# CHILDREN'S EXPERIENCE OF A GRIEF SUPPORT PROGRAM: A QUALITATIVE STUDY

by

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A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfilment of the Requirements for the Degree of

MASTER OF SOCIAL WORK

Faculty of Social Work
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## ABSTRACT

The purpose of this qualitative study was to explore children's experience of a group intervention for bereaved young people. The grief support program for children associated with this study is an eight week closed group for children who have experienced the death of a significant person in their lives, and is designed to facilitate children's healthy adaptation to loss.

Semi-structured interviews were conducted with parentally bereaved children who had attended the group within the preceding two years. Data analysis was based on the qualitative strategies for social work researchers outlined by Tutty, Rothery and Grinnell (1996), and Padgett (1998)

Study findings suggest that the group's most significant role may be to create a safe and unique context for group members in which their bereavement experiences may be normalized and their sense of isolation diminished.

Participants' feedback was characterized by or connected to the following three themes: the primary importance of a safe context in which to explore one's grief experience; the unique benefits of listening to and talking with other bereaved children, and the development of a new or enhanced sense of awareness and/or insight. These themes have been conceptualized as a process associated with children's experience of the group.

Most of the children interviewed found the Grief Group useful, but there was emphatic and instructive negative feedback as well. Recommendations that flow from this study involve modifications to the program's approach, a call to educate clinicians, families and communities about healthy grieving,  and areas of theory and practice in need of further exploration.

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# CHAPTER ONE: INTRODUCTION

> We have created systems which protect us in the aggregate from facing up to the things that as individuals we most need to know.
>
> Jocelyn Evans (1971)
> Living With a Man Who Is Dying

## PURPOSE OF THE STUDY

The purpose of this qualitative study was to explore parentally bereaved children's experience of a grief support group. The phenomenon of childhood bereavement and grief has been thoroughly examined and described. Factors that influence children's healthy adaptation to loss have been researched and ranked, and the rationale for intervening persuasively argued. These areas of theory and research support a growing body of interest in group interventions with bereaved young people. Unfortunately, research to date does not offer clarity or assurance that this type of approach is effective from the child's perspective.

This study was designed to address the following questions:

1.) What themes characterize children's experience of this grief group?

2.) Do children's perceptions of the program reflect the program's targeted goals?

3.) What do children's experiences tell us about the strengths and weaknesses of this group intervention?

# A GRIEF SUPPORT PROGRAM FOR CHILDREN AND TEENS: EVOLUTION AND EVALUATION TO DATE

This study involves a group intervention for bereaved children that was developed by a team of hospital social workers in 1987 who recognized a gap in the services available to grieving families. Inspired by the work of Ben Wolfe and his colleagues at the St. Mary's Grief Support Center in Duluth, Minnesota, this program was designed to help children and teens deal with loss in a way that would foster emotional health, growth and the development of effective coping skills. The goals of intervention included the following: promotion of a realistic and developmentally appropriate understanding of death; acknowledgment and expression of grief related feelings; normalization of the experience of loss and grief; cultivation of effective coping strategies, and the sanctioning of acts of remembrance.

This grief program has been offered twice a year as an eight week closed group for children between the ages of five and 17 years of age who have experienced the death of a significant person in their lives. Referrals are received from hospital social workers, school teachers and counselors, clergy and mental health professionals in the community. The program does not advertise and there is no fee associated with attendance. Financial support has been provided by the sponsoring hospital's auxiliary.

Group facilitators conduct pre-group visits with children and their care givers . These visits provide families and program staff with an opportunity to assess the potential for fit between the child and the intervention. If the facilitators or the clients believe that a child would not be well served by a group intervention focusing on bereavement, efforts are made to refer the family to a more appropriate resource (e.g. family therapy clinic, individual counseling).

Participants are clustered into three age groupings, each having five to eight members and two facilitators. The group offers children the opportunity to meet with others who are in a similar situation, explore their own thoughts and feelings about their loss, learn about grief, and discuss a variety of topics such as memories and changes in their family since the death of their loved one. During the eight weeks facilitators make use of books, games, art work and discussion to address the following themes and aspects of group process:

> Week 1: The establishment of comfort within the group and social sanctioning for the discussion of death. (e.g. each child tells their story, children draw pictures of the deceased, 'getting acquainted' games, brainstorming and agreement concerning group ground rules)
>
> Week 2: Working on group cohesion and discussion of memories of the deceased. (e.g. members are asked to bring in a memory of their loved one to 'show and tell')
>
> Week 3: Death education. (e.g. drawing and discussion about death and funerals, brainstorming facts and fantasies associated with death)
>
> Week 4: The identification, expression and normalization of all grief related feelings. (e.g. brainstorming feelings associated with loss, art exercises to identify where in the body we feel our feelings, miming of various feelings)
>
> Week 5: Discussion of effective coping strategies. ( e.g. listing strategies used by members, discussion and practice of alternative approaches)
>
> Week 6: Consideration of changes in the family since the death, and of a future without the deceased. (e.g. drawing and sharing pictures of member's families in the past, present and future, diagraming

support system and potential additions to it)

Weeks 7 and 8: Closure and feedback. (e.g. completion of group evaluations, return of art work, exchange of cards, phone numbers and addresses if desired, pizza party)

A concurrent, companion support group for parents/caregivers developed spontaneously in 1994. This adult group is facilitated by a social worker but the focus of each session is determined by the participants. Typical topics of discussion include coping with the emotional and practical needs of a bereaved family, ways in which children's grieving differs from that of adults, and ways to support and encourage children as they adapt to an altered life without the deceased.

A review of some of the literature on grief support programs suggests that the theoretical framework and format of this program are roundly supported by others working in this area (Beswick & Bean, 1996; Graham, Athen & Sontag, 2001; Heiney, Dunaway & Webster, 1995; Huss & Ritchie, 1999; Lohnes & Kalter, 1994; Mulcahey and Young, 1995) . Program facilitators are convinced that the program's approach is sound and feel confident that clients value the service given the following: program advertising has been limited to word of mouth, yet there is never a shortage of referrals; families sometimes drive long distances and alter work and school schedules to ensure attendance; attrition is minimal; facilitators observe that most of the children become more relaxed and communicative over the course of the eight weeks, and feedback, both verbal and written, from the families involved is predominantly positive.

In spite of these positive indicators, there are a number of reasons to question their validity as evidence of the program's success in attaining its therapeutic goals. This grief support program is one of very few accessible and affordable options available to bereaved families in the area. While continued demand for and utilization of the program confirms an ongoing need on the part of this population, it says little about the quality or efficacy of the intervention offered.

The evaluation forms designed and administered by group facilitators ask children and their parents to comment on the following: aspects of the program they like most and least; changes in children's behavior or understanding attributable to group participation; whether they would recommend the group to bereaved friends and family, and any additional recommendations or feedback they care to share. There has not been any disciplined review of these forms but feedback has been generally positive. The majority of children and caregivers have stated that they would recommend the service to other bereaved families and the most common recommendation is that there is a need for more than six to eight weeks per session.

The grief group has not undertaken any formal review or analysis of the client feedback obtained thus far, but generally speaking, written and informal feedback from participants and parents suggests that the vast majority of families who have accessed this service have appreciated it. Parents often associate some positive changes in their children with group involvement, and most state that they would recommend the program to other bereaved families.

The client evaluation forms used by this program appear to be a practical and focused approach to program evaluation; unfortunately they are not the best approach to evaluation if the goal of inquiry is to assess the actual impact of a service for the participants. Stipak (1982), writing on the use of client feedback to evaluate programs, advises that while predominantly negative feedback on participant evaluation forms usually indicates significant problems

> "..social and psychological theory would predict a positive evaluation bias due to several factors, including social desirability response bias, ingratiation attempts and cognitive consistency, also both program clients and program staff often receive a variety of benefits from participation in the program , regardless of the program's effectiveness in attaining official program goals" (p. 589).

Stipak's caution applies to formal evaluation forms completed by participant families and to the impressions and anecdotal reports of group participants and facilitators.

## CONCLUSION

Chapter two describes the phenomenon of childhood grief and parental bereavement and provides a review of the literature on group interventions with bereaved children. Chapter three introduces qualitative research in general and outlines the rational for using this type of methodology for this particular study. The findings of this study are presented in chapter four. The final chapter offers an overview of what was learned in the process and as a result of this research project.

Writing on the process of qualitative research, Kirby and McKenna (1989) assert that the 'honorable' researcher must contextualize herself in the research by declaring the assumptions and experience that frame the topic she has chosen to investigate and the questions she has elected to address. I have woven some of my own perspectives and beliefs into this report in order to take up the challenge of acknowledging and accounting for myself as a key determinant of the trajectory, substance and texture of this project.

# CHAPTER TWO: LITERATURE REVIEW

> John LaRoche: Adaptation is a profound process -
> figuring out how to thrive in the world.
> Susan Orlean: But it's easier for plants. They have no memory.
>
> From the motion picture Adaptation (2002)
> Magnet/Clinica Estetico, Intermedia Films
> (Producers)

## CHILDHOOD PARENTAL BEREAVEMENT

Our individual instincts and collective wisdom concur that childhood parental bereavement is one of the most tragic and unjust accidents that can befall an individual. Lyricists and storytellers employ the archetype of the parentally bereaved child to reliably evoke reactions of empathy, anguish and indignation that so tragic a loss should befall one so unprepared and undeserving. Contemporary images of the anonymous orphans of war and the much photographed children of deceased public figures remind us that neither a tradition of adversity or a bequest of privilege appear to significantly mitigate the impact of this type of loss.

The parentally bereaved child is faced with the challenge of living with what for many proves to be the most catastrophic experience of their lives. Not only must they cope with this crisis at a young age, they must do so without the assistance of a primary support. The confusion and insecurity that may be occasioned by the death of a parent can lead to a sense of increased vulnerability, an inability to trust and a decrease in self esteem for the bereaved child (Graham, Athens & Sontag, 2001).

There is, however, another dimension to the archetypal image of the parentally bereft child which offers inspiration, optimism and direction. Many who have known or worked with bereaved children can attest to the strength, resilience and insight often displayed by these young people. Children's ability to resume their daily routines, to rest their spirits in play, and to fashion a context of understanding in the face of the apocalyptic loss of a parent, reminds us that we ought not to underestimate young people's strength and capacity to cope with profound challenges.

## Bereavement, Grief and Mourning: Connections and Distinctions

Bereavement is an objective descriptor for the reaction of individuals to the loss of a close relationship through death. Burnett, Middleton, Raphael, Funne, Moylan & Martinek (1994) define grief as the emotional or affective responses that are typically experienced by bereaved people, and mourning as the process of expressing and enacting grief. They propose a model in which the characteristic phenomena of bereavement grow less frequent and intense, but not substantively different over time.

Uncomplicated grief in children shares much in common with the model for adults proposed by Burnett et al., however, children are generally more inclined to enact (as opposed to articulate) their grief- related feelings. Bereaved children typically manifest strong feelings of sadness, anger and fear in the form of sleep, appetite and/or behavior disturbances, difficulty with concentration, a decline in academic performance, social withdrawal and an increase in somatic complaints(Christ, 2000; Osterweiss, Solomon & Green, 1984; Webb, 2002).

Children's grieving also tends to be less pervasive, more intermittent and more situation specific than that of adults, and although children grieve deeply and often for long periods, it is often less apparent (Christ, 2000; Kranzler, Shaffer, Wasserman & Davies, 1990; Schonfeld, 1993; Webb, 2002). Young children are unable to endure extended periods of strong emotion. In order to avoid being overwhelmed, they visit these emotions for brief periods only, often using denial, distraction, regression and fantasy to protect themselves from prolonged psychic pain (Osterweis , Solomon & Green, 1984; Schonfeld, 1993; Sekaer, 1987). The grieving of adolescents seems to be as intrusive and intense as that of adults but generally not as prolonged (Dane, 2002). Although adolescents are usually more articulate and insightful about their feelings than younger children, they are often disinclined to communicate their grief related feelings for fear of appearing unusual to their peers.

The resurgence of a child's intense grief reactions long after a parent's death is predictable, normal and functional. As children develop new physical, cognitive and emotional capacities, and as they experience milestones and transitions, they are compelled to rework their loss to fit it into their evolving understanding of themselves and their world (Christ, 2000). Baker, Sedney and Gross (1992) suggest that "the resurgence of grief may be interpreted in a positive growth-oriented framework as providing opportunities for understanding and experiencing the loss in the light of new developmental capabilities" (p. 112)

There are common themes that characterize the fears and concerns of bereaved youngsters. Children tend to be egocentric, unsophisticated about death, and continually in the business of fitting experience with understanding. As a result, many are plagued with questions such as: Did I cause the death? ; Can the same thing happen to me or someone else in my family? ; If something happens to my parent(s), who will take care of me? In the absence of repeated, clear, developmentally appropriate information, children will often author explanations for the death that finds them responsible and in peril.

There is a broad variation in the duration and intensity of grieving children. In a review of the DSM III-R and the phenomenology of childhood bereavement, Vida and Grizenko (1989) suggest that the concept of childhood bereavement needs to be expanded to clarify the distinctions between normal bereavement responses and pathological phenomena such as depression and adjustment disorders. They conclude that childhood bereavement "is associated with an increase in psychological symptoms with no specific syndrome that can be considered typical" (Vida & Grizenko 1989, p.153). It is also important to recognize that there is no typical or normative pattern of family grieving and relatives are seldom synchronized in their mourning (Jordan, Kraus & Ware, 1993).

Grief is not merely an array of emotional responses, it is a set of adaptive behaviors related to biological and social systems. Averill and Nunley (1988) assert that the anguish experienced by humans when separated from key relationships is adaptive; Grief "reinforce(s) the fabric of society by assisting surviving members of the group to assign meaning to the loss, renew alliances, and realign commitments" (p. 85). This perspective is compatible with models of bereavement that suggest that there are tasks associated with mourning (Baker, Sedney & Gross, 1992; Furman, 1974). Baker et al. (1992) conceptualize the grief process as a series of early, middle and late phase tasks that must be accomplished over time. They emphasize that this process is neither linear nor efficient, but that it is essential for the healthy resolution of children's grief.

Early phase tasks focus on the child's need to understand the reality of the death and its implications, and the need to protect themselves and their families, physically and emotionally. Children often use regression, denial, distortion and fantasy to cope cognitively with their loss and to limit their experience of psychological pain. Once a child acknowledges the loss of a loved one and begins to face the pain that this realization represents, s/he is able to undertake middle phase tasks. This phase addresses the exploration and reevaluation of the bereaved child's relationship with the deceased. Late phase tasks involve the integration of the significant relationship with the deceased into the personal identity of the child, the return to age appropriate developmental tasks and relationships, and the need to cope with the surfacing of emotion associated with milestones and anniversaries. These late phase tasks are ongoing, and most bereaved children continue to address some aspects of late phase tasks well into their adult years.

To the extent that a child's inner resources, support system and circumstances are adequate, s/he can adjust and adapt to loss in such a way that her/his developmental needs and capacities are not thwarted, and her/his confidence and competence to deal with future losses is enhanced.

## Variables that Influence Children's Adaptation to Loss

Over the past 50 years there has been a growing interest in childhood bereavement and the variables that may influence a child's adjustment. This section focuses on those variables that appear to be the most important, about which there seems to be considerable agreement in the literature.

The consistency and adequacy of parenting of the bereaved child appears to be the most important variable influencing a child's adaptation to the loss of a parent (Bowlby, 1980; Christ, Siegel & Christ, 2002; Furman, 1974; Kranzler et al., 1990; Rosen, 1991). The death of a parent can shatter a child's assumptive world resulting in an inability to trust, an amplified sense of vulnerability and a decreased sense of self esteem (Graham & Sontag, 2001; Osterweis et al., 1984). The maintenance of competent and caring parenting behaviors and a routine appear to provide an important element of protection and predictability that helps the bereaved child maintain some sense of mastery and trust in the drastically altered world they have been obliged to inhabit.

Children's adaptation to the loss of a loved one is more challenging when the relationship between the bereaved and the deceased is characterized by high levels of dependence or ambivalence. The age groups that are most vulnerable to poor outcomes related to childhood parental bereavement are children under the age of five and adolescents (Saler, 1992). Children below the age of five are most dependent and adolescents are most likely to have experienced conflict with their deceased parent.

Kranzler et al. (1990) and Rosen (1991) found that children are especially vulnerable if the deceased parent was the individual most responsible for nurturing the child's self esteem. This finding is consistent with a study by Bloch (1991) that found that bereaved families in general find it more difficult to adjust when the deceased was primarily responsible for the emotional as opposed to instrumental needs of the family.

In order for a child to successfully manage the tasks of grieving, s/he must be able to comprehend the concepts of irreversibility, nonfunctionality, causality and universality as they relate to death (Schonfeld, 1993). The concept of irreversibility speaks to the permanence of death. Nonfunctionality refers to the understanding that living functions end at death. Children who comprehend causality related to death recognize that neither magical thinking nor the negative judgments of others can cause death. The concept of universality involves the realization that all people, including children and loved ones, die. A child's ability to engage with these concepts intellectually and emotionally, is directly related to his/her cognitive development and level of maturity.

According to Piaget's model of child development, children's progression through the Preoperational, Concrete Operational and Formal Operational stages of cognitive development is paced according to their biological readiness and learning. Based on Piaget's theory, children become progressively better able to understand the concepts related to death (irreversibility, nonfunctionality, causality and universality) as they progress through the stages (Lonetto, 1980). Piaget's model suggests that children are unable to fully comprehend the abstract in these concepts until the Formal Operational stage between the ages of nine and 12 years. However, more recent studies have reported that many children acquire mature conceptions of death as early as age seven (Prichard & Epting, 1991; Speece & Brent, 1984).

Whether or not a parent's death was anticipated seems to play a role in their children's adjustment to bereavement. The anticipated death offers the child the opportunity to prepare cognitively, and to some extent emotionally for their loss (Baker et al., 1992; Osterweiss et al., 1984). When the sudden death of a parent is the result of violence (e.g. suicide or murder), children appear to be at greater risk of complicated adjustment. The relationship between the type of death, the psychological and social circumstances of the family prior to the death, and the grief outcome for the child does not appear to be clear.

Studies that describe the similarities across cultures regarding the emotional and affective responses to the death of a loved one (Catlin, 1992; Rosenblatt, 1988). There is also agreement that people's adjustment to bereavement is facilitated by participation in traditional mourning practices. The rituals and roles associated with bereavement appear to "...reinforce the fabric of society by assisting surviving members of the group to assign meaning to the loss, renew alliances, and realign commitments" (Averill & Nunley, 1988, p. 85). Research on cultural variables such as ethnicity, social class and religious affiliation exist but their impact on bereavement outcomes has been inconclusive.

## Fostering Children's Healthy Adaptation to Loss

The fostering of a bereaved child's healthy adaptation to loss does not imply that the process will be either painless or swift. It does imply that the child will be assisted to address the sequential tasks of bereavement, that his/her return to age appropriate developmental tasks will be facilitated, and that s/he will be better equipped to cope with future losses as a result of the experience. This section briefly speaks to the importance of the following themes:

1.) The promotion of a realistic, developmentally appropriate understanding of death;

2.) The acknowledgment and expression of feelings associated with grief;

3.) The cultivation of effective coping strategies;

4.) Normalization of the experience of loss and grief;

5.) Respect for and encouragement of acts of remembrance and commemoration;

6.) The maintenance of quality parenting of the bereaved child;

Children who have permission to be curious and knowledgeable about death and death related issues are provided a valuable tool in helping them gain mastery of their grief experiences. Bereaved children need to be told in simple, direct, age appropriate terms about what has happened and what to expect. They need to be reassured that they will be taken care of, that they are not to blame for the death and that they are not going to die soon in the same way as their loved one.

A child's ability to acknowledge and express their feelings in ways that do not harm themselves or others is another cornerstone of a healthy adaptation to loss. If a child's caregivers are able to provide an atmosphere of open mourning and support there is greater opportunity for a child to have their questions and misunderstandings addressed, and their fears and anguish responded to respectfully. (Christ et al, 2002; Rosen, 1991). Children who have a range of effective options for expressing and coping with the painful feelings and circumstances occasioned by bereavement are less likely to become habituated to defensive strategies that may limit their growth and understanding.

Normalizing the experience of death for children can attach a new social meaning to the experience of loss, helping children see that they are not defective for having lost a significant person, nor are they aberrant for feeling the way that they do (Zambelli & DeRosa, 1992). Normalization of episodes of maturational grieving at times long after the death of a loved one is especially important. Children and their families need to recognize these recurrences as evidence of healthy adjustment as opposed to pathology or regression.

Children's participation in mourning rituals and activities that commemorate and connect with the deceased are associated with better adjustment (Blanche & Smith, 2000; Saler & Skolnick, 1992). In order for a child to forge a new relationship with a deceased parent, s/he needs to be able to tolerate, celebrate and commemorate the relationship that was, and create a new internal connection and identity that incorporates the lost parent (Graham et al., 2001; Lehna, 1995; Lohnes & Kalter, 1994).

A child's most valuable support when faced with the crisis of bereavement is a consistent, caring parental figure who has an appreciation for the relevance of the themes already mentioned (Blanche & Smith, 2000; Glass, 1990). This finding underscores the need to ensure that parents are equipped to meet the needs of bereaved children in ways that promote, as opposed to thwart, young people's ability to cope with loss in healthy ways (Christ et al., 2002).

There is evidence that successful mourning may provide some developmentally advantageous effects. Davis, Martinson and McClowery (1987) studied the effects of sibling death and found long term positive effects related to self-concept and family cohesion. Semmens and Paric (1995) reported that children who experienced the chronic illness and death of a parent "appeared to have an inner strength and resilience that gives them the ability to overcome adversity" (p. 37).

This review of the phenomenon of childhood parental bereavement leads us to a discussion of the rationale of group approaches used to facilitate young people's healthy adaptation to loss.

## GROUP INTERVENTIONS WITH BEREAVED CHILDREN

The experiences of loss and bereavement are universal, and grieving tends to display more similarities than differences across cultures (Catlin, 1992; Rosenblatt, 1988). All cultures and subcultures have crafted tapestries of knowledge, beliefs, symbols, theory and practice to frame and inform the experience of bereavement. In spite of this weaving of wisdom and tradition, many of us today feel ambushed, disoriented and ill-equipped to cope with the challenge of bereavement when it tears at our lives and our hearts.

The stress of parental bereavement in childhood represents an increased risk for the development of a wide array of psychological and physical disorders. This section briefly reviews some of the literature that supports this argument and discusses the rationale for intervening with bereaved children.

## Childhood Bereavement as a Risk Factor

> "Grief is not only a state of intense personal anguish, it is also associated with increased risk for a wide variety of psychological and somatic disorders - some have suggested that grief is like a disease...."
> (Averill & Nunley, 1988, p. 80).

Many studies have suggested a correlation between childhood bereavement and a vulnerability to physical and mental disorders during childhood and adulthood. Delinquency, school dysfunction, depression, introversion, suicidal ideation, above average utilization of health care services and an increased risk for criminality have all been linked to childhood bereavement (Bifulco, Harris & Brown, 1992; Black, 1996; Masterman & Reams, 1988; Reinherz, Gianconia, Hauf, Wasserman & Silverman, 1999; Schilling, Hoh, Abramovitz & Gilbert, 1992).

Not all studies are conclusive regarding the connections between childhood bereavement and later dysfunction and there appears to be a lack of clarity regarding the role of other social variables in the development of disorders in bereaved youngsters. There does however, seem to be reasonable support for the assertion that childhood trauma has the potential to complicate the social, emotional, cognitive and physical development of children.

The anxiety generated by ineffective coping strategies and the new, seemingly insurmountable demands occasioned by bereavement can create "a propensity to adopt maladaptive coping strategies rather than no coping strategies at all" (Johnson, 1989, p. 60). Defensive stances such as denial, social isolation and aggression can provide immediate survival value to the bereaved child, but overspecialization and dependence on coping strategies such as these can disrupt a child's psychological and social development at the stage in which their loss occurs and in the stages of development subsequent to the loss.

## The Social Context of Bereavement

Changes in how we understand the world and live together as families and communities have affected the ways in which we respond to death and bereavement. Advances in the areas of science and technology have resulted in a dramatic decrease in child mortality and an increase in longevity for those living in First World countries. Care of the sick, elderly, dying and dead has been transferred away from the family and social network, into the hands of specialized professionals and institutions. For many adults and most children, direct involvement with death has become a rare and mysterious event that takes place in secluded institution, surrounded by specialized equipment and professional caregivers.

We have come to depend on and defer to the omniscience of medicine when threatened by injury, disease, and the effects of aging. In this world of miraculous repairs and heroic measures, death is not uncommonly perceived as a failure of our best efforts; an unjust or illegitimate ending as opposed to a natural and unavoidable transition. This is especially true if the deceased is a child or the parent of dependent children.

The participation of families and communities in death related rituals and the support of the bereaved has been eroded and transformed by the dilution of cultural and religious traditions, the dispersion of family and community groups, and the prevalence of nontraditional family roles and styles. The circle of support for many families in need has diminished in size and, in many cases, there has also been a diminution of family and community involvement and commitment. The development of self-help/support groups and professionally designed interventions for a variety of stressful family circumstances, including bereavement, can be interpreted as due, in part, to our collective recognition of the need to compensate for the disintegration in our webs of support.

## The Value of Intervening with Bereaved Children

Children continually interpret new experiences, construct meaning and choreograph their emotions and behaviors to fit. We know that the provision of clear, developmentally appropriate information to children about death can correct distortions, and that children are able to learn concepts about death at a much earlier age than many educators and most parents have appreciated in the past (Schonfeld & Kappelman, 1990).

Given that death has to a large extent been medicalized and removed from the domain of the home, many parents are fearful of the experience and feel unsure of how best to manage their own confusion and emotions, let alone that of their children. Bereaved children and parents sometimes need help to express and analyze the questions and conflicts they are experiencing due to their loss, and to recognize that their experience is normal and necessary. An awareness of the feelings, experiences and problems associated with grief and the permission and encouragement to share these can allow children to move ahead with what they need to do for themselves (Rosen, 1991).

Maintenance of consistent and appropriate parenting is widely identified as crucial to a child's healthy adaptation to loss. However, bereaved parents often find it necessary to cope with this challenge with limited support available from family or community. As a result, "Given the shock to the family system, especially to the surviving parent, .....outside intervention, which provides peer group support and education about death, grief, and survival, is recommended to facilitate normal grieving and to prevent pathological grief reactions." (Masterman & Reams, 1988, p. 569).

## The Wisdom of Utilizing Group Interventions with Bereaved Children

Grief work involves the experience, exploration, analysis and response to issues of loss, connection and ethos. The emotional impact of bereavement is embedded in the social circumstance, and a group approach is particularly well suited as a medium in which the bereaved can sort and cultivate their understandings and responses. In their comparative study of family bereavement groups, Hopmeyer and Werk (1994) suggest that peer group interventions with bereaved families provide the bereaved with the experience of commonality, normalization, solidarity, reciprocity, and control. These qualities reflect the potential of a group approach to provide a surrogate social context, a community for grief work.

Attending a bereavement group may be a first step in the countering of a child's denial (Tedeschi & Calhoun, 1993), and an efficient and comfortable venue for the promotion of a realistic, developmentally appropriate understanding of death. Acknowledging that a loved one has died, in a relatively safe but public forum, can provide group members with a context in which they can learn that the grief process is universal. Distressing and embarrassing aspects of the experience, such as acting out behaviors or an inability to concentrate can be normalized and depathologized. The expression of strong feelings may be encouraged and better tolerated in a group with other bereaved persons who may be perceived as more empathetic and safe due to "the credential of their own grief" (Tedeschi & Calhoun, 1993, p. 53).

Group participation, even if only brief, can begin to bridge the gap that grief and loss can create between the bereaved individual and those around her\him. Many people feel burdened by any association with death, and unsure about our ability to meet the needs of the bereaved in general, and bereaved children in particular. Not uncommonly, this combination of fear and self doubt results in a tendency to avoid the issue of loss, and at times to avoid the bereaved altogether. If group members are able to re-experience their ability to connect with others in the group, they may gradually feel encouraged and inclined to reconnect with others outside of the group. Mulcahey and Young (1995) believes that the group's capacity to normalize the grief experience and decrease the bereaved child's sense of isolation is its most significant advantage.

Group interventions with bereaved children can also broaden members' exposure to effective ways of coping with painful feelings and unwelcome changes in their life circumstances. Schilling et al. (1992) cite studies from other risk domains and assert that "... children learn to cope with stress and challenges by watching, listening to, and interacting with their peers" (p. 407). In addition to the support and influence of peers, group facilitators skilled in listening and modeling effective coping strategies can be invaluable resources to youngsters as they learn to manage strong feelings and stressful adjustments (Opie, Goodwin, Finke, Beatty & Van Epps, 1992). Interaction with group members and adult facilitators can also provide children with a practice field for the discussion of emotionally charged issues with family members (Mulcahey & Young, 1995).

The literature on interventions designed to target the needs of bereaved children revealed an increase in the utilization of a group approach over the past 20 years. Most of the group interventions reviewed that addressed outcomes utilized a structured, closed group format and included a parallel component for parents/caregivers (See Appendix A). All of the programs explicitly or implicitly addressed the importance of most or all of the following: death education; the identification and expression of feelings; memory preservation; communication in the family, and the development of constructive coping strategies. Most of the groups designed for children made use of creative art activities and discussion. Many programs utilized games and books and some, particularly those programs working with children under the age of 10, made use of guided play.

Of the programs reviewed, most group interventions designed for children and their caregivers were structured with sessions for the children and the adults running concurrently (Beswick & Bean, 1996; Heiney et al., 1995; Mulcahey & Young, 1995; Stokes, Wyer & Crossley, 1997; Williams, 1998; Zambelli, Clark, Barile & de Jong., 1988). The group interventions designed for the adult caregivers focused on the importance of maintaining a consistent, nurturing environment for the bereaved child while also attending to the emotional and practical needs of the caregivers. Educational components focused on how children grieve, parenting skills and how best to support the grieving child.

Two programs (Lohnes & Kalter, 1994; Zambelli et al., 1988) were fashioned to affect a "reparative" or "corrective" mourning experience for group members. The program described by Lohnes & Kalter was designed to approximate the temporal sequence of issues to be dealt with for the bereaved child starting with death education, followed by funeral experiences, return to school following the death and dealing with issues associated with living in a single parent family. Zambelli et al. reported on a program for families with a similar structure and intent.

One of the most ambitious approaches described in the literature was the Family Bereavement Program at Arizona State University (Sandler, West, Baca, Pillow, Gersten, Rogosch, Virden, Beals, Reynolds, Kallgren, Tein, Kriege, Cole & Ramirez, 1992). This program involved Family Grief Workshops and a Family Advisor Program. The Workshops were designed to do the following: 1.) offer bereaved families the opportunity of meeting together with other bereaved families for the purpose of decreasing their sense of isolation; 2.) to provide families with an opportunity to work on enhancing the warmth of the parent child relationship. The Family Advisor Program consisted of 12 sessions conducted with parents in their homes. These sessions targeted parental demoralization; the prevention of serial negative life events that could result from the death; the development of skills and strategies to foster parental warmth, and assistance with planning for stable positive events in the life of the family.

All of the programs reviewed reported positive outcomes overall and participation in group interventions appeared to be associated with the following outcomes in particular for group members: 1.) Increased ability to communicate in group (Masterman & Reams, 1988); 2.) Improved communication with family members (Beswick & Bean, 1996; Masterman & Reams 1988; Mulcahey & Young, 1995; Sandler et al., 1992; Stokes et al., 1997); 3.) Decrease in behavior problems (Heiney et al., 1995; Masterman & Reams, 1988; Tonkins & Lambert, 1996; Williams, 1998; Zambelli et al., 1988); 4.) Decrease in somatic complaints (Heiney et al., 1995; Opie et al., 1992; Sandler et al., 1992).

Reviews of the research on group interventions with the bereaved are rare.

Hopmeyer and Werk (1994) undertook a comparative study of five peer support/self help programs for bereaved adults in Montreal. The programs included in this study were designed for people who had experienced the death of a family member, each focusing on a distinct population (deaths due to cancer, AIDS, suicide, childhood cancer and death of a husband). Each of the programs utilized different forms of leadership and structure. Three of the programs gathered feedback from group participants and reported benefits including reclamation of hope for themselves, increased confidence, normalization and decreased isolation.

## LIMITATIONS OF THE RESEARCH TO DATE

Schneiderman, Winders, Tallett and Feldman (1994) reviewed 53 articles on child and parent bereavement programs to determine whether or not they "work". The only studies deemed worthy of serious consideration by these authors employed randomized, controlled trials to measure intervention effects. Only four of the 53 studies reviewed met this criteria. The remaining 49 studies were found to have major problems of bias because they were not controlled, and as a result their outcome reports were not considered valid. Of the four studies assessed as worthy of serious consideration, two appeared to show benefit and "all suffered significant methodolgic flaws" (Schneiderman et al., 1994, p. 215). The authors conclude that "It is entirely likely that social class, pre-morbid family functioning, social supports, the age of the dead family member and of the survivors as well as the nature of the death have as much to do with individual and family functioning during the bereavement period as any intervention we might provide" (Schneiderman et al., 1994, p. 217).

A comprehensive review of English language evaluations of community based interventions for bereaved children between 1990 and 2000 yielded similar results (Curtis & Newman, 2001). To qualify for inclusion in this review, studies needed to have utilized a control group or pre and post-testing utilizing a standardized measure. Curtis and Newman (2001) found only moderate empirical evidence of positive effects in the nine studies that were found to be relevant, and they identified a range of concerns related to the reliability of the findings.

The use of standardized measures for the assessment of children's bereavement group outcomes has demonstrated little in the way of significant program effects. Most authors identify the inadequacy of the sample size and controls as the factors that limit the their effectiveness. Stokes, Pennington, Monroe, Papadatou & Relf (1999) suggest that while most researchers call for more experimental and longitudinal studies in the area of children's grief, quantitative methods may not be the most suitable approach.

Quantitative measures are predicated on logical positivism which asserts that a single reality exists, and that knowledge of this reality is accessible only to the objective observer using empirical methods. Quantitative investigations are framed by the testing of hypotheses that specify the outcomes to be measured, and require that the phenomena of interest be observable and quantifiable. Variables with the potential to influence the phenomena of interest must be identified and controlled. The goal of quantitative research is to demonstrate statistically significant findings that will allow the researcher to make generalizations and predictions regarding the targeted phenomenon.

Quantitative methods have served us well in the study of relationships in the natural world but "...the art of social science it is a fact that a number of desirable outcome measures still elude precise measurement" (Kuntz, 1991, p. 106). There are several reasons why the study of interventions with bereaved children may be poorly served by the use of quantitative methodologies alone. A significant limitation of the positivist paradigm of inquiry in this area relates to the complexity of the phenomena of interest and the requirement for experimental control of salient variables. Bereavement and the ways in which people adapt to loss are highly individual, complex processes, influenced by the physical, cognitive, emotional, social and cultural contexts in which they are experienced. The controlled relationships prescribed by a quantitative approach may provide too narrow an aperture through which to investigate some aspects of children's grieving and adaptation.

Grieving and adaptation to loss do not conform well to normative patterns or linear models. This represents a confounding aspect for the interpretation of some of the time sampling approaches commonly used in quantitative studies. For example, a pre-post test design study of an intervention with bereaved children may be at risk of missing or misinterpreting grief related behaviors. An observed increase in somatic symptoms or depressive features following a child's involvement in a bereavement program may indicate that the child is not coping effectively with his/her loss and suggest that the intervention was ineffective. However, these same manifestations may signify that s/he has grasped the finality of his/her loss as a result of a bereavement intervention and is addressing some of the most important early tasks of adaptation to loss as described by Baker et al. (1992). This highlights the need to address the meaning of the cognitive, emotional and behavioral aspects of the child's experience as opposed to measuring the frequency or intensity of an observable fraction of the phenomena.

Studies to date of group interventions with bereaved children have been premised on models, descriptions, theories and measures of juvenile grieving developed by adults. The possibility exists that the focus of these investigations has been trained on aspects of the experience that may be less relevant to the children than they are to the adults formulating therapeutic plans and research questions.

## CONCLUSION

There is an abundance of convincing theory and compelling experience suggesting that group interventions facilitate children's healthy adaptation to bereavement. Although we have some ideas about what a healthy adaptation to bereavement entails, describing and quantifying the cognitive, emotional and behavioral manifestations of this process is immensely challenging, especially when taking into account the wide variation in the patterns and rates of adjustment that are considered normative. Patton (1987) suggests that "The practice of evaluation involves the systematic collection of information about the activities, characteristics, and outcomes of programs, personnel, and products for use by specific people to reduce uncertainties, improve effectiveness, and make decisions with regard to what those programs, personnel, or products are doing and affecting" ( p. 15). This study was designed to investigate the the clients experience of the intervention and what meaning it appeared to have for them.

# CHAPTER THREE: METHODOLOGY

> “Cheshire Puss,...would you tell me please, which way I ought
> go from here?"
> “That depends a good deal on where you want to get to," said
> the Cat.
> "I don't much care where....", said Alice.
> "Then it doesn't matter which way you go." said the Cat.
>
> Lewis Carroll (1971)
> Alice in Wonderland

## QUALITATIVE RESEARCH AND EVALUATION

> At some point a program evaluation needs to know what it is like to take part in the program, what meanings and significance it holds for participants , why they respond to it in the ways they do (MacDonald & Sanger, 1982, p. 178).

Qualitative research is based on a constructivist ontology and epistemology. The constructivist paradigm asserts that there is no single reality but that "realities exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them" (Lincoln & Guba, 1980, p. 17).

One goal of qualitative analysis is to identify themes and patterns that characterize the shared experience of a particular group of people. An equally important goal is to account for the depth and range of experiences represented in the data, and to depict and interpret the zebras as well as the horses. Sandelowski, suggests that qualitative inquiry may be viewed as a "blending [of] scientific rules and artistic imagination" (Sandelowski, 1986, p. 29).

The three main approaches to qualitative research are grounded theory, ethnography and phenomenology. Grounded theory is a method of inductive theory development. Hypotheses are generated, developed, dismantled or verified in the course of constant comparative analysis of data sets. Ethnographic studies focus on the culture of a particular group of people.

Phenomenological studies focus on the question: "What is the structure and essence of experience of this phenomenon for these people?" (Patton, 1990, p. 69). This approach is predicated on the assumption that there will be core essences or meanings shared by persons regarding a common experience.

Bernheimer (1986) has argued that qualitative methods are particularly well suited for studying the perspective of children in health care settings where their typically passive role has limited their input as consumers. Christian and D'Auria (1997) utilized a qualitative methodology to study children's experience of growing up with Cystic Fibrosis. These investigators analyzed the transcripts of in-depth interviews with children suffering from Cystic Fibrosis and identified thematic commonalities in the respondents' recollections of their experience. Semmens and Peric (1995) conducted a qualitative study to explore the experience of children who had suffered the death of a parent due to a chronic illness. The investigators of both these studies attempted to do more than report and summarize the words of the respondents. Their intent was to provide a window into the phenomenological world of these children; to identify commonalities and exceptions in the interpretations and responses of these children to their situation. Insights gained informed the researchers' recommendations regarding ways to understand and improve the care of children in similar life circumstances.

Patton (1987) suggests that qualitative methods are particularly well suited to program evaluation when there are no proven quantitative instruments for measuring program outcomes and when the investigator is interested in any of the following:

1.) The program's strengths, weaknesses and overall processes.
2.) Clients' experience of the program.
3.) Detailed, descriptive information about the program that can be used to help improve the program.

## CHALLENGES ASSOCIATED WITH A QUALITATIVE STUDY

Because the ontological and epistemological underpinnings of quantitative and qualitative research are fundamentally different, the language and methodologies of each culture of inquiry are not neatly transferrable from one to the other. The standards of reliability and validity, as applied in quantitative research, are difficult to apply when considering a qualitative study.

The soundness or trustworthiness of qualitative findings are best adjudicated using the criteria of credibility and fittingness. Credibility refers to the truth value or believability of findings (Morse, 1994). Fittingness refers to the applicability of qualitative findings to situations outside the context of the study and the degree to which consumers consider the findings meaningful and representative of their own experiences (Sandelowski, 1986).

There are a number of threats to the credibility of qualitative research findings that the researcher needs to consider and address. The tendency for the respondents of a qualitative study to be the most accessible, articulate and consequently highest status members of the group being studied has been referred to as the 'elite bias' (MacDonald & Sanger, 1982). Unlike quantitative studies that emphasize the need for research samples to be representative of the population of interest, qualitative samples are selected for their capacity to provide a range of rich data concerning the topic of interest. Sandelowski (1886) suggests that the researcher address the typicality or atypicality of data by including available data on all members of the group or instances of the phenomena of interest, thereby allowing consumers of the research to assess the relevance of the elite bias for themselves.

Krefting (1991) identifies another threat to the credibility of qualitative findings as the 'holistic fallacy'. This concern is associated with the potential for researchers to make their data appear more patterned or congruent than it actually is. Because it is not hypothesis-restricted, the qualitative approach affords the possibility of discovering a range of unanticipated observations and interpretations and presumes that alternative theories and explanations will be considered in the analysis of the data. In order to manage this, the qualitative investigator must be able to conceptualize large amounts of data and consider the utility of a number of theoretical perspectives. S/he needs to have a conceptually broad enough perspective to recognize and interpret the unexpected, and exercise a commitment to resisting the temptation to force data into a preselected theoretical framework (Miles & Huberman, 1984).

The incorporation of peer review into a study methodology can serve as a mechanism of check and balance to combat the development of the 'holistic fallacy'. Review and validation of the qualitative investigator's categories, interpretations and conclusions can lend credibility to the research findings (Lincoln & Guba, 1985) . Member checking is a similar type of review exercised by research participants. Participants may be asked to review aspects of the study in order to validate the findings and/or challenge any tendency on the part of researcher to force the data into convenient, but inaccurate congruency with her/his own theoretical bent.

Another strategy capable of enhancing the credibility of qualitative findings involves the use of multiple approaches to data gathering and analysis for confirmation and validation (Krefting, 1991). Krefting suggests that this can be accomplished within qualitative interviews by repeating, reframing and expanding on questions in order to ensure that the interviewer has attempted to confirm and tap the respondent's views from a variety of angles. Qualitative studies may also use interviews with persons having differing aspects of involvement regarding the phenomenon of interest in order to compare the views of one population of respondents with another.

A third threat to the credibility of qualitative findings involves the potential for the investigator - subject relationship to become so enmeshed that the researcher's ability to separate her/his own experience and interpretations from those of the people s/he is studying is threatened (Sandelowski, 1986).

Respectfulness, empathy and sensitivity are invaluable to the qualitative interviewer, but these attributes must be accompanied by clarity and vigilance on the part of the researcher regarding her/his personal, professional and theoretical integrity. Walker (1985) states, "What is crucial is that researchers choose their actions with a self-conscious awareness of why they are making them, what the effects are likely to be upon the relationship and indeed whether their own theories and values are getting in the way of understanding those of the respondents" ( p. 47).

Not only must the researcher be hyper-conscious of her/his platforms, biases and theories that underpin and evolve over the course of the study, it is incumbent upon the qualitative researcher to declare these in the report of their work so that consumers of the study can give conscious consideration to their influence on the findings (Cowles, 1988). An auditable study provides the consumer of research with an account of the researcher's theoretical presumptions, personal reflections, and internal debate pertaining to methodological decisions, analysis and interpretations.

## QUALITATIVE RESEARCH INTERVIEWING WITH CHILDREN

When planning in-depth interviews with children, it is essential for the investigator to consider the characteristics, capabilities and relationship patterns that may influence the average child's motivation and ability to participate in a study of this kind. Adults and adolescents may agree to participate in research interviews for altruistic or futuristic reasons such as the benefit and protection of others or the enhancement of their own self-knowledge and well-being. Faux, Walsh and Deatrick (1988) writing about intensive interviewing with children state that children are not generally inspired to participate in interviews for abstract or future oriented reasons.

Children's ability to participate in qualitative interviews may be limited by their level of cognitive and social development but most children age seven and older are considered suitable research interview respondents for the following reasons:

1.) They are unlikely to be upset or offended by psychosocial interviews (Kaplan, 1994);

2.) Children age seven and older are generally cognitively capable of talking about their experiences, stressors and coping ( Lofland & Lofland, 1995; Faux et al., 1988);

3.) They are able to conceptualize problems and experiences using logic as opposed to relying solely on the information of their own perceptions (Lefrancois, 1980).

The disparity in power inherent in the adult child role relationship poses particular challenges for the qualitative interviewer. In most cultures, children are expected to respect and acquiesce to the authority and discipline of adults. Adult roles of parent, teacher or coach do not potentiate the conditions of equality and impunity that a researcher would want to promote in order to facilitate free and honest sharing on the part of the child respondent. Hatch (1990) advises that "...it is the researcher's responsibility to build more equal role relationships and to avoid giving children any sense that their superior adult status is being used to compel children to respond" (p. 255). Hatch's directives can be addressed by an interviewer's clear, explicit and repeated reminders that there are no right answers, that the child is the expert on her/his own experience, and the interviewer is there to learn and not judge. The interviewer's maintenance of a respectful and neutral stance while adhering to some basic, adult role norms (such as taking responsibility for the safety and structure of the encounter) is recommended.

The qualitative interviewer must make every effort to provide for the physical and psychological safety and comfort of the child participant. Qualitative interviews with children are best conducted in a setting that affords comfort and privacy. It is helpful if the interviewer attends to the child at eye level and makes direct inquiries regarding any adjustments the child might like made to the setting (Erdman & Lampe, 1996).

Decisions regarding the duration of the interviews ought to be guided by the interviewer's understanding of the child respondent's energy rhythms and capacity to attend (acquired in consultation with the child and her/his caregiver), as well as the interviewer's sense of the child's needs while the interview is in progress. The interviewer must also consider the potential for the interview to impact on the child's ability to rest and concentrate following the encounter. In consultation with the child's caregiver, the interview should be scheduled to allow for maximum support and comfort of the child following the interview.

Rosenblatt (1995) states that it is essential for researchers in thanatology to have training and supervision in dealing with people who are bereaved. The qualitative researcher planning to interview bereaved children ought to be well grounded theoretically in the areas of childhood bereavement and grief, have strong interpersonal skills, and some clinical experience communicating with children.

## ETHICAL CONSIDERATIONS

Lofland and Lofland (1995) remind us that ethical dilemmas in the context of research are not substantively different from those we encounter in everyday life. I would add that the core determinants of our ethical conduct as professionals and as researchers are those by which we live and interpret our day to day lives. It therefore behooves the researcher to thoughtfully consider the potential for fit and tension among his/her own world view and moral code, those that underpin the intended approach to research, and the standards imposed by the institutions with which s/he may be affiliated.

Deontological ethical theory (also known as Kantian) serves as a template for the constructivist paradigm of inquiry in general, and qualitative methods in particular. The deontological position affirms that the moral researcher adheres to ethical standards not merely because they are required, but because s/he is committed to treating research participants with "the respect and moral dignity to which every person is entitled" (Beauchamp & Childress, 1994, p. 58). The deontologist asserts that persons ought not to be coerced to act nor treated as means to a researcher's end.

The constructivist paradigm that invigorates the qualitative approach affirms the authority of the individual to define her/his own experience and generates a profound respect for a research participant's input and personhood. The research participant is regarded as a co-creator of the research process, affording the opportunity for the study to be ethically consistent and morally relevant for both the investigator and the participant. Rosenblatt (1995) suggests that the qualitative approach is better able than other approaches to "recognize ethical issues, to acquire information that could help on ethical decisions and to engage in a genuine give and take about ethical issues with people being studied" (p.140).

This section will focus on the following aspects of a qualitative study involving bereaved children: informed consent of the children's parents/guardians and informed assent of the child participants; the minimization of risk to the respondents that may be associated with their participation in the study; the provision of support and/or intervention following the interviews if required; the need to address the sometimes conflicting interests associated with the therapeutic and research imperatives, and the researcher's obligation to account for and care for herself/himself in the context of the work.

When children are invited to participate in a study, they and their parents/guardians need to receive clear, complete and developmentally appropriate explanations for the purpose and methods of the study (Faux et al., 1988). The explanations given should include the researcher's intentions regarding preservation of participant's anonymity, maintenance of privacy, and plans for the dissemination of the research findings.

It is incumbent upon the qualitative investigator to discuss potential risks associated with participation in a study with prospective participants. Page

(1998), writing on ethical considerations associated with qualitative studies, points out that it is impossible for the qualitative investigator to predict the course and content of a qualitative research encounter. Because the researcher cannot predict the nature of the respondent's disclosure, it is impossible for her/him to predict the full range of adverse effects that may be occasioned for the participant. Similarly, at times it can be difficult for the researcher to guarantee the protection of respondent's anonymity and privacy. The researcher can promise to alter names and other types of identifying information in the report of the study, however in certain studies it may be difficult to sufficiently camouflage participants' identities such that their stories would be unrecognizable to people who know them well.

Page cautions that qualitative researchers need to be aware of the special challenges associated with disclosure and privacy in order to adequately maintain standards of ethical and respectful treatment of qualitative research participants. It is an interesting and challenging paradox that a research approach so dedicated to the maintenance of respect for the research participant, by its' very nature, makes this obligation extremely complicated and difficult to manage.

Qualitative theorists emphasize the need for processual consent, defined by Rosenblatt (1995) as "repeatedly giving people opportunities to stop [the interview] or at least avoid a particularly difficult question" (p. 144). Participants need to be informed that the interviewer is required by law to report any disclosures of abuse, threats of abuse or threats to harm themselves or others

(*Child and Family Services Act*, 1985-86). Munhall (1988) suggests that qualitative interview respondents be discouraged from telling secrets unless they can be used as part of the study.

Investigators must advise parents and children that families are not obligated to participate in the study and that a child's decision not to participate needs to be respected. These directives must be accompanied by an assurance that a decision not to participate will in no way affect the family's access to appropriate support or information from any party associated with the study.

Research in the area of bereavement supports the position that it is therapeutic to discuss our losses and give expression to our grief related emotions. Koocher (1974) writing on research with the bereaved states that in the light of his own experience, "talking about death seems to have been considerably less stressful than not talking about it " (p. 21). Rosenblatt (1995) suggests that loss interviews have the potential to provide respondents with new insights, integration and healing. A study by Reich and Kaplan (1994) involving children and their parents, reported that children are unlikely to be upset or offended by psychiatric and psychosocial interviews. Findings of this sort provide reassurance to the researcher planning to consult with bereaved youngsters, but in no way mitigate the investigator's obligation to attend to as many aspects of a respondent's comfort and safety as s/he can during all phases of the study.

Although it is advisable for the research interviewer to be skilled in the therapeutic approach to interviewing, the focus and intent of the research interview are fundamentally different from those of the therapeutic interview. The qualitative interviewer must guard against the temptation to act as clinician or therapist when interviewing bereaved respondents (Faux et al., 1988; Rosenblatt, 1995). If the researcher suspects or is advised that a research participant is experiencing distress or is in need of interventive follow up, the investigator must have appropriate resources available and facilitate the study participant's contact with them.

The qualitative investigator is obligated to ensure that the therapeutic imperative takes precedence over the research imperative in that above all, the research activity must be humane and respectful. S/he must also maintain standards that will support the credibility of the data (Faux et al., 1988). Misconceptions and confusion revealed in the course of interviews with bereaved children must be viewed as important data therefore corrections or clarifications ought to be addressed when the research interview has been concluded. If significant support or intervention appear to be indicated, it should be attended to by someone who has the mandate, time and skill to become involved to the extent that may be required.

Offering participants the opportunity to delete data in the process of member checking is controversial. I favour the honoring of processual consent into all phases of a qualitative study which would allow participants to withdraw any or all of their responses.

Quantitative researchers usually report on the reliability and validity of the measurement tools employed in the report of their studies. Given that "the act of interpretation underlies the entire research process..." (Kirby & McKenna, 1989,

p. 23), some acknowledgment of the 'self' of the researcher in the report of study findings seems ethically necessary. The theoretical, philosophical and experiential perspective of the qualitative investigator will have a profound influence on her/his interpretations of the human phenomena s/he is investigating and should therefore be acknowledged in the report of the research.

## METHOD

This exploratory, phenomenologically oriented study involved semi-structured interviews with parentally bereaved children, age 9 years or older, who had completed the grief group program within the preceding two years. The study proposal was approved by the Research Ethics Committee of the Faculty of Social Work at the University of Manitoba and the research review committee of the hospital that sponsors this program.

### Sample

The sampling strategy was purposeful in that children involved in the group were invited to participate. The goal was to obtain "information-rich cases for study in depth" (Patton, 1987, p. 52). The inclusion criteria allowed for variation in the circumstances associated with the parents' death, as well as heterogeneity of the sample group in terms gender, age and cultural background. Patton suggests that small, purposeful samples of great diversity can provide two kinds of findings: 1) high-quality, detailed descriptions of individual cases which are useful for documenting uniqueness, and (2) significant shared patterns which emerge out of heterogeneity (Patton, 1987).

The literature suggests that children over the age of seven are suitable research interview respondents (Lofland & Lofland, 1995; Faux et al., 1988). Mitchell (1974) states that by age ten, children are capable of thinking abstractly, giving informed, autonomous assent, and articulating authentic opinions and impressions (Mitchell, 1974). A minimum age of nine years was selected for this study.

The size of the sample group was based on the number of interviews required for the researcher to notice repetition and redundancy in the data; "This state of grace is known as saturation" (Padgett, 1998, p. 79). The initial plan was to recruit participants from the fall and spring sessions of a single school year. Eight interviews were completed during this first phase of data collection, however, saturation was not apparent. Consequently the period of data collection was extended over a second program year. A single interview was conducted with each of the 13 participants.

## Recruitment

Program facilitators contacted the parents/guardians of former grief group members who met the study's inclusion criteria and provided them with a brief introduction to the research project ( See Appendix B). Facilitators sent information packages about the study to those who expressed an interest in the study. The package included a cover letter from the facilitator (See Appendix C), a letter from the researcher describing the study and a pre-addressed and stamped form for families to return to the researcher if they were interested in participating (See Appendix D).

Upon receipt of the return form, the researcher contacted the parents/guardians by phone to discuss the study and answer any questions (See Appendix E). Interviews were scheduled at a time and place convenient for the participant families. This recruitment process was designed to potentiate families' comfort and confidence in the project, but to avoid any direct recruitment by program facilitators.

There were 35 children from 26 families who met this study's inclusion criteria. Two of the 26 families contacted declined. Thirteen of the remaining 24 families who agreed to receive information packets contacted the researcher and agreed to proceed with interviews. Two of the 13 families cancelled their interviews due to holiday plans. Eleven of the 26 families or 13 of the 35 children initially contacted regarding the study followed through with study interviews.

The researcher met with each prospective participant and her/his parent/guardian and reviewed the purpose and process of the study with them (See Appendix F ). Consent ( See Appendix G) and assent forms (See Appendix H) were reviewed and signed. If the parent and child appeared to understand and be in agreement with participation, the researcher and the child participant proceeded with the interview in private.

Interviews were conducted by the researcher. I am a middle aged Caucasian female, employed as a social worker. I have been a facilitator with the Kid's

Grief Group for six years and am well acquainted with the history, goals and format of the program. I am also a parent.

## Data Gathering

An interview guide was developed in consultation with the Kid's Grief Group coordinator and two program facilitators (See Appendix I). The guide ensured that each interview covered the same material but allowed the interviewer to alter the wording and sequencing of questions to fit the participant's style, ability and comfort (Patton, 1987). Questions were intended to tap into participant's recollections and impressions about the program and were not designed to explore their grief experience in detail, or test for any specific outcomes. The semi-structured format allowed for exploration and expansion based on individual responses. The guide was pretested with one participant to evaluate and modify the wording and sequencing of the questions, and to identify potentially biasing influences of the interviewer (Faux et al., 1988).

At the conclusion of each interview the parent/guardian was asked to complete a demographic face sheet (See Appendix J). Participants and their parent/guardians were reminded that they could contact the researcher or the faculty adviser regarding any questions or concerns regarding the study, and made them aware that if the participant experienced any distress or anxiety as a result of the interview, consultation or supportive counseling would be made available to them through the grief support program.

Verbatim transcription of the interviews was completed by an experienced transcriber who was a hospital employee bound by the institution's Pledge of Confidentiality. The transcriptions included notations regarding pauses and non-verbal events such as laughter or sighs. All names and identifiers (e.g. names of family members, institutions) were omitted and a code was assigned to each interview. The transcriptions were formatted with a wide right hand margin for notations. Two copies of each interview transcript were made, one for the researcher to write on during the course of data analysis, and a second to be kept as an archival copy. Audiotapes, transcripts and data analysis materials have been stored in a locked cabinet in the researcher's office, to be destroyed seven years following the completion of the study.

## Data Analysis

The plan for data analysis was based on the qualitative strategies for social work researchers outlined by Tutty, Rothery and Grinnell (1996) and Padgett (1998). The following steps were adapted from their work:

1.) Previewing the data: Interview tapes and transcriptions were reviewed as soon as possible following each interview. Any ideas or potential categories or themes that occurred to the researcher during this process were noted but no coding was done.

A research journal was kept to record impressions and insights regarding the context, process and content of the interviews, and to explain the rationale for any methodological or analytical decisions made. Documentation in this journal was intended to help ensure consistency regarding interviewing, coding rules and decision making. Journaling was also designed to help the researcher identify biases and limitations.

2) First level coding: Coding of qualitative data is the "process of identifying bits and pieces of information (meaning units) and linking these to concepts and themes around which the final report is organized" (Padgett, 1998, p. 76). Meaning units can be composed of words, phrases or sentences that appear to convey important elements of what the participant is saying.

Each transcript was reviewed and meaning units were identified and highlighted. Using a process of constant comparison, meaning units within each interview transcript were categorized and named based on their similarity to one another. This process was systematic and logical. Units that did not fit with existing categories generated new categories. Refining and reorganization of coding continued until no new categories emerged.

3.) Second Level Coding: Second level coding is more abstract than first level coding and involves speculation regarding the relationships among the first level categories. A 'cut and paste' method was used to group meaning units belonging to the same category. Categories were compared and contrasted to reveal relationships among them. The goal of this process was to "integrate the categories into themes and sub-themes based on their properties" (Tutty et al., 1996, p. 108).

4.) Interpreting Data and Theory Building: Themes that appeared to connect and illuminate the categories were distilled using a variety of methods including examination of the prevalence of individual meaning units, the creation of matrix diagrams, speculations regarding missing links and outliers, and the consideration of metaphors that offered some coherence to the categories (Tutty et al., 1996).

## Establishing the Trustworthiness of the Results

The following measures were taken to enhance the trustworthiness of the research findings:

1.) Some descriptive information concerning the study participants and the pool of potential participants are summarized in Chapter Four;

2.) Circumstances of the interviews as well as the researcher's method decisions, insights and interpretations pertaining to all phases of the study were recorded in a research journal are available for review;

3.) The researcher tried to ensure the use of a variety of ways of framing questions and confirming the answers to significant questions within each interview (e.g. re-framing, repeating and/or expanding on a question later in the interview);

4.) Member checks were conducted with two of the study participants;

5.) Peer review of the data analysis and findings was carried out by three people.

Three participants were asked to assist with member checks. The researcher prepared a single page summary each of the three participant's interviews, highlighting the main points made by each child. One of the participants had been generally positive about the group, the other two relatively negative. Each child was asked to review the summary of their own interview and comment on how well it reflected what s/he remembered of it, and whether or not it represented how s/he felt about the program at the present time. Each member check was conducted within six months of the participant's interview.

Participants were invited to provide their feedback in person or over the phone. One participant did not provide any feedback. The other two reported that the summary accurately captured the main points they had made. The participant who had been positive about group chose to meet with the researcher to clarify and expand on a few points. The other participant who had been negative about the program left a brief voice mail for the researcher stating that the summary was 'fine'.

Peer reviews were conducted by three health care professionals. One reviewer is a nurse researcher with experience in qualitative research. The other two reviewers are social workers with no qualitative research experience, but considerable experience in the area of bereavement work with children. The reviewers reported that they found the coding understandable and consistent, and the themes and related conceptualization credible.

## CONCLUSION

Unlike Lewis Carroll's Alice, the organizers of this group intervention care a great deal about where their program is going and how it gets there. They also appreciate that when considering the social and emotional aspects of human life, the researcher of human experience must make every effort to ensure that the investigative means justify the ends.

This qualitative study was not designed to provide a clear and comprehensive image of all that happened over the course of the sessions, nor was it expected to enable the investigator to predict how the intervention will affect all children. It was hoped that glimpses into the study participant's experience would permit the investigator to interpret some themes, patterns and exceptions that characterize aspects of the program that seemed meaningful, helpful, harmful or irrelevant to this group of bereaved children.

# CHAPTER FOUR: FINDINGS

He is quick, thinking in clear images;
I am slow, thinking in broken images.
He becomes dull, trusting to his clear images;
I become sharp, mistrusting my broken images.
Trusting his images he assumes their relevance.
When the fact fails him he questions his senses;
When the fact fails me I approve my senses.
He continues quick and dull in his clear images;
I continue slow and sharp in my broken images.
He in a new confusion of his understanding;
I in a new understanding of my confusion.

Robert Graves (1965)
<u>Collected Poems 1965</u>

## DESCRIPTION OF SAMPLE

Nine girls and four boys from 11 different families agreed to be interviewed. Seven of the participants were between nine and 11 years of age. The remaining six were 12 to 17 years of age (See Appendix K).

## CATEGORIES

Categories were created using the constant comparative method described by Tutty et al. (1996) and are composed of interview excerpts that share a common focus or meaning. Some of the categories relate to participants' responses to specific questions but many categories are composed of responses to various questions.

The following section presents the 11 categories and sub-categories that emerged from the data analysis. Participants' comments appear in italics with the age range within which the child falls noted in brackets. When portions of transcript which include the words of the interviewer are cited, the interviewer's words are indicated with the letter 'I' and the participants' with the letter 'P'.

### The Most Important Thing About Grief Group:

Participants were asked what they considered to be the most important thing about the grief group for them. This question was posed at the very beginning and at the end of each interview. The question was presented twice to see if new insights or impressions developed over the course of the interview. Most participants gave the same response when asked a second time.

There seemed to be two main clusters of responses to this question. The first significant cluster emphasized the importance of meeting other parentally bereaved kids. The phrase "I'm not the only one" or words to that effect came up repeatedly.

> *Probably knowing that I'm not like the only one in Winnipeg that's going through this because no one else in my school has nothing like that so when I'm there, there's like twenty kids and I'm like, oh, I'm not the only one. (12-17)*
>
> *Just hearing how other people are dealing with things...because it gives you perspective on your own and makes you feel more like you're not just the only person dealing with it and dealing with it and coping with it that way. (9-11)*

A second cluster of responses indicated that the opportunity to talk and listen was a very important aspect of group for some of the participants.

> *Talking about what happened to other people and then talking about what happened to you. (12-17)*
>
> *...the freedom to talk about it and talk about it and talk about it, you know because you need that but it's hard to burden the people that you care about with that because it's hard for them too. (9-11)*

Three participants were either unsure about what had been the most important thing about grief group or reported that they had not found anything of importance.

**Decision to Attend:**

Participants were asked to comment on how and why they decided to attend the program. Nine of the 13 children interviewed stated that they were interested in attending group the first time they learned of it and required no encouragement to go. Several participants stated that they wanted to attend because they hoped to meet other kids who had lost a parent.

> *I thought it would be kind of good...because like, I knew that it wasn't only me that like those kinda things happen to. (9-11)*
>
> *I guess I just wanted to see if there was other people like me. (12-17)*

Several participants reported that they did not want to attend group or that they had attended because their parent wanted them to.

> *My mother forced me..because she wanted us to like get over it or something. (9-11)*

> *...my Mom was always looking for stuff and she wanted us to do this to deal with it or whatever so that's just kind of something to make her happy. (12-17)*

## Group Sessions:

One of the purposes of this study was to learn which aspects of the program seemed relevant and meaningful to participants and which aspects did not. Participants were asked to comment on their recollections of and reactions to each of the weekly sessions. The results that emerged concerning the weekly sessions have been grouped into categories that relate to the context and delivery of the group sessions, and those that relate to their content and process.

## Context and Delivery:

### Location:

This grief group took place in an education building adjacent to the main hospital building. Most of the participants' parents had died at this hospital and several participants reported that they had been worried that returning to the building for the group would be upsetting. Each of the children with this concern reported that they had felt comfortable in the education building because it was sufficiently removed from the hospital and did not have a hospital-like 'feel'. One participant who disliked the group in general stated that he was very disappointed by the location:

> *I thought it would be like a big place with games and we could talk to each other and then it was just a boardroom when we got there. (9-11)*

Group Composition:

Each participant was asked about the members of her/his group and the impact of different aspects of group composition was explored throughout the interview as opportunities arose. The size of the groups attended by the study participants ranged between three to 10 members with an age range with in each group of up to four years. Most of the interview participants reported that they had been comfortable with the size and the range in ages of the groups they attended. One participant who had attended a group with 10 members reported that at times she felt her group was overcrowded and kids sometimes did not get a turn.

Most study participants stated that the gender mix within their groups was comfortable. One participant was intensely disappointed because in his group of three he was the lone male.

> *... and he told me that there was going to be another boy but then he backed out, in my age group...so I was stuck with only girls. (9-11)*

Two of the three participants whose parents had taken their own lives reported that they had found the group very helpful. When asked if it had been a drawback to be the only group member with a parent who had died this way, one teen replied:

> *I think it was ok, I didn't think that there would be that many similarities but there was...because you still lost your parent and you still have to deal with those issues. (12-17)*

A third participant whose parent had taken his own life was negative about his group experience. He reported that it had not been helpful to hear other people's stories.

> *I didn't see anyone like me...because my father was suicidal and then um, those two died because of like poison, because of like illness. (9-11)*

Several of the children interviewed had attended a group with a child whose parent had taken their own life. Several participants commented on their surprise and interest in the circumstances of these deaths and one participant was critical of having been in a group with a child whose parent had taken their own life.

> *I think it was good for her [member whose parent had taken his own life] to have an experience like that and I think maybe she did need the group but maybe not that group. I think it's a very different process like illness to someone committing suicide. I felt that when she talked about her experience it was very different and especially like, even like a car accident, it's quick, it's fast and a lot of my issues were leading up to that for months. We were with my Dad when he was sick so other people who had an illness knew what that was like... (12-17)*

This participant was also troubled by the inclusion of a child who had experienced multiple losses in addition to her parent's death.

> *...it was a bit hard to relate to someone who had had so many things gone wrong. (12-17)*

## Format:

This program has been offered as a series of six to eight weekly sessions. Approximately half of the children interviewed felt that the number of sessions was just right. Four participants felt that there was a need for more sessions and three participants suggested that six sessions might have been too many. Many of the children interviewed were satisfied with hour long sessions but the five teen-aged participants suggested that each meeting needed to be 15 to 30 minutes longer.

## Timing of Participation:

The interval between the parent's death and the participant's group attendance ranged from four months to 2 years. Eight of the 13 children interviewed had strong opinions regarding the timing of group attendance for bereaved children. Two participants, both of whom attended group approximately 18 months following their parent's death, were satisfied with the time frame for them. They stated that they might have been shy or uncomfortable expressing the intense emotions that characterized the early months of their bereavement.

Of the six other participants who expressed an opinion regarding the optimum timing for grief group attendance, all felt that they would have derived greater benefit from the program if they had attended earlier in their bereavement experience, when their grief related feelings were stronger and more disruptive of their everyday lives.

> *Two years after it gave me perspective on it... but six months after I think would have been more helping me to just get it out so I'm not really sure...I think it would have been more helpful earlier because that was when I was more feeling, like afterwards I can look back... it probably would have been more emotional for me...I think it would be better more when I was feeling the strongest emotions...(12-17)*

> *I'd like to go to the group sooner...cause I dealt with most of it myself,...I don't know I just wish it was sooner. (9-11)*

Parents' Group:

The companion support group for parents offered at the same time as the children's group was attended by all but one of the study participants' parents. All of the children interviewed were comfortable with their parents' involvement with the adult support group.

> *...because I knew she was hurt inside...so, I kind of felt relieved that she wouldn't be sad anymore. (9-11)*

> *...it made me feel better that she was only a couple of rooms away from me. (12-17)*

> *I kind of wanted her to because I didn't want to be the only person doing that. (9-11)*

Two participants stated that they were relieved that the parents and children would not meet together.

> *I was happy that we were separate in the group because I think there's, you know, maybe certain issues that I'd want to talk about that involve my Mom and she would maybe want to talk about things that would involve me. (12-17)*

The child whose parent did not attend felt that her parent should have gone:

> *... well she'd meet like some of my friend's parents that went there and they know that like a wife or husband has died. She never really talked about it to anyone. (9-11)*

### Group Content and Process:

Participants were asked to recall the themes and activities focussed on at the weekly sessions. The children often had difficulty recalling specific events and were provided with suggestions about what they likely did in a particular session in an effort to stimulate their memory.

Group Rules:

Group rules are generally discussed in the first session. Participants were asked if they could recall any of the agreed upon group rules and which, if any, of the rules seemed important to them. The majority of the children interviewed had ready and strong opinions about this. The two rules that seemed to have been most important to participants concerned permission to pass and the prohibition against put downs of other group members.

> *If we felt like we didn't want to talk about it say pass and if you don't want to talk about it anymore just tell them...and no making like comments on other people's, what they're saying. (9-11)*

Weekly Themes:

When the study participants were asked to recall the weekly sessions, most were able to remember details concerning only two or three of the weeks they attended. Specific activities tended to be remembered more readily than general themes or topics of discussion.

One of the earliest sessions focusses on death education. During the session on death, group members are usually asked to share with the group the story of their parents' funeral. Several study participants reported that this was the most difficult session for them because it was hard to relive such a painful event. Eight of the 13 children interviewed reported some degree of surprise related to the manner in which someone else's parent died or the beliefs of other members regarding what happens to people once they are dead. In spite of this, most participants reported that they had not learned anything new about death at group.

Another of the early sessions concentrates on memories of the deceased parent. Group members are asked to bring an object that reminds them of their deceased parent, and to share a memory associated with the object. This session seemed to be remembered and appreciated by most of the study participants. Most participants were able to remember what they brought to group and how it felt to share their memory. One participant was particularly animated as he related what seemed to have been a powerful and healing experience. He stated:

> *I wanted to bring everything...(when he shared his memory) ...it felt like a big blob of memory...Dad just popped out of my stomach... it felt like a big piece of hurt just came right out. (9-11)*

Group participants recalled relatively little about the sessions focussing on feelings, coping and changes in their family following the death of a parent. Participants occasionally made reference to an interesting or surprising comment made by another group member during these sessions, but the actual content of the session seemed to have been largely forgotten.

Activities:

The Grief Support Program relies heavily on drawing to relieve tension and facilitate memory and the sharing of personal stories. Several of the children interviewed spontaneously commented on how much they had enjoyed drawing and one participant stated that drawing had helped her remember things about her deceased parent. Two of the boys interviewed stated that they did not like drawing and found the routine of drawing and sharing pictures annoying. When asked if anything might have made group more comfortable or helpful, one of the boys replied:

> *Nicer chairs...and more interesting things than just drawing. (9-11)*

Participants recalled very little about the paper and pencil exercises used during some of the group sessions. These activities are intended to target specific topics but participants' feedback suggests that most of the exercises were poorly understood and not well appreciated. An impressive majority of the participants who could recall the exercises were unclear as to their purpose. Kicking boxes during the session on coping and the pizza party held on the final week of the program were enjoyed by all participants. Four of the children interviewed stated that they had liked the exchanging of keepsake cards at the final session. Three of the four retrieved and shared this item during the course of our interview.

Group Facilitation:

The interview guide did not target the topic of group leadership or facilitation but comments arose during some interviews that related to this aspect of group process. Two of the teens interviewed commented on the flexibility of facilitators to stimulate discussion with ready topics and questions. One teen expressed impatience with the group process and suggested that the facilitators needed to be more aggressive in getting group members to participate:

> *...like, the group was good but I found like there were many times when we were just sitting there and no one was saying anything, like, it's good in a way to be less structured and you don't want to make someone talk, but I just felt, really, like, you know, um, to ask like more thought provoking questions or ask questions to draw them out... there would be like three minutes where you'd just sit there and we'd be quiet. I'm here for an hour and a half, let's get something done here, you know. (12-17)*

### Sharing Stories and Memories:

Most of the children interviewed stated that they had been very nervous the first week of group and were not looking forward to talking with a group of unfamiliar people. A majority of the study participants reported that sharing in group got easier as they became more familiar and comfortable with the other group members.

> *[by week four] I felt like I could say anything I wanted to. (12-17)*
>
> *Like it was good, going there was comfortable ... (11)*

Participants frequently referred to the value of telling their stories and being listened to. Several participants commented on the freedom they felt in group to talk as much as they wanted and to share thoughts and feelings with their group that they did not feel comfortable sharing anywhere else.

> *In group we had the freedom to talk about it and talk about it and talk about it you know because you need that but it's hard to burden the people you care about with that because it's hard for them too...It's just, it's just such a traumatic thing that you just want to talk about it, you know, like all the time, especially right after. (12-17)*
>
> *It was nice to have people listening to me talk about it. (12-17)*
>
> *They didn't rush you or anything,,, like not many people listen to what I've got to say so it helps. (12-17)*

When asked what kinds of things she talked about in group, one participant replied that she talked about her Dad, his death and how hard things had been.

> *They were pretty much all the things I never talk about with anyone. (12-17)*

Four other participants stated that they had shared feelings or thoughts concerning their bereavement experience in group that they had never shared with anyone else.

Many of the children interviewed stated that they had found it interesting to listen to the experiences and perspectives of other bereaved children and to note how the experiences of others differed from their own. One of the younger children whose father had died suddenly at home reflected on how different it had been for others in her group:

> *It was sort of fascinating because most of the kids, when their Mom or Dad died, like usually they're already in the hospital and they get sicker. (9-11)*

Several stated that they had been surprised by things that other group members had shared.

> *One that surprised me is how like, how soon some of them went back to school. And also I was surprised at how some of the people felt everything right away and just like had to cope with it... my Dad was the soonest that he had died so, mine was like the freshest and to me it still feels like not really real. (12-17)*

Only one participant spoke of feeling annoyed by what another group member had to say.

> *[One girl} she was really, like, outspoken. She would say things like, not really thinking of how it could affect other people and it was never really addressed...[it] would annoy me because she'd say something kind of insensitive...(12-17)*

**Privacy and Anonymity:**

Comments relating to the importance of privacy and anonymity in group and how it impacted on participant's comfort emerged in response to a wide variety of issues. Five of the children interviewed stated that it was helpful to be able to discuss their experiences related to their bereavement in a context that would not impact on their surviving parent

> *I also felt free to talk about him because I wasn't sure about what my Mom's feelings were about it. (9-11)*
>
> *Like I talk with my friends a lot and I talk with other adults from my church or whatever, um, I don't talk, like our family is pretty close but I don't talk with my Mom as much now especially if it's about my Dad. (12-17)*

Participants generally stated or implied that they liked the fact that there was no one in their group that they knew or who was involved in their day to day lives.

> *You need someplace where you can just talk... especially that way where you don't have to see them... (12-17)*

Only two of the 13 people interviewed for this study maintained any contact with fellow group members following the conclusion of the program.

**Changes Attributed to Group by Participants:**

Participants were asked what, if any, changes they experienced as a result of attending the program. Four of the children interviewed stated that they were better able to communicate with their surviving parent as a result of their participation in the program and more likely to talk about their parent's death than before they attended group.

> *P: Actually, after I, um, was finished, I started talking to my Mom more. I used to not talk to my Mom about grief and that but now I can.*
> I: Why do you think grief group helped with this?
> *P: I don't know, I just like, I learned to say things because to other people, I wasn't so shy. (9-11)*

Questions focussing on participants' impressions regarding changes or outcomes associated with group attendance elicited some responses that did not seem genuine. One participant who remembered almost nothing specific about group and who seemed markedly unenthused about her experience with the program stated the following when asked about any changes she felt were associated with her attendance:

> *I didn't take it out on other people. On my brothers or sisters or friends...I just like, vent off some issues, feelings... (12-17)*

This response seemed unconvincing given the content of this participant's other responses, her use of a jargon that she had not used before, as well as her demeanor and affect when she gave this feedback. When asked to elaborate on a change associated with her group experience, another teen acknowledged that she was reporting a benefit that she felt others expected her to experience as opposed to something she had actually experienced.

> I: How did it feel when group was over?
> *P: Kind of felt good*
> I: Un huh, because?
> *P: Because I let out most of my feelings.*
> I: Why did that feel good?
> *P: I was keeping them inside.*
> I: Did you feel better because you're supposed to feel better, because everyone says you will or could you really feel a difference?
> *P: Sometime I just feel better because people say I will. (12-17)*

## What Bereaved Kids Need:

Participants were asked several times during the interviews to comment on what parentally bereaved children need and how the adults in their lives can help them cope with the loss of a parent. Most of the children consulted had ready answers which ranged from the practical and immediate to the spiritual.

One young participant was adamant that children need to see the body of their dead parent and be included in the funeral.

> *Always bring them to the funeral....all feelings can be expected.* (9-11)

One teen suggested that it was important to maintain a routine and minimize change but another participant cautioned that families need to allow the situation to change.

> *One day was about change a lot of them were at the point where they didn't want anything to change ad I guess I realized as time passes that it's better for things to change. Like, it's a major part of your life if you lose your parent, it's a major part of your life and it's, it seems to me very false and strained if everything stays the same...I think it's probably better for things to change because that's expected... this is a major change you know. (12-17)*

Two participants stated that their faith and the belief that they would be reunited with their parent someday was an important foundation and source of hope for them.

> *I believe I'll see my Dad again so that's hope for me...it's not really helpful at first because you want to feel sorry for yourself and you don't want to hear that...but in the long run it is and to go and get reassurance of that even when you don't want to hear it, it helps. (12-17)*

Other suggestions included reading books about grief, looking at pictures of the deceased so that you can preserve your memories and having cooperative people at school who are aware of the death.

Five of the thirteen participants identified talking as primary need and suggested that facilitating this was something that adults could help bereaved kids with.

> *Well, I would tell them they should talk to somebody and they wouldn't feel as depressed. (12-17)*

Two of the participants were specific about who a bereaved kid should talk to. Both of these children stated that bereaved kids need to talk with people who have had a similar experience.

> *Knowing peers who have gone through the same thing really helps. (12-17)*

**I'm Not the Only One:**

Participants' comments related to the value of being one among others who have experienced the death of a parent were pervasive. Ten of the 13 children I consulted spoke specifically about this issue, sometimes several times in the course of an interview in response to a variety of different questions.

The desire to meet other children who had suffered the loss of a parent was identified by several participants as the main reason they agreed to attend the program.

> *I guess I just wanted to see if there was other people like me. (12-17)*
>
> *I thought it would be kind of good...because like, I knew that it wasn't only me that like those kinda things happen to. (9-11)*

For some participants, meeting with other bereaved children seemed to diminish feelings of isolation associated with their relatively uncommon predicament.

> *[Group] finally made me feel good that I'm not the only one here now, you know, as a family, like the family's not the only one here now... (9-11)*
>
> *I think all of us felt that it had helped us and that it made the grief a bit easier, to find someone else who had been going through the same thing,... (12–17)*
>
> *Um, it felt okay because like, one of the other people , their Dad died, same disease so it was like, they understood too. (12-17)*
>
> I: Did anything happen that first day that helped you feel comfortable?
> *P: That some, like, I'm not the only one who has like somebody die in their family and I'm not alone. (9-11)*
>
> I: Why is it helpful to know you're not the only one?
> *P: Because sometimes you'll feel alone and most of the time I would rather have empathy than sympathy, I feel like* one of the worst *in the world compared to everyone else. (9-11)*

A young boy who did not seem to enjoy group stated the following:

> I: Was there anything about being at group that made you feel good?
> *P: Only that I wasn't the only one that it happened to. (9-11)*

Some of the comments that settled into this category suggested that meeting with other parentally bereaved children normalized some of the participants' experiences and reactions. Teens in particular seemed to be reassured that there were other teens who were struggling with the same issues and coping in similar ways.

> *Just hearing how other people are dealing with things...because it gives you perspective on you own and makes you feel more like you're not just the only person dealing with it and coping with it that way. (12-17)*

One teen referred to a discussion her group had had about feelings of frustration and anger with the surviving parent's displays of emotion following the death of their spouse:

> *That week was reassuring because it was nice to hear the other kids had the same sort of feeling and worries and things that I did...I felt like it was horrible of me to feel that way but I couldn't help it...but when I heard that was how all the other kids felt, I felt well OK, Im not quite so rotten. (12-17)*

Another teen reported that it was helpful to learn that other bereaved teens felt frustrated with and burdened by the surviving parent's need for companionship and emotional support.

> *... [It] helped me...know that you're not the only one who feels this way. In the group the other kids are having problems like this too..,.even if it does sound like an excuse, it's true. Like I told my Mom... (12-17)*

One teen whose father had taken his own life expected that her experience would be significantly different from those of other parentally bereaved kids. She found that she had more in common with other group members than she had expected.

> *It was interesting because I didn't have a very good experience with my funeral and it was interesting how other people, like some people didn't and that really surprised me that other people as well, even though they've had circumstances that are different, they still didn't {a positive experience at} their funeral. (12-17)*

The experience of being with other parentally bereaved children seemed to provide an opportunity for participants to acquire a sense of perspective regarding their family's circumstances and their own adaptation to their loss. Several of the children consulted for this study reflected on the value of recognizing that their family was not the only or most beleaguered family in the world.

> *I: Did anything surprise you when you went to group?*
> *P: Um, not really except for some people had it worse than me so I didn't feel so bad. (12-17)*
>
> *Like, I kind of got the sense that I heard everybody's story,,,like, you know, maybe I don't have it that bad. (12-17)*
>
> *I felt a little less, you know like everything was happening to us, you know, ...rather a paranoid way of having things so I think it maybe eased that. (12-17)*

Teens spoke eloquently about the perspective and insight they acquired in group regarding their own process.

> *Meeting people who have gone through the same thing and realizing that everybody goes through the same things, like not the identical, every feeling is exactly alike, and just knowing that you've survived. Like it was nice to have people at different points in the process..... (12-17)*

This teen attended group later in the course of her bereavement than others in her group and she spoke about noticing that she had already gone through some things that her fellow members were just now experiencing.

> *I found that out in myself how it was now different for me and it was interesting to, you know, recognize that I'd been dealing with that and how it changes and*

> *stuff...It was something for me anyway, how you can know the difference in time. I was like a lot of people, if their [parent was], you know, irritating them more, like they were becoming more irritable at everyone rather easily and I'd found that ya, I had that period but then after I was less easily irritated. (12-17)*

For the majority of the children interviewed, the experience of 'not being the only one' seemed to be translate into a decreased sense of emotional isolation, a normalization of their bereavement related experiences and reactions, and a sense of perspective with regard to their family's circumstance and their own process.

**Negative Feedback**

There were criticisms and complaints offered regarding various aspects of the program. Several of the children interviewed expressed annoyance concerning other group members who did not engage with the group in ways that were considered appropriate.

> *[one girl] she was really, like, outspoken. She would say things like, not really thinking of how it could affect other people and it was never really addressed, [that] would annoy me because she'd say something kind of insensitive... (12-17)*
>
> I: Did anything make you angry?
> *P: ...the one person that didn't want to be there, I was kind of angry because she would talk and then she would kind of, you know, discount what she was saying as being nothing...very ineffective in the group. (12-17)*

A concern related to group composition was voiced by one teen. This participant felt that differences in the nature of group members' losses had negatively impacted on group process. She specified that there had been a child in her group whose parent had committed suicide and a child who had experienced multiple traumas in addition to the death of a parent. This participant suggested that these two members tended to dominate the group because the nature of their losses were more profound than those of other group members.

Two teens commented on the need for the group sessions to flow and feel complete. In order for this to happen it seems that there needed to be sufficient time for all members to share and input from facilitators to ensure satisfactory group process and closure.

> *And so then I had to tell my story and then walk out. And it's like, I didn't get to hear anybody else's, everyone just heard me and then I'm walking out...like, I would have rather not been rushed and say it next time or something... (12-17)*
>
> *[more time per session] would have been good you know, because we often ran out of time or we'd stray off topic a lot and you know...ya, it just takes a while to wind back to a satisfying conclusion. (12-17)*

Four of the 13 children interviewed found the group sessions uninteresting. Prior to her involvement with this program, one child had attended a group for children who had a family member with cancer. This child felt that the content of the group was very similar to the group she attended while her parent was ill and therefore not very stimulating. Two of the boys interviewed did not like drawing. One boy was clearly not impressed with anything about group. When asked if he learned or heard anything new at group, he replied,

> No, except I saw some new books of dead birds, so interesting. (9-12)

Two participants commented on feelings of discomfort or disappointment that seemed to be related to a lack of information about what to expect at group. One of the teen participants had been unable to meet with a facilitator or have a home visit prior to group and reported feelings of surprise and discomfort when she arrived at the first session.

> *It's a weird feeling to walk into a room and see like 50 people maybe, or 40 people ...and to know that everyone of them has either lost a spouse or parent, like it's just a weird feeling, and I didn't expect as many people and I didn't expect the feeling. I didn't realize, um, young kids were going to be there, I thought it was just going to be teens. (12-17)*

This participant was also surprised and anxious when she learned that her mother would be attending a 'Parent's Night' on the afternoon of the event.

> *I was a little concerned. I was wondering what they were going to discuss. We were told [what was said in group] was confidential and they wouldn't talk to our parents about it and I didn't realize that they were going to have a parent's night. And then when my Mom told me, I was kind of like, hmm, I was thinking well they're not really going to be talking about me, hopefully not. (12-17)*

One young boy had expected that the setting would be 'fun' and was disappointed when he arrived the first week.

> *I [thought] it would be like a big place with games and we could talk to each other and then it was just a board room when we got there. (9-12)*

Finally, one participant whose parent had died at the hospital that sponsors this group reported that her family had been very upset that they had not been advised about the availability of the program at the time of their loved one's death.

## THEMES

Three themes characterize and connect elements in many of the categories.

### ( I ) Safety:

A review of the categories reveals that study participants often referred to aspects of the program that contributed to feelings of comfort, control, and respectful behaviour among group members. These conditions seem to have created a sense of safety within the groups for a majority of the children consulted.

Most of the study participants reported that they had been comfortable with most aspects of the program's context and delivery. Participants were generally satisfied with the location of group sessions as well as the size and composition of their groups. Group rules established guidelines and a predictable framework for group participation. The group rule affirming group members' right to pass allowed participants to have some control over the pace and nature of their involvement in the group.

> *I: What do you think was the most important thing about group for you?*
> *P: [That you] can express yourself and you won't be forced to answer. (12-17)*

Several participants identified the importance of the rule designed to discourage put downs or disrespectful comments among group members. This aspect of group culture appeared to reassure several of the study participants that it would be safe to share their stories.

> *I thought I would find some people, oh they'd think my Dad was psycho or something and that my Dad was weird, so I was kind of afraid to tell my story the first time, but the first time we went over the rules I kind of got the feeling that it was going to be okay to tell my story. (9-11)*

The privacy and anonymity afforded by the program allowed group members to voice their grief-related thoughts and feelings in a context that would not impact their social circle or family. The value of this aspect of the program was mentioned by several participants in response to a variety of questions.

> *I [would] feel really awkward if a person that I knew from somewhere else was in the group. (12-17)*
>
> *Just gives us the freedom to talk about it and talk about it and talk about it, you know because you need that but it's hard to burden the people you care about with that because it's hard for them too. (12-17)*
>
> *It's like, you know, you don't have to be friends with these people, you're just there to adapt it to yourself. (12-17)*

As participants shared their stories in group, most felt reassured to find that [They] Were Not the Only One. An atmosphere of mutuality, comfort and trust seemed to develop for a majority of the children interviewed.

> *I felt a lot more comfortable talking to these people and I would bring up things that I wouldn't normally say [to] just a friend because these , the people understood and they wouldn't like laugh at me or*

> *something. (12-17)*
>
> *[By week four] I felt like I could say anything I wanted to. (12-17)*

The structure and culture established by the format of this grief support program facilitated a gradual development of familiarity, comfort, trust and safety for most of the young people interviewed.

### ( II ) Talking and Listening:

The value of talking and listening was expressed by almost every person interviewed for this study. The communication activities they referred to were the parallel activities of expressing their own feelings and experiences, and listening to others do the same. Participants did not seem to be describing conversations or dialogues. The scope and import of this theme is emphasized by participants' opinions regarding the Most Important Thing About Grief Group and is vividly expressed in the Sharing Stories category.

> *...it made me feel good, like to actually express those feelings, to talk, so that kind of helped me. (9-11)*
>
> I: What was the most important thing about group for you?
> *P: That they would listen...because um, I had to get those things out and like, there was nobody else I could really talk to about it that would listen. [Kids at school] just kind of avoid the subject . (12-17)*
>
> *It was certainly a relief because I know a lot of people didn't really talk about it, kind of outside of that [group]. It was a place you could be... you didn't have to worry about being afraid with the people or anything usually, you could just go out there and talk*

> *about one subject even if your friends were sick of it and you didn't feel like you could talk about it that much anymore...there are some people they didn't want to burden other people, they thought they had their own problems...I think it's helpful for that. (12-17)*

The importance of talking and listening is further underscored by the fact that these two activities provided the substance and momentum for every session.

### ( III ) Awareness and Insight:

Attending a group with other parentally bereaved kids appears to have created an opportunity for some participants to feel less isolated and alone, to view their reactions as within a range of normal for their circumstance, and to acquire a sense of perspective and/or insight with regard to their family's predicament and their own process. The categories The Most Important Thing About Grief Group and I'm Not the Only One provide a window into the enhanced consciousness of participants with respect to their bereavement. For some of the children interviewed, this new or enhanced sense of awareness appeared to be linked to insight and change.

> I: Did anything make you feel more comfortable?
> *P: That they were just like me. (12-17)*
>
> *[The most important thing was] meeting other teenagers who are going through the same thing because I don't know other kids, or before the group I didn't know any others who had lost a parent or anything so and it was nice to see that, you know, my reactions and feelings were normal. (12-17)*
>
> *Just hearing how other people are dealing with things... because it gives you perspective on your own*

> *and makes you feel more like you're not just the only person dealing with it and dealing with it and coping with it that way. (12-17)*
>
> *I understood my own feelings more...[before group] I didn't realize how I felt or if it was right or whatever and it's hard for my Mom to understand my feelings if I don't understand them. So it was easier to verbalize how I felt or how I was dealing with it and stuff. (12-17)*

A few participants associated their group experience with changes in their behaviour and sense of self. For a minority of participants, the group experience was not grounded in a sense of comfort and safety and it seems unlikely that the program managed to facilitate any of the goals associated with children's healthy adaptation to loss.

## CONCLUSION

The words of the children consulted for this study were pieced together to create an image of their experience of the grief support program. This image is made up of the themes that emerged in the process of data analysis. Although the image is incomplete and imperfect, it provides a framework within which children's experiences of the group, positive and negative, can be considered.

# CHAPTER FIVE: DISCUSSION, RECOMMENDATIONS AND CONCLUSION

The Nature of this Flower is to Bloom

> And for ourselves, the intrinsic "Purpose" is to reach, and to
> remember and to declare our commitment to all the living, without
> deceit, and without fear, and without reservation. We do what
> we can, and by doing it, we keep ourselves trusting, which is
> to say, vulnerable, and more than that, what can anyone ask?
> June Jordan, in a personal letter, 1970
>
> Alice Walker (1973)
> Revolutionary Petunias

## LINKS BETWEEN STUDY FINDINGS AND THE LITERATURE

Aspects of participants' experience that influenced their sense of comfort and trust while in group constitute the theme of Safety. Elements of group process and context that contributed to participant's sense of safety such as a comfortable and private meeting place, group rules, and attention to factors that potentiate group cohesion, are common themes in the literature on group work in general (Corey & Corey, 1992; Toseland & Rivas, 2001) as well as the literature on group interventions with bereaved children in particular (Goldberg, 1998; Lohnes & Kalter, 1994; Samide & Stockton, 2002; Tonkins & Lambert, 1996).

The theme of Talking and Listening reflects participants' opinions regarding the importance of expressing oneself and hearing about the experiences of others. Most participants stressed the importance of talking to others about their loss and several associated the expression of feelings in group with a sense of relief. This finding echoes the experience of children involved with a similar program as reported by Lohnes & Kalter (1994).

Writing on group psychotherapy with children who have experienced trauma or loss, Keyser, Seelaus and Kahn (2000) suggest that the act of speaking one's own story aloud in the company of compassionate peers validates the reality of the traumatized child and enables him/her to experience a sense of distance and objectivity regarding the tale. Many grieving children lack family or peer support networks able to tolerate or facilitate the type of exchange advocated by Keyser (Christ, 2000; Dane, 2002; Samide & Stockton, 2002). Several children consulted for this study indicated that they did not have many people in their circle with whom they felt comfortable talking about their grief, and that the group provided a unique opportunity for them to express themselves and connect with others.

The theme of Awareness and Insight relates to the connection between the grief support group and participants' perception of themselves and / or their circumstances. Many participants found it helpful to be with other children who had suffered a similar loss. This sentiment is powerfully articulated in the category I'm Not the Only One which dominates the theme of Awareness and Insight. A qualitative study by Graham et al. (2001) used art to evaluate a children's grief group from the children's perspective. The authors reported on three themes that characterized the experience of bereaved children in a grief support program, one of which mirrors the category I'm Not the Only One.

A majority of study participants experienced a sense of commonality with other group members. For many of the children interviewed for this study, this sense of commonality was associated with the normalization of some aspects of the bereavement experience, as well as a sense of decreased isolation. This finding is corroborated by a number of other studies (Christ et al., 2002; Goldberg, 1998; Graham et al., 2001; Stokes et al., 1997; Tedeschi, 1996).

Tedeschi (1996) highlights the special utility of support groups to provide a sense of universality as well as a new reference group for bereaved children. He suggests that the opportunity for bereaved children to revise their sense of perspective on themselves based on a new reference group of peers, can translate into enhancement of their self esteem. The findings of Williams (1998) and Zambelli & DeRosa (1992) associate group interventions with bereaved children with an increase in self esteem for some group members. A small minority of the children who participated in this study associated their group experience with positive changes in their communication with others, and a new and helpful sense of perspective regarding themselves and their ability to cope with their loss.

Another positive outcome associated with group that was identified by four study participants was an improvement in their communication with family members. Similar findings as assessed by program staff or caregivers have been cited by other studies on group interventions with bereaved children (Beswick & Bean, 1996; Mulcahey & Young, 1995; Sander et al., 1992; Stokes et al., 1997).

## THEMES AS PROCESS

The themes distilled from and supported by the categories of this study can be interpreted as a process. To the extent that safety was experienced in group, the opportunity existed for participants to talk about their own experiences and listen to the experiences of others. For some of the children interviewed, this exchange was associated with a new or reinforced sense of awareness regarding themselves or their bereavement. This awareness or enhanced consciousness was associated with insight or change for some of the people interviewed (Figure I).

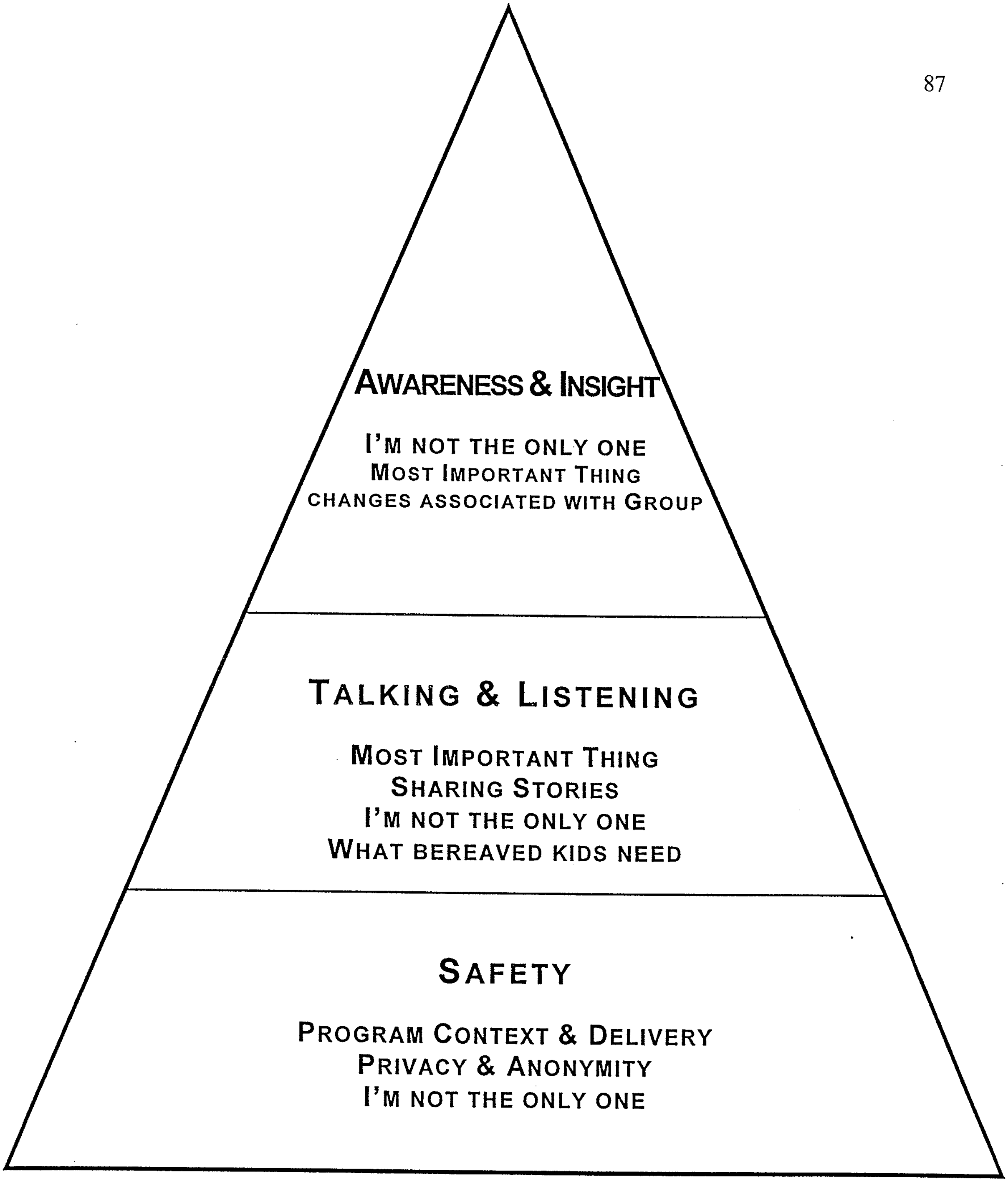

FIGURE I: THEMATIC PROCESS MODEL

For a minority of the children consulted, the awareness and insight associated with their group experience did nothing to enhance their sense of self or competence to adjust to the loss of their parent. This leads to a consideration of those participants whose experience of the grief group appeared to differ from the majority of those interviewed.

## VARIATION / OUTLIERS

Most of the children interviewed for this study were generally positive about their group experience. A couple of participants seemed relatively unenthused and the positive feedback they offered seemed inconsistent and unconvincing. Many participants offered some negative feedback regarding specific aspects of the program, however only one participant was comprehensive and emphatic about his disappointment with and disdain for the program. A consideration of participants' negative experiences, particularly the individual who was most dissatisfied with the program, offers some perspective on how this group intervention may have failed some of the children interviewed.

There were a number of complaints concerning the negative impact other group members had on group process. The following behaviours were cited by participants as problematic:

- The misbehaviour of other group members particularly when the group facilitator found it necessary to intervene;
- Instances when group members did not engage with the group;
- Instances when a group member devalued his/her own contribution to the group;

These troublesome events may well have compromised some group members' sense of comfort, trust and safety in the group and ultimately may have interfered with their ability to participate and develop a sense of belonging in group.

The participant who was the most negative about the group reported the following:

- He was compelled to go to group by his parent;
- The setting for the group sessions was very disappointing, not at all what he had expected;
- Although he had been advised that there would be another boy in his group, when he arrived on the first day this was not the case;
- He did not like to draw; .
- He was the only group member whose parent had committed suicide;
- He did not enjoy the group and would not recommend the program to another bereaved child.

The fact that this child felt 'forced' to attend group and found that his expectations of the setting were not met would not have potentiated the development of trust or safety. The group's reliance on drawing did not facilitate this participant's ability to share and interact with other group members, and the composition of the group did not facilitate any sense of commonality or belonging for him.

There was no indication that this child felt validated or affirmed in any way by his group experience. Unfortunately, it seems likely that his group involvement amplified any feelings of isolation or stigmatization he may have brought with him.

## RESEARCH QUESTIONS, FINDINGS AND IMPLICATIONS

The purpose of this study was to explore parentally bereaved children's experience of a grief support program for children and teens and the research was designed to address three main questions.

### Question #1: What themes characterize children's experience of the Kid's Grief Group?

The themes that emerged from the children's words spoke of the importance of safety in group, the value of talking and listening to other people who had experienced a similar loss, and the development of a new or heightened sense of awareness regarding themselves or their circumstance. For many of the children consulted, this enhanced consciousness was associated with feelings of relief, reassurance, and affirmation.

Although the themes appeared to associated with positive outcomes for most of the children interviewed, one child's experience graphically demonstrated the limitation of the group process. In the process of talking and listening to fellow group members, this child became aware that the nature of his loss and circumstances were quite unlike those of the other group members. He did not feel a sense of comfort with his peers and found the group unenjoyable and unproductive.

### Question #2; Do children's perceptions of the program reflect the program's targeted goals?

The purpose of this grief support program is to foster bereaved children's healthy adaptation to loss by focusing on four main goals. The first goal is to promote a realistic and developmentally appropriate understanding of death. None of the children interviewed stated that they had learned anything new about death as a result of their group involvement. However, most study participants were over ten years of age and likely came to group with a relatively sophisticated understanding of death. This goal may be more relevant for younger grief group members.

A second program goal is to facilitate the acknowledgment and expression of grief related feelings. The importance of talking and listening emerged as a theme characterizing participant's experience of the grief group. Many participants commented on the unique sense of comfort and freedom they experienced in group to talk about their bereavement and grief. Four participants reported that they had shared grief related material in group that they had never shared with anyone else, and several children reported that they were better able to talk about their feelings as a result of their group experience.

Normalization of the experience of loss and grief is the third program goal. The category 'I'm Not the Only One' spoke to participant's sense of themselves as one among others who shared their experience of loss. Comments related to the importance of this aspect of participants' group experience were pervasive and emphatic. These findings suggest that the program was successful in providing a context in which most study participants' experience of loss and grief was normalized.

The cultivation of effective coping strategies is the fourth program goal. Most participants were unable to remember much about the group session devoted to coping and none of the children reported that they had learned anything new about how to cope with bereavement. Even though no new learning was reported, group discussion about coping styles may have sanctioned or normalized some behaviors for group members. Several participants identified talking with family or friends as something bereaved kids need, and four participants felt that they were better able to talk to their surviving parent about their feelings as a result of their group involvement. These findings suggest that the Kid's Grief Group may encourage children to make better use of coping skills and resources already available to them.

The final goal of this group intervention is to sanction acts of remembrance of the deceased. The group session recalled by the greatest number of participants in the greatest detail was the week devoted to bringing in a memory of the deceased. Most participants were able to recall what they, and their fellow group members brought to share. Participants generally spoke with enthusiasm about sharing memories in group and several added that there were not many places where they felt comfortable to do so. The grief group provided both sanctuary and sanctioning for acts of remembrance for a majority of the children consulted.

### Question #3: What do participants' experiences tell us about the strengths and weaknesses of the program?

Some of the strengths and weaknesses of the grief support program were specified by study participants and some have been extrapolated from their comments. For many of the strengths identified by a majority, there was a minority voice that identified the same aspect of the program as a weakness.

1.) Pre-group Visit

The pre-group visit appeared to be an important and generally well executed first step in the creation of a safe and trustworthy atmosphere for most participants. A majority of the children interviewed were not able to recall much about the pre-group visit but several remembered that they had been told at this meeting that they would not be forced to speak in group and that the program encouraged families to let their child stop attending if they wanted to. The information imparted at the pre-group visit seemed to reassure these children that they would have some control over their involvement and a few described this as pivotal in their decision to attend.

There was some feedback suggesting that the attention to the pre-group phase could be improved. Two participants reported strong feelings of disappointment related to the group setting and format. In one instance there had been a pre-group visit, but in the other, the visit was omitted due to late registration.

Unrealistic or misunderstood expectations may undermine children's trust in the program. It seems important to ensure that each child is well informed prior to the group about what to expect. The development of written material for children concerning the group might be a useful addition to the pre-group phase to ensure that important aspects of the program are clear and available for review after the pre-group visit.

An aspect of the pre-group visit that could be more focused involves its' utility as a screening process for group membership. Children's personality type, level of maturity and ability to concentrate (Williams, 1998) as well as their preferred modes of expression are important factors impacting on group cohesion. It is important that visiting facilitators assess these areas directly over the course of the visit, and indirectly based on the input of caregivers.

### 2.) Group Rules

Many of the children consulted specified or implied that group rules were an important and valuable aspect of the program. Rules concerning voluntary attendance and participation, as well as respectful behavior towards one another, seemed to provide structure and reassurance for most of the children interviewed. This aspect of the program appeared to be a strength in that it allowed the children to participate in the creation of safety within the group.

### 3.) Group Composition

Most participants were comfortable with the other members of their group. There were a few concerns expressed by participants that offer some direction to program organizers regarding group size and the inclusion of children who have suffered multiple losses or the death of a parent due to suicide.

Participants indicated that groups of four or less, although tolerable, were not preferable, and groups of 10 or more seemed too large for everyone to have a satisfactory turn. This is precisely the range recommended by Tedeschi (1996) for group work with bereaved adolescents.

Participants' feedback suggested that group members were not significantly disadvantaged by the inclusion of children who had experienced multiple losses or the death of a parent due to suicide. One participant reported some frustration regarding a fellow group member who tended to dominate group discussion with concerns related to a variety of losses and challenges in addition to the death of a parent. This participant suggested that there should be another type of group for children suffering from 'super grief'. In spite of these concerns, this participant was positive about the group in general and stated that she would recommend it to other bereaved children.

Dane (2002) states that separate groups for child survivors of sudden or violent death (e.g. suicide, murder) are preferable if possible, but that generally differences in the familial relationship to the deceased (e.g. parent vs. sibling) and the type of death do not appear to be a barrier to group cohesion for bereaved children.

Several of the children interviewed had been in groups with children whose parents had taken their own lives and only one commented on her sense of temporary shock and discomfort when she first learned of the suicide. Two of the three participants who were suicidally bereaved found group very helpful and spoke specifically about how they could relate to the experiences of the other parentally bereaved children in their groups.

Tedeschi (1996) states that group composition may be the most crucial factor in group work with bereaved children. The power of group composition to facilitate or thwart the group process for an individual member is powerfully depicted in the experience of the most dissatisfied group member interviewed for this study. This child was suicidally bereaved, the only boy in an uncommonly small group of three, and the only group member who did not enjoy drawing. It seems that the manner in which his parent died was only one of several factors that may have influenced his sense of fit with other group members.

Assessing a child's potential to develop a sense of safety with other group members is a complicated and inexact undertaking. However, it is essential that group organizers do their best to avoid the inclusion of members who are likely to be significantly different from the others. In addition to age and the circumstances of bereavement, it is critical that factors such as levels of ability and maturity, personality type and the identification of learning disabilities be considered in the process of group composition (Tedeschi, 1996; Williams, 1998).

The experience of the most dissatisfied participant interviewed points out that there are compelling reasons to consider alternatives to a group intervention for children who seem unlikely to fit with the other children in his or her group. It may be preferable to refer a child to another resource, suggest that s/he wait until the next session when there may be more people in their age range, or flex the group age ranges so this child can be included with a more suitable mix of children.

4.) Timing

Of the 13 children interviewed, 12 stated that they would have liked to attend group sooner following the death of their parent, when their feelings of distress were the strongest. This program has been reluctant to set a firm standard with regard to the timing of group attendance following the death of a close family member and feedback from study participants suggests that the program's flexibility in this regard has been a strength.

The amount of time allotted per group session seemed to be satisfactory for most of the study participants, but teens in particular stated that they needed more time per session. Program facilitators may want to consider restructuring the hour and a half available in order to maximize the amount of time the teens have to spend on their own in discussion.

5.) Activities

The grief group's use of drawing as a focus for expression and sharing appeared to be well received and productive for most of the children interviewed. Unfortunately, the reliance on drawing was a significant drawback for two male participants, age nine to 12 years who reported that they did not like to draw and found this aspect of group boring. The program may want to consider ways of identifying group members' preferred modes of expression during the pre-group visits or the early group sessions, and make a greater effort to adapt group activities to accommodate different styles.

6.) Facilitation

Although there were no questions designed to directly explore participant's assessment of the group facilitators, it was possible to extrapolate some of their impressions regarding the management of group sessions. Participants seemed generally positive about the facilitators and the process of the sessions. They seemed particularly appreciative of the unpressured atmosphere established in their groups. One teen expressed some frustration with other group members' reluctance to participate and suggested that the facilitators needed to be more aggressive in getting group members to talk in group. This was a minority opinion.

## LIMITATIONS OF THIS STUDY AND THEIR IMPLICATIONS

### Limitations Related to the Researcher's Skill, Biases and Knowledge Base

Audits enhance the reflexivity of the researcher "by encouraging self awareness and self correction" (Padgett, 1998, p. 104). During the course of data collection, I regularly reviewed my interview journal in order to identify my biases and learn from mistakes I was making along the way. When the data analysis was completed I undertook a casual qualitative review of my journal and memos in an effort to identify the themes associated with my own process. Many of the observations I make concerning limitations associated with the researcher have been drawn from this exercise.

Patton (1987) states that the fundamental principle of qualitative interviewing is to provide a framework with in which respondents can express their own understandings in their own terms. The researcher's interviewing skills are the tools that build this framework. Defects or weaknesses related to the researcher's skill set can damage or distort the structure, form and content of the exchange. My professional training and work experience would suggest that I have a skill set and knowledge base particularly well suited for this project. Unfortunately, conducting a clean and productive interview proved to be much harder than I had expected.

The first area of concern related to my skills as an interviewer involved my failure to maintain a reliably neutral stance with respect to what the participant was telling me. Patton (1987) advises that the interviewer needs to establish rapport with the person s/he is interviewing but that establishing rapport must not undermine neutrality regarding what the person tells him/her. In spite of my best intentions and self reproach following each transgression, I managed to identify myself with the program during six of the 13 interviews. In each case my lapse was associated with an attempt to validate what the participant was telling me in an effort to enhance rapport.

The second and more complex process that limited my effectiveness as an interviewer was made manifest in my tendency to become rigid or sloppy when I sensed that a participant was bored or distracted. Following three of the 13 interviews, I noted that I ought to have broken from the guide format and taken more time to enhance comfort and rapport. My journal entries make it clear that my interviewing was more flexible and creative when the participant seemed relaxed and interested in our conversation. If a participant seemed uncomfortable or remote, I sometimes assumed that s/he was feeling disinterested in or inconvenienced by the interview. These assumptions tended to trigger my own insecurities and limit my ability to maintain or manufacture an atmosphere of flexibility and openness.

The researcher must report biases and theories that underpin and evolve over the course of a project so that consumers can consider their influence on the study findings. Sandelowski (1986) identified the potential for a researcher to become enmeshed with study participants as a significant threat to the credibility of qualitative research findings.

Journal entries reveal that I experienced a strong sense of identification with six of the 12 single mothers I worked with during the course of this study. Although I would not characterize this identification as enmeshment, the feelings of sympathy and empathy I experienced for the social, practical and emotional demands on these women affected the way I behaved when I met with their children. I had a strong sense of conscience regarding the favour these families were doing for me with no expectation of gain for themselves, and was acutely aware that I did not want to cause them any inconvenience or distress. As a result, I was overly cautious on several occasions, missing opportunities to go deeper into responses at the risk of making the participant feel anxious or uncomfortable. My identification with the mothers and children in these families influenced my judgement and at times limited my effectiveness as a researcher.

Bias associated with the researcher's knowledge base involves the potential for the researcher to make the data appear more patterned than it really is. Krefting (1991) referred to this risk as the Holistic Fallacy. Member checking and peer review was incorporated into this study as a means to address this concern. I favour and relate to humanistic and developmental theories of psychology. These perspectives are compatible with the ontological and epistemological underpinnings of qualitative research and are evident in my conceptualization of the findings. This is identified and owned throughout the project and therefore available for the consumers of the study to consider as a factor impacting on the trustworthiness of the findings.

## Limitations Related to the Methodology

There may have been limitations imposed by the pacing and amount of time allotted for data collection. The description of this study stated that the researcher might conduct a second interview if required. It was not necessary to interview any of the participants a second time in order to address all of the pertinent topics, however the richness of the interviews might have been enhanced if there had been more than one contact with each child. An unrecorded initial meeting to introduce the study and assess the participant's communication style followed at a later date by the data collection interview might help establish a greater sense of familiarity and rapport between the interviewer and participant. The need for two interviews would represent a greater commitment on the part of the researcher and the participant families, but would likely create a better foundation of comfort and safety for both the participant and researcher, and ultimately a more relaxed and freer exchange.

There did not seem to be a correlation between the amount of time elapsed since a participant's attendance of the grief group and the quantity or sophistication of his/her memory of or reflection on the group experience.

## RECOMMENDATIONS FOR SOCIAL WORK PRACTICE AND EDUCATION

This qualitative study offers a glimpse of children's experience of a group and their perceptions and opinions on the relevance and value of the service. The process illuminated by this study suggests that the most significant role this type of intervention may play is to create a context of safety within which children can explore their own bereavement experience and hear the stories of other bereaved families. It appears that the most remarkable outcomes were likely related to group members interpersonal and intra psychic exchanges and connections as opposed to any teaching or training that may have taken place.

In her book The Needs of Children, Kellmer Pringle (1980) argues that improvements in health care, housing and education will not address the social and emotional problems that interrupt and divert children's functioning. Kellmer Pringle had particular interest in facilitating children's ability to learn in school but was broadly interested in raising children's general level of emotional and social resilience. Kellmer Pringle identifies the need for love and security as the primary requisite for healthy development. She argues that social and emotional health and function is rooted in one's sense of self- approval and self-acceptance and that "the most important element in shaping behaviour and development is the environment in general and more specifically, other human beings." (Kellmer Pringle, 1980, p. 29)

Social work educators and practitioners need to advocate for greater awareness concerning the normative aspects of grieving, and the importance of social contexts that not only acknowledge and honour the experience of loss, but permit and facilitate grieving. Work with individuals, families, schools and communities would be enhanced if education and discussion related to loss, grief, communication skills, and the connection between feelings and physiology were prioritized. The call for increased education in the area of grief and loss for professionals and families is being persuasively argued in the literature (Stokes et a., 1999; Christ et al., 2002). If these issues were treated as basic life skills, then families, schools and communities would be better able to encourage and support children in their efforts to connect with other people, their own experiences, and themselves.

## RECOMMENDATIONS FOR SOCIAL WORK RESEARCH

The suggestions I offer with respect to future research focus on validation and exploration of study findings, improving the quality and richness of the data, and evaluating the effect of any changes made to the program as a result of this study.

Efforts to validate the findings of this study might include replication of the study as well as the use of other methodologies and client perspectives to triangulate findings. A similar study focussing on parent's feedback, or a focus group format with children and/or their parents would provide alternative or additional perspectives.

Inspite of the limited use of quantitative measures in this area of research thus far, there are some standardized measures that may be of particular use regarding individual themes. The theme concerning Awareness and Insight related in part to how children viewed themselves and their families. There are standardized measures that target self esteem, self concept, self efficacy and family functioning. Given the goodness of fit with the phenomena associated with Awareness and Insight, it would be worthwhile to explore the possibilities these tools may represent.

The theme of Safety in group emerged as a key element warranting more study. It seems reasonable that we explore this aspect of group process more thoroughly and study how best to create and maintain this key element of group culture.

Participants made a number of suggestions regarding the format and content of the program. If the program elects to implement any of these recommendations it would be useful to study the impact of the changes.

## CONCLUSION

It is a uniquely human endowment that we not only accommodate challenges, we also construct meaning from our experience. Micheal Mahoney (1991), a psychotherapist writing on the topic of human change processes observes that the meaning of life "must be endlessly and individually re-created in our lived-life struggles and triumphs" (p. 354). The crucible of bereavement is one of life's struggles that compels us most forcefully to engage with our questions, fears, strengths and understandings. The parentally bereaved child is called to this challenge with relatively little life experience, yet many demonstrate a capacity to cope that belies their youth.

Children's capacity to adapt and even flourish subsequent to the death of a parent has been a source of wonder for me. Their resilience seems testimony to our hardwired compulsion to grow physically, psychologically and spiritually. Most of the children consulted for this study experienced grief group as a place of safety where they could focus on the experience of their loss and themselves. Many of them seemed to feel reassured and fortified in some way by the experience. When that was not the case, the participants provided us with valuable feedback that will hopefully improve this program's ability to serve families in the future.

APPENDIX A

## TABLE 1:
## Literature Review Group Interventions with Bereaved Children

| Author(s) | Intervention | |
|---|---|---|
| Beswick & Bean (1996) | The Children's Bereavement Project<br>-Weekly sessions x 8 focussing on the building trust, death education, effective coping, sharing and dealing with feelings, and looking to the future<br>death and funerals, looking to the future<br>Books, storytelling, worksheets, creative arts | **Evaluation:** Self-esteem assessment tool used at session one, session 8 and 4 mos. post group<br>Written evaluation sheets for children and care givers<br>Reports from teachers<br>Impressionistic data from families, program staff and teachers<br>**Outcomes:** Most enjoyed group.<br>Facilitators noted that children 'benefited' from attention they received<br>Families reported improved communication in family |
| Graham & Sontag (2001) | -Weekly sessions x 10 over a period of 6 mos.<br>-Goals: 1. Provide opportunity for children to see other children who had experienced similar loss<br>2. Educate children re death and grief<br>3. Assist children in maintaining memory of deceased. | **Evaluation:** Qualitative analysis of Interviews and drawings designed to examine following questions: 1. What contributes to child's changing perceptions and understanding of grief?<br>2. What is the role of the group in the child's grieving process?<br>**Outcomes:** Re. contribution of group- Children comforted by realization that they were not alone in their grief. Provided important self objects for children- comfort and reassurance |

APPENDIX A

## TABLE 1:
## Literature Review Group Interventions with Bereaved Children

| **Author(s)** | **Intervention** | |
|---|---|---|
| Heiney, Dunaway & Webster (1995) | -Day long workshops offered 4 times per year for children age 5-19 yrs.<br>-Each session focussed on a season and one of the following goal: death education; increasing children's experience of feelings; enhancement of coping strategies for the future.<br>-Educational evening sessions for parents offered prior to each workshop. | **Evaluation:** Older children completed simple scales, forced choice and open-ended questions. Younger children given visual analogue versions of scales and ope-ended questions. Parents interviewed re. changes observed in their children following group.<br>**Outcomes:** Caregivers reported decrease in children's somatic complaints and behaviour problems. Feedback was 'overwhelmingly positive'. |
| Huss & Ritchie (1999) | -Weekly sessions x 6 focussing on grieving process, memories, communication with others about grief, and developing appropriate ways to respond to feelings. | **Evaluation:** Solomaon four-group design used. Standard Measures used: Piers-Harris Self-Concept Scale, Children's Depression Inventory, and Child Behaviour Checklist. Support Group Rating Scale developed by author also used.<br>**Outcomes:** No statistically significant findings. |

APPENDIX A

## TABLE 1:
## Literature Review Group Interventions with Bereaved Children

| Author(s) | Intervention | **Evaluation:** Descriptive information re. children's reactions and participation in group presented. Themes related to children's thoughts and feelings inferred. |
|---|---|---|
| Lohnes & Kalter (1994) | Weekly, hour long sessions x 12 for parentally bereaved children 6-12 yrs.<br>-Goals included the following: death education; normalization of grief; reworking emotional aspects of the experience; enhancement of coping strategies; maintenance of an emotional tie to the deceased, and communicating with parents.<br>-Themes arranged in a temporal sequence that parallels course of bereavement. | **Outcomes:** Authors reported observations of program effects (e.g. sharing of experiences produced relief). |
| Masterman & Reams (1988) | Weekly discussion sessions x 8 focussing on children's losses. | **Evaluation:** Observations and impressions of program facilitators.<br>**Outcomes:** Children appeared less constricted and angry, more able to understand and cope with strong emotions.<br>Parents reported generally positive effects and a decrease in children's communication about bereavement issues. |

APPENDIX A

## TABLE 1:
## Literature Review Group Interventions with Bereaved Children

| Author(s) | Intervention | **Evaluation:** Parents completed written evaluation. Facilitators impressions.<br>**Outcomes:** Parents reported increased communication within family. Facilitators reported that parents appeared to be more relaxed, less isolated and less fearful. |
|---|---|---|
| Mulcahey (1995) | -Weekly sessions x 5 for preschool-age to teenage children. Objectives included the following: sharing of death related experiences with one another; facilitate reduction of loneliness and isolation; provide education re. bereavement and grief: facilitate ability to express and cope with grief, and to enhance family's ability to communicate and cope.<br>-Companion psycho-educational series for parents focussing on children's grief and how to support grieving children | |
| Opie, Goodwin, Finke, Beattey, Lee & van Epps (1992) | -Weekly discussion group sessions focussing on the children's losses designed for 16 inner city, low income, bereaved children age 9 - 15 yrs. | **Evaluation:** Structured interviews based on the following standardized measures: Loss Resolutions Scale conducted with each child. Adolescent Life Assessment Checklist administered pre and post group.<br>**Outcomes:** Only significant finding was decrease in somatic complaints for elementary school age group. |

APPENDIX A

## TABLE 1:
## Literature Review Group Interventions with Bereaved Children

| **Author(s)** | **Intervention** | **Evaluation:** Pre and post-test design with experimental and control groups. Following standardized measures used: Depression and Conduct Disorder Child Assessment Schedule: Child Depression Inventory: Child Behaviour Checklist; Family Environment Scale; Children's Report of Parental Behaviour Inventory; Stable Negative and Positive Events Scale Reports from children and parents re following: family functioning, group participation, satisfaction with family and social support.<br>**Outcomes:** Parents reported increased warmth in their relationship with children, increased family discussion re grief related issues and decrease in depression and conduct disorders of older children. No significant program effects for children demonstrated. |
|---|---|---|
| Sander, West, Baca, Pillow, Gersten, Rogosch, Virdin, Beals, Reynolds, Kallgren, Tein, Kriege, Cole & Ramirez (1992) | -Series of Family Grief workshops x 4 for up to 8 bereaved families at a time<br>-Family Advisor Program - 12 private sessions for parents of child participants<br>-Goals include: prevention of mental health problems in parentally bereaved children, and improvement of family environment variable specified as mediators of effect of parental bereavement on children's mental health. | |

APPENDIX A

## TABLE 1:
## Literature Review Group Interventions with Bereaved Children

| Author(s) | Intervention | Evaluation |
|---|---|---|
| Schilling, Koh, Abramovitz & Gilbert (1992) | Sessions x 12 for parentally bereaved children focussing on death education, communication and coping. | **Evaluation:** Pre-test post-test design. Standardized measures used: Behaviour History Questionnaire, Attitudes and Concepts of Death and Bellevue Index of Depression as Perceived by Child and Caregiver.<br>**Outcomes:** Evidence of some increased maturity in children's concept of death. Most children remained depressed. |
| Stokes, Wyer & Crossley (1997) | Winston's Wish<br>Comprehensive service to children aged 6-14 years.<br>Two day residential camp with companion parents' group<br>Wilderness activities, small group sessions , sharing sessions, look at difficult emeoitns, art projects | **Evaluation:** n 35<br>Pre and post camp assessments:<br>Children's Behaviour Questionnaire completed by parent<br>Content analysis of semistructured interviews with parents and children.<br>**Outcomes:**<br>Questionaires: No significant difference<br>Interviews: Normalization of experience of bereavement (not only me), enhanced ability to identify, express and understand grief related feelings, enhanced ability to communicate about loss and feelings with family and others |

APPENDIX A

## TABLE 1:
## Literature Review Group Interventions with Bereaved Children

| Author(s) | Intervention | |
|---|---|---|
| Tonkins & Lambert (1996) | Weekly psychotherapy group x 8 focussing on memories, feelings impact of grief, changes in self since the death and the importance of a support system. | **Evaluation:** Pre-test post-test within group wait-list control research design. Standardized measures used: Children's Depression Inventory, Achenbach's Child Behaviour Checklist. Measurement tools developed by authors: Parent and Teacher Report Forms, Bereavement Group Questionnaire for Parents. Interviews by therapists with children and parents.<br>**Outcomes:** Significant decrease in children's levels of depression as well as reduction in overall emotions and behavioural problems. |
| Williams (1998) | The Kingfisher Project -structured weekly group sessions x 10. Parallel group for parents<br>Made use of storytelling, games, art and poetry to address tasks of mourning<br>n36 | **Evaluation:** 'Tool' designed by staff and qualitative analysis of feedback<br>**Outcomes:** 60 % of children showed 'clear evidence of improvement'<br>Children were generally positive, valued opportunity to express feelings<br>Carers reported decrease in children's anger and sense of isolation, increased sense of confidence and self esteem. Teachers reported improvement in emotional and behavioural states of children. |

## APPENDIX A

### TABLE 1:
### Literature Review Group Interventions with Bereaved Children

| Author(s) | Intervention | |
|---|---|---|
| Zambelli, Clark, Barile & de Jong (1988) | -Weekly creative arts therapy group x 8 for bereaved children. Companion support/educational program for parents.<br>-goals of both groups , to increase communication skills and provide a corrective mourning experience | **Evaluation:** Evaluation forms completed by parents and children.<br>-Facilitator's observations cited<br>**Outcomes:** Positive feedback from parents. |
| Zambelli & DeRosa (1992) | -Weekly group x 11 for 4 bereaved children<br>-Group focussed on communication of emotions and coping | **Evaluation:** Pre and post-testing using Piers -Harris Self Concept Scale Descriptive and impressionistic data from facilitators<br>**Outcomes:** No significant quantitative results. Facilitators noted improved self-esteem, increased ability of children to discuss parent's death and greater 'social relatedness' |

# APPENDIX B

## RESEARCH ETHICS COMMITTEE APPROVAL CERTIFICATE

Faculty of Social Work
University of Manitoba
Winnipeg, Manitoba.

September 21, 1999.

To: E. Payne.

THE MODIFICATIONS TO YOUR PROJECT ENTITLED *Children's Experience of a Grief Support Program, A Qualitative Study* HAS BEEN APPROVED BY THE RESEARCH ETHICS COMMITTEE.

**CONDITIONS ATTACHED TO THE CERTIFICATE:**

1. You may be asked at intervals for a progress report.
2. Any significant changes of the protocol should be reported to the Chairperson of this Committee so that the changes can be reviewed prior to their implementation.

Yours truly,

Grant Reid
Chair
Research Ethics Committee.

# APPENDIX C

**interoffice**
MEMORANDUM

**TO:** Elizabeth Payne

**FROM:** Co-Chairperson, Research Review Committee

**DATE:** October 25, 1999

**SUBJECT:** **Experimental Protocol Submission**

This is to inform you that the Research Review Committee, at its meeting held on October 20, 1999, reviewed your response to the Committee's response regarding the protocol titled "Young People's Experience of Grief Support Program - A Qualitative Study", Ref # RRC/99/0029, and was approved as submitted.

Thank you for your cooperation.

JF/clr

cc: Social Work

the Medical Staff
Pharmacy Department
Finance Department

## APPENDIX D

## Information for Facilitators

Dear --------------------,
I am a social worker at ______________ and graduate student at the University of Manitoba. I am conducting a study entitled 'Young People's Experience of a Grief Support Program' in partial fulfillment of the requirements of a Master of Social Work degree. This study is under the supervision of Tuula Heinonen and Kathy Levine from the Faculty of Social Work, and David Gregory, Faculty of Nursing. Your help in introducing this study to potential participants would be greatly appreciated.

Purpose of the Study
The purpose of this qualitative study is to learn how young people experience and make sense of their involvement in [Grief Support Program for Children and Teens]. The study is not designed to evaluate the performance of former group members or individual facilitators. I hope to learn which aspects of the program seem meaningful and useful to participants and which aspects do not. This information may be used as evaluative feedback upon which to base modifications to the program, it may provide information to be shared with potential participant families and interested professionals, as well as current and potential funders.

Design
I plan to conduct 30 to 60 minute interviews with program participants age 9 and older who have completed the program within the past six to eight months. I expect to interview participants only once but if there seems to be a need for or an interest in a second interview I will ask participants' permission to return. Interviews will be conducted based on an interview guide formulated with the assistance of the program coordinator and two senior program facilitators.

Ethical Considerations
Please advise parents that their children are not obliged to participate in this study and that a refusal to participate, answer certain questions or withdraw from the study will in no way affect their ability to access support or service from anyone associated with ________________ Hospital.

The study is designed to evaluate the program, not the performance of program participants or program facilitators. Information obtained in this study will be kept confidential. The researcher will be the only person who will have access to the names of those children who agree to participate and all names and identifying information will be omitted from any reports of the study.

Please ensure that parents/guardians are clear regarding the following points:

a.) the purpose of your call is to let them know that the study is taking place
b.) the purpose of the study is to find out what children thought and felt about their involvement with the [Grief Support Program]
c. ) if a parent/guardian is interested in learning more about the study or if s/he believes that her/his child may be interested in participating in the study you will send them an information package about it
d.) the researcher will not have access to their name unless they choose to contact the researcher directly using the phone number or the pre-stamped form provided in the information package.

Please contact me at ________ if you have any questions and thank you very much for your assistance.

Sincerely,

## APPENDIX E
## Cover Letter for Information Package

Dear ------------------,

Thank you for expressing an interest in the study involving the [Grief Support Program]. I am sending you the information we discussed. If you have any questions about the study or if your child/children would like to participate, please contact the researcher by phone at the number provided or return the pre-stamped form included in the package.

Thanks again for your interest.

Sincerely,

(facilitator)

## APPENDIX F
## Information Letter for Parents

Dear ----------------,

I am a social worker at _______________ Hospital and graduate student at the University of Manitoba. I am writing to invite your son/daughter to participate in a study entitled 'Young People's Experience of a Grief Support Program'.

Young people , nine years of age and over, who have participated in the [Grief Support Program] are being invited to take part. The aim of the study is to explore children's impressions and opinions about the program in some depth. It is not intended to evaluate the performance of individual children or program facilitators.

I am a social worker at _____________ Hospital and former facilitator with the Grief Support Program. I am undertaking this study as part of a Master of Social Work degree, at the University of Manitoba under the supervision of Professor Tuula Heinonen.

This study has been approved by the Research Ethics Committee of the Faculty of Social Work at the University of Manitoba and the Research Review Committee of ____________Hospital.

Your child's participation in this study would involve a private, 30 to 60 minute tape recorded interview conducted in your home or in another location of your choice. If there appears to be a need for or interest in a second interview I may ask to meet with some children a second time. Participants may choose to draw during the course of the interview and I may ask to use their pictures in my study also. I will contact some study participants once following the interview and request their feedback on my interpretation of the interview. This conversation may take place over the phone or in person and will not be tape recorded.

Your child is not obligated to take part in this study and may withdraw from the study at any time. Refusal to participate or withdrawal from the study will not affect your family's ability to access services from ____________ Hospital or the [Grief Support Program].

Although is not expected that there will be any immediate benefits to you or your child, the study will help program organizers learn about the strengths and weaknesses of the program. We hope to use this information to improve and perhaps protect the work being done by the [Grief Support Program].

It is not expected that this interview will be the cause of undue distress to your child/children. The only risk I can foresee is the potential for some children to feel some anxiety regarding the interview situation or the recollection of the grief group experience. It is not my intention to press children to share information which makes them feel uncomfortable. Children will be advised that they may refuse to answer any questions they choose and may end the interview any time if they feel anxious or uncomfortable.

Information obtained will be kept confidential. I will be the only person who will know the names of the children participating and all identifying information will be changed or omitted from all reports of the study. A summary of the findings will be provided to you and your child if you wish.

If you are interested in discussing this study or if you and your child/children are interested in participating, please complete the tear off section of this letter and return it to me in the pre-stamped envelope. Upon receipt I will contact you by phone. Please feel free to contact me by phone if you prefer at ________.

Thank you for considering this invitation.

Sincerely,

Elizabeth Payne BSW, RSW

- - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - - -

I am interested in discussing my child's participation in the study entitled 'Young People's Experience of a Grief Support Program'.

Name of
parent/guardian:------------------------------------------------------------------------------
--------------------------------------------------------------------------------------
Name(s) of the child/children who participated in the [Grief Support Program]:
----------------------------------------------------------------------------------------------------
----------------------------------------------------------------------------------------------------
----------------------------------------------------------------------------------------------------
-------------------------------------------------------------------------------------------
Phone number:--------------------------------------------------------------------------------
Most convenient time of day for researcher to contact
parent/guardian-------------------------------------------------------------------------------
------------------------------

## APPENDIX G
## Phone Call to Parents of Potential Respondents

I will contact the interested persons by phone. The purpose of this phone call is to thank people for their interest, to answer any preliminary questions and if possible set a time for me to meet with the parent and child at their home.

Hello, my name is Elizabeth Payne and I am calling about the study involving the [Grief Support Program]. Is this a convenient time to talk? Thanks for your interest in this study. Do you have any questions about the study?

Have you discussed the study with your child?
Is s/he interested in participating?
Would you tell me your child's name and age?
When did s/he attend the [Grief Support Program]?
How is ---------------------- doing in general?
Can you think of any reason why this may not be a good time for her/him to participate in this study? (e. g. recent significant loss, unusual stressors at school or at home)

If the parent and child are in agreement with participation, I will schedule a time to meet with them at a time and place that is mutually convenient.

## APPENDIX H
## Explanation of the Study for Children

Hi, my name is Elizabeth. I am a social worker at _________Hospital. I am interested in learning what kids think about the [Grief Support Program]. I would like to talk to you about the grief program. If it is OK with you, we will spend about an hour talking and I will tape record our conversation.

This interview is part of a project I am working on for university. I will be writing a report about what I learn from the children I will be interviewing. What you tell me in the interview will be kept confidential. I plan to use what you tell me about the program but I will not use your name or describe who you are when I write up my project.

I hope that after I have spoken with a few children from the program I will learn what parts of the program seemed useful to them and which parts seemed less useful. I will not be giving you any reward to help me with this project but I hope that the information I gather will help to improve the Grief Support program for other children who may need to attend it someday.

You don't have to talk to me if you don't want. If you decide to meet with me but find that there are some questions you don't understand or prefer not to answer that will be OK. If you want to end the interview at any time that will be OK too.

Do you have any questions?

## APPENDIX I
## Parent's Informed Consent for Child to Participate

I, -----------------------------------, agree to allow my child to participate in a study entitled 'Childrens' Experience of a Grief Support Program'. The study will explore children's' memories and impressions of the program. The study will be conducted by Elizabeth Payne, BSW, a graduate student in the Master of Social Work program at the University of Manitoba, under the supervision of Professor Tuula Heinonen, Faculty of Social Work.

I understand that the researcher, Elizabeth Payne, will interview my child in our home or another location of my choice. The interview will be tape recorded and I will not be present in the room during the interview. If there is a need or interest, a second interview may be considered. My child may choose to draw during the course of the interview and her/his art work may also be used in the study. My child may be contacted by the researcher following the interview for the purpose of clarifying and confirming the researcher's understandings of the interview content.

I understand that information obtained will be kept strictly confidential; the researcher will not reveal the name of the participant to anyone. Identifying information will be changed or omitted from any reports of this study. I understand that I may receive a summary of the results if I wish.

I understand that this study is not expected to produce any direct benefits for my child or myself, but that information obtained by the study may help to improve the [Grief Support Program]'s service to bereaved children. I also understand that this interview is not intended or expected to be the cause of undue distress to my child/children. If my child feels uncomfortable or anxious at any time during the interview s/he may refuse to answer a question, ask to have the tape recorder turned off or end the interview.

I understand that I am under no obligation to have my child participate in this study and that my child may withdraw from the study at any time. I understand that if my child and I decide not to participate in this study or to withdraw from it while it is in progress our ability to access service from __________ Hospital will not be affected.

I understand that if my child discloses information regarding any type of abuse to herself/himself or any plans to harm herself/himself or others that the researcher is obligated by law to report this to the appropriate authorities.

If I have any questions or concerns about the study, I may contact the

researcher, the researcher's faculty advisor or the Patient Relations Officer at ____________ Hospital at the following numbers:
Researcher: Elizabeth Payne (_________)
Faculty Advisor: Professor Tuula Heinonen (_________)
Patient Relations Officer: __________ (_________)

| | |
|---|---|
| Signature of Parent | Signature of Researcher |
| Date | Date |

(Copy for parent and copy for researcher)

## APPENDIX J
## Child's Informed Assent to Participate

I, ----------------------------, agree to participate in a study called "Children's Experience of a Grief Support Program". This study will be asking children who attended the [Grief Support Program] what they thought about it. I understand that Elizabeth Payne, a social worker at ___________ Hospital, will use what she learns to complete a university project called a thesis.

I understand that Elizabeth will come to my house and talk with me for about an hour. We will tape record our talk so that Elizabeth can write down what I had to say later. If I decide to draw while we talk she may ask to use my drawings also. If we need more than an hour for the interview, Elizabeth may ask my permission to return for a second interview. I understand that she may call me sometime after her visit to make sure that she understood all that I had to say.

I understand that the only person who will listen to the tape and know whose voice is on the tape will be Elizabeth. I understand that what I say will be kept confidential. Elizabeth may use my thoughts and my words in her project, but she will not describe me or use my name when writes about or talks about the research project. If I want to, I may receive a summary of her project when it is finished.

I understand that I will not receive a reward for participating in this study but that the information that I and other children will provide may be used by the [Grief Support Program] to improve their work with children.

I understand that it is up to my parent(s) and I to decide whether or not I will participate in the study. I don't have to participate if I don't want to and if I agree to participate I can change my mind at any time. I can also choose not to answer certain questions if I want to and that won't be a problem.

If I have any questions or concerns about the study, I or my parent can contact the researcher or her professor at the following numbers:
Researcher: Elizabeth Payne (________)
Thesis Advisor: Professor Tuula Heinonen (________)

| | |
|---|---|
| Signature of Participant | Signature of Researcher |
| Date | Date |

(Copy for participant and copy for participant)

# APPENDIX K
## Interview Guide

Time and attention will be given to ensuring that the participant is comfortable. The researcher will try to establish some rapport with the participant and remind her/him of the following; 1) The interview is not a test and there are no wrong answers.
2) The participant is the expert and the researcher is here to learn.
3) It is not the intention of the researcher to get the participant to tell secrets or information they would prefer to keep to themselves.
4) The participant may refuse to answer any question and the tape recorder can be turned off any time the participant wishes.

### Opening Questions

I know that you attended children's grief group because your --------------- died. Can you tell me a bit about your Mom's/Dad's death?
(When; Where; Cause; Were you present?, Did you attend the funeral?)

What do you think was the most important thing about the Grief Group?

### Pre-group Questions

How did you first hear about the grief group?
(Who; When; Where)

What did you think about it when you first heard about it?

What do you remember about the facilitator's home visit?

What did you think about going to grief group after that visit?

How did you decide whether or not to attend group?

Did you talk to anyone about it besides your parent?

Did your parent decide to attend the parent's group?

How did you feel about that?

### Session1

(Getting acquainted activities- setting ground rules, sharing stories of parent's death)

When you think of the first day of grief group, what do you think of?

Tell me what you remember from your first grief group session?
(room, other members, activity, discussion)

Was there anything that surprised /disappointed/ pleased/ confused/ made you feel uncomfortable/ helped you that day in group?

Did being at group remind you of anything?

**For sessions 2-8 I will try to facilitate and tap into participant's memories and thoughts about the session. I will ask participants if they can recall what was discussed at each session and if they have difficulty remembering I will mention the topics and activities they likely experienced that week**
**in order to jog their memory. I plan to address the same types of questions for sessions 2-8 as those noted for session 1.**

Session2 (Group cohesion and memories of the deceased- bringing in a memory, pictures of memories)

Session 3 (Death Education -death, funerals, facts and fantasies)

Session 4 (Identification, expression and normalization of grief related feelings- brainstorming feelings associated with loss, ginger bread man, feeling charades)

Session 5 (Effective coping strategies- brainstorming, alternative approaches, box kicking, book ripping)

Session 6 (Changes in the family since the death, consideration of the future without the deceased- kinetic family drawings, diagrams of support system)

Session 7 and 8 (Closure and feedback- evaluation forms, return of art work, exchange of phone numbers and good wishes, pizza party)

What was it like to know that group was about to end?

<u>Post- group Questions</u>

What was it like when the grief group was over?

Do you ever think about group now?

Do you ever talk to anyone about what you did in group now?
With who, about what?

Are you in contact with anyone from group?

If you were going to plan a kid's grief group, what would it be like?

Now that we have reviewed your time in group, tell me again what you feel was the most important thing about grief group for you.

## APPENDIX L
## Demographic Face Sheet

To be completed by parent/guardian

Please list the ages of all persons living in this child's household and the nature of their relationship to the child (e.g. sister, mother, foster parent ).

Do you consider your family to be part of an ethnic or cultural group?
If yes, please name.

Does your family practice a particular religion?
If yes, please name.

## APPENDIX M
## Table 2: Sample Group

| Gender and Age | Parent and Cause of Death | Interval Between Death and Group | Interval Between End of Group and Interview |
|---|---|---|---|
| male, age 11 | father, suicide | 1 month | 9 months |
| male, age 10 | father, cancer | 4 months | 3 months |
| female, age 15 | father, cardiac | 1 year | 3 months |
| male, age 12 | father, ALS | 7 months | 11 months |
| female, age 13 | father, ALS | 7 months | 11 months |
| female, age 12 | father, cancer | 2 years | 1 year |
| female, age 11 | father, cardiac | 3 months | 1 year |
| female, age 11 | father, cancer | 15 months | 4 months |
| female, age 17 | father, cancer | 4 months | 5 months |
| male, age 11 | father, suicide | 2 years | 5 months |
| female, age 17 | father, suicide | 2 years | 5 months |
| female, age 10 | mother, cancer | 5 months | 8 months |
| female age 9 | father, cause unknown | 9 months | 2 months |

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