

**CHILDHOOD BEREAVEMENT AND PEER SUPPORT: EPIDEMIOLOGY,  
IDENTIFICATION OF EVALUATION CONSTRUCTS, AND THE PROMOTION OF  
RESILIENCE**

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# **CHILDHOOD BEREAVEMENT AND PEER SUPPORT: EPIDEMIOLOGY, IDENTIFICATION OF EVALUATION CONSTRUCTS AND THE PROMOTION OF RESILIENCE**

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University of Pittsburgh, 2008

The death of a close family member is a profound insult to a child's developmental course. Though early research assumed that childhood bereavement was a risk factor for mental and behavioral disorders in childhood and adult life, recent research has taken an ecological view of childhood development and considers a child's exposures to risk and protective factors. Yet, it remains unclear as to how many children are affected by the death of a close family member each year and how peer support groups can help children to adapt to such an adverse event. This dissertation represents three distinct stages in the development of a comprehensive evaluation for an agency that provides a peer support service for bereaved children and their families.

First, a primary question that arose during initial consultations with the agency was to determine how many children are affected annually within Pennsylvania. This led to an exploration of the epidemiology of childhood bereavement. The methods and data sources used to produce these estimates were critically evaluated and modified to offer a new interpretation of available data.

Second, it was important to identify constructs that could be used in an outcomes evaluation of the peer support program. Focus groups were used to explore the perceived benefits of attending peer support groups among caregivers and teens who had attended a spring session at the center. The intention to use focus groups was to increase the validity of constructs and, ultimately, the results of an outcomes evaluation.

Third, after identifying evaluation constructs a feasibility study was conducted to pilot an outcomes evaluation instrument. The study involved 30 families who attended the spring 2007 sessions at the center. Results suggested that peer support programs can improve children's coping efficacy while helping to improve their caregivers' perception of social support. The program also improved both children and caregivers' sense that they are not alone in their grief.

As demonstrated in this dissertation, including the loss of siblings and primary caregiving grandparents in prevalence estimates of childhood bereavement and applying resilience theory to peer support research is of public health relevance.

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## PREFACE

Curiosity. I believe it is this wonder about the world that has driven me to pursue and complete this degree. Since I was a boy, I have always been curious to know things in an intimate way. As I grew wiser, I became thrilled on those occasions when I learned how much I didn't know about something. After studying psychology and philosophy, working as a family therapist, and becoming a political animal I realized that I wanted to learn how to affect change in order to improve human health. The DrPH has provided me a new path to explore.

That my dissertation was on the topic of bereavement was synchronicity. Not long after I received notice of my acceptance into the doctoral program, my mother, Fahimy, died. Not long before I defended this dissertation, my best friend and grandfather, "Chuck", died. I dedicate this dissertation to them both. To my parents, the opportunities they created for me (opportunities they didn't have) to pursue post-secondary education resulted in this degree. To my grandfather, in just a few generations the family went from being sharecroppers in the South to receiving the highest degree awarded by the academy.

Of course, I could not have completed this work without help. For Ed Ricci's help in securing this project and his personal attention to my professional development I will always be grateful. Diane Abatemarco's frequent guidance on how to approach each stage of the project was invaluable both to the quality of the work and to my state of mind. The staff at the Highmark Caring Place were just great. Their thoughtful comments and input into the evaluation process truly made it a collaborative project. Finally, the dissertation committee's thoughtful critiques were extremely helpful to the refinement and improvement of this work.

## **1.0 INTRODUCTION**

For the existentialists, the only certain thing in human life is death. Since death is inevitable, it can be considered as a part of normal human experience. The manner in which each individual deals with his or her own death and mourns the death of others is often shaped by the social and cultural context in which it occurs. For any context, however, children must respond and adapt while they are still negotiating social, emotional, and cognitive developmental tasks. The impact of parental loss on psychosocial development has been the subject of much discussion in the literature.

The aim of this first section is to orient the reader to conceptions of childhood bereavement, to the program that was being evaluated, and to the approach that was used to engage in a comprehensive evaluation with an agency that provides a peer support service for bereaved children and their families.

The second and subsequent sections represent three distinct stages in the development of the project over the course of two years. Each section is intended to stand alone as an independent article yet each represents a unique aspect of this comprehensive evaluation. Background research on childhood bereavement is embedded within a section of each article.

## 1.1 MODELS OF CHILDHOOD GRIEF

In the growing body of literature on childhood grief, several different approaches have contributed to an understanding of what happens to children who have experienced loss. Clark and colleagues (1994) characterize these different approaches to childhood grief as the blunt trauma model, the shock/aftershock wave model, and offer a life trajectory/developmental cascade model that accounts for how children adapt to loss over time. The blunt trauma model assumes that the loss was a single event bound in time, powerful in impact, and particularly disruptive for younger children (Clark et al. 1994). This model includes researchers who have tried to establish an association between childhood bereavement and adult psychiatric disorder. Much of the early research in bereavement developed from attempts to understand adult depression. Hypotheses were shaped by a psychodynamic conceptualization of depression as resulting from early object loss, the similar clinical presentations of grief and depression and the frequency of parental loss in the histories of depressed clients (Tremblay and Israel 1998). While some studies have found a link between early parental loss and adult depression, the model has been criticized as oversimplifying the complexity of the life situation of the bereaved child, failing to identify a causal relationship, and depending on seriously flawed methodologies, including inadequate comparison samples (Clark et al. 1994; Tremblay and Israel 1998).

The shock/aftershock wave model hypothesizes that the loss of a parent has long-lasting, changing repercussions over time in many domains of child functioning (Clark et al. 1994). These repercussions can affect mental and physical health, school performance, interpersonal relations, and identity. The impact of the death can trigger a series of reactions and changes that give rise to others, hence, the term “aftershocks” given by Clark et al. This model includes secondary consequences of parental death, such as changes in family circumstances, as an

aftershock affecting the child. Studies from this model began to elaborate the links missing from the blunt trauma model and found that the preloss relationship with the parent, relationship with the surviving parent, and quality of parental care increase the risk of adult psychopathology (Tremblay and Israel 1998).

Clark et al. describe how the shock/aftershock wave model evolved further into the life trajectory model which suggests that a parent's death can change the speed or direction of the child's long term developmental course. The model is an attempt to empirically describe how the child's life direction is unaffected and then affected by the parent's death. They find it inadequate because the ecological context in which the child's life course is embedded may itself change, with implications for grief processing well into the future, and because life trajectories are not easily amenable to empirical investigation.

Finally, Clark et al. offer the life trajectory/cascade model of childhood grief. This model states that the changes emerging after a death can influence the psychological state of the bereaved person as much as the loss itself for the remainder of the person's lifetime (Clark et al. 1994). Having to move and change schools or relational difficulties with the surviving parent are considered secondary consequences of the death that have a significant impact on the child's development. The child experiences a never-ending series of events that are tinged by the experience of the parent's death and future stressful events are shaped and interpreted according to the loss experience (Clark et al. 1994). The model views these changes and stressful events as potential triggers for vulnerability to psychopathology or other less healthy outcomes as the child develops into adulthood.

### **1.1.1 Clinical Categories of Grief**

Clinical conceptions of grief in childhood have been variously categorized according to the quality of functional impairment in the child. Normal or uncomplicated grief can include emotional responses such as sadness and crying, guilt, anxiety, and anger, and changes in health status, school performance, and self-perception. Complicated or pathological grief in children is often defined by the degree to which a child can carry on usual daily activities and proceed with normal developmental tasks despite the grief (Sood, Razdan, Weller, and Weller 2006). Disabling interference in social, emotional, and physical development which can include suicidal hints, somatic problems, new difficulties with school work, nightmares, sleep problems, changes in eating patterns, and frequent regression in behaviors can warrant professional intervention (Sood et al. 2006). Childhood traumatic grief is distinguished from complicated grief, referring to a condition in which characteristic trauma-related symptoms interfere with children's ability to grieve (Cohen, Mannarino, Greenberg, Padlo, and Shipley 2002). This condition relates to a child's subjective experience of death, rather than an objective classification of the death as traumatic (such as a suicide or parents who died in the September 11 attacks), and includes trauma symptoms such as re-experiencing in response to trauma reminders, exaggerated avoidant symptoms, and traumatic estrangement from others, even from family members who have also experienced the same death (Cohen et al. 2002). While clinical classifications of grief are varied, this discussion will focus on the normal bereavement course.



### **1.1.2 Child's Concept of Death and Capacity to Mourn**

There has been some debate in the literature as to when a child has the capacity to mourn. One side of the debate stems from attachment theory. Bowlby discussed three phases of the child's responses when separated from his mother – protest (separation anxiety), despair (grief and mourning) and detachment (a defense leading to attachment to a new object) (1960). “Mourning responses are displayed by infants as young as 6 months and, from this age until about 3 or 4 years, loss of the mother figure is an event of high pathogenic potential for future personality development” (Bowlby 1960). Others have argued that the capacity to mourn relate to the child's cognitive development and his ability to achieve a ‘mature’ understanding of death. Most researchers who have examined the child's concept of death have assessed the abstract concepts of irreversibility, that death is permanent, nonfunctionality, that all life-defining functions cease at death, and universality, that all living things die (Speece and Brent 1984). In a classic early study, Nagy (1948) assessed 378 children between the ages of 3 and 10 using written compositions, drawings and discussion. She characterized 3 stages in the development of the death concept. In the first stage, characteristic of children between 3 and 5, death is temporary and everything, including lifeless things, is living. In the second, children between 5 and 9, death is personified and not universal. In the third, around 9, death is inevitable, takes place in us, and is permanent. More recent scholarship has observed parallels between the child's concept of death and Piaget's descriptions of cognitive development as a the child moves from pre-operational thought to concrete operations and find that this is achieved around 5-7 years (Speece and Brent 1984), earlier than Nagy suggested. Most of the bereavement research contained within this dissertation had been conducted with children age 5 or older.

## 1.2 CHILD-CENTERED FAMILY-BASED PEER SUPPORT

The evaluation project was conducted with a center for grieving children and their families based in Pittsburgh, Pennsylvania. The center also has satellite sites in Erie and Lemoyne, Pennsylvania. The center states that its central goal is to have the children and adults express their grief in an atmosphere of acceptance and trust. According to the stated aims of its service model, the center facilitates peer support to allow children to help one another cope and to decrease the stigma or the child's perception that she is the only one experiencing grief. One of the aims of the program, therefore, is to help children by facilitating the modification of individual level variables.

The center's mission states that it serves families because 'grief work' happens within the family. As a result of a family member's death, family members must adjust to new roles and parents and caregivers are supported in their grief so that they may be able to be emotionally available to their children. Another aim of the program, then, is to help children by facilitating the modification of family or social-environmental variables. Additionally, the program screens families prior to enrollment to determine whether the family is appropriate and can benefit from a level of a non-clinical service such as peer support. Families whose members warrant mental health or drug/alcohol treatment referral may not be appropriate for peer support services and are referred to appropriate services in the community.

Families learn about the center through referrals from local schools, funeral homes, healthcare professionals or advertisements. After an initial phone call and screening, families visit the center for an initial orientation session. Thereafter, families visit the center for 10 bi-monthly family nights. Families arrive in the evening, spend a half-hour in a common room eating a meal with staff, volunteers, and other families, then children, teens and adults meet in

separate group sessions for approximately one-hour. Group sessions are led by trained volunteer group facilitators. Families then reunite in the common room and leave.

### **1.3 EVALUATION APPROACH**

The evaluation project was guided by the principles of utilization focused evaluation (Patton 1997). The center was interested in identifying program outcomes to be used in community outreach efforts to highlight the potential benefits a prospective enrollee may expect from attending its peer support programs. Therefore, in the ensuing body of work, every effort was made to address concerns of key staff and to include these staff each step of the way to ensure that this work was both practical and useful for their purposes.

At the outset of the project, the Executive Director needed to know how many children in Pennsylvania experienced bereavement for service planning purposes. This question was addressed prior to the start of the evaluation and is described below in this section. The article in section 2 of the dissertation on the epidemiology of childhood bereavement developed from initial work on this question.

Ongoing meetings with the Executive Director and Program Managers for direction, input and feedback were essential to this project. In an initial meeting, program managers identified several questions they wanted to answer with this evaluation. These questions included:

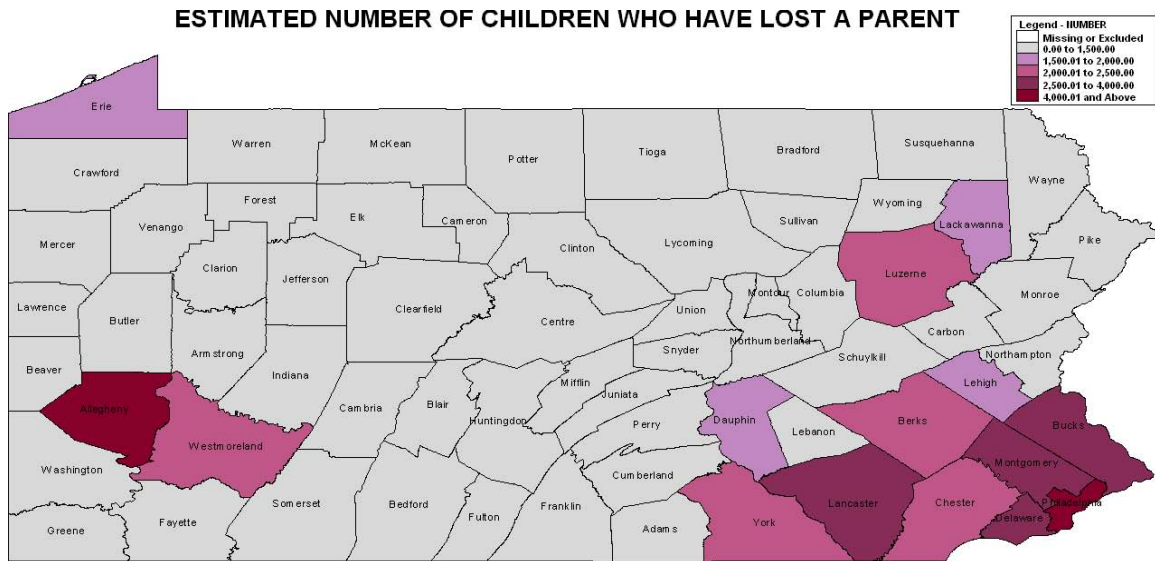
1. Which family member died and what was the manner of death?
2. What is the duration between the event and initiating with center?
3. According to different types of death, do parents who lose a child desire to stay longer than children who have lost a sibling?
4. How does the center affect behaviors or well-being of a person grieving?
5. How do families change and how do they see improvements?

6. What behaviors do parents see change?
7. How many families are involved in other types of care or referred to other types of care?
8. For families who have left and then returned when there was another death that occurred, why did they choose to return to the center?
9. How many families make an initial call but do not enroll in the program?

Though the task of the evaluation was to identify program outcomes, many of these questions represented program management questions. Therefore, it was decided that a process evaluation was an appropriate first step for the project.

### **1.3.1 Bereaved Children in Pennsylvania**

A common method used to estimate the number of children who have lost a parent is to depend on the number of beneficiaries of the Social Security Administration's Old Age, Survivors and Disability Insurance (OASDI). This federal reporting accounts for the number of dependent children enrolled to receive benefits due to the death of one or more parents. According to an average estimate of the number of beneficiaries in Pennsylvania between the period of 2000-2003, there were 82,055 children who had experienced the death of a parent. In the counties where the center provides services 11,055 children are affected (8,138 in Allegheny, 2,020 in Erie and 923 in Cumberland). Figure 1.1 below presents a map we created in order to display the number of children affected within Pennsylvania by county.



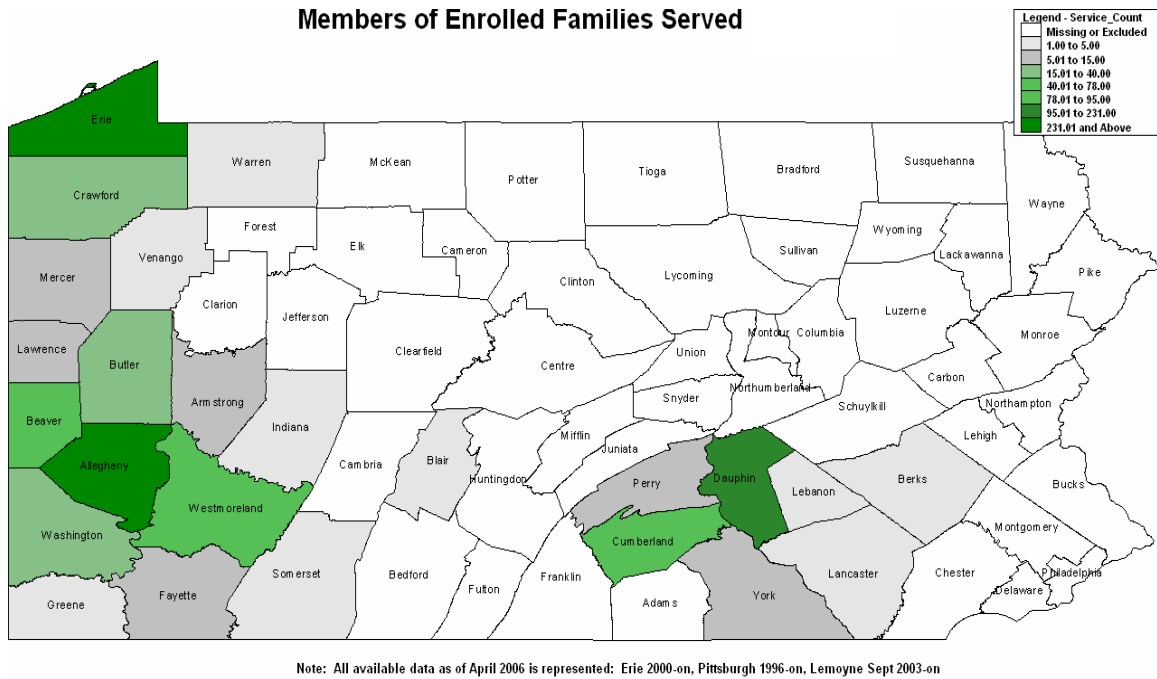
**Figure 1.1.** Estimated number of children who have lost a parent in Pennsylvania

Further discussion about the methods and state of knowledge about the epidemiology of childhood bereavement is contained within section 2 of the dissertation.

### 1.3.2 Phase 1: Process Evaluation

Phase 1 of the evaluation project involved a process evaluation which attempted to answer several of the questions raised by Program Managers during our ongoing evaluation planning meetings. Information was gleaned from the center’s database, cleaned for missing or incorrect data, analyzed and displayed in a useful fashion. Program managers contributed a great deal to the interpretation of the data. Presented in the figures below only represents the center’s Pittsburgh site but each analysis was repeated for the two other sites and was presented back to the center’s ‘all staff’ meetings for discussion among all the center’s staff.

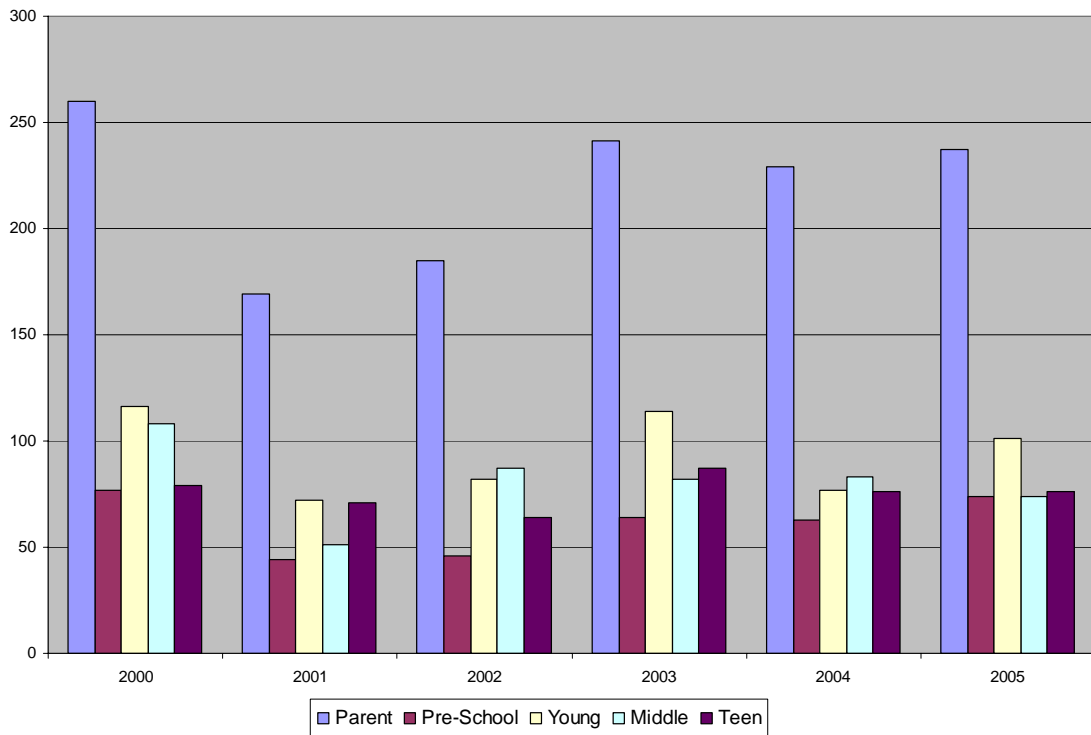
A map was produced to display the center’s service area and the number of family members it serves through its three sites across Pennsylvania. The figure below displays the service area.



**Figure 1.2.** Members served by the center’s three sites.

As the figure displays, most of the individuals served live in proximity to one of the center’s sites in Allegheny, Erie and Cumberland counties. However, this service area does not include several of the counties with the greatest number of bereaved children (the southeastern counties, for instance) that are displayed in figure 1.1 above. Figure 1.3 below displays individually enrolled family members by group attendance by year. In 2003, one of the years used in calculating an estimate of the annual number of children receiving OASDI benefits, the center’s site in Pittsburgh served 347 children in its pre-school, young, middle, and teen groups. Yet, according to OASDI data, 8138 children in Allegheny county were receiving benefits that year for the loss of one or both parents (see Figure 1.1). While some of these children may have

sought other professional services or no services at all, there is likely a large service gap between the children who would benefit from some type of bereavement service and those being served by the center’s peer support groups. Answering the program managers’ question about how many families are involved in other types of care would have required a much larger community assets survey and other efforts beyond the scope and available resources for this project.



**Figure 1.3** Enrolled family members by group attendance by year.

Having identified which counties the center’s families came from, the center’s database was then used to determine family sizes, number of sessions attended (1 session equals 10 bi-monthly group nights), family member lost, and types of death experienced by families (see Tables 1.1 and 1.2 and Figures 1.4 and 1.5 below).

**Table 1.1.** Number of 10-week sessions per family.

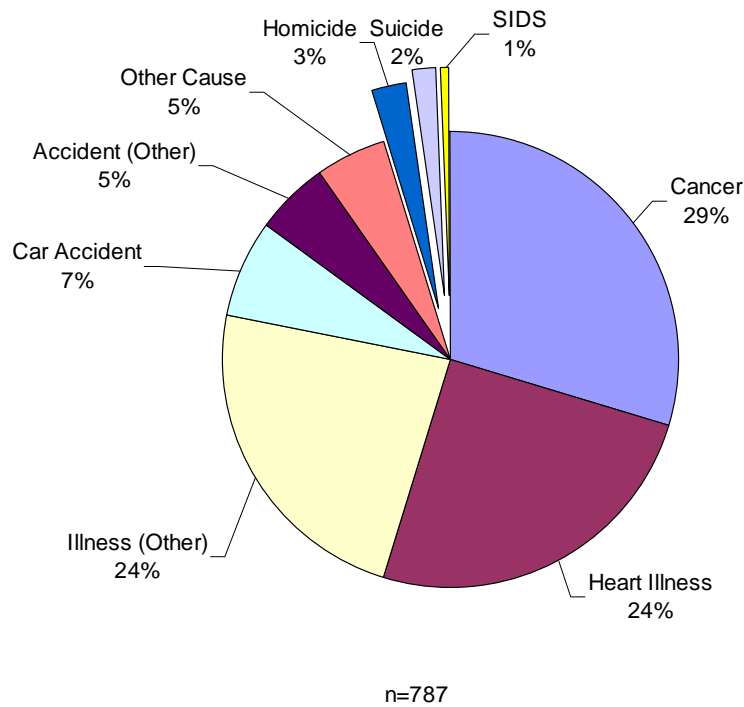
<b>NUMBER OF SESSIONS PER FAMILY PITTSBURGH 2000 - 2006</b>			
Sessions	Freq.	Percent	Cum.
1	467	70.86	70.86
2	146	22.15	93.02
3	26	3.95	96.97
4	7	1.06	98.03
5	5	.76	98.79
6	5	.76	99.54
7	3	.46	100

**Total number of families = 659**  
**Avg. number of sessions per family ~ 1.5**

**Table 1.2.** Family size.

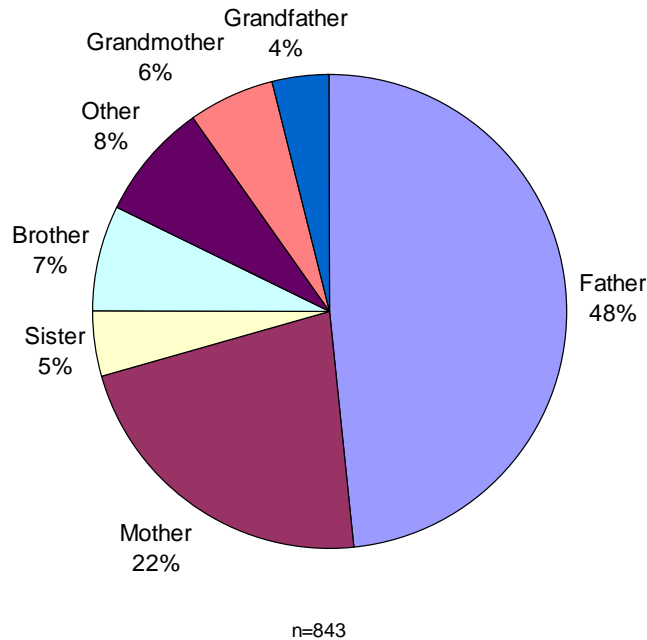
<b>MEMBERS PER ENROLLED FAMILY PITTSBURGH 2000-2006</b>		
# of Members	Frequency	Percent
2	304	36.15
3	299	35.55
4	143	17.00
5	37	4.40
1	31	3.69
6	18	2.14
7+	9	1.08

**Average family size ~ 3**



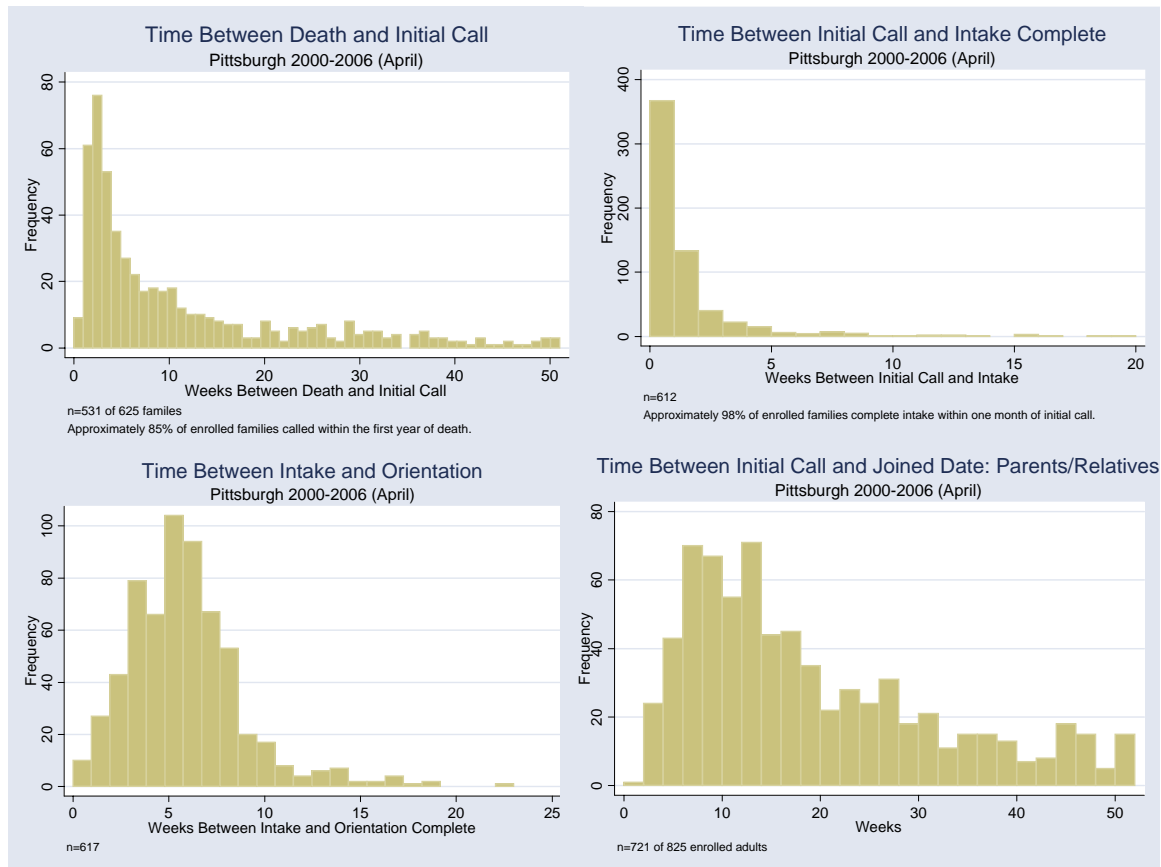
**Figure 1.4.** Types of death experienced by families and children: 2000-2006





**Figure 1.5** Relationship of deceased to child: 2000-2006

Finally, the database was queried to gather data on service information. Figure 1.6 below displays the time between the family member’s death, the initial call to the center, the completion of an intake, scheduling and attending an orientation and, finally, the total time between the initial call and the start of a first group night. As the figure shows, most families call within 2 months after the death. Intakes are generally completed within 2 weeks (this includes time for staff and families to leave messages and return calls). Orientation sessions are generally attended within 1-2 months (this includes no-shows and rescheduling). While it appears that it takes approximately 3 months from the time families call to the time they actually enroll and begin a session, discussion with and feedback from staff suggested that families who call during late spring-summer must wait until the fall sessions begin since summer sessions are not offered. Working collaboratively with staff provided a much richer interpretation of all of the data contained within the database.



**Figure 1.6** Service information

### 1.3.3 Phase 2: Developing and Testing Outcome Measures

Phase 2 of the evaluation project was to begin to understand how the center’s peer support groups benefit children and their families. From the work conducted during phase 1 of the project we learned that most families (~71%) attend only 1 session (again, 1 session equals 10 bi-weekly group nights) (see Table 1.1). Therefore, we decided that we would attempt to learn from children and caregivers who had recently attended a session what they perceived to be the benefits of attending the peer support groups. We decided to utilize focus groups to explore these perceptions since the literature had little to say about how a peer support group intervention

benefits bereaved children and families. We conducted focus groups with caregivers, adolescents and program volunteers. The themes or constructs identified through this process would then inform the development of outcome measures and an evaluation instrument.

As stated above, each of the following chapters is intended to stand alone as an independent article yet each represents a unique aspect of this comprehensive evaluation. Chapters 3 and 4 below represent the results of the focus groups and a feasibility study to pilot the evaluation instrument. The article which directly follows this section in chapter 2 below, however, contains analysis and discussion about the epidemiology of childhood bereavement and developed from the task begun at the outset of this project discussed in section 1.3.1 above.

Following the presentation of these articles will be a discussion section that will include a synthesis of what we learned from this project, the public health significance of this body of work, and suggestions for future research on childhood bereavement.

## **2.0 THE EPIDEMIOLOGY OF CHILDHOOD BEREAVEMENT**

### **2.1 ABSTRACT**

This article examines the literature to date and explores the epidemiology of childhood bereavement. Largely, published prevalence estimates of childhood bereavement have only considered parental loss. This article serves two purposes. The first is to examine the methods and data sources used to produce these estimates and critically evaluate their utility in estimating the magnitude of childhood bereavement. The second is to modify these methods and offer a new interpretation of available data. The article concludes with methodological suggestions that aim to generate academic discussion about how to calculate a more accurate prevalence estimate of childhood loss.

### **2.2 INTRODUCTION**

A chapter of an edited volume prepared in 1984 by the Institute of Medicine's Committee for the Study of Health Consequences of the Stress of Bereavement states, "It is not exactly clear how many young people are affected by the death of an immediate family member" (Krupnick 1984). Over 20 years later, it still remains unclear as to how many young people are affected by the death of an immediate family member.

Prevalence estimates of childhood bereavement published in the literature have frequently depended upon data presented in the Statistical Abstracts published by the U.S. Census Bureau. The Statistical Abstracts' annual estimates of childhood bereavement have ranged from 3.4% (1990) to 5.2% (1977). Irrespective of this variance in estimation, by the age of 18 more than 2 million American children will have experienced the loss of at least one parent or caregiver. Not included in these published figures are the numbers of children who lose a sibling or a caregiving grandparent. The exclusion of the latter is not insignificant. A recent report from the U.S. Census Bureau reported that 5.6 million children were living in households with a grandparent present while 1.27 million were living with one or more grandparents with no parent present in the household (Fields 2003).

The death of a close family member is a profound insult to the child's developmental course. Though early research assumed that childhood bereavement was a risk factor for mental and behavioral disorders in childhood and adult life (Tremblay and Israel 1998)(Harrington and Harrison 1998), this psychopathology paradigm is being traded in for an ecological view of childhood development, considering a child's exposures to risk and protective factors. Childhood bereavement compromises the emotional availability of the surviving caregiver(s) (Bifulco, Brown, and Harris 1987; Harris, Brown, and Bifulco 1986; Worden 1996) and the child's social supports (Kaffman and Elizur 1983), challenges the child's self-efficacy and self-esteem (Worden 1996), disrupts continuity in daily family life (Bifulco et al 1987)(Harris et al 1986), and inhibits open communication with the parent (Black and Urbanowicz 1987; Cohen, Dizenhuz, and Winget 1977; Raveis, Siegel, and Karus 1999); factors that may otherwise act as protective resources that prevent against risks from future stressful events (Christ, Raveis, Siegel, Karus and Christ 2005; Sandler et al. 2003).

Though many programs exist for children and families who have experienced loss, a method to accurately estimate the number of bereaved children in the United States has yet to be defined by the community of researchers and practitioners interested in meeting the needs of these children and families.

This article examines the literature to date and explores the epidemiology of childhood bereavement. While several published estimates about childhood bereavement have referred to governmental data, others have depended upon different data sources. Largely, published estimates have only considered parental loss when estimating childhood bereavement. The methods used to produce these estimates are examined and critically evaluated for their utility in understanding the magnitude of childhood bereavement. These methods are then modified, offering a new interpretation of available data. The article concludes with methodological suggestions that aim to generate academic discussion about how to calculate a more accurate prevalence estimate of childhood loss.

### **2.3 BACKGROUND**

The range of estimates presented in the literature makes clear that there is no agreed upon standard used to estimate the prevalence of parental bereavement. While estimates have ranged widely over a period of about 20 years, it is unlikely that the gross difference in these estimates is due to public health interventions that have reduced death rates so dramatically. Rather, different data sources and calculation methods account for these differences.

### 2.3.1 Early estimates

Early estimates of parental bereavement exemplify these differences. In 1979, though limiting the generalizability of the findings from their study to other high school populations, Ewalt and Perkins concluded that, “experience with death among adolescents is by no means negligible”. They found that 11% of students had lost at least one parent through death (Ewalt and Perkins 1979). Yet, the US Statistical Abstract states that, as of July 1979, there were 3,186,000 orphans or 4.9% of the child population under 18 years who had lost either one or both parents.

Ewalt and Perkins based their findings about adolescent experience with death on a survey conducted among juniors and seniors in two public high schools in Kansas City, KS. This study followed up on a previous survey study of high school students in an English elective course that found that one parent of 10% of the students had died (Perkins, Todd, and Ewalt 1978). The two schools differed slightly on demographics, most strikingly on median income; \$9,000 for school A and \$12,000 for school B, in 1979 dollars. Total sample was approximately 1448 students.\* The researchers found that 11% of students had lost a parent through death by the time of their senior year. Other findings pertinent to the discussion in this paper were that experiences with death were more frequent for seniors than juniors and 15% of the seniors at school A reported that a parent had died, higher than school B, possibly suggesting that income level mediates the experience of death in adolescence. A weakness to the study was that while the sample was racially and culturally mixed, differences within groups were not explored (Ewalt and Perkins 1979).

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\* Figure adapted from percentage and numbers displayed in article: “*Nearly 90% of students at both schools (1303)...*” Ewalt and Perkins (1979).

In an edited volume on childhood mourning published that same year, Kliman estimated that 1.5 million children will lose one or both parents by the age of 15 (Kliman 1979). In the chapter in which he stated this estimate he did not inform the reader as to what sources or method he used to calculate his estimate. Yet, the IOM publication mentioned earlier in this paper claimed Kliman had estimated that 5% of children in the US lose one or both parents by the age of 15 (Krupnick 1984). The US Census indicates that the number of children under 15 years of age in the U.S. in 1980 was approximately 51.3 million. According to this arithmetic, approximately 2.9% of children are affected by the loss of one or both parents by the age of 15. Perhaps the US Statistical Abstract estimate of 4.9% remains the most reliable estimate for 1979.

### **2.3.2 Estimates using governmental data**

*US Statistical Abstracts.* Several published national estimates of parental bereavement have depended upon figures represented in government publications. A variety of estimates have been published using the Statistical Abstracts. These estimates were culled from a table on orphans produced by the Social Security Administration (SSA). In a span of about 20 years, the same data source provides a range of estimates from slightly over 5% (1977) to 3.4% (2002). In 1983, Critelli cited the 1977 Statistical Abstract to state that 5.2% of children under the age of 18 have lost either parent by death; 3.5% paternally bereaved, 1.5% maternally, and .1% full orphans (Critelli 1983). In 1988, Masterman and Reams cite the 1986 Statistical Abstract to state that, in 1984, 3.7% of all children under the age of 18 have lost a parent by death (Masterman and Reams 1988). Recent estimates published in 2002, cite the 1990 Statistical Abstract and state that over 2 million children under the age of 18 (approximately 3.4%) experience the death of a parent (Christ, Siegel and Christ 2002; Goodman 2002).



**Table 2.1** Social Security table on orphans.

<b>NO. 613. ORPHANS, BY TYPE: 1960 TO 1988</b>								
As of January, includes Puerto Rico and Virgin Islands; beginning 1970, also includes American Samoa and Guam. Covers children under age 18 who have been orphaned at any time. Paternal orphan refers to loss of father only, maternal orphan to loss of mother only, full orphan to loss of both parents. Percent of child population based on source's estimates of number of children under 18, as of January 1. Data not exactly comparable for all years because of changes in methodology.								
Year	Number * (1000)				Percent of Child Population			
	Total	Paternal	Maternal	Full	Total	Paternal	Maternal	Full
1960.....	3,333	2,281	975	77	5.0	3.4	1.5	0.1
1970.....	3,665	2,584	1,027	75	5.0	3.5	1.4	0.1
1980.....	2,932	2,104	775	53	4.4	3.2	1.2	0.1
1985.....	2,352	1,713	606	33	3.6	2.6	0.9	0.1
1986.....	2,293	1,674	588	31	3.5	2.6	0.9	(Z)
1987.....	2,252	1,649	575	29	3.4	2.5	0.9	(Z)
1988.....	2,213	1,625	561	27	3.3	2.5	0.9	(Z)

Z: Less than .05 percent

Source: U.S. Social Security Administration, unpublished data

The table above was recreated from the table on orphans from the 1990 Statistical Abstract. A note on the table indicates that data is not exactly comparable for all years because of changes in methodology. A critical discussion of this statement as well as the published estimates derived from the Statistical Abstracts and other government data sources is provided later in this paper.

*Census Bureau.* Another data source of published national estimates of childhood loss is the Census Bureau's Current Population Survey Reports (CPS). In 1992, Silverman and Worden referred to the 1989 "Marital Status and Living Arrangements" CPS chapter and stated that 1.5 million children live in single-parent families because the other parent is dead (Silverman and Worden 1992). According to the number of children in the US as reported by Census 1990, this would estimate childhood loss at approximately 2.3%. Yet the same chapter of the 1994 CPS states that 4% of children are living with a widowed parent (Saluter 1994).

*Social Security Administration.* Yet another source of a published national estimate is the Social Security Administration based on assumptions used by the SSA to project future OASDI beneficiaries of child survivor benefits paid out by the agency to children whose parent(s) has died. Sandler et al (2003) state that data from 1997 indicated that approximately 4% of children

younger than 18 had experienced the death of their parent. The “Assumptions and Models Underlying the Actuarial Methods” section of the 2000 SSA Trustees Report indicates that the number of entitled children was developed by applying award rates to the number of orphaned children and by applying termination rates to the number of children already receiving benefits (Social Security Administration 2000).

## **2.4 STATE OF THE DATA ON CHILDHOOD BEREAVEMENT**

In order to understand the magnitude of the impact of childhood bereavement in the United States it is essential to gather the most accurate representation of the loss of an immediate family member experienced by children in the country. As presented above, there is a wide range of estimates for parental bereavement suggesting that no standardization exists for either calculating or presenting a prevalence estimate. Furthermore, the available data is limited in its own right. For cross-sectional studies, as conducted by Ewalt and Perkins, there will inevitably be concerns about the generalizeability of results and, particularly, the difficulty in securing adequate sample sizes. Additionally, one of the core functions of public health as defined by the Institute of Medicine is to monitor health status, which includes the identification of threats to health and assessment of health service needs. Survey studies of school children are likely to be impractical and inefficient for the purpose of estimating the prevalence of parental bereavement and, therefore, for assessing the needs of children and families who have suffered a loss in a timely manner.

Government data sources are necessary but insufficient to estimate parental bereavement. The US Statistical Abstracts present information that is supplied by the SSA, which has since

discontinued that particular data series on orphans (Johanson, L.B., US Census Bureau, personal communication, March 7, 2006). The children represented in the SSA table on orphans presented above are those children who have lost at least one parent and who enrolled as well as received survivor benefits. The most current information published by the SSA in the 2008 Statistical Abstract reports that 1,903,000 (approximately 2.63%) children under age 18 in 2005 had enrolled and received benefits.

The estimates of parental bereavement for children under the age of 18 that have been variously cited are actually stating the conservative estimate of children receiving survivor benefits, a subset of all children who have a parent that is deceased. Not included in this estimate is the number of children who have lost a parent employed in an occupation that did not qualify the adult employee's child(ren) to receive survivor benefits or who lost a parent but do not receive OASDI survivor benefits because she was either not enrolled or was the child of a parent that was unemployed. Perhaps a figure indicating the proportion of children who have lost an eligible parent but did not enroll for benefits would be helpful in gathering a more accurate picture about parental bereavement. Additionally, the table on orphans which had used OASDI records mentioned that data was not exactly comparable for all years because of changes in methodology. Using a method depending on current OASDI records, data suggests that only 2.63% (1,903,000) of children receive benefits. While that method does not seem to produce a percentage comparable to those in the orphan tables, it represents the most current information on bereaved children as it has previously been defined.

Primary caregivers who seek either clinical or support services for their child certainly do not only seek services for their parentally bereaved child. Rather, barring the death of peers due to violence, it seems reasonable to build into any prevalence estimate of childhood bereavement

the loss of siblings and the loss of a primary caregiver other than a parent. A report prepared from the CPS data presenting a broad picture of the characteristics of children across several domains relating to their well-being suggests that there are a significant number of grandparents serving as primary caregivers to children under 18 years of age. As of March 2002, 5.6 million children were living in households with a grandparent present and 1.27 million were living with one or more grandparents with no parent present in the household (Fields 2003). Certainly, the latter 1.27 million (approximately 2.39% of all children) children have a grandparent as their primary caregiver and would then qualify as an immediate family member. If data were available for the average age of the grandparents of these children, a death rate of that age cohort (and that rate is much higher than the death rate of a parent cohort) could be used to assess the risk of loss to the child of that primary caregiver.

Information necessary to construct a rough prevalence estimate on sibling bereavement for children under 18 is available but an estimate has yet to be reported. The discussion above served to review the literature on published estimates about parental bereavement, examine the methods used to produce these estimates, and critically evaluate what these measures mean for understanding the magnitude of childhood bereavement. It is clear that there is no standardization to either calculating or presenting a prevalence estimate for parental bereavement in children under 18, that the information available is at best limited and at worst inadequate, and that there is merit to include the loss of siblings and primary caregiving grandparents in an estimate. The case for a method to include siblings in a prevalence estimate of childhood bereavement is presented in the section below.

## 2.5 ESTIMATING SIBLING BEREAVEMENT

As of March 2002, 96% of children were living in households with one or more parent and about 80% of all children were living in households with one or more siblings (Fields 2003). To truly understand the number of bereaved children within the United States it is important to include parents as well as siblings. Excluding the deaths of peers due to violence, what follows below is a method which can be used to estimate the annual incidence of sibling bereavement. The method uses data that is widely available to the public and depends upon both death counts retrieved from CDC Wonder and the number of siblings retrieved from Current Population Survey data.

The calculation begins by using the CPS data to develop a proportional model of the number of siblings in American families (U.S. Bureau of the Census 2003). The CPS provides data on the number of siblings of children living in family households. Taking each category of siblings, from “None” to “Five or more” a proportion of family sizes with children who have 0 to 5 or more siblings is created. For example, of the 72,320,000 families with children under 18 years of age 18,436 families have 3 children (25.49%). In other words, each child in that family has two siblings. See Table 2.2 below.

**Table 2.2** Living arrangements of all children under 18: March 2004

<b>LIVING ARRANGEMENTS OF ALL CHILDREN UNDER 18: MARCH 2004</b>		
<b>C3 Table. 2002 Current Population Survey</b>		
<b>Presence of Siblings</b>	<b>Number of Siblings</b>	<b>%</b>
<b>None</b>	<b>14,693</b>	<b>0.2032</b>
<b>One sibling (2 child family)</b>	<b>28,498</b>	<b>0.3941</b>
<b>Two siblings (3 child family)</b>	<b>18,436</b>	<b>0.2549</b>
<b>Three siblings (4 child family)</b>	<b>6,965</b>	<b>0.0963</b>
<b>Four siblings (5 child family)</b>	<b>2,132</b>	<b>0.0295</b>
<b>Five or more siblings (6+ child family)</b>	<b>1,596</b>	<b>0.0221</b>
<b>Total Children (in thousands)</b>	<b>72,320</b>	<b>1.00</b>

Next, 1999-2002 CDC Wonder data on death counts is used to determine how many children die in any given year. It is worth noting here that queries to the database return age categories through 19 years of age. While this does not contaminate the estimate of family size or number of siblings above, death counts are inevitably higher when individuals 18 and 19 years of age are included than the under 18 age range typically used to calculate parental bereavement. Debate is in order to adjust the estimate due to how many individuals 18 and 19 years of age actually live in households with children under 18.

An average annual death count is presented in Table 2.3 below. This was produced by gathering the death counts for the 4 year period 99-02 and dividing by 4, assuming there are no significant differences in death rates in this age range between years.

**Table 2.3** Death counts for children under 20

<b>DATA FROM CDC WONDER 1999-2002: ALL RACES, BOTH GENDERS, UNDER 1 YEAR THROUGH 19 YEARS</b>		
<b>Ages</b>	<b>4 Yr Death Count</b>	<b>Avg. Annual Death Count</b>
<b>Under 1 Year</b>	<b>111,574</b>	<b>27,894</b>
<b>1- 4 years</b>	<b>20,193</b>	<b>5,048</b>
<b>5- 9 years</b>	<b>12,838</b>	<b>3,210</b>
<b>10-14 years</b>	<b>16,415</b>	<b>4,104</b>
<b>15-19 years</b>	<b>54,708</b>	<b>13,677</b>
<b>Total</b>	<b>215,728</b>	<b>53,932</b>

The proportions of family sizes presented in Table 2.4 are used to determine the proportion of the annual death count (53,932) that occurs by each family size. The operating assumption is that deaths in this age range are normally distributed by family size. For example, if the assumptions hold, of the 53,932 deaths 25.49% (13,748) of the 53,932 deaths are experienced by Two Sibling Families (families with 3 children).

**Table 2.4** Proportion of death count by family size.

<b>PROPORTION OF DEATH COUNT BY FAMILY SIZE</b>			
<b>Presence of Siblings</b>	<b>Proportional Family Sizes (%)</b>	<b>Death Count</b>	<b>Proportion of Death Count</b>
<b>None</b>	<b>0.2032</b>	<b>x 53,932</b>	<b>10,957</b>
<b>One sibling</b>	<b>0.3941</b>	<b>x 53,932</b>	<b>21,252</b>
<b>Two siblings</b>	<b>0.2549</b>	<b>x 53,932</b>	<b>13,748</b>
<b>Three siblings</b>	<b>0.0963</b>	<b>x 53,932</b>	<b>5,194</b>
<b>Four siblings</b>	<b>0.0295</b>	<b>x 53,932</b>	<b>1,590</b>
<b>Five or more siblings</b>	<b>0.0221</b>	<b>x 53,932</b>	<b>1,190</b>
<b>Total</b>	<b>1.0</b>	<b>-</b>	<b>53,932</b>

Finally, families with one or more siblings have living children who experience sibling bereavement when a child dies. More than one sibling is affected by the death of a child in families with 3 or more children. In Table 2.5 below, family size is built into the estimated incidence of sibling bereavement. For the proportion of children who have died in each family size I account for the number of siblings those children had. For example, the 13,748 children who died have 2 siblings, yielding 27,497 living siblings affected by the deaths of those children.

**Table 2.5** Number of siblings affected by the death of a child.

<b>NUMBER OF SIBLINGS AFFECTED BY DEATH OF A CHILD</b>			
<b>Presence of Siblings</b>	<b>Proportion of Death Count</b>	<b>Multiplicative Factor</b>	<b>Living Siblings Affected</b>
<b>None</b>	<b>10,957</b>	<b>x 0</b>	<b>0</b>
<b>One sibling</b>	<b>21,252</b>	<b>x 1</b>	<b>21252</b>
<b>Two siblings</b>	<b>13,748</b>	<b>x 2</b>	<b>27497</b>
<b>Three siblings</b>	<b>5,194</b>	<b>x 3</b>	<b>15582</b>
<b>Four siblings</b>	<b>1,590</b>	<b>x 4</b>	<b>6360</b>
<b>Five or more siblings</b>	<b>1,190</b>	<b>x 5</b>	<b>5951</b>
<b>Total Children (in thousands)</b>	<b>53,932</b>	<b>-</b>	<b>76642</b>

## 2.6 DISCUSSION

This estimate methodology provides a rough annual estimate of the incidence of sibling bereavement. A total of 76,642 children are affected nationally each year by the original number

of children who die in this age range (53,932). This suggests that for each child who dies 1.42 siblings are affected annually, approximating a ratio of 2:3. To any estimate of childhood bereavement this method could add approximately .11%, a rather modest, but by no means negligible, adjustment to conventional estimates of childhood bereavement that only captures parental loss. Any adjustment should be considered an underestimate since prevalence would include the cumulative number of children who have experienced parental or sibling bereavement in a given year.

Several weaknesses are evident with this methodology though the operating assumptions used to calculate the estimate are reasonable. It was assumed that there are no significant differences in death rates in the age range between years and that deaths in this age range are normally distributed by family size. Also, as mentioned above, debate is certainly in order to adjust the estimate due to how many individuals 18 and 19 years of age actually live in households with children under 18.

## **2.7 CONCLUSION**

This article examined the literature and explored the epidemiology of childhood bereavement. Largely, published estimates have only considered parental loss when estimating childhood bereavement. A critical evaluation of the methods used to produce prevalence estimates suggests that available data can only serve to approximate an estimate. This article has also shown that there is no standardization to either calculating or presenting a prevalence estimate for parental bereavement in children under 18. Certainly, a discussion amongst researchers is warranted on this matter.



While OASDI child survivor benefits appear to provide the most accurate estimates of parental bereavement, these estimates could be informed through periodic supplemental surveys. One survey could be used to estimate the number of children who are eligible for OASDI benefits but do not enroll to receive benefits. Like the children included in the Statistical Abstracts, these children also represent the pool of children who are parentally bereaved. Another survey, perhaps a modification of the Current Population Survey, could be used to gather information about the age of grandparents serving as a primary caregiver. Information about the age of this cohort would permit the calculation of a death rate, and, therefore, a third contributor to an estimate of childhood bereavement. Both of these approaches would supplement existing data.

This article also offered a method to roughly estimate the incidence of sibling bereavement each year using available data. The resulting conclusion suggests that any estimate of childhood bereavement can be positively adjusted approximately .11% due to sibling bereavement. Adding the 76,642 children who experience sibling bereavement (table 4 above) to the 1,903,000 children receiving OASDI survivor benefits in 2005, a prevalence estimate for childhood bereavement would be adjusted from 2.63% (parent only) to 2.74% (parent or sibling).

A concluding question remains to be answered: Should not childhood bereavement be explicitly and formally defined as a child's state of loss following the death of an immediate family member; be that a parent, sibling, or grandparent who is a primary caregiver?

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### **3.0 WHAT DO PEER SUPPORT GROUPS OFFER BEREAVED FAMILIES? USING FOCUS GROUPS TO IDENTIFY EVALUATION CONSTRUCTS**

#### **3.1 ABSTRACT**

This study used focus groups to explore the perceived benefits of attending peer support groups among bereaved adults and adolescents. One focus group was held with each group. Focus group data was analyzed for themes. These themes were then translated into constructs to be used to guide an outcomes evaluation. In this study, the results of the focus groups suggest that perceived social support, universality, caregiver-child warmth and communication, and coping are constructs that are relevant to the study of how peer support groups impact bereaved families.

#### **3.2 INTRODUCTION**

This study used focus groups to explore the perceived benefits of attending peer support groups among caregivers and teens who had attended a spring session at a center for grieving children in their families based in western Pennsylvania. Results from the focus groups are organized into themes. Discussion then follows to compare these themes from caregiver and adolescent focus groups and translate them into constructs which can then be measured.

The rationale for the use of focus groups stems from the literature on childhood bereavement. Early research focused on the increased risk of depression and other psychiatric disorders during adulthood among individuals who were bereaved as children (Tremblay and Israel 1998). Recent reviews of research on childhood bereavement have called for molecular analysis of grief processes, such as grief-related interactions between parents and children, rather than rates of presence or absence of psychiatric disorders as objects of study (Dowdney 2000; Tremblay and Israel 1998). Therefore, using focus groups to learn from bereaved children and adults the perceived benefits of attending peer support groups can increase the validity of constructs and, ultimately, the results of an outcomes evaluation of peer support groups.

### **3.2.1 Child-centered Family-based Peer Support**

A brief introduction to the service model will serve to orient the reader to the services the center provides and the object of the evaluation. In its family services guide, the center states that its central goal is to have the children and adults express their grief in an atmosphere of acceptance and trust. According to the stated aims of its service model, the center facilitates peer support to allow children to help one another cope and to decrease the stigma or the child's perception that she is the only one experiencing grief. One of the aims of the program, therefore, is to help children by facilitating the modification of individual level variables.

The center states that it serves families because the family is adjusting to new roles, that parents and caregivers are supported in their grief so that they may be able to be emotionally available to their children, and that grief work [sic] happens within the family. Another aim of the program, then, is to help children by facilitating the modification of family or social-environmental variables.

After an initial phone call and screening, families visit the center for an initial orientation session. Thereafter, families visit the center for 10 bi-weekly group nights. Families arrive in the evening, spend a half-hour in a common room eating a meal with staff, volunteers, and other families, then children, teens and adults each meet in separate group sessions for approximately one hour. Group sessions are led by trained volunteer group facilitators. Families then reunite in the common room and leave for the evening.

### **3.3 METHODS**

#### **3.3.1 Purpose for focus group method**

Nearly twenty years ago, Greene, Caracelli, and Graham argued that mixed-method evaluation designs could be used to serve purposes beyond triangulation and they aimed to develop a conceptual model that could inform and provide for a more defensible mixed-method evaluative approach (1989). From a review of the literature on mixed-method evaluation, these authors proposed five purposes for mixing-methods: triangulation, complementarity, development, initiation and expansion (Greene et al. 1989). The development purpose was of interest for the present study. This purpose for mixing methods was conceived as using the results from one method to help develop or inform the other method to increase the validity of constructs and inquiry results by capitalizing on inherent method strengths (Greene et al. 1989). This study utilized focus groups in order to inform the conceptualization and development of outcome measures.

### **3.3.2 Setting**

One focus group each was conducted with caregivers and teens at the center's northwestern Pennsylvania site.

### **3.3.3 *Participants and Recruitment***

After a series of evaluation planning meetings with the program managers and the program director, these staff decided that the family services coordinator at the site would be best to recruit participants and coordinate focus groups with family members because of the established relationship she had with family members. The family services coordinator was asked to purposively select families whose members could articulate well the benefits of attending peer support groups. Selection criteria were caregivers of children under the age of 14 who participated in the program and were between 6 months to 1 year out of the program, adolescents who participated in teen groups and had recently finished a session, and program volunteers. All family members had completed only 1 introductory session (10 bi-weekly group nights). No other exclusionary criteria were applied.

The family services coordinator telephoned families who had recently completed the spring support group session. Caregivers were informed that the center wished to hold focus groups with adults and children who had attended support groups in order learn about what they had gained from attending the support groups. A small incentive was offered for participation.

Five caregivers (ranging in age from late-30's to mid-50's) and 7 teens (ages 13-18) participated.

### **3.3.4 Procedures and Data Collection**

Participants were asked to arrive approximately 15-20 minutes prior to the scheduled start of the focus group to sign-in and allow time to eat. The focus group facilitator began by reading an introductory script welcoming participants, explaining why the focus groups were being conducted, offering to answer any questions, and explaining ground rules. The family services coordinator served as note taker throughout the focus groups with caregivers and teens while the volunteer services coordinator served as note taker for the volunteer focus group. Focus groups were audio recorded and then transcribed for analysis. This study was approved as exempt by the Institutional Review Board of the University of Pittsburgh.

Interview Guides (presented below) were used to guide each focus group discussion:

#### **Caregiver Group**

1. When you decided to enroll your family in the Center, what did you expect your family would gain from participating in the program?
2. What was it like for you as an individual to participate in the parent group?
3. What did your family [child] learn from participating in the program?
4. What changes have you observed in your child(Speece and Brent)?
5. What is important about being with other families who have also experienced loss?
6. How does the Center help families who grieve the loss of a family member?
7. How do you think your family would be now if you did not come to the Center?
8. What changes occurring in your family after the loss were not affected by the Center?

#### **Adolescent Group**

1. What did you expect your family would gain from participating in the program?
2. What was it like for you to participate in the teen group?
3. What did you learn from participating in the program?
4. What is important about being with other teens your age that have also experienced loss?
5. How does the Center help families who grieve the loss of a family member?
6. How do you think you would be now if you did not come to the Center?
7. What was the Center unable to help you or your family with after the loss?

*Analysis.* Analysis of focus group data followed a systematic procedure which included transcribing, coding, sorting, and integrating (Weiss 1993). Each focus group was transcribed



into a digital Word file. Upon initial reading of the texts, benefits to program enrollment as expressed by participants were coded as emerging themes. These codings were also compared to notes on emerging themes and group processes as observed by the note taker during the focus group. Codings were modified on subsequent readings of the text and were then sorted into separate files by topical unit. Integrating the variety of responses was achieved through summarizing the codings and grouping themes. Careful attention was paid to interpersonal processes, so as to distinguish between individual opinions and group consensus, and variant responses were noted (Kitzinger 1995).

### **3.4 FOCUS GROUPS**

Interpretations grounded in the transcriptions of the focus groups are described in this section. Themes from each focus group important to the development of summative evaluation measures are described below. The discussion section that follows will compare these themes from caregiver and adolescent focus groups and attempt to translate them into constructs which can then be measured.

#### **3.4.1 Adolescents**

##### ***“It’s a good place to talk about it”***

There seemed to be a variety of reasons expressed in the focus group as to why the Center is a good place for teens to talk about grief. The Center was distinguished from other

places. One girl explained how “*you can’t really talk about it*” just anywhere, that the Center “*helps everybody to talk about it more*”, and that the center creates a place where “*you can actually talk about it*”. At the Center, people understand and will not make insensitive comments. Two teens explained how other teens at school do not understand what they are going through and how some make insensitive comments. When the focus group facilitator reflected these comments about how the Center is different from the mall or school the note taker made a note that all agreed.

The Center is a good place to talk about it because people “*didn’t want to just keep jabbing at you about how you felt*” and “*they didn’t like force you to do anything you didn’t really want to do*”. Teens in the group seemed to appreciate the uniqueness of a place where talking about grief is on an individual’s terms and no one is “*jabbing*” or probing about feelings. One girl explained how her teacher, who was aware her father had died, angered and upset her by including her in a class activity to make a Father’s Day gift. Perhaps the teacher was attempting to ‘help’ her student by encouraging her to deal with it. Clearly, the student did not appreciate this imposition.

Realizing that one is not alone in his grief seems to be an important role the Center plays in the healing process for teens. At a developmental stage when an individual is attempting establish his or her individual identity outside of the family, peers play a significant role in identity formation. Being around other teens who are “*dealing with the same stuff*” was described as comforting. One girl explained that before coming to the center she knew, cognitively, that there were other people who have gone through a similar experience but still felt alone, that no one else knew what she was going through. She stated that she “*didn’t have anybody else except my family but sometimes you don’t wanna talk to your family*”. A boy

explained that if it were not for the warm environment at the Center “*you kinda feel like you’re secluded and everybody else is different and that’ll make you feel shy*”. Another girl explained how “*we’re growing up, we’re starting like the next stages of our lives and it’s just difficult because like this is the time when I could talk to my dad about stuff and like he’s not here and I know she [referring to her friend in the focus group] feels the same way about her mom*”. The note taker observed that all heads were nodding in agreement after this statement, suggesting that a teen does not feel different and secluded at the center since other teens share a similar identity; each has lost a family member.

***“You can help other people and they can help you”***

Collectively, teens can help one another while, independently, an individual teen may be struggling to manage very strong feelings. The poignant statement above was expressed by a girl in the focus group and it seemed to summarize what many of the group members had expressed regarding one of the benefits of attending peer support groups as evidenced by affirming gestures by other teens in group. It was preceded by “*you don’t have to keep helping yourself*”.

Two girls stated similarly how others in the group helped them to communicate their anger. The girl who was angered when her teacher included her in a class activity to make a Father’s Day gift explained how angry and shocked she was at her teacher’s behavior until she visited the Center. There she was able to speak to a girl with whom she had made friends and with “*people that understand*”. She stated how others in group acknowledged her anger and helped her to process this anger in communion. Another girl described how she felt a great deal of anger regarding the unjustly death of her father. She said that the Center helped her to “*have peace with the situation*”. Both girls’ stories reveal the emotional transformation gained through processing their grief experiences and emotions with peers.

Two girls explained how they attempted to offer their support to a boy in their group whose mother had committed suicide. They said they tried to “*be there for him*” by reassuring him and being “*the friend for him to talk to*” when he was struggling with feelings of guilt. While “*sometimes he tried to still keep to himself*”, they both said that he knew their support was available to him. Expressions like these suggest how adolescents attempt to provide support to one another during groups.

Yet there is a corollary to how peers support one another. For children who have experienced a parental suicide there is a slightly different context. Two girls who had lost a parent (one lost her mother and the other a father) described how they attempted to comfort another boy in their group whose parent committed suicide. They described how his reception of this support varied from being receptive and starting to talk about it to saying “*I’m fine*” and behaving in a way they described as “*macho*”. Perhaps similar to this boy’s occasional response to peer support, another girl in group whose father also committed suicide had indicated that she wished she could have talked more about what had happened and that she had others in her group who had also experienced a suicide.

*“... it can be different than something like passing away in a different way and like sometimes people don’t know how to help you. And even if they had a parent or a family member die...they don’t understand what it’s like when someone commits suicide and I just wish that there were other people like in my group that went through the same thing”.*

This suggests that children who have experienced a parental suicide feel an additional dimension of grief such that even other children who are parentally bereaved cannot fully understand and therefore do not completely share this identity. Not all deaths are the same and the peer support process may work differently for children whose parent committed suicide.

### ***“She just kinda carried it home”***

A few teens in the group suggested that family communication patterns change as a result of the peer support groups. One girl explained that before the Center she felt as though her mother was having a difficult time and did not want to bother her. She then stated that, currently, she and her mom talk more about everything. This change in communication with her mother resulted from the support she was similarly experiencing in the teen groups. Another girl directly followed up on this comment when prompted by the facilitator and described a similar change in her family.

*“Oh, I think its cause she had that [referring to growing comfortable with sharing feelings of about the loss with others] here too. She could talk about it openly with other people and then she just kinda carried it home”*

*“OK DOES THAT RESONATE FOR ANYONE ELSE?”*

*“That’s like almost like the same thing with my mom and me ‘cause my dad died of cancer to and um we talk about it like more”*

This communication process may be carried home in yet another way. A boy stated that the Center helps *“families realize what’s going on in each family member’s own mind and let’s them know how each one has to be treated”*. In a family, processing one’s grief includes considering the needs of another family member.

### **3.4.2 Caregivers/Parents**

***“...if I wanted to I could walk around in my underwear, not literally, but to have that freedom if you wanted to”***

This statement seemed to capture to the depth of the relief parents said they felt at the Center and many in this focus group, while laughing, were gesturing in agreement with the statement. Throughout this discussion parents reported a feeling of safety, and two described it

as freedom to be able to laugh or cry but also feeling, *“I don’t have to cry. I don’t have to laugh. I don’t have to do anything”*. The Center was a place where a parent could just be with her grief.

The relief that the Center offered to these bereaved adults came in a variety of forms. As a surviving adult family member, *“the burden becomes kind of just on you to be the strength...to be the pillar for everybody else”*. The note taker observed several heads nodding as this mother was speaking. Another parent described how sometimes she, herself, would console other family members who would call or visit. *“You don’t have any of that stuff going on in these rooms...it’s a relief”*. In addition to grieving, the surviving parent also must maintain the responsibilities of the household. Dinner seemed to be an important part of the program structure for parents. A father said that he *“didn’t have to cook on Wednesdays”*. A mother said:

*“it was just a relief just to come in, play some cards and have a pizza and the kids would play in the rooms up there and do their project and, just for a minute it, was just nice to step back and think about it and not have to worry about anybody else”*.

The discussion seemed to suggest that the program provided some degree of respite for the surviving parent giving her the opportunity to focus on her own grieving.

Connecting with other people who are in the same situation was also described as a relief. All appeared to express relief in recognizing that they were not alone in their grief, expressing common experiences and feelings, and sharing suggestions with one another. Two parents were in agreement that they were relieved to learn that other parents *“are worse than I am”*, and several heads were nodding in agreement as one spoke. This feeling was qualified by one parent- *“it didn’t make me feel good”*- but both expressed relief in learning to place their grief in context and appreciate their unique situation. In addition to the relief through learning about others’ experiences, parents expressed something akin to relief in having the Center to rely upon in the community.

Comments throughout the discussion illustrated parents' concerns prior to enrolling and how the Center provided a place to turn. One mother stated that she had three different aged kids who were all processing their father's death differently and that she did not know how to help any one of them because she was not *"doing too well"* herself. *"I just don't have a clue and I need help"*. Another mother mentioned that she called the Center in anticipation of the death of her husband, for whom her son was providing some care, so that her son could have the *"opportunity to be with kids and be a kid and not have to be an adult with the really scary responsibility for anyone, let alone a kid"*. Another mother said she called *"out of desperation"*, wondering what to do with her *"angry little child"* until the fall session begins in a few months (there are no peer support groups in the summer months). For his teenage daughter, a father explained how he thought the Center would *"open her a little bit"* since she was close with her mother and how *"it's kinda hard to talk with dad"* about certain things at her age. All of these adults seemed to have realized their limits as parents and turned to this resource in the community.

***"...here where nobody's a teacher but we learn to communicate about death"***

The group support process is unique in that *"just the people who kinda know what they're feeling are the one's that we're gonna be learning from"*. The quote seemed to capture a process described throughout the focus group whereby being with others provides an opportunity to learn from and with others. Another mother responded to this comment by contrasting all the counseling she had been in with her adopted son prior to his mother's death with the group process; it *"never would have prepared us and still [hasn't] touched on any of that...the way this place did"*.

There are several things that parents gain in the groups that help them to parent through the grief process. The group process helps to dereflect one's grief and focus on another's grief. One mother noticed a parallel process between her and her child's experience in the group. She recognized that she was "*self-absorbed*". Being with other adults also experiencing grief "*I suddenly was not, you know, I was feeling for them*". Through communicating in group she was able to examine her grief in the context of others' grief and empathize with them. She and another mother also noticed this process occurring in their sons through the groups. Statements like, "*Suddenly it wasn't all about (her son) anymore, you know*" and "*It did my heart good to see him worrying about somebody else*" described what parents were experiencing directly and also observing in their children. Perhaps as parents process grief with others they are able to recognize their children are doing the same, decreasing their worries about the child's well-being.

Parents support each other by sharing tips and suggestions with one another. "*You see other people's point of view*". Examples of this ranged from things in everyday life, like a mother learning in groups about plumbing problems which her husband used to manage for the household, to having to deal with the holidays.

*"... I didn't want them to suffer, didn't have tree, just like how do you do this...everybody had a first Christmas that they had to get through it was just incredible to be able to get ideas and thoughts and expectations, too, like, you know, this happened and it might happen with you".*

An example of this support appeared during the focus group. One mother was questioning why she had such a difficult time getting her son to want to come to the Center each week. She wondered if he was "*just pushing my buttons*" and another mother later in the group offered that maybe he resisted coming because he was having a good day and did not want to talk about sadness. The first mother replied with a look on her face as if testifying for this feature of the



group process, *“I never thought of that”*. She might have used that information in a way that resulted in decreased parent-child conflict.

In addition to tips and suggestions, adults share parenting skills with one another. Learning what to expect about their child’s behavior a parent can more confidently parent their child through grief. One mother explained how the death of a parent is such a significant event in a child’s life and, about his reactions:

*“...you don’t know, is that ok? Is that normal? Should I be worried about that?...[y]ou just don’t know what to expect and it’s nice to have other parents giving you know their uh experiences so that when you’re watching your kid do these crazy things... you feel like ok this is normal...a natural reaction”*.

She described how, in her group, another mother had shared with her that her son had behaved in a similar way, putting the worried mother at ease. Several other parents in the focus group were chiming in saying ‘yeah’ and beginning dyadic conversations reflecting this mother’s story, suggesting that she was describing a common experience among parents in the adult groups. The mother continued and explained how this helped her to not become overbearing with her child, something she said did not want to do as a parent.

Parents support one another emotionally so that they may be able to more effectively parent their child. One mother explained *“I feel a little better now. I can make it through the next week till we come back here”*. Another described how she could share her frustrations so that *“when you leave here you sorta can set that a little bit aside ...uplifted so that you can you can deal more appropriately with those children”*.

The group process allows parents to place their grief in context with others’ grief, share suggestions with one another about parenting during grief, anticipate their child’s behaviors, and to compartmentalize their individual grief with other grieving adults resulting in feeling more

emotionally capable of effectively parenting their child. Perhaps all of this serves to give parents the confidence to begin speaking with their children about death.

***“I did better than I thought I was gonna do”***

A clear theme in this focus group was that attending the Center resulted in parents and children communicating about death, for which most of the parents were explicitly thankful. Prior to coming, parents explained that there were a number of barriers to parent-child communication. *“I wouldn’t know if I was saying the right thing, making it worse or making it better, I wouldn’t have known”* or, *“You don’t want to put on the kids your pain and the kids don’t wanna talk to you about it cause they’re, like you said, afraid that you’re gonna start crying”* were statements shared during the discussion. Other parents seemed to be in agreement with comments like these through gestures or uh-huh’s.

Parents and children begin to communicate about death through the process of attending groups at the Center. Each of the parents were nodding their heads and three made explicit statements in agreement with the process described by one mother about the process of being able to communicate with her son. Though her son was nine years old at the time of the group other parents whose children are different ages were in agreement with her about this process. This mother explained that after a group night it was a way for her to communicate with him. She said that they would talk about their evening at the Center, about what they heard another say, about what that person might have felt, and about what project he made that night. It served as an opportunity to communicate about death. This mother explained later in the group how she told her son *“I said it’s ok if I cry, you know...I told him I like to cry”*, communicating directly with him about her personal grief response.

Communicating about death after a group night is particularly noteworthy since all but one of the parents in the group agreed with one mother who explained how difficult it was to get her twelve year old son to group each Tuesday. Coming to the Center is much different than leaving the Center. *“Ten weeks I fought my kid tooth and nail...But once he was here, like you said, he walked in the door his whole demeanor changed, he was happy, he played with the other kids...”*. Others described the mood prior to a group night as a tension or as nervousness but agreed that this is resolved by the time group ends.

### ***Life-skills and coping-skills***

Parents perceive that they are teaching their children life-skills through the opportunities created through the Center. All parents gestured in agreement when one mother mentioned that her son was learning a life-skill. This term appeared a few more times during the focus group. *“Well, it’s like a life-skill that you discuss with them because he brings home things from school... we’re teaching him how to cope and showing them that we can cope...”* Another mother agreed that you teach your children that you can cope, *“You can move, you can live, you can you know you can smile again.... our life isn’t over and we need to make the best of our time too, yeah, and teach’em some life-skills”*. A father responded to this latter comment about how his children were learning to cope through talking with other children their age.

Towards the end of the focus group, a mother made a point to say that the events that go on at the Center are a great help. *“...it sort of equates with happiness...You can go somewhere outside these walls, you can laugh and carry on and maybe not talk about your loved one at all and just have a good time”*. Several other parents followed and gave examples of enjoyable events they attended with their children, suggesting that another life-skill that families gain from

attending the center's support groups is that learning to enjoy one another again is part of the healing process.

### **3.5 DISCUSSION**

The aim of this section is to translate the themes presented from caregiver and adolescent focus groups into constructs which can then be measured. As stated above, the rationale to use focus groups stems from the literature on childhood bereavement which has suggested the study of grief processes rather than psychiatric disorders ((Tremblay, 1998 #14)(Dowdney 2000). Using focus groups to learn from bereaved children and adults the perceived benefits of attending peer support groups increases the validity of constructs and results of an outcomes evaluation. In this study, the results of the focus groups suggest that perceived social support, universality, caregiver-child warmth and communication, and coping are constructs that are relevant to the study of how peer support groups impact bereaved families.

#### **3.5.1 Social Support**

A number of researchers have suggested that the perception of supportive relationships buffers the effect of stressful events (Kaffman and Elizur 1983; Sandler 2001). The center's peer support groups fostered social support to reduce feelings of isolation, alienation, and loneliness among family members. Focus group data suggested that both parents and adolescents gained multiple dimensions of support through the groups. Adolescents expressed that they learn to process emotions in communion with others their age and that "you can help other people and

they can help you”. Adults expressed that, with others, they learn to place their grief in context and appreciate their unique situation and that the program structure gave them the opportunity to grieve and get respite from the responsibilities that come with being the surviving parent. Additionally, the center provided institutional support in that it provided a place to turn in the community.

### **3.5.2 Universality**

Irvin Yalom, a major figure in group therapy practice and research, acknowledged identified 11 primary “therapeutic factors” that are involved in the therapeutic experience but rarely operate independently from one another (Yalom 1995). One that operates uniquely in groups is what he termed universality. He finds that, especially in the early stages of group, the disconfirmation of a patient’s feelings of uniqueness is a powerful source of relief (Yalom 1995). While Yalom was strictly speaking of group therapy with clinical populations, it is not inconceivable that a similar ‘therapeutic factors’ could operate during the peer support group process.

Family members in peer support groups appear to experience the healing factor of universality. Among adults, all appeared to express relief in recognizing that they were not alone in their grief and excitement that, *“just the people who kinda know what they’re feeling are the one’s that we’re gonna be learning from”*. Several expressed their satisfaction that their children were in groups with other children who had similar experiences. Among adolescents, occasions of consensus development around the uniqueness of the center as “a good place to talk about it” suggests that a teen does not feel different and secluded at the center since other teens share a similar identity.

For adolescents, however, the manner in which a care giving adult or parent dies seems to modify the degree of perceived support. The girl whose father had committed suicide mentioned how she felt a layer of difference between her experience and that of others her age who did not experience a suicide. This suggests that children who have experienced a parental suicide feel an additional layer of grief such that even other children who are parentally bereaved cannot fully understand and therefore do not completely share this identity.

### **3.5.3 Parent-child Communication**

Much research on bereaved children has stressed the importance of open communication between the surviving parent and the child (Black and Urbanowicz 1987; Cohen, Dizenhuz, and Winget 1977; Raveis, Siegel, and Karus 1999). Focus group data suggested that peer support groups improved parent-child communication. Comparing the data between adult and adolescent groups suggests that this is an important benefit of attending peers support groups. Both claimed that, prior to groups, communication was somewhat awkward; adolescents explained how they did not want to make their parents worse and adults explained how they were unsure whether talking about grief would make the situation worse. After attending groups, adults described how the activities at the center became an opportunity to talk about what happened at group and about others' experiences. Adolescents described a process of how "*she just kinda carried it home*" as a result of the parent's peer support group experience. It is also plausible that better communication between parent and child also leads to an improved parent-child bond.

### **3.5.4 Parent-child Warmth**

Research has provided overwhelming evidence that a positive warm relationship with the parents following divorce or parental death predicts lower levels of mental health problems for children (Sandler 2001). Warmth and support in the parent-child relationship can be measured through expressions of love and affection, positive involvement, responsiveness, and a lack of rejection or hostility (Schulderman and Schulderman 1970). One could imagine a bereaved parent so emotionally distressed that an otherwise benign child behavior could ignite parent-child conflict. Yet, in the focus group, adults described how the sharing of experiences, tips and suggestions allowed them to support one another so that they may be more emotionally capable of parenting their child through grief, minimizing rejection or hostility. Adults explained how they learned to be responsive to their child and not dismiss or punish their child for strange behaviors. Adults also described positive involvements such as how the program structure allowed families to learn how to have fun and enjoy one another again. The results of the focus groups strongly suggest that peer support groups encourage parent-child warmth.

### **3.5.5 Coping**

Coping efficacy is defined as a global belief that one can deal both with the demands made and the emotions aroused by a situation, including the belief that one has dealt well with stressors in the past and can deal effectively with stressors in the future (Sandler 2000). Bandura describes coping efficacy as a specific instance of the broader construct of self-efficacy (1997). Adolescents explained how others in their support groups helped them to communicate their anger and resolve their stressor. Processing grief experiences and emotions with others can teach

a young person how to handle challenging situations that stem from the death of a family member. Learning that this helped you to “*have peace with the situation*” could encourage a coping skill like this in the future. Adults also perceived that their children were learning coping skills in the support groups - “*we’re teaching [them] to cope and showing them that we can cope*”. Focus group data suggest that peer support groups impart coping efficacy for bereaved children, if not concrete coping skills as well.

### 3.6 CONCLUSION

This study attempted to demonstrate the utility of using focus groups to learn from bereaved children and adults the perceived benefits of attending peer support groups. Focus group data suggested that families who attended peer support groups experienced improved parent-child communication, parent-child warmth, coping, and a healing effect when they realize their grief is not unique. Data also suggested that perceived social support in peer support groups reduced feelings of isolation and alienation among family members. Focus groups were an extremely useful method to develop evaluation constructs as expressed by beneficiaries of the center’s peer support groups, however, until they are tested quantitatively construct validity will remain a question.

A recommendation for any future work with this population would be to consider that the needs of children who have lost a parent to suicide or other traumatic cause of death may be quite different than the losses of other children.



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## **4.0 DO PEER SUPPORT PROGRAMS PROMOTE RESILIENCE IN BEREAVED CHILDREN?**

### **4.1 ABSTRACT**

This article represents a feasibility study to pilot an outcomes evaluation instrument for a child-centered family-based peer support program for bereaved children. Contextual resilience has emerged as an empirically supported theoretical framework to understand the impact of interventions for bereaved children. Whereas previous work has applied the theoretical framework to a cognitive behavioral intervention, this study seeks to extend this framework to a peer support program. The study involved 30 families, 35 adults, and 38 children who attended the spring 2007 sessions at a center for grieving children and their families in Pennsylvania. Results suggest that peer support programs can improve children's coping efficacy while helping to improve their caregivers' perception of social support; the program improved both children and caregivers' sense that they are not alone in their grief.

### **4.2 INTRODUCTION**

The death of a close family member is a profound insult to the child's developmental course. Though early research assumed that childhood bereavement was a risk factor for mental

and behavioral disorders in childhood and adult life (Harrington and Harrison 1998; Tremblay and Israel 1998), this psychopathology paradigm is being traded in for an ecological view of childhood development, considering a child's exposures to risk and protective factors. Childhood bereavement can compromise the emotional availability of the surviving caregiver (Zimet, Dahlem, Zimet, and Farley) (Bifulco, Brown, and Harris 1987; Harris, Brown, and Bifulco 1986; Worden 1996) and the child's social supports (Kaffman and Elizur 1983), challenge the child's self-efficacy and self-esteem (Worden 1996), disrupt continuity in daily family life (Bifulco et al. 1987; Harris et al. 1986), and inhibit open communication with the parent (Black and Urbanowicz 1987; Cohen, Dizenhuz, and Winget 1977; Raveis, Siegel, and Karus 1999); factors that may otherwise act as protective resources that prevent against risks from future stressful events (Christ, Raveis, Siegel, Karus, and Christ 2005; Sandler et al. 2003).

A recent literature review claimed that the lack of a coherent conceptual research framework designed to test hypotheses of clinical relevance has hampered the development of systematic and satisfactory research on the impact of childhood bereavement (Dowdney 2000). Sandler and colleagues at the Prevention Research Center at Arizona State University have pioneered the application of resilience theory to the study of childhood bereavement. They developed and tested a cognitive-behavioral intervention designed to modify known mediators of positive mental health outcomes for children who have suffered a major loss (Sandler, Ayers, and Romer 2002). This randomized intervention study has bolstered the empirical validity of the theoretical framework of contextual resilience (Kwok et al. 2005; Lin, Sandler, Ayers, Wolchik, and Luecken 2004). In order to build systematic and satisfactory research about the impact of childhood bereavement, it is necessary for investigators to conduct research within the theoretical framework of contextual resilience.

This study was designed to observe outcomes and seeks to extend resilience theory by piloting an outcomes evaluation instrument for a child-centered family-based peer support program at a center for bereaved children in Pennsylvania. It was a feasibility study that would help to determine whether to proceed with a formal evaluation. The process of conducting this study was guided by the principles of utilization focused evaluation (Patton 1997). The center was interested in identifying program outcomes to be used in community outreach efforts to highlight the potential benefits a prospective enrollee may expect from attending its peer support programs. Therefore, in what follows below, every effort was made to include key staff in the methods and study design to ensure that this work was both practical and useful for that purpose.

#### **4.2.1 Theoretical Framework**

Resilience in children is defined as the achievement of positive developmental outcomes and avoidance of maladaptive outcomes under significantly adverse conditions (Wyman et al. 1999). An adverse condition is defined as a relation between children and their environments that threatens the satisfaction of basic human needs and goals (e.g. need for esteem, social connectedness, and control) and impedes the accomplishment of age appropriate developmental tasks (Sandler 2001). Bereavement, an adverse condition, may affect the child's self-esteem, his parental and peer relationships, and the perception of his ability to control the environment around him, all of which are essential for accomplishing age appropriate developmental tasks.

The theoretical framework of contextual resilience developed by Sandler and colleagues, and that which was used for this study, rests on three propositions: that the effects of adversities on children's functioning can be accounted for by how well they adapt to the disruptions and restructuring of their environments after the death, that both positive and problem outcomes are

of concern, and that resilience is determined by multiple risk and protective factors (Sandler et al. In press). Risk and protective factors operate on multiple ecological levels (at both the individual- and social-level) and affect children differently over time. Certain factors pose risks to the child (e.g. limited emotional availability of surviving caregiver) while others (e.g. positive sense of self) protect the child from the adverse effects of a stressor such as the loss of a family member.

Through a cognitive-behavioral intervention, Sandler and colleagues targeted certain risk and protective factors for change based on evidence of their association with child mental health outcomes (Sandler et al. 2003). Modifying these known factors can minimize their adverse effects, protect the child against future adversities, and promote resilience. In this study, we seek to identify whether a peer support program can modify factors that are known to be associated with child mental health outcomes and promote resilience.

#### **4.2.2 Contributions of the Current Study**

This study offers several contributions to the literature on childhood bereavement. It extends the application of the contextual resilience model. Childhood bereavement research has been hampered by the lack of a coherent conceptual research framework designed to test hypotheses of clinical relevance (Dowdney 2000). Previous research designed and tested a cognitive behavioral intervention to promote resilience in bereaved children, whereas this study will apply the theoretical framework to the evaluation of a peer-support program. Although research has shown that social support is important for positive health related outcomes, the significance of this consistent finding is waning because researchers have not shown that health outcomes can be modified through social support (Hupcey 1998). While this study will not

investigate the relationship between peer support and health outcomes directly, it will examine whether peer support modifies factors known to be associated with child mental health outcomes. If peer support promotes resilience, then peer support may help to minimize adverse mental health outcomes in bereaved children. This study will contribute to social support research by assess the feasibility and utility of using the contextual resilience framework by examining the link between peer support and mental health outcomes.

### **4.3 BACKGROUND**

#### **4.3.1 Child-centered Family-based Peer Support**

This study was conducted with a center for grieving children and their families based in western Pennsylvania. The center states that its central goal is to have the children and adults express their grief in an atmosphere of acceptance and trust. According to the stated aims of its service model, the center facilitates peer support to allow children to help one another cope and to decrease the stigma or the child's perception that she is the only one experiencing grief. One of the aims of the program, therefore, is to help children by facilitating the modification of individual level variables.

The center's mission states that it serves families because 'grief work' happens within the family. As a result of a family member's death, family members must adjust to new roles and parents and caregivers are supported in their grief so that they may be able to be emotionally available to their children. Another aim of the program, then, is to help children by facilitating the modification of family or social-environmental variables. Additionally, the program screens

families prior to enrollment to determine whether the family is appropriate and can benefit from a level of a non-clinical service such as peer support. Families whose members warrant mental health or drug/alcohol treatment referral may not be appropriate for peer support services and are referred to appropriate services in the community.

Families learn about the center through referrals from local schools, funeral homes, healthcare professionals or advertisements. After an initial phone call and screening, families visit the center for an initial orientation session. Thereafter, families visit the center for 10 bi-monthly family nights. Families arrive in the evening, spend a half-hour in a common room eating a meal with staff, volunteers, and other families, then children, teens and adults meet in separate group sessions for approximately one-hour. Group sessions are led by trained volunteer group facilitators. Families then reunite in the common room and leave.

#### **4.3.2 Childhood Bereavement**

Quality of parental care is the most consistent predictor and mediator of the child's bereavement outcome in the literature (Tremblay and Israel 1998). Several studies have found that the gender of the parent, particularly the mother, affects the process and outcome of the child's adaptation to the loss because it was associated with either an increase in daily life changes for the child or due to less physical and emotional availability of the surviving father (Bifulco et al. 1987; Harris et al. 1986; Worden 1996). Others have stressed the importance of open communication between the surviving parent and the child (Black and Urbanowicz 1987; Cohen et al. 1977; Raveis et al. 1999) and the availability of social support for the surviving parent and child (Kaffman and Elizur 1983). One plausible conclusion from the literature would be that physical and emotional availability of the surviving parent (of either gender), continuity

in daily family life, social support, and open communication with the parent play important roles in the child's adaptation to the loss of a parent. These factors may also act as protective factors that prevent risks from future stressful events (Christ et al. 2005; Sandler et al. 2003).

There is evidence that the death of a parent is an insult to a child's self-esteem, often operating as stigmatization or teasing from peers (Bifulco et al. 1987; Worden 1996). The enduring effect of parental death on self-efficacy suggests that active rather than passive coping styles are associated with better outcomes (Worden 1996). Additionally, the perception of an internal locus of control might lead to less emotional dependency (Elizur and Kaffman 1982) and active coping styles may play a role in reducing social isolation (Zambelli and DeRosa 1992).

The age and gender of the child seem to determine the shape and form of the grief responses but not the level of risk. The particular developmental stage of the child may influence how the child responds. While younger children often experience difficulties in regulating strong emotions and older children experience difficulties in social dimensions, age does not appear to place a child at increased risk (Kaffman and Elizur 1983; Raveis et al. 1999; Van Eerdewegh, Clayton, and Van Eerdewegh 1985; Worden 1996). While boys display increased behavioral difficulties or report lower levels of depressive symptoms (Raveis et al. 1999; Worden 1996) and girls experience more anxiety (Elizur and Kaffman 1982; Worden 1996), gender does not appear to place a child at increased risk (Worden 1996).

While there appear to be consistent findings about the impact of childhood bereavement, answers to other questions remain murky. Whether parental death has a delayed effect on the child's developmental course is unclear. While some investigators have found evidence for a delayed effect at 2 years (Worden 1996), others have suggested the effect manifests itself later (Bifulco et al. 1987; Kaffman and Elizur 1983; Rutter 1966). The delayed effect often presents



as an emotional/behavioral disturbance and is often explained as resulting from difficulties in adapting to the changing family environment. Children's delayed responses may range widely from anxiety responses and aggression to social withdrawal and dependent behaviors. It is also unclear as to whether there is a mean time or an increased risk period for these effects to manifest since there have been few longitudinal studies and none that have followed the experiences of bereaved children for longer than 3 ½ years.

Though the literature is consistent regarding how children react after the loss, investigators disagree on how many children are at-risk and qualify for treatment referrals. Whereas some have found that about 20% of their study populations remained at-risk after 2 years (Worden 1996), others found that about one-third remained at risk (Elizur and Kaffman 1982) and still others that have found either relatively low levels or no risk among bereaved children (Fristad, Jedel, Weller, and Weller 1993; Raveis et al. 1999). These inconsistencies likely resulted from differences between sample populations and length of follow-up.

#### **4.4 OPERATIONALIZING CONSTRUCTS**

The study question was whether the center's peer support program affects either risk and protective factors known to be associated with child mental health outcomes. These factors were identified based on research that identifies the risks that bereavement poses for children as discussed in the section above and through consultation with the center's staff members. Embedded within the center's evaluation instruments were scales (either validated scales or those developed for use in the evaluation of the Family Bereavement Program) used to measure these risk and protective factors.

#### 4.4.1 Social Environmental-level Factors

*Quality of parental care.* In a review of the state of knowledge about the consequences of parental bereavement, the quality of parental care, stability of family circumstances, and the availability of social support for children and surviving parents/caregivers emerge as crucial determinants of acute and long-term adaptation to the loss of a parent (Tremblay and Israel 1998). While peer support groups may not directly affect the stability of family circumstances, they potentially may improve the positive quality of the relationship and the open communication between parent/caregiver and child. These two latter variables are operationalized as protective factors.

There is overwhelming evidence that a positive warm relationship with the parents following divorce or parental death predicts lower levels of mental health problems for children (Sandler 2001). *The Children's Report of Parental Behavior Inventory* (CRPBI) was originally designed by Schaefer (1965) to assess children's perceptions of parental behavior. It was revised and shortened by Schludermann and Schludermann in 1970 and 1988 to a much shorter version with 10-item subscales (1970). The acceptance subscale is a relationship quality index that measures warmth and support in the parent-child relationship through expressions of love and affection, positive involvement, responsiveness, and a lack of rejection or hostility. The shortened version was used in this pilot study to reduce the amount of burden on families. This scale was included in the center's evaluation instrument for both children and caregivers.

Research on bereaved children has stressed the importance of open communication between the surviving parent and the child (Black and Urbanowicz 1987; Cohen et al. 1977; Raveis et al. 1999). There is no standardized instrument to measure parent-child communication following the death of a family member, however, Sandler and colleagues developed two

instruments to assess communication quality during this time. The *Sharing Emotions with Parent Scale* (SEP) was designed to determine the extent to which children perceive their caregiver as being an empathic, understanding, helpful, and comforting and with whom to share negative feelings (PRC 2007c). This scale was included in the center's evaluation instrument for children. The *Talk with Reassurance Subscale* (TWR) of the *Parents' Expression of Emotion Questionnaire* assesses how caregivers communicate with their children about stressful family events (PRC 2007b). This scale was also included in the center's evaluation instrument for caregivers.

*Social support.* Research suggests that the perception of supportive relationships buffers the effect of stressful events (Kaffman and Elizur 1983; Sandler 2001). The *Social Provisions Scale* examines the degree to which respondent's social relationships provide various dimensions of social support (Cutrona and Russell 1987). This scale was included in the center's evaluation instrument for caregivers since it was validated with a number of adult populations ranging from college undergraduates to elderly populations. The *Multidimensional Scale of Perceived Social Support* (MSPSS) was designed to measure various dimensions of social support (Zimet et al. 1988) and validated with a number of pre- and adolescent children. This scale was also included in the center's evaluation instrument for children.

*Group Process and Universality.* Irvin Yalom, a major figure in group therapy practice and research, acknowledged that therapeutic change is an incredibly complex process. He identified 11 primary "therapeutic factors" involved in the therapeutic experience that rarely operate independently from one another (Yalom 1995). One that operates uniquely in groups is universality. He found that, especially in the early stages of group, the disconfirmation of a patient's feelings of uniqueness is a powerful source of relief; a feeling expressed by the phrase,

“We’re all in the same boat” (Yalom 1995). In its family service guide, the center states that it uses the peer support model because it is important for grieving children to know that they are not alone. Staff frequently stated that this was an important way the support groups help families so this factor was included in the evaluation instrument. While Yalom was strictly speaking of group therapy with clinical populations, this “therapeutic factor” could operate in other group-based services.

Yalom developed a 60-item Q-sort (approximately 5 questions per therapeutic factor) examining the importance of these therapeutic factors in the group experience (Yalom 1995). Four questions modeled after those that appear in Yalom’s original questionnaire were developed for the center’s evaluation instrument. This measure (UNIV) was designed to determine the therapeutic quality of the group support process for caregivers and children as well as complement the self-esteem measure described below. Children should theoretically experience less stigma and isolation once the group process unfolds and, therefore, improve self-esteem. This scale was included in the center’s evaluation instrument for both children and caregivers.

#### **4.4.2 Individual-level Factors**

*Coping Efficacy.* Coping efficacy is defined as a global belief that one can deal both with the demands made and the emotions aroused by a situation, including the belief that one has dealt well with stressors in the past and can deal effectively with stressors in the future (Sandler, Tein, Mehta, Wolchik, and Ayers 2000). Bandura described coping efficacy as a specific dimension of the broader construct of self-efficacy (1997). In this study, active coping strategies such as depending on trusted peers to process difficult emotions and are differentiated from avoidant coping strategies such as repression. Research has demonstrated the enduring effect of

parental death on self-efficacy and has suggested that active rather than passive coping styles were associated with better outcomes (Sandler et al. 2003; Worden 1996; Zambelli and DeRosa 1992). Sandler and colleagues found support for coping efficacy as a mediator of the relations between active coping and psychological problems (2000).

Two scales were included in the center's evaluation instrument for children; the active coping dimension of the *Children's Coping Strategies Checklist-2<sup>nd</sup>* (CCSC), a self-report inventory in which children describe their coping efforts (PRC 2007a), and the *Coping Efficacy Scale* (GCE), a subjective evaluation of efficacy rather than an objective measure of the effects of coping on outcome (PRC 2001).

*Self-esteem.* As a component of the self-concept, self-esteem is defined as totality of the individual's thoughts and feelings with reference to himself as an object (Rosenberg 1989). Research has observed the negative impact of bereavement on a child's self-esteem (Worden 1996). Any stressful event in the child's life has the potential to either positively or negatively affect the child's self-esteem. It is a common measure used by researchers to gauge a child's perception of self-worth. This measure was used complimentary to and interrelated with coping efficacy and universality. The center's service model aims to decrease stigma related to bereavement. The *Rosenberg Self-Esteem Scale* (SE) is a standardized instrument widely used to measure self-esteem in children (Rosenberg 1989) and was included in the center's evaluation instrument.

*Active Inhibition.* Active inhibition of emotional expression is defined as the conscious effort to avoid revealing one's affective state to another. Expression of emotion is generally considered beneficial to well-being and research has demonstrated that suppression of emotional expression is linked to indicators of physical illness (Pennebaker and Beall 1986). In its family

services guide, the center states that its central goal is to have the children and adults express their grief in an atmosphere of acceptance and trust. The *Active Inhibition Scale* (AI) to assess children's active inhibition of emotion (PRC 1997) and was included in the center's instrument for children.

## **4.5 METHODS**

### **4.5.1 Participants**

Participants in this study consisted of families enrolled in spring 2007 sessions that completed a questionnaire as part of the center's service improvement evaluation. The center informed all families that it would be conducting a service improvement evaluation and asked all families with children 11 years and older who would be attending the spring 2007 sessions at its 3 sites in Pittsburgh, Erie, and Lemoyne, Pennsylvania to complete a questionnaire as part of this evaluation. All eligible families who agreed to participate in the center's evaluation and completed the questionnaire were included in this study. No other exclusionary criteria were applied.

### **4.5.2 Procedures**

The center administered the evaluation instruments to adults and children 11 and over during the first family night and again during the last family night as part of the group session (once individual family members were separated into groups and prior to the activities of the

facilitated group session). The volunteer group facilitator and program staff remained available to answer any questions. Table 4.1 below displays what was contained within the center's evaluation instrument.

The center provided de-identified data for this study which included responses to the evaluation instruments, demographic data, and attendance records. This study was approved as exempt by the Institutional Review Board of the University of Pittsburgh.

### **4.5.3 Analytic Plan**

To test the significance of the differences between pre and post measurements, tests of paired differences was performed. Person mean substitution was used to estimate missing data. This method replaces missing data with the mean of an individual's responses for that scale (Downey and King 1998). When tested, this method produced an accurate representation of original data when both the number of respondents with missing data and the number of items missing were 20% or less (Downey and King 1998). In this dataset, individual respondents who omitted more than 20% of responses on an individual scale were not included in the data analysis. Due to the unknown distribution of differences between pre/post assessments, STATA was first used to conduct a skewness and kurtosis test of normality in order to apply the correct statistical test. Data appeared to be from a normal distribution except for those on the AI and MSPSS scales used in the children's instrument and UNIV and CRPBI scales used in the caregiver instrument. Paired t-tests were performed for data with normal distributions; Wilcoxon signed-rank tests were used to analyze data with non-normal distributions. The research reviewed for this study suggests that age seems to determine the shape and form of the grief

**Table 4.1** Scales Included in the Center’s Evaluation Instrument

VARIABLE	SCALE	AUTHOR	WHAT IT MEASURES	RATER	# ITEMS
<b>Social Environmental-level Variables</b>					
Parental Warmth	<i>Children's Report of Parental Behavior Inventory Acceptance/Rejection Subscale</i>	(Schaefer 1965)	Caregivers' positive or negative provision of acceptance and support	Both	10
Open Communication	<i>Sharing Emotions with Parent Scale</i>	(PRC 2007c)	The extent to which children perceive their caregiver to be an empathic, supportive, and comforting and with whom they can share their negative feelings.	Child	10
Open Communication	<i>Parent's Expression of Emotion Questionnaire Talk with Reassurance Subscale</i>	(PRC 2007b)	How caregivers communicate with their children about stressful family events.	Caregiver	6
Social Support	<i>Social Provisions Scale</i>	(Cutrona and Russell 1987)	The degree to which respondent's social relationships provide various dimensions of social support	Caregiver	25
Social Support	<i>Multidimensional Scale of Perceived Social Support</i>	(Zimet et al. 1988)	Dimensions of social support.	Child	12
Universality	<i>Adapt Yalom's Curative Factors Questionnaire Universality subscale</i>	Adapted from (Yalom 1995)	Group process of identifying with other members of group/normalization of experiences.	Both	4
<b>Individual Level Variables</b>					
Positive Coping	<i>Coping Efficacy Scale</i>	(PRC 2001)	Child's satisfaction with handling problems in the past and anticipated effectiveness in handling future problems	Child	7
	<i>Children's Coping Strategies Checklist Rev 2 Active Coping Dimension</i>	(PRC 2007a)	Active coping skills.	Child	24
Self-esteem	<i>Rosenberg Self-Esteem Scale</i>	(Rosenberg 1989)	Child's perception of self-esteem	Child	10
Active Inhibition	<i>Active Inhibition Scale</i>	(PRC 1997)	Inhibition of emotional expression.	Child	11



response but not the level of risk. Therefore, separate analyses were conducted for children 11 to 14 years and, again, for children over 14 years of age.

## 4.6 RESULTS

A total of 30 families (35 adults and 38 children) were included in this study. Of the 35 surviving caregivers who enrolled with the children, 20 (57.1%) were mothers, 9 (25.7%) were fathers, 5 (14.3%) were other family members, and 1 (2.9%) was a grandmother. Of the 38 children, 23 (60.5%) were female. Eleven children (47.1%) had experienced the death of their father, 5 (18.5%) of their mother, 9 (33.3%) of a grandparent, and 2 (7.4%) of another family member. Cause of death was reported as: 29.6% due to cancer, 18.5% due to heart illness, 11.1% due to homicide, 3.7% due to suicide, and 37% was categorized as ‘other’ which includes accidental deaths and deaths from other illnesses. Mean age of the children was 14.5 years, ranging from 11-17 years. Ethnicity of the families could not be assessed because the center does not record this information.

The center’s overall service population experienced similar proportions of which family member was lost and the cause of death, with the exception of homicides which were overrepresented in this sample (3% from service data and 11.1% in sample).

Table 4.2 below presents the results from the pre/post analysis. The center’s peer support program appears to have a strong effect on a child’s perception of coping efficacy ( $p \leq .003$ ), a factor that can protect him from the negative effects of an adverse event. Coping efficacy includes the belief that one has dealt well with stressors in the past and can deal effectively with

them in the future (Sandler et al. 2000). Participating in the center's peer support groups appears to improve a child's belief about how well he is dealing with the family member's death and how well he will be able to deal with it, as well as new stressors, in the future. The program also appears to have a strong effect on younger children's (11 to 14 years) sense of universality ( $p \leq .045$ ), the perception that his bereavement experience is not unique. While the program

**Table 4.2** Peer Support Group Program Effect on Protective Factors

<b>Peer Support Group Program Effect on Protective Factors</b>			
Pretest/Posttest: Children and Caregivers			
t(n) = paired t-test z(n) = Wilcoxon signed rank			
<b>Measure</b>			
<b>Children</b>			
Active Coping		t(31) = -0.919	p ≤ 0.183
Coping Efficacy*		t(29) = -3.033	p ≤ 0.003
Self-Esteem		t(31) = 0.389	p ≤ 0.650
Active Inhibition <sup>†</sup>		z(31) = 0.305	p = 0.761
Universality		t(30) = -1.416	p ≤ 0.084
11-14 years*		t(15) = -1.824	p ≤ 0.045
Parental Warmth		t(31) = 0.602	p ≤ 0.724
Sharing Emotions with Parent		t(29) = 0.038	p ≤ 0.515
Social Support		z(31) = 0.029	p = 0.977
<b>Caregivers</b>			
Social Support*		t(29) = -1.987	p ≤ 0.029
Universality*		z(27) = -2.543	p = 0.011
Talk with Reassurance		t(29) = -1.176	p ≤ 0.125
Parental Warmth		z(29) = -1.410	p = 0.159
<sup>†</sup> Lower score on scale denotes less inhibition of emotion (i.e. more favorable outcome). Therefore, positive z-score, though insignificant, could suggest program effect on lowering children's inhibition of emotion. * p ≤ .05			

effect on universality approaches significance for all children included in this study ( $p \leq .084$ ), the significant finding for only younger children confirms earlier research suggesting that age determines the shape and form of the grief. Participating in the center's peer support groups appears to help the younger child realize he is not alone in his grief and lessens his sense of isolation.

The center's peer support program appeared to have an effect on caregivers' perception of social support ( $p \leq .029$ ). Previous research suggests that the severity of the child's mourning responses are influenced by the degree of social support available to the surviving caregiver (Kaffman and Elizur 1983). Participating in the center's peer support groups appears to improve a caregiver's perception of available social support. Like their younger children, the center's peer support groups also appear to help caregivers realize that their bereavement experience is not unique (universality,  $p \leq .011$ ).

The center's peer support groups did not appear to have a stronger effect on either individual-level (coping efficacy) or social environmental-level factors (universality and caregiver perception of social support). While the program appeared to have stronger or weaker effect on other variables in the study, the lack of significance of the tests suggests that those differences could be due to chance.

## **4.7 DISCUSSION**

This article represents a feasibility study to pilot an outcomes evaluation instrument for a child-centered family-based peer support program for bereaved children. In light of this, several factors were significant. The findings provide evidence that peer support groups may have an effect on social environmental- and individual-level risk and protective factors for children following the death of a family member. The center's peer support program may improve a child's perceived ability to cope, a dimension of self-efficacy, and provide a sense of healing knowing that other children have experienced loss as well. It also provides surviving parent(s) or caregiver(s) with that same sense of universality as well as the social support necessary to

prevent the parent's own grief from interfering with the loving, supportive parenting the child needs to adjust.

While research has attempted to show that social support is important for positive health related outcomes, it has failed to show that health outcomes can be modified through social support (Hupcey 1998). While this study did not investigate the relationship between peer support and health outcomes directly, it demonstrated that peer support can modify factors that are known to be associated with child mental health outcomes. The application of a contextual resilience theoretical framework to the study of peer support provides insight into the black box phenomenon of previous social support research.

The center's peer support program had no demonstrable effect on many of the variables selected for this study. Because peer support programs intend to provide social support to grieving children we expected the program would have an effect on perceived social support, yet it remained virtually unchanged. This could be due to the self-selection of families choosing to enroll in the program whose children already perceive supportive relationships; the average score for children on the Multidimensional Scale of Perceived Social Support was 5.67 on a 7-point scale. We hesitate to recommend against using this scale in a future study because the constructs of social support and peer support are so closely related and because of the small sample size in this study. However, upon insignificant findings in a future study with an adequate sample size, this scale should be dropped from the evaluation instrument for children.

Since children share experiences with one another in groups and volunteers facilitate activities aimed to help children process and explore their experiences, we expected that the program would be associated with improved active coping skills. It is curious that while the program had a positive effect on coping efficacy, actual coping skills remained unchanged.

Since the risks of bereavement change over time as children adjust to the loss of a family member (Worden 1996), perhaps the belief that one can cope well serves to protect the child against future adverse events. While there were some positive findings for this pilot, future studies would be served to heed the lessons learned from this study.

There are several weaknesses with the design of this pilot study that should be addressed prior to a larger formal study. The pretest-posttest design does not allow one to attribute any observed changes to the program being evaluated (Suchman 1967). For this purpose, it would have been preferable to add a comparison group to the design and ideal to utilize a follow-up group of at least 6 months out of the program since the impact of bereavement (and, presumably, peer support programs) changes over time. However, as stated earlier, the study was aimed to be utilization-focused (Patton 1997) and the program director and program managers were to be the primary users. We made every effort to include these key staff in the methods and study design and, therefore, adapted the design to what was both practical and useful for their purposes.

The study population did not permit a complex analysis of factors determining program impact. The sample was small. While adequate to pilot test the feasibility of an evaluation instrument, the sample size was inadequate to conduct an analysis of variance using variables such as age, time since family member death, cause of death, and relationship of surviving caregiver to child. The sample only permitted simple pre/post analysis and while we did attempt a sub-group analysis of changes by child age, these results should be viewed with caution (n=15). It would be useful to gather a sample that would allow an investigator to understand how peer support programs work, for which children and under what conditions.

Procedures for the center's administration of the instrument limited the extent to which program effects could be observed. Administration of the evaluation instrument should be given to families as early as possible so as to not contaminate true program effects. The center administered the instrument on the first group night for many practical and programmatic reasons. However, by this time, caregivers had already made at least an initial phone call (if not several) to the center and families attended an orientation session prior to providing a baseline assessment. During the orientation session, particularly, families mingle with other families who have also experienced a loss. It is quite conceivable that during the orientation session families derived some benefit on the measures chosen for this study. Mailing the instrument to families after the initial phone call or administering the instrument prior to commencement of the orientation session, perhaps once it is scheduled, may be a preferable approach for future studies.

Finally, this was a feasibility study to pilot an evaluation instrument and the results suggest that the instrument should be modified. Simple changes such as shading even numbered questions would serve to minimize skipped responses, even though this did not appear to be a consistent respondent error. Although most scales included in the instrument had been validated, additional work is warranted to ensure that chosen measures identify the benefits that children experience while attending peer support groups. Perhaps beta testing the instruments and gathering feedback from formerly enrolled children would result in a more tailored evaluation instrument. Though the instrument should be modified, the results of this study also suggest that the center's peer support program is evaluable and can strengthen resilience factors in bereaved children.

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## **5.0 GENERAL DISCUSSION AND CONCLUSIONS**

Included in this section is a review and discussion of the findings from the articles presented in chapters 2-4, suggestions for future research on childhood bereavement and for public health practice.

### **5.1 OVERVIEW OF FINDINGS**

#### **5.1.1 Epidemiology of Childhood Bereavement**

In the first paper, we explored the epidemiology of childhood bereavement and determined that the information available to calculate a prevalence estimate of childhood bereavement is at best limited and at worst inadequate, and that there is merit to include in any estimate the loss of siblings and of grandparents who are primary caregivers.

The Social Security Administration is the most common source of information for determining how many children experience bereavement. Implicit in this calculation is a definition of bereavement as parental loss, excluding the loss of siblings and grandparents. However, as displayed in Figure 1.5, 22% of the losses experienced by children whose families sought services at the center were not parental losses. Parents and caregivers were seeking services for their children who lost siblings and grandparents. Therefore, we made arguments for

the inclusion of grandparents and siblings and offered a method to calculate the annual incidence of sibling bereavement.

The method offered to use existing data to estimate the annual incidence of sibling bereavement. We found that for each child under 18 years of age who dies annually (53,932), there are 1.42 siblings (76,642) who are affected, approximating a ratio of 2:3. Since prevalence would include the cumulative number of children who have experienced parental or sibling bereavement in a given year, this could substantially increase prevalence estimates of childhood bereavement.

### **5.1.2 Focus Groups**

This study attempted to demonstrate the utility of using focus groups to learn from bereaved children and adults the perceived benefits of attending peer support groups. Focus group data suggested that families who attended peer support groups experienced improved parent-child communication, parent-child warmth, coping, and a healing effect when they realize their grief is not unique. Data also suggested that perceived social support in peer support groups reduced feelings of isolation and alienation among family members. Focus groups were an extremely useful method to develop evaluation constructs as expressed by beneficiaries of the center's peer support groups.

### **5.1.3 Feasibility study**

The results of the focus groups were used to develop evaluation constructs. From what we learned through that process, we developed an outcomes evaluation instrument. Embedded

within the instrument were scales used to measure risk and protective factors that we identified through the focus groups but which also reflected the current scientific understand of childhood bereavement.

Though this was a feasibility study to pilot the evaluation instrument, several factors were significant. The findings provided evidence that peer support groups may have an effect on social environmental- and individual-level risk and protective factors for children following the death of a family member. The center's peer support program may improve a child's perceived ability to cope, a dimension of self-efficacy, and provide a sense of healing knowing that other children have experienced loss as well. It also provides surviving parent(s) or caregiver(s) with that same sense of universality as well as the social support necessary to prevent the parent's own grief from interfering with the loving, supportive parenting the child needs to adjust.

While this study did not investigate the relationship between peer support and health outcomes directly, it demonstrated that peer support can modify factors that are known to be associated with child mental health outcomes. We found that the application of a contextual resilience theoretical framework to the study of peer support provides insight into the black box phenomenon of previous social support research.

Though we recognized that the instrument should be modified, the results of this study also suggested that the center's peer support program is evaluable and can strengthen resilience factors in bereaved children.

## 5.2 SUGGESTIONS FOR FUTURE RESEARCH

The body of work contained in this dissertation implies several suggestions for future research on childhood bereavement. First, there are several approaches to improving estimates of childhood bereavement. While OASDI child survivor benefits appear to provide the most accurate estimates of parental bereavement, these estimates could be informed through periodic supplemental surveys. One survey could be used to estimate the number of children who are eligible for OASDI benefits but do not enroll to receive benefits. Like the children included in the Statistical Abstracts, these children also represent the pool of children who are parentally bereaved. Another survey, perhaps a modification of the Current Population Survey, could be used to gather information about the age of grandparents serving as a primary caregiver. Information about the age of this cohort would permit the calculation of a death rate, and, therefore, a third contributor to an estimate of childhood bereavement. Both of these approaches would supplement existing data. Perhaps a new IOM committee on childhood bereavement could be formed to revisit the question about what constitutes bereavement in childhood and to suggest standardization to reporting the prevalence of childhood bereavement.

Second, future research on peer support programs should improve upon the study methods and design but work within the same theoretical framework. Childhood bereavement research has been hampered by the lack of a coherent conceptual research framework designed to test hypotheses of clinical relevance (Dowdney 2000). The feasibility study demonstrated that the resilience framework is useful and applicable to the evaluation of peer support programs. Future research from this framework is needed to demonstrate the validity of resilience theory.

Future evaluations of peer support programs should heed the lessons learned from these studies. It would have been preferable to add a comparison group to the design and ideal to

utilize a follow-up group of at least 6 months out of the program since the impact of bereavement (and, presumably, peer support programs) changes over time. Future research should also attempt to gather a sample large enough to conduct an analysis of variance using variables such as age, time since family member death, cause of death, and relationship of surviving caregiver to child. Additionally, any administration of an evaluation instrument should be given to families as early as possible so as to not contaminate true program effects.

Following any of the above suggestions will substantially improve research on childhood bereavement and how peer support groups help children to adapt to such an adverse event.

### **5.3 PUBLIC HEALTH SIGNIFICANCE**

One of the core functions of public health as defined by the Institute of Medicine is to monitor health status, which includes the identification of threats to health and assessment of health service needs. The body of work contained in this dissertation identifies several gaps where our discipline has performed less than satisfactory and offers suggestions and findings that are of public health significance.

First, as discussed above, a new method using existing data was offered for calculating the incidence of sibling bereavement. In addition to offering a new calculation method, we have argued for the field to consider the loss of siblings as well as grandparents who are primary caregivers, a growing reality in the lives of children in the United States.

Second, in researching the prevalence of childhood bereavement, a service gap was identified. The information displayed in Figure 1.1 tells us that 8138 children in Allegheny County were receiving benefits in 2003 for the loss of one or both parents, yet only 347 children

received services through the center's peer support groups that year. The center is the major provider of peer support services for bereaved children in the county and only a handful of other agencies offer similar services for this population. Therefore, while some of these children may have sought other services or no services at all, there is likely a large service gap between the children who would benefit from some type of bereavement service and those being served by the center's peer support groups.

Second, this work has provided the field with an approach to evaluate how peer support groups help children to adapt to an adverse event such as the loss of a close family member. To date, there has been no published research that has applied the resilience framework to determine the potential benefits of a peer support intervention for bereaved children. The results of the feasibility study suggest that peer support programs could improve the way children adapt to the loss of a close family member. Though the study design could be improved in several ways, it is this new approach to evaluating the potential benefits of peer support that is of public health significance.

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