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A psychoeducational group designed for the social supporters of Sudden Infant Death Syndrome parents

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A PSYCHOEDUCATIONAL GROUP DESIGNED FOR THE SOCIAL

SUPPORTERS OF SUDDEN INFANT DEATH SYNDROME PARENTS

BY

TARA JORDAN

BA, University of New Hampshire, 2004

THESIS

Submitted to the University of New Hampshire

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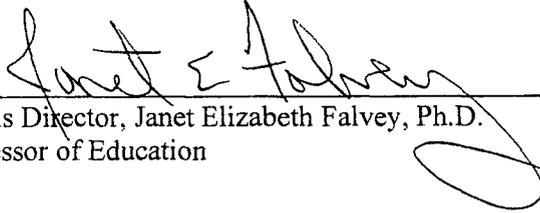
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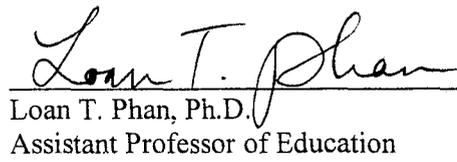
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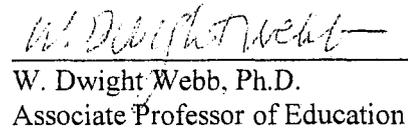
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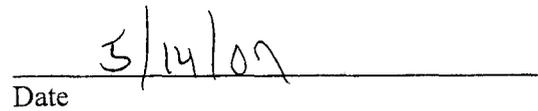
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DEDICATION

I would like to dedicate this thesis to my parents, MaryAnn and Bobby Jordan; I never could have done this without your constant love and support. I am so blessed to have parents as encouraging as you in my life. Thank you.

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ABSTRACT

A PSYCHOEDUCATIONAL GROUP DESIGNED FOR THE SOCIAL

SUPPORTERS OF SUDDEN INFANT DEATH SYNDROME PARENTS

by

Tara Jordan

University of New Hampshire, September, 2007

Sudden Infant Death Syndrome (SIDS) claims 5,000 to 7,000 infant lives each

year. The deaths undoubtedly cause a sense of guilt, depression and hopelessness among

survivors; specifically the parents. Many people supporting SIDS parents tend to feel

uncomfortable around them and thus avoid the grieving family altogether. Many SIDS

parents state that while their friends and family are trying to be helpful and supportive,

many of their attempts actually are hurtful. A psychoeducational group was developed for

the social supporters of SIDS parents, allowing its members to become better equipped to

help support the grieving parents and to give them the opportunity to understand some of

their own feelings about death. The model was derived from various literature and

research focusing not only on death and bereavement, but on various types of

psychoeducational groups as well. This model serves as a stepping stone to lead social

supporters, specifically those who are supporting a SIDS family, to effectively be aware

of SIDS and their own influence on the parents.

CHAPTER I

A PSYCHOEDUCATIONAL GROUP DESIGNED FOR THE SOCIAL

SUPPORTERS OF SUDDEN INFANT DEATH SYNDROME PARENTS

Death inevitably affects everyone at some point in one's life. Some consolation

for people dealing with a death occurs if the deceased lived a long and fulfilling life.

Unfortunately, many parents do not have this kind of solace when their child dies

suddenly without warning. Sudden Infant Death Syndrome (SIDS) claims 5,000 to 7,000

infant lives a year in the United States (McClain & Mandell, 1994). One infant dies every

hour, every day, every year (The Lewis Group, 2005). The math tells us that this leaves

approximately 14,000 grieving parents, plus the innumerable siblings and family

members who are also affected by the loss. It is, therefore, critical that mental health

professionals, as well as all people who are touched by this tragedy, understand how

these parents are affected. While there are many SIDS support groups for parents who

have lost a child, there are not many for the social supporters of that family. Therefore,

designing a group for the social supporters to learn about how they can assist SIDS

families would be beneficial for the entire network affected by the SIDS death.

Rationale

Losing a child has been said to be one of the greatest tragedies a parent can face

and produces the widest range of psychological reactions of any loss (Sanders, 1979). If

this is true, then the support that these parents receive is vital for a healthy adjustment

following their loss. Most may think that, after the loss of a child, support would be

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overwhelming in assisting the parents back to coping with everyday life. However, studies in this area have found that SIDS parents do not seem to receive the support that one would think that they need. While support immediately after the death is important, it has been said that support tends to fade soon after the loss. Brabant (1995) found that friends and family frequently avoided grieving parents, or that the attempts that were made were seen as unhelpful. The purpose of this thesis is to provide a model of a psychoeducational group for social supporters of parents who have lost a child to SIDS to be better equipped to assist parents in the grieving process.

It is important to know what happens to parents in the aftermath of their loss. Gabbi (2004) states that when a child dies from SIDS, the process of grieving involves two aspects. The first is that one must begin to unravel the bonds that have formed with the deceased. Parents also face their own anger and guilt that they failed their child for not taking care of or protecting the child. In addition to Gabbi's (2004) findings about their mental experiences after death, SIDS parents experience the greatest anxiety and depression after their loss compared to other parents (Boyle, Vance, Najman, & Thearle, 1996). They have sleep disturbances, energy loss, social difficulties and existential challenges (Dyregrov & Dyregrov, 1999). These symptoms do not go away over a specific period of time. Miles (1985) found that time did little to alleviate the risk of emotional symptoms through the first thirty months. Hunfeld, Wladimiroff, and Passchier (1997) found that eleven out of 29 women (38%) had general psychological distress four years after the death. Clearly, these parents are in great need of support for much longer than social supporters may realize.

Although SIDS has existed since the Old Testament (1 Kings 3:19), little is known about the long-term affects of social support (Thuen, 1997b). Helmrath and Steinitz, cited in Thuen (1997b), found that the way bereaved parents received social support following a loss is related to their psychological adjustment process. Some ways people give social support in times of pain has been said to hurt the parents more. The United States culture seems to value strength, refusing to cry, and "getting over it" as admirable qualities. Wing, Burge-Callaway, Clance, and Armistead (2001) state that clichés and devaluing comments such as, "you can have other children," add additional distress to bereaved parents. This attitude undoubtedly hurts those who have lost a child. It is, therefore, important to educate social supporters on what these parents have found to be most helpful in the months following the death of their child.

Related to the lack of social support that SIDS parents receive is the isolation into which the parents willingly move. Bereaved parents often are exhausted by their intense emotions, leaving them little to give to others. Also, many emotions they experience are not socially acceptable. These include anger, blaming, or fathers crying. Parents are highly sensitive at this period, and therefore often withdraw to avoid being hurt. They may feel misunderstood and abandoned during this time (Peppers & Knapp, 1980). This may be due to the supporters around them feeling uncomfortable with the bereaved parents and likewise withdrawing from them.

The proposed model will help mental health professionals assist not only the social supporters of SIDS, but could branch out to the nuclear and extended family as well. Price, Carter, Shelton, and Bendell (1985) state that siblings of the infant who dies of SIDS, as well as subsequent children, also have been found to be disturbed after the

death. The surviving children usually have to deal with more than the loss of their sibling. They also have to deal with instability of the home due to the parents' attempts to cope. Mandell, McAnulty, and Carlson (1983) found that 80% of the SIDS mothers changed the way that they interacted with their surviving child. Some of these mothers "babied" their surviving children; some mothers reported feeling anxious and needed to distance themselves. SIDS does not simply affect the parents of the infant, but the entire family system. The role of social support in relationship to understanding parents' psychological adaptations will not only be a service to the parents, but hopefully will influence the entire family's psychological adaptation.

Implications

Creating a psychoeducational model for social supporters is beneficial to SIDS parents, and would potentially help mental health professionals assist people other than the immediate family to access these resources. Counselors can help potential supporters to understand the process that SIDS parents go through and how their presence may be immensely beneficial to the family. Counselors could educate social supporters regarding what has been seen as beneficial to grieving parents and what is perceived as distressful. This research could potentially be generalized not only to people affected by SIDS, but to parents who have lost an infant to other tragedies (i.e., stillbirths). Research in this area will benefit all who are affected by this or other tragedies, whether personally or professionally.

Definition of Terms

Emotional support – This term will be defined as behaviors that are comforting and enable recipients to feel that they are respected and loved (Wills, 1985).

Functional support – The actual functions in which social supporters engage. For the purposes of this thesis, functional support will be further broken down into three separate dimensions: instrumental, emotional, and informational.

Informational support – Information, advice, and knowledge that helps the parent to understand his/her world and to adjust to the changes in it (Jacobson, 1986).

Instrumental support – This term will be defined as behaviors that help solve practical problems (Jacobson, 1986). This would include babysitting, lending money, cooking and other chores (Thuen, 1997b).

Psychoeducational group – A group that has a goal of preventing developmental dysfunction and that also increases social skills (Furr, 2000).

Social supporters – This term will be defined by the relationship that the supporter has to the parent or more generally "the existence of interconnections between social ties" (Cohen & Syme, 1985, p. 11). They include family members, friends, neighbors, health care professionals, support groups, acquaintances, and work colleagues (Dyregrov, 2003; Thuen, 1997b).

Sudden Infant Death Syndrome (SIDS) – A term medical researchers have used for the unexpected sudden death of any infant in which a thorough post-mortem examination fails to demonstrate adequate cause of death in the United States (DeFrain, Jakub, & Mendoza, 1991).

CHAPTER II

LITERATURE REVIEW

"A child's death tells us loudly and clearly that we are all vulnerable and, guard as we may, that we will never be safe from death" (Arnold & Gemma, 1991, p. 48). This quote is from a discussion of why social support toward those who have lost a child to Sudden Infant Death Syndrome (SIDS) may be lacking. Social support in grieving processes has been a topic of discussion since the 1970s. This review will cover many dimensions which previous researchers have studied; their findings regarding social support in general, and specifically regarding SIDS. Social support will be examined from the context of the supporters (i.e., friends and family), and literature on helpful and unhelpful aspects will be reviewed. The more one knows and understands the complex social support system around grieving, the sooner we can begin to respond sensitively to those who have lost a child to SIDS.

Misconceptions of SIDS

Throughout the literature there always seems to be a reference to what Sudden Infant Death Syndrome is and what it is not. This review will cover the most common misconceptions about SIDS. It is important to understand what SIDS is as well what it is not, because SIDS parents often find themselves accused of child abuse when they are nothing but innocent.

The National Institute of Child Health and Human Development (2005) has an excellent website (https://www.sidscenter.org) that was designed to provide information

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on SIDS and the myths and the answers to many frequently asked questions. This website, as well as the SIDS Network Organization (2005), formed the basis of information presented in a fact sheet about SIDS that will be introduced in the present model (Appendix II).

The first myth is that babies can "catch" SIDS. The fact is that it cannot be caught because it is not contagious. There are also no symptoms before the death. In fact, SIDS victims typically appear healthy prior to their death.

The second myth is that cribs cause crib death (another term for SIDS). Cribs do not cause SIDS. Along with this, external suffocation, choking, or vomiting do not cause a baby to die of SIDS.

There has been a debate as to whether putting a baby on his or her back causes SIDS. Parents may think that placing the baby on his or her back may allow the baby to choke on its spit or vomit. Both the SIDS Network (2006) and the National Institute of Child Health and Human Development (2005) encourage parents to have babies sleep on their backs. The reason is that babies swallow or cough up fluid that enters their airway. Doctors have found no increase in choking among babies who sleep on their backs. Placing the baby on his or her back is the safest way for a baby to sleep (National SIDS/Infant Death Resource Center, 2005).

African American babies are twice as likely as white babies to die of SIDS, while Asian American babies have equal or lower rates to white babies (Grether & Schulman, 1989). While many people think that SIDS only occurs in white families, the truth is that any baby is susceptible to dying of SIDS, no matter what race that baby is.

The most devastating aspect of SIDS is that many parents often blame themselves because they feel that the death could have been prevented (Ranney, 1991; Worden, 2002). The truth is that there is no way to ensure that a baby will not die of SIDS. Many parents may think that giving their babies inoculations or certain medicines caused their death, but this is untrue as well. While placing a baby on its back does decrease the risk, it is not a guarantee. SIDS cannot be predicted or prevented, even by a doctor (SIDS Network Organization, 2005).

The saddest myth about SIDS is that the baby suffered while it was dying. SIDS does not cause pain or suffering in the infant. The death occurs very rapidly and usually while the infant is sleeping (Arnold & Gemma, 1991). There is no indication that the infant suffered, because the baby does not cry out that they are in pain (SIDS Network, Incorporated, 2006).

Clearly, there are many myths that circulate when a child dies of SIDS. Perhaps this is due to the lack of a medical explanation that can pinpoint why an infant died. It is extremely important that social supporters, healthcare professionals, and anyone else who is touched by SIDS understand the facts of the syndrome. Misinformation can lead to blaming the parents, accusations of child abuse, and so much more.

Overview of Impact of Sudden Infant Death Syndrome

The impact of Sudden Infant Death Syndrome is devastating not only to the parents of the infant, but also to friends, family, neighbors and the community in which they live. Parents, when compared to spouses or children who have lost a loved one, experience the widest range of emotions (Sanders, 1979).

There are several factors that distinguish a SIDS death from other losses. The first is that the death occurs without warning in babies who appear to be healthy. There is no opportunity to prepare for the death compared to babies who die from some disease that progresses (Markusen, Owen, Fulton, & Bendiksen, 1977-78). Also, since there is no definitive cause, there is a tremendous amount of guilt and blame. Others who have lost a loved one usually know what caused the death, but in a SIDS circumstance the question of "Why" can never be answered medically (Ranney, 1991). The third difficulty is that many of these parents often find themselves involved in some way with the legal system. Police are often the investigators of a SIDS death, and parents usually report an insensitive interrogation process. With the increase in child abuse and neglect cases, parents of SIDS babies are viewed as suspicious and are open to legal investigation. This adds to the stress that these parents are already facing (Ranney, 1991; Worden, 2002). Other deaths do not have the legal system involved because usually there is a medical explanation. SIDS parents, however, usually have to endure having their child autopsied to determine if there was indeed a cause (Ranney, 1991).

When a child dies, many parents experience guilt and anger, feeling that they could have prevented the death or at least should have done something differently (Gabbi, 2004). Parents who have lost a child to SIDS often experience sleep disturbances, loss of energy, social difficulties, depression and anxiety (Boyle et al., 1996; Dyregrov & Dyregrov, 1999). Knowing the somatic conditions grieving parents experience, many may think that social support would help them overcome these troubling symptoms. Yet, many parents do not find support forthcoming (Brabant, Forsyth, & McFarlain, 1995; Chesler & Barbain, 1984; Dyregrov, 2003; Powell, 1991). Understanding this dilemma

makes it imperative to educate supporters about the aftermath of the sudden death, and how these parents fare day to day.

<u>The Grieving Process</u>

The grieving process is usually divided into two categories: normal or uncomplicated grief, and complicated grief. Grief refers to a wide range of feelings and behaviors that are common after a loss (Worden, 2002). These include feelings, physical sensations, cognitions and behaviors. The following sections will provide an overview of each of the manifestations that occur during the grieving process, and specifically address those that affect SIDS parents the most.

<u>Feelings</u>

There are a wide range of feelings that people can experience after a death. Sadness is the most common feeling that surrounds a loss (Worden, 2002). It is important to understand that some mourners have a fear of sadness, especially the fear of how strong the sadness is (Taylor & Rachman, 1991). This is often expressed when a person says; "I just completely lost it at the funeral". When people repress their sadness it can frequently lead to complicated bereavement.

Anger is also frequently experienced after a loss (Littlewood, 1992; Worden, 2002). Anger may be directed at the deceased, the people who failed to prevent the death (or caused it), himself or herself, or society in general. In SIDS cases, parents many times are angry with the pediatrician (Fuller, Barnickol, & Mullins, 1991). Anger can have a lot of harmful consequences when occurring during the grief process. If it is directed toward other people it may alienate them, and if it is directed at the self it may result in suicidal behavior (Littlewood, 1991).

Fuller, Barnickol and Mullins (1991) also describe a term called cosmic anger, defined as "an all consuming anger; the death is everyone's fault yet no one's fault" (p. 172-173). This type of anger would be viewed as a complicated grief reaction. It has been said that people who react in this manner were already hostile people to begin with, and the death of their baby fuels their fire even more so. They often are articulate and successful and soon try and to find a "cause" for the infant's death. This is harmful because they have not had time to work through their own grief (Fuller, Barnickol, & Mullins, 1991).

Guilt is a common experience of the survivors of a SIDS loss. There is the guilt of not being kind enough, not being good enough parents, or failure to see that something was wrong. When referring to parental guilt, the sense of parental competence is seriously challenged. One father stated after the loss of his child, "You are supposed to protect your child" (Klass, 1988, p. 14-15). Guilt can be a general feeling of failure or a specific search to the question "What did I do wrong?" As a rule, these feelings usually diminish over time (Leick & Davidson-Nielsen, 1991).

Physical Sensations

Physical sensations are often overlooked, but play an important role in the grieving process. Many times the sensations will be experienced as a somatic complaint of the survivor that they bring to a physician in a check up. Some common physical sensations include hollowness in the stomach, tightness in the chest and throat, a sense of depersonalization, feeling short of breath, weakness in the muscles, energy loss, sleep disturbance and dry mouth (Dyregrov & Dyregrov, 2004; Worden, 2002).

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Behaviors

Sleep disturbances are common in the early stages of grief. They can include both difficulty going to sleep and early morning awakening. A feeling of dread and despair is also common. "I'd finally get to sleep about two in the morning and wake up at dawn. For a split second I'd wake and feel all right, then I'd remember, it'd all come flooding back to me and I'd wish I'd never woken up in the first place" (Littlewood, 1991, p. 48).

Other behaviors that are common in mourners include appetite disturbances, withdrawal, dreams of the deceased, searching for the deceased, crying, and forgetfulness (Boyle et al., 1996; Littlewood, 1991; Worden, 2002).

Having social supporters understand these manifestations of grief is an important part of helping the family of a SIDS death. Knowing what feelings and thought patterns families are going through can help social supporters assist families in the grieving process. It can also be beneficial to the social supporters themselves by helping them realize, that if they are also enduring any of these ideas, it is considered normal and healthy in the grieving process. Cognitions will be one of the main emphases in the proposed psychoeducational group, because these ideas are basic to understanding what SIDS parents go through.

Cognitions

There are certain thoughts that are common in the early stages of grieving and usually will disappear after a short time. Yet, it is important to know that sometimes these thoughts persist and can trigger depression or anxiety.

Disbelief is common among SIDS parents because the death was so sudden: "This must be some mistake." Each new situation that would have included the child must now

be processed with the child not there (Klass, 1988). Klass (1988) also notes that many parents reported that the time after the death was hazy, and had no memory of the funeral a year later.

Preoccupations are obsessions about thoughts of the deceased (Littlewood, 1991; Worden, 2002). Many mourners are preoccupied with the deceased's image, and these thoughts take up a lot of time and energy of the survivors. Replaying of events leading up to discovering the dead child is common in SIDS parents; for example, how they put the baby into the crib (Arnold & Gemma, 1991). Many people feel that the death could have been prevented, and that review of it might give more details as to what might have caused it.

Tasks of Mourning

There are many theories about the process of grief and mourning. One that seems most useful when discussing SIDS in a psychoeducational group is Wordens's (2002) four "tasks of mourning." These tasks appear to reflect what SIDS parents endure throughout the grieving process. Understanding how these four tasks unfold is imperative when trying to support those who have lost a child. Worden (2002) notes that these tasks do not necessarily follow a specific order, although there is some ordering in the titles. One can not begin to experience the emotional impact of the loss, for example, unless they realize that the loss has occurred.

Task I: Accept the Reality of the Loss. The first task of grieving is to realize that the death has happened and that the person is never going to come back (Worden, 2002). After a death there are often comments such as, "This can't be happening to me" and "I

don't believe it" (McNurlen, 1991). Parents who have had an infant die may imagine their infant is crying, or continue to buy formula at the store.

The opposite of accepting the loss is not believing it happened through some type of denial, keeping the person stuck in the grieving process at the first task. There are many types of denial, ranging from a slight distortion to full blown delusion. Parents who lose a child often leave their room untouched. If this occurs for a short amount of time it is not seen as unusual, but if it is kept untouched for years it is now denial.

Another way that people protect themselves from reality is to deny the meaning of the loss. They say the loss was less significant than it actually is. In the case of a SIDS parent he or she may state, "She was only 5 months old" or "How could I miss him, I barely knew him." Worden (2002) states that some people immediately throw out clothes and other memorabilia that remind them of the deceased, which in turn reminds them of the loss.

"Unreality is particularly difficult in the case of a sudden death, especially if the survivor does not see the body of the deceased" (Worden, 2002, p. 30). Unfortunately, this is where many SIDS parents find themselves in the aftermath of their child's death. Many times parents are talked out of seeing their dead infant in the hospital, and this may make the reality of knowing that their infant is gone forever especially difficult (Ranney, 1991).

Task II: Work through the Pain of Grief. "Families that have a SIDS death are dealing with pain from the instant the child is found dead" (McNurlen, 1991, p. 189). Society seems to encourage people to move on from the pain, yet this may lead to complicated bereavement or manifest somatically (McNurlen, 1991; Worden, 2002).

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Society may give the mourner a subtle message that grieving is just feeling sorry for yourself, or even a more harsh response; "he wouldn't want you to feel this way." Of course, it is imperative to realize that not everyone experiences pain the same or at the same intensity. Yet it is impossible to lose someone that you have loved without experiencing some level of pain.

The opposite of working through the second task is not to feel. There are a number of ways that a person is able to do this. The person may cut off their emotions and deny that the pain is present. They do this by numbing themselves, thus avoiding painful thoughts. Alternately, some people hide their pain through the use of substances, idealizing the dead, or avoiding reminders of the deceased altogether. In grief counseling the goal is help people work through this grief task so they do not carry the pain with them throughout their entire life. In the present model, the goal is to make the members aware of Task II and to be better equipped to help parents work through it. At the same time, the group will strive to educate members not to indulge in society's typical way of denying parents the right to grieve openly.

Task III: Adjust to an Environment in which the Deceased Is Missing. In the third task the grieving person has to learn to act in new ways (Leick & Davidson-Nielsen, 1991). Worden (2002) describes three areas of adjustment that a person needs to make after losing someone that they love. First is external adjustment. In the case of SIDS parents, this may involve not going to the pediatrician with their baby or not being able to hold them. Another external adjustment that affects SIDS parents is answering the question "How many children do you have"? This adjustment requires learning the skills to be able to handle their new environment.

The second adjustment is an internal adjustment that occurs when death confronts the survivors with the challenge of adjusting to their own sense of self. This includes how the death affects self esteem, self efficacy and self definition of the person in mourning. In relation to SIDS parents, how does the role of parents change if their only child is now deceased? "They are still parents yet have no one to parent" (McNurlen, 1991, p. 191).

When addressing self efficacy with SIDS parents, they may begin to experience intense regression, feeling incapable, helpless and inadequate (Worden, 2002). Attempts to fill the deceased's role may fail, and consequently could lower a person's self esteem (Worden, 2002). Parents may find themselves trying to have another child before they have had a proper chance to grieve for the one that they lost. In extreme cases parents have even named a subsequent child the same name as the one who has died (Davies & Segal, 1991). No child can take the place of the deceased child; when parents hope for this it is not only unhealthy for them but for the child who is deprived of his or her own unique self (Davies & Segal, 1991).

The last adjustment is spiritual; how one's sense of the world is affected. Loss through death can challenge one's life values and beliefs. Parents may feel that they are directionless. "The bereaved person searches for meaning in the loss and its attendant life changes in order to make sense of it and to regain some control of his or her life" (Worden, 2002, p. 34). Most people, however, are able to move through the spiritual adjustment, learning the skills they need to cope, adjusting to their new roles, and ultimately moving forward.

Task IV: Emotionally Relocate the Deceased and Move on with Life. Worden (2002) suggests that the mourner find a psychic place for the deceased where they can still feel connected to that person, but that will also allow the mourner to go on with his or her life. Many times parents may see "moving on" as synonymous with "forgetting," and parents never want to forget their child. This may be why parents have a difficult time completing this task (McNurlen, 1991; Worden, 2002). It is common for parents to do some type of work to make meaning of their child's life, such as advocating for SIDS or become involved in fundraisers (Barnickol, Fuller & Cunningham, 1991). While Worden (1982) states that this may be a difficult task for parents to complete, he also contends that many times parents will naturally find a way to make the infant live on in their lives.

Understanding these four tasks is an essential key to the proposed psychoeducational model. It is important to understand the process of mourning and know what each person most likely will be going through. While the model will be directed toward SIDS parents, the tasks and general grieving process can undoubtedly be used in any situation where death occurs.

Defining Social Support

Little is known about the long-term effects of social support after the death of an infant who has died of SIDS (Thuen, 1997b). It is important, then, to begin the journey of examining long-term effects and applying our knowledge to assist these families. Before one can begin to do this it is important to understand how social support is defined and what these definitions imply.

Social support has been studied from two perspectives; structural and functional. "Structural measures describe the existence of an interconnection between social ties (e.g., marital status, number of relationships, or number of relations who know one another)" (Cohen & Syme, 1985, p. 11). Functional measures determine whether interpersonal relations serve particular functions such as providing affection, financial aid, and comfort to the person. Structural measures are usually assessed by self-report, and are generally considered to measure the objective characteristics of social networks. Functional measures, on the other hand, ask the person their perceptions of the availability or adequacy of resources provided by people in their lives. Structural assessment provides information about social supports in the system, and determines the extent to which they contribute to someone's health. Research studies that define social support will fall under one of these two constructs, depending on the area of interest (Cohen & Syme, 1985).

Sidney Cobb's definition (as cited in Jacobson, 1986) described social support as consisting of information belonging to one of three classes: (1) information that makes the person believe that he or she is cared for and loved; (2) information leading the person to believe that he or she is valued; and (3) information leading the person to believe that he or she belongs to a group where others can count on him or her when the need arises. A simplistic example would be a friendship. One friend tells the other that he or she loves him or her, or "I don't know what I'd do without you." Many friends also tell each other that if they ever need them that they will be there for them. Later researchers would categorize Cobb's informational support into the more developed dimension of emotional support (Brownell & Shumaker, 1984; House & Kahn, 1985; Jacobson, 1986).

Jacobson (1986) divides social support into three separate entities, the first being emotional. Emotional support consists of behaviors that provide comfort, leading the individual to feel that they are admired, respected, and loved even though they are having problems in other areas of their lives (Wills, 1985). This individual also feels that emotional supporters around him or her are available and can provide compassion and support. Most supporters in this category are usually so close with the affected person that he or she can reveal negative things about himself or herself (Wills, 1985). This type of support would be expected to have the greatest effect for people under a considerable amount of stress (Price, Carter, Shelton, & Bendeli, 1985). The idea of emotional support will be discussed at great length in the present model, and the concept will be utilized in a worksheet as well. However, Thuen's (1997) study on the long-term perspective of losing a child concluded that emotional support was not found to be as highly correlated to psychological adaptation as other forms of support.

Cognitive or informational support consists of information, advice, and knowledge that helps an individual to understand his/her world and to adjust to the changes in it. If problems are not resolved quickly, people look for information about the nature of the problem or seek resources to find out for them. Powell (1991) reported that 91.3% of parents felt a need to talk about information associated with SIDS. Wills (1985) stated that it is not uncommon for supporters to give not only emotional support but also informational support. One example of this may be a SIDS support group designed to help the parents with their emotions as well as to give advice and information about their loss.

Material support, sometimes referred to as instrumental support, can include a wide variety of services that help solve practical problems (i.e., taking out the garbage, babysitting, or financially aiding the individual). Instrumental support is particularly helpful when the individual has faced a loss to SIDS, because the family is almost completely unable to do these tasks on its own, especially in the first few weeks after the loss. By doing chores and assisting the bereaved family, material support allows them to begin the grieving process, make funeral arrangements, and rest a little bit easier (Thuen, 1997b). Wills (1985) also suggested that it is not so much the actual instances of doing these chores, but knowing that people are dependable and reliable if they are needed.

Most researchers, despite the variety of definitions of social support, use a derivative of the three constructs mentioned above. Some studies have also characterized social support by quantitative measures. Brownell and Shumaker (1984) claimed that, "few researchers have defined 'social support' explicitly" (p. 5). Social support was defined by these authors in measurable terms: quantity (connections such as number of friends), quality (having people one can trust), utilization (time actually spent with people), meaning (the importance of friends), availability (the likelihood of having someone there when needed), and satisfaction with one's support (Brownell & Shumaker, 1984).

Although these authors tried to define social support explicitly, problems remain with these operational definitions. For example, the number of good friends may be easy to count, yet what about acquaintances who would be there when a tragedy strikes? Also, a best friend may be very supportive but may live in another state, so how does this

measure into the utilization aspect? Clearly, defining social support as a measurable construct is complicated when conducting research in this area.

<u>Perceptions of Social Support</u>

House and Kahn (1985) define social support as the emotional, economic, and practical help or information provided to an affected individual by significant others such as family members, neighbors, coworkers and friends. It would seem, with all of the people who are in some way connected to families who have lost an infant to SIDS, that social support would not need studying. Many people are under the assumption that when tragedy occurs those who are willing to help the family "get back on their feet" surround the family. Unfortunately, this is far from true for many families who have lost a child. Research shows that social support for these families is often either lacking or at times even hurtful (Brabant, Forsyth, & McFarlain, 1995; DeFrain, Jakub, & Mendoza, 1991; Price, Carter, Shelton, & Bendell, 1985). This tragic shortcoming is not limited to just family and friends. Healthcare workers, mental health professionals, clergy and funeral directors are also included in these studies (Brabant, Forsyth, & McFarlain, 1995; DeFrain, Jakub, & Mendoza, 1991; Price, Carter, Shelton, & Bendell, 1985). This misconception regarding available social supporters will be addressed in the present model.

Powell (1991) and Thuen (1997b) concluded that, while family members often provided emotional and instrumental support, informational support was limited. This could be because family members lack experience with death related issues, especially when it involves the death of a child. Yet, many bereaved parents seek this information and have a strong need for knowledge regarding issues such as cause of death,

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preventability, and the normalcy of their grief reactions. Golding, Limerick, and

MacFarlane (1985) recommend that counselors be sufficiently knowledgeable about

infant loss and bereavement so they can answer the questions that arise as a result of an

infant's sudden death. This is especially important when the family will never know the

exact cause of death of their baby (Carrol & Shaefer, 1994; DeFrain, Jakub, & Mendoza,

1991; May & Breme, 1982; Thuen, 1997). Sharing this information with social

supporters may help them become confident enough to reach out to the immediate family

and facilitate discussions.

Some studies have found that family members are perceived as the most

supportive in the aftermath of an infant's death (DeFrain & Ernst, 1978; Dyregrov, 2003;

Thuen, 1997a; Thuen, 1997b). Others studies, however, conclude that family members

are among the most deficient in terms of social support. Powell (1991) discovered that

only 36.5% of parents felt that other family members met their needs. In addition,

Brabant, Forsyth, and McFarlain (1995) found that half of the parents in their study

perceived a lack of social support from their families. This information will be addressed

in the model, noting that sometimes family members are not as supportive as others may

think they are.

Since family members are closest to the child, biologically and most likely

emotionally, why is it that they are seen in a negative light by parents? Dyregrov (2003)

coined the term "social ineptitude" and defines it as "the difficulty a social network

encounters in responding to and supporting those bereaved by sudden, traumatic deaths in

a manner that is appreciated by the bereaved" (p. 31). The construct of social ineptitude

was divided into three categories: non-communication, abrupt communication, and

unsuccessful communication. These three entities are important for social supporters to understand because, throughout the literature that discusses difficulties in helping, the most harmful or hurtful perceived incidences fall into one of these three categories. Therefore, the idea of "social ineptitude" will be addressed in the present psychoeducational group. The following will describe what researchers have found regarding these categories.

Chesler and Barbain (1984) studied parents who had lost a child to cancer, finding that many friends of parents withdrew or failed to communicate with them. One woman in their study stated, "Some friends we didn't hear from, they didn't want to say the wrong thing so they didn't say anything" (Chesler & Barbain, 1984, p. 124). It was also suggested that stigma might have contributed to the non-communication. Some parents felt that people stayed away from them because they feared that if they were close to the child with cancer, they might be more vulnerable to it. This idea could be applied to SIDS as well since

> Avoiding the grieving family is a way to deny reminders of our own personal vulnerability. Avoidance feels justified as a way to protect our own boundaries from the invasiveness of death . . . We fear contamination of death as though it were a communicable disease that is transmitted by touching and connecting with each other. We think that as long as we remain detached and disengaged we are helpingourselves (Arnold & Gemma, 1991, p. 48).

Researchers also found abrupt non-communication when studying parents who lost a child. Social invitations start to dwindle and social support withdraws when it is needed the most. Support was especially needed when friends and families got back to their normal routine, leaving the parents in the grieving process alone. Informal support was found to subside early, leaving parents without any additional support (Powell, 1991). Parents told stories about how people looked away from them, walked in another

direction on the street, or ignored them (Dyregrov, 2003). Non-communication is of special interest in the present study, focusing on when social support begins to fade and how it relates to parents' psychological adaptation.

While this may be noted as physical withdrawal, grieving parents also experienced conversational withdrawal. In Dyregrov's (2003) micro-sociological analysis of social support, the most common social support withdrawal was conversational avoidance. This avoidance has been noted in other studies as well (Brabant, Forsyth, & McFarlain, 1995; Chesler & Barbain, 1984; Taylor, DeFrain, & Ernst, 1986). When people are in conversation with a grieving parent they will talk about anything else except the dead child. Some have stated that people will not even mention the child's name in conversation (Dyregrov, 2003; Taylor, DeFrain, & Ernst, 1986). Parents stated that, while they wanted to talk about their dead child, it didn't mean that was the only thing they were capable of talking about. Dyregrov (2003) concluded that one way to help this tension was simply to be open about it. An example of this could be to provide cues or to directly inform the individual that it was acceptable to talk about his or her deceased child.

Unhelpful or hurtful communication is also a common theme in the literature regarding social support with SIDS families (Dyregrov, 2003; Dyregrov & Dyregrov, 1999; Klass, 1988; Wing et al., 2001). Clichés such as "time heals all wounds" were seen as uncomforting, hurtful and usually not true. Miles (1985) found that time did little to alleviate emotional symptoms through the first thirty months after a child's death. Some supporters did not really understand that having an infant die is just as terrible as it would be if the deceased were a grown child, saying "you can have other children" or "it was

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only a baby" to the grieving parents. Supporters forget that, while the infant may not have lived long, that should not imply that the parents were any less attached than to an older child (Taylor, DeFrain, & Ernst, 1986).

Parents who have lost a child to SIDS are already under a great deal of stress. Some relief might include having a social support network in place to help them through it. However, this is not the case for many parents. Social supporters can actually make the situation worse by patronizing them, avoiding them, or disregarding the deceased infant altogether (Dyregrov, 2003; Dyregrov & Dyregrov, 1999; Klass, 1988; Wing et al., 2001). This social ineptitude undoubtedly puts more strain on already exhausted and bereaved parents. It is therefore important to monitor any trends that focus on the departure of social support as time passes.

Gender Differences

Literature also suggests that survivors may have a large part to do with what support they receive and how they receive it. Most of the research in this area has focused on gender differences between males and females. It is interesting to see that, while both partners experienced the same tragedy, they perceive social support differently, they cope differently, and people often treat them differently.

Dyregrov and Dyregrov (1999) conducted a follow-up study of 26 parents who had lost a child to SIDS fifteen years prior. These researchers explored how parents perceived social support following the loss, how each couple dealt with communication (i.e., did some want to talk or remember the dead infant more than others), subjective meanings regarding the effects of the loss and, lastly, parents' experience of the interview.

Questionnaires were used to assess various aspects of the parents' psychological

and somatic state. These questionnaires assessed traumatic after-effects, general

psychological well-being, anxiety, somatic complaints, and depression. To understand

parents' subjective feelings, the researchers conducted semi-structured, in-depth

interviews.

In their quantitative analysis, Dyregrov and Dyregrov (1999) concluded that

gender differences were not significant over time. The authors found that mothers' scores

from the 1990s on the *Impact Events Scale, GHQ, State Version of the State Trait

Inventory*, and the short form of the *Beck Depression Inventory*, compared to their 1980

scores, had decreased significantly. This was interesting because in the initial study the

women's psychological complaints were more frequent and different than their male

counterparts. Yet, when reevaluated in 1996, men had higher scores on all the inventories

except for the *Beck Depression Inventory* and the *Impact Events Scale*. The authors

concluded that the men may have had to be the "strong one" to help their wives through

the beginning of the tragedy. While doing this they suppressed their own emotions, which

may have prevented them from working through their grieving process in a timely

fashion, as their wives were allowed to do. This "male need to be strong" expectation is

also mentioned in Smialek (1978) when interviewing parents during their immediate

reaction to the death.

Dyregrov and Dyregrov (1999) also concluded that men who experienced the loss

of an infant might be more expressive of their emotions compared to men who have not

lost a child. This study found that at the beginning of the loss the gender differences

revealed a large discrepancy; however, over time psychological functioning grew closer

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between the two parents. This study did not account for the differences in coping styles to which different genders are accustomed.

Mandell, McAnulty, and Reece (1980), in a qualitative study on paternal grief, concluded that men tended to keep busy by taking an extra job or an extra school course. Men may appear to others to lack interest in their dead infant when compared to their partner, who often expresses grief more openly, such as by crying. Men in the study did not cry once during the interviews compared to their wives, all of whom cried.

The lack of crying in Mandell et al.'s (1980) study coincides with findings by Carroll and Shaefer (1994), who asked men if they cried with their friends as a way to cope. The men responded "never." They stated that they did acknowledge their loss but decided not to express their feelings by crying or seeking support beyond their partner. Fathers have been found to be less willing to talk about the dead child (Wilson, Fenton, Stevens, & Soule, 1982) and to avoid professional support (Mandell et al., 1980).

This idea is consistent with Littlewood and Cramer (1991), who found that men prefer active styles of coping compared to women's passive, comfort focused approach. Some examples of active styles of coping include spending more time either at work, at the gym and/or doing yard work. In addition, in Schwab's (1996) study focusing on gender differences in parental grief, it was found that mothers' scores on the *Grief Experience Inventory (GEI)* compared to the fathers' were different. Among higher levels of hurt, feeling cheated and depressed, Schwab also found that mothers indicated they were less able to control their overt emotional behaviors. This included crying and the desire to scream. This is consistent with other literature reporting that women prefer more

passive styles of coping when compared to their partners (Feeley & Gottlieb, 1988; Littlewood & Cramer, 1991; Wing et. al., 2001).

Problems may occur due to differences in coping. The husband may see his wife as overemotional, and the wife may see her husband as uncaring. The way that males and females react to the death could evoke problems when perceiving and receiving social support. One example is the expectation that bereaved females may receive more social support than males (Thuen, 1997).

Littlewood and Cramer (1991) hypothesized that, if hospitals prefer passive styles of grieving as a general rule, mothers would be more likely to get support from the staff. Their partners, on the other hand, would be left feeling ignored and avoided by hospital personnel. Since supporters may also tend to use passive styles of coping, receivers may perceive such support differently based on their gender.

Nikolaisen and Williams (1980) studied SIDS parents' perceptions of which support they received as being the most helpful for meeting their needs. The authors constructed and mailed a survey based on their literature review. Part of the questionnaire included a five point Likert scale asking about positive and negative aspects of support. In their analysis of parents' views of support after losing an infant to SIDS, the researchers found that fathers and married couples saw support as more helpful than did mothers and single parents. One conclusion that could be drawn from this is that fathers may not be used to being around support in general, thus were surprised by the many people who came to help. Mothers were more critical of the support, perhaps expecting more support or of a longer duration. How men and women perceive social support could be related to their psychological well-being.

Carroll and Shaefer (1994) also found that men who have lost an infant to SIDS were more likely to depend on their partners for SIDS information when compared to women who had a SIDS infant. Those who did not have good communication with their wives, or were unmarried, were less likely to have access to SIDS information. This, of course, may be a reason why many men do not seek professional support; they do not have access to information regarding grief therapy as well as organizations designed to help with their grief (Carroll & Shaefer, 1994; Mandell et al., 1980; Wing et al., 2001).

Needs Following a SIDS Death

It is hard to know what parents in this critical time need from others. Some people may need a shoulder to cry on, while others need friends to perform tasks for them, giving them a sense of relief. Research has found that, while it varies from person to person, there are some trends. It is essential for social supporters to become aware of these needs so that they will be better equipped to give the family what they are searching for. Therefore, the trends of what a family's typical needs are after the death of a child will be addressed in the psychoeducational group.

In a qualitative study that interviewed parents zero to three months after their child's death, parents recalled a need for information and empathic social support (Powell, 1991). Prompt, frequent, or intermittent contact was useful to parents. Parents felt more comfortable to decline company if they were in their home. Many also felt a need to hang the deceased child's picture on the wall and to let their other children know about their brother or sister that they lost (Dyregrov & Dyregrov, 1999). Pine and Bauer (1985) stated that parents felt that they needed permission to talk about their grief and confusion. Perhaps they did not want to make their company feel uncomfortable by just

bringing it up in conversation. This also resembled Dyregrov's (2003) study, which categorized parents' greatest needs. These included: (1) telling the story, (2) informing others, and (3) clarifying their own needs. Clarifying needs was found to be the most beneficial to those parents dealing with inadequate social support. It seems that parents have a great need to talk and inform people about what happened. It would also seem that parents who are in the grieving process mostly need emotional support. However, some studies have found the opposite of this popular belief.

<u>Contrary Evidence</u>

Thuen (1997b) studied social support after loss of an infant, and the effects of this social support months after the death of the child. He recruited 251 members from the Norwegian SIDS society. This study focused on three purposes. First, it assessed the three types of support that bereaved parents received (instrumental, emotional, and informational), provided by members of their social support network. Thuen's (1997b) second purpose was to assess the relationship between the mothers' and fathers' levels of received social support. His last purpose was to see if there was a relationship between the various kinds of social support provided and long-term psychological adaptation of the bereaved parents.

Social support was operationalized as consisting of family members, friends, neighbors, professionals, and the Norwegian SIDS Society. "Help to solve practical problems, emotional and social support, and guidance and information" were asked about in regard to what support parents received after the death. The *Symptom Check List-90* (Derogatis, Lipman, & Covi, 1973) was used to measure psychological adaptation, and psychological well-being was assessed using the *Bradburn's Affect-Balance Scale*

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(Bradburn, 1969). The *Bradburn's Affect-Balance Scale* contains ten items that focus on positive and negative affects experienced during the last few weeks. Two other measures of psychological adaptation were also used. One was a question about reestablishing a normal life and routines, and the other regarded intensity of grief over the last two months.

Thuen (1997b) found that family members provided predominately emotional and instrumental support. Friends also provided predominantly emotional, then instrumental, followed by informational support. While neighbors supported the parents significantly less, types of support given followed the same pattern as the friends' sample. The Norwegian SIDS Society provided mainly informational and some emotional support; instrumental support was negligible.

Females received slightly more support than the males in the study, yet it was only significant in the area of emotional support. Surprisingly, social support from the family was weakly related to psychological adaptation, while support from the neighbors was significantly related to psychological adaptation. Thuen (1997b) also found that instrumental and informational support were more related to psychological adaptation than emotional support. These findings indicate that neighbors may play a prominent role in parental psychological adaptation. In regard to the emotional support being weakly correlated, it may be "that practical help and information given to such a vulnerable group as the parental bereaved, will generally be perceived to contain large amounts of emotional supports" (Thuen, 1997b, p. 108).

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Problems Researching Social Support

Social support and its effects on well-being and health began to garner interest in the 1970's (Cohen & Syme, 1985; House & Kahn, 1985). Even though it has been an area of interest for some time, many researchers still cannot define social support clearly (Brownell & Shumaker, 1984). Many people know what social support is; however, despite decades of research measuring, defining and applying social support, there are still many problems in this area of interest.

"Anyone attempting to review research on the relationship between social support and health faces the problem of trying to integrate a literature that has almost as many measures as studies" (Cohen & Syme, 1985, p. 14). Throughout the literature conducted by Heitzman and Kaplan, measurements and scales encompass a wide range and variety (as cited in Cohen & Syme, 1985). Some of these introduce differences in defining social support and the subjectivity of perceptions of this social support. As mentioned earlier, some studies focus on the actual numbers of friends while others focus on the effects of that friendship. It is clear that differences in the conception of social support might lead to different findings and confusion about this subject.

Jacobson (1986) reports that more attention should be paid to functional areas of support since most of the research focuses on the structural area (i.e., marriages, number of friends). Peoples' relationships as well as their duties change throughout their lives, yet little research has examined how support changes throughout people's lives. Does a close friend who was a social supporter before now become distant after a death? Given that relationships often change, more research should explore how these changes influence perceptions of social support.

Thoitis (1995) states that structural and functional support concepts have not been studied together, and believes this is a definite gap regarding social support. "It is possible that the number and structure of individuals' social ties matter less for perceptions of support than the possession of at least one tie that is close and confiding" (p. 64). However, the underlying assumption in most of the literature is that the more social support people receive, the better they fare in the adaptation process (Thuen, 1997).

Psychoeducational Groups

Psychoeducational groups are designed to help participants develop knowledge and skills for coping adaptively with potential environmental challenges, developmental transitions, and life crises (Jones & Robinson, 2000). According to Rice, structured psychoeducational groups have been growing in popularity as the use of short term treatment models has increased (as cited in Furr, 2000). In 1990, the standards for training group workers were revised and adopted by the Association for Specialists in Group Work (ASGW) (ASGW, 1991), to include four group types or socializations. Psychoeducational/guidance groups are among the four, with goals of preventing the development of dysfunction as well as improving members' coping skills. The proposed model differs from this definition because its goal is to decrease the developmental dysfunction of secondary members (i.e., parents who have lost a child to SIDS) by increasing the primary group members' skills in giving social support.

While psychoeducational groups are a type of group work, there are subcategories within psychoeducational groups. Brown, (as cited in Capuzzi, Gross, & Stauffer, 2006) classified psychoeducational groups by their primary purpose: psychoeducational,

experiential, skills training or self understanding. The first category is an education group. This group focuses on learning material through lecture, discussion, observation or participation. The leader acts as a teacher who educates his or her members regarding new information on a particular subject (Brown, 1998). The proposed model is primarily an education group, since it is more cognitively focused than experiential. Skills training groups, however, do have a strong experiential component. Members are asked to practice new skills that are modeled by the group facilitator. The last type of psychoeducational group is the self-understanding/self-knowledge group. These groups resemble traditional counseling groups but de-emphasize self-disclosure, working through resistance, and past relationships. Their purpose is to build self-confidence and give feedback to members about their impact the behavior has on others.

Knowing the differences among psychoeducational groups is as important as understanding what a psychoeducational group is to begin with. Some members may prefer to focus on building skills and not as much on the cognitive focus. Some members may want to understand their impact on people, while others may just want to develop better social skills. Clearly, understanding the focus of the group as a whole, as well as the differences within these types of groups, is important before one joins a group.

A recent increase in psychoeducational groups may be due to the flexibility of their use with a variety of populations and age levels, and their ability to cover a variety of topics in a relatively short period of time (Jones & Robinson, 2000). There are many topics that psychoeducational groups have addressed over the last decade. Among them are loneliness, marriage enhancement, athletes in transition, stress reduction, parenting, mood disorders, HIV/AIDS, divorce adjustment, sexual abuse and cancer (Furr, 2000).

Although psychoeducational groups seem to be very popular, the literature suggests that they are often not researched when compared to more therapeutically based groups (Furr, 2000). The following sections will discuss what a psychoeducational group is, and its implications for social supporters to parents who have lost a child to SIDS.

Differences between Psychoeducational and Other Groups

The most important distinction is that, in a psychoeducational group, the leader is usually presenting information (Jacobs, Masson, & Harvill, 1998). In comparison to a support group, the psychoeducational group leader presents information rather than facilitating a safe environment where the group members can share. Many parents who have lost a child to SIDS may attend a support group to share their ideas and concerns. The focus of a support group is not on learning and skill building but rather on trust, commitment and genuine caring among members (Jacobs, Masson, & Harvill, 1998). Although psychoeducational groups are more cognitive in nature, they still are consistent with the wellness model of counseling because they focus on prevention, personal responsibility, and empowerment (Aasheim & Niemann, 2006).

The most important dynamic in support groups is the interactions among group members. In contrast, the most important goal for psychoeducational groups is to learn (Aasheim & Niemann, 2006; Jacobs, Masson, & Harvill, 1998). In an education group, members usually have common goals that include learning new information, developing or increasing new skills, finding more effective ways of communicating or relating, and developing personal insights (Aasheim & Niemann, 2006). Therefore, although psychoeducational and support groups often address the same topic, presentation and focus, group members' interactions and expectations would be distinctly different.

Group Dynamics

Most literature that discusses group work tends to focus on the process of therapy groups rather than group design (Furr, 2000). Yet, in a psychoeducational group, group design is important because it inherently is a more structured format. Group size, time, length and meeting places are important considerations in many if not all types of groups. However, in addition to these types of concerns, group leaders of an education group also have to plan content and exercises that fit with the group needs.

Screening

Screening is a vital process in most groups; however the research seems to focus on screening for therapy groups rather than psychoeducational ones. Brown (1998) states that group screening has limited applications for psychoeducational groups. However, she does note that if the group emphasizes development, life skills or social skills, then screening may be beneficial. Generally, group leaders would want their members to have a minimal level of interpersonal skills, reasonable degree of motivation for therapy, and an expectation of gain from involvement in the group (Woods & Melnick, 1976). Other literature examines when exclusionary screening is necessary (i.e., to screen out those who are suicidal, narcissistic, paranoid, or in severe crisis), yet the focus is mostly aimed at traditional group therapy (Herlihy & Flowers, 2006; Klein, 1985). Screening in a psychoeducational group, especially one that deals with death and could be potentially misleading to new members, is a necessity in the present model.

There are many screening processes that are available, such as phone interviews, small group interviews, or questionnaires (Herlihy & Flowers, 2006; Jacobs, Masson, & Harvill, 1998). While these methods are suitable, the method of face to face/personal

interviews seems to be the most beneficial, although it is the most time consuming

(Jacobs, Masson, & Harvill, 1998). This method allows a two-way exchange between the

facilitator and prospective members. It allows the facilitator to evaluate group members

as well as ask questions as to what kind of group they are looking for, what goals they

have, how willing they are to share personal information and to communicate with the

group. While the last two questions are geared toward traditional therapy groups, a

psychoeducational leader may ask how much the members know about SIDS and/or

grief. This is important because sometimes members may know too much or too little

about the topic for the group to be useful to them (Jacobs, Masson, & Harvill, 1998).

The personal interview also allows members to ask the facilitator questions and to

begin to become familiar with the leader (Herlihy & Flowers, 2006). Group members

may have questions on the content, format or process of the group. The facilitator at this

point would have to be clear with the prospective members about the focus of the

psychoeducational group (information) and what it does not supply (support). If members

are interested in attending a psychoeducational group, but feel that they also have grief

issues to work through and need support, the facilitator would give references for support

groups in the area (see Appendix VI). Ideally, the facilitator would have personal

interviews with all prospective members. However, this is often time consuming and

inconvenient. If one could not be available for a personal interview, one would be

arranged by phone.

Size

Group size in most therapy groups is an important aspect for many reasons. If the

group is too large people might not have a chance to share, or may feel hesitant about

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talking in such a large forum (Rose, 1989). On the other hand, there are also problems if the group is too small in size. In a small group, members may feel pressured to participate, feel forced into intimacy too soon, or feel overly exposed (Rose, 1989; Rutan & Stone, 2001). The counselor plays an important part in deciding how large the group should be. Some counselors feel comfortable with ten members, while others feel that is not a comfortable group size (Rutan & Stone, 2001). Another important concern for counselors is that if the group is too small, the group process may be overlooked. The temptation to counsel four or five individuals is immense, and may override the rationale of group therapy (Rutan & Stone, 2001; Yalom, 1995).

Yalom (1995) suggests that seven to eight people is an ideal size for a therapy group, while five to ten members is acceptable. Most literature agrees with this range (Jacobs, Masson, & Harvill, 1998; Rose, 1989; Rutan & Stone, 2001). However, these numbers are typically used for traditional therapy groups, and not psychoeducational groups. Psychoeducational group literature has a broader range as to what is an ideal size.

Capuzzi and Gross (2002) state that psychoeducational groups can have as few as five members, yet can still remain effective with fifty members. Jacobs, Masson, and Harvill (1998), in contrast, state that psychoeducational groups can be effective with five members but should not exceed fifteen members. Furthermore, Brown (1998) states that psychoeducational groups usually range from five to fifty members, but notes it is possible that group size can reach up to one hundred members.

When this occurs group leaders may have to break down the group into more manageable subgroups. When trying to establish an acceptable group size, facilitators should be concerned with the average dropout for new therapy groups. Rutan and Stone

(2001) state that the dropout rate for therapy groups is one to three members. Therefore, a group starting with only five members could diminish to only three members (Rutan & Stone, 2001). Consequently, it may be necessary to have a few more group members added in the beginning of the group, so that if dropouts occur there are still enough members to allow the group to flourish.

Length

Group length is also a significant aspect of psychoeducational groups. Group length often depends on group composition. Some groups may meet once a week, while some meet monthly. The idea is that groups should not meet so frequently that the material becomes boring, but not so infrequently that every meeting seems like the first. Adult groups usually meet weekly for one to two hours (Rutan & Stone, 2001), and groups meet for between four to twelve sessions (Rutan & Stone, 2001). Yet Brown (1998) states that psychoeducational groups can vary widely, from one group lasting one hour to long-term, ongoing groups. Education focused groups generally have fewer sessions than self-help or skill training groups. Jacobs, Masson, and Harvill (1998) state that groups should be at least an hour, and should not exceed two hours. In schools, however, psychoeducation groups may be much shorter in time due to the shorter class periods.

Closed Groups

Closed groups do not allow new members to attend once the group has been initiated (Capuzzi, Gross, & Stauffer, 2006). Closed groups offer stability of membership and facilitate cohesion and trust in psychotherapy groups. Groups that are short term, such as the present model, usually are closed (Brown, 1998). It would not be beneficial to

join a short term psychoeducational group in session three because the members would have missed information provided in the previous meetings, which could lead to confusion. Closed groups help ensure that all members receive the information at the same time and decrease members feeling confused because they missed previous information.

Time

Facilitators should be reminded that there are always going to be the usual problems of getting eight to ten members together weekly. Yet, if the group leader is aware of the members' availability it may help the facilitator plan accordingly. This of course may be a disadvantage to group leaders who may have to sacrifice their personal time and own convenience for the group's success (Rutan & Stone, 2001).

Daytime groups are often preferred for non-workers, the self employed, professional students and night-time working populations. While the time may be convenient for this population, Jacobs, Masson, and Harvill (1998) point out that among groups that begin after lunch, members are often are tired and unmotivated. Facilitators should inform members of the time that the group begins and ends before the group actually initiates, so that group members can plan accordingly.

Leader/Facilitator

Facilitators, depending on what type of a group they are leading, have many responsibilities. In a traditional therapy group they must have a good understanding of basic human conflicts and dilemmas, theories, and potential group problems (Jacobs, Masson, & Harvill, 1998). In a psychoeducational group, the leader should be aware of the ideas above but also focus on other issues. An effective leader, as outlined by Jacobs,

Masson, and Harvill (1998), should have experience with groups: "In the development of any skill, practice and experience increases one's effectiveness" (p. 27). One cannot be an effective leader without practicing the skills that are needed to facilitate a group. Of course, one can not develop skills by simply reading or observing others. Jacobs, Masson, and Harvill (1998) advise that novice leaders might begin leading education and tasks groups with four or five members. As leaders' skills and comfort increase, they might co-lead counseling or therapy groups before they lead a group on their own.

Among important traits that a good leader should possess, especially one who is leading a psychoeducational group, are planning and organizational skills. Effective leaders give considerable thought to topics, and to the activities and exercises that pertain to those topics. Group leaders typically have to plan topics and exercises for each session in advance, the same way a teacher would prepare a curriculum (Jones & Robinson, 2000). Leaders of a psychoeducational group use their knowledge and skills to understand participants and their needs. Effective leaders have topics flow from one to another so that the group process can also flow smoothly (Brown, 1998; Jacobs, Masson, & Stauffer, 2006).

Unfortunately, this flow can be interrupted if the leader does not have adequate information about the topic at hand. A leader will only gain expertise by researching the latest literature in the field and constantly increasing his or her knowledge (Brown, 1998). This is a crucial issue in a psychoeducational group setting. The leader in any psychoeducational group must have a solid knowledge of the material.

Leadership in Groups

There are three types of leadership styles that are discussed in Capuzzi and Gross (2006) which were developed by Kurt Lewin (1994). The styles are labeled as authoritarian, democratic, and laissez- faire. It should be noted that these leadership styles seem to be focused on therapy or counseling groups rather than psychoeducational groups. The authoritarian category will be discussed first since it is the most relevant to psychoeducational groups. Authoritarian style is when the leader assumes the "expert" role. The leader who has this leadership style directs the movement of a group and controls most of the group process. An authoritarian leader generally does little self disclosure, and creates a structure that protects them from self disclosing. It would seem that most psychoeducational groups would have the leader assume this role, given that the leader is seen as a teacher, guiding his or her classroom (Jacobs, Masson, & Harvill, 1998).

Democratic and laissez-faire styles would not be a good fit with psychoeducational groups. Democratic group leaders place more responsibility on the group members to create a meaningful experience. They are seen as more self-disclosing than authoritarian leaders. Laissez-faire leaders do not provide any structure or direction to the group members. These styles would not work well in a psychoeducational group because members do not have knowledge of the topic. Psychoeducational groups emphasize structure and direction. They are considered leader centered because the leader is the center of focus and determines what information will be most beneficial. The leader accentuates predetermined content, structured exercises and format in each session (Capuzzi & Gross, 2006). Again, this form of psychoeducational group does not

emphasize trust or the interpersonal process, but rather gaining information (Aasheim & Niemann, 2006; Jacobs, Masson, & Harvill, 1998).

Goal and Selection of Content. One of the most important tasks of a leader is determining goals as well as selecting content. Unfortunately, little information is available in the literature to assist group leaders in conceptualizing and designing a psychoeducational group (Jones & Robinson, 2000). However, there has been some information regarding this subject.

When designing a group, the general characteristics of members should always be kept in mind. This includes age, developmental level, education, maturity and culture, since all of these characteristics influence the way one learns (Aasheim & Niemann, 2006; Brown, 1998).

Goals are an important aspect when designing a group. If goals are too broad, members may not be able to reach them (i.e., learn about SIDS). On the other hand, if the goal is too narrow the viability of the group maybe compromised due to exclusion of certain members and experiences. Goals should be realistic, specific, clearly articulated and challenging but also should allow for individual differences (Aasheim & Niemann, 2006; Rutan & Stone, 2001).

Group Sessions. In structured groups, the leader decides what the particular goal will be for each meeting and outlines the objectives that will reach that particular goal. The objectives within each group session consist of activities that the group leader selects. Group members have little involvement in selecting activities (Brown, 1998). While it has already been stated that there is insufficient literature on designing a group,

Jones and Robinson (2000) provide guidelines for choosing activities for a psychoeducational group.

The first step in the process is brainstorming group activities that are appropriate to the group's theme. In the present model, one activity that was chosen was a questionnaire on the type of supporter each member primarily was. This activity relates to the model's theme of education in supporting SIDS parents. Having members learn different modalities of support and how they relate to them connects well with the group's theme. Jones and Robinson (2000) recommend choosing group activities from a variety of books, journals, and other resources from different theoretical orientations.

The next step is assessing the intensity of each activity. This step is primarily tied into the stages of the group process. How one can determine the intensity of a particular activity is by evaluating the extent that the activity evokes anxiety among the members, and by how much the activity raises awareness, focuses on feelings, focuses on the here and now, and focuses on threatening issues. Less intense activities are generally introduced in the beginning and ending stages of the group, while more intense activities are included the middle stages of the group (Jones & Robinson, 2000).

In the beginning stage of the group there is usually a sense of anticipation, excitement, dread, confusion and/or apprehension (Brown, 1998). Although psychoeducational groups usually do not have much self disclosure, members are still unsure of what to expect (Brown, 1998). Due to this, activities for the beginning stages should focus on reviewing goals and objectives, the group process, and assisting members in expressing their expectations of the group (Brown, 1998; Jones & Robinson, 2000). The leader must plan ahead to help ease some of the tension that usually manifests

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in the beginning stages of the group. He or she must make sure that the facilities are adequate, supplies are ready for use, schedule and agenda are prepared, and the meeting begins on time. When the meetings are organized and the leader is prepared it promotes safety and trust for the members (Brown, 1998). In the first meeting of the present model the leader introduces himself or herself, explains the group structure and other common group issues, and then passes out a handout on the myths of SIDS. This handout is considered a satisfactory beginning stage activity because the researcher deemed it is a low anxiety activity, does increase awareness, and does not focus on feelings or threatening personal issues.

Brown (1998) separates what Jones and Robinson (2000) would call the "middle stage" of group process into two different categories: the Conflict and Controversy stage, and the Working and Cohesion stage. For the purposes of the present paper, Brown's (1998) Conflict and Controversy stage will not be discussed as in-depth as his other stages. The Working stage is generally marked by cooperating and cohesiveness. Members are willing to work on tasks and activities, and also are supportive of one another. Jones and Robinson (2000) state that this middle stage is higher in intensity, focuses more on the group's theme, and had members sometimes disclose threatening issues and express feelings. One may begin to think that this stage resembles a typical therapy group and not a psychoeducational one. While the most important emphasis is to learn material in a psychoeducational group, the experiential component sometimes is necessary to accomplish this goal. Therefore, the facilitator could present a concept and ask members to share their ideas of what that concept means to them. Then the facilitator could weave their answers into the idea that the facilitator wants to convey. The

presentation becomes more than an intellectual exercise if the members relate the concept to their own lives (Furr, 2000).

"Although didactic information is a vital part of the structured group, change is dependent on the participant's ability to apply the concepts to life situations. Experiential learning allows the material to be encountered on a personal level" (Furr, 2000, p. 36). In the present model, the content of the second two sessions focuses on feelings, the grief process, and tasks of mourning. The content was chosen for these two sessions based on Jones and Robinson's (2000) criteria for assessing the intensity of content/activities. Research suggests that these issues are more anxiety provoking, challenge group members to self-disclose, focus on feelings and are considered threatening issues (Furr, 2000; Jacobs et al., 1998; Jones & Robinson, 2000).

Throughout these two sessions, the leader allows group members to ask questions to process the material better. Processing refers to spending time discussing feelings, thoughts and ideas that result from the material or activities (Jacobs et al., 1998). "Ultimately, the process component becomes the link between the group content and the participant's life outside the group" (Furr, 2000, p. 37). Processing may include a discussion of what thoughts and feelings were generated and how these insights can be applied outside the group. While the main emphasis of the present psychoeducational group is not for support of what one is feeling, there is time for members to ask questions and talk about issues that arise from the content of the meeting.

Psychoeducational groups typically do not go through a long termination process when compared to therapy groups, but they still come to an end (Jacobs et al., 1998). Termination is a time to tie up loose ends, summarize the covered material, and

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sometimes react to the information presented (Brown, 1998; Jacobs et al., 1998). Since the focus of the termination stage is summarizing material, it is not wise for a facilitator to plan intense topics and activities for this stage. Facilitators may end a group or session but this does not necessarily mean the group was terminated. If residual feelings or loose ends are still present, the termination was unsuccessful even though the group ended (Brown, 1998).

Presenting anxiety provoking material in this stage will most likely lead to an inadequate termination. One activity that would be useful for this stage is assessing the growth of members, and determining whether the members met their goals. It is also a useful time for the facilitator to receive feedback on how the group was run, what members thought was useful or ineffective. In the present model, the facilitator reviews goals of the group members which consequently leads to a discussion of whether group members have met their goals. This gives the facilitator details on how to improve the group's content and activities. In addition, the facilitator passes out community resource information to members who are interested in exploring a broader scope of SIDS.

Planning a group's content and exercises is a difficult task, especially when there are no existing models. While psychoeducational groups are increasing and are addressing many topics, there is limited information on the actual content and structure of these groups (Furr, 2000; Jones & Robinson, 2000). Future researchers should make an effort to evaluate existing psychoeducational groups, and the process that led to defining the group's structure, dynamics, and content.

Conclusions

Research on social support and the effects it has on grieving parents needs to continue. It is clear that parents, no matter how social support is defined, do not always receive its (Littlewood & Cramer, 1991; Thuen, 1997b). If they do receive it, it is not always given efficiently or effectively (Klass, 1988; Powell, 1991). Supporters are often inept in handling a situation as traumatic as the death of a child, due to its unnaturalness, fear of itshappening to them, or fear of saying the wrong thing (Arnold & Gemma, 1991; Chesler & Barbain, 1984; Dyregrov, 2003). Despite these reasons, grieving parents need their supporters to act with compassion and decency. While there are many support groups available for parents, social supporters do not have the same access to information and support. Creating a psychoeducational group may assist SIDS families to receive better support than the literature suggests, and also may give social supporters time to educate and heal themselves.

It is also relevant to understand the differences among support that parents receive based simply on their gender. In the United States, men are socialized to be strong and support their wives when tragedy strikes (Mandell et al., 1980; Smialek, 1978; Taylor et al., 1986). It may be the case, then, that when tragedy strikes men will not psychologically adapt because of their suppressed emotions.

Although much of the research has concluded that emotional support such as listening to the parents' story, having permission to talk about the dead infant, and "being there" are seen as beneficial, some parents report different views (Chesler & Barbain, 1984; Dyregrov, 2003; Thuen, 1997b). It should be understood why this may be the case. Perhaps being relieved of daily tasks is seen as more beneficial, especially if parents are

tired of talking and just need to relax (Thuen, 1997b). It is important to educate social supporters about which tasks are seen as most beneficial to grieving parents. It may be that emotional supporters are the same individuals who provide instrumental support as well. This "double supporting" may be seen as a limitation when trying to decipher who (i.e. family, friend, neighbor) does what, and how it is perceived (Thuen, 1997b).

More research needs to focus on the area of SIDS and social support, particularly since empirical studies have decreased sharply in the last fifteen years or so. This may be because rates of SIDS are declining, or because researchers have moved on to study other diseases that have not been around as long as SIDS, such as AIDS. SIDS still does affects many families' lives, and therefore, research should continue to explore what can best help SIDS parents.

CHAPTER III

A MODEL FOR A PSYCHOEDUCATIONAL GROUP DESIGNED FOR SOCIAL

SUPPORTERS OF SUDDEN INFANT DEATH SYNDROME PARENTS

Although there are many support groups for SIDS parents, there are few

psychoeducational groups for friends and relatives who are connected to the immediate

family who lost an infant. Establishing a group which educates on this matter would

serve not only its members but the immediate family as well, since it would take the

burden off the family needing to educate their support group on SIDS and what they are

going through.

The overarching goals of this model group include: (1) providing information

about Sudden Infant Death Syndrome; (2) discussing emotions and the tasks mourning

parents may face as they are adjusting to the death; (3) educating group members of their

own loss and developing insight about those losses and (4) educating group members on

what type of supporter they are and how they can make themselves valuable resources to

parents.

Recruitment and Screening

In general, the first week following a SIDS death is too soon for a counselor to

recruit members because the supporters are most likely in a state of shock (Worden,

2002). Recruitment will thus begin at a minimum of two weeks after the death. Parents

will be contacted by either the hospital's crisis counselor or a hospice care provider

informing the family about a group that is offered to social supporters of families who

have lost a child. The family then can give the counselor a list of names of people who

they think might benefit from participating in such a group. The counselor will contact

these individuals and inform them of the psychoeducational group that is being offered to

friends and family of the parents of this particular infant. This is where recruitment would

begin to identify potential social supporters. Willing participants would schedule a

personal interview with the facilitator. If a personal interview cannot be scheduled, a

phone method would be used. Potential members would be told during the screening

process what the group provides, meeting places, times and any other necessary

information.

Format and Structure

The group would be a short-term, closed group of at least five individuals who are

all friends and relatives of one family who has lost a child to SIDS. The maximum

capacity for the group would be ten members. Since most dropout rates are one to three

people, the group most likely would be targeted to eight to nine members (Rutan &

Stone, 2001).

Group Length

The model will consist of a closed, four week psychoeducational group. While

some psychoeducational groups may be ongoing, literature suggests that they are usually

short term, with four to twelve sessions (Brown, 1998; Rutan & Stone, 2001). The benefit

to having a closed group is that members as well as the facilitator are aware they have

devoted a clear amount of time to the group (McNurlen, 1991). Another advantage of a

closed group is that members can start feeling comfortable with each other and not worry

about feeling vulnerable all over again as new people begin to attend. In the present

model, all group members have the common characteristic of knowing the parents, yet

that does not necessarily mean that all the members will know each other. It should also

be noted that people in any type of support group may feel hesitant about attending.

Having a group that is short-term may ease some of the anxiety about making an ongoing

commitment.

Members

This group will consist of at least five people who are connected to one family

who has lost a child to SIDS. Members will have to be eighteen years of age to attend;

any younger children and adolescents wishing to participate will be referred to a support

group that would serve their age group. In this group all the members will be supporting

the same family.

Meetings

There will be four weekly group meetings that will each last for an hour and a half

(Rutan & Stone, 2001). This will allow enough time for the facilitator to present the

material and facilitate discussion. It is also a short enough time for members to go over

each topic without feeling anxious after a busy day. Meetings will be held from 6:30 p.m.

to 8:00 p.m. This time was selected to allow most people to not miss work, to eat dinner

and return home at a reasonable hour, especially if they have children themselves (Rutan

& Stone, 2001).

Location

Meetings should be held in a neutral setting that is easily accessible to group

members (Jacobs, Masson, & Harvill, 1998). Appropriate sites might be a school or spare

room in a library. Such public places may make group members feel more comfortable in

contrast to a clinical setting (McNurlen, 1991; Worden, 2002). In any setting, facilitators should be aware of the issue of privacy. The room should be closed to any other distractions during the meeting time. The facilitator, especially if meeting in an institution, must do as much as he or she can to ensure members' privacy (Jacobs, Masson, & Harvill, 1998).

Facilitator

The facilitator will be a bereavement counselor having experience working with grief groups, ideally with those who have dealt with losing a child. The therapist must have knowledge of SIDS and the particular issues that surround this type of a death. A leader who has knowledge about the topic and group process will do a better job of being effective and facilitating the group (Jacobs, Masson, & Harvill, 1998).

Content

The facilitator will present specific psychoeducational material throughout the hour and a half meetings. While the facilitator is providing content, members are invited to join in the discussion as well as to ask questions. Therefore, each meeting will have both educational and experiential components that allow for group members to share thoughts and ask questions. There will be no breaks given due to the short time frame of the group. Members are encouraged to take brief breaks as needed.

Meeting 1

6:30-6:45 Introduction of the Facilitator and Orientation

Goal. The goal of the first meeting is to have the group learn a little about the facilitator's background and personality, so they can begin to feel at ease. It also allows the members to become aware of the expectations in group, become familiar with the group format, and allows for any presenting questions to be addressed.

Objective. The facilitator begins with an introduction of him or herself. They should tell the group any background information which may be relevant, such as with what groups he or she has worked and what professional training they have had. It would be especially beneficial if the facilitator described any professional experience with bereavement groups.

The facilitator should also address meeting times, location of restrooms and phone numbers at which the facilitator can be reached. At this point the leader can give an overview of the psychoeducational group process, such as what can be expected, what materials will be covered and what role the facilitator will play. Once the facilitator is done with explanations, the group is asked if they have any questions or concerns.

Notes for the Facilitator. The facilitator can begin to become aware of the group dynamics in the initial meeting. Questions that he or she can start to think about are: Are group members sitting next to each other or are they spaced out? Do they seem relaxed or reluctant? Are there apparent conflicts or allies among these members given their prior associations? In the beginning stages of groups, members may be anxious, excited or confused about what to expect (Brown, 1998). The facilitator should be aware of group dynamics as soon as possible so he or she can address them sooner rather than later. For

example, if members seem bored or confused ask them to offer suggestions alternating the material so they can get the most out of the education process.

6:45-7:00 Confidentiality and Group Structure.

Goal. It is important that group members, especially those who have never been in a counseling setting before, understand issues such as confidentiality, advice giving and accepting how each person can contribute in his or her own way.

Objective. The facilitator explains confidentiality, what it is and why it is a necessary component of the group process. He or she also explains the limits of confidentiality such as if a group member states that he or she is suicidal or is planning to hurt someone. Group members sign a statement that they understand what confidentiality is and that they agree to abide by it (see Appendix I). Although the facilitator has already informed group members about the structure of psychoeducational groups in the screening process, it is beneficial to remind group members of the difference between a psychoeducational group and a support group.

The leader will inform the members that this group was established solely to provide members with information regarding SIDS, what the grieving process is and how it affects SIDS parents, and information on how they can aid the parents through the grieving process. This group was not formed to give support but rather to inform the social supporters of SIDS and hope that the information will help them to aid the grieving parents. While group members are encouraged to ask questions about the material, this group was not established to have members "tell their stories." The facilitator states that in some exercises there is a processing component that may allow members to discuss how the material relates to their life, but this is only a conjunction to the presented

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material, not the focus. If members feel that a support group would be better for them instead of this group, resources will be made available to them (see Appendix VI).

The last topic to be reviewed is the idea of making a commitment to the group. The facilitator acknowledges that it might not be easy attending every week, but that being present all four meetings is essential. Everyone in the group is a valuable tool and is needed. Missing a meeting means missing valuable information.

The leader will make sure to leave room for questions regarding confidentiality and group structure.

Notes for Facilitator. The facilitator can get a sense of group members' understanding of confidentiality and the group structure through their comments and questions concerning these issues. The facilitator can also assess whether the group is reserved or participating by the number of questions and comments.

7:00-7:15 Specific Goals of Group Members

Goal. Having each group member specifically state what they want to gain from this group will assist the facilitator if modifications need to be made. It is helpful to understand their goals specifically. For example, many members state they would like to know more about the grieving process, the group could be moderately altered to spend a little more time on this topic. It also can help the facilitator identify what additional resources may be useful to satisfy group needs.

Objective. Group members volunteer to state their goals in an order in which they feel comfortable. The facilitator will monitor to make sure that no one takes up too much time and sees that everyone has a chance to state his or her goals. The facilitator will write down each member's stated goals and what he or she hopes to gain from this group.

In the last group meeting the leader will hand back each member's goal statement to see if he or she feels that this group has met his or her needs.

Evaluation. Up to this point, group members have not disclosed information about themselves. They have only been asked to describe goals that might be useful for the facilitator in tailoring the psychoeducation to the group. Therefore, the chances of their return rate are much higher. Klein and Carroll noted that many dropouts occur in the beginning of the group process (as cited in MacNair-Semands, 2004). Furthermore, Mamar, Horowitz, Weiss, Wilner, and Klatreider, concluded dropout rates can reach as high as 77% (as cited in MacNair-Semands, 2004). With this understanding, it is wise for the facilitator not to ask the group to disclose too much personal information in the beginning of the group. Stating goals, rather than personal feelings or circumstances, is probably a safer topic for many members (Jones & Robinson, 2000).

7:15-8:00 Myths about SIDS

Goal. There are many erroneous myths about SIDS of which people may be unaware. It is important that these myths be clarified with the correct information for group members' own knowledge, as well as to help aid the SIDS family.

Objective. The facilitator explains that many people are mistaken about what SIDS really is and how it often gets confused with child abuse (Ranney, 1991; Worden, 2002). The facilitator passes out a handout (see Appendix II) that includes some of the myths about SIDS and asks group members to fill it out. After everyone has completed his or her sheet, the facilitator goes over each myth, supplying the correct information. Group members are invited to ask questions about the statements on the handouts and to have any other related concerns addressed.

Notes for the Facilitator. The facilitator can determine how the group is processing by group members' involvement in the presentation, the type of questions that are asked, and the discussion that members have when responding to the presentation. He or she may also note the overall comfort of group members, such as whether they look wary, challenged, bored, or anxious. If the group is quiet or members are not asking many questions, the leader can try to facilitate the processing part of the group. One way to do this is by having group members go into dyads and process the information with their partner. Some questions they might ask each other are "What did you learn?", or "What was the most surprising information about this presentation?" (Jones & Robinson, 2000). The facilitator, when there is an activity involved, must implement techniques to get them involved, ease their anxiousness, or relate to their cognitive abilities (Aasheim & Niemann, 2006; Jones & Robinson, 2000).

Meeting 2

6:30-7:00 Triad of Issues

Goal. To summarize what issues parents may face on their journey through coping with their child's death, and what social supporters may also find themselves going through.

Objective. The facilitator outlines some of the issues SIDS parents and social supporters may face in the format of a presentation. Issues that parents face are outlined below. They are divided into three sections: New Parent Issues, Later Issues, and Ongoing Issues (McNurlen, 1991).

New Parent Issues. These issues include telling the story of finding their dead baby, discussing the funeral, noting who was supportive and who wasn't, anger issues,

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searching for the cause of death, discussing guilt about not being able to save their baby, talking about what to do when people may not know that their baby has died.

Later Issues. SIDS parents need to develop coping tactics for birthdays, holidays and death anniversaries. It is also at this time that support usually stops (four to six months after the loss), and parents usually are looking for new support circles. Also, the issues of how this is affecting their other children or of having another child usually come into focus in this period of grief.

Ongoing Issues. SIDS parents usually would like to help their surviving children deal with the death; learn how to answer the question, "How many children do you have?"; and seek support for other areas of life that may have been affected by the loss, such as their marriage.

Once the facilitator has identified issues that people experience with a SIDS death, the facilitator asks each group member to identify an issue that he or she either has experienced or is experiencing at the present. Once the group has stated their issue, the facilitator leads a discussion of how group members try and deal with their issues appropriately.

Evaluation. The facilitator assists group members to explore how they will deal with the issues that they are facing. The facilitator allows members to process the material in terms of what they seem to have the most trouble with. Having the members relate this information to their lives makes the material easier to use outside of the group (Furr, 2000).

7:00-8:00 Grief Reactions

Goal. Many people may be under the impression that once a baby dies, sadness is

the only emotion that parents face. Grief, however, is much more complicated than this.

In this session, the facilitator will present common feelings, physical sensations,

cognitions, and behaviors that SIDS parents are likely to go through.

Objective. The facilitator will present information in a lecture format that covers

the topics listed above. The facilitator also covers what social supporters can do to help

parents who are experiencing these emotions. Additionally, the leader explains that social

supporters may themselves go through these emotions and thoughts, and how to

recognize what they need to do to help themselves. As the presentation continues, there

will be room for questions and comments. The facilitator begins with the topic of feelings

first, since most members are probably most aware of feelings after a death, and then

lesser known topics are introduced.

Feelings. Many people feel that sadness is the only emotion that grieving parents

experience on the loss of their child. While it is the most common emotion, the facilitator

describes that many other emotions follow. Anger is also frequently an emotion that

parents find themselves feeling (Littlewood, 1992; Worden, 2002). It is important that

social supporters be able to identify healthy anger and unhealthy anger. Healthy or

normal anger fades a few months to a year after the death (Worden, 2002). Anger can be

directed at oneself, at pediatricians, or at society in general.

The term that Fuller, Barnickol, and Mullins (1991) use to describe unhealthy

anger is "cosmic anger." This type of anger consumes the person's entire being. The

death is everyone's fault, yet in reality is no one's fault. Parents' anger may push people

whom they need most away from them. SIDS parents usually take a great deal of time to realize that they have pushed people away with their anger, before they can begin to reestablish these relationships.

Parents place a tremendous amount of guilt on themselves and/or each other when a child dies (Rando, 1996). While the fact is that nothing could have been done to prevent the infant's death, the parents may start to minutely examine events that led up to the death (Arnold & Gemma, 1991). The facilitator explains that, while it is important to know that the parents did not cause the death, it is also important to let the parents show that they feel guilt and to let them "tell their story." SIDS parents often begin to question their competence as parents. The facilitator explains that these feelings usually pass with time (Leick & Davidson-Nielsen, 1991).

Physical Sensations. The facilitator explains that many times people who are grieving experience physical symptoms, almost as if they are sick. Often they will go to the doctor because the symptoms are so real. Common physical sensations include tightness in chest and throat, emptiness in the stomach, shortness of breath, weakness in the muscles, lack of energy, dry mouth, and depersonalization (Worden, 2002).

Cognitions. Disbelief is the most common pattern of thinking among SIDS parents, since the death was completely unexpected. The parents did not have time to prepare and make peace with their baby's death as parents of children with cancer might have (Ranney, 1991). This is important, because it will take time for the parents to come to terms with how the death will affect their lives.

Behaviors. Parents who have lost an infant may also experience sleep disturbances. The difference between difficulty of going to sleep and early morning

awakening are explained to group members. It is also explained that parents having

dreams of the deceased or who report crying, forgetfulness, and appetite disturbances are

behaving quite normally during the grieving process.

Evaluation. The facilitator can respond to group members' with their questions

about the material and how they can better assist SIDS parents who are going through

these grief reactions. The facilitator can also ask if any feelings or ideas arose while

listening to presented material, and how it relates to their lives (Furr, 2000).

Meeting 3

6:30-7:15 The Grief Process/ Tasks of Mourning

Goal. Everyone will undoubtedly experience the death of someone they love.

While many people experience the grief process, many do not know that the grief process

is more or less a similar experience for everyone. Of course there are exceptions, yet

most people experience common emotions and behaviors after a loss (Worden, 2002).

After this lecture, social supporters should be able to understand the tasks of mourning as

outlined by Worden (2002), as well as what is considered abnormal in each stage.

Objective. The facilitator outlines the four tasks of mourning in a lecture format. Group

members are encouraged to ask questions.

Task I: Accept the reality of the loss. The facilitator explains that the first task is

to realize that a death has occurred and that mourners need to realize that the infant is

never coming back. As mentioned in the previous group meeting, there is usually

disbelief that this has even occurred: "This isn't happening to me." When one cannot

move past this task, it is seen as maladaptive. It can also be called denial. One example of

denial in a SIDS case is keeping the child's nursery for many years. Mourners may also

deny the meaning of the loss by stating that the infant was so young they weren't even attached to him or her.

Task II: Work through the pain of grief. The facilitator explains that this is seen as the hardest task for society in terms of helping SIDS parents. Society often wants mourners to move on from their pain as quickly as possible (McNurlen, 1991). Supporters may feel that they are helping the parents to be strong, yet that doesn't help them work through their grief. Not allowing parents to work through their pain may lead to complicated bereavement. One example of this is the person who denies they even have emotions about the loss. They may also hide their pain through drugs or alcohol abuse. It is stressed to group members that, while it is difficult for them, to try their best to allow the parents to talk about their grief and express their pain as they go through this task. At the same time, the leader can express that he or she knows that group members are also working through their own pain and grief. Group members are encouraged to talk about their experiences with their loved ones, friends and colleagues. They too, may feel that people want to rush them, yet telling their story to others is a therapeutic and healthy way to work through their pain (Dyregrov & Dyregrov, 2003).

Task III: To adjust to an environment in which the deceased is missing. In the third task, adjusting to a new environment means different things to different people depending on what the relationship with the deceased was and what role the deceased played. The survivors are not usually aware of all the roles the deceased played until after the loss (Worden, 1982). For example, was the infant an "younger brother" to an existing child that role is now lost or a first born that represented stability and start of a new life to a newly married couple? The facilitator describes three areas of adjustment that people

need to make after losing someone that they love. The first is external adjustment, which

involves learning the skills to be able to adjust to their new environment. The grieving

person has to learn to act in new ways and sometimes may resent having to learn new

skills (Leick & Davidson-Nielsen, 199; Worden 1982). One example is coming to terms

that there will always be an empty space in their family. While supporters may or may

not be able to help with these challenges, it is important for them to know that they exist.

The second adjustment is internal, which involves confronting the parents with the

challenge of adjusting to their own sense of self. The death will likely affect the self-

esteem, self-efficacy, and self-definition of the person in mourning. An example, in

regards to self-esteem is that the mother or father may begin to feel that they are bad

parents because they didn't 'do something." Also, parents may have defined themselves

as 'parents,' 'mother of three' or 'older brother' and these defining roles may have been

lost with the infant's death or at least altered.

The last adjustment is spiritual, challenging one's values and beliefs. SIDS

parents may feel that they are directionless. As they learn coping skills and begin

adjustment to their new roles, they ultimately seek ways to live their lives in a meaningful

way.

Task IV: Emotionally relocate the deceased and move on with life. Many times

parents may see "moving on" as the same as "forgetting," and parents never want to

forget their child. This may be why parents have a difficult time completing this task

(McNurlen, 1991; Worden, 2002). The facilitator explains that it is common for parents

to pursue something that gives meaning to their child's life such as advocating for SIDS

research or becoming involved in fundraisers (Barnickol, Fuller, & Cunningham, 1991).

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Supporters are encouraged to help parents remember their child, but also to assist them to go on with their life. "The fourth task is usually hindered by holding on to a past attachment rather than going on and forming new ones" (Worden, 2002, p. 37). For many people this task is the hardest task to complete, but with time and support it can be accomplished.

Evaluation. The facilitator responds to group members' questions about the material and how they can better assist parents who are going through the grief process. The facilitator can also ask if any feelings or ideas arose while listening to presented material, and how it relates to their lives (Furr, 2000).

7:15-8:00 What Kind of Supporter Are You?

Goal. Social supporters who care for someone who has lost a child may experience anxiety about their role and their ability to help. It is important for social supporters to know that SIDS parents are not expecting them to be the "miracle supporter" and do not expect them to do things that make them feel uncomfortable. The goal of this exercise is to allow group members to see what their strongest capabilities are and be able to utilize their strengths to help the parents.

Objective. In this exercise, the facilitator passes out a handout titled, "What Kind Of Supporter are You?" (see Appendix III). This handout was constructed from literature on the differences between emotional, instrumental and informational support. Group members are given five to ten minutes to complete the handout. The facilitator then reviews the description of each type of supporter and determines whether the social supporters' answers indicate predominately informational, emotional, or instrumental types of support. If questions 1, 3 and 8 were answered "True" the member would be

seen as someone who is an emotional supporter. Questions 2, 5 and 6 if answered "True" are geared toward people who are instrumental in their support or like to do chores and "help out." Those who like to gather information to learn about a problem and to gain insight will most likely answer questions 4, 9 and 7 "True." Of course, people can never be put simply in one category or another; some may find that they may be two or three types of supporters while some may just be one. The facilitator at this point begins a discussion of why members feel comfortable with a certain type of support. Discussion may also include how to incorporate different types of support into their comfort level when helping the family.

Evaluation. Group members should begin to understand that everybody has different strengths and weaknesses. Group members hopefully will understand that they possess strengths to help the grieving family. It is important that the facilitator educates the members to be themselves and to do what is most comfortable for them. The leader should point out that it is an uncomfortable situation for everyone, and that people sometimes will say or do the wrong thing. Yet, as long as the supporter is genuine in his or her efforts, he or she is doing the best that can be done.

Meeting Four

6:30- 7:15 Understanding your loss history

Goal. To express to members how their early losses are likely to shape our attitudes toward death, dying, and loss. This exercise has members realize how early loss still may be affecting them now, and how prior losses can affect the grieving parents either positively or negatively. It also allows members to take the time and think concretely about their prior losses and give specific examples of what was helpful or not.

Objective. This handout was adapted from Worden (1982). Members are asked to

fill out the handout that is given to them (see Appendix IV). Facilitator asks members to

put down whatever first comes to mind. Members are given ten minutes to complete the

handout. After the handouts are completed the facilitator asks members if they would like

to share anything that they learned from the exercise. The facilitator may focus on

statement number two (i.e., what others around me said or did was helpful or was not).

The facilitator can discuss with the members why certain support was unhelpful and what

might have been the reason this support was given.

Evaluation. Facilitator can assist group members with their questions about the

material and how they can assist parents more effectively based on the experiences they

have had with their previous losses.

7:15- 7:45 Review

Goal. This activity will let members begin to close the group process and allow

time for their questions and concerns.

Objective. The facilitator passes out each individual's goals that were identified in

the first group meeting. Group members discuss whether or not they reached their goals

and share their thoughts on the group process. The group may also discuss problems and

concerns about the loss to their family and friends from this SIDS death that they have

now or might have in the future. The facilitator passes out an evaluation (see Appendix

V) and asks each group member to fill it out to guide future group curriculum.

Evaluation. The facilitator can observe how the group came together over the four

week period, and assess whether comments were relatively positive or negative regarding

the material and exercises presented.

7:45-8:00 Additional Resources

Goal. Some people in the group may want to continue with counseling services, gathering information, or perhaps would like to become an advocate for SIDS. It is important that these resources are given to them, to make it easier for each individual to receive his or her individual needs.

Objective. A community resource handout with recommended readings (see Appendix VI) will be given to all members.

CHAPTER IV

DISCUSSION AND IMPLICATIONS

It has been said that, compared to all other deaths, losing a child elicits the widest

range of emotions and emotional toll (Sanders, 1980). It is because of this that any efforts

to support parents who have lost a child should include the knowledge that can ease their

pain. Throughout the literature, there are numerous articles that discuss the negative

effects that social supporters may inadvertently have on a grieving parent. Yet, there are

none which address education on how nonprofessionals can be helpful in a time of crisis.

It seems to be the case that most people who provide support following a child's death,

"wing it' and do the best they can. Often their efforts are not helpful.

Creating a psychoeducational group in the aftermath of a SIDS death would seem

beneficial. It would provide group members with the tools of knowledge as well as

resources to help support grieving parents in a positive manner. A psychoeducational

group is a valuable tool for any type of death, especially when the question "What caused

the death?" can never be answered.

Drawbacks to the Model

The first challenge in implementing a model such as this one is finding resources

and finances to establish it in the first place. Funds for social supporters may be seen as

lavish; after all, the parents and immediate family are usually seen as the "real victims."

Some may also believe that if supporters want to learn what works and what doesn't

work, then they can simply read materials or call a hotline. Yet, neither of these ideas

takes into account both the education and processing that is important after a SIDS death. The challenge to establish such a group becomes even more difficult if the model has been untested and, therefore, research on its effectiveness does not exist.

The largest limitation that this model does not address entirely is the interpersonal dynamics that takes place in many groups. This model is cognitively focused; self-disclosure and processing time are limited. Although members in the screening process are told that this model is not a support group, many members may not be able to control talking about how the loss affects them. The facilitator, depending on his or her theoretical orientation, may want to alter this model to allow more time for self-disclosure and processing of material (Furr, 2000). The facilitator should make members aware of how much disclosure is expected before they begin the first meeting.

There is also a valid argument that the members, too, are in the process of grieving and will have needs that may require some attention. It may be naïve to think that education alone will satisfy their needs. While many people are at first attracted to psychoeducational groups because they are less threatening than traditional therapy groups, members may realize that they are in need of traditional counseling (Aasheim & Niemann, 2006). In the screening process, the facilitator could recommend a support group or individual counseling, in addition to attending this psychoeducational group. However, attending two different sessions may be overwhelming for many people, especially in a tragedy situation.

While designing the present model, it was thought that having all the group members connected to just one family would be beneficial. All members would be supporting the same family, be familiar with the circumstances of the child's death, and

the group could be established fairly quickly since the death affected the entire group at the same time. As the model evolved, it became clear that while having the group support one specific family has its benefits, it also has its limitations. The concern is that pre-existing family relationships could result in stressful and conflictual dynamics. Some members may have discord with others from many years ago, while some may have fairly recent negative feelings. For example, some members may feel more connected to the grieving family, especially if they are close to the parents, while some may feel neglected or overlooked by the family. These underlying dynamics may cause hostility among members within this present model. Members may not be able to put their feelings about one another aside, and the group may begin to process their issues with each other while losing the educational component. Discord may be seen as beneficial if the model focused on group members' relationships with each other and allowed ample time to process feelings, but like most psychoeducational groups, it does not (Aasheim & Niemann, 2006; Jacobs, Masson, & Harvill, 1998).

In rural areas which may not have enough supporters to even form a group, especially if the group is dealing solely with SIDS deaths, the idea of targeting just one family may be impractical. However, in metropolitan areas where infant deaths are more prevalent, it would be possible to form a group with members supporting different families. However, the goal is to have the information given promptly after the infant's death. When recruiting from different families, the deaths probably occurred at different times. While the problem of discord among members may be decreased, the time of establishing the group most likely would be prolonged.

The last limitation to this model involves the question, can education alone counter the effect which social supporters have on grieving parents? The literature review made the case that grieving parents all too often find that, while they need social supporters to help them with a wide variety of tasks, they often find social supporter attempts hurtful (Brabant, 1995; Peppers & Knapp, 1980; Wing, Burge-Callaway, Clance, & Armistead, 2001). While this model intends to educate social supporters about what SIDS parents are going through and what they describe as helpful and unhelpful gestures, it may not be enough. Many times, education cannot counter culture norms. For instance, while educating adolescents on the hazards of sex, the majority of adolescents still engage in high risk sexual activity (Guttmacher Institute, 1999). As valuing strength, refusing to cry and "getting over it" are seen as admirable qualities and reinforced in the dominant United States culture, social supporters need to be educated about how these qualities may not be helpful to parents recovering from SIDS (Parkes, 2001). Consequently, the difficulty of countering these embedded beliefs may prove to be a challenge to the group leader. However, knowledge is empowering. Knowledge of available tools, such as psychoeducational groups, can begin the journey to self understanding and healing.

Future Directions

The most important future direction would be to implement this psychoeducational group in practice. It is important to see if this group could be effective when applied to real people facing such a tragic issue. From that perspective, modifications could be made to the model. Perhaps an hour and a half is insufficient time to process the material, or perhaps the number of group meetings should be extended as

well. Once the model is conducted, modifications for improvement will be beneficial to the facilitator, the group, and the SIDS parents.

In addition, research that focuses on SIDS and social support has decreased sharply in the last fifteen years or so. As stated previously, it may be because rates of SIDS are declining, or because researchers have moved on to other areas of study. While the rates of SIDS have decreased, it still claims 5,000 to 7,000 infant lives a year in the United States (McClain & Mandell, 1994). SIDS, then, still affects many families' lives and therefore, research should continue to explore what can best help SIDS parents.

While there are enormous amounts of literature on therapeutic groups and their dynamics, there is very little in print regarding psychoeducational groups. Psychoeducational groups are increasing dramatically, yet there is sparse research on these groups (Furr, 2000; Jones & Robinson, 2000). Information on how to design a group and what content should be included was extremely scarce while conducting research for this model. The facilitator in a psychoeducational group is often looked at as a teacher. Yet, teachers are held to standards of what will be taught in the classroom. Facilitators, unfortunately, cannot be held to this same standard if there are no guidelines or research informing them of which content is most effective. Future studies should make an effort to evaluate existing psychoeducational groups at all levels, so future facilitators can conclude and draw from what is most effective for the population they wish to serve.

One SIDS death has been said to affect over 100 people (Marquez, 1991). That is an immense amount of support that could be available to one family who has lost a child. If a psychoeducational group can decrease the amount of harm by providing information

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on relevant topics, it would be worth establishing the group. SIDS has been in the world since Biblical times. Unfortunately, SIDS death rates, while decreasing, are still significant. A first step to help parents start piecing their lives back together is making mental health professionals, supporters, doctors and nurses aware of what they can do to help.

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APPENDICES

APPENDIX A

CONFIDENTIALITY STATEMENT

The facilitator agrees to treat all information that he or she receives throughout the group's duration, as strictly confidential and will not release information about members to anyone without that person's written consent. Please be aware that facilitators are required to disclose certain information in order to protect group members and/or others in the following situations: a) if a group member is in danger or risk of imminent harm to her/himself or harm to specifically identified others; b) if the facilitator reasonably believes that a child, a disabled or elderly person is suffering injury as a result of neglect or abuse; and c) if a judge orders that he or she provide information in the process of a court proceeding.

The responsibility for confidentiality is not only shared by the facilitator(s) but by all group members. Every member of the group is required to sign an agreement to adhere to these rules of confidentiality. In signing this agreement, group members make a personal pledge that nothing occurring in the group, including names of other group members, will be shared with anyone outside of the group. These rules are critical to the development of a safe, respectful, and trusting atmosphere, which allows individuals to openly share their thought and experiences.

I _____understand what confidentiality means as well as the limits to it. I agree that I will respect confidentiality by not sharing other group members' private information with those outside of the group. In return, I expect the same conduct from the other members of my group and my group facilitator.

X_____   Date_____

APPENDIX B

FACTS ABOUT SIDS[1]

1.	Babies can "catch" SIDS.	T	F
2.	Cribs cause "crib death," or SIDS.	T	F
3.	Babies who sleep on their backs can choke on spit and vomit.	T	F
4.	Only Caucasian babies die of SIDS.	T	F
5.	A SIDS death can be prevented.	T	F
6.	Shots or medicine cause SIDS.	T	F
7.	SIDS can occur at any age.	T	F
8.	Babies who die from SIDS have a painful death.	T	F
9.	A physician can detect if a child could die from SIDS.	T	F
10.	SIDS is a relatively new syndrome.	T	F

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[1]Adapted from: National Institute of Child Health & Human Development (2005). SIDS Facts. Retrieved February 4, 2006, from: http://www.nichd.n.h.gov/sids/PART_II.pdf.

APPENDIX C

WHAT TYPE OF SOCIAL SUPPORTER ARE YOU?

1. I feel uncomfortable when people cry around me.   T   F

2. I like to keep busy with errands and chores.   T   F

3. It s easy for me to tell people I love them and care for them.   T   F

4. When a problem occurs, I tend to often look for answers to solve the
    problem.   T   F

5. When a problem occurs, I tend to do things to help others such as
    cook and baby-sit.   T   F

6. I make sure people know that I am there to help out with everyday
    activities.   T   F

7. Reading self-help books is a good way to find out about a problem as
    well as its solutions.   T   F

8. I feel fairly comfortable listening to others who are going through
    difficult situations.   T   F

9. I like finding information about things that I do not know much about. T   F

[2]Adapted from: Thuen, F. (1997) Social support after loss of an infant child: A long-term perspective. *Scandinavian Journal of Psychology, 38*, 103-110.

APPENDIX D

UNDERSTANDING YOUR LOSS HISTORY[3]

1. An early, significant loss **not** due to death was: _____

_____

_____

2. What others around me said or did that was or wasn't helpful to me was: _____

_____

_____

3. How I felt was: _____

_____

_____

4. The first death I can remember was the death of: _____

_____

_____

5. I was age: _____

_____

_____

____

6. What I remember from that time: _____

_____

_____

7. My primary style of coping with loss is: _____

_____

_____

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[3]Adapted from: Worden, J. D. (1982). *Grief counseling and grief therapy: A handbook for the mental health practitioner.* New York: Springer Publishing Company.

APPENDIX E

EVALUATION

1. What I liked about the group was: _____

_____

_____

2. What didn't work for me was: _____

_____

_____

3. For the next time I would suggest: _____

_____

_____

4. One ting I really want to tell the facilitator is: _____

_____

_____

5. One thing I am taking away is: _____

_____

_____

6. The goals I identified in the beginning of the group were/weren't met because: ____

_____

_____

7. One of the group's goals was providing information on SIDS. This goal was/wasn't met because: _____

_____

_____

8.   The goal of discussing emotions and tasks of mourning was/was not met because:

_____

_____

_____

9.   The goal of educating myself on my own loss and how social support affected me
was or was not met because: _____

_____

_____

10.   The goal of finding out what type of support I was and how I can help parents was
or wasn't met because: _____

_____

_____

Other Comments _____

_____

_____

_____

_____

APPENDIX F

COMMUNITY RESOURCES (MASSACHUSETTS) AND ADDITIONAL
INFORMATION

Sudden Infant Death (SIDS) Support Centers

Connor's Place
   192 Stafford Street
   Worchester, MA 01603
   1-508-757-5043

   *Provides support services and outreach to families who have lost an infant in the
   Worchester County. They also educate families, doctors, funeral directors and the
   community about handling issues that surround infant death.*

Massachusetts Center for Sudden Infant Death Syndrome
   Boston Medical Center
   One Boston Medical Center Place
   Boston MA 02118
   1-617-534-7437

   *The SIDS Center offers many services to families and the community of
   professionals involved with infant and child mortality. Some of them include:
   Care and follow-up for families, public education about SIDS, professional
   training and legislative advocacy.*

Readings

Corr, C. A, Fuller, H., Barnickol, C. A,, & Corr, D. M. (1991). *Sudden infant death
   syndrome: Who can help and how*. New York: Springer Publishing Company.

Horchler, J. N., Rice, R., & Morris, R. R. (2003). *SIDS and infant death survival guide:
   Information and comfort for grieving families, friends & professionals who seek
to help them*. Maryland: SIDS Educations Services Inc.

Websites

http://sids-network.org
http://www.sidsalliance.org