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"Over the Rainbow": A Prevention Group for Bereaved Children and Families in a Rural Area

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“OVER THE RAINBOW”
A PREVENTION GROUP FOR BEREAVED CHILDREN AND FAMILIES IN A RURAL AREA

A Dissertation

Submitted to the School of Graduate Studies and Research

In Partial Fulfillment of the

Requirements for the Degree

Doctor of Psychology

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Indiana University of Pennsylvania

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Title: “Over the Rainbow” A Prevention Group for Bereaved Children and Families in a Rural Area

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The death of a loved one is a difficult experience for a child. However, prior research has found several characteristics that put some children at a greater risk than others. This study examined the unique needs that rural communities face trying to provide services to bereaved children and their families. The primary purpose of this study was to evaluate the effectiveness of a one-day bereavement camp for children and families in a rural area who have lost someone close to them. Participants completed quantitative and qualitative measures designed to evaluate the group. The camp was offered on four occasions, but despite intensive recruitment only seven participants attended. Although the group was well-liked and beneficial to those who attended, the recruitment and attendance difficulties suggest this may be an inefficient use of time and money for the provision of bereavement services to the community. A follow-up study was created to investigate the barriers and possible solutions to aid future programs. Fourteen key informants in the community were interviewed to address this topic and grounded theory was utilized to examine the results. Findings were consistent with the difficulties for other rural mental health programming in regards to accessibility and acceptability. Rural core providers must be aware of these unique variables in rural culture that lead to barriers to

treatment and determine which strategies fit best to meet the needs of individuals in these communities.

In Loving Memory of
Suzanne Elling Seacrist

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This project is dedicated to my mother, Suzanne Elling Seacrist, who showed me how to love, and even though our time together was short, I feel grateful for the moments we shared.

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CHAPTER I

REVIEW OF THE RELEVENT LITERATURE

In the United States, children are often shielded from the topic of death. However, children who lose someone close to them are forced to deal with the reality of death and loss. 5% of children in the United States will experience a crucial loss before the age of 15 (Shneiderman, Winders, Tallett, & Feldman, 1994). Children who have experienced the loss of someone close to them are at risk for a number of detrimental outcomes. Preliminary research on bereaved children showed that the intense feelings children have can manifest in a variety of different forms such as depression, anxiety, acting out behavior, and somatic symptoms (Dowdney, 2000). Children often do not have the cognitive or emotional capacity to express their feelings after a loss and symptoms may manifest in other ways such as somatic complaints, withdrawal, distractibility, irritability or aggression (Baker, Sedney, Corr, & Corr, 1996; Worden, 1996). Children's grief also differs from adults in that their symptoms may not manifest immediately after the loss. In fact, Worden and Silverman's (Worden, 1996) study comparing bereaved and nonbereaved children found an increased amount of maladaptive effects at two years following the death of a parent compared to one year. Due to the wide variety of responses to loss, recent studies have focused on both protective and risk factors associated with different outcomes (Dowdney, Wilson, Maughan, Allerton, Schofield & Skuse, 1999; Fristad, Jedel, Weller & Weller, 1993; Greeff and Human, 2004; Sandler, Ayers & Romer, 2002). While a great deal of progress has been made identifying these factors, the suggestions offered by structured research studies cannot always be practically applied to clinical settings. For example, research studies may exclude children with a diagnosis such as attention deficit disorder or with complicated losses (Sandler, Ayers, Wolchik, Tein, Kwok & Haine, 2003). Nonetheless, these children may need these services the most. Specifically, little has been done to look at the limitations of applying proposed interventions to rural communities, where there are fewer available resources to which individuals and families may be referred. The purpose of this study was to examine bereavement programs in the literature and adapt them to meet the needs in a rural community with limited resources and a diverse bereaved population. A bereavement camp curriculum was developed and was conducted on three separate occasions. A fourth camp was scheduled, but cancelled due to lack of attendance. The program was evaluated using quantitative and qualitative measures.

Despite intense efforts to advertise the program, recruitment was a difficult process and each camp had less than five children participating. Due to the lack of participants, a second goal was added to determine what barriers exist in this community that prevents residents from utilizing services and to inform future programming. Grounded theory was used to qualitatively examine the barriers and potential solutions to families utilizing support programs. In depth interviews were employed to gather data from 14 key informants.

Understanding Grief

Defining Terms

The grief literature uses many terms in relation to grief and loss. Despite different meanings many of these terms are used interchangeably. Bereavement refers to “the loss to which the person is trying to adapt” (Worden, 1996, p. 11). Grief is defined as the “experience of one who has lost a loved one to death” (Worden, 1996, p.11). Lastly, mourning refers to “the process that one goes through in adapting to the loss of the person” (Worden, 1996, p. 11).

Differences Between Adult and Child Grief

While early psychoanalysts believed that children were not capable of mourning, more recent literature supports the perception that children as young as three years old are capable of grieving (Worden, 2002). Additionally, more recent literature highlighted the fact that children show unique patterns of grieving different from that of adults (Baker et al., 1996; Worden, 2002). Children’s grief may last longer than adults, children may not experience the intense reactions that adults immediately experience, and instead children may gradually process the loss. Consequently, children’s grief may be more intermittently, and it is not unusual for a child to be upset one day and to be laughing and playing the next. Children may also revisit grief throughout their development. As children’s cognitions develop and become more complex they may re-process the death, and experience different emotions and develop new questions regarding the death. In particular, it is not unusual for children to revisit grief during developmental milestones. For example, a child may appear to have adjusted well after a loss but later experience difficulty when changing schools or following another loss (Stokes, Wyler, Crossley, 1997).

Theories

There are numerous theoretical models that have been created to assist in the understanding of grief and coping. The study of bereavement can be traced back to Sigmund Freud. Freud coined the term “grief work” which stressed the importance of detaching oneself from the deceased individual (Freud, 1917). Since then the notion that grief proceeds through a series of stages or phases has been posited by several theorists (Bowlby & Parkes, 1961; Jacobs, 1993; Kubler-Ross, 1969; Rando, 1993). Bowlby and Parkes (1961) were the first to create a stage model to discuss grief. Their model included four stages: shock-numbness, yearning-searching, disorganization; and reorganization. Kubler-Ross (1969) adapted her model to describe the trajectory of terminally ill individuals to that of grieving individuals. Her model included five stages: denial-dissociation-isolation; anger; bargaining; depression; and acceptance. In 1993, Jacobs adapted the Kubler-Ross model to create a four stage model: numbness-disbelief, separation distress (yearning, anger, anxiety); depression-mourning, and recovery. Similarly, Rando (1993) described three phases in mourning: avoidance, confrontation, and accommodation. In 2007, an empirical study was implemented to determine the accuracy of these stage models (Maciejewski, Zhang, & Block, 2007). This study examined the grief reactions of 317 participants over a period of 24 months post loss. When the researchers examined the peak expression of each grief indicator (disbelief, yearning, anger, depression, and acceptance) they found that the “five indicators achieved their respective maximum values in the sequence predicted by the stage theory of grief” (p. 716). However, they found that disbelief was not the initial dominant grief reaction and that yearning was the dominant negative reaction. Acceptance was the most frequently endorsed reaction. It is important to note that this study only included deaths from natural causes and uncomplicated grief.

An alternative to stage models were the “task” models of Sandra Fox (1985) and William Worden (2002). Worden chose to use “tasks” instead of stages because he maintained that these tasks can be completed in any order and that they can be revisited at a later time. According to Worden, the mourning process consisted of four tasks that must be performed in order for children to adapt to the loss. The four tasks identified by Worden were accepting the reality of the death, experiencing the emotional aspects of the death, adjusting to an environment without the deceased, and emotionally relocating the deceased and moving on with life. Worden described his fourth task as, "to find a place for the deceased that will enable the mourner to be connected with the deceased but in a way that will not preclude him or her from going on with life” (Worden, 2002, p. 35). This notion of maintaining the bond with the deceased has seemingly replaced and has been found to more adaptive than Freud’s original posit that one must detach themselves from the deceased (Klass, 2006).

Traditional theories have been criticized for underestimating the resilience of individuals, particularly children. One theory that took into account an individual’s resiliency is Stroebe and Shut’s (1999) Dual Process Model of

Coping. This model posited that bereavement is “an oscillation between focusing upon and avoiding the loss experience” (p. 198). This theory defined grief as a cyclical model opposed to the more traditional linear models.

Lastly, data from Sandler’s Family Bereavement Program has been utilized to develop a Resilience Resource Model (Sandler et al., 2002; Sandler et al., 2003). This study compared 244 children (135 intervention, 109 control) over 11-months post-interventions. This model emphasized the role that the individual, the family, and secondary loss play in increasing or decreasing the risk for children who have experienced a parental death. This theory discussed the role of the stress related to the death, as well as the role secondary stressors play in affecting the child’s outcome. Additionally, the researchers found both individual and family level mediating variables. Family level variables were parental warmth, communication, positive time spent with child, surviving parent’s depressive symptoms, and effective discipline. Individual level variables found to play a role were self-esteem and locus of control (Haine, Ayers, Sandler, Wolchick, & Weyer, 2003; Sandler et al., 2003).

Grief Reactions

Grief can manifest itself in many different ways. Many children experience short-term symptoms after the loss of a parent. These reactions could be emotional, cognitive, physical, and behavioral. Typically, children experience a wide range of reactions that do not constitute a specific disorder (Dowdney, 2000; Kalter, Lohnes, Chasin, Cain, Dunning, & Rowan, 2002). Some studies have found children to be relatively symptom free (Weller, Weller, Fristad, &

Cain, 1988). However, it should be taken into consideration that the literature is still unclear about the length of time it takes for children to develop symptoms. While children's initial responses such as crying and sadness appear to decline shortly after the loss, some longitudinal studies have found that mental health and other problems can persist and may even increase over time (Dowdney, 2000; Worden & Silverman, 1996).

Emotional reactions. Normal emotional reactions following the loss of someone close to us included sadness, anger, guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief, and numbness (Worden, 2002). Parentally bereaved children were found to have increased Child Behavior Checklist scores on Internalizing Problems, in particular Anxiety and Depression (Kalter et al., 2002). Oftentimes this manifests in a form of separation anxiety because the child fears losing his or her surviving parent. Parentally bereaved children were also more likely to have social withdrawal and social problems, low self-esteem, and low self-efficacy (Worden & Silverman, 1996). There was also evidence that some children may even meet criteria for diagnostic disorders such as depression and/or an anxiety disorder (Dowdney, 2000; Gersten, Bearls, and Kalgrem, 1991).

Cognitive reactions. Certain thoughts are also common following the loss of someone close to us; they include disbelief, confusion, preoccupation, sense of presence of the deceased, yearning, and hallucinations. Parents, in an attempt to protect their children from painful experiences, may choose not to tell their child about the death; however, this approach can leave children confused and alone with their fears and fantasies (Thompson, Kaslow, Kingree, King, Bryant, & Rey, 1998). Moreover, children often try to “protect” those around them who are also grieving. According to Silverman and Worden (1992) 42% of children reported beliefs that they should hold back their expression of negative emotions to avoid upsetting their surviving parent. Preoccupation with thoughts about their deceased loved one may also affect their ability to concentrate. Dowdney (2000) found that teachers rated parentally bereaved students as significantly less attentive than their peers. Similar cognitive difficulties were expressed with sibling loss and peer loss (Davies, 1988; Ringler & Hayden, 2000). This may lead to a decline in school performance (Worden, 2002). Parental bereavement has also been found to negatively impact a child’s self-efficacy and self-esteem; children find it difficult to be different than their peers in such a significant manner (Worden, 2002). Sibling loss was also associated with increased feelings of loneliness and isolation for children because their peers did not understand what they were experiencing. Moreover, they may avoid becoming close to others for fear that they will lose them as well (Hogan, 2008).

Physical reactions. Physical reactions are also normal following a loss, and include hollowness in the stomach, a lump in the throat, tightness in the chest, aches, oversensitivity to noise, shortness of breath, lack of energy, depersonalization, muscle weakness, and dry mouth. Somatization was common for children who were not developmentally able to verbalize the feelings they are having (Worden, 1996).

Behavioral reactions. Sleep or appetite disturbances, absentmindedness, social withdrawal, loss of interest in activities, dreams of the deceased, crying, avoiding reminders of the deceased, searching and calling out, restless overactivity, and treasuring objects that belonged to the deceased are all common behavioral reactions following the death. Grief was often found to manifest in physical and behavioral manners in children who were unable to label the thoughts and feelings they are experiencing (Baker et. al., 1996).

Long-Term Risks

There was also evidence that linked parental death during the years of childhood with adult psychopathology. Parental death has been linked to an increased incidence of bipolar disorder (Tsuchiya, Agerbo, & Moretensen, 2005), depression (Barnes & Prosen, 1985; Lloyd, 1980), and anxiety disorders (Sanchez, Fristad, Weller, & Weller, 1994; Worden & Silverman, 1996).

Normal and Complicated Grief

Currently, the Diagnostic and Statistical Manual of Mental Disorder- 4th Edition Text Revision of the American Psychiatric Association (APA, 2000) does not recognize bereavement as a psychological disorder. However, researchers have begun developing criteria for complicated grief for future editions (Horowitz, Milbrath, Bonanno, Field, Stinson, & Holen, 1998). Nonetheless, this research has focused on adults and little has been done in terms of children and adolescents. Horowitz and colleagues (1998) define complicated grief as “the intensification of grief to the level where the person is overwhelmed, resorts to maladaptive behavior, or remains interminable in the state of grief without progression of the mourning process towards completion" (p. 257).

Worden (2002) identified four types of complicated grief reactions in individuals. These four types were labeled as chronic, delayed, exaggerated, and masked. Chronic grief reactions are "excessive in duration and never come to a satisfactory conclusion" (p.89). Delayed grief reactions occur when individuals experience intense emotions to a later loss because the intense emotions were never experienced at the time of the original loss. An exaggerated grief reaction refers to a reaction that is more "intense" than a typical reaction. Lastly, masked grief reactions occur when individuals "experience symptoms and behaviors that cause them difficulty but they do not recognize that these symptoms are related to the loss" (p.94).

In general, there is no clear trajectory that children follow after the death of a parent. It appears that there are a wide range of symptoms and severity of symptoms experienced. Little is known about the time line following the death of a loved one. Additionally, parents may be poor predictors regarding their child's symptoms. In a study where parent report of their child's depressive symptoms was compared to the child's report, the child report expressed higher symptoms of depression than the parent (Weller et al., 1991). This indicated that parents may not always be cognizant of the symptoms children are experiencing. Adults also tend to try to protect and distance children from the death and often do not keep them informed or allow then to participate in the grieving rituals of the family (i.e. funerals). These are all important experiences that can allow individuals to grieve for their loved one. Therefore, children are often not given the opportunity to adequately grieve for their loved one when they are shielded from these experiences. These are important considerations when developing any intervention.

Mediators of Grief Reaction

There has been much debate around children's grief reactions, the intensity of these reactions and what role bereavement will play throughout the life of a child. Some of these mixed findings may be related to the many factors that play a mediating role in how a traumatic event will impact a child's life. A review of the literature indicated that the death of a loved one can place children at risk for a wide range of negative outcomes including increased mental health problems and behavioral problems, decreased academic success, or decreased self-esteem and social competence (Applebaum & Burns, 1991; Dowdney, 2000; Lutzke, Ayers, Sandler, Barr, & Wolchick, 1997, Tremblay & Israel, 1998; Wilker & Lowell, 1996; Worden & Silverman, 1996). Although this population is at risk, many children who suffered a loss displayed a great deal of resilience after the death of a loved one (Worden & Silverman, 1996). Estimates of children who will experience significant problems range from 20% to 50% depending on the outcome measure that was utilized (Dowdney, 2000; Hogan & Greenfield, 1991). Research has examined many factors that may influence the child's ability to cope after the loss of a loved one. These factors fall into many categories including developmental factors, child characteristics, family characteristics, environmental factors, and factors associated with the death of their parent.

Developmental Factors

Many of the child’s individual characteristics have been shown to have an effect on how the child grieves following the death of a parent, one of the most influential factors is the developmental stage of the child at the time of the death (Christ, 2000). One way to appraise a child’s developmental understanding of death is to examine it within a framework for human development, such as those created by Erik Erikson and Jean Piaget. The model of human development created by Erik Erikson focused on the “stages of psychosocial development” that occur throughout a person’s life (Erikson, 1963). Each stage of development involves a “crisis” that requires a response from the individual. Piaget’s model focused on “cognitive transformations” that occur throughout childhood (Piaget, 1972). A great deal of work has been done using these developmental stages as a model for how children understand death (Christ, 2000; Schoen, Burgoyne, & Schoen, 2004). For example, a child who is three years old when their parent dies has just entered Piaget’s preoperational stage. This child would struggle with irreversibility of their parent’s death and may believe the parent has just gone away for a while, but will be back. According to Erikson, this child would be struggling with issues of autonomy versus shame and doubt. A loss for this child may interfere with the goal of independence; he/she may regress to earlier behaviors of clinging, crying and being more demanding. A child who is seven years old when their parent dies is in Piaget’s later preoperational period. This child is more likely to show grief reactions of sadness, anger, and dejection (Christ, 2000). These children are also more likely to have somatic complaints and are tuned into physical symptoms, which may lead to thoughts such as, “I could die, too.” Children in this cognitive stage may also have cognitions which lead them to feel guilty about the death. They may wonder if they have done something wrong to cause the death or believe that their thoughts or actions killed their parent (Christ, 2000). A seven year old corresponds to Erikson’s stage of industry versus inferiority. Children during this stage may compare themselves to peers more frequently to determine their own self-worth. A child who loses a significant person during this stage not only loses a significant source for validation and encouragement, but can also experience increased feelings of being different compared to peers. The developmental stage of the child at the time of the death is critically important to understanding the child’s grief reaction and also to guide treatment. For example, research showed that rates of depression increased with age, whereas younger children may manifest their distress through separation anxiety (Dowdney, 2000). This has important implications for interventions with children and should be taken into consideration before any intervention begins. However, the developmental stage is often overlooked. Many of the diverse results found in the psychological literature for children’s grief reactions may be attributed to comparing samples that include children in different developmental stages with differing cognitive abilities.

Another important consideration was the role children’s development plays in their ability to understand the concept of death. A child’s cognitive-language ability will affect how they conceptualize death and consequently influence their grief experience. According to Speece and Brent (1984; 1996) there were four basic factors associated with a child's ability to understand the concept of death. These factors were universality, nonfunctionality, irreversibility, and causality. Universality referred to the child's ability to understand that death is inevitable and that eventually everyone will die, including him or herself. Nonfunctionality referred to the child's ability to understand that all "life-defining functions" end when a person dies. In other words, the child was capable of understanding that when someone is dead they are no longer breathing, and they no longer need to sleep or eat. Irreversibility was the child's ability to understand that when someone has died they are not able to come back to life. Lastly, causality referred to the child's ability to understand the objective and biological causes of the person's death. There does not appear to be a consistent age when children are capable of mastering these concepts. However, most studies reported that children were generally able to understand these four concepts by the age of seven (Speece, Brent, Corr, & Corr, 1996). Speece and colleagues (1996) review of the literature looked for other factors associated with the child's development of the concept of death and found that ethnicity, gender, socioeconomic status, and religion were not significant influences.

Child Characteristics

Other factors that have been linked with outcome are individual child characteristics. One of these factors was the child's self-esteem (Webb & Webb, 2002a). Children who rated higher on scales measuring self-esteem prior to the loss were more likely to have a resilient outcome. Additionally, children who had a greater personal efficacy in coping with stress also tended to have resilient outcomes (Lin, Sandler, Ayers, Wolchik, & Luecken, 2004). Poorer outcomes were linked to children who were diagnosed with psychological disorders prior to the death (Dowdney, 2000). Children who have had prior psychological disorders are significantly more likely to have increased psychopathology after the death of a parent.

Many factors centered on the child’s perceptions have been shown to influence outcome, including the child’s perceptions of him or herself and the world (Lutzke et al., 1997), the child’s perceptions of the threat in response to negative events (Lin et al., 1997), and child’s perceptions of the loss (Nader, Pynoos, Fairbanks, & Frederick 1990).

There have been mixed results found for the influence of the gender of the child. Some research has shown that boys were more likely to show externalizing disorders following the death, whereas girls were more likely to show internalizing disorders (Dowdney, 2000; Saler & Skolnik, 1992). Research has also looked at potential interaction effects between the gender of the child and the gender of the deceased parent. They found that there was a significant interaction for girls and the death of their mothers and boys and the death of their fathers, resulting in poorer outcomes for same sex combinations (Dowdney, 2000).

In conclusion, although there are many individual factors that could influence how the child responds to the death of a parent; little is known about how these factors interact with each other, as well as with additional family and environmental factors.

Family Characteristics

Beyond individual factors there were a multitude of family-level factors that have been linked to outcome in bereaved children. The first was the stability of the environment after the death (Tremblay & Israel, 1998). It has been found to be extremely important for the environment to remain consistent for the child. Other factors involve the surviving parent's adjustment after the death (Kalter et al., 2002; Lin et al., 2004). Parents who had difficulty adjusting to their spouse's death or developed a psychological disorder were less able to meet the needs of their children and this was linked to poorer outcomes. Additionally, parents who were diagnosed with a psychological disorder prior to the death were more likely to have difficulties adapting following the death (Dowdney, 2000). Conversely, high parental warmth and high levels of effective discipline were associated with resiliency within the child (Sandler et al, 2002). Other factors that have received mild support are family organization, cohesion, communication, and role differentiation (Dowdney, 2000). In particular, an open communication style where the family is able to openly discuss their thoughts and feelings about the death has been linked to a more positive outcome (Greeff & Human, 2004). Role differentiation has also received mild support; this entails not discussing "adult" matters, such as financial difficulties, with the children. This also referred to not having the child take on the role of the deceased parent (e.g., telling a son, "you are the man of the house now").

Environmental Factors

The literature has shown mixed results for the importance of environmental factors. There was a great deal of evidence suggesting that support from extended family and the community was extremely beneficial following the death (Dowdney, 2000; Webb & Webb 2002b). However, there were mixed results for the effect of the family's socio-economic status (Dowdney, 2000; Lin et al., 2004). Some felt that it has an effect on the child's outcome (e.g., higher socio-economic status is linked to better outcome) and others have shown that this is not statistically significant (Lin et al., 2004). Another topic related to environmental factors was that of multiple losses, also called secondary losses (Webb & Webb, 2002a). The effect of these secondary losses has been hypothesized to play a major role in how a child copes with the death. Often after the death of a parent many significant changes are made in the child's environment, this could include moving, changing schools, a different caregiver, and a lower socio-economic status. Secondary losses appear to have a cumulative effect, in other words the more losses experienced the poorer the outcome.

Factors Associated with the Death

There was also mixed results for the impact of factors associated with the parental death. For example, some suggested that the child's relationship with the deceased parent was significantly related to outcome (Christ, 2000). Some literature suggested poorer outcomes for children who had ambivalent relationships with their deceased parent, (e.g., a child whose father physically abused him). This may lead to more complicated reactions because the child may be experiencing contradictory emotions, such as sadness and relief.

Some suggested that there was a relationship between whether or not the death was expected or unexpected, however more recent literature does not support this claim (Dowdney, 2000). This confusion may be related to whether or not the child was knowledgeable about the fatality of the disease (Tremblay & Israel, 1998). Just because adults were expecting the death does not mean they have made the child aware of the impending death. Lastly, the cause of death may have an impact on the outcome of the child, particularly if the death was a murder or suicide. Research has linked more complicated grief patterns with children who have lost a parent to murder or suicide (Dowdney, 2000). These children have typically faced more difficult emotional reactions including guilt and shame.

In conclusion, it appears that there is a complex cumulative risk and protective model that best explains the outcome of the bereaved child. Although the literature has yet to put all of the pieces together to form one single model, it does appear that many of the pieces have been found.

Group Interventions

It is important to recognize that although “therapy" may not be necessary for all bereaved individuals, that does not mean that different levels of formal and informal support cannot be offered. The idealistic belief that most children will get all the support they need from friends and family does not appear to be borne out in the literature (Worden, 1996). Many times parents and other family members are also grieving, which may prevent them from attending to the child's needs as effectively as they typically would. Additionally, children may not have adequate support from their peers either, as peers may not know what to say or how to act towards the grieving child. The importance of peer support was evidenced by Silverman and Worden (1992) who found that children with the poorest peer support had the highest psychological distress scores. Lastly, even teachers and other adults may not address the child's needs sufficiently because they are unsure of what to do and fear upsetting the child (Healy-Romanello, 1993). The possible deficiency of support from these areas makes it critical to provide alternatives for children.

Worden posited that there were three types of intervention strategies following a death (Worden, 1996). The first level was to offer intervention only when children display emotional and behavioral difficulties following the death of a loved one. However, this type of intervention was insufficient in that it assumes that only children who show observable signs of distress are suffering and that those who are not showing overt signs are not in need of support. When this type of intervention was utilized, children's levels of distress has often reached an extreme level before any intervention occurs. Worden's second level of intervention was to offer services to children who are labeled "at risk" by use of a screening measure. One of the strengths of this strategy was that it intervened before high-risk individuals develop extreme distress. However, one of the difficulties related to treating this population was that it is difficult to identify individuals that are at a greater risk for developing significant problems.

Nonetheless, Worden argued that since so many children show resiliency after the death of a loved one that screening for high risk children was the most efficient and cost effective approach to providing services for bereaved children. Worden created preliminary measures that would help identify children and adolescents who are most at risk for negative outcomes after the death of a parent (1996). According to Worden, individuals should be assessed within the first 6 months of the parent's death. The factors he included were the surviving parent's age, level of stress, coping, and depression, as well as the number of children in the family and the child's own level of symptomology. However, concerns have been raised about using measures that do not have established reliability and validity over time and across cultures. Therefore, others have advocated for the development of universal interventions that can be offered to all bereaved children and their families (Stokes, Pennington, Monroe, Papadatou, & Relf, 1999). Worden's third level of intervention suggested just that—offering intervention *routinely* to all bereaved children and their families. The goal here was to prevent problems from escalating to a level where professional intervention is necessary. However, the drawback to this level of intervention was the time and financial resources that were necessary to offer services to all bereaved children and their families.

Community based intervention has many benefits. One of the benefits of a community based prevention group is that it can offer support to a large number of children. Another benefit of community based intervention is that it can play a role in providing psychoeducation, which may help to normalize bereavement and help individuals avoid the stigma associated with mental health problems (Stokes et al., 1999). Bereavement groups could also offer the support network that is beneficial in assisting children and their families in their grieving process and is more cost effective than providing individual treatment.

Rationale for Group Format

Utilizing a group format for providing services to children and adolescents is a logical choice, primarily because peers serve as their primary social influence throughout development. Groups designed for a targeted population not only provide peer support, but they tend to facilitate normalization. Studies have shown that bereaved children tend to feel more isolated from their peers than non-bereaved children (Webb & Webb, 2002a). Groups focused on a targeted population help break the sense of isolation to which children and adolescents may be particularly prone following the death of a loved one. Yalom (2005) discussed “universality” as one of the therapeutic factors associated with groups that accounts for therapeutic change. “Universality” was defined as recognizing that others have experienced similar events and that people with similar issues tend to have similar thoughts and feelings. “Universality” may be a particularly advantageous concept for children and adolescents whose peer group plays such an important role in their development.

Legal and Ethical Issues for Group

Group interventions with children also produce unique legal and ethical issues that must be considered. According to the Association for Specialists in Group Work (ASGW) Practice Guidelines, groups require special consideration to confidentiality, screening procedures, and leader training (1998). For example, confidentiality is different in groups than in individual treatment. Confidentiality cannot be guaranteed given that other members are present. Additionally, when working with children, the leaders are under the same obligations as American Psychological Association (APA) Code of Ethics which requires therapists to obtain parent's written consent and to follow mandated reporting guidelines. Moreover, ASGW states that it is unethical to run a group without group training and training with children. Group leaders should have a solid understanding of group theory and group counseling skills (ASGW, 1998). In working with children, leaders should also have a thorough understanding of children's development and the abilities of that particular age group. Group specialists feel that training group facilitators receive for work with adults does not generalize to work with children (Van Velsor, 2004). Van Velsor (2004) identified several areas of importance for child group facilitators to master, including group screening with children, child development, facilitating children's groups at different stages, evaluating individual and group process, and protecting children's confidentiality in groups.

Structural Details

There are also many structural details to consider when implementing a group intervention for bereaved children and adolescents. When screening members, it is important to determine whether to include different genders, different ages, different losses, and different manners of death. Dowdney (2000) did not find a statistical relationship between the manner of parental death and the child’s level of psychological distress. However, this has been disputed. Some researchers found increased levels of anger, anxiety, and shame when the death was a murder or suicide (Curtis & Newman, 2001). It is important to take this into consideration when forming a group. It may also be important to look at the balance of the group. For example, if only one child’s significant other died by suicide, they may feel isolated from the group.

Additionally it is important to look at how long it has been since the death. Research shows that children who enter into a group too soon after the death may still be in shock and not capable of discussing the death (Corr& Corr, 1996). Most researchers believe that group interventions are most beneficial after the intense support of friends and family members dwindles. Groups have been found to be effective at one to two years following the death. However, it is important to take into consideration that children appear to take longer to begin processing grief than adults. Most studies suggest that children would not benefit from group interventions any earlier than three months following the death (Corr & Corr, 1996). Moreover, research has not found any indication that children in different stages or “tasks” of grieving cannot benefit from being in the same group (Corr & Corr, 1996). It may even be beneficial for children to learn from other children’s strategies.

Group size is also an important practical consideration, particularly for children. According to Corey & Corey (2006) a general rule to be considered is, “the younger the children, the smaller the group and the shorter the duration of the sessions” (p. 294). Most studies suggest keeping the ratio between children and adults as low as possible, and having at least two facilitators per group. This is particularly important in case a child needs individual attention and another adult will be necessary to continue attending to the group. The place where the group meets is also an important consideration when children are involved. It will be important to provide a safe space for them to play games and make noise, but the same space must also fulfill their need for confidentiality (Corey & Corey, 2006).

Leaders for interventions aimed at grieving children should have a solid understanding of the grief process, understand children's reactions to loss, as well as have the ability to sit with the children's intense feelings. Working with bereaved children also requires the leaders to acknowledge and be willing to share their own personal grief issues.

Efficacy of Group Interventions

Most research looking at the efficacy of group interventions with children uses a qualitative approach to evaluation. There have been few empirical studies conducted. However, this number is increasing as the field begins to recognize the importance of empirically validated interventions. Despite recent efforts the results are unclear at this point. In 1990, Weisz & Weiss conducted a meta-analysis looking at the outcomes of children's groups and their "findings showed unquestioned advantage of treatment over no treatment for troubled children" (p. 542). In 2007, Currier, Holland, and Niemeyer conducted a meta-analysis and concluded that "the overall results do not support the assumption that the bereavement interventions with children have a significant influence on adjustment" (p. 257). The differences may be due to a variety of reasons including weak methodology, making comparisons of children in various developmental stages, as well as the variety among different group interventions that are offered.

There has been an increase in empirical studies focused on the evaluation of bereavement interventions with children and while the data is still lacking it is promising. In general, individual studies have indicated that groups aimed at preventing maladaptive outcomes for children have been found to be generally effective (Masterman & Reams, 1988; Sandler, West, Baca, & Pillow, 1992; Tonkins & Lambert 1996).

In 1996, Tonkins & Lambert evaluated an eight-week psychotherapy group for children ages seven to eleven. They found a decrease in depression, as well as a reduction in overall internalizing and externalizing problems as measured by Achenbach's Child Behavior Checklist at post-test compared to a wait-list control group. Other studies have found improved family and peer relationships, improved school performance and decreased somatization and withdrawal symptoms (Greenberg, 1985). Other studies examining the effectiveness of group interventions with bereaved children and adolescents have not found significant program effects quantitatively (Huss & Ritchie, 1999; Lohnes & Kalter, 1994; Zambelli & DeRosa, 1992). Qualitative research has found that group interventions with bereaved children and adolescents normalized the experience of bereavement, enhanced the ability to identify, express, and understand grief, increased self-esteem, and increased children's willingness to discuss the death with a trusted adult (Stokes et al., 1997; Zambelli & DeRosa, 1992). However, the researchers cautioned generalizing these results to community settings where the interventions are often adjusted to fit a particular community's unique needs.

As previously mentioned, caution should be used when generalizing any results to community based interventions. "There is a small amount of quantitative evidence that community interventions benefit parents and children within a bereaved family, but evidence is too weak to make judgments about the relative effectiveness of different models of community-based interventions" (Curtis & Newman, 2001, p. 492).

Rural Culture

The literature supports that there are significant cultural differences in rural communities that contribute to rural culture being an area of diversity (Slama, 2004a). Like any area of diversity, it is important to note differences, as well as similarities when looking at the culture as a whole. The term "rural" refers to a wide variety of communities including small towns, villages, farms, and countryside.

One difficulty lies in defining the term "rural." According to the United States Economic Research Services there are many definitions of "rural" used by different government agencies (2007). The Census Bureau has several definitions that vary from areas outside of urban areas with upper limits ranging from 2,500 to 50,000 people (US Dept of Agriculture, Economic Research Service, 2007). The Farmers Home Administration defines rural as "open country communities of up to 20,000 in nonmetropolitan areas, and towns of up to 10,000 with a rural character in metropolitan areas" (Cromartie & Swanson, 1990). Another common way of defining rural has also been by determining what it is not. The office of Management and Budget defines rural areas as "all counties outside metropolitan areas" (US Dept of Agriculture, Economic Research Service, 2007). Still others define it on a rural-urban continuum taking into account population density, distance from metro areas, and population growth (Cromartie & Swanson, 1990). In general, there does not appear to be a consensus as to the definition of "rural." Another confounding factor in understanding "rural culture" is that almost one third of the nation's poor and approximately 29% of the nation's elderly are rural residents (Human & Wasem, 1991). These factors play an important role in understanding "rural culture" and it can often be difficult to tease apart which factors are influencing the culture of a rural community.

Program Development

The intervention devised for the current study was based on commonalities between successful bereavement interventions for children (D. Harshman, personal communication, July 2005; J. Formaini, personal communication, June 2005;). Several objectives were considered and then those that seemed most able to be met during a one-day intervention were selected. The first objective of the program was to reduce feelings of isolation and normalize the experience for the children (Huss & Richies, 1999; Lomonaco, Scheidlinger, & Aronson, 2000; Stokes et al., 1999; Tedeshchi & Kilmer, 2005).

One third of the children in the Family Bereavement Project reported feeling embarrassed or different after the death of a parent and nearly half reported that other children did not understand how if felt to lose a parent (Worden, 2006). At the two-year follow up, social problems and changes in self-perception began to show. A second objective of the program was to help the children understand a wide range of emotions, including negative emotions, with an opportunity to express these emotions in a safe environment (Lomonaco et al., 2000; Stokes & Crossley, 2001; Tedeschi & Kilmer, 2005; Tonkins & Lambert, 1996). Research shows that children adjust better when families are open to expression of anger, guilt, sadness, and loss (Vollman, Ganzert, Picker, & Williams, 1971). In addition to the objectives for the children, there were two objectives for the adults. The first objective was to increase communication within the family about the deceased individual (Sandler, et al., 2007; Stokes & Crossley, 2001). Research has shown that open communication, which allows children and caretakers to share feelings, can facilitate the child's ability to mourn (Brice, 1982; Siegel, Mesagno, & Christ, 1990). Moreover, children have shown better adjustment when they are informed about events, have prepared for the death, and were given the opportunity to ask questions (Stokes et al., 1999). A second objective for the adults was to provide them with information about children and grief (Haine et al., 2003; Stokes et al., 1997; Sandler et al., 2007). Research has shown that the better a caretaker understood the psychological issues regarding child bereavement the more support the child received (Siegal et al., 1990).

CHAPTER II

PROCEDURES

Camp Method

Pilot Study

A pilot study was conducted in September 2006. Prior to the pilot study the author and colleagues met with the Indiana Visiting Nurses Association (VNA) Hospice staff to conduct an informal needs assessment. It was determined that there was a need for a children's intervention focusing on bereavement in the county and surrounding areas. The author and colleagues met with other professionals who conducted similar programs. Areas that were explored were funding, recruitment, consent, group activities, and other procedural details. Due to the rural nature of the community in which this study was conducted, many unique circumstances had to be considered. For example, after meeting with other programs it was decided that it would not be feasible to run a weekly bereavement group. A major reason for this decision was the limited bereaved population in the area with a limited number of bereaved children in different age categories, and the distance that families would have to travel for attendance. Therefore it would be unlikely that there would be enough children in the same developmental stage for a weekly group. Additionally, one group serving only a small age bracket would ignore the needs of the other children in the community who were also in need of support. It was decided to conduct a one-day camp to introduce the community to the program. A budget was developed, approved, and funded in part by the VNA Hospice. A manual was developed that included psychoeducational materials, group activities, as well as information on budget, funding, and advertisement. For more information regarding the manual, please contact the author.

The camp was a one-day, five-hour intervention that included group activities, family activities, child activities, and caregiver activities (for complete schedule see Appendix A). Groups were co-led by two advanced doctoral students and/or trained hospice volunteers.

The pilot group, entitled Sharing Our Family's Tears, was held on September 23, 2006 from 9am-1:30pm. Three families participated, the children's ages ranged from five to ten years old. The children participated in activities that allowed them to tell their story and label their feelings in a fun, safe way. Due to the number of participants, all of the children were combined into one group. While the children participated in activities, the adults participated in their own group which helped them to normalize the grief their children were feeling, to recognize when their child needs professional help, and to discuss the difficulties of being a grieving caregiver. The adults accompanying the children were a diverse group including parents, grandparents, aunts, uncles, and counselors. Advanced doctoral level graduate students in clinical psychology co-facilitated the group. Training for the graduate students included participating in a one credit course on Issues in Childhood Bereavement offered through the university.

A great deal of qualitative and practical information was gained from this experience. The first key piece of information was about the importance of advertisement and contacting key persons in the community. This appears to be particularly important for a rural community. The group facilitators discussed which activities they felt were most useful and which activities they did not find helpful. The location of the event appeared to be easy for families to find. Lastly, a new name was created that reflected the group's positive atmosphere.

Camp Participants

Following the pilot, families were recruited primarily through flyers, brochures and newspaper/radio advertisement in a rural northeastern town (see Appendices B, C, and D respectively). Because of the importance of key persons in rural communities, the coordinators contacted individuals, either by phone or by mail, who would be in a position to make referrals, including funeral directors, guidance counselors, and other service providers (see Appendix E for letter). There were four eligibility criteria for families to participate in the group: a) at least one child in the family was between 6 and 16 years of age, b) the child had experienced the death of someone close to him or her, c) the loss occurred no sooner than 6 months ago and no longer than 60 months prior to the group, and d) at least one caregiver was willing to be present and participate in the camp (see Appendix F for decision tree).

Camp Procedures

Families interested in the camp participated in a brief 15-20 minute screening interview over the phone (Appendix G). This interview was used to determine the family's eligibility for the program and to explain the objectives of the camp and answer any questions the family may have. Children, who were not appropriate for the group, i.e. if the death was too recent, were referred to local resources for individual counseling.

Two of the camps were held at a local park pavilion and one of the camps was held at a university facility. On the day of the camp, participants were asked to complete the registration. At this time, confidentiality was explained and caregiver informed consent (Appendix H) and child assent (Appendix I) was obtained. Any family who declined to participate in the evaluation was still able to participate in the camp activities.

Following registration, participants were asked to complete the evaluation measures. Caregivers and children were asked to complete the appropriate pre-test evaluation form (Appendices J and K). Camp facilitators assisted the children in answering the questionnaire.

The camp was a one-day, five-hour intervention that included group activities, family activities, child activities, and caregiver activities (for complete schedule see Appendix A). Groups were co-led by two advanced doctoral students and/or trained hospice volunteers. The first segment consisted of group activities focused on cohesion and universality. During the next segment, the children participated in developmentally appropriate groups and the caregivers participated in their own group. Caregivers were asked a series of open-ended questions about how their child and family was coping with the death (see Appendix L). The answers were audio taped to assure accuracy. The focus of this segment was to build rapport and to use developmentally appropriate activities to open the discussion of death. Following the first group of activities, the children participated in a focus group where they were asked open-ended questions about their loss and their thoughts about the camp (Appendix M). The participants then worked within their family to begin making a quilt square in remembrance of their special person who has died; the focus of this activity was to increase communication within the family about the deceased person. After lunch, the participants broke back into groups divided by age. The activities focused on feelings associated with grief. Lastly, the group came together to present their quilt squares and closed with a final activity about coping strategies.

Upon completion of the final activity all participants were asked to complete a post-test evaluation form and answer several open-ended questions verbally (see Appendices L, M, N, and O). Again, camp facilitators assisted children in completing questionnaires. All verbal responses were audio taped to assure accuracy. Group leaders were asked to complete the facilitator evaluation form (Appendix P). Participants were given both a verbal and written debriefing paragraph explaining the purpose of the study and a list of local mental health resources should they wish to seek counseling services (Appendix Q).

Camp Measures

Pre-test evaluation form. Each caregiver and their child completed a pre-test evaluation (Appendices J and K). The pre-test evaluation was created by a local VNA Hospice (J. Formaini, personal communication, June 2005) and adapted by the author to address the child’s experience following the death of their special person and the objectives of this camp. Child and caregiver measures were similar in content, but were worded at a developmentally appropriate level.

The caregiver pre-test measure consisted of four demographic questions (e.g., name, age, gender), four yes/no questions (e.g. has your child received counseling for the death(s)?), three open-ended questions (e.g. what changes have there been in your family since your special person died?), and 14 attitude scale questions. For the attitude scale questions each respondent was asked to rate each item on a 1-to-10 response scale where one equals not at all and 10 equals very much. Sample statements include, “My child has talked with other kids his/her age who have had someone special in their lives die” and “My child’s life has changed since their special person died.”

The child pre-test measure consisted of six demographic questions (e.g., name, age, gender), two yes/no questions (e.g. have you ever been in a grief group before?), three multiple choice questions (e.g. what are some of your fears about coming to “Over the Rainbow?”), and 12 attitude scale questions. For the attitude scale questions each respondent was asked to rate each item 1(not at all)-to-10 (very much). Sample statements include, “I feel comfortable talking about my special person who died” and “I am comfortable expressing my feelings about the death of my special person.”

Post-test evaluation form. Each child and caregiver was asked to complete a post-test evaluation (Appendices N and O). This measure included topics similar to those that were in the pre-test; however participants were asked to reflect any changes in behavior given the intervention. Additional open-ended questions were added to gain feedback about the child's favorite activities and suggestions for future camps (Appendices L and M).

The caregiver post-test measure consisted of three demographic questions (e.g., name, age, gender), five yes/no questions (e.g. were the goals of "Over the Rainbow" explained to you?), nine open-ended questions (e.g. what did you like the most about the camp?), and four multiple choice questions. For the majority of the multiple choice questions each respondent was asked to choose, extremely, very, somewhat, or not at all, for each question. Sample questions included, "Are you satisfied with the services and support provided to you and your child(ren) at 'Over the Rainbow?'" Following the completion of the post-test measure caregivers were asked a series of open-ended questions about the camp and their experience.

The child post-test measure consisted of 12 attitude scale questions. For the attitude scale questions each respondent was asked to rate each item on a 1(not at all)-to-10 (very much). Sample statements include, "I feel comfortable talking about my special person who died" and "I am comfortable expressing my feelings about the death of my special person." Following the completion of the post-test measure children were asked a series of open-ended questions about the camp and their experience.

Facilitator evaluation form. This measure was designed by the author and was administered to group facilitators following the intervention to determine which activities facilitators found beneficial and which activities they would change or eliminate (Appendix P). Facilitators were also asked to elaborate on any changes they would recommend regarding procedural areas including volunteer training, location, and organization.

Key Informant Method

The grounded theory method guided the collection and analysis of data for this portion of the study. Grounded theory was introduced by Glaser and Strauss (1967) as a systematic approach to the study of social interactions. Grounded theory is a method that has been used extensively across a variety of social science disciplines. The basic tenet of this approach is that a theory must emerge from the data, or in other words, a theory must be grounded in the data. The objective of grounded theory is to develop an account of a phenomenon that identifies the major constructs, their relationships, the context, and process, thus providing a theory of the phenomenon that is much more than a descriptive account (Becker, 1993). The aim of this portion of the study was to identify potential factors that enable and impede the use of child and adolescent grief services in a rural community.

Sample

In grounded theory, sample selection involves participants who are experiencing the phenomena, events and incidents related to the process under investigation. The target population for this study was children and families who have experienced the death of someone close to them. The convenience sample of key informants consisted of fourteen members of the community that come in contact with grieving children and their families on a regular basis. Sampling continued until the researcher verified the content of the data and obtained a range of responses indicating the data was repetitive and yielded no new information (Chenitz & Swanson, 1986).

Key Informant Participants

Key informants were chosen using an informal snowball sampling approach, using contacts established during the piloting of the project. The convenience sample consisted of 14 members of the community including guidance counselors (N=3), psychologists (N=5), clergy (N=2), VNA Hospice staff (N=3), social workers (N=1), grief group coordinators (N=2), and university faculty (N=3). (Note that N=19 because some key informants fit into more than one category). The only eligibility criteria for key informants were that they regularly came into contact with grieving children and their families and that they were a member of the rural community.

Key Informant Procedures

After selecting informants, they were contacted via phone or email to schedule an interview. The interviews were conducted over a period of three months. Each interview lasted approximately 30-60 minutes. The interviews took place at the informants' respective offices. Prior to beginning the interview, the consent form was signed and the participants were asked permission to audio-tape the interview (Appendix R). At this time, the semi-structured interview process began. The Key Informant Interview (Appendix S) was used as a guide and additional follow-up questions were asked to seek clarification.

Key Informant Interview

This was a semi-structured interview created by the evaluator consisting of five open-ended questions (see Appendix R). The interview took approximately 30-60 minutes. The interview was designed to obtain the key informant's opinion regarding barriers to treatment utilization and possible solutions for the targeted community.

CHAPTER III

DATA AND ANALYSIS

Camp Results

The results for this section were obtained from the pre- and post- test child measures, pre- and post- test caregiver measures, as well as the information collected through interviews that were conducted throughout the camp.

Demographics

The sample for this study included seven children who had experienced the death of a family member. The pilot study in fall 2006 (N=3) accounted for 43% of the sample, 43% attended the camp held in spring 2007 (N=3), and 14% of the sample attended the camp held in spring 2008 (N=1). Ten additional children who signed up for the various camps did not attend. Therefore, the drop out rate was high at 41%.

The age of children participating in this study ranged from 5 to 11 years of age, with a mean age of eight years. The child sample consisted of five males (71%) and two female (29%). Four children had lost a parent (57%), two children had lost a sibling (29%), and one child lost a grandparent (14%). The length of time since the death of the family member ranged from eight months to three years, with a mean of 14 months. A diverse group of adults attended the various camps with their child(ren) including three mothers, two fathers, one grandmother, one aunt, one uncle, and one counselor.

Multiple causes of death were represented in this sample. The sample included three children (43%) who lost their family member in an accident, two in a vehicular accident and one in a work related fire. Three of the children lost their family member to disease (43%), one to a heart attack (14%), one to cancer (14%), one to a stroke (14%) and one lost their loved one to a drug overdose (14%).

None of the children had previously attended a grief camp. Two children had received counseling regarding the death prior to the camp. Only one adult attendee had attended a grief support group for adults and one of the adults received counseling following the death.

Child Data

The child pre-test measure was given to each child prior to beginning the camp and the post-test measure was completed following the last activity. Additional information was obtained through individual and group interviews held throughout the day. As reflected in Table 1, seven items showed adaptive responses and two items indicated areas that children were struggling with following the camp.

A paired-sample t-test was conducted to compare pre- and post-test scores on the child evaluation measure to determine any immediate changes in behavior following the intervention. A sum score was calculated by combining the scores of all of the attitude scale questions for pre- and post- test (scale ranged from 1(not at all)-to-10 (very much)). The mean score increased from 71.00 (SD =9.42) on the pretest to 87.00 (SD =12.81) on the posttest. The difference between the 2 means was statistically significant at the .05 level (t=-2.75, df=6). Generally, a higher score on the attitude scale questions indicates a more adaptive response, and item number five “I have questions about the death of my special person that I would like to have answered” was reverse coded. Therefore, these results suggested that the intervention was able to significantly produce positive change in the overall behaviors that were examined by the questionnaire.

Paired sample t-tests were also conducted on each of the 15 items individually at pre- and posttest, only one item revealed statistical significance. However, it is unclear if this is because there is truly no difference between the items at pre- and post- or if it is just a reflection of the inadequate sample size. Item number 10, “I am comfortable expressing my feelings about the death of my special person” showed a statistically significant difference from pre- to posttest. The mean score increased from 1.86 (SD=1.57) on the pretest to 6.71 (SD=3.50) on the posttest. The difference between the two means was statistically significant at the .01 level (t=-3.91, df=6). Again, a higher score on the attitude scale questions indicates a more adaptive response. These results suggested that the children were more comfortable expressing their feelings about the death of their special person following the intervention (see Table 1).

Although not statistically significant, eight items were interpreted based on data trends and answers obtained from the interviews. Six of these items showed adaptive responses. The first question asked how the children felt about attending the camp, pre-test results yielded a mean of 6.9 (SD=3.58) whereas post test yielded an 8.4 (SD=3.36). Interview data indicated that children expressed some initial anxiety about attending the group, who would be there, what they would have to talk about and why they had to come. Interview data also indicated that most children were glad that they came and that they had a lot of fun. One child stated, “I didn’t think that I would have fun or make friends, but I did.” The second question asked how often the children talked with their peers about the death of their loved one, pre-test data generated a mean of 5.7 (SD=3.82) and post-test data generated a mean of 9.0 (SD=1.91), suggesting that the camp gave the children the opportunity to discuss their loved one with their peers, something they may not have had the opportunity to do pre-camp. Question four asked the children how comfortable they felt talking about their special person who died. Pre-test data yielded a mean 7.7 (SD=3.95) whereas post test yielded a 9.1 (SD=1.86). Data from the interviews revealed that it was less difficult for children to talk about their loved one than they had imagined and that the camp allowed them the opportunity to talk about their loved one. When asked what he liked about the camp, one child simply stated, “they actually talk about it.” The fifth question asked if the children had questions about the death of their special person that they would like to have answered. Pre-test results produced a mean of 5.7 (SD=3.82) and post-test results produced a 3.9 (SD=3.18), a lower mean score suggests that the camp may have given children the opportunity to have some of their questions answered. One child did not know how his special person died and expressed sadness and confusion related to not knowing. The child’s guardians were unaware that they had shielded the child from this information. The camp gave the family a safe place to talk about the death and to answer questions that the child might have been afraid to ask.

The sixth question asked if the children talked with their parent/guardian about the death of their special person. Pre-test data generated a mean of 5.4 (SD=4.03) and post-test data generated a 6.7 (SD=3.35) implying that the children felt that they were given the opportunity to talk with their parent/guardian about their special person. Information obtained from the interviews signified how difficult it might be for children to talk to their parents/guardians about the death. One child stated, “I don’t like talking about [my special person] because it makes everyone sad.” The seventh question asked if the child could remember good and happy times with their special person. Pre-test results yielded an 8.7 (SD=2.21) and post-test results yielded a 10.0 (SD=0), indicating that the camp gave the children the opportunity to reflect on positive memories of their loved one.

Two items reflected that children were having more difficulties following the camp. The eighth question asked if it was hard for the child to look at pictures of things that belonged to and/or reminded them of their special person. Pre-test results generated a mean of 6.7 (SD=4.31) and post-test results generated a mean of 8.0 (SD=2.08), suggesting that it may have been more difficult for the child to be reminded of their special person. Question nine asked the children if their lives had changed since their special person died. Pre-test data produced an 8.3 (SD=2.63) and post-test data produced a 9.6 (SD=0.79), implying that children became more aware of how their lives have changed since their special person died. This may be related to children not associating certain feelings or behaviors with the death of their loved one. For example, one child stated that he "talks back to mom" more since the death of his loved one and stated that he believes he does that because he is angry about the loss.

Adult Data

The adult pre-test evaluation form was administered prior to the camp and the post-test evaluation form was administered following the final activity. Adult pre- and posttest data were not compared because different items were asked at pre- and post. Paired sample t-test analysis was used to compare child and adult sum scores, as well as individual items at pretest for attitude scale questions. Again due to the small sample size, descriptive statistics were calculated and general trends in combination with interview data were utilized to draw preliminary conclusions. The term "adult" (opposed to parent/guardian) is used in describing the data because a variety of adults attended the camp with their children including parents, grandparents, aunts/uncles, and in one case the child's counselor. All of the adults completed the data regardless of their relationship with the child.

Comparing Child and Adult Data

The child pre-test measure and the adult pre-test measure were compared to get an idea of how parents perceived their child's ability to cope with the death of their loved one. Only pretest data is compared, as adults were not asked the same questions at post test. As reflected in Table 1, parents over-estimated their child's ability to cope in four areas; parents appeared to have a better estimation of their child's ability in the remaining areas.

A paired-sample t-test was conducted to compare child and adult scores on the pre-test evaluation measure to determine any differences between child and adult's perception of child functioning related to grief. A sum score for each was calculated by combining the scores of all of the attitude scale questions for both child and adult pre- test (scale ranged from 1(not at all)-to-10 (very much)). The mean score for the child pre-test was 72.0 (SD =9.90) compared to the mean score on the adult pretest, which was 87.5 (SD =5.75). The difference between the 2 means was statistically significant at the .05 level (t=-4.91, df=5). Generally, a higher score on the attitude scale questions indicates a more adaptive response, therefore, these results suggest that the adults perceived their child as adapting better to the loss than the child perceived themselves adapting.

Additionally, a paired sample t-test was conducted comparing each attitude scale item individually for child and adult at pretest (scale ranged from 1(not at all)-to-10 (very much)), only one comparison revealed significance. Again, item number 10, “I am comfortable expressing my feelings about the death of my special person” (adult item read “My child is comfortable expressing his/her feelings about the death of their special person.”) showed a statistically significant difference between child and adult pretest means. The mean score on the child pretest was 1.86 (SD=1.57) whereas the mean score on the parent pretest was 7.14 (SD=1.68). The difference between the two means was statistically significant at the .01 level (t=-5.93, df=6). These results suggested that the parents overestimated how comfortable the child felt at expressing their feelings about the death of their special person following the intervention (see Figure 1).

Parents over-estimated their child's ability to cope with the grief in three other areas as well, including how they felt about coming to the camp, how comfortable they were talking to their parent/guardian and how difficult it was for them to look at pictures. These items are reported combining data trends and information obtained from the interviews. The first item asked how the children felt about attending the camp and how the adults felt about their child coming to the camp, child results yielded a mean of 6.9 (SD=3.58) whereas parent results yielded 9.4 (SD=0.79). These results suggested that the adults felt better about their child attending the camp than the child did. It is important to point out that the child post test data generated a mean of 8.4 (SD= 3.36), suggesting that some of the children's initial anxiety about attending the group dissipated throughout the day. The sixth question asked if the child talked with their parent/guardian about the death of their special person. Child data generated a mean of 5.4 (SD=4.03) and adult data generated a 7.7 (SD=1.60), implying that the adults felt that their child talked more with them about the deceased than the child felt. The eighth question asked if it was hard for the child to look at pictures of things that belonged to and/or reminded them of their special person. Child results generated a mean of 6.7 (SD=4.31) and adult results generated a mean of 3.6 (SD=2.23), suggesting that it may be more difficult for the child to be reminded by pictures and belongings than the adult may have anticipated.

Parents were better able to estimate their child’s ability to cope in the remaining areas. The following items were also reported combining data trends and information obtained from the interviews. The second question asked how often the children talked with their peers about the death of their loved one and how often the parent thought the child talked with their peers, child data generated a mean of 5.7 (SD=3.82) and adult data generated a mean of 6.0 (SD=1.79). Interview data suggested that parents were often uncertain how often their child talked with peers with a similar loss, nonetheless parents appeared fairly accurate at estimating how often their child discussed the loss with their peers. Question four asked the children how comfortable they felt talking about their special person who died. Child data yielded a mean 7.7 (SD=3.95) whereas adult data yielded a 7.86 (SD=1.35). It appears that generally the adults were able to perceive how comfortable their child was talking about their special person. The seventh question asked if the child could remember good and happy times with their special person. Child results yielded an 8.7 (SD=2.21) and adult results yielded an 8.6 (SD=1.68). Both children and adults felt that the children were able to remember positive memories of the deceased individual. Question nine asked the children if their lives have changed since their special person died. Child data produced an 8.3 (SD=2.63) and adult data produced a 9.0 (SD=1.53), implying that both children and adults were aware of how their lives have changed since their special person died. Question eleven asked the child if they have people in their lives that can help them cope with the death of their special person. Child results produced a mean of 7.9 (SD=3.39) and adult results yielded an 8.6 (SD=1.21). Both the children and adults recognized that the child had people in their lives to help them cope with the loss.

Table 1

Mean Ratings for Child and Adult Attitude Scales*

	Child Pre-test n=7	Child Post-test n=7	Adult Pre-test n=9
Q1 glad came	6.9	9.4	8.4
Q2 talked with peer	5.7	5.1	9.0
Q3 hard to have fun	4.7	3.9	4.3
Q4 comfortable talking	7.7	7.9	9.1
Q5 have questions	5.7	5.0	3.9
Q6 talk with parent	5.4	7.7	6.7
Q7 remember good times	8.7	8.9	10.0
Q8 hard to look at pictures	6.7	3.6	8.0
Q9 life changed	8.3	9.0	9.6
Q10 comfort express feelings	1.9	7.1	6.7
Q11 people can help cope	7.9	8.9	8.3
Q12 3 things to feel better	8.9	7.7	8.0

***1=not at all; 5=some; 10=very much**

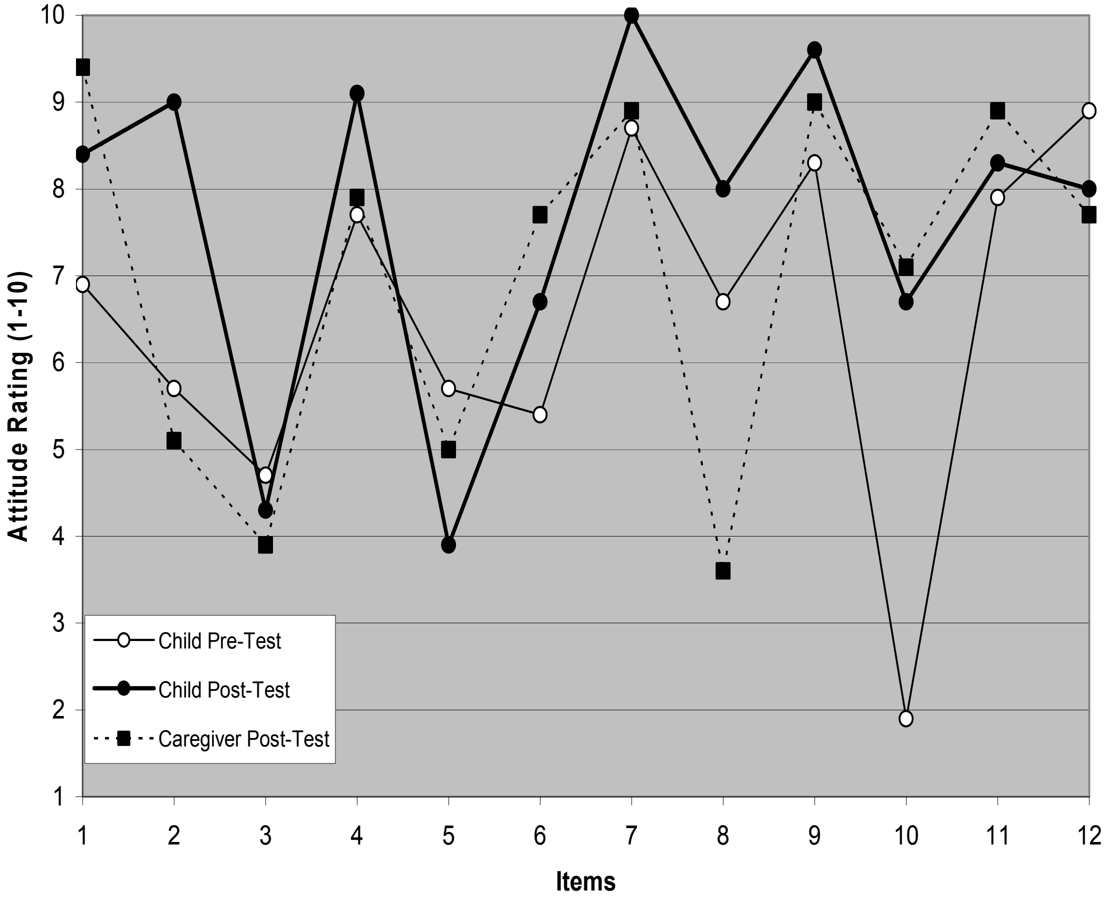

Figure 1

Mean ratings for child and adult attitude scales.

Key Informant Results

Fourteen key informants in the community were interviewed. All interviews were audio taped. The recordings were independently reviewed by the researcher and by a research assistant. Two categories of responses, barriers and solutions, were pulled from each interview and each example was placed on an index card. Each quote was placed on its own index card. Later the index cards were sorted independently into broad categories. After the cards were sorted into categories, the two researchers compared their categorization and labels were discussed. The broad categories for barriers included:

(1) Lack of communication about the help that is needed
(2) Access
(3) Fear of Group Process
(4) Rural Culture

The following broad categories were created for solutions:

(1) Community Integration
(2) Creating Access
(3) Education
(4) Communication
(5) Trust Building

These categories were later broken into sub-categories. The following sections will examine each category and its subcategories, and explain some of the comments that produced the categories. The broad categories and sub-categories were then presented to two of the faculty experts for further review.

Minor changes were made in regards to the names of categories and three of the comments were determined to fit into more than one category.

Barriers Categories

(1) Lack of communication about the help that is needed

This category was separated into two different areas where communication was problematic—people in the community not knowing about the programs available for a variety of reasons and people being misinformed about the program.

(i) Lack of information about program (N= 6)

Many of the informants discussed lack of communication in the community regarding available programming. One informant answered emphatically, “People just don’t know they [programs] exist.” Due to the rural nature of the community informants hypothesized that getting word to families may be more complicated than traditional advertisement. Informants felt that placing ads in newspaper and on the radio would not be enough. This category included more than just not knowing that the programming existed, it included families not having enough information about the program to feel comfortable attending. Several informants discussed families’ reluctance to attend programs because they were unsure what to expect when they get there. Other informants discussed the role the large difference in the social strata in this particular community may make in communication efforts. Informants felt that the information was not getting to the people who need the programming the most. This division in the social strata may make it more difficult for information to spread to populations of lower socio-economic status and programs are often held by members of a higher socio-economic status. Data from the 2007 US Census demonstrated this divide in the social strata, reporting that approximately 35% of the population had an income of $25 thousand or less and approximately 38% of the population had an income of $50 thousand or more.

(ii) Misinformation (N=2)

The second subcategory was misinformation about grief. A few informants discussed how they felt that many families were unaware of their child's grief because children's grief can often manifest in less obvious ways. Many adults may not recognize that children grieve at all. Moreover, families may not recognize symptoms as being related to grief. For example, a family member may not recognize that a child who has frequent physical complaints such as stomach aches or headaches or a child who is struggling with behavioral difficulties at school may actually be struggling with grief. Lastly, informants expressed that families may not recognize the needs of grieving children or may assume that these needs are being met elsewhere. For example, adults may assume a child's needs are being met by a school counselor or by peers.

(2) Access

This category included many practical differences of rural communities and a fundamental lack of accessibility. Subcategories under this topic included three different types of barriers to families accessing programming, physical barriers, financial barriers, and time barriers.

(i) Physical barriers (N=10)

The subcategory of physical barriers includes transportation, parking and other accessibility issues. Over half of the informants cited transportation, or rather lack of transportation as a barrier to utilization of community programming. This community, like many other rural communities, has limited public transportation. Less than 0.5% of the community utilizes public transportation to commute to work (US Census, 2007). Moreover, the community is spread out across 830 square miles and regular and consistent public transportation does not reach where a large portion of the families live. A second frequent response was convenient parking. One informant stated, “You need to make it as easy as possible for families to come. If they can’t find a parking spot they are going to leave. It’s as simple as that. If families are already unsure about attending your program, they will use any inconvenience as a reason to turn around and go home.” Others felt that the lack of a consistent “brick and mortar” place to go was a barrier. Informants expressed that families who could not see the location and could not check it out prior to the group would be less likely to attend the program.

(ii) Financial barriers (N=5)

The second subcategory was financial barriers which included financial barriers for program development and sustainability as well as the financial difficulties of the families. Informants discussed difficulty with financial sustainability of programs in rural communities stating that there is a great deal of demand for funds. Informants felt that competition from other non-profit groups made it difficult to maintain programs. In regard to families, informants felt that any cost associated with programs would be a deterrence. This included the cost of transportation (e.g., gas, parking), the cost to attend program, and missing work to attend. Approximately 17.9% of individuals are living below poverty in Indiana County which is 4% higher than the national average (US Census, 2007). Therefore many families cannot afford any cost associated with programming, or travel for support services.

(iii) Time barriers (N=3)

Lastly time barriers were discussed. Informants felt that it would be difficult for families to make a commitment to an ongoing program. Difficulties that were discussed were time flexibility, a significant portion of the community has shift-work and this increases the difficulty of attendance. Additionally, because of the rural nature of the communities there is often the time of a commute to be considered. A program in this community may be the closest program for 30 or more miles, however this commute may be a deterrent for families to attend.

(3) Fear of Group Process

The third category was fears related to what has been labeled the “group process.” This category included both families’ concerns about attending a group as well as the concerns of referral sources and group facilitators in regards to referring to group and facilitating groups.

Subcategories were as follows:

(i) Psychoeducation about grief (emotion/avoidance of emotion) (N=6)

Informants discussed many hypotheses related to the families' grief related emotions and their avoidance of these intense emotions as a deterrence to them attending a group focusing on grief and loss. Informants felt that families would have a great deal of anxiety about what would happen in the group, what they would have to share with the group, and how other people would perceive them. Many of the emotions related to grief are intense negative emotions including sadness, anger, guilt, and shame. Informants felt that many grievers attempt to avoid these difficult emotions and felt that they would be hesitant to attend a group that they believed felt may bring these feelings to the surface. One informant felt that the adults of these families are often overcome by their own grief and many times cannot see the grief of their children as well. Other informants suggested that adults may be protective of their children and not want to bring them to a group where their child may have to experience intense emotions.

(ii) Facilitator Education/Provider concerns (N=4)

The second subcategory was referral and group facilitator concerns. Most informants agreed that it was important that the referral sources were aware of the program and were confident that it was a successful program. Informants hypothesized that one of the fears of the community providers might be that that the program would be overly faith based. A faith based program appears to be a double edged sword in this particular community, where some informants felt that it would be comforting and others felt that it would be detrimental. Another area of importance centers on educating referral sources about what stage of grief the group would be focusing on (i.e. early grievers or long-term support), types of losses, and age of individuals included in the group. One informant shared a story where she referred an individual to a group a year after the loss of her child and the individual reported back that the group was a poor fit because the other members had all lost their husbands recently and were much older than she. She felt that this individual was reluctant to take future referrals following this experience. Providers felt that they would need more details about the criteria for the group before referring individuals to the group. One informant stated that the key was to "Educate the educators so that they will refer to the program. They must also trust in the program." Other concerns that were mentioned was the fear of people "without training" running the groups and the fear of other group process oriented concerns such as having a mixed gender group and individuals in differing stages of grief.

(4) Rural Culture

Rural Americans arguably have some cultural differences compared to urban Americans that affect attitudes towards mental health related services and make it more complex to provide successful services (Slama, 2004b). The category of rural culture included many different subcategories.

(i) Public perception of mental health care (N=3)

According to a 2004 survey by the American Psychological Association (APA) approximately 20% of “Americans may not choose to seek help from a mental health professional because they fear there is a stigma associated with therapy” (APA, 2004, Stigma, ¶ 1). Informants suggested that this fear of mental health stigma may be even greater in rural communities. Informants also discussed individuals “shying away from the medical model.” Informants felt that individuals in the community would only seek professional services if there was a problem rather than for support and they may often see grief as a normal process of life. One informant stated, “They think of the groups as therapy and that makes them feel that there is something wrong with them, something wrong with their grief, something must be wrong if they need a group.”

(ii) Privacy (N=1)

One informant discussed the importance of privacy and the lack of privacy for rural residents. According to the same APA survey approximately 21% of Americans said that “concerns about other people finding out might be a reason not to seek help from a mental health professional” (APA, 2004, Privacy, ¶ 4). This also may be more likely for rural residents. This informant stated, “Due to the nature of a rural community, there are fewer people and people are more likely to know each other and to talk about each other.” One author coined this phenomenon the “goldfish bowl effect” (Slama, 2004b). The “goldfish bowl effect” is defined as rural individuals being “aware that other people are very interested in their lives and in talking to others about them” (Slama, 2004b, p. 11). This lack of anonymity makes it more difficult for individuals in rural communities to seek services.

(iv) Stoicism (N=6)

Stoicism has often been associated with rural communities. Many informants described an attitude in this community as a “do it yourself” stance. They described individuals having a belief that people are “self sufficient” and that they “don’t need other people.” One informant added, “People here believe you need to take care of yourself and your family. Maybe they can, maybe they can’t, but that’s the way they feel.” Several informants described the community as more “conservative” and members wanting to keep private matters to themselves. Another informant stated that the community is not “psychologically minded” explaining that they rarely look to the mental health field when they are experiencing distress.

(v) Mistrust (N=4)

Another topic that occurred frequently among the informants was trust. Informants stated that rural individuals do not trust the “experts,” particularly if they do not have a pre-established relationship with the organization or individual providing the services.

(vi) Intimidation (N=2)

A fifth topic that emerged was intimidation. Informants felt that the programs and the “experts” that do the programming might intimidate individuals. This topic emerged in relation to the difference in social strata that was previously discussed. Informants felt that those in the higher socioeconomic status would intimidate individuals from lower socioeconomic status and they often believe that the individuals running the programming are those from a higher socioeconomic status.

(vii) Low population base (N=1)

Rural communities by nature have fewer individuals living there and therefore have fewer bereaved individuals to attend programming.

(viii) Insularity (N=4)

A seventh theme that emerged in the category of rural culture was insularity. One informant described this as “what happens in the family stays in the family.” Informants discussed the idea that rural community members feel that they should be able to handle their difficulties within their family without outside help. Another informant described rural communities as a “closed shop,” the informant went on to say that if the program or individuals running the program are not originally part of the community they will have a difficult time joining in the community and being accepted by the community. A third informant described the community as “reserved” and described again a culture that had difficulty letting “outsiders” into the community.

(ix) Lifestyle (N=4)

The last subcategory discussed the lifestyle of rural Americans. One informant stated, “They just don’t have enough energy. They need a break.” This informant went on to explain that they felt that these families have “a lot on their plate” and cannot attend to areas they may not see as a priority. Another informant described the rural lifestyle as “not as structured,” this informant felt that rural individuals were used to more flexibility in their daily schedules and this led to more difficulty agreeing to attend a structured program. This same informant stated in regards to grieving families, “They don’t have the same sense of urgency to just get on with their lives.” This individual felt that it was not as necessary for rural individuals to get on with their daily lives and “move on.”

Solutions Categories

(1) Community Integration

The two subcategories were as follow:

(i) Long-term investment into program (N=4)

One area addressed to overcome the barriers of rural communities for programming was the organization having a long-term investment into the program. One informant commented on the perseverance necessary stating, “You have to keep trying—it won’t happen overnight.” Several other informants discussed the need of patience. They felt that it would take several years for a program to catch on. One informant stated, “Three years, if you can stick with it three years then they might think it is here to stay."

(ii) Networking in community (N=3)

Another theme that emerged was the necessity of networking within the community. Informants discussed the need to ensure that the program maintains a good reputation in the community. Informants also discussed the need for the program to be established as a regular social service in the community. One informant stated, "Everyone needs to know that when a child loses a loved one, this is the place to refer them every time—teachers, guidance counselors, everyone." Several informants discussed a need for "community ownership" of the program—a program run for the community, by the community.

(2) Creating Access

(i) Central physical location (N=7)

Creating access was an important solution discussed by informants. They discussed making it as easy as possible for families to attend. Suggestions included providing transportation for families, having convenient parking, and a central location. Other topics discussed were to have a "brick and mortar" place where families could "drop in and check it out" before committing to the program.

(ii) Consistency of the program (N=2)

A second theme discussed was consistency of the program. Informants felt that having a program that was at the same place and same time would make families more comfortable. They expressed that a program that was available on an ongoing basis for families to access when they were ready to attend would increase utilization. Informants stressed the need of the program to be a "safe haven" for families, "something they knew would be there when they needed it."

(3) Education

(i) Educating community (N=5)

Informants discussed the need to educate the community about children and grief. They stressed the importance of educating not only the families, but other professionals such as guidance counselors, teachers, physicians, and clergy as well. Informants felt that many professionals, despite working regularly with children, were often unaware of how children grieved. Informants also felt that it was necessary to educate the families about children's grief. One informant stated, "If you want families to attend, they need to see the need for it." Another informant discussed the need for outcome measures to be able to educate the community about the effectiveness of the program.

(ii) Educating providers (N=3)

Another theme emerged regarding educating providers. They stressed the importance of educating the people who will be providing the services. One informant discussed the need to educate providers about grief so that they can "meet people where they are in the grieving process." Another discussed the need to educate about the role of the family, "You can't just treat the kids. The whole family needs to be involved." Lastly, the use of outcome measures should be utilized to educate the providers about what is working and what is not working so that the program can adapt to meet the needs of the community.

(4) Communication

(i) Promotion (N=5)

In regards to communication, the first theme that emerged was the importance of promotion. Informants discussed the need for advertising, marketing, and publicity throughout the community. They discussed more labor-intensive ways to reach the community such as hanging up flyers. One informant used the term "super saturating" and went on to explain that the community needs to be aware of it and then reminded later that it exists, "For example, they might hear about it on the radio and think, 'oh my sister's kids should go to that,' but might forget; but if they see it again on a flyer in the grocery store they might just follow through."

(ii) Involving community to promote program (N=13)

In regards to promotion, the informants almost unanimously discussed the need for community involvement in the promotion. People will be more likely to attend if they are being referred from someone in the community whom they already know. They discussed the importance of involving key persons in the community to help spread the word. They suggested that volunteers speak at various community organizations. Most all felt that the majority of referrals were going to come via "word of mouth." One informant summed it up as “just keep people talking about it!” Others suggested using families that attended the program, “if it was successful they will spread the word.” Informants felt that the referral would carry more weight if it was from another caregiver who is also grieving. Another felt that the kids needed to be involved in spreading the word, “kids are going to listen to other kids.”

(iii) Outreach in the community (N=2)

A few informants discussed the importance of outreach in the community to “let them [the community] know who you are and what your program is about.” Suggestions included leading a teacher in-service on children’s grief, setting up a booth at school orientations, setting up a booth at community events, and presenting to other service organizations. One informant felt that it would be important to utilize e-resources, “kids want to check it out, and maybe they could check it out online or chat with other kids about it.”

(5) Trust Building

(i) Personal connections (N=5)

Many Informants felt that having a personal connection with the community and the families was essential to getting people to attend programming. This included utilizing personal connections for referrals and building trust in the community. Informants felt that a program could begin to do this by having a good reputation, by being consistent, and by being available to families. One informant discussed the role of the "human connection." Families need to be able to connect with a person involved in the organization stating, "They need that connection before they can trust the program."

(ii) Support of professionals (N=1)

Lastly, one informant discussed the need of support from the professionals in the community. Similarly, this informant discussed the importance of trust in order to gain support from the professionals. A program needs to maintain its reputation and to be consistent. Referral sources need to know that they are giving a good referral to their clients.

CHAPTER IV

SUMMARY, CONCLUSIONS, RECOMMENDATIONS

This project was designed to develop and evaluate a bereavement program specifically designed to meet the needs of children and families in a rural community. Several bereavement program models were examined to identify the key aspects of successful bereavement programs (Caring Place, personal communication, May 2005; D. Harshman, personal communication, July 2005; J. Formaini, personal communication, June 2005; Sandler, et al., 2003) and the various programs were then adapted to fit the needs of a particular rural community. An informal needs assessment revealed no other bereavement programs for children and their families within 30 miles of the community. The final program consisted of a one-day camp for children ages six to twelve and their families. The camp was attempted on four occasions, but despite intensive recruitment only seven child participants attended the camp. There was evidence that the group was well-liked and beneficial to those who attended, however the lack of attendance made the camp an inefficient use of time and money in order to provide services to the community. Nonetheless, it was encouraging that some positive results were found given such a brief intervention with such a small, wide-ranging age sample. Several reasons were hypothesized as to why recruitment for the program was unsuccessful and a follow-up study was created to investigate the barriers and possible solutions to aid future programs. Because the brief intervention was successful, it was important to find ways for more children to benefit from this or similar resources in the future. Fourteen key informants in the community were interviewed to address this topic and grounded theory was utilized to examine the results.

Camp

Qualitative results revealed that both children and adults enjoyed the experience and found it beneficial. Quantitative results suggested that the intervention was able to make a significant positive change in a composite measure of behaviors. The questionnaire was loosely based on the objectives of the program. The first objective of the program was to reduce feelings of isolation and to normalize the experience for the children. Data trends suggested that the program appeared to give children an opportunity to discuss their loved one with their peers, something they may not have had the opportunity to do pre-camp. Moreover, information obtained through the interviews revealed that it was easier for children to talk about their loved one than they had imagined and that the camp allowed them the opportunity to talk about their loved one. This study was consistent with previous findings that grief groups are an ideal opportunity to normalize children’s feelings of grief and to reduce feelings of isolation (Huss & Richies, 1999; Lomonaco, Scheidlinger, & Aronson, 2000; Stokes et al., 1999; Tedeshchi & Kilmer, 2005). A second objective of the program was to help the children understand a wide range of emotions, including negative emotions, with an opportunity to express these emotions in a safe environment. Research has shown that children adjust better when families are open to expressions of anger, guilt, sadness, and loss (Vollman et al., 1971). Results from this study suggested that bereavement support can facilitate a positive change in behavior regarding expression of emotion and feelings about the death of their special person following the intervention. This was the most significant finding of this study and was consistent with previous findings (Lomonaco et al., 2000; Stokes & Crossley, 2001, Tedeschi & Kilmer, 2005; Tonkins & Lambert, 1996). Despite only seven participants, significant results were found suggesting that the children were more comfortable after the camp expressing their emotions related to the death of their loved one. One hypothesis that might explain this result was that the camp gave the children to express both positive and negative emotions related to the loss, and also aided the children in labeling the emotions they were feeling.

In addition to the objectives specific to the children, there were two objectives for the adults. The first objective was to increase communication within the family about the deceased individual. Both quantitative and qualitative findings indicated that the children felt that they were given the opportunity to talk with their parent/guardian about their special person. Research has shown that families with more open communication patterns have been found to be more adaptive following a loss (Sandler et al., 2007; Stokes & Crossley, 2001). This study showed that bereavement support targeted at the family can facilitate this positive change in behavior for the children. A second objective was to provide adults with information about children and grief. Overwhelmingly all of the adults who attended the group felt that they understood children's grief better and this appeared to normalize their children's reactions for them. Adults who are more knowledgeable and better prepared for their child's response to a death are better able to support the child (Siegal et al., 1990). In keeping with the findings of Sandler and colleagues (2003), this study has found that bereavement support with a psychoeducational component can increase adults' knowledge regarding children and their grief.

Overall, it appears that for those who attended the one-day program that it was successful at meeting the goals set for this level of intervention. It was also encouraging that results were found despite only five hours of intervention, a small sample, and a heterogeneous group of children and families.

Child pre-test data was also compared to adult pre-test data to identify how accurate adults were at determining how their child was coping with the death of their loved one. In general, the adults felt that their child was coping with the death better than the child felt that they were coping. Most notably, the adults felt that their child was more comfortable expressing emotions. Other areas where parents over-estimated their child's level of comfort included how their child felt about coming to the camp, how comfortable the child was talking to their parent/guardian about the death, and about how difficult it was for them to look at pictures of their loved one. The camp was an opportunity to facilitate open communication between the adults and children so that the adults could better understand how their child was coping and how they could help their child. One potential strength of the program was that it combined psycheducational components with activities designed to increase communication within the family. This not only allowed caregivers to become more aware of how they may be over-estimating their child's ability to cope, but also helped the children to be better able to communicate their needs to their caregivers. One theme that emerged from the children was their concern for their caregivers, at times to the detriment of their own needs. For example, one suppressed his need to talk about his loved one because it made his mother cry and another child chose not to ask his caregivers the questions he had about the death of his loved one because “talking about her makes them sad.” It appears important for adults be able to model healthy expression of negative emotions and acceptance of these emotions. This would better prepare children to accept their own emotions and to better tolerate such expression by their caregiver.

Key Informant Interviews

Key informant interviews supported what is known in the literature about the barriers for mental health programming in rural areas. In the past, the VNA Hospice has also struggled to form adult support groups due to lack of attendance. Individuals involved in this project hypothesized six barriers regarding the community that made it challenging to run bereavement support groups (Demaree, Thornton, & Zanich, 2000). Demaree and colleagues (2000) suggested the following barriers: confidentiality concerns; desire to restrict contacts; inadequate mass transportation; marketing difficulties; “critical mass” problem; and attitude of self-reliance. These are all consistent with the barriers suggested by the key informants in the current study.

The Office of Rural Health Policy (OHRP; US Department of Health and Human Services, 2005) has outlined three areas that were obstacles for rural community mental health programming to overcome. They are availability, accessibility, and acceptability.

The first area that was outlined by the ORHP was availability, “over 85 percent of the 1969 federally designated mental health professional shortage areas are rural” (Bird, Dempsey, Hartley, 2001, p. 6). One of the reasons the second phase of this study was conducted was because of the disparity between the needs assessment and the attendance at the program. It appears that although there is a shortage of mental health program and professionals in rural communities there is still some resistance to individuals utilizing these resources when they are available, partially because of the other barriers discussed, but it may be partially related to the idea that the communities are used to getting along without the programs. This highlights the key informant’s discussion on the importance of stability in a community and patience for them to become comfortable dealing with grief in a different way.

Accessibility was broken into three areas—knowledge, transportation, and financing. All areas were similarly supported by the key informants’ interviews. The ORHP further described knowledge as, “an essential element to access is knowing when one needs care, where the care options are, and what options are available to address needs” (2005, p. 56). The need for education regarding children’s grief and grief programs, as well as the need for extensive advertisement and community involvement was suggested by the informants as ways to help increase knowledge. A second area of accessibility is being able to get to the programs. The lack of transportation was cited by most all of the informants. Similarly, the financial constraints of rural communities and rural individuals were noted by several of the informants.

Finally, OHRP discussed acceptability. OHRP's data were consistent with the key informant's opinions that rural community members value self-reliance and utilizing family or other close relationships to solve problems. Because of this value it may be more likely for rural individuals to attach stigma to having or seeking help for mental health related problems. Because grief in and of itself is not considered a "mental health problem" there may be more stigma attached to seeking support for grief. An additional difficulty with the increased stigma in rural communities is the lack of anonymity. Higher levels of perceived stigma have been associated with more negative attitudes towards help-seeking among rural residents (Wrigley, Jackson, Judd, & Komiti, 2005).

In summary, rural providers face many additional unique difficulties when implementing programs related to mental health. The information from the key informant interviews supported the data collected by the OHRP in that the three major barriers to individuals utilizing mental health related programs are availability, accessibility, and acceptability. This study found more evidence for problems with accessibility and acceptability.

This program attempted to address many of these barriers; other barriers were not addressed simply because they were not known at the time or because of the lack of resources available. Many of the barriers were addressed utilizing solutions that were later suggested by the key informants.

The first barrier identified by the key informants was lack of communication about the support that is available within the community. This area included lack of information, as well as misinformation. The key informants suggested promotion, outreach, and utilizing word-of-mouth to communicate more clearly with the community. This program attempted to attend to this barrier by meeting with key persons in the community; however it may have been beneficial to meet with even more key persons. For example, instead of sending announcements for church bulletins, it may have been helpful to meet with the ministers individually. Additionally, community education would be valuable to increase knowledge of the program, as well as decrease misinformation about children's grief and the goals of the program. For example, while in the process of completing the key informant interviews with a local guidance counselor, the counselor mentioned that she often only thought of children who had lost a family member more recently. After discussing the goals of the program and the knowledge of children revisiting grief at different developmental stages, as well as symptoms that may be connected to grief that would not be obvious, this counselor was able to come up with several additional children that she would have referred to the camp. This highlights the need for more education in the community. For example, this particular key informant suggested an in-service day directed at educating school personnel about children's grief and the services available to these students and their families. This would be an efficient manner to educate a large number of potential referral sources at one time. This method would help to overcome a second barrier identified by the key informants which was encapsulated by "fear of the group process." This barrier focused on psychoeducation about grief for community providers and grieving families. Increased outreach to not only community referrals, but also to potential families may help to overcome this barrier. Another suggestion was to set up tables at different events geared towards families, such as at back to school night and at the local county fair. This would give families an opportunity to put a face with the name and to ask any questions that they may have regarding the program.

A third barrier identified by the key informants was accessibility. Three barriers to accessibility were identified: physical, financial, and time. This program addressed many of the physical barriers by holding the camp at a centrally located area with convenient parking. One physical barrier that this program was not able to overcome was the lack of a “brick and mortar” place that was available to families when the camp was not running. The camp did not have the resources to have an office that was staffed to answer questions for potential families. However, the camp did utilize another organization’s phone number and personnel took messages regarding the camp. Another physical barrier that was not able to be addressed was the lack of transportation. More families may have been able to attend if a shuttle had been available, unfortunately the program did not have the financial resources to provide transportation to families. This leads to the second barrier which was financial barriers, although the program did not have the financial means to provide transportation, the program was able to sustain itself with community donations and families were not asked to pay for the camp. Additionally, local community companies provided breakfast and lunch for the families free of charge. The last barrier, which was time, was addressed by having a one-day intervention, opposed to a weekly group. We were unable to accommodate families who had members working different shifts, but because the event was only one-day, we had hoped that families could attend despite the inconvenience.

The last barrier introduced by the key informants was that of elements specific to rural culture. This barrier included many subcategories. Two main categories of solutions, trust building and community integration, developed out of the key informant data to address this area of difficulty. The key informants felt that in order to improve the trust of the community it would involve families being told about the program by individuals who were a part of the community and those with whom they had a personal relationship with prior to the camp. This program attempted to address this by working through the local county Visiting Nurses Association (VNA), it was hoped that by working with a community partner that had a long-standing history within the community that families would increase their trust in the program. Another resource that was not utilized was that of the author's personal connection to the community and to loss. The author and her family lived in the community when the author's mother died when she and her siblings were children. One of the reasons the author was interested in pursuing this program was because there were not any resources available to her family after the loss. In retrospect, it may have been beneficial for the author to advertise her personal connection to the community, as well as to share her personal connection to grief and loss. It is possible that this would have helped families trust the program more and trust the intentions of the program. One of the main themes regarding the solutions identified by key informants was having the community integrate the program as one of their own and this may have been easier if the community was aware that it was developed by someone from within the community. Although the camp was attempted four times over the span of two years, key informants predict that it would take longer for the community to recognize the program as a stable resource. This highlights the importance of stability, as well as continuous networking within the community to spread the word about the program. It appeared critical that, despite all other obstacles, the community must accept the program as one of their own so members are comfortable utilizing the resources.

Limitations

It is important to note several limitations of this study. First, was the small sample size in the camp study. Consequently, virtually all of the camp results were created combining data trends and information obtained from the interviews. Caution should be used in drawing conclusions from these results which are quite tentative in nature because they did not show statistical significance. A second important limitation in regards to the camp study was the lack of a control group. In order to assess program effectiveness, a study needs to be able not only to track the outcomes of program participants, but also to determine how they would have fared in absence of the program. As a result, it was difficult to interpret findings on outcomes. A third limitation was that information collected in the study was of a self-report nature, which depending on the subject areas being queried, may be prone to some inaccuracy as a result of discomfort with self-disclosure or socially desirable responding intended to please the evaluator. A limitation in regarding the key informant interviews was that they were a convenience sample that also may have been biased in ways that were not known. Finally, rural communities are a heterogeneous population and the sample utilized for this study was a homogenous group from a specific rural community limiting the ability to generalize these findings to other rural communities.

Suggestions for Future Research

There is little research regarding children's mental health programming in rural areas and even less literature regarding bereavement programs. The results of this study suggest that further research needs to be done to examine the specific needs of children's program development for rural communities. In particular, it appears that having and evaluating a consistent program on an on-going basis would be beneficial to determine the factors that make a program successful. Moreover, given the support for resiliency and children's grief it would be imperative to include a control group, as well as long-term follow-up.

Conclusions

"Health care programs will not be accepted nor well utilized by rural people unless they address relevant needs through methods congruent with rural life styles" (Flax, Ivens, Wagenfeld, & Weiss, 1979). Rural community providers are faced with a unique set of challenges and it appears that unless those obstacles are addressed, community-wide prevention programming may not be the most cost-efficient, efficacious mode of treatment. However, fostering community acceptance of the program by establishing community ownership in the endeavor and highlighting their common goals with the facilitators may be a slow process. Ultimately, the goal would be to meet the most basic needs of grieving children and families, particularly regarding psychoeducation. Despite recent debate about the effectiveness of grief groups for children (Currier et al., 2007; Forte, Hill, Pazder, & Feudtner, 2004; Stroebe, Stroebe, & Schut; US Dept of Agriculture, Economic Research Service, 2007) and grief counseling in general, most people in the field believe that it can be beneficial given the right circumstances. The heart of the debate lies in discovering what those circumstances are and how those circumstances may require adaptation depending on the population. The current study showed that it is possible to create a brief, one-day intervention that appeared to have positive short-term effects for participants. In the future, a more long-term goal would be to gain the trust of the rural community and to increase utilization of this resource.

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Appendix A
Schedule of Events

“Over The Rainbow”
Schedule of Events
April 2008

10 am Caregivers & Children Arrive

REGISTRATION: Volunteers help caregivers and children find nametags and T-shirts, as well as complete consent forms and liability forms. Volunteers mingle with families and assist them in completing pre-test measures. All children ages 11 and under will be paired with a volunteer. Children over 11 and caregivers will have the choice of meeting with a volunteer or answering questions on their own.

INTRODUCTORY PROJECT: Children begin *Handprint Rainbow Craft* while waiting for all participants to arrive and register. The purpose of this activity is to build feelings of universality around the theme of loss, as well as coming together for a common purpose.

10:15 am Introduction & Icebreaker

Introduce group and volunteers. Review objectives for group. Review group rules. Discuss metaphor of rainbow by showing handprints- What do we all have in common? – Different phases of grief etc. The next activity will be a group activity focused on the “yucky” feelings of grief.

10:30 am Break into small group according to age

Segment 1: “Getting to know you” → developmentally appropriate activities focused on allowing the children to get to know one another, while reiterating that we are all here because we have lost someone. [Caregivers will meet and discuss the common symptoms of grief and how children’s symptoms will differ depending on their developmental stage and how it differs from adult’s grief.]

Move Game
Musical Chairs

11:00 am

Segment 2: “Telling the Story” → developmentally appropriate activities focused on allowing the children to tell as little or as much of their story as they would like to tell their group. [During this time, caregivers will meet and begin telling as little or as much of their own story to the group.]

Memory Lane

11:30 Focus Group 1- Have children answer open-ended qualitative questions in their small group

11:45 Move back into families and start family quilt project → Families will create quilt squares to memorialize their special person who died. The focus of this activity is to increase positive communication around the person who died within the family.

Noon Lunch

12:30 Have families explain quilt squares → Families will share with the group what they chose to symbolize their special person, this activity will continue to build the group bond among members. No family is forced to participate.

12:45 Break back into small groups

Segment 3: "Feeling Activity"→ developmentally appropriate activities focused on the difficult feelings associated with grief to help normalize some of the feelings the children are feeling. [During this time, caregivers will begin discussing the normal symptoms of grief and the signs to be aware if their child may need additional services. Lastly, caregivers will discuss how to talk to their child about grief.]

Feelings Ball
Feelings Mask
Body Map

1:30 Focus Group 2- Have children answer open-ended qualitative questions in their small group

2:00 Start closing ceremony → activity will focus on coping strategies to help children and families deal with the strong feelings associated with grief.

2:30 Volunteers mingle with families and assist them in completing post-test measures. All children ages 11 and under will be paired with a volunteer. Children over 11 and caregivers will have the choice of meeting with a volunteer answering questions on their own.

Appendix B
Flyer

OVER THE RAINBOW

Sponsored by VNA Hospice of Indiana and IUP Center for Applied Psychology

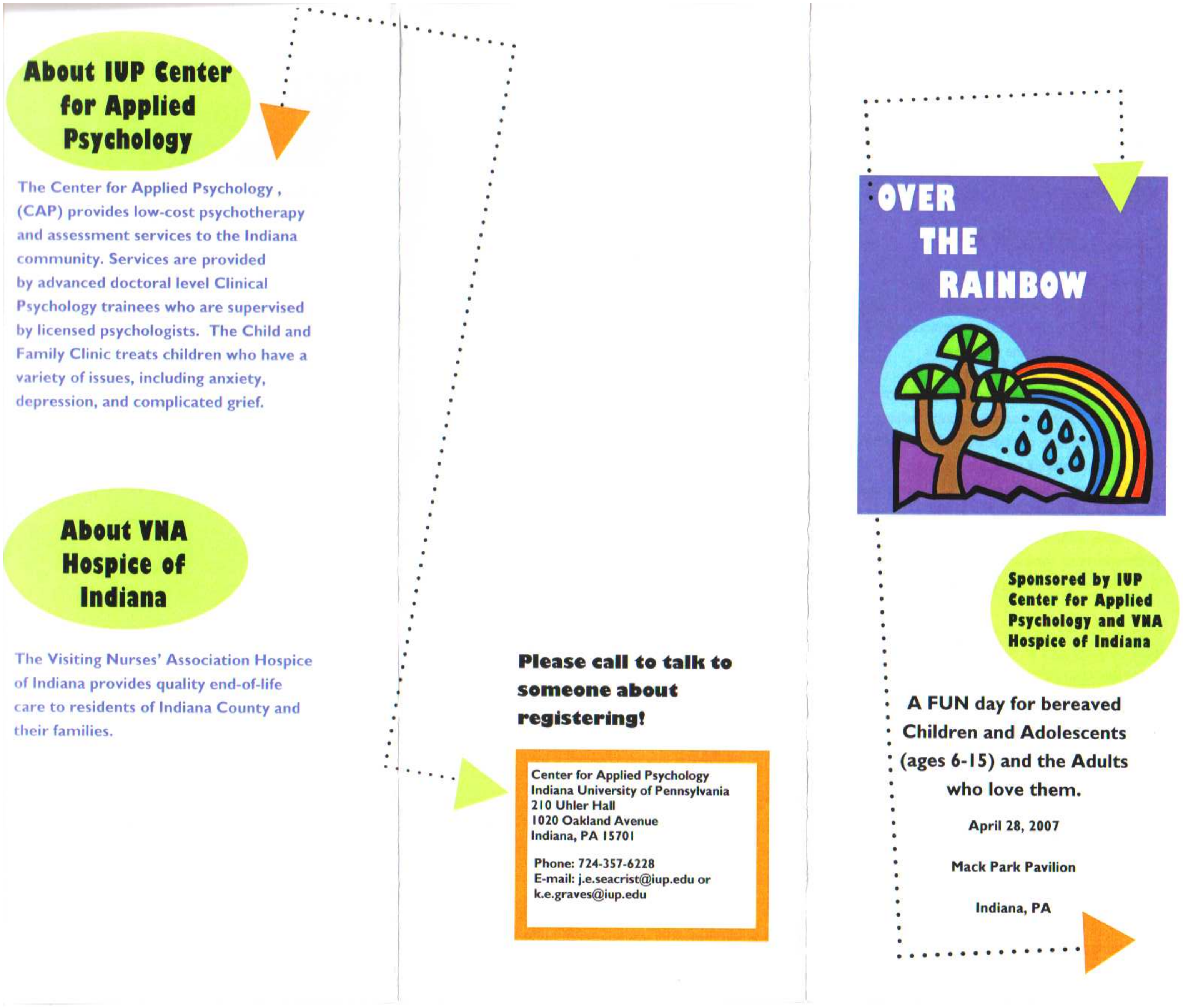
DATE: 4/28/2007
9AM TO 3PM
MACK PARK PAVILION

This FREE experience is for families with children & adolescents ages 5 to 15 who have experienced the death of someone very close to them between 6 months and 5 years ago. Children will have an opportunity to share both with others their age & their family.

This event will provide opportunities for support, friendship, and learning about normal reactions to grief.

Please contact us for more information about registering!
724-357-6228
or email:
j.e.seacrist@iup.edu or
k.e.graves@iup.edu

Appendix C
Brochure



About IUP Center for Applied Psychology

The Center for Applied Psychology , (CAP) provides low-cost psychotherapy and assessment services to the Indiana community. Services are provided by advanced doctoral level Clinical Psychology trainees who are supervised by licensed psychologists. The Child and Family Clinic treats children who have a variety of issues, including anxiety, depression, and complicated grief.

About VNA Hospice of Indiana

The Visiting Nurses' Association Hospice of Indiana provides quality end-of-life care to residents of Indiana County and their families.

Please call to talk to someone about registering!

Center for Applied Psychology
Indiana University of Pennsylvania
210 Uhler Hall
1020 Oakland Avenue
Indiana, PA 15701

Phone: 724-357-6228
E-mail: j.e.seacrist@iup.edu or
k.e.graves@iup.edu

OVER THE RAINBOW

Sponsored by IUP Center for Applied Psychology and VNA Hospice of Indiana

A FUN day for bereaved Children and Adolescents (ages 6-15) and the Adults who love them.

April 28, 2007

Mack Park Pavilion

Indiana, PA

OVER THE RAINBOW

About the Camp

This one day camp experience is for families with children and adolescents ages 6 to 15 who have experienced the death of someone very close to them within the past 5 years.

The camp provides an opportunity to interact with peers in age appropriate groups, helping them to know they are not alone. They will be in a safe place among trained volunteers, doctoral trainees, and grief specialists who will provide companionship as well as guidance. As they participate in FUN activities, they will learn healthy ways to cope with the strong feelings that often emerge after a significant loss.

Parents or other adult guardians must accompany their children to camp. While the children enjoy their own activities, the adults will be able to participate within the supportive atmosphere of an adult group. They will learn ways to help their grieving children and will have a chance to share with other adults who have had similar losses.

This camp experience is intended to provide opportunities for support, friendship, and learning about the normalcy of grief. It is NOT intended to be grief therapy.

How to Register

Pre-registration is required and begins on February 1. Space is limited so please register as families will be selected on a first-come, first-serve basis. Once we receive your registration form, you will be contacted by phone for additional information and for an opportunity to discuss any issues or concerns with camp coordinators.

Please complete the pre-registration form, detach, and mail after April 14, 2007 to:

Center for Applied Psychology
Indiana University of Pennsylvania
210 Uhler Hall
1020 Oakland Avenue
Indiana, PA 15701

Pre Registration Form

Name of Adult(s) who will be attending:

____

____

Address: ______________________________

____

Phone Number: Daytime ________________

Evening ________________

Names of Children	Age	School Grade
____________	___	____
____________	___	____
____________	___	____
____________	___	____
____________	___	____

Name of person who died:

____

Child's relationship to the person who died:

____

For more information about the camp, please call 724-357-6228.

Appendix D
Sample Press Releases

Sample Press Release

Over the Rainbow, is a one day, FREE camp for children ages 6-16 who have lost someone close to them through death. It will be held April 28th from 9am - 5pm at Mack Park Pavilion in Indiana, PA. At Over the Rainbow, children and teens will have the opportunity to meet others who have had similar experiences. Over the Rainbow offers fun activities and a chance to make new friends.

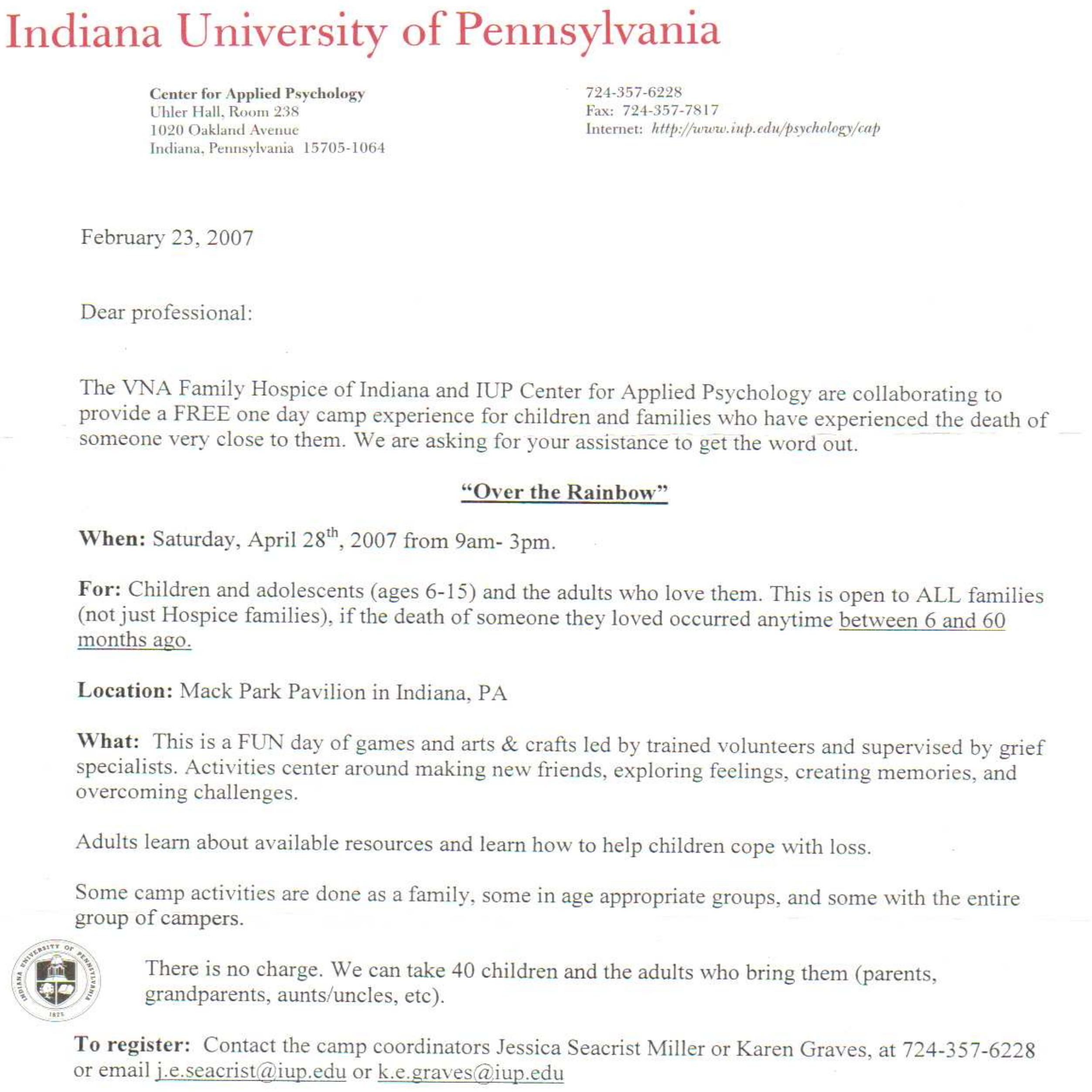
Over the Rainbow is co-sponsored by Indiana VNA Family Hospice and IUP's Center for Applied Psychology. Activities include: games, arts and crafts, and special activities designed to provide peer support while dealing with feelings of loss. Counselors include professional staff and trained volunteers. Pre-registration is required.

For more information, please contact Jessica Miller (j.e.seacrist@iup.edu) or Karen Graves (k.e.graves@iup.edu) or call Center for Applied Psychology at (724) 357-6228.

Sample Radio Announcement

Do you know a child who has lost someone close to them? A FREE, fun day is being held for bereaved children and families on April 23rd at Mack Park Pavilion. Call 724-357-6228 for more information. Pre-Registration is required. Again that number is 724-357-6228.

Appendix E
Letter to Professionals



Indiana University of Pennsylvania

Center for Applied Psychology
Uhler Hall, Room 238
1020 Oakland Avenue
Indiana, Pennsylvania 15705-1064

724-357-6228
Fax: 724-357-7817
Internet: *http://www.iup.edu/psychology/cap*

February 23, 2007

Dear professional:

The VNA Family Hospice of Indiana and IUP Center for Applied Psychology are collaborating to provide a FREE one day camp experience for children and families who have experienced the death of someone very close to them. We are asking for your assistance to get the word out.

"Over the Rainbow"

When: Saturday, April 28th, 2007 from 9am- 3pm.

For: Children and adolescents (ages 6-15) and the adults who love them. This is open to ALL families (not just Hospice families), if the death of someone they loved occurred anytime between 6 and 60 months ago.

Location: Mack Park Pavilion in Indiana, PA

What: This is a FUN day of games and arts & crafts led by trained volunteers and supervised by grief specialists. Activities center around making new friends, exploring feelings, creating memories, and overcoming challenges.

Adults learn about available resources and learn how to help children cope with loss.

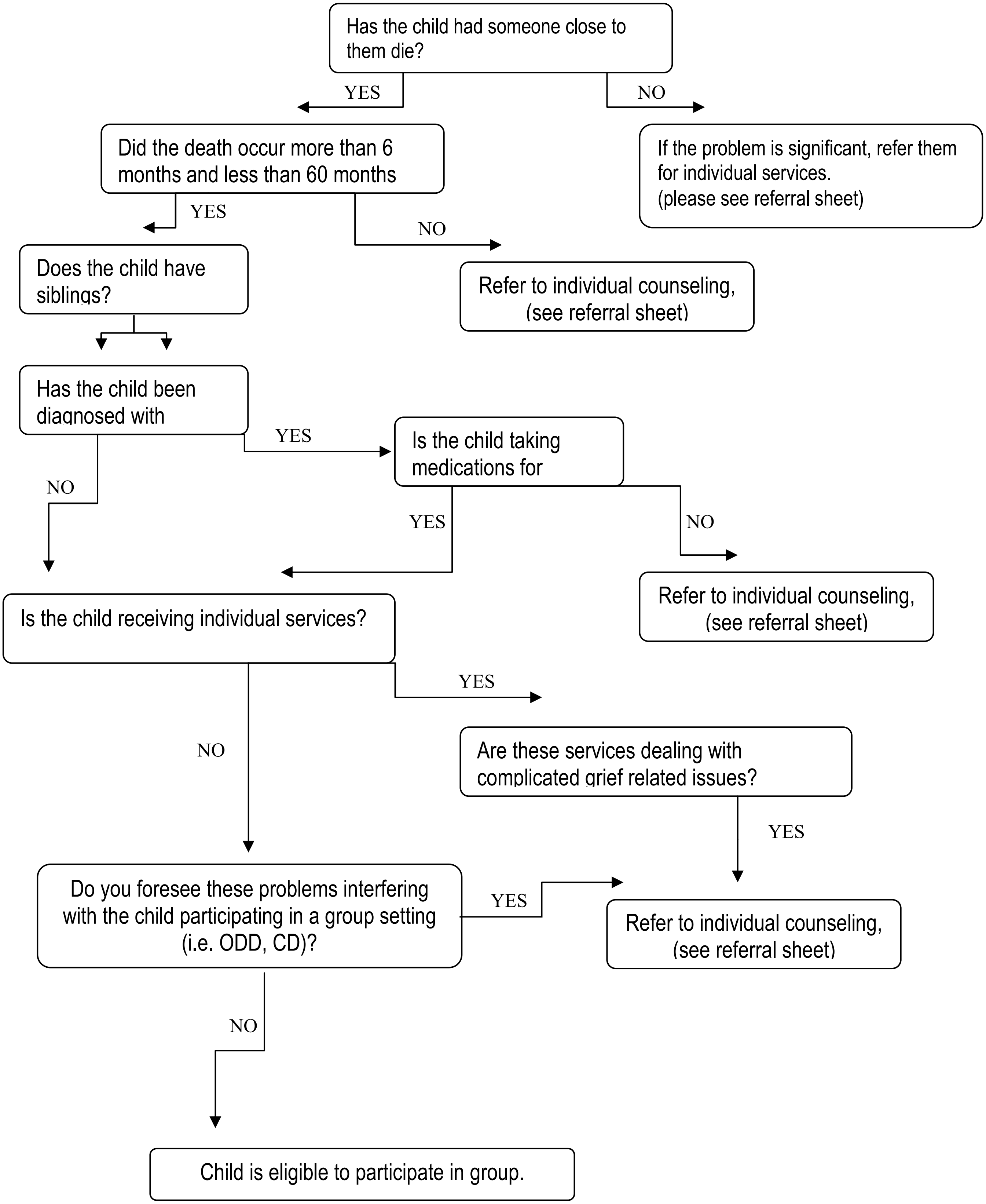
Some camp activities are done as a family, some in age appropriate groups, and some with the entire group of campers.

1875

There is no charge. We can take 40 children and the adults who bring them (parents, grandparents, aunts/uncles, etc).

To register: Contact the camp coordinators Jessica Seacrist Miller or Karen Graves, at 724-357-6228 or email j.e.seacrist@iup.edu or k.e.graves@iup.edu

Appendix F
Decision Tree for Camp Acceptance



Appendix G
Screening Interview

Once families have registered a brief phone screening interview will take place.

Sample Protocol

Hello, my name is ______________ and I am calling because I received your registration for "Over the Rainbow" bereavement camp. Is this a good time for you to talk?

If no, ***when would be a good time for you to answer a few questions?***

If yes, ***I have a few questions for you, but first I would like to give you a brief explanation of the group and see if you have any questions or concerns for me.***

Most of the activities will occur in age appropriate groups. While the children are participating in their groups, the adults will be able to participate within the supportive atmosphere of an adult group. This group will focus on ways to help your grieving child and to have an opportunity to share with other adults who have had similar losses. There will also be group activities and family activities. Do you have any questions?

Now, I would like to ask you a few questions about your child(ren) and the death of your loved one.

See Screening Interview (Appendix C). Remember this is a rough outline, please make sure you answer all of the questions. However, some persons may be more talkative and answer some of the questions in a narrative form and that is okay too.

- **What is your name?**
- **What is the child(ren)'s name(s)?**
- **What is your relationship to _____ (child's name)?**
- **What is the best telephone number to reach you at?**
- **How old is _______ (child's name)?**
- **What is _______ (child's name) birthday?**
- **Is _______ (child's name) a boy or a girl?**

- **Does _______ (child’s name) understand why he/she is coming to the camp?**

- **How did you hear about the camp?**

- ***Now I would like to ask you some questions about the person who has died and how your child is dealing with the death.***

- **What is the name of the person who died?**

- **What was their relationship to _______ (child’s name)?**

- **When did they die?**

- **How old was _______ (name of deceased) when he/she died?**

- **How did ________ (name of deceased) die?**

- **Has _______ (child’s name) received any professional support (i.e. school counselor, support group, psychologists, psychiatrist)?**

- If yes**, did the child receive professional support for grief related issues?**

- If yes**, please describe.**

- **Has the child ever been diagnosed with Attention Deficit Hyperactivity Disorder?**

- If yes**, are they taking any medication for ADHD?**

- If yes, **who? where? For how long? Are they still in treatment?**

- **Was the professional support helpful?**

- **What other changes/stresses/losses have occurred in this child’s life (i.e. divorce, pet death, foster care, moving, change of schools, any type of abuse, major illness, friend moving, fire/theft, parent loss of job etc.)?**

- **How did_______ (child’s name) find out about the death?**

- **Has _______ (child’s name) been told the facts about the death?**

- **Did _______ (child’s name) attend the wake/funeral/memorial service?**

- **How did _______ (child's name) react immediately following the death?**
- **How is _______ (child's name) reacting now to the loss?**

- **Is this _______ (child's name) first experience with death?**

- **Has _______ (child's name) or another member of you family experienced emotional or mental health issues for which they received professional services?**

- If yes, **please explain.**

- **Is there anything else we should know about your child?**

The camp will be held on April 23rd at Mack Park Pavilion in Indiana, PA. Do you need directions? Registration will begin at 9am, we will have a continental breakfast. Lunch will be at noon and we will provide lunch.

We also wanted to let you that part of our program includes filling out some evaluation forms and the information collected will be used in a research study to determine if the group is helpful to people. Do you have any questions or concerns about the evaluation or the research study?

Lastly, we will be providing T-shirts for the children. What size T-shirt does your child wear?

Do you have any other questions or concerns at this time?

Thank you for taking the time to answer our questions. We look forward to meeting you on April 23rd. Would you like us to call and remind you?

Appendix H
Parent/Guardian Informed Consent Form

Dear Parent or Guardian,

You and your child are invited to participate in this research study. The following information is provided in order to help you to make an informed decision whether or not to participate and allow your child to participate. If you have any questions please do not hesitate to ask. You and your child are eligible to participate because you lost someone close to you and are attending “Over the Rainbow.”

I am a graduate student at Indiana University of Pennsylvania, in partial fulfillment for my requirements of a doctorate in Clinical Psychology I have chosen to develop and evaluate a bereavement camp, “Over the Rainbow” for children and families in this area. I am writing to ask for your assistance in evaluating “Over the Rainbow.” I would like to know how families feel about this program. Because no one knows your child better than you, I am asking for your assistance. The evaluation will consist of filling out a behavioral checklist and answering some questions about how you and your child’s experience with the death of your loved one. The survey will take about 15-20 minutes to complete. After the program, you will be asked to complete a brief survey about the group. Your child will be asked to answer similar questions about his/her experience with the death of their loved one before the program and his/her experience at the group during and after the program. Your child will be asked to complete questionnaires and answer questions in his/her group that will be audio taped. The tapes will be transcribed and then erased. All identifying information will be removed from the transcription in order to protect your privacy. The transcriptions will be examined for thematic content. This study will be used to help identify strengths and areas for program improvement. The results will be used to improve this program in the future.

You and your child’s participation in this study is voluntary. If at any time you and/or your child choose you no longer wish to participate in the research study your materials will be shredded following the camp. However, verbal information that was collected during the audio taped group sessions will still be included due to difficulty identifying individual children’s contributions. There are no risks involved in participation and no repercussions for non-participation.

Additionally, we would like to ask for your permission to mail behavioral checklists and contact you and your child in 30 days by phone to answer some brief questions. Everyone who participates in the follow up evaluation will receive a $5 gift card to Wal-Mart.

If you choose to allow your child to participate, he/she may withdraw at any time by notifying the researcher or informing the person administering the survey. Upon his/her request to withdraw, all information pertaining to your child will be destroyed except for the audio taped material. If you choose to allow your child to participate, all information will be held in strict confidence. All information is strictly confidential and will not be released to any third party. The information your child provides us will be considered only in combination with that of other participants. The information obtained in the study will be presented to the VNA to help us build future programming and may be published in scientific journals or presented at scientific meetings but your child’s identity will be kept confidential.

If you are willing to allow your child to participate in this study, please sign the statement below and return it to one of the volunteers. If you have any questions or concerns, please ask any of the volunteers for more information. You will also be given a copy of this form for your own records. Also, if you would like information concerning the outcome of this study, we would be more than happy to send you the results of our investigation. Please contact us if this is something that would interest you. Thank for your time and consideration. It is very much appreciated.

______________________________	______________________________
Parent/Guardian Name (please print)	Child Participant Name (please print)
______________________________	______________________________
Parent/Guardian Signature	Date

Student Researcher:
Jessica Seacrist Miller, M.A.
Doctoral Candidate, Clinical Psychology
Uhler Hall
1020 Oakland Ave
Indiana, PA 15705

Dissertation Chair:
Laurie Roehrich, Ph.D.
Licensed Psychologist
Uhler Hall 103
1020 Oakland Ave.
Indiana, PA 15705

This project has been approved by the Indiana University of Pennsylvania Institutional Review Board for the Protection of Human Subjects (Phone: 724/357-7730).

Appendix I
Child Assent Form

We would like your help to make “Over the Rainbow” better for other kids who have lost someone close to them and we need your help. We are going to tell you about a research study so you can decide if you want to help us or not help us with this study. It is OK for you to ask questions about the study. We would like you to help us because you have lost someone close to you and you are attending “Over the Rainbow” day camp.

We would like to know what you and other kids think about this program. Helping us with this study will take about 15-20 minutes of your time. If you would like to help us, you will be asked to answer some questions before the camp, during the camp, and some more questions after the camp. Some of these answers will be audio taped so we can write them down later. Also, I may call you later so we can talk about the camp.

Your parent(s) know about this study, but I wanted to tell you about it also. The things we will learn from this study will help us make the camp better for other kids.

No one is making you help us, and you don’t have to if you don’t want to. If you don’t want to help us with the study nothing bad will happen to you. No one will be mad at you. If you decide later that you don’t want to be part of the research study, you or your parent/guardian can tell one of the volunteers, and we will put all of the answer sheets in the garbage and not include you in the study, however we will not be able to remove your statements that were audio taped because it will be difficult to tell who was talking. If you do want to be in the study, nobody else will know your answers. We am asking everyone who came today to participate in the study, so the information from you and your parents will just be a little part of the big research study. When we finish the research study, we might talk about what we learned with other people, or write it down so other people can read it, but we will always talk about groups of kids, never about you.

If you would like to help us in the study, please print and sign your name on the top of the next page.

I agree to volunteer to be a subject in this study.

My Name (PLEASE PRINT)

____ ____

My Signature____

____ ____

Date

____

Student Researcher:	Dissertation Chair:
Jessica Seacrist Miller, M.A.	Laurie Roehrich, Ph.D.
Doctoral Candidate, Clinical Psychology	Licensed Psychologist
Uhler Hall	Uhler Hall 103
1020 Oakland Ave	1020 Oakland Ave.
Indiana, PA 15705	Indiana, PA 15705

This project has been approved by the Indiana University of Pennsylvania Institutional Review Board for the Protection of Human Subjects (Phone: 724/357-7730).

Appendix J
Pre-Test Evaluation Form (Caregiver Version)

“Over The Rainbow”
Pre-Test Evaluation Form

Name of Child	Age	Gender

1) Has your child ever been in a grief camp for children or teens?

YES NO

2) Has your child ever received counseling for the death(s)?

YES NO

3) Have you ever participated in a grief support group for adults?

YES NO

4) Have you received any counseling for the death(s)?

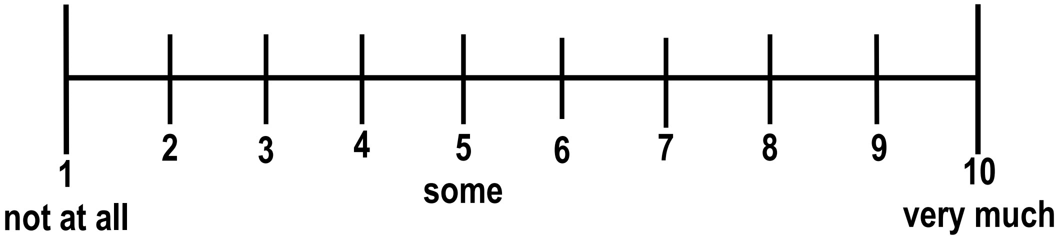
YES NO

5) How long has it been since the death (s)?

____

Please complete the following statements by circling a number on the scale of 1-10 that best matches your response at this time.

1) **Please circle the number that matches your child’s ability to cope with the death at this time.**



2) Please circle the number that matches your ability to cope with the death at this time.

1 2 3 4 5 6 7 8 9 10

not at all — some — very much

3) I am glad that my child is coming to “Over the Rainbow”

1 2 3 4 5 6 7 8 9 10

not at all — some — very much

4) My child has talked with other kids his/her age who have had someone special in their life die.

1 2 3 4 5 6 7 8 9 10

not at all — some — very much

5) It has been hard for my child to laugh, play, or have fun since the death.

1 2 3 4 5 6 7 8 9 10

not at all — some — very much

6) My child is comfortable talking about their special person who died.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

7) My child has questions about the death of their special person that they would like to have answered.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

8) My child talks with me about the death of our loved one(s).

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

9) My child can remember good and/or happy times with their special person.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

10) It is hard for my child to look at pictures or things that belonged to and/or reminds him/her of their special person.

1 2 3 4 5 6 7 8 9 10
not at all some very much

11) My child's life has changed since their special person died.

1 2 3 4 5 6 7 8 9 10
not at all some very much

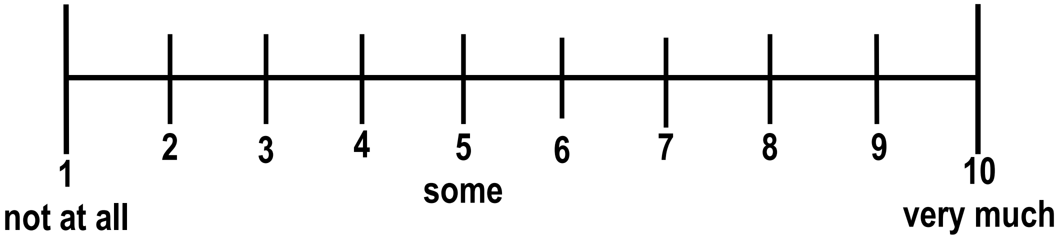
12) My child is comfortable expressing his/her feelings about the death of their special person.

1 2 3 4 5 6 7 8 9 10
not at all some very much

13) My child has people in his/her life who can help them cope with the death of their special person.

1 2 3 4 5 6 7 8 9 10
not at all some very much

14) **When my child is feeling down, they know of at least 3 things they could do to try and feel better.**



15) **What changes have there been in your family since your special person died?**

____

____

____

Appendix K
Pre-Test Evaluation Form (Child Version)

"Over The Rainbow"
Pre-Test Evaluation Form

☺ Name____

☺ I am _________years old. I am in __________ grade at

_______________________________________ school.

☺ I am a BOY GIRL (please circle one)

☺ I am coming to "Over the Rainbow" because…
(check all that apply)

___ My parent/guardian is making me go
___ I wanted to get away from home for awhile
___ I would like to make new friends and have fun
___ I miss my special person who died
___ I would like to meet other kids who also have had a special person in their life who died
___ I would like to learn ways to cope with change and death
___ Other (explain) ___________________________

☺ What are some of your fears about coming to "Over the Rainbow"?

___ I don't want to be away from home all day
___ Maybe other kids won't like me
___ I am afraid I might not have anything in common with the other kids
___ I feel uncomfortable talking with others about death
___ Other (explain) ___________________________

☺ How did you feel about coming to “Over the Rainbow”?


SAD


HAPPY


NERVOUS


MAD


SCARED


OKAY

☺ If you have any other feelings that are not listed above, please write them here:__________________________

☺ How long has it been since your special person died?
____

☺ Have you ever been to a grief group before?

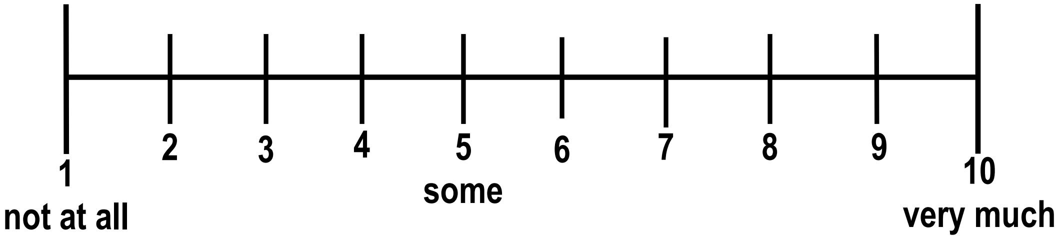
YES NO

☺ Have you ever received counseling for the death?

YES NO

PLEASE COMPLETE THE FOLLOWING STATEMENTS BY CIRCLING THE NUMBER ON A SCALE OF 1 TO 10 THAT BEST MATCHES HOW YOU FEEL.

1) I am glad I am going to “Over the Rainbow”



2) I have talked with other kids my age who have had someone special died.

1 2 3 4 5 6 7 8 9 10

not at all some very much

3) It has been hard for me to laugh, play, or have fun since my special person died.

1 2 3 4 5 6 7 8 9 10

not at all some very much

4) I feel comfortable talking about my special person who died.

1 2 3 4 5 6 7 8 9 10

not at all some very much

5) I have questions about the death of my special person that I would like to have answered.

1 2 3 4 5 6 7 8 9 10

not at all some very much

6) I talk with my parent(s)/guardian(s) about the death of my special person.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

7) I can remember good and/or happy times with my special person.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

8) It is hard to look at pictures or things that belonged to and/or remind me of my special person.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

9) My life has changed since my special person died.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

10) I am comfortable expressing me feelings about the death of my special person.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

11) I have people in my life who can help me cope with the death of my special person.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

12) When I am feeling down, I can think of at least 3 things I could do to try to feel better.

1	2	3	4	5	6	7	8	9	10
not at all				some					very much

Appendix L
Qualitative Interview (Caregiver Version)

Qualitative Open-Ended Questions for Caregivers:

Pre-Test Caregiver (to occur before the group during the pre-test evaluation):

What changes have there been in your family since _____ died?
What changes have there been in your child since ______ died?
What changes have there been in you since ______ died?
Tell me what it was like for you to talk with others who are caring for a grieving child.
What did you learn about your child's grief that you didn't know before the camp?

Post-Test Child (to occur at the end of the camp during the post evaluation):

Tell me what it was like to make the quilt square with your child.
If you knew another parent/guardian who was caring for a grieving child, what would you tell them about the camp?
What did you like the most about the camp?
What did you like the least about the camp?
What would you like to change about the camp?
What is the most important thing that you got out of the camp?
What is the least important thing that you got out of the camp?
The camp used to be called, Sharing Our Family's Tears, which name do you like better (compared to "Over the Rainbow")? Do you have any other suggestions?
Is there anything else you want to tell me?

Follow-Up Child (to occur during the follow-up phone evaluation):

What changes have you seen in your family since the camp?
What changes have you seen in your child since the camp?
Is there anything else you want to tell me?

Appendix M
Qualitative Interview (Child Version)

<u>Qualitative Open-Ended Questions for Children:</u>

Pre-Test Child (to occur after the first 2 segments and before lunch):

Who suggested that you attend the grief camp?
At first, did you want to attend the grief camp?
How did you feel about coming?
What changes have there been in your family since _____ died?
What changes have there been in you since ______ died?
How did you like the _______ activity?
Tell me what it was like for you to tell other children/teens about your special person who died.

Post-Test Child (to occur at the end of the camp during the post evaluation):

What did you like the most about the camp?
What did you like the least about the camp?
What would you like to change about the camp?
If you knew some other child/teen that had a special person die, what would you tell them about the camp?
What is the most important thing that you got out of the camp?
What is the least important thing that you got out of the camp?
What did you learn about grief that you didn't know before the group?
How did you like the _______ activity?
Tell me what it was like to make the quilt square with your family.
The camp used to be called, Sharing Our Family's Tears, which name do you like better (compared to "Over the Rainbow")? Do you have any other suggestions?
Is there anything else you want to tell me?

Follow-Up Child (to occur during the follow-up phone evaluation):

What changes have you seen in yourself since the camp?
What changes have you seen in your family since the camp?

Appendix N
Post-Test Evaluation Form (Caregiver Version)

"Over The Rainbow"
Post-Test Evaluation Form

Name of Child	**Age**	**Gender**

Please answer the following questions, making any comments that you think will help us improve our camp program. We want to know your honest opinions, whether they are positive or negative.

1) Were the goals of "Over the Rainbow" explained to you?

YES NO

Comments: ____

2) Has the staff explained common grief reaction you could see in your child?

YES NO

Comments: ____

3) Has the staff provided helpful tips on how to support your grieving child?

YES NO

Comments: ____

4) Was this a convenient location for you?

YES NO

Comments: ____

5) Was the program: (please circle one)

TOO LONG TOO SHORT JUST RIGHT

Comments: ____

6) Would you recommend this program to friends/family who have a grieving child?

YES NO

Comments: ____

7) Are you satisfied with the services and support provided to you and your child(ren) at "Over the Rainbow"? (please circle one)

EXTREMELY VERY SOMEWHAT NOT AT ALL

Comments: ____

8) Overall, how helpful do you feel "Over the Rainbow" was for your child(ren)? (please circle one)

EXTREMELY VERY SOMEWHAT NOT AT ALL

Comments: ____

9) How concerned are you with your child's coping with the death(s) at this time?

EXTREMELY VERY SOMEWHAT NOT AT ALL

Comments: ____

10) Tell me what it was like to make the quilt square with your child.

11) If you knew another parent/guardian who was caring for a grieving child, what would you tell them about the camp?

12) What did you like the most about the camp?

13) What did you like the least about the camp?

14) How can we improve “Over the Rainbow”?

15) What is the most important thing you got from the camp?

16) What is the least important thing you got from the camp?

____

____

____

17) The camp used to be called Sharing Our Family's Tears, which name do you like better (compared to "Over the Rainbow)? Do you have any other suggestions?

____

____

____

18) Is there anything else you want to tell me?

____

____

____

☺ ***Thank you for taking the time to improve our program***

Appendix O
Post-Test Evaluation Form (Child Version)

“Over The Rainbow”
Post-Test Evaluation Form

☺ Name____

PLEASE COMPLETE THE FOLLOWING STATEMENTS BY CIRCLING THE NUMBER ON A SCALE OF 1 TO 10 THAT BEST MATCHES HOW YOU FEEL.

1) I am glad I went to “Over the Rainbow”

1 2 3 4 5 6 7 8 9 10
not at all — some — very much

2) I have talked with other kids my age who have had someone special die.

1 2 3 4 5 6 7 8 9 10
not at all — some — very much

3) It has been hard for me to laugh, play, or have fun since my special person died.

1 2 3 4 5 6 7 8 9 10
not at all — some — very much

4) I feel comfortable talking about my special person who died.

1 2 3 4 5 6 7 8 9 10

not at all some very much

5) I have questions about the death of my special person that I would like to have answered.

1 2 3 4 5 6 7 8 9 10

not at all some very much

6) I talk with my parent(s)/guardian(s) about the death of my special person.

1 2 3 4 5 6 7 8 9 10

not at all some very much

7) I can remember good and/or happy times with my special person.

1 2 3 4 5 6 7 8 9 10

not at all some very much

8) It is hard to look at pictures or things that belonged to and/or remind me of my special person.

1 2 3 4 5 6 7 8 9 10

not at all some very much

9) My life has changed since my special person died.

1 2 3 4 5 6 7 8 9 10

not at all some very much

10) I am comfortable expressing me feelings about the death of my special person.

1 2 3 4 5 6 7 8 9 10

not at all some very much

11) I have people in my life who can help me cope with the death of my special person.

1 2 3 4 5 6 7 8 9 10

not at all some very much

12) When I am feeling down, I can think of at least 3 things I could do to try to feel better.

1 2 3 4 5 6 7 8 9 10

not at all some very much

Appendix P
Facilitator Evaluation Form

"Over the Rainbow"
Group Facilitator Evaluation Form

Name:
Date:
Group:

If you get a minute…would you mind briefly giving us any suggestions you may have for future camps? Any feedback would be greatly appreciated!

What was your favorite activity?

What would you do differently in future camps?

Anything else….

Thanks again for all of your help!!! ☺

Appendix Q
Debriefing Form

Indiana University of Pennsylvania

Department of Psychology
Uhler Hall, Room G25
1020 Oakland Avenue
Indiana, PA 15705

Debriefing Form

Thank you for your participation in our program. We value your input into the group. The information that you provided today will help us improve the group for the future.

We would be happy to provide you with a copy of any published materials that result from our work. If you would be interested in receiving these materials, please email us at: sfjm@iup.edu.

Additionally, because of the nature of the study, we would like to provide you with a list of resources should you feel the need for additional support.

Following is a list of mental health providers available in the Indiana area:

Center for Applied Psychology Uhler Hall, IUP	(724) 357-6228
Indiana County Guidance Center 793 Old Route 119 N. Hwy	(724) 465-5576

Thank you,

Jessica Seacrist Miller, M.A.
j.e.seacrist@iup.edu

Indiana University of Pennsylvania
Department of Psychology
G25 Uhler Hall
1020 Oakland Avenue
Indiana, PA 15705

Appendix R
Key Informant Informed Consent

Informed Consent Form: Key Informants

You are invited to participate in this research study. The following information is provided in order to help you to make an informed decision whether or not to participate. If you have any questions please do not hesitate to ask. You are eligible to participate because you are a key informant in the community and may come across families with grieving children.

The purpose of this study is to evaluate a bereavement camp, “Over the Rainbow” for children and families in this area and determine if this service is needed in the community. I will ask you a set of questions to help to determine the need for grief programming and to examine some of the barriers to families accessing such programs. You will be asked several open-ended questions as part of a semi-structured interview. Participation in this study will require approximately 20-30 minutes of your time. Ideally these sessions will be audio taped, with your permission, to create a transcript, however if you decline audio-taping the interview can still be completed and the interviewer will take notes during the session. The results of this study will be used to help identify strengths and areas for program improvement.

Your participation in this study is voluntary. You are free to decide not to participate in this study or to withdraw at any time without adversely affecting your relationship with the investigators or IUP. Your decision will not result in any loss of benefits to which you are otherwise entitled. There are no risks involved in participation and no repercussions for non-participation.

If you choose to participate, you may withdraw at any time by notifying the Project Director or informing the interviewer. Upon your request to withdraw, all information pertaining to you would be destroyed. If you choose to participate, all information will be held in strict confidence. All information is strictly confidential and will not be released to any third party. The information you provide will be considered only in combination with that of other participants. The information obtained in the study will be presented to the VNA to help us build future programming and may be published in scientific journals or presented at scientific meetings but your identity will be kept confidential. This study is being conducted by Jessica Miller, M.A, a candidate for a doctoral degree in clinical psychology.

If you are willing to participate in this study, please sign the statement on the next page and return it to the experimenter. Take the extra unsigned copy with you.

Student Researcher:
Jessica Seacrist Miller, M.A.
Doctoral Candidate, Clinical Psychology
Uhler Hall
1020 Oakland Ave
Indiana, PA 15705

Dissertation Chair:
Laurie Roehrich, Ph.D.
Licensed Psychologist
Uhler Hall 103
1020 Oakland Ave.
Indiana, PA 15705

<u>Informed Consent Form (continued)</u>

VOLUNTARY CONSENT FORM:

I consent to have my interview audio-taped. _____ YES ______ NO

I have read and understand the information on the form and I consent to volunteer to be a subject in this study. I understand that my responses are completely confidential and that I have the right to withdraw at any time. I have received an unsigned copy of this informed Consent Form to keep in my possession.

Name (PLEASE PRINT) ____

Signature____

Date____

I certify that I have explained to the above individual the nature and purpose, the potential benefits, and possible risks associated with participating in this research study, have answered any questions that have been raised, and have witnessed the above signature.

______________________ ______________________.

Date **Investigator's Signature**

Appendix S
Key Informant Interview

INTERVIEW FOR KEY INFORMANTS

What is your position?

How do you come into contact with grieving children and their families?

DESCRIBE PROGRAM

Do you think there is a need for this type of program in our community?

What population (ages) do you think has the greatest need?

What setting do you feel would be most comfortable for families?

Do you know about any alternative programming that meets this need?

What barriers can you foresee to families seeking this program?

What do you think it would take to have a program like this catch on in a community and be successful?

Any other feedback.