sensitive in their approach to the parents.

Along with sensitivity to the emotions finances may evoke, some of the parents added that they experienced a lack of sensitivity to divorced families and other issues. One parent described being left in the "coffin room" for an extremely long period of time with no assistance. She and her ex-husband were not able to negotiate the choosing of the casket themselves, or the vault. She felt that the funeral director could have been of some assistance. Another mother felt that the funeral director did not keep things running smoothly during visitation, as he should have. In fact, one young man brought in two bottles of beer and stood at the casket and drank one. The funeral director told her that they allow for this type of behaviour.

Other issues included not allowing the family private viewing time, either before

visitations began, or immediately before the funeral. Those who did not receive these special times spoke of how important it was to have had such moments with their child, both for themselves as well as for the child's siblings:

> *I didn't know we could spend as long as we wanted with Jamie with the casket open. It wasn't offered. I didn't think of asking.*

Failure to assist parents with suggestions that would have been helpful to the process of saying goodbye to their child was also raised by parents. Aside from spending time with the child, respecting wishes regarding arrangements was also discussed. One parent was not able to understand why the funeral home would not allow the pallbearers to carry the child's casket into the church. Another was asked how many cards they would need, which was a question they were in no position to answer but felt the funeral home could have provided some guidance.

One parent had a particularly traumatic experience regarding the state of the child's body at viewing. The funeral home indicated they had had some difficulty in repairing some of the damage caused in the accident. When the family finally saw the child, which did not occur until the public viewing had begun, the child's nose was flattened out and her beautiful spiral permed hair was straight:

> *So we went in there and what we saw just blew our mind. They had cut her mouth. They had cut her mouth and you could see where they had tried to stitch her mouth up. And she had no nose. The nose was up and over flat. Her hair was as straight as a pin. Her spiral perm was gone. No idea how they straightened her hair. My daughter! Her hair was as straight as a board. And my daughter wanted a spiral perm so bad, and she had got it two weeks before she died. And that was one of the things that gave me comfort. That she got some of the things she wanted before she died...Well who would you think you would see a body like that. Who would – who would display a body with no nose and stuff? Like, who would do that?*

This parent felt forced to close the casket. She subsequently discussed the problems with her daughter's face and hair with another funeral director, and she believes them to be the result of negligence on the part of the funeral home. More importantly, when she approached the funeral home later with her concerns, they denied what she and her family had seen. In the interview it was clear that this issue is still distressing for this parent.

One couple also had the experience of a young funeral director, whom they felt was inexperienced in loss herself and this inexperience was demonstrated in her lack of understanding of the family's needs. One parent thought she was compassionate in spite of that, while the other experienced her as cold in that regard. They both agreed that the funeral director's youth and inexperience led to some difficulty:

> *She was very understanding. I mean because she was young, I think she didn't gage how we wanted – and what we wanted, what she should show us, what she should not and what she should tell us about Frank. Maybe not seeing him, and do seeing him. You know, and that sort of thing.*

Because the father had not seen his body, his mother wanted him to do so as her own experience with that was helpful. However, the father felt discouraged by the funeral home:

> *I wanted [the father] to see him, because I knew from my father's death how helpful that could be. And just clarify that that person was dead. As ugly as it was, I wouldn't even say ugly – it was Frank with his head being open. Even though it was a bit gruesome...in my mind it would have clarified everything for him. And at that stage I was still too fragile and I'm not sure how he felt about death, that I didn't push it... Because she had never personally had the need to see the person dead, and because, maybe I'm reading too much into it, people, um, view death as gory, gruesome – she didn't, she didn't encourage that. She didn't encourage [the father]. She didn't understand my need to see him. Or encourage him to want to see him.*

Because the mother did not want to push her feelings regarding viewing on to her husband, she left the decision with him. He on the other hand felt pushed away from seeing his son, and this has had long term negative consequences for him in his grief:

> *She was a bit pushing that way. I did not ever have any doubt about something like that – it's very hard. It's your child. I would have loved to have seen him again, and I also think the kids should have seen him again. Ah, it's happened and we can't change it but she really pushed me that way. And I think they should be a bit more, I don't know, understanding. Or they should try and encourage it even though – it doesn't matter what the injuries are. ...They should be more supportive towards seeing the body. Whether the body has been mutilated or not. [If he had been able to see his child's body] I think a chapter would have ended for me that is now still open ended. It's like a never-ending story, do you know what I mean?*

One parent summarized her experience of the funeral home:

> *The thing that strikes me the most is that you are so much a victim of the industry at that point in time. I mean you have no, no option. You have a child who has died and you have to make arrangements to bury your child. And you have very little time in which to make these choices. They want to know where is this body going. And then they tell you - you have to have visitation tomorrow night and then the next night and the funeral has to be within so many days. And you've got these really important decisions to make that you have to live with for the rest of your life, and no time in which to do it. They were very focused on doing their job and what they were used to doing. And anything that we wanted to do that was different from what they were used to doing, they didn't really want to have any part of and were uncomfortable with.*

The range of experiences parents in this research had with funeral directors does reflect what I have seen in clinical practice. Certainly funeral directors are in a position where they have both the family and the child's body for the longest period of time after the death. They have a unique opportunity to assist parents in the beginning of their grief journey by providing opportunities to ritualize the final contact of parents with their children in a manner that is meaningful and helpful to the parents. They also have the

opportunity to support parents in access to their child's body, which is helpful in the first phase of grief – the intellectual and emotional understanding of the loss. The parents in this research, for the most part, felt that the visitation and funeral were very important in their healing. Some described it as the last opportunity to take care of their child or to provide something for their child. While everyone acknowledged that funeral homes are a business, many felt that there should be more emphasis on the fact that they are in the business of helping people say goodbye to a loved one.

Chaplains and Clergy

Eighteen participants discussed significant involvement with various clergy during the research interviews. Although all had some type of funeral service for their child, two parents did not comment on the effect of the clergy's involvement in their situations. Eight parents were involved with hospital chaplains, while the other twelve parents did not have access to this service. Of the eight parents who met with hospital chaplains, all but one also had other clergy for the funeral service. One of the parents who did not receive service from a hospital chaplain felt that such a service would have been beneficial. Brabant, Forsyth, & McFarlain (1995) detailed the significance of the support of the clergy in their study. Families who experienced the clergy as supportive identified being available, compassionate, and following up with the family as very important. Those who had negative experiences identified lack of attention, lack of compassion, lack of follow up, being late, and failing to understand the significance of the loss as having a major effect on them.

Four of the parents had mixed experiences with the clergy they met. One had a positive experience with the hospital chaplain, but not the clergy person who was

involved with the funeral. Another had an unhelpful experience with a hospital chaplain, but very helpful experiences with their church clergy person. The other two parents had mixed experiences with their own church clergy person.

Three parents had negative experiences ranging from mildly unhelpful to severely distressing. Two of these parents' experiences were with their home church clergy, while one was distressed by the system of on-call clergy and chaplains in general. One parent also commented on the lack of support experienced from their home church community in general, and the negative impact that had on her faith. The two parents who had serious issues with their own clergy also discussed the impact of those experiences on their faith and religious practices.

Eleven of the parents had positive experiences with chaplains and clergy and gave detailed information with respect to what they found helpful about their interventions. In general the helpful behaviours ranged from taking time to find out about their child, being present for support, showing compassion, respecting parents' wishes, and being straightforward with them. Again the themes of provision of instrumental support, compassion and information dominated the discussion respecting clergy and chaplains. Many parents found that the hospital chaplains were far more helpful in providing information than many doctors were, and were more direct about what was happening to the child.

Clergy and chaplains assisted some parents instrumentally, driving them to the hospital, sitting with them at the hospital, making referrals to Bereaved Families, or providing counseling themselves for the family. Parents who had positive experiences commented on the clergies' guidance through the process and willingness to respect their wishes

regarding every aspect of the funeral. Follow up home visits and phone calls were also meaningful to parents who received them.

The clergy person's interest in the child was of great importance to the parents. When clergy asked about the child in order to prepare the service, parents felt supported. This was particularly true for parents of older children. When the clergy person did not know the child well and went to some effort to ask about the child's interests and character, and even to use a preferred nickname, the parents felt that their child was valued, and that the eulogies were meaningful. One of the mothers gave a detailed description that illustrates the significance of this intervention well:

> *Our [clergy person] was wonderful. Very supportive and very helpful. [He came and asked questions about their son, as he had not known him]. By the time he did the service, he actually knew Ian pretty well. And it was really neat too, Linda, because he, um, he – we were choosing the music and he said we would have to use a hymn titled Spirit of Gentleness. And I kind of looked at him and he said that was Ian's favourite hymn. And I said "It was?" and he said, "Yes". This person who had taught Ian in Sunday school in grade six or seven had told him this story about how, every Sunday he would ask that this hymn be sung. And he drove the whole room crazy because every Sunday they had to sing Spirit of Gentleness. And I had no idea that that meant anything to him, but [the clergy person] did.*

Making the sermon or eulogy meaningful was mentioned as being very helpful by many parents. One parent particularly appreciated the clergy's efforts to recognize the mixed denominational backgrounds of the people attending the funeral. Some parents had tapes of the service and in one case a chaplain typed out the entire service for the parents

The combination of instrumental assistance provided in a compassionate manner was very significant. One parent shared her experience with a clergy person who was

particularly sensitive and supportive:

> *And he helped us a lot with figuring out what we wanted to do, and who would do it. He stepped us through it all. He made contact right away and spoke with us frequently, sometimes two or three times a day. He kept a very close eye on us and talked to us a lot. And came over and had tea and phoned and said "Are you guys ok? Do you need me or not?" I mean he was wonderful. He was a major support. And I've often thought about the previous minister who was not a people person. And I've thought how this experience would have been if he had still been here. And I kind of have a feeling in some way that there was some divine intervention that arranged for [their clergy] to be here when we needed him to be here. Because the other person wouldn't have done anything anywhere near like what he did in terms of supporting us. So he was terrific. He came, he just, he listened. A lot of "How do you feel about – what would you like to do about – how would you feel about". And if I didn't know, he would make a suggestion. But he would never say "Well I think you should do this or that". But he would say "How would you feel if we did it this way?" and he'd make a suggestion. From our point of view, he was the rock, the steadfast port in the storm the week after Ian's death.*

Information was also viewed as a significant contribution that clergy persons and chaplains could provide. The information that accompanied instrumental assistance around the funeral was very important. Many parents had no previous experience with arranging funerals and appreciated the assistance that they received from the clergy person or chaplain with whom they were involved. Clergy and chaplains were often able to obtain information regarding the dying child's status as well. Chaplains generally were highly regarded by parents in this regard. Two parents specifically spoke of feeling that the chaplains were not only helpful by getting information on their child's condition for them, but also were more honest about the child's status than the doctors were, and generally providing support that was helpful later in processing grief:

> *...She also asked whether we would like to see a chaplain. And when I think of a chaplain I think religion. I don't want to be bombarded with religion. No, please. And err, I'm glad we did because she was the most*

wonderful person. She gave us support when we were in the ICU... And she would inform us what they were doing with him. She was always there for us...Just a certain aura about her. You know I think we needed somebody like that. They're always concerned. She's just, some people are just so genuine and it's just right off the bat...[She was with them when the child died which was] important, important because um, she came in. She, she – we wanted her to give Jamie to God. I asked my friend to phone her up and ask her if she would come and do Jamie's funeral service and – because – I – I couldn't. Because I was afraid she would say no and that would just devastate me because I had grown so close to her. And she said yes. And she even typed out the funeral service and everything. Because I didn't hear a word of it almost. I just was so emotional. [She tried to be] helpful after, for keeping his memory alive and getting in touch with what really happened and to work it through.

For this family the chaplain was a solid support. Their own clergy person told them on the telephone that he would come to the hospital, but never showed up or called to explain. The impact of this is that this parent doesn't care for attending church any longer, and would still like to know why he did not show up.

One family, who had no ties to any church, received assistance from the hospital chaplain who found a church and a clergy person for the funeral for them, and arranged for the clergy person to attend the hospital as well. The chaplain continued to spend time with the family to provide support while another of their children was hospitalized. This chaplain provided significant support to the family, and again the clergy person doing the service took the time to find out about the child, asking the family to share some of their experiences with him.

While the themes of instrumental assistance, compassion, and information predominate, they are clearly intermingled. The impact of supportive interventions from clergy and chaplains left a lasting effect on families. One mother told me that they still talk about how helpful the chaplain was, years after their child's death.

Some parents were not so fortunate in their dealings with clergy. As previously mentioned one parent had a clergy person who failed to show up at the hospital as promised. Another parent's clergy person promised to visit the home but never did. One parent was offered the services of the chaplain but preferred her own clergy person. This parent was somewhat distressed that the hospital could not easily access an on-call clergy of her denomination to attend at her son's deathbed. One parent felt rushed at the hospital because of the presence of the doctor and the chaplain:

> *...And I felt like we weren't there for very long, and it didn't seem like the – the doctor was there and I guess it was a chaplain...and we asked to pick the baby up and they both just stood around kind of waiting for us to like finish with our good-byes, kind of thing. So I kind of – I felt like we weren't – we weren't given any time. Because this doctor and [the chaplain] were standing there watching us. We weren't actually able to – you know what I mean – not say proper good-byes but maybe spend as much time as we might have liked to have spent.*

Another parent described having to comfort her clergy, as it was his first time experiencing the death of a child in his pastoral charge. This parent felt that had a chaplain been present it would have been very helpful as they have more experience with sudden death.

Two parents expressed anger at their clergy for a lack of compassion. They both felt the clergy person's response had a negative effect on their grief, and on their faith. The father described their experiences with this clergy person:

> *...And then somebody said that our [clergy person] was coming. And he came in and saw us for a minute. I still think to this day, what a stupid, stupid man he is...Well he turned, he put, he had his hand on my shoulder. And he said that he was going to go and say a prayer over the body! And I could have killed him. And I said that wasn't a body – that was my son! And his name is Luke! What a jerk! Every time I see that guy – I remember at Easter time, and I don't know why to this day I did it, and I'm sorry I did it in a way. I went and said sorry to him. I apologized for*

what I said, and I wish I never had. And I don't know why I did it because this guy is still a jerk. I have no respect for him...I'm so disappointed. I remember the [clergy] came to the house, and some of our friends told me that I put my arms around him and cried. And I remember it too. And, and I might as well been hugging that pole. You know, I'm looking for something to lean on and it was like "Oh my God, what am I going to do now." You know the guy didn't have a clue, didn't have a clue. You know, his hands were down by his side. Not even a pat on the back, you know. Nothing...I mean they marry you and they bury you. There's you know, I mean that's the best you can offer? Whoa – you're a crappy [clergy]...I guess I've lost a lot of faith in the people you should have faith in and trust in because they weren't there for it

Clergy and chaplains have the potential to provide great assistance and comfort to parents in the crisis of the death. Clearly hospital chaplains can play a significant role where they are available. Providing information and support at the time of the death can reduce the trauma the parents' experience. Demonstrating compassion and an understanding of the immensity of the loss can give parents a great deal of support. Helping them to plan their child's funeral in a way that is respectful of the parents needs and wishes assists with the beginning of grieving. Providing some follow up contact when desired by parents can be enormously helpful. In addition, the trauma of the death of a child, which precipitates a shattering of the assumptive world, may call the parents' faith into question. The support of clergy at that time may strengthen the parents' beliefs and faith, which may be helpful in the long term grieving process.

The following summarizes the helpful interventions of each professional group experienced by the participants:

Summary of Helpful Interventions

Professional Group	Interventions
Police	. helping to contact relatives/friends . transportation to the hospital . being thorough in the investigation . respecting parents wishes . providing information . demonstrating empathy and sensitivity
Nurses	. preparing parents for seeing the child's body . providing information re: status of child . offering food, blankets, a cot etc. . helping parents get medical attention for themselves . explaining procedures and processes . comforting the dying child . providing empathy and support to parents and family . ensuring access to child's body, time and privacy . offering a naming ceremony (stillbirths) . respecting that a real baby was born and lost (stillbirth) . normalizing and validating feelings
Doctors	. meeting medical needs of parents . showing compassion . giving information .explaining procedures and processes . providing referrals and follow-up
Coroners	. showing compassion and sensitivity . providing information . giving access to the child's body, time and privacy . ensuring accuracy on documentation
Social Worker/Crisis Counselors	. normalizing and validating feelings and experiences . providing information about grief . providing referrals . obtaining information for parents . offering assistance in problem solving issues . listening . facilitating the meeting of basic needs of parents . advocacy
Funeral Directors	. allowing participation in setting up visitation room

	. access to body . offering opportunity to assist in final preparations . running interference during visitation . ensuring smooth visitation and funeral process . providing support and follow-up . encouraging the personalization of the visitation/funeral
Chaplains and Clergy	. being available . following through with commitments . assisting in transportation, contacting friends & family . learning about the child to personalize the funeral . respecting parents' wishes re: funeral . obtaining and providing information . attending at hospital and home to be with parents . suggesting appropriate referrals . providing tapes of funerals . follow-up support and counseling if necessary

Other Issues

In the previous chapter the impact of the media on parents' level of trauma was mentioned. The invasion of privacy and level of intrusiveness was often traumatizing for parents. In addition to the difficulty with the media, several parents were involved in inquests, criminal trials and civil litigation that went on for years after the death of the child. The effect of these procedures was essentially like tearing a scab off of a wound that was not fully healed. It is outside of the scope of this dissertation to examine the impact of these systems in detail, however it is important to note that the impact is strong. Parents often feel that they have to be at such proceedings to represent their child. I experienced a sense of protectiveness of the deceased child in the parents' description of their need to be present during the proceedings. There is often outrage over the minimal kinds of penalties imposed, such as two years less a day in jail, or a $78.00 ticket and a 30-day license suspension for the life of a child. Parents hear that their child has little value when this happens. In terms of the grief process, the parent is held in the

confrontation phase of grief, recollecting and re-experiencing the death and thus they are constantly put back into the most painful part of grieving:

> *It's not like you can have a three-day funeral and bury the person and get on with your life. It's almost two years. There's been a trial, there's now an appeal, there's an inquest. How can you get on when it keeps being dug up? I can't let it be put to rest.*

Going through these proceedings revisits the trauma of the death over and over, and along with it the memories of additional traumas experienced at the time. Professional support would likely be very helpful at these times as well.

Summary

It is apparent from these interviews that professionals have a strong impact on parents at the time of the sudden death of their child – whether positive or negative. Negative impacts add to the trauma, while positive ones help mitigate the trauma and assist parents with the beginning of the grieving process. In terms of instrumental assistance, having their wishes respected, having access to their child's body and having some control over the flow of events subsequent to the death were central issues. In addition, any number of instrumental aids were identified, such as transportation, assisting with telephone calling and so forth. The need for understanding and compassion, and the valuing of the child as a person were also clearly expressed needs in all of the interviews. The significance of information was a theme with most of the interviews. Several themes have emerged from the interviews with respect to the immediate time frame of the death. The need for information and the ability to make sense of the death are central to the grieving process.

While the provision of instrumental supports, compassion and information were

viewed as significantly helpful from all professionals; there were individual differences between some of the various professional groups. Police provided positive interventions through giving instrumental assistance, particularly regarding transportation and helping families access supports. The demonstration of compassion through respect, thoroughness and empathy were viewed as helpful. Further, the provision of timely information was an extremely important intervention police could provide. Positive instrumental interventions that nurses could provide were related to the meeting of parents' physical needs. In terms of compassion, the presence of nurses and their comforting of the dying child and the parents were key. Assisting parents in preparing for the death of their child was helpful. With respect to information, explaining processes and procedures, giving information regarding the condition of the child and preparing parents for death of the child and the viewing of the child's body were perceived as very helpful. Doctors were viewed to be helpful when they met the parents' instrumental needs for their own medical care, were compassionate by demonstrating empathy and providing some form of follow up to the family, and were willing to provide information regarding the child's medical status and answer questions regarding the death of the child.

Coroners had the opportunity to provide helpful interventions by demonstrating compassion and by providing key information with respect to the child's death. The provision of information was seen to be the most important role the coroner could play in assisting the parents at the time of the child's death and afterward. Social workers and crisis workers were able to provide a great deal of instrumental assistance to families that was very meaningful. Providing community referrals was important, as was offering to

assist families in dealing with contacting people, providing transportation, advocating for families, and assisting with problem solving. In addition, their compassionate presence and emotional support was the most significant involvement they could have. Recognizing the significance of the loss and validating and normalizing feelings was very helpful. Where they were able to assist families in accessing information and explaining processes, this was viewed as very helpful. Instrumentally funeral directors were helpful in guiding parents through the process, making helpful suggestions, providing parents opportunities to assist in preparing the child or the room for visitation, running interference during visitation when parents felt overwhelmed, and providing follow up after the funeral. Demonstrating compassion was clearly important. While parents recognized that funeral directors are running a business, those funeral directors that acknowledged by demeanor and action the significance of the parents' loss were experienced as compassionate. Taking care to present the child's body well and ensuring that parents had private time with their child's body was another way of demonstrating compassion that was helpful to the grieving process. Most important was demonstrating respect for parents' wishes regardless of how strange they may seem. Providing information regarding visitation and funeral procedures and processes was also very helpful to parents. Sensitivity around the financial aspects of the funeral arrangements was also viewed to be very important. Helping divorced families negotiate their differences was also important. The role of the funeral director was often a key one. Understanding how to be helpful to parents at this time can have a strong impact on the parents and their grieving process.

Instrumental assistance from clergy and chaplains regarding funeral planning was

highly valued in this research. In addition, some clergy provided other instrumental assistance that was helpful, such as transportation to hospital, being present with them, making referrals, providing transcripts or tapes of the funeral service, providing counseling and problem solving. Compassion was demonstrated through meaningful eulogies, respect for parents' wishes, and providing emotional support. Many chaplains were able to offer information at the hospital for families, which was most helpful. Positive interventions not only assisted the parents with their grief, but also had a positive impact on the parents' continuing faith.

In the above discussions, it is evident where professionals have assisted, and where they have hindered the parents in their trauma and grief. The need for instrumental support, compassion, and timely and sensitively provided information was demonstrated. The expressed wishes of the parents were that professionals not assume what they needed, nor should they "take over"; rather they should respect the parents' wishes. Golan's (1979) work in Crisis Theory is highly applicable in these situations. Professionals not owning the problem, listening to clients, and allowing them to make choices, as Crisis Theory suggests, were perceived as highly important qualities of interventions for the parents in this study. From the themes related to types of interventions emerged five primary themes related to the grieving process and trauma. The next chapter will examine these five primary themes and how those themes relate to the grieving process in general as well as to the reduction of trauma.

Chapter Seven

Thematic Analysis

You are here in my heart, and my heart will go on, and on. (Celine Dion, 1999)

Introduction

This chapter begins with comments respecting the context and emotional milieu of the interviews. I have highlighted specific characteristics of the interviews that stood out for me as a researcher. In this chapter I will outline the five primary themes that emerged in this research study. Each of these themes is directly related to a specific phase of the grief process. For the purpose of the analysis, I will be utilizing Rando's 6 R Processes of Grieving as a model to understand the themes. The themes are further related to the reduction of or processing of the trauma of the deaths of the children. Each theme is presented in detail. A table will be presented that relates the five themes of this chapter to specific interventions that professionals can implement in order to facilitate the reduction of additional trauma to the parents, and it is hoped, to facilitate the grieving process. The chapter concludes with a summary of the information presented.

The Context of the Interviews

In the process of analyzing the interviews in this research, several notable commonalities were present. The intensity of the interviews was striking. Although five major themes emerged throughout the interviews, the context of the interviews themselves was significant.

Most of the parents in this research made a point of telling me things about their deceased child. Some of them showed me many pictures of their child. Some showed me things their child had made, or personal belongings of their child, which they held dear as keepsakes. After many of the interviews, I had a sense of who their child was, what they were like, and what they liked to do. In others, I had a strong picture of the nature of the relationship between the parent and child. The value of the relationships with their children and the immensity of the loss they had experienced were evident in each interview.

Each parent gave detailed information about the death, and often about the circumstances leading up to the death, or the death surround. As well as parents could recall, the deaths were described in minute detail. The time surrounding the deaths was also described in significant detail. One parent, who could not remember some of the detail, was distressed by the missing pieces of time. In recounting the story of their child's death, many of the parents went beyond remembering into reliving of the experience. As previously indicated, occasionally the memories held the intensity and frozen-like characteristics described in traumatic memories seen in PTSD. I was intensely moved by their stories, and felt privileged to have been allowed into their grief. For some of the parents, my phone call requesting an interview moved them into a reflective period regarding their experience of their child's death. In two situations, parents had contacted certain professionals regarding issues they had previously wanted to address, but had not been able to make the attempt until they were asked to participate in the interviews.

Five themes emerged in the interviews, which I will outline here and then examine in detail. These themes are directly related to the grieving process and to the processing of the trauma of the death. The themes arise from the experiences parents had with professionals, as well as from their own identification of their needs and emotional experiences. From these themes, one can clearly see how sensitive intervention can be of assistance to parents in moving through this traumatic time and beginning a healthy grieving process.

Identification of Primary Themes

The first theme that was identified was the need to reconstruct the death scene of their child. For parents who were present for the dying and the death, the information they needed to remember and process the death scene was known to them. For those who had not been present for the death, or for the accident that had caused the death, the need for information to piece together the last moments of their child's life and to develop a death scene script was often intense. As will be described by the parents, many of them went to great lengths to obtain detailed, specific information with respect to the last moments of the child's life and exactly how he or she died. This information has two purposes that relate to the grieving process; one to assist with processing the trauma that stems from the violation of the assumptive world (Rando, 1998), and the other to accomplish the first phase of grieving – intellectually and emotionally understanding the loss (Rando, 1993). The need for information and the significance of parents feeling adequately informed (Winje, 1998) has been discussed earlier. Intrusive remembering allows parents to assimilate the experience of the loss (Lindemann, 1944), and modify the level of affect associated with the trauma the death of the child creates (van der Kolk & McFarlane,

1996). It is a normal response to trauma. Information assists in the construction of a narrative regarding the trauma. Failure to construct a narrative may lead to the development of PTSD (van der Kolk & Fisler, 1995).

The second theme that was present in the interviews was the feeling of loss of control and shattering of the world the parents knew prior to the death. This stems from the shattering of the assumptive world (Janoff-Bulman, 1985; Parkes, 1971; Epstein, 1980 & Figley, 1984). The discussion of this theme, as well as the descriptions from Chapter Six demonstrate the parents' appreciation for those who assisted them in regaining some sense of control, as well as the intense anger many experienced towards professionals who were perceived to have interfered with their efforts in that regard. Supporting parents in regaining control is vital to processing the trauma of the death, as feelings of control help reduce feelings of helplessness and powerlessness, and lower rates of PTSD in trauma survivors (Regehr, Cadell, & Jansen, 1999; Silver, Wortman & Kloss, 1982). It is also important to rebuilding the assumptive world, which is a significant task of the grieving process (Rando, 1993).

The third theme evident was the need to say goodbye. This incorporates the need to have access to the child's body, the need to have professionals demonstrate an understanding of the extent of the loss through treating their child with respect and dignity and showing compassion to the parents, and is part of the process of reconstructing the death scene. Saying goodbye is a vital part of the first phase of grieving, and can also assist in the processing of the trauma. Again, where professionals facilitated this process, parents felt supported, and where professionals were perceived to

have interfered, for whatever reason, parents felt additionally traumatized and had increased difficulty with the first phase of grieving.

The fourth theme, the attempt to make sense out of the death and find some kind of meaning in it, is affected by access to information and is related to the reconstruction of the death scene. This assists in the first phase of grieving: intellectually and emotionally understanding the loss (Rando, 1993). Furthermore, it is significant to the process of rebuilding the assumptive world and gaining some semblance of control in a chaotic experience (Janoff-Bulman, 1985; Figley, 1984; & Rando, 1998). The ability to understand and make sense of the death is a factor in the future psychological adjustment of the survivor (Bowman, 1999; Winje, 1998). Many parents shared the struggle they engaged in to make sense out of the death, and to find some meaning in it.

The final theme was the attempts many parents have made to carry a new relationship with their deceased child forward in their lives. This was often attempted through memorializing, ritualizing, and carrying on active involvement in activities related to their child's life and/or death. This theme relates to the third phase of grieving, where the parent moves forward in a new world without the child (Worden, 1991), the relationship of self to the deceased is changed and the parent reinvests in life with an integrated past and present (Rando, 1993). The following table summarizes the relationships of the themes. The balance of this chapter will examine the parents' discussion of these themes and the meaning for professionals involved.

Table One

Helpful Interventions Professionals Can Provide

Processes	Instrumental Assistance	Compassion and Empathy	Provision of Information
Reconstruction of Death Scene	.offering/providing pictures & reports if desired . provide access to child's body . being thorough in responsibilities	. give control over timing and detail of information . provide active listening . present a calm, warm presence	. providing details of death & death surround . timely information . written information . repetition of information
Issues of Control	. listening to needs/wishes of parents . respecting parents' decisions . providing access to child's body	. be sensitive to parents' vulnerability . be present, but not intrusive . offer & provide comfort as requested by parents	. explain procedures & processes . offer explanations if parents' wishes cannot be provided
Saying Goodbye	. allow time and privacy with child's body . encourage involvement in planning visitation & funeral . if desired permit parents to assist in dressing child's body	. show respect for the child's body . make child's body appear cared for (eg cover with blanket, remove apparatus etc.) . provide support	. explain what to expect as child dies . explain what parents will see, hear etc. when seeing child's body . provide information re: processes and procedures
Making Sense of the Death	. inform parents of and provide access to child's medical charts, autopsy report, police reports, pictures if requested	. be an active listener . acknowledge the immensity of the loss . be sensitive to parents' needs . facilitate process of making sense of the death	. provide information re: death, death surround, & outcomes . help process information . be prepared to repeat information often if needed
Carrying the Deceased Child Forward	. assist parents to identify mementos of their child to keep	. be supportive of parents' faith beliefs . support parents in carrying out rituals . provide follow up support if desired	. assist in developing rituals and memorials

Theme I: The Reconstruction of the Death Scene

Over and over in the interviews parents clearly demonstrated their need for information about the death of their children and about the time leading up to the death. Parents particularly demonstrated this need with the police, medical professionals, and coroners, as well as social workers and hospital chaplains. They indicated that those professionals who were able and willing to provide them with these details were very helpful to them in their time of crisis. Parents often stated that they went over and over the details in their minds in the initial stages of the grieving process. Not only did the details help them to understand what had happened, but also going over the details helped them in the process of making sense of the death.

Many parents said that hearing the details from people who were actually present at the death was very helpful. Some parents found answers in the autopsy reports. Reading the detailed descriptions of the cause of death helped them to reconstruct the death scene. For those parents who had difficulty obtaining detailed information, many spent a great deal of time afterward trying to find the information. Some felt intimidated by the system and thus were deterred in their attempts to find the level of detail they felt they needed:

> *As far as her passing away, we, I still don't know what happened. I don't know whether his mother had – I didn't know how long it took for her to die, you know, between – there were no time frames. So I don't really know what happened...Maybe I didn't even persist because I felt like I was being, you know, a pain. He [the coroner] just told me that she didn't, she wasn't alive that long. And, um, he told me the size of it [the nut the child choked on], and the – it went in her windpipe and her lung collapsed and that was the extent I got. Well it would have been nice to have more, maybe if they had an explanation...*

Another parent described how to this day she couldn't understand the accident that

killed her son. This parent, after setting up the appointment for our interview, again attempted to get answers to her questions:

> *Last week I phoned the constable that was on the case. So I did that, but I got absolutely nowhere with him. And I don't even know why he came [to her house]. In fact he was more concerned about my feelings and how I felt about [the other man involved in the accident]. Now maybe he thinks I'm blaming [the other man], but I wanted to find out how if Stephen fell on his back, how a branch he had in front of him could come down and hit his head from behind. But he couldn't answer my question...And I thought if he would come here and explain things to me, then I would feel that it would ease my mind a little bit. Because I had this on my mind since Stephen had been killed, and I just can't seem to get at ease with myself – that it haunts me day and night. Because it's there, and you know, and I sit around questioning, wondering.*

Another mother described the process she went through in needing the details, but struggling to be able to ask the questions and hear the answers:

> *And I remember going downstairs and falling apart. And [her friend] came down and he...and I remember saying, "You gotta take the pain away" and (her friend] going "I can't do that." And we sat and we talked, and I can remember it was a month, and [her friend] tried to start about where the forklift was and I don't know – and I didn't want to know. He always said, " Well it didn't touch his heart." And I'm having visions that the day his body was severed – that his body was severed. Like I can't picture – I didn't know about the ribs. I didn't want to know, ok? I just could not handle that he died. But then you go through, well were did it land? Did it hit his head? No, then it would have squashed his head. You know, and I'm just – and I can't figure it out...Because as I said a month after the death I couldn't even with [her friend] here in my own home. I – I couldn't listen to him. I didn't want to know. And it took eleven weeks before I finally was able to say "Ok, which way?" Saying "Well was his head facing towards Swiss Chalet?" "No." "Were his feet facing Swiss Chalet?"...In a way it was relief. Oh, so he was folded up – because I thought maybe he'd been cut in pieces...So after eleven weeks I had to play the game out. Ok, is the story going to change finally? Are you going to tell me the story? And he says, "I can't tell you that story because that's not the story." I guess it was eleven weeks it took me to finally gain some acceptance that the fantasy world was just that. That the story wasn't going to change.*

One parent shared her experience of going on a quest for information after she had recovered from her injuries, in order to be able to put together in her head exactly what had happened in the accident and throughout the emergency treatment prior to her daughter's death. This mother had a head injury that affected her ability to remember, and thus her search for information started some time after the death of her daughter:

> *Not only was I not there [when Melanie died], but I tried so desperately to search and search in my mind for those lost moments of what did I do in the car. Was I any comfort to them? Did I say any words? Did they say any words? Were they crying? Were they ok? You know, was there any communication at all? And, and I don't remember any of it. It was about two months after that I was pulling together and feeling that I needed to put this puzzle together, because it didn't really make sense. So I began with the doctor. I tried with police officers. I tried with the ambulance. I went to [the hospital]. I needed – I made an appointment with the doctor – [doctors name] was the one that attended. And I, and my purpose was I needed to see the room she was in. I needed to see the ICU area and to talk to him...By this time I had formed images in my mind about what these rooms were like, and I needed to know if it was true or not...So this assistant took us on a tour of the hospital room she was admitted to. It was a very pleasant room, lots of light, right near the nurses station. And then she took us downstairs to the ICU, and it was in the very far room and it had a rainbow, which was very, very nice. But it just, I just remember it must have been so scary for her to be in this room with all these machines. And then I went and met with [the doctor]. [Her husband] and I went together, and I just wanted to know what happened. How did she die? Why did she die?...Then I, a few weeks later I wanted to talk to the police officer. And the police officer came to our home...and he got out the file and he showed us the pictures of the accident that he had, and he showed us the pictures of the roadway, and saying that's where my coffee cup was, because I didn't know where my coffee cup was...I proceeded to contact the ambulance department to ask whether they could tell me what was I like in the car, like, did I talk to them? They refused to talk to me because this was a paralegal matter...The police officer however did tell me that he remembers going in the car and Melanie was asking for her baby. Melanie went everywhere with her Raggedy Ann. And that's what he remembers. He said he doesn't remember any bouts of hysteria. It seemed very calm. He couldn't remember whether I was awake or not. Um, the fire department also refused to talk to me because it was now a paralegal matter and therefore they would not talk to me. And all I wanted was to know what we were*

like inside. Did I say goodbye? Did I kiss her? Was she crying?

This parent received further answers later when her lawyer received disclosure on the case:

> *I guess about two years after the accident, I requested all the files, which at this point my lawyer had had, and all of the transcripts from the hospitals and the emergency rooms and so on. And that was really difficult. I still have those papers. I have all of the nurses' notes. I have everything. But it was very helpful for me to see what had happened, hour by hour, minute by minute. They documented everything. It helped. It helped me to substantiate what I had been told. It was very, very painful seeing the number of times that Melanie was screaming for her mommy. Very painful. And it compounded my guilt for not being there. Because up until then, I knew that this was a three year old. Three year olds don't understand that mommy is in the hospital – she can't come. I knew within my heart of hearts this must have been hard, but to have it confirmed on paper – it affected the last minutes of her life. It was very difficult. The documentation however, was very eye opening...*

This mother described the process of trying to remember and trying to get information as very frustrating, and felt that the lack of information impeded her grief and added to the strain on herself and her husband in their grieving as a couple. As painful as the information regarding her child's last moments was, it was very helpful to her in beginning her grieving and dealing with the trauma of the death of her daughter.

Another mother echoed the story of an intense search for information to understand and process the death of her child:

> *I was desperate for the details. Desperate. I read those papers over and over and over again. I had to reconstruct that accident. I needed to know what went on in the final ten or fifteen minutes before he died, and what happened. Very important. Very important for parents to do. I don't think authorities know how important that it is. That's why an accident is so important for parents to reconstruct. You need that final fifteen minutes.*

More than one parent did not want to hear details at the beginning, but felt that later it

was very important to have them in order to process their grief. In the previous chapter, one mother spoke of how she wasn't ready for the details at the time of her daughter's death. In much the same way, this father was unable to use a lot of information at the time of the death, although he felt some was helpful, and more was needed later in his grieving process:

> *It helped [having information] because at the time you really don't want to hear a whole pile of information...because in my situation I only wanted to know where the guy [who was responsible for the accident] was, and how I could get at him. So they basically were giving me all this other stuff [information regarding the accident] trying to change my mind and get it off the subject [of finding the guy]. But the information was good for later on when things do calm down and you get your bearings straight.*

Another parent highlighted the value of immediate information to her. She was present at the scene of her child's death and was permitted to stay there while the police did their work:

> *So I sat there... I could replay it over and over and over, and just see what happened. Just come to terms with the whole thing.*

This is an excellent example of the work of processing trauma, wherein reconstructing and replaying of the events assists the person in processing the trauma into their cognitive schema (Figley, 1997; Simpson, 1997 & Nader, 1997), and understanding the loss both intellectually and emotionally (Rando, 1993). This replaying helps to modify the affect associated with the event so that individuals can assimilate the event and readjust (Lindemann, 1944).

Clearly the reconstruction of the death scene, and the reviewing of it, is a significant process in working through the first phase of grief and in processing the trauma of the loss. Putting a narrative to the trauma has been described as important by van der Kolk

and McFarlane (1996) and Herman (1992). Seeking information has been described as a normal part of adjusting to a trauma, and feeling well informed as important to that adjustment for parents (Winje, 1998). The need for information that was demonstrated in this research is central to this process. Accordingly, professionals who assisted parents in accessing information were viewed to be helpful, while those who were perceived to have impeded access to information were viewed to increase the trauma. A significant aspect of the access to information is timing. As was demonstrated in these interviews, it is essential that professionals be sensitive to the parents' own time frames around receiving information as well as the amount of information provided at specific time frames. Given the individual differences in needs with respect to amount and timing, it is particularly important that professionals listen clearly to the parents' wishes. To highlight a basic social work tenet: start where the client is. In doing so, professionals can help parents determine when and how much information they need, and can thus support them in the process of reconstructing the death scene. The key in this assistance is the following of the parents leads instead of acting on behalf of them. This concept is central to Crisis Theory (Golan, 1979) and significant in the manner in which professionals can be helpful. Rather than viewing the reconstruction of the death scene as a morbid pre-occupation, it can be understood as a vital part of trauma resolution and crucial to the initial phase of a healthy grieving process.

Theme II: Issues of Control and the Assumptive World

A significant theme interwoven through the interviews was that of control. When the child's death occurred, many parents expressed the feeling that their world had shattered; that things were out of control. Many parents expressed feeling powerless at least part of

the time during the period studied. One father described his feelings of powerlessness while his wife was being assessed to determine the cause of her "profound grief". In the previous chapter, many interventions were identified that heightened the feelings of loss of control, as well as interventions that assisted parents in beginning to regain control.

A sense of control is important at such a traumatic time. Van der Kolk and McFarlane (1996) and Caruth (1995) have noted that a sense of helplessness and powerlessness is a central element in a traumatic event and impacts on the survivor's experience of the trauma and level of distress. The police who insisted on interviewing a mother without respecting her need to absorb the fact of her daughter's death, and the police officers who refused to leave the parents home, staying there with the child's blood on one officer's pant leg increased feelings of powerlessness. Professionals who did not listen to parents' needs, for example in disregarding parents' desire to access their child's body or in rushing the parents through their goodbyes heightened the parents' experience of loss of control. Those professionals who utilized good Crisis Theory practices (Golan, 1979) by providing information and suggestions regarding the death and subsequent processes, assisting parents to make their own decisions, and then supporting them in carrying them out were seen to increase the parents' sense of control.

Individuals with an internal locus of control experience reduced helplessness in traumatic situations (van der Kolk & McFarlane, 1996; Silver, Wortman & Klos, 1980). Further, individuals who perceive themselves to have a higher degree of control over events may experience lower rates of PTSD (Regehr, Cadell & Jansen, 1999). Highly traumatized parents had difficulty knowing how to regain some sense of control and were not inclined to argue with professionals at the time. When they did, they often felt that

their wishes were disregarded. In some of the interviews there was even a sense of victimization experienced by parents. For example in one case, the parents had a lawyer arrive at the hospital in what they felt was an ambulance chasing approach. Another parent talked about having medication forced down her throat at the hospital:

> *They [the nurses] tried to get medication in my mouth...I remember going into that room and them fighting with me to put that pill down my throat. I'd lost that control.*

Her husband remembers feeling helpless as he watched this happen. He also recalls the feeling of powerlessness at the hospital, and particularly expressed this in regard to the issue of an autopsy:

> *I remember going to that room [quiet room] a couple of times, but at one point they made me sign a – they didn't make me sign, I guess. They asked me if it was ok to do an autopsy. Now I often thought after, what if I had of said "No." They would do it anyway...I felt like, I don't know, from then on I felt like I was always interrogated continually. I was kind of intimidated.*

Although parents understand that certain procedures such as forensic autopsies are out of their control due to legal requirements, it would be helpful to be sensitive to parents' needs in approaching them with regard to such procedures and to explain the need for such procedures thoroughly.

One parent described the difficulty she experienced when she attempted to take control of one aspect of the situation:

> *No control. Also with the funeral home I had made one request. I said I needed to see my daughter's coffin lowered to the ground level. I don't need it all the way down into the ground. I don't know why. I can't tell you why. I know I needed to see that coffin lowered to ground level because that was the last time, the last time I would ever – at any time during visitation after hours I could say "Open the coffin" and I could see her. But to me once it sat down at ground level, I'll never get the chance to say to go back and open up her coffin or anything. And when I*

requested they denied it to me. And I said "That's not fair. This is something I need to do." I didn't know why but – I didn't know at the time. I needed to do this. And I persisted on it. It's just like [when] I had to see her in the hospital. So with that they finally gave in and said "Ok fine, we'll lower it to ground level"...So isn't that ironic? What harm would it do to lower her coffin to ground level? I'm not asking them to put it all the way down into the vault or anything. It did nobody harm. Why were they giving me such a hard time about it? Like I said, it's not hurting anybody.

Parents found their own individual ways to obtain some control in what seemed an out of control situation. One parent shared her thinking process wherein she attempted to gain some control in a different way:

We want control as humans over our lives, and we sometimes seek...it's a way of getting control. This was an uncontrollable situation, and as a means of getting control we go through this "what if". [This mother had purchased burial plots and had switched the deeds when burying her first child that died]. So because Kevin was born in 1973 and I have lot 73, I doom that child born in 73 to die. Is that logical? Absolutely not. Does it make sense? Most likely not. But it's my way to gain control – to get control. But I can't have control. It 's not mine to have. But that doesn't stop you as a human. Whatever way.

This kind of counterfactual thinking may provide parents with some feeling of control, however it may lead to or add to self-blame and feelings of personal responsibility (Mandel & Lehman, 1996; Davis, Lehman, Silver, Wortman & Ellard (1996). It would therefore be important for more healthy ways of promoting feelings of control to be facilitated by professionals. One parent summarized her sense of vulnerability and feelings of powerlessness:

...in the beginning you're vulnerable. And I think a lot of them [professionals] take advantage of that in the sense that they figure "Well it looks like you're really going to give me a hard time", you know. You're not in any mental state to do that, and I think some of them take advantage of that. And it's kind of their way, and "This is what I've got planned for you." And I don't know what their situation would be, but I know in mine it was just like they took over, this is what's going on. And I felt pushed

around a lot because you're not in any state or any position to be able to say "No, I'm not going to do this" and sort of stand up for yourself.

As one father said:

You know you get so lost. I really just wanted people to do – do what I wanted them to do, and don't give me a hassle. This is what I want. And I think the more these people [professionals] can understand that that's the way you are, you know, you don't want an argument. This is what you want. You don't need to be told "No you can't do that. You can't do this or this or this". And you say "Well I want that". And, "We can't do that", you know. It's um, very important for you to be able to get what you want, however ridiculous it may seem to them. I think they should be more open to whatever – whatever you want.

The shattering of the assumptive world created by the loss of a child is viewed as the worst violation of the assumptive world that an individual can experience (Rando, 1993). This shattering is often experienced by parents as chaos, and/or a loss of control in their lives. Without a sense of control, parents can easily feel victimized by the circumstances of the death as well as by the behaviour of others around them, particularly professionals. In fact one parent specifically identified feeling like a "victim" with respect to the funeral industry. Without any sense of control, parents are left with a diminished capacity to make decisions that are going to have a lifetime effect on them. Interventions by professionals that facilitate parents' experience of regaining a bit of control will assist them in cognitively assimilating the death, making decisions that will be helpful to them in their grief process, and will start them on the road to rebuilding their assumptive world.

Interventions that assist parents in regaining control include: listening to and respecting parents' wishes, advocating on behalf of parents for their expressed needs, encouraging parents to make decisions regarding the care of their child before and after

the death, facilitating and supporting access to the child's body, involving parents in preparing for and planning visitations and funerals, and providing parents with information according to the expressed desires of the parents with respect to detail and timing. Information is particularly crucial because the suddenness of these deaths constitute a major trauma for parents, diminishes their capacity to cope and creates a shattering of the assumptive world for these parents. This massive assault on the assumptive world contributes to the difficulty parents have in making sense of the death (Rando, 1998). The randomness of the deaths leaves parents feeling unable to guard other loved ones in their lives against a similar fate (Rando, 1998; Figley, 1997; Simpson, 1997; Nader, 1997) and this was expressed by many of the parents in this research. If parents are able to understand the cause of the death and can identify how it might have been prevented, their ability to restore a sense of safety and security in the world is increased and they can begin to rebuild their assumptive worlds (Gilbert, 1997; Janof-Bulman, 1985; Klass, 1992-1993; Lerner, 1980; Perloff, 1983; Rando, 1986, 1993,1996).

Gyulay (1989), Neidig and Dalgas-Pelish (1991), and Winje (1998) have highlighted the importance of understanding such issues and providing interventions that facilitate the parents' grief experiences. This theme identified in the analysis of this research study clearly supports the literature cited. I would also suggest that where parents feel that they have no control whatsoever over the circumstances, there may be an increased likelihood to escape into the overuse of denial, to the detriment of the parent's grieving process.

Theme III: Saying Goodbye

Issues related to saying goodbye to their child's physical body were presented in many ways throughout this research. Intimately related to saying goodbye were issues related

to how the child's body was treated, the recognition by professionals of the value of the child to the parent, and the need to take care of or provide for the child's body one last time.

Many parents spoke of the importance of being able to see their child's body before the funeral home had access to it. Access to the body was seen to be extremely important, and those parents who had professionals attempt to talk them out of seeing their child described the distress this created in the previous chapter of this research. Guylay (1989) and Neidig and Dalgas-Pelish (1991) have reinforced the need for professionals to respect parents' wishes and needs particularly in this area, and to resist the temptation to make decisions or unduly influence parents against their own wishes "for the protection" of the parents.

Having access to the child's body begins the process of saying goodbye. Time and privacy are significant needs in this process. Several parents mentioned the distress of feeling rushed with their child's body, and the importance to them of the time alone both at the hospital, as well as at the funeral home. One parent described how intensely she felt about that time alone:

> *I will tell you I did have a bit of a hissy fit. They were to close the casket the day of the funeral at noontime, and I can remember saying to the funeral director "Ok, I want the doors closed because I need my time." And my little one needed her time. We all needed our time to say goodbye...and we were starting to have our goodbye and some neighbours and friends came, and they wanted in. And I said, "I am sorry. They have had Sunday. They have had Monday. They have had until now. No." And he [the funeral director] said "Well you can be last, but when you're gone I'm opening the doors and letting these people in." Well I went to the door, and I, this was not very nice. And I opened the doors and I said "This is most inappropriate. This is my time. You've got a minute starting now." I went down to the office [of the funeral director], and I flipped...and I said, "I will be the last to see Kevin"*

Viewing the dead body of their child often provides additional information regarding the death and aids in the reconstruction and future reviewing of the death scene in the grief process. It further assists parents to confront the reality of the death, thus assisting in the first phase of grief; the intellectual and emotional understanding of the death. It also assists in processing and incorporating the trauma (van der Kolk & McFarlane, 1996). While viewing the body and hearing the details of the death may quickly achieve intellectual understanding, the emotional understanding of the death is a lengthy process. The beginning of the struggle to achieve this can be seen in the distress parents experience with respect to the condition of their child's body and/or to the way professionals had treated the body. More than one parent discussed their distress regarding their child's appearance when they were prepared by the funeral home. Parents also described how distressing it was to see their child at the hospital in cold clinical settings where little or no preparation was given and where the child was perceived to be treated with a lack of dignity or respect. The emotional struggle to understand the death of the child was evident in one mother's description of her son's body:

> *I remember at one point [after the child was pronounced dead] him [the child's father] coming into the operating room. And they still had an endotrachial tube in. I remember looking at Kevin and the IV was in sight. It was even taken down to the morgue because the autopsy reads it was in situ there. I remember thinking "It's not very comfortable the way they've got his arm. [And then], Well what does it matter, right?"*

Another mother described similar feelings and also identified what would have been more helpful for herself and her husband:

So we walked into this empty emergency room. And he still had the cardiac monitor attached, and the electrodes were still on his chest, and it was just like they left him there. There wasn't anybody around. And I just thought, he died at six in the morning and by the time we got there it was ten. He'd just been lying there in this room all by himself for four hours with nobody around, and they hadn't even taken the electrodes off him. It was cold. It was very cold. It was a very clinical room, and it was cold. And I think, I'm in the health care profession and I've been in that situation lots of times treating people, and I see or whatever...And I think if I didn't have the experiences that I had that it would have been much more difficult for me to walk into this room... I think if he'd been, but then I don't know. I would have preferred to see him wrapped in a blanket and covered up somehow so that he didn't look like he was a slab of meat on a gurney. But if they could have removed the electrodes from his chest and put a blanket around him, and wrapped him up to make him look cozy somehow and maybe moved him into a smaller cubicle which was a little more private, and not so cold and austere looking that might have been a nicer thing. It just seemed like he was so alone.

Another mother expressed the same feelings of pain for her daughter lying alone as if she had no value as a person, and what would have been helpful:

She was just lying on one of those, like one of those, I guess it was not a stretcher. I don't even know what it was. It was something like a mattress, and her lying there. She was just lying there with nothing around her – with her diaper. No blankets. No nothing...They could have made it more inviting. Like, she just looked like she was a piece of – you know – equipment sitting there. It was very disturbing. She didn't have any clothes on. Put a blanket around her. She didn't look comfortable. She was just lying there.

One couple shared their experience of seeing their son's body in the hospital. They had found him dead, however they were brought in to see him after resuscitation efforts had been made at the hospital. His mother echoed the wish that his body had been treated with some respect:

They had him laying on one of those metal tables. Not tables, you know, those tables they push with. It was disgusting. Why couldn't they have put a nice blanket – why couldn't they – they must have blankets upstairs in the maternity ward, with a, with a pillow. It was, it was bad enough...I still have nightmares about that. You know, but, they could have had him

so that he was, you know, or even put some clothes back on him. Why didn't they put clothes back on him...He wasn't even dressed at all. I don't care if he was dead or not. To me though, now that I think of it, they should have let me hold him, and that to this day bothers me.

Luke's father described the trauma of seeing the way Luke had been left in the emergency room. In this description you can see the physiological effects of trauma such as effects on vision and body temperature. This is one of the memories shared that demonstrates the intensity and frozen quality of the memory, as well as the difficulty that can be experienced in attaching a narrative to the traumatic experience (van der Kolk & McFarlane, 1996; Herman, 1992):

We saw Luke. That was really tough. He was on a black kind of stretcher thing. I wanted to put a blanket on him – because it seemed so cold in there. [He was lying there] just like a piece of wood they threw out...I wish I could tell you the words. It felt so – you see the way I was seeing that police officer earlier – like that black. I, I felt – it feels like everything seemed black. I was in a little tunnel in this room full of people...it felt very confining and – I felt like it was a cold cellar kind of a thing – you know, it was a very cavernous feeling.

Another parent described how helpful some preparation for identifying her daughter was and how meaningful it was to her to see that someone had taken care to present her daughter with dignity in the emergency room subsequent to her death:

She [the nurse] explained to me "She's going to be very cold...She will be very cold, and she will be stiff". She had the mouthpiece in. She had the collar on. She explained "We can't take it out till the coroner comes. It has to stay there until the coroner sees her". But somebody had taken an awful lot of care, I would say, in the presentation of Christina. She had, she had the sheet up to her neck, but you could still see the collar and that. But they had taken her long hair and laid it out. Her long hair was all laid out properly. It wasn't like where she threw back, they were working on her. Somebody went to a great extent with her hair to lay it out nicely. I'll always remember that.

Part of the process of saying goodbye included a sense of providing for or taking care

of the body. One parent greatly appreciated the opportunity to put nail polish on her daughter's fingernails. Parents spoke of the importance of selecting the right casket and having a proper funeral. Things that were done that implied a disregard for the human value of their child disturbed them. For example, the autopsy report with several errors, another autopsy report with the child's name spelled incorrectly, being asked by the hospital where to send the "body", and referring to praying over the "body" were all very hurtful to parents. When I was interviewing parents and asking for the spelling of the child's name, one mother spelled it out and added, "There's a little heart around it", indicating the child's name. Another parent was distressed at the length of time her child was left alone, dead, in hospital before anyone notified her of the death:

> *I guess it's just knowing she was unidentified for so long. That she was unknown for so long. She's a somebody. She's not a nobody. She is a somebody. She is my daughter. That bothered me that nobody knew who she was.*

Parents wanted their child treated with respect, regardless of the circumstances of the death, as so many of these quotes illustrate. One parent summarized the general view of this:

> *I think the respect for your child's body, to treat it as a human being. To look at that and say "That's somebody's child". And I mean that can be the case if the child is 50. It needs to be acknowledged that that is the fact.*

There is agreement in the literature that the child is viewed as an extension of the parent (Rando, 1986, & 1993; deVries et al, 1994; & Klass, 1992-1993) and a symbolic representation of the parent (Klass, 1992-1993). This is evident in the quotes above. The distress parents felt when children were not accorded the care they felt was deserved was genuine and often intense. In addition parents were not able to give up the role of

protector and nurturer immediately upon the death as evidenced by the desire that the child's body be properly and comfortably cared for. The fear and increased arousal experienced from the trauma of the death, and the beginning of the struggle to incorporate the deceased person into a new life (Worden, 1991; Rando, 1993) is evident in these quotes. It is so unbelievable to the parents that the child is dead, that the emotional understanding of the death is a struggle. To have their child's body cared for with respect and compassion assists parents with this process by reducing the trauma they experience, and by validating the enormity of their loss. Professionals who provide this for parents are assisting in the reduction of trauma and in the accomplishment of the first phase of grieving.

The private moments of saying goodbye are virtually imprinted in parents' memories. In chapter five Melanie's father described the importance for him of being able to hold her as she died. Her mother, who was not able to attend even the funeral due to her own injuries, described the devastating effects of not being able to say goodbye to her daughter:

> *Every time I think about it, I think how lucky [Melanie's father] was to be able to say goodbye. But, um, he always says, she was a c-section baby, and he always says that he was the first to hold her when she came into this world and he was the last. And that brings a lot of comfort to him because he said everything that he needed to say to her and he truly believes that she heard what he said. [Not being able to say goodbye had] a tremendous effect. The early months were horrifying for me. I wanted so badly to end my life so that I could go and do what I didn't do.*

Another mother described the process of saying goodbye when her son was removed from life supports in the hospital and how important that was to her:

> *...and placed him in our arms...so I could hold him one last time and whisper to him – to him what I wanted to say to him. And to stroke his hair*

again, and kiss his forehead, and just to hold him. [That was] a very big part of saying goodbye. And they left the room and made sure we were alright, and closed the door...It was really nice and private.

Privacy and support were identified as important components of seeing the child's body and saying goodbye. One parent discussed the effect of the lack of privacy, as well as the effect of a very compassionate nurse in helping her say goodbye.

I had to see my own, my own daughter. And um, I knew in my heart she was dead. I knew. I had to see her. And I think it was more to apologize to her [they had argued prior to the death]. And when I saw those police officer legs on the other side of the curtain, I feel like I was robbed of that opportunity. Because I no longer had that private moment with her. But with [the nurse], she let me hold her hand. And she said I could hold her hand for as long as I wanted. And, it was the way she did it. She lifted up the sheet and she took my daughter's hand out. Then she took my other hand in her one hand. And then she gently lowered my daughter's hand into mine. I think it was done so lovingly. It wasn't "Here, grab it". It was the way she took her hand out and told me that it was going to be cold, and that, that it was going to be very white. And then she, she held my hand out, and she took my hand and just very gently didn't force. Yes, there was no force in it. And I could pull my hand away any time. And then she gently lowered Christina's hand into mine.

In these stories of saying goodbye can be seen the difficult struggle with processing the trauma and with the first phase of grief, understanding and acknowledging the death. Given appropriate preparation, support and time with their child, parents may have a better opportunity to begin their grieving process in a healthy way (Gyulay, 1989). Saying goodbye facilitates the first phase of grief. Having their wishes regarding this process respected may also reduce the amount of trauma experienced by the parents through experiencing a sense of control (van der Kolk & McFarlane, 1996). This is an area in which parents can usually be given control. In the subtext of the stories lay the nature of the parent/child bond and the complex issues of facing the unnatural death of one's child. As parents face that death, they begin a process of attempting to make sense

of it.

Theme IV: Making Sense of the Death

Making sense of the death and finding meaning from it is the next theme identified in this research. The process of collecting information and reconstructing the death scene assists parents in attempting to make sense of the death and to find some meaning in it. This process of making sense of the death and attributing meaning to it is necessary for the mourner to successfully resolve grief (Figley, 1984; Gilbert, 1997; Wheeler, 1994). Parents wanted to know how and why the deaths happened and what could be done to prevent another such death. The major trauma that these deaths constituted increased the difficulty of making sense of the death (Rando, 1998).

The parents in this research devoted a great deal of time to gathering information about how the deaths happened, what caused them, and whether they could be prevented in the future. Many parents talked about their quest for information from professionals to help them make sense of the death of their child. One mother talked about how important information from professionals was to her in order to intellectually and emotionally make sense of the death of her child. Another parent described seeking information from the police officer in charge of the case, and continuing to have contact to ask more questions. The experience of the mother who had no memory of the accident that killed her daughter has been detailed earlier and demonstrates the intensity of the need to understand and make sense of the death.

Parents went to great efforts to understand the cause of the death. One parent, whose daughter completed suicide, learned after her death of her bipolar illness. Subsequently, this mother attempted to understand the disease that led to her daughter's suicide:

Well she always thought her illness was physical. And she thought she had food allergies. And she always had a different explanation. She thought of it as a physical problem. I think I've been to so many meetings since then, and read so much about it [bipolar affective disorder] that I feel I understand it better. And I can see in her childhood indications of it.

Another parent talked about her daughter's physical illness, and how understanding the contribution that made to her death was helpful. A mother whose child died in an automobile accident was relieved to know that she was in perfect health and that the death was caused by a head injury that had no outward markings. The autopsy report provided her with the information she needed to understand the cause of death. The need for understanding was expressed by one parent in a way that showed the need to try to prevent the same kind of death from occurring again to her other children and hopefully not to any others:

I know it won't happen again [with her own children]. Once a child is age five they have built up their own natural immunity to the meningococcal bacteria where they are more at – they're more or less have the same immunity as you and I do...I'm always a wondering kind of person. For my own satisfaction I have to have all the answers. So a lot of people ask me "Well, what is that? How could the doctor let him go at that high fever?" I have to know these answers. I'm just that way. I can't be left wondering. If I find the answers I'm more at peace with myself and I can help other parents. You know, when their child is sick in an emergency department setting.

Having information to make sense and meaning of the death also aids in coming to terms with the cause of the death. For one mother, understanding her daughter's state of mind helped her to reconcile the suicide. For another mother, understanding her daughter's behaviour in crossing a highway, which led to her death, was reconciled this way:

Like I, I come to learn to expect – I sure was mad at God that night. But I've learned to expect, this is life's circumstances. It's not God that killed

Christina. Maybe God let her go fast. And we said even if she was a vegetable I would take her. But I know Christina. She was too free spirited. She wouldn't want to be tied down. So like, we all make mistakes. We all do. And unfortunately Christina's mistake cost her her life. And that's how I deal with her.

Being able to make sense of the death is essential to the grieving process. Finding meaning in the death helps facilitate grieving as well. Information is essential to this process. The attribution of meaning to the death impacts on the subjective experience of the trauma as well. Professionals who facilitate access to information will be helping to facilitate a healthy grieving process for parents.

Theme V: Carrying the Deceased Child Forward in The Parents' Lives

Although this theme is only indirectly related to the initial period of time following the death, I felt it was important to include, as parents often spoke of it. This particular theme relates to the final processes Rando (1993) and Worden (1991) describe in the grieving process. Rando describes it as readjusting to the new world without the child and reinvesting energy in life, while Worden talks of relocating the deceased emotionally and moving on with life. Rando (1998) also speaks of transcendence, where parents transcend the loss of the child and carry on with life in a meaningful way. The adjustment to a world without the child is a slow and painful process that occurs gradually over time. Klass (1992-1993) discusses the importance of the inner representation of the dead child and the three common ways that he found among members of Compassionate Friends (a support group for bereaved parents) for maintaining relationships with their deceased children. These are: linking objects, which evoke the presence of the deceased child; religious ideas and devotion, in which parents experience the presence of the child; and, memory, which over time provides solace and

helps bind families and communities together. In Chapter Five, parents shared the changing face of grief over time, and spoke of how their priorities had changed and how they themselves had changed significantly following the death of their child. The parents who participated in this research were in varying places in their grief journey. Many however, had reached a place in their lives where they had found positive ways to carry forward the memory of their child in concrete ways. For some parents their faith helped them carry on. Many found ways of incorporating some aspect of their child's character or interests forward with them. Rituals and memorializing are a large part of this process. For many of the parents, finding ways to help other bereaved parents was a way to honour their own deceased child.

Several parents indicated that they felt they would be reunited with their child in some form of afterlife, and this belief was helpful to them. One mother expressed this concept eloquently:

> *They don't die. You know we're so silly. They don't die. They – they live on, and I mean you know, it's – it's scientific. Matter cannot be created nor destroyed...And they don't want to come back. God no. No, no, the only thing that makes them sad is seeing us, you know. They get very sad, because we're so sad. And so lonely. And they would do anything they could do to remove that, and they would, and they try. But we're such human, physical beings. We just don't get it...the acceptance of the whole thing is definitely connected with, um, she had not died. She has gone on, you know. But I have on her tombstone, um, burial stone – whatever it is – "Be not concerned. The light that is Buzzy can never be extinguished. Buzzy shines on." Isn't that pretty?*

Some parents spoke of gaining strength from their child and/or trying to be more like their child. One parent took over the sponsorship of her daughter's foster child, which was not something she would have been interested in before. This was a way for her of being a bit more like her daughter and of carrying on her daughter's contribution in life.

Two other mothers spoke of trying to be more like their deceased child:

> *So when I got to the point where I could come to terms with her death, I decided that I would try to take on some of her characteristics, and try to be a little less aggressive, and try to be a little less judgmental...I think I've mellowed a lot.*

> *I think that in the beginning I really didn't care about things. But then I realized that I get some of my strength from Jay. I mean there isn't anything that he didn't do. He lived so much in that 23 years. So I draw some strength from him.*

Most parents have kept mementos and belongings of their child, which keep the memories alive. In this regard, several parents mentioned the significance to them of having the clothing that their child was in at the time of the death. Often they were not able to get them for a variety of reasons, none of which seemed reasonable to the parents. Often the clothing simply disappeared. One parent had a box of things that were her child's. Another parent said that she has a cedar chest that contains her child's belongings. As one parent expressed it, having the child's belongings gave her something to hold on to. One parent was grateful to the chaplain who helped her put together things to remember her very young child by.

Parents mark anniversaries of births and deaths of their children in many different ways. Visits to cemeteries are frequent. Memorials are written for newspapers. Memorial masses are said. Special occasions are marked with reminders of the child. Some parents make special donations in memory of their child, or set up special scholarships and funds. Parents found ways to begin rituals at the funeral or shortly after. One mother described in detail her ways of memorializing her son and creating rituals that help carry his spirit on for her and her family:

> *[Another bereaved parent] has helped me create ceremonies and rituals. I*

was scared to death of going to Jamie's park [the park she always took him to play at]. I knew I had to be there, and I took a little piece of his hair, because he had long hair. I'd never cut it at the back. I gave him bang trims, and err, I took a little bit of the hair and wrote a little note and um, sprinkled some of his hair into the wind. So I consider it Jamie's park. And those things help me cope. We do have ceremonies and mini rituals that we do on special days. Jamie was born on Dec. 31st, New Year's Eve. And that's a difficult time of year. But I have made certain rituals and ceremonies to help us through it. And I go to the park, what I call Jamie's park every July 28th, because that's where I want to be on that day when I knew I – I had him. I had him there last. Before I knew he was sick. And I take things there, his shoes, and I put little imprints in the sand and sit and think.

The parents in this research had accessed support through Bereaved Families of Ontario, and many of them continue to work to support newly bereaved families in their own affiliates. This was a frequently used way of memorializing their child. The parents who continue to be involved were motivated by their own experiences. For some parents the difficulties they experienced when their child died led them to help others:

What happened to me should never have happened to anybody else. And I think that's one of the reasons why I found I needed to crusade for the rights of parents who are bereaved. I went through hell and back. It's [working with Bereaved Families] a way [to help work through the grief also] and I am very privileged that I am able to do that.

Many parents involved in this kind of work indicated that it helps them with their own grief, helps them carry on, and gives meaning to their child's death:

I think it helps carry her [her daughter] on. I don't want her to have died for nothing. And that's one of the reasons I'm involved with Bereaved Families. Because I'm not sure if there is a God. I'm not sure about these kinds of things. But whatever powers that be gave me this burden in my life. This burden, this burden happened to me. I have to carry this now. So I could just fold up and pack it in and say "Well I'm not going to do anything now. I had this rotten thing." Or I could try to help other people who have a similar burden to carry. And by doing that I'm not keeping Tammy alive, but I'm making her life and her death mean something. I mean, I go to the office, and I see her picture on the wall, and I smile. And I think "I wish I wasn't here Tammy, but I am. I am here, and I'm here

because of you. And I'm trying to help someone else."

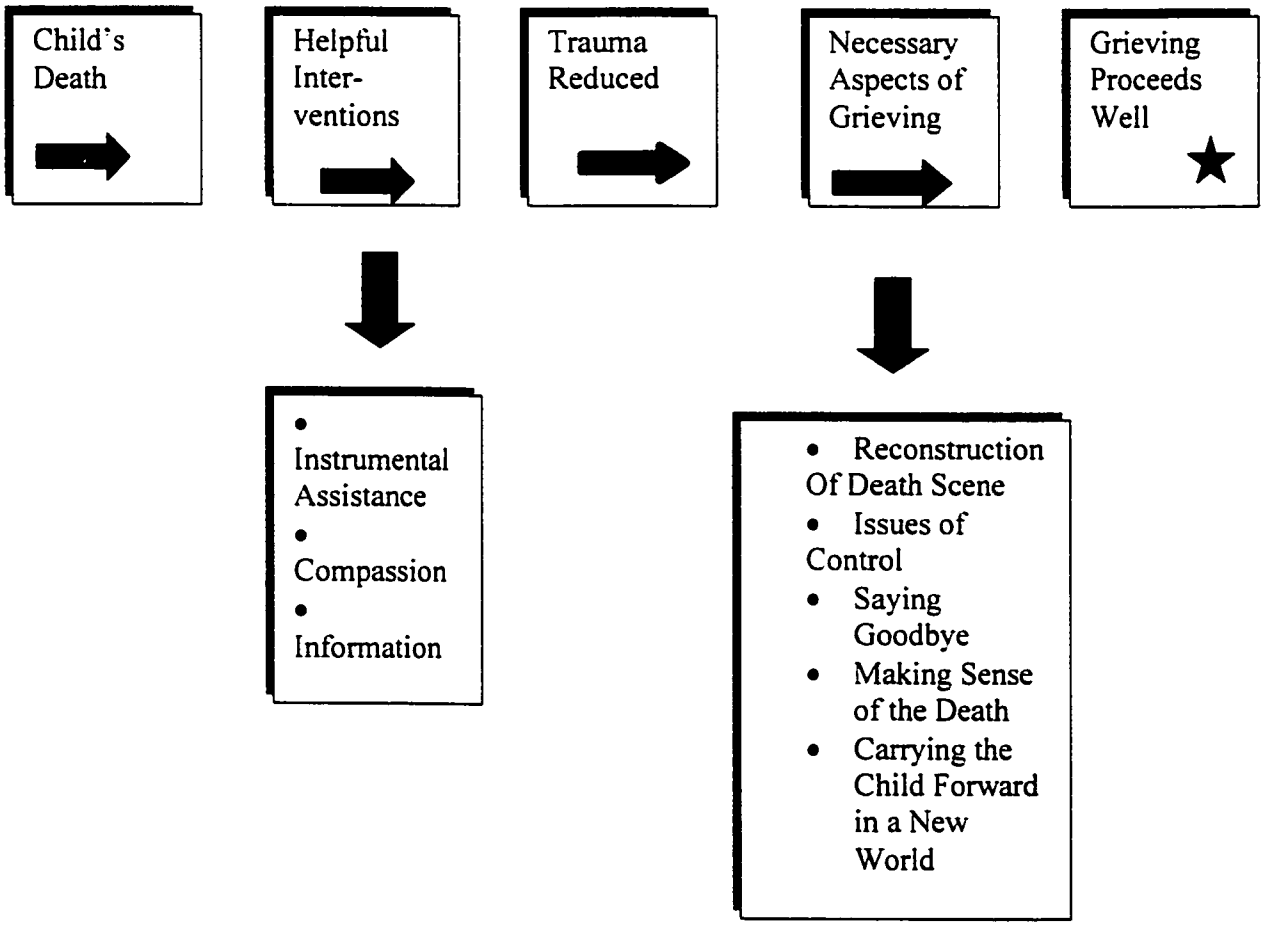
Each parent has attempted in their own way to carry their child forward in life with them, and to attribute meaning to their deaths. This has not been an easy struggle for any of the parents in this research. They have all reached different places in this process, but each one is forging ahead. As Rando (1993) and Worden (1991) indicate, mourning is repetitive and re-occurs at various times in the life of the bereaved.

Relationships Between Themes: What Professionals Can Do

In Chapter Six the interventions of professionals were analyzed according to three themes: the provision of instrumental assistance, the provision of compassion, and the provision of information. In this chapter five themes regarding the grief process have been presented. The following chart (Chart One) demonstrates relationship between the process of intervention and grieving needs. On the next page, the following table (Table Two) is a supplement to the discussions respecting the two sets of themes outlined in Chapter Six and Chapter Seven.

Chart One

The Effects of Helpful Interventions on the Grieving Process



This chart illustrates the effects of helpful interventions on grief and the necessary aspects of grieving supported by these. Through the provision of instrumental assistance,

compassion and information, trauma is reduced and necessary aspects of grieving are facilitated. Necessary aspects of grieving are: the reconstruction of the death scene, dealing with issues of loss of control, saying goodbye to the child's body, making sense of the death, and carrying the child forward in a new world. Through the facilitation of these necessary aspects of grieving in a traumatic death, a healthy grieving process is initiated.

Summary

The themes associated with the grieving process identified in this chapter have been discussed in detail. They are: the reconstruction of the death scene, issues of control and the shattering of the assumptive world, saying goodbye, making sense of the death, and carrying the deceased child forward in the parents' lives. These themes have been related to each specific phase of grief according to Rando's model of the 6 R Processes. Further, the relationship of these processes to the psychological effects of trauma have been identified..

Ultimately, the goal of grief is moving from losing what you had, to having what you lost (Fleming & Robinson, 1991). The parents in this study have each found their own way to do this. Professionals have a unique opportunity to contribute to this process in the early stages of grief by helping parents to create rituals and memorials for their children in the processes of saying goodbye and making sense of the death. Most importantly, they can contribute to the accomplishment of the first phase of grieving, which will promote a healthy grieving process and a positive readjustment to life by helping parents identify their needs and supporting them in meeting those needs. Crisis Theory provides a sound basis upon which to inform the role of a professional at such a

time.

The themes identified in this chapter highlight the significance of professional intervention at the time of the child's death, and the enormous impact that such interventions have. Each parent participated in this research because they wanted professionals to have a better understanding of what they can do to help and what it is like to have your child die, so that better-informed professionals will assist others whose children die. A clear understanding of the themes identified here will enable professionals to inform their interventions in a manner that supports parents' grief in a positive manner.

Chapter Eight

Conclusions

> Our lives are shaped as much by those who leave us as they are by those who stay. Loss is our legacy, insight is our gift, and memory is our guide. (Hope Edelman, 1990)

Introduction

This chapter provides an overview of the dissertation and conclusions. The research question and the themes that emerged are reviewed. The clinical implications of the findings are discussed in general, as well as with respect to each specific professional group. The next section addresses some general comments regarding the process of this study. Areas of further research are identified. The chapter concludes with some final thoughts. Four of the parents who reviewed drafts of the findings have written their final thoughts, and the dissertation ends with those.

The Research Question

When I first decided to examine the difficulties faced by parents at the time of the death of a child in this research, my motivation came from my own and other parents difficult experiences. After some time and discussions with many parents, it was evident that there were things professionals did at the time of the death that were extremely helpful in reducing the trauma and beginning the grieving process in a healthy way, as well as things that increased the level of trauma and later interfered with grieving. I developed an increasing interest in the interactions of professionals and parents during

that time period, and in interventions that were helpful and those that were not. The purpose of my interest was to better educate professionals with respect to parents' needs at what is certainly, in the words of these parents, the worst time of their lives.

The research question was then framed as: *what can involved professionals do to assist parents through the initial period of the sudden death of a child in order to help facilitate the most healthy grieving process possible in the given circumstances?* The interviews sought information regarding the specific experiences that parents had and what they perceived the impact of those experiences to be. Parents were also asked what would have been helpful, and many were able to identify specific interventions. In the course of analyzing the 20 interviews that were conducted in this research, five primary and related themes were identified, and the parents highlighted specific interventions. In short, the parents in this research were very clear about what was helpful and what was not. They collectively had a very strong contribution to make to the professional understanding of the experience of the sudden death of a child and to which interventions were useful to them and which were experienced as additionally traumatizing.

A Review of the Themes

Five primary themes were identified through the analysis of the interview data. Other themes were present, however they did not relate to the research question and were therefore not analyzed. The first theme was the reconstruction of the death scene. This theme expanded our understanding of the significance of detailed information about the death and the death surround for the parents. For those present at the death, reviewing of the death scene provided a way to assist in achieving the processes of trauma reduction, and the emotional and intellectual understanding of the death, the first phase of grieving.

For those not present, great efforts were made to obtain information in order to reconstruct the death scene and process it similarly. The timeliness of information was identified as a significant issue. Thorough and detailed information presented when requested by the parents was viewed to be helpful.

The second theme that emerged was issues of control and the shattering of the assumptive world. Feelings of powerlessness, helplessness and a loss of control were identified. Attempts to regain some sense of control was identified as important to the parents' ability to function, move through this traumatic period and to engage in activities and behaviours that facilitated the first phase of grieving. Information and respect for their wishes were beneficial to parents in this process.

Saying goodbye was the third theme that emerged. The importance of access to the deceased child's body was highlighted. Time alone with the child and privacy were identified as significant needs. Seeing the body was viewed to facilitate the emotional and intellectual understanding of the loss, and assisted in the reconstruction of the death scene. The importance of having the deceased child's body treated with respect was identified. Where the behaviour of professionals did not appear to validate the importance of the child to the parent, additional trauma was experienced by the parents. Emphasis was placed on the presentation of the child's body. The cold, clinical setting of the hospital, with no attempt to make the child look cared for or comforted added to the parents' trauma. The view of the child as an extension of self helps to explain the importance of sensitively presenting the child's body to the parents. Again, the issues of privacy and support were significant.

The fourth theme discussed was making sense of the death. The process of making sense of the death and attributing meaning to it was viewed to be significant in the process of grieving. Parents went to great lengths to understand the death, through seeking detailed information regarding the process and the cause of the death. There was a strong need for them to feel that their child did not die in vain. Information and access to the child's body were important factors in achieving this process. The rebuilding of the assumptive world requires this process be completed as successfully as possible. Eventually, in the reconciliation of the parent to the death of the child, some meaning must be attributed – it must in some way make sense to the parent. Parents actively sought ways to assimilate this trauma into their assumptive worlds through processing the event of the death, making sense of it and seeking meaning in it.

The final theme discussed was the carrying of the deceased child forward in a different relationship into a new life for the parents. This theme related primarily to the final phases of grief, however the process was facilitated by rituals and memorializing that were sometimes initiated at the time of the death. Parents often identified the significance of helping others as a way to honour their own child. Some parents actively sought to take on special characteristics of the child, or to continue a project or interest of the child. Interventions in the early stages of the loss were viewed to be helpful in facilitating movement toward these processes, or in some cases to impede this movement.

The Findings and The Theory: Interconnections

The findings of this research fit well with Rando's model of the Six R Processes of Grieving as well as the literature in the review respecting parental loss, the trauma connections with grief, and basic Crisis Theory. This section will identify the ways in

which the findings support the literature and reinforce the current thinking with respect to parental loss and traumatic death, and Rando's model of the grief process. As well, the connection of the literature to the parents' self-identified needs will be addressed.

Parental Loss

The primary issues relevant to the immediate period of the death identified in the literature review section of this dissertation are the age of the child and the psychological relationship of the child and parent. The literature indicates that the loss of a child through death is a violation of the natural order of things regardless of the age of the child (deVries et al, 1994; Sanders, 1979-1980; Rando, 1986). The specific issues said to be related to the age of the child arise from the developmental stage of the child and family. Issues specific to developmental stages particularly arise when the child is a stillbirth or very young infant and when the child is an adult child. Stillbirths and young infant deaths, as well as the death of an adult child often leave the bereaved parents disenfranchised in their mourning. With the death of an infant, or a stillbirth, parents may not receive adequate social support as the people in their support network have limited if any personal knowledge of the child, and it is often expected that young parents may simply have another child. This was certainly the experience of some of the participants who experienced stillbirths in this study. In addition, some parents experienced a lack of support from medical staff and funeral homes regarding still births and/or very young infant deaths. These experiences were described as making their loss more traumatic.

The literature identifies that parents of adult children may not receive social support as the concern may be focused on the child's spouse or children (Rando, 1986). That was

the experience of one mother in this study. Additionally the literature mentions that parents of deceased adult children may fear a breach in their grandparenting relationship with their grandchildren, which was also the experience of a participant in this study.

The psychological relationship issues identified in the literature review were the connection of self and child (Rando, 1986; deVries, Lana & Falck, 1994), and the inherently assumed and socially assigned roles and responsibilities vis a vis the child (Rando, 1986; Gilbert, 1997 & Rosof, 1995). The intensity of the parent-child bond was evident in each interview. The symbolic representation of self, as well as the importance of the relationship between parent and child was demonstrated through the parents' need to have their child treated with dignity and respect. Further, some of the parents who had experienced other significant losses commented on the fact that the loss of their child was the most difficult loss of all. The issues respecting roles and responsibilities were frequently demonstrated through the feelings of guilt many parents spoke of in the interviews. Furthermore, the difficulty in letting go of the parent role with the child was demonstrated in the theme of saying goodbye, and the parents' intense need to find ways to take care of their child in death.

Traumatic Death

Rando (1993; 1998) has identified six factors that make a death traumatic. These are: suddenness and lack of anticipation; violence, mutilation and destruction; preventability and randomness; multiplicity; the mourner's personal encounter with death; and the death of a child. Five of these were demonstrated in this research: multiplicity was not. The sudden nature of these deaths, the violence, mutilation or destruction associated with them, the preventability and randomness of the deaths, and the parents' personal

encounter with death were all demonstrated in the interviews.

Each of these deaths was sudden and unanticipated. The circumstances of the deaths were a massive violation that radically changed each parent's world. Parents described the changes in the interviews. They described their diminished capacity to cope at the time of the death. They spoke of the loss of a sense of security that they experienced. They talked about the difficulty they experienced in making sense of the deaths. The themes of control and making sense of the death spoke specifically to those issues.

In each of these deaths there was some aspect of violence, mutilation, or destruction. The literature speaks of these factors arousing in the bereaved shock, fear and vulnerability. The parents in this research all spoke of those feelings. The literature speaks of the bereaved in these kinds of deaths imagining the experience of the deceased and being constantly re-traumatized by these imaginings (Rando, 1993). As can happen with any trauma survivor (Herman, 1992; van der Kolk & Fisler, 1995) who then live in a state of hyper-arousal (Murphy et. al., 1999), parents in this research did imagine what their child had experienced, and were often traumatized by not knowing. The theme of the reconstruction of the death scene demonstrates the significance of detailed, accurate and timely information regarding the death to assist parents to know what did happen and thus to process this in a healing way. This finding supports Winje's 1998 findings with respect to the significance of feeling adequately informed on the parents' psychological adjustment, as well as Gyulay's (1989) work.

The deaths of these children all had an aspect of preventability or randomness. The literature indicates that these features of a death can lead to guilt, self-blame, fears of inability to protect themselves, and the need to identify a controllable cause that will

restore feelings of safety and security in the bereaved. In this research many parents identified feelings of guilt. Many described fears of losing their remaining children. They all went to great lengths to identify a cause that can be controlled – that is to make sense of the death. In doing so they were able to restore some sense of security and safety to their lives.

The mourner's personal encounter with death can create a massive shock and threat to personal survival. Many of the parents in this research described the feeling of being unable to survive the death of their child. Some parents spoke of being unable to understand how they were alive when their child was dead. Parents in this research, very much supporting the work of theorists in this field, described all of these aspects of traumatic death.

The Six R Processes of Grief

The five primary themes identified in this research have been specifically related to Rando's processes of grief, primarily the first process. The 6 R processes are: recognizing the loss; reacting to the loss; re-collecting the relationship; re-experiencing the deceased; relinquishing the deceased; and readjusting and reinvesting. The reconstruction of the death scene is necessary for the first process – the intellectual and emotional understanding of the loss. Issues of control and the assumptive world relate to the accomplishment of the first process as well. Making sense of the death and saying goodbye, the next two themes, are also significant to the first process, as well as to the process of reacting to the separation. Finally, the theme of moving forward in a new world without the child is necessary to the final process, readjusting to move adaptively into the new world without forgetting the old, and reinvesting in life.

The themes identified in the analysis of the interviews are an excellent fit with this model of grieving.

Needs of Parents

Although there was little literature regarding the needs of parents at the time of the child's death, what was available was well supported by this study. The work of Guylay (1989), Kalkofen (1989), Neidig & Dalgas-Pelish (1991), and Winje (1998) identify specific needs of parents, all of which were identified by the parents in this research. Most particularly addressed are issues of assisting parents in having control and the provision of information. Clearly, this study reinforces what is known about the connections between trauma and grief, the identification of parental loss as traumatic, and the identification of the needs of parents in the literature. Each parent described the loss of their child as the worst loss, and extremely traumatic as described by Rando (1986), Rosof (1995) and Schiff (1977). Parents described their attempts to process the trauma by seeking information regarding the death and death surround, and by attempting to reconstruct the death scene, as did the parents in Winje's study (1998). The process of intrusive remembering described by van der Kolk and Fisler (1995) and van der Kolk and McFarlane (1996) was seen in the interviews as parents described attempting to come to an understanding of the death and make sense of it.

As each parent described the death of their child, they spoke of the shattering of their worlds described by Janoff-Bulman (1985), Parkes (1971), and others. Attempts to gain control were evidenced in parents' interactions with professionals, demonstrating the significance of control identified by Regehr, Cadell and Jansen (1999) and Silver, Wortman and Klos (1982). Where professionals acted within the framework of good

crisis intervention skills based on Crisis Theory (Golan, 1979), parents felt greatly assisted in establishing some control over the events immediately following the death. These parents identified this sense of control as helpful in their processing of the trauma and in their grieving.

Gyulay (1989) and others have identified the importance of access to the body of the child, and the parents in this study clearly demonstrated this. They identified the significance of this access in coming to an understanding of the death, processing the trauma, and on their grief process.

The importance of making sense of the death and attributing meaning to it identified in the literature (Gilbert, 1997; Wheeler, 1994; Figley, 1984) was demonstrated in this study through the fourth theme, making sense of the death. Parents went to great lengths in this study to obtain and process information that would help them understand the death. Further, they invested significant energy in seeking some meaning in the loss of their child. Finally, many parents demonstrated Rando's discussion of transcendence (1998) as they found ways to reinvest in a new world and carry their deceased child forward in some way (Worden, 1991; Rando, 1993).

Crisis Theory

The findings of this study that are supported by Crisis Theory are specifically those with respect to the nature of professional interventions. The importance of professionals not assuming control, but rather listening to parents was highlighted. The facilitation of instrumental assistance in the alarm reaction and exhaustion of the crisis described by Selye (1956) was identified as extremely helpful by parents. Offering information regarding processes and options, an important function described in Crisis Theory

(Golan, 1979) was viewed as extremely helpful. What parents in this study really valued from professionals was support in regaining some of their ability to function in the trauma. This is at the heart of Crisis Theory.

The themes of provision of information, instrumental assistance, and compassion are imbedded in Crisis Theory. The first two objectives of crisis intervention, that is the relief of symptoms, and the restoration of prior functioning (Golan, 1979) are important undertakings for professionals at the time of the sudden death of a child. While symptoms cannot and likely should not be fully relieved, they may at least not be increased if the intervention is sensitive to the needs of the parents.

Facilitating parents' own thinking about their needs may assist in restoring some degree of functioning capacity in the trauma. The findings in this study demonstrated that professionals who act in concert with both of these principals were of assistance to parents in reducing trauma. Central to the findings of the study are the timeliness of interventions, as well as the ability of the professional to listen to and respect the parents' wishes. Not owning the problem (Golan, 1979) is extremely important for professionals to remember. Sometimes, in this study, doing nothing was found to be the most helpful thing a professional could do. The ability to keep out of the way, to be present with compassion and respect, without making assumptions or acting on behalf of parents was highly valued by parents in this study and should not be underestimated. Sometimes less is more!

Clinical Implications: How Professionals Can Help

There are many ways that have been identified through this research in which professionals can assist parents to reduce the trauma and begin a healthy grieving

process. The significant ways in which they may be helpful can be categorized as: flexibility in providing instrumental assistance, demonstration of compassion and respect, and provision of information. These interventions are all inter-related.

Instrumental assistance can be offered in many ways. Providing parents with information with respect to their rights vis a vis information, access to the body of their child, access to their child's possessions, and access to reports is helpful. Any offer of instrumental help is usually appreciated, although it may not be accepted. When it is declined professionals should be respectful of that, and when it is accepted, professionals need to be conscious of following through on commitments made. Professionals should be aware that parents who request assistance or accept offers of such, rely upon the professional to follow through and may be devastated by their failure to do so.

Professionals who are providing written information should be sensitive to the importance of accuracy. Where an error is made, a genuine apology and correction of the error is most supportive of the parents.

Professionals can support parents by offering to assist in the planning of rituals around saying goodbye. Initiating rituals at the time of the death and funeral can provide ways for parents to cope later in the grieving process. In the initial trauma of the loss, parents level of arousal is high and the pain so intense that there is often both an emotional and cognitive shutting down (van der Kolk & McFarlane, 1996; Herman, 1992). In the process of facilitating parents to regain some functioning and accomplish the tasks of the period from death notification through the funeral, opportunities exist to assist them to see the importance of ritual in the moment and to identify rituals that may be helpful to them later.

The role of the professional in this instance is again to facilitate parents thinking. In a multicultural society with diverse customs, religious and spiritual beliefs and practices and widely ranging boundary sensitivities, it is critical to listen to and respect families. Individual needs of parents within these sensitivities will differ as well. Exploring with parents what they feel would be useful and then helping them to identify how to carry these rituals forward in a way that facilitates grieving is an important functions professionals can fulfill.

Providing concrete items that will assist parents in remembering what happened is useful. For example, providing a tape of the funeral service, or a written copy of the eulogy is helpful. Allowing parents who wish to participate in preparing the child's body for visitation to do so, decorating the visitation room, or personalizing the funeral service is helpful. The lighting of a special candle during visitation and funeral services, or at the home during this period to represent the child is another suggestion that many parents value.

Offering these ideas and then identifying how they might be used later helps parents begin to identify other uses of ritual. For example, the candle burned during the funeral may be lit again on special occasions such as birthdays, anniversaries of the death etc. to represent the child's continuing presence in the parents' lives in a changed way. Within each family's cultural and faith belief systems will be opportunities to suggest rituals that can be carried forward to assist in grieving. Each professional who raises the suggestion of the use of ritual must do so through exploration with the parents in a manner that is sensitive to and respectful of their differing needs as well as their cultural and religious contexts.

Offering to provide follow up by telephone or in person is an instrumental task that is experienced as caring and supportive by parents. Again, it is important to respect their wishes regarding this, and equally important to be sure to follow through with whatever arrangement has been made, or speak to the parent to explain any disruption in the plan.

It is extremely important to parents that they be treated with compassion and respect and that their child's body be treated in the same way, regardless of the circumstances of the death. Whether an accident, suicide or any other form of sudden death; whether the child's own error caused the death, the same respect and acknowledgement of the enormity of the loss should be accorded to parents. Through verbal interactions and behaviour, professionals should demonstrate their understanding that this child was a person of great importance to the parent, and the loss is shattering.

Honesty and genuine concern is important to parents at this time. Calm and reassuring professionals who are gentle and supportive, but not attempting to 'protect' parents assist them to work through the trauma of the death. Being prepared to listen to parents who are able and wanting to talk about what is happening is very helpful. It is also important to recognize that parents may become repetitive and that this reaction is normal.

A way to demonstrate respect and compassion is to take the time to find out about the living child who has died. This is relevant for all professionals, and particularly for those who will be involved in funeral arrangements or in providing support to the parents. It is also important that professionals demonstrate respect by not making assumptions about what parents want or need, rather asking and listening to their responses. Finally, it is important to be sensitive to the presence and needs of other children in the family and to be respectful of parental rights regarding these children.

With respect to the provision of information, there are many areas in which this is significant. A major role of professionals involved at this time is to facilitate parents' thinking, through breaking down processes into small steps, providing information regarding the procedures and processes, offering suggestions and choices, assisting parents to identify what their needs are, and providing support to them in the meeting of their unique needs. In order to facilitate the reconstruction of the death scene and the processing of the trauma, it is important to provide information needed by the parents. Assisting them in accessing detailed information, autopsy reports, police reports or whatever else they feel they may need is extremely helpful. Parents may need to have information repeated to them frequently due to their traumatized state and the effect of trauma on memory retention. It is equally important to be sensitive to and respect parents' wishes regarding the timeliness and amount of information given. All parents are different, and will have different needs with respect to when and how much information is given to them. Professionals should always be guided by the parents' desires in this regard.

It is helpful to parents to have information regarding medical, legal and funeral procedures explained to them. Offering suggestions and respecting decisions will help reduce feelings of powerlessness. Professionals should use opportune moments to provide parents with information about what they might expect in the future, both in terms of procedures, and in terms of normal grief responses. Normalizing and validating parents' emotional responses is very helpful to them.

Regarding access to the body, it is important to respect parents' wishes and where desired facilitate the access. It is important to prepare parents for what they will see, feel,

smell, and hear in the room. Offering support in the viewing of the body and providing as much privacy as the parents wish, within any legal limitations is very helpful. Should there be legal limitations, for example in a forensic case, these limitations should be carefully and thoroughly explained to parents. Flexibility in providing privacy and time for the parents to be alone with the child's body is most helpful.

Flexibility in support provided is important in many ways. It is most helpful to parents for professionals to be present and available to them, yet not be intrusive. Offering to check in on the family is helpful. The definition of intrusive will differ from family to family, and at times from one parent to the other, therefore it is important to ask the family what they need from the particular professional in terms of presence and support.

Flexibility is important in other areas as well. Professionals should be prepared to adapt procedures to meet the family's needs within the scope of the law and their ability to do so. For example, adapting the usual protocols in visitation or funeral services, or allowing parents specific wishes such as being the last to be at the gravesite is helpful. Where families' wishes cannot be met, professionals should offer thorough and considerate explanations.

The parents in this research offered these suggestions throughout the interviews. Many of them felt that professionals should take some time to try to put themselves in the parents' shoes for a moment before dealing with a bereaved parent. All of the parents felt strongly that all professionals should be educated about the impact of the death of a child on parents, and about how to help parents through this traumatic period before they are faced with such a situation. The parents' motivation to participate in this research

was to help professionals understand what is needed at such a time, and it is their great hope that their participation will result in improved assistance for newly bereaved parents in the future.

Helpful Interventions Specific to Particular Professional Groups

From this research has come a substantial listing of specific interventions that parents find very helpful. These interventions are sometimes common among various professional groups, and those have been discussed. There are however, specific suggestions for each particular professional group, and these will be listed hereunder.

Police

- Offer instrumental assistance to parents, for example, transportation, phoning friends or relatives, making referrals, and obtaining written reports.
- Be sensitive to the varying needs of parents when their child dies.
- Acknowledge and be respectful of the severity of the loss the parents have sustained.
- Be aware of the range of reactions parents have at such a time, and be open to validating parents' responses to death notification.
- Allow parents access to the body if at all legally possible.
- Conduct investigations sensitively and thoroughly, showing professionalism with compassion.
- Provide detailed information verbally and in writing if requested. Ensure the parents understand procedures that may be required.

- Be sensitive to the differing needs of families around the timing of information and the level of detail required by them. Be prepared to meet with them at a later time to review information.
- Demonstrate a non-judgmental attitude towards parents regardless of the circumstances of their child's death.
- Ensure that you carefully explain all processes and procedures and inform parents of their rights.

Nurses

- Provide for the physical needs of parents to make them as comfortable as possible.
- Provide emotional support to parents, family members, and particularly the dying child.
- Listen to and validate feelings.
- Use the child's name in discussions with the parents or within their hearing. Allow the parents to talk about their child's life.
- Acknowledge the loss without judgement.
- Facilitate private access to the dying or deceased child for as long as possible. Ensure the family has privacy.
- Provide information regarding the child's status and progress and what to expect as the child dies.
- Provide information regarding what parents will see, hear, smell and feel when viewing their deceased child's body.

- Try to make the viewing of the child's body less traumatic by making the child more presentable, for example covering the child with a blanket, removing apparatus etc.
- Ensure the child's possessions and clothing are offered to the parents.

Doctors

- Provide medical attention to the parents.
- Provide follow up phone calls or appointments to the parents.
- Demonstrate empathy.
- Provide as detailed information as possible regarding procedures, the child's status and how the child died. Be respectful of parents' timing in receiving this information. Be prepared to meet with them at a later time to review information.

Coroners

- Ensure accuracy on all written reports.
- Inform parents of all procedures and what to expect.
- Explain parents' rights to them.
- Facilitate access to the child's body according to the parents' wishes and within the scope of the law.
- Be willing to review detailed information with parents both at the time of the death and later.
- Offer to provide autopsy reports and the coroner's summary and explain the procedure for obtaining these.

Social Workers/Crisis Counselors

- Provide instrumental assistance such as transportation, phone calls, problem solving, referrals, and advocacy.
- Listen to parents and validate and normalize feelings.
- Be calm, reassuring and empathetic.
- Encourage parents to make decisions themselves and offer suggestions respectfully.
- Provide a follow up phone call.
- Assist in obtaining information for families.
- Provide information regarding the effects of trauma and grieving.
- Assist families to plan what they will do when they leave the hospital, the funeral is over, etc.

Funeral Directors

- Offer parents opportunities to assist in preparing their child, and/or preparing the visitation room.
- Ensure parents are satisfied with how their child's body looks prior to visitation.
- Respect parents' unique wishes regarding the visitation and funeral.
- Be aware of situations in visitation that may overwhelm parents and offer assistance.
- Be sensitive to the need to mediate family issues with respect to the funeral and visitation.
- Ensure the family has private time before the first visitation and before the funeral.
- Be sensitive as to how financial issues are dealt with. Use a balance of professionalism and empathy.

- Provide information and guidance through the procedures and protocols of funeral arranging while respecting parents' wishes.
- Explain any limitations carefully.
- Provide a follow up call to the parents after the funeral. Offer referrals to community resources where appropriate.

Chaplains and Clergy

- Be present for the family but not intrusive. Come when asked and follow through on commitments to the parents.
- Take a genuine interest in who the living child was and what he or she meant to the parents.
- Make the service and eulogy meaningful and personal.
- Understand the importance of the funeral service in saying goodbye to the child's physical presence on earth.
- Tape the service, or provide a written copy of the eulogy.
- Assist parents in planning rituals they can carry on after the funeral (for example lighting candles).
- Offer assistance with referrals, or to provide pastoral counseling.
- Acknowledge the immensity of the loss the child's death represents, and validate the parents' pain, anger and other emotions.
- Be aware of the potential impact of the loss on the parents' faith.
- Provide follow up calls and home visits after the funeral.

These are the specific suggestions that emerged from this particular research. Several parents added that professionals who are going to deal with bereaved parents at the time of the death need to educate themselves about parental loss issues. They further added that if a professional does not feel they can be helpful to the parents or manage their personal emotional responses adequately, they should request that some other colleague respond to the situation. Finally, many parents suggested that any professional involved spend a few minutes before seeing the family in trying to imagine themselves in the place of the family in order to develop some empathy.

Comments and Observations Regarding the Process of this Research

Although this research comprises a small sample of bereaved parents, who have all been part of a mutual aid support model organization (Bereaved Families of Ontario), I believe as a researcher and as parent, that professionals who deal with parents at this time should have a solid understanding of the effects of trauma and the grief process, and how to facilitate parents' movement through this period of time.

For many parents, participating in this research produced another opportunity to process the death of their child, often at a different level of understanding. For some of the parents the act of being asked to participate moved them into a review of the death and elicited more questions for them. In these situations, some of the parents were actually moved to action to obtain information, or make approaches to professionals with respect to their issues either prior to the interview, or shortly after it. Many parents felt that they expanded their own understanding of their grief process through discussions in the interviews and subsequently through the follow up telephone calls. In the final

section of this chapter I will share some of the thoughts of the parents who reviewed the material in draft form.

Initially this research was driven by my personal interest in how parents were treated by professionals at the time of the sudden death of their child. This interest, as is often the case, stemmed from my own difficult experiences with certain professionals involved at the time of the death of my son. The process of reviewing the literature, interviewing parents, transcribing interviews, analyzing interviews, and having ongoing discussions with some of the participating parents greatly enhanced my own understanding of my personal grief process, how interventions affected it and what I needed to do to address the personal issues I had in my grief. In short, the entire process of this dissertation mirrored my own grief process. At various stages of the work, I moved from frozen and overwhelmed, to working through the pain, to rethinking my assumptive world, reviewing and recollecting both the losses of the participants as well as my own loss, to reconciliation and finding meaning in all of our mutual losses and discovering a way to move forward in life incorporating my own son and what I have learned from these parents and their children.

As I moved into the actual writing of the dissertation I became increasingly aware of a fundamental shift within my work from a personal interest born of my own experience that I wanted to understand and compare to others, to becoming a voice for the parents who guided my thinking and understanding of the grieving process. Working with these parents, both in the actual interviews and in subsequent conversations and receiving feedback from drafts has immensely broadened my understanding of the process of surviving and reconciling to the death of a child. I believe it will be of significant value

to professionals working with parents at this time to learn what these parents are teaching us through their interviews.

Further Research

The interviews in this research study provided a wealth of data that included rich description of areas outside of the scope of this study. In addition, the entire process opened up numerous areas for further research regarding professional intervention. One of the thoughts that immediately came to mind in analyzing the data was how valuable it would be to look at therapeutic interventions beyond the initial period of the loss and examine the impact of these interventions on the continuing grief process. This might include how the medical profession. counselors and mutual aid organizations deal with parents.

From the analysis also came the desire for myself to look at the impact of the social justice system: criminal and civil courts and inquests. on the parents' grief processes. A number of participants were involved in these systems and commented on them. The question of what effect these proceedings have on parents, and how parents move through a grieving process in a healthy way when they are constantly being pulled back into the detail of the traumatic event and it's antecedents, is an important one for researchers to examine.

An in depth study of how parents actually rebuild their understanding of their world, and the specific methods they use to emotionally relocate their child and move forward in the world would be of great value to grief therapists working with parents who have lost a child. This is such an important aspect of the grief process that it deserves a great deal more investigation than has yet been done.

Finally, throughout many of the interviews, parents offered information regarding the effects of family and friends on their grief as well as the impact of professional interventions. The entire area of social support during the trauma of the death and the impact of that would be of great benefit to study. Friends and family are frequently at a loss as to how to help parents, and I believe research in this area would be valuable.

Understanding how to assist traumatized parents through this period in order to facilitate a healthy grieving process will require continued research studies. Further research examining PTSD as an outcome of the sudden death of a child would be beneficial to our understanding of how to help parents during the trauma. Much of the work being done in traumatology will be of benefit to this understanding and is currently helpful in treating the PTSD that often results in part from well-intentioned but poorly informed interventions. I believe it is important to look specifically at the initial time period in more depth to understand more clearly how to mobilize parents to their own benefit.

Final Words

In concluding this dissertation, I would like to say that I have been privileged to have had these parents share their most intimate and painful losses with me. I have grown professionally and personally from the knowledge they have given me, and I admire their courage and commitment to others that has been demonstrated in the way they live their lives and in their participation in this research. I will leave the final words of this paper to some of the parents who participated in reading drafts of the data analysis:

Jay's Mother

I was glad to be able to participate in this research in the hopes that because of it, positive changes could be made when dealing with a family who has just lost a child. The unbelievable pain leaves us so vulnerable and the added impact that some professional people we are left dealing with leaves us feeling lost in strange unknown territory and we don't know how to deal with it. Nothing can change the pain I feel and the fact that I was robbed of my future when I lost Jay, but if this can bring some changes to the lives of other parents I will feel some good came out of my tragedy, and feel some comfort thinking "help is on the way". We are changed forever and continue to work through our grief remembering always our son and brother Jay.

Ian's Mother

When [Linda] asked me to participate in her research I was pleased to do so.. I was honored to be asked to participate.

Grief was a new experience for me. When my son died, I had not experienced the death of anyone I loved. I had no idea what to expect, either in terms of my own emotional reactions or in terms of other people's reactions. I suppose that I expected that the professionals we encountered would be kind, compassionate and helpful. After all, we are conditioned to respect police officers, doctors, clergy etc., and the assumption is that they know what to do in a crisis. They are trained to handle these things. In actual fact, some were kind, compassionate and helpful, and some were not. It is amazing what an impact the actions/reactions of others can have during this traumatic and very vulnerable time. I remember very clearly the things that were said and done which were comforting. I remember just as clearly, in fact, perhaps more clearly, the things that were said and done which were hurtful and upsetting.

The first people we encounter after the death of a child are the professional people listed in this document. These people can have a tremendous impact. I hope that the conclusions on the final pages of this document will reach the appropriate professional groups and will be included in training. Hopefully, positive changes will result.

Luke's Mother and Father

When we were asked about participating in this study, we didn't really hesitate at all. We were ready and looking for a way in which we could in some way help after the death of our son Luke. For us, our dealings with various professionals at the time of and after Luke's death made us wish there was more education available for professionals, to guide them in

their dealings with grieving parents. We knew what we thought they did 'wrong' but in most cases, couldn't do anything about it. Naturally, we were only 'grieving parents' as we were reminded by both the police and church officials.

It was scary to know, however, that we would have to retell 'our story' and emotionally open ourselves up once again. Deep down though, we knew, or at least hoped, that one more telling would perhaps bring us to that final acceptance, to that final inner peace which we so desperately needed.

We hope that all the information acquired through this study will make it's way into the offices of professionals and into their everyday dealings with people like us, people whose lives have been turned upside down and who need understanding and compassion as they make their way to redefining what their life now means without their child.

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Appendix I
Interview Guidelines

1. The interview will begin with an explanation of the purpose of the research as outlined on the consent form and in the letter to participants. The time frame of professional involvement will be specified (i.e. death notification through funeral) and the range of professionals identified (i.e. police, ER staff, coroners, chaplains, funeral directors, and any other professionals such as social workers who may have been involved at the time).

2. Participants will be asked to explain the circumstances surrounding the death of their child, up to and including the funeral, and to identify what professionals were involved during that time frame.

3. For each professional that was involved the participants will be asked:
   . how that professional was involved
   . what interventions were helpful, or not helpful and why
   . what impact those interventions had on their functioning, at that time and long term
   . what the participant felt would have been more helpful

4. Participants will be asked what professional involvement was not available to them that they felt might have been helpful.

5. The experiences of the participants will be summarized.

6. Their suggestions will be summarized.

7. Participants will be asked if they feel there is anything they would like to add or is important for the researcher to understand.

Appendix II

Consent to Participate

I understand that I am being asked to participate in a research study that is being conducted by Linda Maxwell, supervised by Dr. Anne Westhues of the Faculty of Social Work at Wilfrid Laurier University.

The purpose of this study is to better understand how parents are affected by the interventions of professionals at the time of the sudden death of their child. The data collected in this research will be used to promote this understanding.

The following procedure will be used: I will be asked to participate in a face to face interview with the researcher. This interview will be tape recorded so that the researcher can transcribe the tape and analyze the data. The interview should last approximately one hour. After the interview, the researcher and I will talk briefly about how I feel about the experience of the interview. In addition, I may be asked to participate in a group discussion to discuss the issues that are identified in this research. I understand that I may decline to participate in the group discussion should I prefer an individual interview only.

I understand that there is a risk that in discussing my child's death, painful emotions may be brought forward. I understand that I am free to stop the interview at any time, and that the interviewer will assist me to deal with such a situation. I understand that I am free to contact the researcher at the telephone number listed below if I have any questions.

The benefits which I may gain from participating in this study include: I will have made a contribution to the professional understanding of parent's needs at the time of the sudden death of their child; I will have another opportunity to process the death of my child; and, I may gain an understanding of how other parents feel about professional interventions at that time.

I understand that my participation is voluntary. I may refuse to participate in this study without penalty to me. I may also withdraw from this study at any time without penalty. I may choose not to answer any particular question asked by the researcher.

I understand that my research records will be kept confidential and that I will not be identified in any publication or discussion. The transcribed data from my interview will be maintained in a locked filing cabinet in the researcher's office. I understand that my name will not be recorded on tapes or transcripts. I further understand that only the researcher and her dissertation committee members may have access to my interview

records. The tapes from my interview will either be erased, or at my request given to me subsequent to the completion of the dissertation.

I understand that direct quotes may be used in reporting the data. The use of these quotations will be limited to those that do not disclose my identity. Only first initials will be used in reporting quotations. The researcher will obtain my consent to use quotes that may disclose my identity. I understand that I am free to decline to consent to the use of such quotations.

I understand that I have the right to have all of my questions answered by the researcher in sufficient detail to clearly understand the answer.

I understand that I may receive feedback on the overall results of this research by access to the completed paper or by discussion with the researcher.

If I have any questions about the research, the procedures employed, my rights, or any other research related concerns, I may contact Linda Maxwell, Dr. Anne Westhues, or Dr. Linda Parker at the numbers listed below.

I acknowledge receiving a copy of this informed consent.

Signature of Participant: _____

Date: _____

Signature of Researcher: _____

Linda Maxwell
905-331-5106

Research Advisor:
Dr. Anne Westhues
519-884-1970 ext. 2474

Assistant Dean
Graduate Studies and Research
Dr. Linda Parker
519-884-0710 ext. 3126

Appendix III

Letter to Participants

Dear Participant:

You have been asked to participate in a study that examines the effects on parents of professional interventions at the time of the sudden death of their child. The purpose of this study is to better understand the effects of professional interventions, in order to develop more helpful interventions in future situations.

I am a doctoral candidate at Wilfrid Laurier University in the Faculty of Social Work. As part of the requirements for a doctoral degree, I am conducting research in the area of parental loss. This study has been approved by the Research Ethics Board of Wilfrid Laurier University.

The study will involve a face to face interview in your home or at a mutually agreable location, which will last approximately one hour. The interview will involve questions regarding the death of your child and the interventions of the various professionals involved at that time. Your privacy will be protected, and the data will be kept in a safe location. Every effort to protect your identity will be made in reporting the data. Further information with respect to the procedures regarding privacy is contained in the attached consent form.

Attached you will find a consent to participate form, which clearly outlines your rights as a participant. Please review it carefully before signing it. If you have any questions regarding this research, please contact the researcher at the number listed on the consent form. Dr. Anne Westhues, Research Advisor, and Dr. Linda Parker, Assistant Dean, Graduate Studies and Research may also be contacted at the numbers listed on the consent form.

Thank you for your participation in this research.

Sincerely,

Linda Maxwell
Doctoral Candidate