# UNIVERSITY OF CENTRAL OKLAHOMA

Edmond, Oklahoma

Jackson College of Graduate Studies

# Married Couples' Perceptions of Support Following the Death of a Child:

# A Phenomenological Study

# A THESIS

# SUBMITTED TO THE GRADUATE FACILITY

in partial fulfillment of the requirements

for the degree of

# MASTER OF SCIENCE IN FAMILY AND CHILD STUDIES

By

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Edmond, Oklahoma

2013

# Married Couples' Perceptions of Support Following the Death of a Child:

A Phenomenological Study

A THESIS APPROVED FOR THE

# DEPARTMENT OF HUMAN ENVIRONMENTAL SCIENCES

April 25, 2013

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# DEDICATION

This paper is dedicated to my angel baby, Laynie Hope, who taught me what it means to be brave, and to all the brave families who participated in this study.

# ACKNOWLEDGEMENTS

I'd like to thank Dr. Brandon Burr for his leadership and guidance throughout this study. Thank you for the thorough inspections of the many drafts that came your direction and for always being there to answer the countless questions that I had for you. I am very appreciative of the time you spent assisting me with this study that is so near and dear to my heart.

Thank you to my wonderful committee members: Dr. Kaye Sears, Dr. LaDonna Atkins, and Dr. Malinda Green for your dedication to the project and for volunteering to assist. I truly appreciate your encouragement and for being my cheerleaders along the way.

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# ABSTRACT

Social support after the death of a child is often thought of as a buffer to help parents with the grieving process. Previous research has focused on grief and support from an individual's perspective but has failed to explore the meaning that couples assign to support and the role it plays in their marital relationship following the death of a child. The main area of focus for this phenomenological study was get a better understanding of the ways that social support is helpful as well as harmful to the parent's marital relationship after a child's death. Five married couples that have experienced the death of a child were recruited to participate in a series of interviews from two local bereavement agencies, Calm Waters and Oklahoma Family Network. Using the phenomenological method, the researcher sought to gain further insight into their lived experience of support after their child's death as well as meaning the couples assigned to this support. The ABC-X Model by Reuben Hill was used to guide the literature review and findings for this study, where "A" was the non-normative stressor event, or death of a child, "B" was the couples resources, "C" was the couples' perception of the event, and finally, crisis, "X", or conflict in the relationship, would occur depending on the couples' perception of "C". Two common themes developed after reviewing the interview transcriptions and selective highlighting: Strengthened Marriage, and Tension and Conflict. A marriage was thought to strengthen with support that was perceived as beneficial, such as general support, incorporating the child, and seeking outside help. The opposite was true for tension in the relationship. Conflict was attributed to lack of communication about the child from others, family expectations, and lack of support. The couples mentioned that outside help was beneficial to their relationship, but that ultimately it was their choice to decide to get through the loss of their child together.

# BEREAVED PARENTS' PERCEPTIONS OF SUPPORT CHAPTER ONE: INTRODUCTION

## Introduction and Statement of the Problem

With the death of any loved one come complex feelings of grief and sadness, loss and anger, which all compiled together can create a stressful environment for families. Many studies have found the impact associated with grief to be long lasting, and even higher with bereaved parents than other types of grievers (Hendrickson, 2009; McCarthy et al., 2010; Meij et al., 2005; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008). After a child dies, family dynamics are likely to change, including the marital relationship. Roles in the relationship have to be redefined, especially if the couple does not have other children (Toller, 2011). To make the situation more complicated, not only has the parent just lost a child, but also the person he or she would generally turn to for support is suffering and may be too distressed themself to meet the needs of the partner (Meij, et al., 2007).

Social support in the form of family, friends, or bereavement groups is often thought of as a buffer to help with the grieving process. The meaning that couples assign to this support in relation to their marriage requires further investigation. Riley, LaMontagne, Hepworth & Murphy (2007) describe perceived social support as strongly correlated to parent's perception of personal growth, which was especially true for mother's self identity and improved interpersonal relationships. Other studies such as Dyregrov (2003) and Toller (2011) provide evidence that social support is not always perceived as helpful.

What is the role of social support as experienced by married couples following the death of a child? What meaning do bereaved parents attribute to this support and what is

its effect on their relationship? These questions were explored with bereaved parents throughout the course of this phenomenological study.

Keeping with this qualitative method, it was important for the researcher to bracket any preconceptions and personal experience with this phenomenon in order to reduce bias during the research process. This allowed for the true experiences of the participants to shape the project rather than those experiences or opinions of the researcher. Because the researcher had experienced the death of a child, it was of utmost importance to keep a personal journal of emotions and reactions after interviews with the participants in order to process through the reactions so they would not affect the data analysis process.

# Background of the Problem

The death of a child is never something anyone wants to face, but the fact of the matter is, it happens everyday. The National Vital Statistics Reports listed 2,465,936 deaths in the United States in 2010; of this number, 34,240 were between the ages of zero and 14 years old (Murphy, Xu, & Kochanek, 2010). According to the Oklahoma Institute for Child Advocacy Kids Count Factbook (2010), well over four hundred babies born in Oklahoma do not live to see their first birthday (431 annual, 2006-2008). Almost four hundred children and youth die each year in Oklahoma; half are children (47.5% or 197, ages 1-14); half are teenagers (50.5% or 201 teens, ages 15 through 19). About half (48.3% or 200 average annual, 2006-2008) of all current child and teen deaths in Oklahoma are accidental with those remaining a result of disease (34.8% or 144 average annual, 2006-2008) or violence (16.9% or 70 average annual, 2006-2008).

Preconceived notions on the cycle of life and the fact that parents should die before their

children add to the complexity of the stressful situation. With the life expectancy in the United States being 76.2 years for males and 81.1 years for females (Murphy, Xu, Kochanek, 2010), the thought of one dying at a younger age may not be a completely conscious idea. The death of a child is an unexpected event, in general, because most parents do not have thoughts that the child may die young. Though anticipated deaths, such as those related to a pediatric cancer diagnosis, may give families more time to prepare for the loss compared to unexpected deaths such as accident or homicide, which may take the family by more surprise. McCarthy et al. (2010) found the expected nature of deaths from childhood cancer gave parents the chance to prepare for the death, which may contribute to the lower rates of traumatic distress. They noted, "A lower level of preparedness for the child's death was correlated with more separation distress and depression" (p. 1324).

The emotional outcomes following a child's death can be overwhelming for parents and family members. Kreicbergs, Lanmen, Onclov and Wolfe (2007) found bereaved parents are likely to suffer from long-term anxiety and depression. White, Walker and Richards (2008) studied the effects of intergenerational support after and infant's death. They state, "All parents and grandparents, even those familiar with hard times, described this death as the most difficult situation ever experienced by their families" (p. 193). Various other findings have supported the severity of the impact of a child's death on parental well-being and on the parental relationship. For example, Aho, Astedt-Kurki, Tarkka, & Kaunonen (2010) found "the death of a child may have an impact on the health of the parents and their social relationships and network and may contribute to a sense of isolation and lack of intimate social relationship" (p. 409).

Not only are social relationships affected but the marital relationship changes as well.

Ungureanu & Sandberg (2010) stated, "Basic assumptions about safety and justice in this world, meaning of life and interpersonal relationships are shattered by the death of a child, with the potential of precipitating an existential crisis as well as a marital crisis for the bereaved parents," (p. 303). Research by Rosenblatt (2000) explained that for some couples with previous marital problems, grief could increase their difficulties. He found, "Problems that were hard to deal with before the death can become intolerable afterward," (p.69). Schwab (1992) mentioned general irritability between spouses after the death and that minor events tended to be magnified when partnered with the tragedy of a child's death. On the other hand, some studies show that this experience can have positive effects on the marital relationship such as high degrees of bonding and involvement with each other (Thomas & Striegel 1994), feelings of growing closer to one another (Fish 1986), and feeling better about their marriage since the death (Bohannon, 1991) (as cited in Oliver, 1999). The conflicting views of positive versus negative effects of a child's death on a marriage provide more fuel for the need to research in this area.

A common assumption among many people is that because a couple has experienced the death of a child, they are more likely to get a divorce. Najman et al. (1993) argue, "While such stresses appear to have the capacity to affect negatively a small number of marriages, the evidence suggests that the overwhelming proportion of marriages survive such an event" (p.1009). Additional research on the marital relationship after the death of a child is vital to understanding and learning how to support the relationship throughout the grief process. The researcher hoped that interviews with bereaved parents would assist in examining first hand experiences on the role of social support and how it is perceived to affect the marital relationship after the death of a child.

# Purpose of the Study

The purpose of this phenomenological study was to describe the role of social support to the marital relationship as experienced by bereaved parents after the death of a child. What meaning do bereaved parents attribute to social support and their marital relationship? What is seen as helpful versus harmful to their relationship? Because few studies focus on the role social support has on the marital relationship following the death of a child, this research topic was warranted.

Phenomenology focuses on the lived experiences of one or more individuals and meanings attributed to these experiences in a relation to a phenomenon of interest (Daly, 2007). This method was chosen for the current study because the death of a child is a very personal experience that cannot be explained without having lived through it. Parents who have experienced this phenomenon provided specific insight in telling their stories and meaning they attributed to the experience.

#### Definition of Terms

BereavementRefers to the state of having lost a loved one (Barrera, et al., 2007).ChildFor the purpose of this study, child refers to an individual between the<br/>ages of birth and 18 years old. Most research found on child death tends<br/>to focus on a specific age range, premature babies or infant death, for<br/>example (Najman et al., 1993; Buchi et al., 2009). This range was<br/>selected for this study in an effort to have a broader view of the<br/>phenomenon of child death.

Couple	For the purpose of this study, couple refers to the parents of the deceased
	child who were married at the time of the child's death and whose
	relationship is still intact at the time of the interview.
Grief	The emotional response to loss that typically includes changes to physical,
	mental and emotional health, social relationships, and spirituality
	(Bertman, Sumpter & Greene, 1991; Rando, 1993, 2000; as cited in
	Barrera, et al., 2007, p. 146).
Social Support	Verbal and nonverbal communication between recipients and providers
	that reduces uncertainty about the situation, the self, the other, or the
	relationship and functions to enhance a perception of personal control in
	one's experience (Albrecht & Adelman, 1987, as cited in Toller, 2011, p.
	19).

# Significance of the Study

Studies on individual experience of the death of a child from a father's or mother's perspective have been explored (Aho, Tarkka, Kurki & Kaunonen, 2010; Aho, Kurki, Tarkka, & Kaunonen, 2009; Laasko & Illmonen, 2002), as well as the importance of support as experienced in marital bereavement (Stroebe, Zech, Stroebe, & Abakoumkin, 2005), but research on the phenomena of perceived social support in parental bereavement is lacking. One study by Toller (2011) explores the topic of supportive versus unsupportive communication and support for bereaved parents, but fails to explore how such support may have impacted the marital relationship. Further knowledge on the impact social support has on a marital relationship

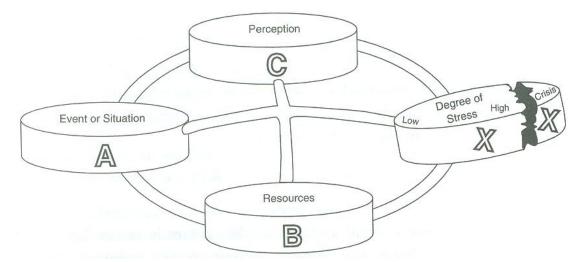
following a child's death can help family life educators and those in the field of family sciences know how to better serve these parents who experience this phenomenon. We will gain greater insight into what is helpful versus what is harmful to the relationship and ways to foster hope and healing to the marital relationship after the death of a child.

# **Theoretical Framework**

#### Family Stress Theory: ABC-X Model

As highlighted in chapter one, the death of a child is an extremely stressful event that can have a lasting impact on family functioning and marital relationships (Buchi et al., 2009; Song, Floyd, Seltzer, Greenberg & Hong, 2010). Randall & Bodenmann (2009) noted the importance of stress theories as contrived from a dyadic, or couple perspective. Dyadic stress can be defined as a stressful event or encounter that concerns both partners; either directly when both partners are confronted by the same stressful event or when the stress originates inside the couple, or indirectly when the stress of one partner spills over to the close relationship and affects both partners.

A well-known family stress theory is the ABC-X model developed by Reuben Hill (1949), based on his early research on family adjustment to the crisis of separation and reunion during wartime. This model focuses on the stressor event (A), family resources (B), family perception of the stressor (C), and finally, crisis (X) will occur if the family is unable to handle the stressful event. When a stressor event occurs, the family will immediately need to rely on its resources or strengths, which may come from within the family itself or from outside sources. If the family is unable to recognize and utilize their available resources or find and attribute meaning of the situation, a crisis could occur (Smith, Hamon, Ingoldsby & Miller, 2009). A visual of the ABC-X model is shown in figure 1.



#### Figure 1. Hill (1958) ABC-X model (as cited by McKenry & Price, 2005, p. 8).

Though additional family stress adaptations to Hill's original model have developed, the purpose of this study will center on Hill's theory as it pertains to marital stress associated with the death of a child. Hill's ABC-X model was used as a theoretical framework through which to organize the following literature review. The literature review was divided into sections based on the various aspects of the ABC-X model including: the non-normative stressor event (the "A" in Hill's model); resources such as individual characteristics (associated with the "B" in Hill's model), social support (associated with the "B" in Hill's model), coping mechanisms and communication with spouse and others (associated with the "B" in Hill's model); and finally, the perception of the stressor (the "C" in Hill's model) event which includes finding meaning after the death.

# The Stressor (the "A" in Hill's ABC-X model)

#### Non-normative Stressors

Stressors, as described in family stress theory, can be viewed in terms of normative and non-normative events. A normative stressor can be predicted or expected. These types of

stressors occur in most families, such as the formation of a marital union or the birth of a child, for example. A non-normative stressor is often sudden and unpredicted. As the focus of this study, the death of a child is a non-normative stressor (Smith, Hamon, Ingoldsby & Miller, 2009).

Non-normative events/stressors are more likely to lead to a crisis because they are unanticipated (Smith, Hamon, Ingoldsby & Miller, 2009). Determining whether the anticipated or unexpected death of a child is associated with longer-lasting grief, and heightened depression requires further empirical evidence and careful interpretation before conclusions can be made. Meij et al. (2005) attempted to fill a gap in this literature during their assessment of couples at risk following the death of a child. Parents who lost their child to traumatic death had the most grief symptoms, followed by those whose child died of an illness or disorder. Parents who experienced a stillbirth or neonatal death had the lowest levels of grief symptoms. In their study of 219 parent couples, the more the parents expected the loss, the less grief they experienced. This study had limitations in that it only focused on grief and depression, excluding other variables such as traumatic responses or anxiety symptoms.

In another study of the long term effects of child death on parent's health later in life, Song et al. (2010) noted bereaved parents whose child died in violent circumstances had particularly low levels of health related quality of life; this was measured by the Health Utilities Index Mark 3 which assessed multiple dimensions of mental and physical health including emotion, cognition, and pain. In an effort to discuss grief in a more comprehensive and inclusive manner, parents who fall in each category of anticipated child death or unexpected child death were invited to participate in the research conducted during this study.

Another aspect for potential, amplified grief for parents is the relation of gender of the parent and the gender of the child who died. Sidmore (1999) conducted a study of bereaved parents to see if grief symptoms were higher for men versus women; if levels of grief were higher for fathers who lost a son, versus fathers who lost a daughter, and if levels of grief were higher for mothers who had lost a daughter, versus mothers who had lost a son. Though the sample size was quite small (N = 19) to provide generalized results across the entire bereaved population, it does show implications that mothers' grief symptoms were higher than fathers which is consistent with other research (Moriarty, Carroll, & Cotroneo, 1996; Meij, et al., 2005; Meij, et al., 2007; Meij, et al., 2008). Also, mothers whose daughter had died reported higher levels of grief on eight out of nine bereavement scales in comparison with fathers who had lost a daughter. Thus, the impact of the stressor may also depend on the gender matching of the parent to the child. Further research in this area is necessary in order to provide more conclusive results, but the concept of gender of the deceased child in relation to the parent's grief symptoms should be kept in mind when helping parents whose child has died.

## Resources (the "B" in Hill's ABC-X model)

#### Individual Characteristics and Social Support

According to the ABC-X model, once a family experiences a stressor event the family must learn how to deal with the event by accessing their resources or strengths. Williams (1995) noted, "The more resources a couple has, the less likely they will be to perceive the stressor event as taxing or exceeding their resources" (p. 220). Resources can come from within the immediate family unit, extended family, friends, or other social support in tangible forms such as

physical help or financial assistance, or emotional forms such as quality time, talking about the death, or simply listening.

Sometimes the family itself may be a cohesive unit when facing a crisis and may pull together to help one another, but they also may learn when they need to go outside the family to seek help (Smith, et al., 2009). Such is true in the case of child death; as both parents are faced with the death of their child, they are also faced with their individual grief, which may include differences in grieving resulting in the need to seek outside help. Meij et al., (2007) pointed out that, "Although both parents are likely to suffer greatly from the loss, there can be substantial differences in reactions among them, and this difference could affect the grieving process" (p. 537).

Toller and Braithwaite (2009) focused on the phenomenon of grieving together versus grieving apart. Parents reported that grieving together was difficult due to the differing ways in which they and their partners handled their grief. For example, some mothers expressed their grief through crying while the bereaved fathers would express grief through active outlets such as building things. Sometimes these different expressions of grief caused tension in the relationship and left them believing they were alone in their grieving differences and dissimilarities, by compromising in ways to grieve, and by seeking outside help to ultimately help them honor each other's different way of dealing with grief (Toller & Braithwaite). What was not explained or addressed in this study was the meaning the couples assigned to the perceived social support. In what ways did the couples perceive the outside sources of help to impact their marriage and the grieving process?

# Coping Mechanisms

Coping mechanisms are an important resource for families in overcoming a stressful situation. Coping may represent an intersection between resources and perceptions. Smith et al. (2009) noted, "Coping is really an interaction of our resources and our perceptions as we choose those resources we draw upon based on our perceptions of what will work and what won't" (p. 100). In one particular study, Meij et al. (2008) investigated bereaved parents' interdependence in coping. The researchers examined the relationship between the parents' own and partners' ways of coping and psychological adjustment after a child's death. Interestingly, the study found that the adjustment process for men was not only related to their own coping strategies, but also to those of their wife. The researchers stated, "The more his wife was oriented towards rebuilding their lives after the loss (restoration-orientation coping), the lower were the levels of depression and grief of the husband" (p. 39). This study demonstrated the importance of understanding different coping strategies for bereaved parents in order to help them work together through the grief instead of allowing it to create distress and divergence in the relationship.

#### Communication Between Spouses

As with any relationship, communication plays an important role in the grieving process, both among the married couple suffering their child's loss, as well as how the couple communicates to those around them regarding social support. A recent study by Buchi et al. (2009) indicated that, "Among couples whose prematurely-born baby has died, the way that the partners experience and share their grief can profoundly influence not only their suffering but

also their posttraumatic growth" (p. 129). Kamm & Vandenberg (2001) took this area of study a step further to research the relationship between grief communication, grief reactions and marital satisfaction. This study of 36 married couples who had experienced the death of a child an average of four years and ten months prior to the study, found couples with more positive attitudes about grief communication showed greater marital satisfaction and lower levels of grief over time. Men's attitudes about grief communication were related to their grief whereas women's attitudes were related to marital satisfaction, but not vice versa. The men who valued open communication experienced greater grief in the earlier stages and less grief in the later stages of bereavement. Women who valued more open communication had higher marital satisfaction in the earlier stages of grief (Kamm & Vanderberg).

Family and cultural norms can influence the manner grief is expressed differently by gender. In the American culture, for example, men are seen as the dominant or strong force in the family; this could affect a man's grieving process. Walsh (2006) indicated that, "Cultural sanctions against revealing vulnerability and dependency can block emotional expressiveness and ability to seek and give comfort," (p. 208). Because of this social taboo, men may be less willing to talk about their grief or express emotions with their spouse, which may result in problems in the relationship. Laasko & Illmonen (2002) also described the importance of talking about the death of the child as an important part of undergoing the grief process for mothers.

Schwab (1992) found five themes experienced by bereaved parents, three of which surrounded the differences in expression of grief and communication about grief between men and women following the death of their child. In the first theme mentioned, fathers were concerned and frustrated about their wives' grief and were ready for her to move on with daily

activities faster than she was ready. The second theme mentioned wives in the study expressed anger and disappointment and felt their husbands were not willing to share in their grief. The third theme involved differing grief reactions among partners that resulted in a temporary halt in communication. Schwab agreed with previous research findings of accepting differences between spouses individual grieving styles making the statement, "Becoming aware of the ways their experience of loss affects spouses differently can prevent or minimize its long-term negative impact on their relationship" (p. 153). These findings reinforce the importance of communicating through grief, as well as the differences in how men and women handle their grief and its effect on the healing process.

#### Communication with Support Network

Communication after the death of a child is not only important between spouses, but also equally important for clarification of support to outsiders. Dyregrov (2003) explored the experience of social support following traumatic losses due to suicide, SIDS, or accidents with 69 bereaved parents. The participants in her qualitative study described their experience with social ineptitude and the importance of openness. Dyregrov notes, "Social ineptitude refers to 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). Parents described encounters with friends, coworkers, neighbors, and even family members who would purposefully avoid conversation about the deceased child or withdraw from contact altogether. Survivors stated they probably would have reacted the same, helpless way before their child's death and had now learned a lesson they would like to remember for life. Parents in this study

stressed the importance of openness, which included telling the story about what happened, informing others about the event, and clarifying their own needs to their support network. By telling the support system what assistance they need, it also signals to the supporters that it is ok to talk about the deceased with the bereaved parents. The author noted, "It is necessary to improve people's communicative competence in adverse life situations in order to improve social support for the bereaved populations," (p. 41).

Because findings from several of these studies point to the importance of communication through grief, the current research study was justified in order to learn more about the phenomenon of the marital relationship after the death of a child. The researcher in the current study was interested to hear firsthand accounts of bereaved parents' perception of communication with one another and with social support through the grief process as experienced with the death of a child. The researcher was also interested in learning how communication and social support affect the marital relationship through the meaning assigned to both.

## Perception of Stressor (the "C" in Hill's ABC-X Model)

## Finding Meaning

In keeping with the theoretical framework for this literature review, the final component of the ABC-X model that determines if a stressor will develop into a crisis, often known as complicated grief, or tension in the marital relationship, in the instance of a child's death, is the family's perception of the event, or the meaning they assign to it. Previous research confirms the benefits of finding meaning surrounding the death of a child and its effect on coping and

resilience for families and individuals facing grief (Keesee, Currier & Neimeyer, 2008; Meij et al., 2008; Rogers et al., 2008). Walsh (2006) noted that, "Coming to terms with loss involves finding ways to make meaning of the loss experience, put it in perspective, and weave the experience in to the fabric of one's individual and relational life passage," (p.188).

Neimeyer, Prigerson & Davies (2002) agree, noting:

Human beings seek meaning in mourning and do so by struggling to construct a coherent account of their bereavement that preserves a sense of continuity with who they have been while also integrating the reality of a changed world into their conception of who they must be now (p. 236).

A family's sense of normalcy is shattered with the death of a child. Part of the healing process includes coming to terms with a new reality and finding acceptance. Riley et al. (2007) stated, "Bereaved mothers who managed distress by acceptance and reframing of the negative experience in a positive light experienced less intense grief responses and less complicated grief" (p. 291).

As previously mentioned, the cause of death could have an effect on the parent's grief process. In addition, the cause of death could also affect the parent's ability to make sense of the loss or to come to a place of acceptance. Keesee, Currier & Neimeyer (2008) focused their study on individual and contextual factors related to losing a child in conjunction with the degree to which bereaved parents found meaning in the loss experience. The researchers described "sense-making" and "benefit-finding" as they related to coming to terms with the child's death and the ability to avoid complicated grief. Results from this study showed that violent death accounted for significant difference in sense making and normative or maladaptive grief reactions. Parents

who lost a child to homicide, suicide, or fatal accident reported making significantly less sense of the loss experience compared to parents whose child died of natural causes. Results from this study also showed a positive correlation between length of bereavement and sense-making or benefit finding which indicated that parents who had more time to adjust to the death had a greater likelihood of making sense and finding benefit from the loss experience (Keesee, Currier, & Neimeyer).

Neimeyer, Prigerson & Davies (2002) explained grief as a human experience that is influenced by social and cultural framework, psychological and personal relationships, as well as psychiatric makeup and mental health. Although horrific or sudden forms of bereavement can shake a person's foundation, some individuals are more susceptible to developing complicated grief reactions than others. The researchers described an "internal working model" as a potential vulnerability factor. This model usually develops from a person's experiences with their primary attachment figure, generally one's parents. Adverse childhood experiences could result in an insecure attachment style.

Barrera et al. (2007) found three patterns of bereavement in their study of parents who experienced the death of a child: Integration of Grief, Consumed by Grief and Minimal Expression of Grief. Individuals who were considered Consumed by Grief were unable to reframe their loss and struggled with accepting their child's death. Mothers who were overwhelmed with grief perceived themselves to be alone in the situation with limited social support from their spouse, other family members or friends. The lack of recognizing and utilizing their resources led to feelings of isolation that eventually led them to overwhelming grief. Crisis, as defined by the death of a child, could occur in the form of complicated grief or

unresolved grief issues if the family is unable to, first, recognize and utilize available individual and community resources, and second, find meaning or make sense of the child's death.

#### Summary

In summary, grieving is a complicated and multifaceted process, and the death of a child is no exception. Hill's ABC-X model gives insight into the process of family adaptation to stressful life events. Because the death of a child is a non-normative stressor and parents are sure to have their own ways of dealing with the grief, the likelihood of crisis occurring in the family is greater. A family may learn to live through the grief by examining and utilizing their resources whether they come from within the family unit or from outside help. Communication between spouses as well as with the support network plays a vital role to a family's healing. Coming to terms with the death and finding meaning in the painful life event can assist in the possibility of avoiding a family crisis. Current literature confirms the usefulness of support systems in overcoming grief symptoms and helping the families form acceptance of the death. The premise of the current phenomenological study was to gain further insight into couple's perceptions of social support after the death of a child and how these factors relate to their marital relationship.

The two primary aims of this study were as follows:

1) To explore the role of social support as experienced by married couples following the death of a child.

2) To define the meaning bereaved parents attribute to this support and the effect it has on their relationship.

# BEREAVED PARENTS' PERCEPTIONS OF SUPPORT CHAPTER THREE: METHODOLOGY

# Phenomenology

The purpose of this phenomenological study was to describe the role of social support and its effects on the marital relationship as experienced by parents who have lost a child. According to Creswell (1998) a phenomenological study describes the meaning of lived experiences for several individuals about a concept or the phenomenon. Researchers seek to find the "essential, invariant structure (or essence) or the central underlying meaning of the experience and emphasize the intentionality of consciousness where experiences contain both the outward appearance and inward consciousness based on memory, image and meaning" (p. 52). The aftermath of losing a child cannot be explained by anyone but those parents who have experienced the phenomenon. Because phenomenology revolves around learning the essence of a lived experience by interviewing people who have been through it, this method was chosen for the current study.

Disclosure of personal or sensitive information was necessary in the process of the interviews that focused on the couples' experience with social support after the death of their child. Disclosing this information could have presented slight psychological or social stress because of the emotional bond with the deceased child or having to recall the instances surrounding the child's death. However, Dyregrov (2004) conducted a study of bereaved parents experience of research participation and found that almost all the parents stressed the importance of having the chance to talk about the loss and to tell their child's story from beginning to end. Seventy-three percent of the parents claimed the interview to be "a little" painful, but 100

percent claimed they did not regret participating in the research and 94 percent would recommend it to a friend in the same situation.

Having the opportunity to share their child's story and to talk about the loss was incorporated into the interview process during this phenomenological study. Each couple was reminded of their right to withdrawal from the study at any point if they appeared too distressed to continue. Since participants for this study were recruited on a volunteer basis based on their involvement with either local support group agency, Calm Waters or Oklahoma Family Network, they were thought to be familiar with available counseling resources but the researcher had resources available if the families would have needed them. The researcher did not attempt to provide therapy to the couples.

#### Procedure

Participants were recruited through purposeful sampling of married couples that have experienced a child's death. According to Creswell (1998), in this type of qualitative interview, "It is essential that all participants experience the phenomenon being studied" (p. 118), hence the reason behind the purposeful sampling. Upon receiving approval from the Institutional Review Board at the University of Central Oklahoma, participants were recruited via an informational letter distributed by the program directors at two local support agencies, Calm Waters and Oklahoma Family Network and from referrals by other participating families from these agencies. These agencies were selected as sites for participation recruitment because the researcher had existing relationships with the program directors. All participants were recruited on a volunteer basis and were reminded of their right to refuse to participate in the study.

The researcher hoped to conduct a series of interviews with married couples versus individual parents because a dyadic focus has been cited as beneficial for studying couple processes. On the subject, Daly (2007) noted, "Using the couple as a unit of analysis serves as an important means for understanding the relational aspects of family dynamics," (p.180). Dyregrov (2004) emphasized the importance of family interviews versus individual stating, "By participating in the same interview, family members had the opportunity to share each other's perspectives, facts, and beliefs about the tragedy" (p.397).

All participants were given a consent form at the time of the initial interview which included the right to voluntarily withdrawal from the study at any time, the general purpose of the study, information regarding the confidentiality of the participants, the expected benefits of the study, and the researcher's contact information (Creswell, 1998). Because phenomenological studies aim for depth (Padgett, 2008), the researcher conducted interviews with five couples. In order for the participants to feel as comfortable as possible to share the experience of their child's death, interviews took place in participant's homes (N=2) or location of their choosing (N=3).

## **Participants**

Five couples that had lost a child between the ages of birth and 18 years old that were married at the time of their child's death and are still married today agreed to participate in this study through recruitment from Calm Waters (N=1), Oklahoma Family Network (N=1), and referrals from other participants (N=3). Four of the couples were in their first marriage; one couple was in their second marriage. The length of marriage at the time of the interview ranged from 4-18.5 years, averaging 9 years. The length of marriage at the time of their child's death

ranged from 2.5-17 years, averaging 6.02 years. The age of the child that died ranged from 3.5 hours-8 years. All five families reported that the children died of illness or natural causes.

Demographics for the husbands were as follows: Age ranged from 30-47 years old, averaging 34.4 years; Education ranged from some college (N=1), college graduate (N=2), some post graduate (N=1) to postgraduate degree (N=1); Ethnicity was reported as Asian or Pacific Islander (N=1), African American (N=2), Hispanic or Latino (N=1), and Caucasian (N=1). Demographics for the wives were as follows: Age ranged from 28-41 years old, averaging 23.52 years; Education ranged from some college (N=2) to college graduate (N=3); Ethnicity was reported as African American (N=2), Hispanic or Latino (N=1), and Caucasian (N=2).

During the initial interviews for this research, four out of five couples attended the interview together. One initial interview took place with only the mother so the researcher conducted a follow up interview with both parents the following week. The validity and reliability of the information collected in this study is increased because the research conducted at least one follow up interview to expand and clarify data with each couple after the initial interview and after allowing the couples to review their interview transcripts. Padgett (2008) explained, "Repeated interviewing brings engagement and sets qualitative methods apart from their quantitative one-shot counterparts" (p. 115).

### **Research Questions**

The researcher asked retrospective, semi-structured questions that explored the meaning of the experience for parents and asked them to describe their everyday, lived experiences of the phenomena of social support after the death of a child. Phenomenological studies generally

include in-depth interviews as a way to extract detailed descriptions of the participants' reality (Daly, 2007). By way of further explanation, Daly (2007) noted:

This may involve repeated interviews with the same participant or interviews with a range of people experiencing the same phenomenon...The goal is to understand how participants use everyday language to give shape and meaning to their typified, familiar world. (p. 98)

The underlying questions the researcher hoped to explore through this study asked, "What is the role of social support as experienced by married couples following the death of a child? What meaning do bereaved parents attribute to this support and what is its effect on their relationship?"

After allowing the parents the opportunity to share their child's story and fill out a basic demographic profile survey, the researcher asked each couple the following open-ended questions:

- Describe an experience of support that was beneficial after your child's death.
- Describe an experience that was not helpful.
- In what ways does support, specifically related to your child's death, from family or others affect your marriage?
  - How does this support strengthen your marriage? How is this social support ever harmful to the marriage?
  - How did social support help with conflict or tension in your relationship?

# Data Analysis

Interviews were audio recorded and transcribed verbatim, aside from names or any identifying information. Padgett (2008) explained that recording audio does not pose the same threat of identity exposure as photographs or videos since statements are less identifying than visual images. The author also noted, "Phenomenological analysis examines interview transcripts in search of quotes and statements that are emblematic in meaning. These are clustered into themes that form the architecture of the findings" (Padgett, 2008, p. 36).

Daly (2007) described that data analysis begins during the transcription process as the researcher has "the opportunity to re-experience the interview at a slow place" (p. 217). After transcription was complete, the researcher read and reread the transcription in order to: appreciate the subjective experience of the participant; break down descriptions of the experiential reality into meaningful parts; transform meanings in data from implicit, or internal meanings, to explicit, or visible meanings for the lived experience; and finally, to highlight the typically essential units of meaning (Daly, 2007).

The researcher followed the format and procedure mentioned by Daly (2007) to create typologies and underlying meaning structures, which were assigned based on the detection of common elements throughout each transcript. Through reading and rereading of the transcripts, the researcher used selective highlighting as well as memo notes to identify common themes among the transcripts. The next step in the data analysis was to connect similar themes and cluster them together with broader conceptual labels. Daly noted, "The overall aim is to identify the underlying essence of the phenomena being studied" (p. 220).

The researcher excluded names or any identifying information of the participants in order to protect their anonymity during the transcription process. All information provided during the

interviews was kept confidential. Data collected was kept on a password-protected computer operated by only the researcher. Written transcripts were kept in a secure location at the researcher's home.

# BEREAVED PARENTS' PERCEPTIONS OF SUPPORT CHAPTER FOUR: FINDINGS

The findings highlighted in this chapter represent the themes that developed after reviewing the interview transcripts and selective highlighting. In order to verify the researcher's interpretation of the initial interviews, each couple was given the opportunity to review their interview transcript and expand on thoughts or explanations at a follow up interview.

These themes were categorized into two groups: Tension and Conflict and Strengthened Marriage. The groups were further explained by breaking them down into subgroups. Tension and Conflict was broken down into subgroups including: Lack of Communication, Family Expectations, and Lack of Support. The theme of Strengthened Marriage was broken down into subgroups including: General Support, Incorporating the Child, and Seeking Outside Help. Each of these groups and subgroups will be explained throughout the following pages.

#### **Tension and Conflict**

## Lack of Communication

When asked to describe an experience of support that was perceived as unhelpful after the child's death, most responses centered around the lack of or unhelpful communication. Avoidance from others, especially family, in remembering and talking about their child was perceived as one of the most harmful forms of support.

A husband explained his experience with some coworkers; "They had said like, 'Does it bother you when other people talk to you about it?' And I'm like, 'No. The worst thing to do is *not* talk about it. To acknowledge it never happened." Parents reported that talking about the

child was very therapeutic for them. One wife explained, "People aren't afraid to come up to us and ask about our daughter. And I think that's been very therapeutic. I mean, we like talking about her." Only one parent mentioned that most of the time she didn't like others to talk about her child unless she initiated the conversation. She felt, though it had been a year since the death, she was still too emotionally unstable to talk about her daughter, and that these emotions varied from day to day depending on how she was feeling.

Comments from others that were meant as well-meaning advice such as, "He's in a better place; Everything happens for a reason; My mom and dad died so I understand" were perceived as unhelpful communication. One wife said, "And I think that sometimes people just don't know what to say, but just don't say anything, just don't talk, you know?" One husband stated, "Honestly, I feel like less is more. Like if I didn't know what to say I probably would just be there for someone instead of trying to think of the right thing to say."

Comments from others about moving on or getting over their grief were also viewed as unhelpful communication. One husband told a story about his first day back to work after his son died. A coworker said, "I know you've just been through something terrible, but you're moving kinda slow." He perceived this as being told that he should be past his grief.

# Family Expectations

A consistent topic among all the couples during the interview process was support perceived as unhelpful from family members. Examples of the unhelpful support include: Failure of family members to talk about or acknowledge the deceased child or to include the child's memory in family activities (holidays, birthdays, etc), making decisions without asking, expectations to be somewhere or do something because it is for family (birthday parties, church, etc).

As previously stated, talking about their child was perceived to be very therapeutic for the parents. Several couples shared experiences where an in-law or other family member would consistently avoid talking about the child that died. This lack of communication or acknowledgement from family members was often the main source of conflict described by the couples in this study. Failure for family members to include the child in holidays or celebrations was perceived as hurtful to the parents. One wife described an experience at Easter where she confronted her in-laws, "I told them they have got to mention him. 'But y'all have got to mention it. He was here. He was my child and he's a part of my family.' But it didn't really change anything."

Failure of the family members to first ask the parents before making certain decisions was perceived as hurtful. One couple had an extended family member bring pictures to the funeral home because she felt like there weren't enough pictures of their side of the family. Another described an aunt who named her baby daughter (middle name), who was born shortly after her niece's death, after the child without asking the family first. This action was perceived as disrespectful.

Some family members held unrealistic expectations for the grieving parents. One couple mentioned their family expecting them to be at a birthday party. The wife reported on this event: "Called to know why we weren't at our nephew's one year birthday party which was just a few weeks after he died, and he was five weeks apart from [son], and I wasn't going to go because it was too hard." One wife described an instance where the mother in law didn't come to a family

event and later told her it was because "she felt unwelcomed and felt like I wasn't welcoming her with open arms." The wife felt that her mother-in-law was making the death more about her own feelings than considering how it may have affected her daughter-in-law as the child's mother. The wife goes on to explain,

> I think when somebody *dies*, when your baby *dies*, and you're trying to get back to that normalcy. People think that you're ok, but you're really not ok yet...And I think, because I'm not dressed in all black or hiding under the bed people think that I'm ok and that they can just say anything and they can't.

# Lack of Support

A few of the wives mentioned a lack of support for their husbands, either in their jobs, from their friends, or from their families. Most of the wives mentioned that people often asked about how they were doing more than asking about their husband. A wife explained, "I feel like maybe he hasn't had that support so much. I feel like maybe that's where the resentment comes in on his part. Like sometimes he'll say, 'I don't get as much support as you do.' The husband replied, "Yeah but I don't get hung on that. I've said it but I don't resent you for it." Another wife shared, "I think that everybody always asked me if I was ok but they didn't really ask about him. But I don't think that anybody realized he lost his child too. Maybe because it was a baby."

A few couples mentioned that support groups were perceived as too general. Parents wanted similar stories or situations. For example, one couple mentioned wanting to be with families who also experienced the death of a two-year-old versus those who experienced a stillbirth or suicide of a teenager. One of the couples confirmed the importance of being with

other couples in similar situations when they described their experience at a local support group known as Grief Share. The husband said about the group leader, "I really admired him because it seemed like everything he went through was kinda the same."

The wife added,

It was kinda the same thing because she was at work, I was at work, she was a nurse, I'm a nurse. It was just crazy listening to their story because it was like those were the perfect people for us to be with.

The couples that felt support groups were too general did mention, however, that the good thing about the groups was that they gave them an opportunity to talk about their child, even though there was often no reciprocation with the other parents since the deaths were always so different. A husband explained their experience with a local support group, "The only thing that happened was just you and me talking about it. Getting it out in the open. Nobody could say 'Oh I feel your pain.' They lost a kid under totally different circumstances."

### **Strengthened Marriage**

#### General Support

In terms of helpful general support, actions often spoke louder than words after the death of the child. General support in terms of day to day things such as meals, mowing the lawn, helping with the other children, financial support, patience from employers, and physically being with the parents that had just lost their child by spending time with them were all thought to be helpful, and in turn, were perceived to help strengthen the marital relationship.

A few families mentioned helpful support from the hospital, not just with expenses, but assistance from the staff after their child's death, respect for the child's body, and communication about the process of what was to come (autopsy and transporting to the funeral home). More than one family mentioned that the funeral home was willing to offer services for free or at a discounted rate, which was perceived as a blessing.

Parents mentioned the relief they felt when employers were patient and accepting to allow time off work and to come back when they felt ready instead of at a certain date. One husband explained, "Throughout that entire time [after their child's death] we were truly blessed that [wife's] job was waiting for her when we got back, whenever she was ready. And, uh, we had to prepare for that." A wife shared about her relief to have time to grief, "I don't know how people work. I didn't go back until February. He died in October. I don't know how people do it. If I had to go back to work, I dunno."

Many parents felt that daily help from others after the death, having others talk about the child, or asking how to help the parents strengthened their relationship with each other, but ultimately the decision to stay close was felt to come from within the couple itself. One dad mentioned, "But without support, I don't know how people do it, because we would not have. Fortunately, it's not in our story." Another dad mentioned, "Nobody or nothing has helped *us*, by the way, it was *us*. We can probably say family and friends lent aide, but it was us."

All of the couples mentioned that the death brought them closer together or made them stronger. One couple mentioned marital problems before the death but that their child's death gave them a new perspective. The husband explained, "We took a second look at ourselves. It made us totally reevaluate."

The wife stated,

I think that unlike some things, losing him brought us closer. Because before [the death] we were kinda caught up in the hustle and bustle. We were having some issues and I think it has definitely brought us closer and made us realize what is really important."

Another husband said, "As far as the marriage goes, our marriage, has become stronger; stronger because of our faith, because of all the support, because we understand that we grieve differently."

Another couple discussed their thoughts on this subject, the husband explained, "I think more than our relationship changed, we just changed." The wife stated, "Yeah, and as a result, our relationship did. One thing that I think is good about this that I feel we've been more open with each other." Another wife explained, "I think that things, all the support I've gotten, makes me a better person. And more, I actually think it's made me a better nurse. I'm more patient with my patients."

One of the husbands felt like his marriage will be strengthened with time but that it was a work in progress.

He said,

I think that eventually it will strengthen our relationship but right now, it's still new...all last year I was just going through the motions...trying to stay positive. And right now I feel like we are kinda breaking out the fog, for me personally, I feel like I'm just now breaking from the fog.

### Incorporating the Child

Many of the couples expressed a desire to incorporate the child that died into their "new normal". Parents mentioned holding birthday parties for their children, decorating at the gravesite, including the child's name or memento on Christmas cards, and remembering the child at family celebrations, for example. One couple described a stuffed bear, named "Brother Bear", that they were given prior to the birth of their terminal son and shared with their two-year-old child at the time. "But he's been a part of the family. He's in our Christmas card pictures every year. We incorporate Brother Bear as much as we can. And that's kind of our little [baby] that's more tangible for us."

One wife described her feelings of why she decorates at the cemetery,

Like I'm a mom and I have to keep on doing stuff for him and I can't throw birthday parties and I can't...So if I go out there and decorate and do stuff for him. I don't feel like he's out there, but I feel like that's my way of continuing to do stuff *for* him.

Two of the couples described instances where the hometown high school sports teams dedicated their seasons to the children that died. The husbands in both situations perceived this as a helpful way for their friends to honor their children.

Another topic that was mentioned under this subgroup was how special it was for parents to hear the impact of the child's life on others. When people would remember the child and tell stories or memories to the most of parents, it seemed to help with their grief. One wife stated,

We went to buy flowers for [daughter's] service. We went to the flower shop, and we didn't know it at the time, but the lady at the counter that was serving us, her granddaughter was a friend with our daughter at school. She said when her granddaughter first started at [school], none of the other little girls wanted to play with her but our daughter did...stories like that, even though we weren't around, we knew our daughter had a very loving heart. And we enjoy hearing stories other people tell us about how our daughter impacted their lives in some way, in some fashion, and it makes us feel good.

One wife mentioned, "Knowing that they just genuinely felt it, you know like other people who were awful their whole life, and people say 'Oh they were so great.' But just to hear that she was such a light."

A husband shared,

But just to hear that [how their daughter's life impacted others] has been very comforting to me in that way. To me, that is a huge support. It just kind of puts an emphasis on everything. I mean, you raised your little girl and this is what she grew up to be. And even though she didn't live a full life, but she lived eight years...and what a life she lived. And being able to talk to people and hear all those stories is a form of support that I don't know if you can get from anywhere else.

### Seeking Outside Help

More than one husband mentioned that support for the wife actually helped him because it gave her an outlet, which released him from having to bear all her pain. This type of support came from a counselor, mom, friends or blogging.

One husband explained,

It would have been hard if she didn't have her family, her friends, her getting on those blogs. Yeah, I hope we would have lasted but I dunno. Cause as many fights as we had *with* her getting on blogs and everything, if it wasn't there, it probably would have been more arguments to the point where it's like 'I'm not dealing with her.'

One wife mentioned that a counselor was good for her when she explained,

I think it was helpful for me because she was always there for me to talk to. My friends had kinda gotten tired of it. They didn't want to talk about it anymore.

That was her purpose and so I didn't feel like I was driving her crazy with it. Talking to a counselor helped some of the couples realize differences in their personality and grieving styles. Husbands tended to make decisions and take action (funeral choices, going back to work, etc.), wives wanted to talk about feelings or the situation. Men tended to talk less and share less. One husband mentioned that talking with a counselor helped him realize when she needed to talk, he needed to listen instead of avoid the conversation.

One husband said,

We tried the counseling together, but I'm not the sit down-hash out your feelings type, I didn't do real good with it. So I think it helped her have someone else to talk to, like about stuff with me.

Another husband explained,

I would say her getting support, helped me. Cause I know I don't like to talk, especially about death. Maybe it's the military side of me or I haven't dealt with it. But knowing she was getting help when she wanted to, I guess, without me, because she wasn't getting it from me. We argued a lot.

When asked about the effect of support groups, two of the wives and one husband explained that being around other parents whose child has died helped them realize that because others have gotten through it, they could too. One wife said, "I think hearing how other people have dealt with it and how they've coped, to hear that it's not unnormal, you know, makes me feel better."

One of the husbands explained how a support group helped him come to terms with his emotions.

He said,

Sometimes I don't know how to express myself. And it really did help. I got to the point where I was comfortable talking about it rather than just holding it in. And that helped a lot, helped me deal with it.

The same husband also discussed how the Grief Share program helped him understand the stages of grief and to not take things personally that his wife might say or do out of anger or sadness.

# BEREAVED PARENTS' PERCEPTIONS OF SUPPORT CHAPTER FIVE: DISCUSSION

The main area of focus for this phenomenological study was to get a better understanding of the ways that social support is helpful and also harmful to the parent's marital relationship after the death of a child. Insight into this phenomenon was gained through a series of interviews with parents who have experienced such a death. The overarching question of interest was, "In what ways is outside support after a child's death perceived to strengthen or harm the parent's marriage?" Recognizing what is helpful versus what is harmful to the marital relationship can give a better understanding in how to assist these couples and families more effectively through their grief.

### Discussion of Findings

After completing a series of in-depth interviews with each couple, the transcription process, and reviewing notes from selective highlighting of the transcripts, a set of themes began to develop. In general, tension and conflict in the marital relationship seemed to be related to support that was perceived as unhelpful, whereas a strengthened marital relationship seemed to be related to be related to support perceived as helpful.

According to the ABC-X model, discussed in the literature review of this study, how a couple perceived their resources would be one important aspect that would determine if a crisis would occur. Parents described resources as outside support from friends or groups, support or communication from within the couple or the family, for example.

The couples in this study also described various forms of support that were thought to be unhelpful and were perceived to contribute to conflict or tension in their relationship. Unhelpful support included: Lack of communication or avoidance from others in acknowledging the life of the child, unrealistic family expectations, the perception from wives of lack of support for the husbands, and support groups that were perceived as too general.

Related to lack of communication or avoidance, Dyregrov (2003) described similar findings in her study of suddenly bereaved parents, which she labeled as "social ineptitude" including anticipated support that failed to appear, people that withdrew from the bereaved parents both physically and in conversation, and unhelpful advice and support. In relation to some of the parents' need to be in a support group or receive support from someone who had been through a similar experience, Laasko & Paunonen-Ilmonen (2002) agreed,

[Mothers] felt that the experience of losing a child could only be shared by a mother who had gone through a similar experience, and reported having received the most help from other parents who had cared for a dying child (p. 181).

The couples in the study also described various outlets of support that were perceived as helpful and, in turn, were thought to strengthen their relationship. Helpful support included: Day-to-day support like meals, expenses, and helping with other children, patience from employers in returning to work, incorporating the child into their new life, hearing from others about the impact the child had on their lives, or seeking outside help. The couples explained the importance of talking about and remembering the child that died and the tension it caused in their relationship when family would avoid this acknowledgement.

These findings are similar with those of Toller (2011) who found that parents valued action facilitating support including day-to-day help, tangible aid, and nurturing or emotional support more than unhelpful advice or comments from others. The study described the parents desire to hear memories of the child or the impact the child's life had on others (Toller); the findings from the current study reflect this same desire from parents.

The couples mentioned that outside help was beneficial to their relationship but that ultimately it was their choice to decide to get through the loss of their child together. Differences in grieving styles among men and women have been noted elsewhere in research (Oliver, 1999; Sidmore, 1999; Song et al., 2010; Toller & Braithwaite, 2009), but the current study gives insight into how the couples perceive these differences. For example, some husbands mentioned that outside support helped them realize the differences between how they grieved versus how their wife grieved and ways to handle these differences such as listening when the wife needed to talk or respecting when the wife needed to seek outside support.

#### Implications for Professionals

Grief experienced after a child's death varies among individuals, cultures, and families. The results from this study give insight into perceptions of support after a child's death, but it is important to remember that every individual and every family is different in their grief.

In keeping with the ABC-X model, professionals should aim to increase, or make known, a couple's resources in order to help relieve some stress of day-to-day issues such as meals, expenses, housework, and help with other children. Also, in order to allow the parents the opportunity to process their grief work in a meaningful way, a professional should be willing to

talk with the parents and remember the child that died, as well as inform the couple's support network to do the same. If the parents have not already learned ways to incorporate the child into their new lives, the professional can help the parents identify ways to do so, such as honoring the child's birthday, special family outings or memories, or specific things that are meaningful to their family culture.

Since parents expressed the desire to seek support from other parents who have experienced a similar death or occurrence with their child, the professional should work to keep support groups, or support networks, as specific as possible. For example, parents of stillbirths or infants could be in a group, and parents of teenage accidents or young cancer victims could be in a group in an effort for parents to feel like they are being understood.

Professionals should be aware of the mother's perception of lack of support for the father and make an effort to include him in discussions or groups. Though a father may not always voice how he is feeling, he may appreciate being included in discussions or decisions. Men in this study admitted to often lacking the desire to discuss their emotions with their spouse, which was similar to fathers in other studies. For example, Schwab (1992) stated, "In addition to men's tendency to control their emotional expressions, their culturally derived notion that they had to remain strong to protect the family couple with their work responsibilities may have necessitated husbands keeping their emotions under control" (p. 151). Buchi et al. (2009) agreed, noting, "Where couples differ considerably in their grief, it may be that the father is less likely to acknowledge the extent of his distress, perhaps trying to appear 'strong'" (p. 129).

Professionals should also keep in mind that though outside resources do help ease stress and emotions for the parents, they do not erase the fact that these parents have experienced a

significant loss. As explained by the ABC-X model, a couple's perception of the non-normative stressor, in addition to the couple's resources, will play a role in determining if a crisis might occur. The beneficial support with resources such as day-to-day stresses, communication, and understanding is helpful for the marital relationship, but ultimately it is up to the couple to communicate and to decide to work together through the loss of their child.

### Implications for Researchers

Previous grief research has focused on bereavement and support from an individual parent's perspective (e. g., Aho, Tarkka, Kurki & Kaunonen, 2010; Aho, Kurki, Tarkka & Kaunonen, 2009; Laasko & Illmonen, 2002) but has failed to acknowledge how support might affect the marital relationship. The current study provided insight into the benefits of support in strengthening parents' marriages after the death of their child or ways that support is harmful to their relationship. As previously mentioned, the population for the study included parents who have experienced a child's death due to illness or natural causes. Future research should aim to include a more diverse population in order to compare grief responses across various causes of death (Meij, 2005). With adequate time and available researchers, future studies should aim to include a larger number of participants who have experienced this phenomenon in order to gain broader results across the population. Future research might also explore ethnic and cultural differences in terms of perceptions of social support, or how religious or spiritual beliefs might act as a resource and shape meaning making after a child's death.

#### Limitations

This phenomenological study aimed to explore the lived experiences of parents who have lost a child. Because of the time required for the in-depth interviews, transcription process, and follow up interviews, the sample size was limited. The results of this study were true across the small sample size, but are too small to be generalized across the entire population who experience this phenomenon.

Recruitment for the current study was limited to families selected by the program directors at two local bereavement agencies, Calm Waters and Oklahoma Family Network, or through referrals from other participating families. As a result of this recruitment process, all the families selected for the current study had experienced the death of an ill child. As mentioned by Meij (2005), there was a difference in grieving styles from parents who experienced the sudden death of a child versus those who experienced an anticipated death. The researcher would have liked to have more diversity in the causes of death in order to hear the similarities and differences amongst the couples. Future research should aim to include parents who have experienced the death of a child through various causes.

### Conclusion

The death of a child is never something a married couple wishes to experience but this phenomenon happens every day. Unlike common assumptions that a couple will automatically get a divorce after enduring such a significant loss, this phenomenological study showed that a marriage can actually improve in the end if meaningful resources are in place to help ease tension and conflict in the marital relationship.

In this study, two common themes developed after reviewing the interview transcriptions: Strengthened Marriage, and Tension and Conflict. A marriage was thought to strengthen with support that was perceived as beneficial such as general support, incorporating the child, and seeking outside help. The opposite was true for tension in the relationship. Conflict was attributed to lack of communication from others, family expectations, and lack of support.

According to the ABC-X model, how a person perceives their resources, or lack thereof, will determine how he or she finds meaning in the situation or if a crisis will occur. The couples in this study attributed a strengthened marriage to finding meaning and value through their available resources, or tension and conflict in their relationship to resources perceived as unhelpful. Knowledge on how social support is helpful or harmful to the relationship can unlock the door to fostering hope and healing to a marriage after the death of a child.

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### APPENDIX A

# IRB Approval Letter



December 13, 2012

Proposal Title: Married Couples' Perceptions of Support Following the Death of a Child

Type of Review: Initial-Expedited

Investigators:

Ms. Lacey Payne Dr. Brandon Burr Department of Human Environmental Sciences College of Education and Professional Studies Campus Box 118 University of Central Oklahoma Edmond, OK 73034

Dear Ms. Payne and Dr. Burr:

#### Re: Application for IRB Review of Research Involving Human Subjects

We have received your revised materials for your application. The UCO IRB has determined that the above named application is APPROVED BY EXPEDITED REVIEW. The Board has provided expedited review under 45 CFR 46.110, for research involving no more that minimal risk and research category 7.

Date of Approval: 12/13/2012 Date of Approval Expiration: 12/12/2013

If applicable, informed consent (and HIPAA authorization) must be obtained from subjects or their legally authorized representatives and documented prior to research involvement. A stamped, approved copy of the informed consent form will be sent to you via campus mail. The IRB-approved consent form and process must be used. While this project is approved for the period noted above, any modification to the procedures and/or consent form must be approved prior to incorporation into the study. A written request is needed to initiate the amendment process. You will be contacted in writing prior to the approval expiration to determine if a continuing review is needed, which must be obtained before the anniversary date. Notification of the completion of the project must be sent to the IRB office in writing and all records must be retained and available for audit for at least 3 years after the research has ended.

It is the responsibility of the investigators to promptly report to the IRB any serious or unexpected adverse events or unanticipated problems that may be a risk to the subjects.

On behalf of the UCO IRB, I wish you the best of luck with your research project. If our office can be of any further assistance, please do not hesitate to contact us.

Sinderely emport

JillA. Devenport, Ph.D. Chair, Institutional Review Board Director of Research Compliance, Academic Affairs Campus Box 159 University of Central Oklahoma Edmond, OK 73034 405-974-5479 jdevenport@uco.edu

#### Office of Research Compliance, Academic Affairs

100 North University Drive · Edmond, Oklahoma 73034 · Phone (405) 974-5497 · Fax (405) 974-3825 · www.uco.edu

### APPENDIX B

# Approved Informed Consent Letter

University of Central Oklahoma Department of Education and Professional Studies Human Environmental Sciences Box 118, 100 N. University Drive, Edmond, OK

Dear Potential Participant,

You have been identified as a possible participant in a research study regarding married couples' perception of support following the death of a child. Through this research, we hope to gain insight into the impact of social support on the parent's marital relationship following the death of a child. We understand talking about your experience may be difficult or emotional and we respect your consideration to participate. Findings from this study could be very helpful for the participants as you have the opportunity to share your story, as well as for those who wish to know how to help someone who has experienced such a significant loss.

Through two or more interviews with you and the researcher, we will discuss your experience with social support after your child's death as well as the benefits and/or affects it had on your marriage. Interviews can take place in your home, or a quiet location of your choice. Interviews will generally last an hour or longer, if needed. These interviews will be audio recorded and you will have the chance to review the interviews after they have been transcribed to check for any errors made by the researcher. All data analyzed will be kept anonymous. You may choose to withdraw from the study if at any point you become too uncomfortable to continue.

If you are interested in participating or have any questions about this research study, please contact us as we hope you will be willing to participate in what we believe to be an important issue.

Thank you, Lacey Payne, 405-550-3773 lacey.payne@att.net

Dr. Brandon Burr, 405-974-5793 bburr1@uco.edu

\*Permission for this research study was obtained through the Institutional Review Board at the University of Central Oklahoma. For questions regarding research participation, please call 405-974-5479 or email, irb@uco.edu.

\_\_\_\_\_

Name(s):

I hereby voluntarily agree to participate in the above listed research project and further understand the explanations and descriptions of the project. I also understand that there is no penalty for refusal to participate, and that I am free to withdraw my consent and participation in this project at any time without penalty. I acknowledge that I am at least 18 years old. I have read and fully understand this Informed Consent Form. I sign it freely and voluntarily. I acknowledge that a copy of this Informed Consent Form has been given to me to keep. I understand that my interview will be audio recorded and that the researchers will not use any identifying information and will use full confidentiality in reporting the results.

Signature(s): \_\_\_\_\_

Date: \_\_\_\_\_

Phone: \_\_\_\_\_

\_\_\_\_\_ Email: \_\_\_\_\_



APPROVAL DEC 1.2 2013 EXPIRES

# APPENDIX C

# Demographics Survey

### **1. General Background Information**

What is your age in years?

What is your sex? a. Male

Which of the following categories best describes your race/ethnicity?

a. Asian or Pacific Islander d. Native American or Alaska Native

b. Female

- b. African American or Black e. White or Caucasian
- c. Hispanic or Latino f. Middle Eastern or Arab

Which of the following best describes your religious preference?

a. Catholic	f. Other Christian (e.g., Apostolic, Mormon, Jehovah's Witness)
b. Jewish	g. Atheist
c. Evangelical	h. Agnostic
d. Protestant (Baptist, Methodist)	i. Other, please specify
e. Non-denominational Christian	j. None

What is your family's approximate current yearly total household income? Select the most accurate response.

a. under \$5,000	g. Between \$50,000 to \$60,000 per year
b. Between \$5,000 to \$10,000 per year	h. Between \$60,000 to \$70,000 per year
c. Between \$10,000 to \$20,000 per year	i. Between \$70,000 to \$80,000 per year
d. Between \$20,000 to \$30,000 per year	j. Between \$80,000 to \$90,000 per year
e. Between \$30,000 to \$40,000 per year	k. Between \$90,000 to \$100,000 per year
f. Between \$40,000 to \$50,000 per year	1. More than \$100,000 per year

What is the highest education grade you finished, received credit for, or the highest degree you have earned?

- a. Less than high school (0-11)
- b. High school graduate or GED equivalency (12)
- c. Trade/technical/vocational training
- d. Some college
- e. College graduate
- f. Some post graduate work completed (attended some graduate school)
- g. Post graduate degree (e.g., Master's degree, Doctorate degree, etc.)

### 2. Family Information

How long have you and your spouse been married?

How long had you been married at the time of your child's death?

Please indicate if your current marriage is your first marriage, second marriage, etc.

Including the child who died, how many children do you have?

What was the age of the child at the time of his or her death?

What was the primary cause of your child's death?

- a. Accident
- b. Illness
- c. Suicide
- d. Homicide
- e. Natural Causes
- f. Other, please specify \_\_\_\_\_

# APPENDIX D

Interview Questions

### **Interview Questions**

- Describe an experience of support that was beneficial after your child's death.
- Describe an experience that was not helpful.
- In what ways does support, specifically related to your child's death, from family or others affect your marriage?
  - How does this support strengthen your marriage? How is this social support ever harmful to the marriage?
  - How did social support help with conflict or tension in your relationship?