
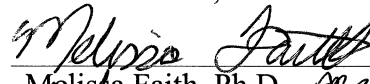


A FAMILY BEREAVEMENT CAMP: EMERGING THEMES REGARDING ITS IMPACT  
ON THE LIVES OF BEREAVED PARENTS AND SIBLINGS

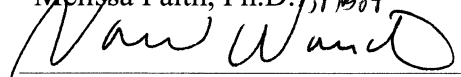
APPROVED BY SUPERVISORY COMMITTEE

 | PWD

Julie Germann, Ph.D.

 Ph.D., ABPP

Melissa Faith, Ph.D., ABPP

 MD

Naomi Winick, M.D.

## DEDICATION

I would like to thank the members of my Graduate Committee, my family, and my friends.

A FAMILY BEREAVEMENT CAMP: EMERGING THEMES REGARDING ITS IMPACT  
ON THE LIVES OF BEREAVED PARENTS AND SIBLINGS

by

MELISSA ANNE CARAWAN

THESIS PROPOSAL

Presented to the Faculty of the School of Health Professions

The University of Texas Southwestern Medical Center

Dallas, Texas

In Partial Fulfillment of the Requirements

For the Degree of

MASTER OF CLINICAL REHABILITATION COUNSELING

Copyright © 2015

by

MELISSA ANNE CARAWAN

All Rights Reserved

### Abstract

**BACKGROUND:** Within the grief literature, family bereavement camps have yet to be researched in a combined population of bereaved parents and siblings. Camp Sol is a weekend retreat for families who have experienced the death of a child/sibling. The goal of the current study is to establish areas reported by parents and sibling campers as being impacted by their experience at camp in hopes of identifying standardized measures that can be implemented in the future evaluation process. This will provide future researchers the ability to quantitatively evaluate the overall efficacy of a family bereavement camp among bereaved parents and siblings.

**SUBJECTS:** Camp Sol evaluations were collected post-camp over the span of five and a half years totaling 656 evaluations. Parents comprised 50.2% of the sample, where the majority of them spoke English versus Spanish (81.4% vs. 18.5%). The children comprised 49.8% of the sample and ranged from the age of 4 to 19.

**METHOD:** Data coding and analysis followed a mixed-methods design, specifically the convergent parallel design, which utilizes both qualitative and quantitative data. The constant Comparative Method (CCM) was used to analyze and code the qualitative portion of the evaluation to arrive at core themes. A variety of quantitative analyses (independent t-test, ANOVA, MANOVA) was used to analyze potential differences between groups according to family role, language, and age.

**RESULTS:** The prominent themes that emerged from the qualitative data were social support, communication, continuing bonds as a coping skill, increased knowledge of the grief process, adjustment, family interaction, and camp environment. Quantitative results revealed that fathers rated the Understanding Index significantly lower than unspecified parents, and siblings' ages 8

to 11 and 12 years and older had significantly higher mean scores on communication than siblings' ages 2 to 7.

**DISCUSSION:** This study is the first to research both parent and sibling benefits of a family bereavement camp, which identified the importance of non-pathological constructs (e.g. social support, communication, family relationships) while providing richness of information about how a uniquely structured camp may facilitate positive adjustment and coping for entire bereaved families. The camp structure may provide cost effective and accessible grief intervention for bereaved families (English *and* Spanish) in a safe and supportive environment. Future research would benefit from the use of pre- and/or post- intervention measures assessing for social functioning and mental health, as well as the implementation of a control group to allow discrimination of participants' outcomes.

*Keywords:* bereaved, grief, parent, sibling, family, interventions, camp, bereavement, effectiveness, social support, communication, knowledge, continuing bonds, adjustment, coping skills, Spanish.

## TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION .....	9
CHAPTER TWO: REVIEW OF THE LITERATURE .....	13
Expression of Grief Among Bereaved Parent and Siblings .....	13
Parent Grief Experiences .....	14
Sibling Grief Experiences .....	18
Grief Interventions and Their Effectiveness .....	20
General Grief Interventions .....	20
Parent Grief Interventions .....	23
Child Grief Interventions .....	26
Family Grief Interventions .....	30
Bereavement Camp Interventions .....	36
Latino Grief and Cultural Perspective .....	44
Current Study .....	45
CHAPTER THREE: METHOD .....	49
CHAPTER FOUR: RESULTS .....	56
Qualitative Results .....	56
Quantitative Results .....	82
CHAPTER FIVE: DISCUSSION .....	86
REFERENCES .....	99

## LIST OF TABLES

TABLE 1	.....	109
TABLE 2	.....	110
TABLE 3	.....	111
TABLE 4	.....	112
TABLE 5	.....	116
TABLE 6	.....	120
TABLE 7	.....	123
TABLE 8	.....	127
TABLE 9	.....	128
TABLE 10	.....	131



LIST OF FIGURES

FIGURE 1 .....	132
FIGURE 2 .....	133

## LIST OF APPENDICES

APPENDIX A	.....	134
APPENDIX B	.....	137
APPENDIX C	.....	139
APPENDIX D	.....	154
APPENDIX E	.....	169
APPENDIX F	.....	185
APPENDIX G	.....	193
APPENDIX H	.....	237
APPENDIX I	.....	249
APPENDIX J	.....	256
APPENDIX K	.....	266
APPENDIX L	.....	272

## **CHAPTER ONE**

### **Introduction**

According to the Centers for Disease Control and Prevention, approximately 67,800 children between the ages of 0 and 19 died in the United States in 2013, leaving thousands of parents and siblings to experience the natural reactions to death: bereavement and grief. Bereavement is commonly used in reference to the state of experiencing a loss (Rando, 1995). In comparison, grief includes the involuntary reactions of being bereaved, which may include emotional, cognitive, behavioral, physical, and/or spiritual responses to the death (Ziosook & Shear, 2009; Rando, 1995; Servaty-Seib, 2004). Bereaved individuals differ in how they express grief and cope with loss, which is suggested to be related to various circumstances around the death such as cause of death and/or time since death (Murray, 2002). While many stage theories have been developed to describe how different grief reactions may manifest, Miles (1985) developed a phase theory to specifically describe grief reactions among bereaved parents. In contrast, sibling grief reactions may be better conceptualized by utilizing Piaget's (1967) stages of cognitive development rather than grief stage theories because of the significant impact developmental age has on the grieving process (Herberman Mash, Fullerton, & Ursano, 2013).

The efficacy of parent, sibling, and family grief interventions, as well as bereavement camps, has yet to be determined due to inconclusive study results resulting from inconsistent use of long-term outcome measures, small sample sizes, and the simple descriptive nature of many publications. Regarding parental grief interventions, one factor potentially contributing to inconsistent results or a lack of demonstrated effectiveness is the focus on outcomes measured by changes in complicated grief symptoms or psychopathology. The majority of bereaved parents are not experiencing high levels of distress or symptoms that are associated with complicated

grief (McCarthy, Clarke, Lin Ting, Conroy, Anderson, & Heath, 2010; van der Houwen, Schut, van den Bout, Stroebe, Stroebe, 2010; Bonanno & Kaltman, 2001; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Piper et al., 2001; Aoun, Breen, Howting, Rumbold, McNamara, & Hegney, 2015); therefore, it may be unlikely that researchers will see improvements in the measured outcomes if parents are experiencing low levels of distress prior to the intervention.

Information regarding the distress levels of bereaved siblings is minimal because the majority of articles outlining common grief reactions of children do not focus on psychopathological functioning. Conversely, the literature provides information on the social functioning of children following the death of a sibling. Scholars have reported common manifestations of grief between some of the developmental stages including behavioral issues and difficulties with communication between family members, both of which may result in strain on the parent-child relationship (Barrera et al., 2013; Dowdney, 2005; Lyles, 2004; Lancaster, 2011; Gibbons, 1992; Wender, 2012; McCown & Davies, 2001; Heiney, 1991). Primarily, studies of child grief interventions have measured psychopathological symptoms (prolonged grief disorder, posttraumatic stress disorder, as well as emotional functioning) but have not found consistent change in these areas, whereas social functioning has been infrequently measured (Pfeffer et al., 2002; Currier et al., 2007; Rosner et al., 2010). The discrepancy between commonly reported child grief reactions (social functioning) and symptoms commonly measured by grief intervention studies (psychopathological functioning) may be contributing to inconclusive study results. A brief overview of parental and sibling grief responses, as well as an understanding of studies that have measured changes in non-pathological areas are needed in order to inform appropriate evaluation of parental and sibling grief interventions, and accordingly, family grief interventions.

As previously mentioned, findings across studies that have measured the efficacy of family interventions are inconclusive. Rather than focusing on the bereaved family as a whole, “family” interventions are often intended to reduce grief reactions of surviving siblings, while the parent’s principal role is to guide, comfort, and counsel the surviving child through the grief process. When compared to individual parent and sibling intervention studies, family intervention studies commonly assess and measure more features of social functioning (social support, communication, and quality of relationships) and have reported positive outcomes. For instance, families reported increased communication between family members, discussion about the deceased, knowledge about the grief process, quality of parent-child relationship, and expression of emotions (Hopemeyer & Werk, 1994; Horsley & Patterson, 2006; Sadler et al., 2003; Sadler et al., 2010; Black & Urbanowicz, 1987).

The use of bereavement camps in lieu of more traditional modes of grief interventions is increasing, specifically in the population of bereaved children. Bereavement camps were designed to incorporate a variety of creative and therapeutic techniques that aim to allow bereaved individuals the opportunity to express emotions, learn about the grieving process, establish healthy coping skills, and share experiences with other bereaved individuals. The existing publications of bereavement camps provide information and descriptions of camps exclusively targeting the population of bereaved children. However, the literature concerning bereavement camps designed to target grief reactions of bereaved families following the death of a child/sibling is absent, thus prompting the rationale for the current study.

The aim of the current study was to use qualitative data to identify areas that are being affected by attending Camp Sol in order for standardized measures to be implemented in the

future and, in turn, helping quantitatively evaluate the overall efficacy of camp among bereaved parents and siblings.

## **CHAPTER TWO**

### **Review of the Literature**

#### **Expression of Grief Among Bereaved Parents and Siblings**

##### **Introduction to Parental and Sibling Grief Experiences**

As mentioned above, approximately 67,800 children between the ages of 0 and 19 died in the U.S. in 2013, leaving thousands of parents grieving the death of a child. Due to the assumption that a parent should die before a child, the literature suggests that parental grief is longer lasting, more intense, and more devastating than other types of grief (Sanders, 1980; Li, Hansen-Precht, Mortensen, & Olsen, 2003; Nolen-Hoeksema & Larson, 1999; Kreicbergs, Lannen, Onelov, & Wolfe, 2007; Arnold & Gemma, 2008; Thompson, Miller, Barrera, Davies, Foster, Gilmer...& Gerhardt, 2011). Consequently, bereaved mothers and fathers may be at an increased risk for developing complicated grief (Jacobs & Kim, 1990; Piper, Ogrodniczuk, Azim, & Weideman, 2001); however, the literature indicates that the majority of bereaved parents do not seem to experience high levels of intense or complicated grief (McCarthy et al., 2010; van der Houwen et al., 2010; Bonanno & Kaltman, 2001; Lichtenthal et al., 2010; Piper et al., 2001; Aoun et al., 2015). The theory of parental grief (Miles, 1985), as well as contributions of the continuing bonds theory (Klass, Silverman, & Hicksman, 1996) and the importance of social support (Walter, 1996), will be used as the framework for exploring grief reactions commonly associated with highly distressed parents and reactions that may be more common in parents experiencing lower levels of distress.

Although the literature provides minimal detail about how sibling death impacts the surviving siblings (Rosen and Cohen, 1981), scholars suggest that bereaved siblings may develop behavior and emotional problems, as well as symptoms of complicated grief (Herberman Mash

et al., 2013; Cain, Fast, & Erickson, 1964; Lohan & Murphy, 2001; Hogan & DeSantis, 1994; Dowdney, 2005; Silverman & Worden, 1992). Grief reactions manifest differently in each bereaved child due to developmental age and their understanding of death (Herberman Mash et al., 2013; Dowdney, 2005); therefore, it may be beneficial to describe siblings' grief reactions according to their developmental stages. The stages of cognitive development (Piaget, 1963) will be used as the framework for describing commonly reported sibling grief reactions; however, every child is unique and some may regress into lower developmental stages as they grieve. An understanding of the most common and normative grief responses and coping strategies in parents and siblings are important to inform appropriate evaluations of parent and sibling grief interventions.

### **Parental Grief Experiences**

Bereaved mothers and fathers may be at an increased risk for developing clinical complications and unresolved grief (Jacobs & Kim, 1990; Piper et al., 2001). Unresolved grief refers to high levels of intense grief and/or extremes in the duration of symptoms and commonly co-occurs with the clinical complications (anxiety, depression, social and familial dysfunction, unhealthy behaviors, etc.). These two phrases are collectively referred to as "complicated grief" (Piper et al., 2001). The potential for bereaved parents to experience longer lasting and more intense grief may be due to the assumption that a parent should die before a child, which the literature suggests plays a large part in the grief journey of bereaved parents (Rando, 1985; Miles, 1985). Therefore, in an attempt to describe the unique grief experiences of parents, a theory of parental grief (Miles, 1985) was developed that consists of three phases, including the immediate reaction phase, the intense grief phase, and the reorganization phase. However, it is to be noted that each parent may experience the phases differently, ranging from 'normal' grief to



intense or complicated grief reactions. For an overview of the theory of parent grief (Miles, 1985), see Figure 1.

**Phase One and Two of Miles (1985) Theory.** The first phase of the parental grief theory (Miles, 1985) is characterized by the immediate grief reactions of bereaved parents, including shock, numbness, and disbelief (Hunt & Greeff, 2012; Wheeler, 2001; Barrera, D'Agostino, Schneiderman, Tallett, Spencer, & Jovcevska, 2007; Rando, 1985; Miles, 1985). The immediate reaction phase is also characterized by a perceived reduction in cognitive understanding (i.e. psychological viewpoint that focuses on how an individual may process, understand, and reason or solve problems to a specific stimulus or event), resulting in a sense of unreality and the inability to accept the death of a child (Miles, 1985; Wheeler, 2001; Braun & Berg, 1994; Arnold & Gemma, 2008; Litchenthal et al., 2010; Rando, 1985). Subsequently, the second phase of the parental grief theory (Miles, 1985) is the intense grief phase. Although grief may be expressed vastly differently among bereaved parents, the most common grief symptoms expressed during this phase may include: emptiness, loneliness, and isolation (McClowry et al, 1981; Wheeler, 2001; Arnold & Gemma, 2008; Arnold, Gemma, & Cushman, 2005; Gilmer, Foster, Vannatta, Barrerra, Davies, Dietrich,...and Gerhardt, 2012; Miles, 1985), as well as a perceived loss of parental identity (Gilmer et al., 2012). In addition, anger (Miles, 1985; Alam et al., 2012; Nolfi; 1967; Hunt & Greeff, 2012; Meert, Eggly, Berger, Zimmerman, Anand, Newth...Nicholson, 2011; Rando, 1985; Schwab, 1992; Wheeler, 2001; Gilmer et al., 2012; Umphrey & Cacciatore, 2011; Arnold & Gemma, 2008; Alam et al., 2012; Callahan, 2011) and guilt (Miles, 1985; Davies, 2001) are common characteristics associated with the intense grief phase.

When considering the symptoms of complicated grief (Shear, Ghesquiere, & Glickman, 2013), the feelings and reactions that characterize the first two phases of the parental grief theory (Miles, 1985) appear to overlap. The characteristics that are associated with the immediate reaction phase of the parental grief theory (Miles, 1985) appear to be consistent with 4 of the 16 complicated grief symptoms (Shear et al., 2013), while the intense grief phase of the parental grief theory appear to share similarities with 7 of the 16 complicated grief symptoms. For an overview of the comparison between the first two phases of parental grief (Miles, 1985) and the symptoms of complicated grief (Shear et al., 2013), see Table 1.

**Phase Three of Miles (1985) Theory.** In contrast to the relationship phases one and two had with complicated grief, the reorganization phase of the parental grief theory (Miles, 1985) is more associated with the ability to learn and establish adaptive coping strategies, resulting in the ability to accept the death and accommodate it into a new reality. The grief literature indicates that the concept of continuing bonds is one of the most common and beneficial adaptive coping strategies, as it plays an important role in social adjustment to bereavement (Field, Gao, & Paderna, 2005). The continuing bonds theory (Klass, Silverman, & Nickman, 1996) refers to the opportunities for parents, as well as siblings, to remember positive memories and reconstruct relationships with the deceased in an adaptive, meaningful, and socially acceptable way. However, continuing bonds are not entirely adaptive and can be associated with failure to acknowledge the finality of the death, as well as preoccupation with the deceased and circumstances of the death (Field et al., 2005), both of which are symptoms of complicated grief. Although continuing bonds may vary between families, the most commonly reported bonds included remembering the deceased by displaying pictures (Thompson et al., 2011; Davies, 2003; Gentry, Kennedy, Paul, & Hill, 1995), keeping personal belongings (Gentry et al., 1995;

Thompson et al., 2011; Harper, O'Connor, Dickson, & Carroll, 2011; Field et al., 2005), visiting the graveside (Gentry et al., 1995; Schwab, 1990; Harper et al., 2011), and creating fundraisers in their name (Harper et al., 2011; Thompson et al., 2011; Davies, 2003). Furthermore, the ability to discuss and include the deceased in topics of conversation with friends and family that evoke happy memories (Harper et al., 2011; Thompson et al., 2011; Davies, 2003) and keep their memory alive (Thompson et al., 2011; Arnold & Gemma, 2008; Gentry et al., 1995; Davies, 2003) was highlighted by many parents as an adaptive coping strategy.

The continuing bonds theory (Klass et al., 1996) played a large part in the development of the biographical theory (Walter, 1996), which highlights the importance of social support. The ability to engage in conversations with family, friends, and neighbors, as well as participate in various activities (church or faith based activities, volunteering, career, etc.) may help alleviate an individual's stress, anger, sadness, and guilt (Walter, 1996), as well as help reduce feelings of isolation, sadness, and anxiety among newly bereaved parents (Arnold et al., 2005; Walter, 1996; Riley et al., 2007). Social activities, such as volunteering, educating others about grief, participating in religious and faith-based activities, communicating with others, exercising, and writing, are common activities that have reportedly helped bereaved parents cope with loss of a child (Schwab, 1990; Wheeler, 2001; Arnold et al., 2005; Thompson et al., 2011). Furthermore, the literature suggests that participating in various social activities may help bereaved individuals establish continuing bonds (Walter, 1996). Engaging in adaptive coping skills (continuing bonds and social support) has been shown to help bereaved parents appreciate relationships with others and acknowledge positive changes in personal-growth (Wheeler, 2001; Arnold & Gemma, 2008; Arnold et al., 2005), as well as move forward with life as the deceased would have wanted

(Arnold & Gemma, 2008; Arnold et al., 2005; Thompson et al., 2007; Callahan, 2011; Wheeler, 2001; Berstein et al., 1989).

An understanding of the most common and normative grief responses and coping strategies is important to inform appropriate evaluation of parental grief interventions. Although bereaved parents are likely to experience some complicated grief symptoms described in phase one and two of the parental grief theory (Miles, 1985), the literature indicates that the majority of bereaved parents do not seem to experience high levels of intense or complicated grief. The percentage of parents meeting diagnostic criteria for complicated grief (7 or more of the 16 possible symptoms) (Shear et al., 2013) ranges between 9% and 38% (McCarthy et al., 2010; van der Houwen et al., 2010; Bonanno & Kaltman, 2001; Lichtenthal et al., 2001; Aoun et al., 2015). Alternately, a different study found that the percentage of parents' categorized as 'non-complicated' griever (6 or less of the 16 possible symptoms) (Shear et al., 2013) is 78%, which is larger percentage than individuals who lost a spouse (36%) or parent (21%). When considering all the information, it is possible that the majority of parents categorized as 'non-complicated' are establishing and actively practicing adaptive coping skills, resulting in a reduction of the number of complicated grief symptoms (e.g. intense sorrow or emotional pain, marked difficulty accepting the death, feeling alone or detached, etc.).

### **Sibling Grief Experiences**

Bereaved siblings may be at an increased risk for developing behavioral and emotional problems, as well as symptoms of complicated grief following the death of a sibling (Herberman Mash et al., 2013; Cain, Fast, & Erickson, 1964; Lohan & Murphy, 2001; Hogan & DeSantis, 1994). Although literature on sibling grief is minimal, research suggests that siblings may express similar symptoms to those expressed by bereaved parents (Dowdney, 2005; Silverman &

Worden, 1992); however, bereaved children express their grief differently according to developmental stages and understanding of death (Dowdney, 2005). Therefore, sibling grief reactions are better conceptualized within the stages of cognitive development (Piaget, 1963). Grief reactions are unique to each developmental stage, but some grief reactions may either manifest across all stages or between two or three stages. First, an overview of the stages of cognitive development and unique expressions of grief in each stage will be discussed. Next, common manifestations of grief between some stages (the impact of family communication on avoidance and personal blame, and acting out of negative behaviors) will be described. For an overview of Piaget's (1963) stages, see Figure 2.

**Grief Reactions Unique to Each Developmental Stage.** The stages of cognitive development (Piaget, 1963) consist of four different stages (i.e. sensorimotor, preoperational, concrete operational, and formal operational), each characterized by unique grief reactions. Unique grief reactions of each stage are primarily related to the bereaved children's knowledge of death or lack thereof. However, each stage of development may be characterized by other unique grief reactions, including topics regarding family environment, circumstances surrounding the death, continuing bonds, and role-confusion. For an overview of the unique grief reactions of each developmental stage, see Table 2.

**Common Manifestations of Grief Across Different Stages.** In comparison to the unique grief reactions of each developmental stage, there are common manifestations of grief across different developmental stages, however, in varying degrees. With the exception of the sensorimotor stage, the common manifestations of grief across stages include the impact of communication on avoidance, as well as placing personal blame, and acting out of negative behaviors. Consequently, literature suggests that the tendency to avoid communication regarding

the deceased siblings (Barrera et al., 2013; Dowdney, 2005), as well as the tendency to participate in more attention seeking and/or risky behaviors (Barrera et al., 2013; McCown & Davies, 2001), have been linked to a negative parent-child relationship. For an overview of common manifestations of grief across different stages of cognitive development, see Table 3.

In summarizing the grief reactions of surviving siblings, all of the developmental stages are characterized by unique grief reactions, especially regarding knowledge of death. Conversely, with the exception of the sensorimotor stage, surviving siblings appear to manifest similar problems across some of the developmental stages (i.e. the impact of family communication on avoidance and personal blame, as well as acting out of negative behaviors). Scholars suspect that communication difficulties and acting out of negative behaviors are highly correlated with negative parent-child relationships (Barrera et al., 2013; McCown & Davies, 2001; Dowdney, 2005). The literature has highlighted various concepts (social support of peers, communication, knowledge of death and grief process, expression of emotions, and coping strategies) that appear to shape how a child perceives, reacts, and/or copes with the death of a sibling. An understanding of the most common and normative grief responses and coping strategies is important to inform appropriate evaluation of sibling grief interventions.

### **Grief Interventions and Their Effectiveness**

#### **General Grief Interventions**

Although various types of interventions are highly researched in the grief literature, the question of their effectiveness still remains because of inconsistent results, lack of longitudinal studies, and studies merely describing an intervention without measuring for outcomes. In order to examine the overall effectiveness of grief interventions in general, researchers conducted a meta-analysis on 61 grief intervention studies, consisting of a variety of intervention modalities

(group, individual, and family) and a wide range of participants (adults and/or children who lost a relative or friend) (Currier, Neimeyer, & Berman, 2008). The overall outcome is evidenced by grief interventions producing small, yet significant, effect sizes (.2 to .4) immediately following intervention but not at follow-up (.05 to .08), indicating that bereaved individuals only experienced small, short-term benefits (Currier et al., 2008). Of the eight domains researchers used to gauge participation improvement (general distress, depression, well-being, grief, relational functioning/social adjustment, physical health, anxiety, and trauma symptoms), well-being was the only domain that produced a significant effect size (.25) at follow-up, while depressive symptoms (effect size = .16) and relational functioning (effect size = .21) slightly, yet significantly, decreased only immediately following intervention (Currier et al., 2008).

In spite of the overall lack of demonstrated effectiveness regarding general grief interventions (Currier et al., 2008), a follow-up study that examined factors associated with lesser or greater intervention value found that specific grief interventions targeting marked distress may be more effective and produce long-lasting results (Neimeyer & Currier, 2009). The follow-up results revealed that individuals who participated in indicative interventions (targeting individuals manifesting problems adjusting to the loss, and/or expressing psychiatric disorder or other clinically significant difficulties) appeared to experience significantly greater intervention benefits than individuals who participated in selective (targeting particular groups of bereaved individuals with a heightened risk of experiencing distress symptoms) and universal (interventions that did not attend to death-related risk factors) interventions (Currier et al., 2008; Neimeyer & Currier, 2009). Bereaved individuals (indicative intervention group only) also appeared to experience benefits comparable to those reported by individuals participating in general psychotherapies that treated *specific* symptomatology (depression, posttraumatic stress

symptoms, or anxiety, etc.) (Wampold, 2001; Currier et al., 2008; Neimeyer & Currier, 2009). In comparison to the indicative interventions, the selective interventions produced a small but significant benefit for bereaved individuals *only* at post-intervention, while participants in the universal interventions failed to show any improvements (Currier et al., 2008; Neimeyer & Currier, 2009). This finding led researchers to hypothesize that grief interventions may be more effective especially in circumstances where researchers are able to focus primarily on individuals who are classified as needing help.

Although the literature indicates that grief interventions may be more effective for highly distressed individuals, the current grief symptomatology literature indicates that the majority of bereaved families (parents *and* siblings) do not express significant psychopathology or complicated grief symptoms (Aoun et al., 2015). The literature regarding grief intervention for bereaved families (parents *and* siblings) provides inconsistent results, and given the relatively low levels of clinical symptoms, the interventions may fail to show more significant amount of changes due to the lack of appropriate symptoms or functioning being measured. However, the meta-analysis (Currier et al., 2008), which consisted of general grief interventions that did not *only* target highly distressed individuals, did find significant changes in well-being and relational functioning when measuring improvements across all subjects. This finding lends support to the importance of conducting further research that may aid in determining non-clinical symptoms and levels of functioning that are impacted by grief interventions. The majority of research has been conducted on the efficacy of parental grief interventions, while information on sibling grief interventions is scarce because intervention studies commonly target children grieving the loss of a parent. Articles assessing family interventions and child bereavement camps are typically descriptive in nature; however, the literature concerning bereavement camps designed to target



grief reactions of bereaved families following the death of a child/sibling (the focus of the current study) is nonexistent. The next sections will briefly review interventions that focus on bereaved parents and children grieving any type of loss. Then, because of the current study's focus on a family bereavement camp, a more in-depth review of family interventions and child bereavement camps will be conducted.

### **Parent Grief Interventions**

Traditionally, significant improvements in mental health and social functioning following parent grief intervention have been specific to parents reporting higher levels of distress. However, parent grief intervention studies tend to measure and report more significant improvements in mental health (depression, complicated grief symptoms, posttraumatic stress symptoms, etc.) than social functioning (dyadic relationship, communication, social support, etc.). Although only specific to highly distressed parents, parent grief intervention studies have reported significant improvements in grief responses, posttraumatic stress symptoms, and overall mental distress (Murphy et al, 1998), as well as depressive symptoms (Murray et al., 2000) of 'high-risk' mothers when compared to control groups. Significant improvements in anxiety of 'high-risk' fathers when compared to control groups have also been reported (Murray et al., 2000). Furthermore, an intervention study consisting of adults grieving any type of loss (64% being bereaved parents) reported significant improvements in all complicated grief symptoms being measured (i.e. intrusion, avoidance, and failure to adapt) (Wagner et al., 2006); however, the intervention study was specific only to participants categorized as 'complicated grievers.' In contrast to the positive impacts of interventions on mental health, the impacts of interventions on outcomes related to social functioning (e.g. dyadic relationship, coping skills, positive attitudes, etc.) appear to be not as promising for 'high-risk' participants evidenced by only one

intervention study reporting significant improvements in ‘high-risk’ fathers’ reliance on avoidance coping and seeking support (i.e. need to talk about the loss with others) (Murray et al., 2000). In summary, significant results appear to be specific to highly distressed parents and to focus primarily on significant symptomatology; however, that does not necessarily imply that parents reporting lower levels of distress are not benefiting from parent grief interventions.

While interventions for highly distressed parents have shown significant improvements in mental health and social functioning, interventions for bereaved parents reporting lower-levels of distress or complicated grief generally have non-significant results. Regarding aspects of mental health, parent grief interventions produced improvements (*ns*) in depression (Wagner et al., 2006; Wagner et al., 2007; Videka-Sherman & Lieberman, 1985), anxiety (Wagner et al., 2006; Wagner et al., 2007; Videka-Sherman & Lieberman, 1985), and physical health (Wagner et al., 2006; Wagner et al., 2007; Videka-Sherman & Lieberman, 1985), as well as psychotropic medication use, self-esteem, life satisfaction, and masterful orientation (Videka-Sherman & Lieberman, 1985). Interventions reporting changes in social functioning, specifically regarding the dyadic relationship, found that when compared to control groups ‘low-risk’ parents reported improvements (*ns*) in their dyadic relationship (Murray et al., 2000) and marital satisfaction (Murphy et al., 1998). Regarding improvements in coping skills, ‘low-risk’ parents reported increases (*ns*) in positive grief responses (taking direct action, support seeking, adaptive behaviors) (Murphy et al., 1998) and attitude toward the devastation of losing a child (Videka-Sherman & Lieberman, 1985), as well as a reduction (*ns*) in the use of avoidance coping (Murray et al., 2000). In addition, results showed that ‘low-risk’ parents in the experimental group used less (*ns*) positive grief responses (cognitive coping, support seeking) (Murray et al., 2000). The reductions in the use of positive coping strategies may be construed as unfavorable; however,

perhaps the results are suggesting that parents have begun to accept the death of their child, resulting in less need to talk to others about issues regarding the death.

In contrast to intervention studies measuring for mental health and social functioning, some intervention studies, specifically support groups, are more descriptive and solely discuss parental satisfaction of specific interventions. Descriptive studies indicate that the majority of bereaved parents reported being highly satisfied with their chosen parent grief support group. The positive satisfaction results are evident as parents described how the interventions provided them with social support (Darbyshire et al., 2012; Feigelman et al., 2008; Umphrey & Cacciatore, 2011), a safe environment (Schwab, 1996; Nair et al., 2006; Feigelman, Gorman, Beal, & Jordan, 2008; Umphrey & Cacciatore, 2011; Murphy, 1996), quality leaders and an organized structure (Schwab, 1996; Nair et al., 2006), and information about the grieving process (Schwab, 1996; Nair et al., 2006; Feigelman et al., 2008; Umphrey & Cacciatore, 2011; Murphy, 1996). Furthermore, grief intervention studies employing a less traditional mode of therapy, including telephone support group (Nair et al., 2006; Darbyshire et al., 2012) and an internet-based support group (Feigelman et al., 2008), found that bereaved parents were satisfied with the accessibility and cost effectiveness of the intervention. Although descriptive and evaluation based intervention studies provide information relative to bereaved parent's overall experience, they fail to provide clinically useful outcomes regarding the impact of support groups on parental grief symptomatology.

Although the current grief symptomatology literature indicates most bereaved parents do not express high levels of intense grief (Aoun et al., 2015), researchers tend to emphasize mental health over social functioning when reporting significant improvements in high-risk bereaved parents. Regarding reports of mental health, the use of pre-screening measures to assess for

intense or complicated grief (Murray et al., 2000; Murphy et al., 1998; Wagner et al., 2006) may explain why the results are more specific to parents reporting higher distress level. By pre-screening parents, these studies were able to identify highly distressed parents, which allowed researchers to target ‘high-risk’ parent’s improvements. However, parents who were pre-screened and categorized as having lower levels of distress potentially lacked the variability to show clinically significant improvements (as significant scores were seen only in parents with high distress at baseline), resulting in a perceived lack of demonstrated intervention efficacy. Regarding social functioning, the results may not have been significant because the studies either failed to measure for social functioning, or, if the study did measure for social functioning, the intervention itself did not focus on aspects of social functioning. The interventions mainly focused on improving the mental health of bereaved parents (Murray et al., 2000; Murphy et al., 1998; Wagner et al., 2006). Therefore, the lack of significant improvements in parent’s social functioning (Videka-Sherman & Lieberman, 1985; Murray et al., 2000) may be better explained by the absence of interventions covering topics such as communication and coping skills, as well as marital and/or parental roles following child death. For a detailed listing of parent grief intervention study characteristics reviewed below, see Table 4. (Note: unless specifically noted in the text, the intervention did not include a control group).

### **Child Grief Interventions**

The majority of research on child grief intervention emphasizes mental health symptomatology to evaluate the effectiveness of child grief interventions on children grieving any type of loss, including bereaved siblings. The domains that are being measured to assess for intervention effectiveness include anxiety (Pfeffer, Jiang, Kakuma, Hwang, & Metsch, 2002; Prchal & Landolt, 2009), prolonged grief disorder (Spuij, van Londen-Huiberts, & Boelen,

2013), childhood traumatic grief (Kalantari, Yule, Dyregrov, Neshatdoost, and Ahmadi, 2012), and depression and posttraumatic stress (Pfeffer et al., 2002; Spuij et al., 2013; Prchal & Landolt, 2009). Additionally, a systemic review (Rosner, Kruse, & Hagl, 2010) evaluated the studies by separating them into confrontation (structured discussion or exercise relating to the actual loss) versus non-confrontation (the opportunity to share feelings and emotions without structure) interventions, as well as preventive (participants with either non-symptomatic or missing information of symptoms) versus psychotherapy (participants who showed symptoms and impaired functioning) interventions. While some studies used specific criteria to evaluate outcomes, a meta-analysis (Currier et al., 2007) analyzed the sample as a whole *versus* separating the studies based on specific criteria. Overall, results revealed significant reductions in symptoms of anxiety (Pfeffer et al., 2002; Spuij et al., 2012), depression (Pfeffer et al., 2002; Spuij et al., 2012; Prchal & Landolt, 2009), childhood traumatic grief (Kalantari et al., 2012), prolonged grief and posttraumatic grief (Spuij et al., 2012), and children's health-related quality of life (Prchal & Landolt, 2009). The research regarding effectiveness of different intervention structures (Rosner et al., 2010) revealed that interventions that consisted of confrontational elements were found to be significantly more effective when compared to non-confrontational interventions (uncontrolled studies only). In contrast to significant results, other research results revealed small to moderate, but nonsignificant improvements in participants' posttraumatic stress (Prchal & Landolt, 2009; Pfeffer et al., 2002), anxiety (Prchal & Landolt, 2009), and grief symptoms (Rosner et al., 2010; Currier et al., 2007), and did not find significant differences between psychotherapy interventions (uncontrolled and controlled studies) and preventive interventions (Rosner et al., 2010).

Although various aspects of social functioning (communication, behavior issues, parent-child relationship) are frequently reported in the child grief literature, child grief intervention studies do not seem to focus or measure improvements within this domain. Regarding significant results, intervention studies revealed significant improvements in children's internalizing behaviors and externalizing behaviors (Spuij et al., 2012), and behavioral functioning (Spuij et al., 2012; Prchal & Landolt, 2009), as well as interpersonal relationships, child communication, and knowledge about death by cancer (Prchal & Landolt, 2009). In contrast to significant results, intervention studies reported *non-significant* improvements in social adjustment (Rosner et al., 2007) and self-esteem (Prchal & Landolt, 2009). Unfortunately, while some interventions failed to improve children's social adjustment (Pfeffer et al., 2002), other interventions failed to measure for aspects of social functioning although specifically aiming to improve children's coping skills and communication.

In addition to studies that measured for outcomes in mental health and/or social functioning, some intervention studies were more descriptive in nature, which may provide useful information about the overall intervention experience. The research suggests that many bereaved children were satisfied with the grief intervention experience as evidenced by reports that interventions provided an age appropriate way to discover and express feelings (Slyter, 2012; Roberts & McFerran, 2013), as well as provided a safe environment to talk to other bereaved siblings, create continuing bonds with the deceased sibling/parent, establish other coping strategies, and process and understand many grief-related issues (Roberts & McFerran, 2013; Lohens & Kalter, 1994). Furthermore, children indicated that the intervention helped them understand aspects related to family relationships and family functioning (single-parent

households, remarriage, dating, and difficulties in the parent-child relationship), resulting in a perceived reduction of anxiety (Lohens & Kalter, 1994).

After reviewing the child grief intervention studies, there appears to be inconsistent outcomes regarding improvements on mental health, and a lack of measured and/or reported improvements in children's social functioning. In addition to the possibility of small sample sizes affecting overall results (Spuij et al., 2013; Pfeffer et al., 2002), researchers may have been measuring for symptoms not targeted by the intervention, therefore contributing to a lack of demonstrated intervention effectiveness. Given that the majority of bereaved siblings do not seem to be experiencing complicated levels of grief (Aoun et al., 2015), perhaps the children are failing to show significant improvements in symptoms of mental health simply because they do not seem to be highly distressed, thus lacking the room to significantly improve on various measures of mental health and/or social functioning. Alternately, those studies that targeted those children who were experiencing high levels of distress showed more promising results (Rosner et al., 2007; Kalantari et al., 2012; Spuij et al., 2013). Furthermore, it does not seem that studies typically measure for bereaved children's social functioning, thus limiting the information regarding specific areas in which children, specifically bereaved siblings, are having difficulty. Many of the interventions had components that covered topics pertaining to social adjustment (behavior, communication, coping skills, etc.) (Currier et al., 2007; Pfeffer et al., 2002; Spuij et al., 2013; Kalantari et al., 2012; Slyter, 2012; Roberts & McFerran, 2013). However, these studies found unfavorable results, did not measure social functioning, or were descriptive studies that failed to assess improvements in children's social functioning. In summary, it may be beneficial to measure intervention efficacy based on improvements of symptoms of social functioning in addition to, or in lieu of, symptoms of mental health. The questions of what areas

of social functioning are impacted by child grief interventions, as well as how interventions impact children with low or non-clinical levels of distress, still remain. For a detailed listing of child grief intervention study characteristics reviewed below, see Table 5. (Note: unless specifically noted in the text, the intervention did not include a control group).

### **Family Grief Interventions**

Research studies pertaining to family interventions are limited, resulting in little information about their effectiveness on the impact of families' mental health and social functioning following the death of a loved one. Family interventions that are available, however, typically focus on the children's grief process, while parents play a supportive role. Fortunately, most of the studies being reviewed are longitudinal in nature, which will provide a better picture of the long-term effects of family grief interventions. First, family intervention studies measuring improvements in mental health will be discussed followed by the impact of family interventions on social functioning will be reviewed. For a detailed listing of family grief intervention study characteristics reviewed below, see Table 6. (Note: unless specifically noted in the text, the intervention did not include a control group).

The literature on family grief interventions that measured for symptoms of mental health were small in comparison to the literature on individual parent and child grief interventions. The interventions that measured various aspects of mental health included a family focused grief therapy (Kissane, McKenzie, Bloch, Moskowitz, McKenzie, & O'Neill, 2006), a family-based cognitive behavioral therapy (Groot, Neeleman, van der Meer, & Burger, 2010), an in-home counseling therapy (Black and Urbanowicz, 1987), and a family bereavement program (Sandler, Ayers, Wolchik, Tein, Kwok, Haine...Griffin, 2003). The family focused grief therapy (Kissane et al., 2006) focused on measuring improvements in distress and depression in three different



types of families. Using the Family Relationship Index, the researchers were able to classify families as sullen (moderate, but may have higher levels of distress, and poor family functioning), intermediate (moderate levels of distress and lack of cohesiveness within the family), or hostile (high levels of distress, low cohesiveness, and lack of expression of feelings), while the family-based cognitive behavioral therapy (Groot et al., 2010) targeted individuals with complicated grief and suicidal ideation. The in-home therapies (Black and Urbanowicz, 1987; Sandler et al., 2003) both utilized creative therapeutic strategies, and both programs were aimed to focus more on the bereaved children's problems, while parents learn how to manage behaviors and grief reactions of the children. Overall, only a couple of interventions revealed a small, but significant, reduction in distress (Sandler et al., 2003; Sandler, Ma, Tein, Ayers, Wolchik, Kennedy & Millsap, 2010; Kissane et al., 2006) and depression (Kissane et al., 2006). The family focused grief therapy (Kissane et al., 2006) proved to be more beneficial for the top 10% of individuals (irregardless of family) who scored higher on baseline measures because their depression and distress significantly improved more when compared to individuals with lower baseline measures. In regards to the differences among family types, sullen families' depressive symptoms significantly improved when compared to hostile families; however, the number of sullen families was small ( $N = 14$ ) (Kissane et al., 2006). In contrast to significant results, the intervention studies produced a high number of insignificant results. When compared to the control groups, interventions produced small improvements (*ns*) in complicated grief symptoms, maladaptive grief reactions, suicide risk for individuals classified as 'suicide ideators' (high-risk) (Groot et al., 2010), physical health (parents only), emotional/psychological state (Black and Urbanowicz, 1987), intrusive negative thoughts about stressful events (bereaved children) (Sadler, et al., 2003; Sadler et al., 2010), distress, and depression (Kissane et al., 2006). Younger

children, however, who participated in the in-home therapy sessions (Black & Urbanowicz, 1987) failed to show improvements (*ns*) on scores of physical health when compared to the control group.

When compared to individual parent and sibling grief intervention studies, family grief intervention studies appear to measure more aspects of social functioning. Scholars evaluated various types of family grief interventions and their impact on social functioning. A family focused grief therapy (Kissane et al., 2006), family bereavement program (Sandler et al., 2003; Sandler et al., 2010), and a parent guidance intervention (Horsley & Patterson, 2006) measured communication/social adjustment, relationship quality, and family functioning. An in-home family therapy (Black & Urbanowicz, 1987) measured change in social behavior of parentally bereaved children. Unfortunately, only two interventions produced significant improvements regarding social functioning. For example, when compared to the control groups, the results revealed a significant increase in positive parenting, parent's communication about feelings, parent's adaptive control beliefs, coping skills (parents and young girls, externalizing behaviors (parents and children), internalizing behaviors (young girls), and parent-child relationships (Sandler et al., 2003; Sandler et al., 2010), as well as a significant reduction in conflict levels in intermediate families (Kissane et al., 2006). In comparison to the positive significant results, researchers found that hostile families significantly deteriorated in conflict level scores when compared to the sullen control families (Kissane et al., 2006). This information is important to the current study because it provides small, yet promising, evidence to show the parents *and* children with lower levels of grief, specifically in social functioning, may also be benefitting from grief interventions rather than just the population of highly distress parents and children.

Although not significant, research showed that family grief interventions produced small (*ns*) improvements in communication regarding the deceased sibling (parents and children) (Horsley & Patterson, 2006; Black & Urbanowicz, 1987), sharing stories and memories about the deceased (parents) (Horsley & Patterson, 2006), children's behavior (sleep and appetite problems, smoking, drugs, alcohol, and crying), school performance, and ease of communication with surviving parent (Black & Urbanowicz, 1987), internalizing behaviors (young boys), feelings of social detachment and insecurity (Sandler et al., 2010), children's self-esteem (Sandler et al., 2010; Hopemeyer & Werk, 1994), and positive family dynamic in sullen and intermediate families (Kissane et al., 2006) when compared against the control groups. Specifically, an in-home therapy intervention (Black & Urbanowicz, 1987) found that children who cried on a regular basis and communicated more about the deceased parent had fewer (*ns*) behavioral and emotional problems than the controls. In addition to the studies that used measures to assess social functioning, a study reviewing various types of family bereavement support groups revealed that parents and children reported an overall satisfaction with their selected group (well-led, ideal for specific situation, helpful, and provided knowledge on the grief process) (Hopemeyer & Werk, 1994). The families reported that the interventions helped them learn the importance of not being alone, sharing experiences of personal grief, supporting other bereaved individuals in their grief, increasing one's hope, strength, and developing coping strategies (Hopemeyer & Werk, 1994). However, a minority of women reported dissatisfaction with negative and abrasive individuals in the group, which slightly hindered the group experience.

The results of the studies appear to provide little evidence of the interventions' impact on bereaved families' mental health and social functioning, as only a few studies reported

significant improvements in mental health and social functioning (Sandler et al., 2003; Sandler et al., 2010; Kissane et al., 2006). Inconclusive results regarding family grief interventions' impact of social functioning and mental health may be due to a number of reasons. First, although the majority of reviewed family grief intervention studies appear to be longitudinal, some of the studies lacked control groups (Hopemeyer & Werk, 1994; Horsley & Patterson, 2006), consisted of small sample sizes (Black and Urbanowicz, 1987; Horsley & Patterson, 2006; Kissane et al., 2006; Hopemeyer & Werk, 1994), failed to use baseline measures to track improvements (Black and Urbanowicz, 1987; Hopemeyer & Werk, 1994), used pre-screening measures to target high-risk family members (Kissane et al., 2006), and/or used only one instrument to assess improvements (Hopemeyer & Werk, 1994; Horsley & Patterson, 2006; Sandler et al., 2010).

Additionally, perhaps the interventions failed to provide appropriate materials and/or lessons pertaining to the parent-child relationship and/or communication, as well as focusing more time on targeting children's grief symptoms and not the symptom's of the surviving parent. For example, the unfavorable results of one of the in-home therapy interventions (Black and Urbanowicz, 1987) revealed that children (whose parents reported higher distress levels (depression, anxiety, grief, and suicidal thoughts) scored higher on the communication avoidance scale when compared to children whose parents reported lower levels of distress. It is possible that the correlation between the higher avoidance scores of children and their parent's higher distress levels suggests a lack of communication and/or discussion about the deceased. That is, due to the possibility that these highly distressed parents may have been emotionally unavailable, their bereaved children may have felt the need to refrain from conversation about the deceased or feelings of grief to protect the already vulnerable parent. Within the grief literature, this hypothesis is supported by various studies that discuss the importance of the parent-child

relationship as it relates to the potential that bereaved children may avoid communication with highly distressed surviving parents, which may cause the child to repress various feelings of grief (Gibbons, 1992; Dowdney, 2005; Barrerra et al., 2013; Heiney, 1991). Moreover, researchers failed to provide evidence that a family focused grief intervention (Kissane et al., 2006) was beneficial for highly distressed families (hostile) as these families produced significantly higher scores on conflict levels following intervention. The researchers believed that the unfavorable results may have been due to the content presented in the intervention (lessons on how to handle conflict and cohesion) in lieu of information of other concepts of family functioning (collaboration and commitment following death). In addition, the researchers believed that hostile families demonstrated long-standing and underlying patterns of conflict prior to the death of the family member, therefore, hypothesized that members of a hostile family may likely benefit more from individual therapy (Kissane et al., 2006).

In comparison to the individual parent and child grief interventions, the family grief interventions appear to measure more aspects of social functioning and less symptoms of mental health, but the results regarding intervention effectiveness is still inconclusive. A few of the interventions reported significant results on measures of mental health (Kissane et al., 2006; Sandler et al., 2003; Sandler et al., 2010), but only one study (Sandler et al., 2003) reported significant improvements in social functioning. However, although not significant, other family intervention studies' results revealed that families experienced improvements in communication (Hopemeyer & Werk, 1994; Horsley & Patterson, 2006; Black & Urbanowicz, 1987), parent-child relationships (Horsley & Patterson, 2006; Black & Urbanowicz, 1987), coping skills (Hopemeyer & Werk, 1994), and discussion about emotions regarding the deceased (Horsley & Patterson, 2006; Black & Urbanowicz, 1987). While taking into consideration the hypothesized

reasons that are contributing to the inconclusive efficacy results, it is possible that further research is needed regarding grief interventions' impact on family social functioning and symptoms of mental health. Perhaps the efficacy of family grief interventions may be better explained by measuring the domain of social functioning (communication, expression of emotions, social support, relationship quality, etc) especially pertaining to the *current study*. That is, although only one study (Kissane et al., 2006), the researchers found improvements in families who reported lower levels of distress and not in families who were highly distressed. The results may be useful for the current study (family bereavement camp) because they provide knowledge regarding specific symptoms to measure when evaluating Camp Sol's effectiveness in the future when intervening in the grief process of lower distressed families.

### **Bereavement Camp Interventions**

Research on bereavement camps is limited, but it appears that bereavement camps are becoming more popular for bereaved children; however, the majority of the studies lack clinically useful data regarding camps' impact on mental health and social functioning. Children and parents have reported that bereavement camps have been beneficial in that camps provided bereaved children with a safe and positive environment to express emotions, communicate with other bereaved children (Swank, 2013; Creed et al., 2001; Bachman, 2013; Schachter, 2007; Farber & Sabatino, 2007; Stokes et al., 1997; McClatchey et al., 2009; Nabors et al., 2004), learn new coping skills (Schachter, 2007; Swank, 2013; Farber & Sabatino, 2007), and gain knowledge about the grief process (Creed et al., 2001; Potts et al., 1999; Bachman, 2013; Swank, 2013; Farber & Sabatino, 2007; Stokes et al., 1997). Unfortunately, more than half of the intervention studies are descriptive in nature, while only a few measure improvements in mental health (Nabors et al., 2004; McClatchey et al., 2009) and social functioning (Stokes et al., 1997;

Farber & Sabatino, 2007). First, a review of bereavement camp intervention studies that measured for symptoms of mental health will be reviewed. Secondly, bereavement camp intervention studies that measured for improvements in social functioning will be discussed. Lastly, the descriptive studies will be presented. For a detailed listing of bereavement camp intervention study characteristics reviewed below, see Table 7. (Note: unless specifically noted in the text, the intervention did not include a control group).

To evaluate the impact(s) of child bereavement camps' on symptoms of mental health, researchers aimed to measure improvements in bereaved children's sadness and anxiety (Nabors et al., 2004), as well as posttraumatic stress and traumatic grief symptoms (McClatchey et al., 2009). Overall, the results of the two studies revealed differing outcomes; however, this may be due to inconsistencies between the studies (sample size, use of pre-screening measures, symptoms being measured, etc.). These two bereavement camps consisted of various age appropriate therapeutic activities (arts and crafts, sports, and treasure hunts) and traditional group sessions that aimed to support the emotional needs of campers (Nabors et al., 2004; McClatchey et al., 2009). In addition to the listed activities, the trauma-focused grief intervention (McClatchey et al., 2009) also consisted of techniques commonly used to treat individuals who have experienced trauma (exposure, cognitive restructuring, and relaxation and imagery exercises) and provided surviving parents the opportunity to participate in a daylong psychoeducational seminar. The trauma-focused intervention researchers administered a variety of instruments that assessed for childhood traumatic grief and posttraumatic stress symptoms, in addition to a pre-screening traumatic grief instrument (required for admission to the study) (McClatchey et al., 2009), while the other researchers administered a Likert-scale survey and conducted a semi-structured interview (Nabors et al., 2004). The results of the trauma-focused

intervention (McClatchey et al., 2009) revealed a significant decrease in traumatic grief symptoms, but only a *non-significant* reduction in posttraumatic stress symptoms (re-experiencing, avoidance, and arousal) when compared to the control group (McClatchey et al., 2009). However, the researchers did find significant reductions in the control group's posttraumatic stress symptoms, which suggests that complicated grief symptoms may decrease on their own given the appropriate amount of time (McClatchey et al., 2009). In contrast to the apparent benefits of the trauma-focused bereavement camp, the other researchers did not find any significant improvements in grief symptoms (Nabors et al., 2004). For instance, after researchers coded the children's interviews and uncovered key themes, the results failed to reported changes in children's sadness and anxiety and some parents (N=4) even indicated a continuation of grief related symptoms and intense sadness (Nabors et al., 2004).

Although consisting of only two publications, researchers have conducted studies evaluating the impact of child bereavement camps on bereaved children's social functioning. Similar to the studies measuring symptoms of mental health, the results of the two studies unfortunately did not provide a solid answer to the question regarding bereavement camps' impact on social functioning. Camp Winston's Wish (Stokes et al., 1997) and camp Forget-Me-Not (Farber & Sabantino, 2007) both consisted of psychoeducational components, as well as therapeutic activities, to foster self-esteem, teamwork, trust, and healthy coping. In addition, camp Forget-Me-Not utilized the Three Dimensional Model of Grief (Ward-Wimmer et al., 2002), which is centered around the belief that children must engage and complete the grief tasks in order to adjust to the death of their family member, let go of negative emotions, and reconcile intra-personal differences (Farber & Sabatino, 2007). Although not specifically pre-screening for social functioning difficulties, both interventions conducted semi-structured interviews with



surviving parents to assess the child's suitability and readiness for camp, in addition to questionnaires assessing non-pathological symptoms of social functioning. The interventions either appeared to have negatively impacted children's social functioning, as parents reported slightly, but significantly, more social and behavioral problems following camp (Farber & Sabantino, 2007) or did not improve children's overall behavioral scores (Stokes et al., 1999). However, after camp personnel added pre-screening measures and educational activities (regarding behavior, communication, and social support), the second year campers' scores (Farber & Sabatino, 2007) appeared to reveal more favorable results. Compared to children's baseline scores, the children's parents reported significantly lower degrees of problems regarding social functioning and negative behaviors functioning (acting out, communication, openness, conduct issues) (Farber & Sabatino, 2007).

Although not measuring for children's grief symptomatology, the reviewed descriptive studies of child bereavement camps provided information about camp structure, satisfaction, and activities. Scholars evaluated a variety of interventions including four weekend camps (Bachman, 2013; Creed, Ruffin, & Ward, 2001; Potts, Ferrell, & O'Toole, 1999; Swank, 2013 ) and a weeklong day camp (Schachter, 2007). The majority of the bereavement camps employed psychoeducational components (Bachman, 2013; Creed, Ruffin, & Ward, 2001; Potts, Ferrell, & O'Toole, 1999; Swank, 2013; Schachter, 2007), in addition to a variety of creative therapeutic activities (letter writing, game play, art therapy, and participation in memorial/remembrance ceremonies) that allowed for alternative forms of communication, while the adventure-based therapy (Swank, 2013) specifically evaluated children's satisfaction and experience on a high ropes course. Camp evaluations from parents and children revealed overall satisfaction with child bereavement camps, and their responses generated four common themes: social and peer

support, expression of emotions, communication skills, and knowledge of the grief process (the studies that measured mental health and social functioning also conducted interviews, and the information is compiled into the four major themes below).

The most common theme reported by parents and children was the importance of social and peer support. Specifically regarding camps targeting bereaved siblings, parents of the participating children often expressed that their child's interaction with other bereaved siblings was greatly beneficial (Potts et al., 1999) and helped them realize there are more adolescents experiencing the same devastating loss (Creed et al., 2001). Furthermore, other parents expressed that camp was valuable and allowed children to make lasting friendships with others experiencing grief, helped children feel a sense of normalcy (Bachman, 2013; Stokes et al., 1997; McClatchey et al., 2009), and facilitated positive interactions between bereaved children (Swank, 2013; McClatchey et al., 2009). Similarly, bereaved children expressed the importance of meeting and forming bonds with other bereaved children/adolescents (Swank, 2013; Creed et al., 2001; Bachman, 2013; Schachter, 2007; Farber & Sabatino, 2007; Stokes et al., 1997), having the opportunity to also help other bereaved children (Potts et al., 1999; Bachman, 2013; McClatchey et al., 2009), learning how to ask for support from others (Swank, 2013; Creed et al., 2001; Bachman, 2013), and social support from peers and volunteers while tackling ropes course obstacles and overcoming painful memories of the death (Swank, 2013).

The second common theme of descriptive studies pertained to children's increased ability to positively express feelings and emotions. Parents of bereaved siblings reported that camp helped their children learn that it was normal to feel sad, angry, hurt, and even joyous (Creed et al., 2001), and camp allowed children to express these feelings in a safe environment (Potts et al., 1999). Other parents observed their children expressing and talking about their feelings

(Bachman, 2013; Swank, 2013), in addition to reports that children began to understand their feelings more (Swank, 2013; Stokes et al., 1997). The bereaved children were satisfied with camp because it provided them many opportunities to share feelings with staff, volunteers, and other campers (Creed et al., 2001; Swank, 2013; Bachman, 2013; Stokes et al., 1997), discuss new coping skills that may help regulate emotions (Schachter, 2007; Swank, 2013; Farber & Sabatino, 2007), express negative emotions appropriately (Schachter, 2007; Swank, 2013), and gain an understanding of experienced emotions (Swank, 2013; Creed et al., 2001).

An increase in communication about the deceased family member was also found to be a common theme of descriptive studies. Parents observed their children being more open and communicating about the death, reportedly resulting in a positive impact on the family dynamic (Creed et al., 2001; Potts et al., 1999; Bachman, 2013; Swank, 2013). Some children experienced difficulty discussing the deceased sibling, but reportedly became more comfortable and felt open to communicate with parents regarding the death of their sibling (Potts et al., 1999). After attending camp, bereaved children stated problems pertaining to the parent-child relationship, effective communication of feelings and emotions, and discussion about happy stories and memories about the deceased became easier (Bachman, 2013; Swank, 2013; Creed et al., 2001; Schachter, 2007; Farber & Sabatino, 2007; Stokes et al., 1997). Some children specifically associated increased communication with the ability to establish continuing bonds (Stokes et al., 1997; Nabors et al., 2004).

Lastly, another common theme expressed by parents and children pertained to children's gained knowledge of the grief process. The children's parents expressed how valuable camp was for their children because of the increased knowledge of the grief process and understanding of the concept of death (Creed et al., 2001; Potts et al., 1999; Bachman, 2013; Swank, 2013; Farber

& Sabatino, 2007; Stokes et al., 1997). Some parents' also associated gained knowledge of grief and dying with the decrease in children's acting out and negative behaviors (Bachman, 2013; Creed et al., 2001; Farber & Sabatino, 2007; Stokes et al., 1997). Bereaved children expressed many benefits relating to learning about the grief process, including that many children experience grief (Bachman, 2013; Schachter, 2007), learning grief doesn't have to be a negative experience (Bachman, 2013; Creed et al., 2001; Schachter, 2007), and stories and memories may help reduce negative feelings associated with the grief process (Bachman, 2013; Creed et al., 2001; Swank, 2013). In addition, children who participated in the ropes course associated obstacle difficulties with their problems moving through the grief process, resulting in a better understanding of how slow/fast the grieving process may take (Swank, 2013).

After evaluating the child bereavement camps, satisfaction reports appear to be high; however, quantitative data measuring bereavement camp's impact on mental health and social functioning is inconclusive. There are a few reasons that may be contributing to the inconclusiveness, including lack of control groups (Farber & Sabatino, 2007; Stokes et al., 1997; Bachman, 2013; Nabors et al., 2004; Schachter, 2007; Creed et al., 2001; Swank, 2013; Potts et al., 1999) and small sample sizes (Stokes et al., 1997; Potts et al., 1999; Creed et al., 2001; Nabors et al., 2004; Swank, 2013; Schachter, 2007). Additionally, some researchers failed to administer measures at the time-points recommended by the instrument instructions. For instance, researchers studying camp Wintson's Wish administered a standardized measure at 12-months post-intervention in lieu of the recommended time of 4-months post-intervention (Stokes et al., 1997), which may suggest that results could either be due to intervention participation or the 'normal' regression of grief symptoms over time. The unfavorable results of the psychoeducational summer camp (Nabors et al., 2004) may have been due to the lack of reliable

and viable measures of emotional functioning administered, as the researchers only administered a brief Likert scale survey to assess the camp's impact on children's mental health.

Secondly, researchers may have been measuring for inappropriate symptoms; therefore, contributing to a lack of demonstrated intervention effectiveness. For instance, various camp interventions highlighted the importance of continuing bonds and social support (Nabors et al., 2004; McClatchey et al., 2009), in addition to the majority of parents (89%) ranking social and peer support as the most positive outlet for their children (McClatchey et al., 2009) and parents reporting an increase in children's communication and knowledge of the death process (Stokes et al., 1999). Two of the studies (Nabors et al., 2004; McClatchey et al., 2009) did not assess camp's impact on social functioning, and camp Winston's Wish only measured for improvement in social behavior (not areas relating to communication). Although these studies described important aspects that may be beneficial in the grief process of bereaved children and/or reported increases (*ns*) in communication or knowledge of death, researchers failed to measure improvements in social functioning.

Lastly, researchers may have been measuring for symptoms not targeted by the intervention, therefore contributing to a lack of demonstrated intervention effectiveness. By pre-screening or administering baseline measures to children, some studies were able to identify highly distressed kids, which allowed the researchers the opportunity to target 'high-risk' children's improvements. For instance, the researchers of the trauma-focused intervention (McClatchey et al., 2009) and camp Forget-Me-Not (Farber & Sabatino, 2007) used pre-screening measures to identify children who were highly distressed. The trauma-focused intervention study (McClatchey et al., 2009) only assessed children who met criteria for childhood traumatic grief and did not compare these children with lower distressed children.

Moreover, Camp Forget-Me-Not (Farber & Sabatino, 2007) originally did not administered baseline measures (first year of camp) and the results revealed negative impacts on children's social functioning. However, after adding baseline measures (second year of camp), the results revealed significantly lower degrees of problems regarding social functioning and negative behaviors. This suggests that these children, who were classified as 'high-risk', may have had more opportunities to improve in areas of mental health when compared to children who are not experiencing psychopathological symptoms of grief.

Although satisfaction surveys of child bereavement camps appear to be favorable, the question regarding camp's effectiveness on mental health and social functioning still remains. Perhaps the themes uncovered in the descriptive studies (social and peer support, expression of emotions, communication skills, and knowledge of the grief process), as well as assessing improvements in the parent-child relationship, may be useful when researchers are deciding how to assess bereavement camp's efficacy for bereaved children. Lastly, the descriptive study results may provide the current study with information on what areas may be more beneficial to measure when quantitatively assessing the efficacy of Camp Sol in the future.

### **Latino Grief Experiences, Grief Interventions, and Cultural Perspective**

In the United States, the research on grief reactions within the Latino culture is scarce (Grabowski & Frantz, 1993), which may explain the lack of research regarding the effectiveness of grief interventions on Spanish-speaking parents grieving the loss of a child. In general, the literature indicates that Latino and Anglo individuals grieving the loss of someone close to them experience similar grief reactions, including sadness, pain, despair, and worry (Candelaria & Adkins, 1994; Lobar et al., 2006; Oltjenbruns, 1998), as well as anger, guilt, and social isolation (Oltjenbruns, 1998). The literature, however, also indicates that there is evidence on how

individuals grieve depending on cultural differences (Whitaker, Kavanaugh, & Klima, 2010; Lobar, Youngblut, & Brooten, 2006). The majority of Latino families', including Mexican-American families, grief reactions are highly influenced by religion and spirituality (Lobar et al., 2006; Whitaker et al., 2010; Clements, Vigil, Manno, Henry, Wilks, Das, & Foster, 2003), as well as family support (Whitaker et al., 2010; Huang, 1994; Fuligni, Tseng, & Lam, 1999; Chilman, 1993; Halgunseth, Ispa, & Rudy, 2004). For instance, Latino families believe in the idea of continuing bonds, as they often remain psychologically close with the deceased through prayer, creating shrines, lighting candles, and celebrating "Dia de los Muertos" (Day of the dead) (Clements et al., 2003; Lobar et al., 2006). In addition, Latino families primarily receive social and emotional support from family members rather than individuals outside of the family (Halgunseth et al., 1994; Whitaker et al., 2010). Taking all of this information into account, it would be expected that Spanish-speaking parents participating in grief interventions may discuss topics related to how family support and family relationships, as well as religion/spirituality, may have helped their grief journey. Unfortunately, because of the lack of research on grief interventions for Spanish-speaking parents, it is difficult to know the degree to which Spanish-speaking parents are attending such interventions and exactly how effective interventions are for these individuals.

### **Current Study**

While most research studies focus on outcomes measured by changes in complicated grief symptoms or psychopathology, most bereaved parents are not experiencing high levels of distress or symptoms that are associated with complicated grief (McCarthy et al., 2010; van der Houwen et al., 2010; Bonanno & Kaltman, 2001; Lichtenthal et al., 2010; Piper et al., 2001). Although the majority of the parental grief literature focused on reporting common symptoms of

parental grief that are consistent with symptoms of complicated grief (Shear et al., 2013), other scholars discussed the importance of establishing adaptive coping strategies. A coping strategy discussed in the literature was the concept of continuing bonds (Klass et al., 1996), as it plays an important role in social adjustment to bereavement (Field et al., 2005). Social support (an individual's ability to engage in conversations with family, friends, and neighbors, as well as participating in various activities) was also cited as an adaptive coping strategy that may help improve a variety of grief related emotions (e.g. isolation, sadness, etc.) (Arnold et al., 2005; Walter, 1996; Riley et al., 2007).

The literature on child grief reactions indicate that developmental age of bereaved children has an impact on the longevity and severity of the grief reaction (Herberman Mash et al., 2013; Dowdney, 2005). While all of the developmental stages are characterized by unique grief reactions, especially regarding knowledge of death, the literature reported that surviving siblings manifest similar problems across some of the developmental stages (i.e. the impact of family communication on avoidance and personal blame, as well as acting out of negative behaviors). Scholars suspect that communication difficulties within the family, as well as acting out of negative behaviors, are highly correlated with negative parent-child relationships (Barrera et al., 2013; Dowdney, 2005; Lyles, 2004; Lancaster, 2011; Gibbons, 1992; Wender, 2012; McCown & Davies, 2001; Heiney, 1991). However, studies of child grief interventions have primarily measured psychopathological symptoms including prolonged grief disorder, posttraumatic stress symptoms, and emotional functioning but have not found consistent change in these areas (Pfeffer et al., 2002; Currier et al., 2007; Rosner et al., 2010).

When compared to individual parent and sibling interventions, family interventions measure more areas relating to social support, communication, and quality of relationships. In



these specific studies, researchers found that families reported increases in communication regarding the deceased, increased knowledge about the grief process, quality of parent-child relationship, and increased expression of emotions. These content areas are highlighted throughout the parental and sibling grief literature as being affected or important in coping following the loss of a child/sibling.

Based on the literature, it appears it would be beneficial for a family bereavement camp (the focus of this study) to measure change over time in areas regarding social functioning, relationship quality, communication, and behavior rather than simply focusing on psychopathological functioning, because the majority of this population are non-complicated grievers. It is probable that non-complicated grievers are more likely to attend a camp as compared to complicated grievers. Therefore, it is important to understand areas potentially being impacted by camp for non-complicated grievers. Camp Sol is one such camp that offers bereaved families (parents *and* siblings) the opportunity to interact with other bereaved families, learn about the grieving process, and participate in therapeutic activities as individuals, as well as a family, following the death of a child/sibling.

The purpose of the current study is to utilize qualitative data (from family camp evaluation surveys) to identify content areas (from qualitative themes) that are being affected by attending camp in order to identify quantitative measures of the effectiveness of Camp Sol in the future. The quantitative data will also be utilized (from family camp evaluation surveys) to provide information about parents' and children's personal opinions regarding any knowledge and social support gained, which may provide evidence to support the identified core themes from the qualitative analysis. Camp Sol's mission will be used as a framework to examine what content areas may be affected by attending camp. Camp Sol's mission states the following: to

provide a supportive environment to share experiences with families experiencing the loss of a child/sibling, to learn about the grief process, and to participate in fun, nurturing therapeutic activities, both individually and as a family.

- Aim 1: To evaluate if Camp Sol meets its stated objectives in the mission statement.
  - Hypothesis 1: Camp Sol will meet stated objectives as demonstrated by emerging themes in the qualitative data in the areas of social support, knowledge of the grief process, and family interaction.
  - Hypothesis 2: Camp Sol will meet stated objectives as evidenced by quantitative results in the areas of social support, knowledge of the grief process, and family interaction.
- Aim 2: Explore between-group differences of English versus Spanish speaking parents.

## CHAPTER THREE

### Method

#### Study Design and Procedure

The bereavement camp, Camp Sol, utilized in this cross-sectional study is a weekend retreat for families who have experienced the death of a child/sibling. Camp Sol is the organization that initiated and organizes the family weekend retreats, twice per year, in Spring and Fall. The family weekend retreats are held at Camp John Marc, which is located in the South Central region of the United States and serves a variety of special needs groups from children with cancer or cerebral palsy to bereaved families on different occasions. Parents and siblings completed self-reported evaluations at the conclusion of all camps, which consisted of both Likert scale and open-ended questions (note: the current study will not be evaluating pre-post changes). The evaluations utilized in this study were collected over a span of five and a half years from the 2009 to 2014 Spring camps and the 2009 to 2013 Fall camps. This sample is used in a convergent parallel design, which utilizes both qualitative and quantitative data. Specifically, the qualitative data will be used to assess constructs that were identified by families as being impacted by the camp. The quantitative data will assess personal opinions regarding knowledge of grief, areas of social support, and camp activities, as well as potential differences between language, family role, and age of participants, which may potentially add evidence to support identified constructs.

In consultation with Institutional Review Board, the current study was deemed exempt from IRB approval because it was an existing dataset used for program improvement, and only a small portion of parents provided names, so the majority of participants were not identifiable. Parents were able to identify their family role (mother or father) on the parent questionnaire, and

age of the surviving sibling was reported on the sibling questionnaire. The named participants were deidentified with unique codes. Data from the evaluations discussed above was transcribed and entered into a Microsoft Excel spreadsheet. The data from the Spanish forms was translated and entered in English into the Excel spreadsheet by two raters whom are fluent in Spanish. To ensure appropriate translation, the two Spanish-speaking raters also verified each other's translations. Files were maintained in a password protected computer folder, and the evaluations were de-identified with each camper being generated an identification code.

### **Participants**

For details regarding all camp demographics, see Table 8. Over the span of five and a half years, the total number of parents and children completing Camp Sol surveys was 656. The parents made up 50.2% (329/656) of the sample, with 112 mothers, 90 fathers, and 127 unspecified parents making up the sample. Children ages 4 to 19 made up 49.8% (327/656) of the sample. Of the child participants, 30.6% were between the ages of 2 and 7, 33.9% were between the ages of 8 and 11, and 35.5% were 12 years and older. Parent-rating forms were either completed in English (81.4%) or Spanish (18.6%). The surveys included a space for the parents to provide a family name; however, only a minority (98/656) (14.9%) of parents provided a name.

### **Measures**

Parents (Appendix A) and children (Appendix B) completed separate camp evaluations at the conclusion of camp. The evaluation forms were developed by the staff of Camp Sol and utilized quantitative and qualitative questions to measure overall camp experience. Participants responded to all questions in writing and no audio or video recordings were utilized. The parent quantitative section of the evaluation consisted of 21 items. For the purposes of this study,

quantitative analysis examined items 1-4, which were designed to measure parents' perceived understanding of the grief process, comfort with discussion of the death of their child, networking opportunities with other bereaved parents, and benefits of the adult processing group on their support needs. These items ranged from 1-6 on a Likert scale (e.g. "not very well" to "extremely well"). The qualitative section of the parent evaluation form consisted of eight open-ended questions. For the purposes of this study, qualitative analyses focused on the four items pertaining to the least favorite and most favorite aspects of camp, perceived differences parents feel as a result of attending Camp Sol, and parent predictions about the family dynamic once returning home from camp.

The child's quantitative section of the evaluation form consisted of 15 questions. For the purposes of this study, quantitative analysis examined items 1-4, which were designed to measure how siblings felt regarding open communication about their deceased brother or sister with others and their parents, the opportunity to interact with other bereaved children was helpful, and if they would refer other children who had lost a sibling to camp after experiencing and attending Camp Sol. These items ranged from 1-5 on a Likert Scale (i.e. "I don't know" to "A lot"). Additionally, there were 4 open-ended questions in which to collect qualitative data. Siblings responded to questions about what information and knowledge, if any, was obtained from attending camp, their least favorite and most favorite aspect of camp, and their recommendations for what they would like to at Camp Sol in the future.

### **Data Entry and Coding**

In total, 11 separate camp packets (656 parent and children camp evaluations) were entered into the computer database. Before the data entry process began, 3 English-fluent data analysts were divided into pairs and assigned specific years/terms of camp evaluation packets,

with the data analysts taking turns acting as the primary and secondary data entry person. For the English forms (N=535), the three analysts were paired in all possible combinations so as to prevent response bias in coding as much as possible (e.g., analyst 1 and 2 entered and initially coded Spring 2009, analyst 2 and 3 entered and initially coded Spring 2010, analyst 1 and 3 entered and initially coded Fall 2011). Each of the 3 analysts was assigned to act as the primary data enterer approximately 4 times. The secondary analyst checked for input errors and verified the completion of primary data entry. Two analysts who are fluent in written and spoken Spanish collaborated to translate the Spanish data (N=121) into English and check for translation errors before inputting the data into the Excel spreadsheet. The 2 analysts assigned to Spanish evaluations alternated assuming the same primary and secondary roles.

The coding process followed the Constant Comparative Method (CCM). Commonly referred to as the core of qualitative analysis in grounded theory methodology, the process of CCM includes going back and forth between original data sets and coding various key words and/or construct in order to develop overall themes in the evaluations (Glasser & Strauss, 1967; Boeiji, 2002). When circumstances arise, such as needing more clarification about the meaning of a specific response, the researcher may need to check and re-evaluate interpretations. The fundamental goal is to uncover themes and subthemes across families' responses, which is obtained by reading and re-reading the raw data in order to start forming constructs. These constructs are then compared to emerging constructs, resulting in the discovery of the top occurring themes. The entire study group, including all 5 analysts and the primary investigators, completed the first two stages of analysis (described below). The third stage of analysis (described below) will be the focus of this study's specific analyses.

The initial analysis began with the first stage of the Constant Comparative Method, open-coding. After the data sets were entered and verified, each analyst independently completed the process of reading, discovering, and making note of any temporary, broad concepts that emerged within the raw data. The second stage of coding consisted of the analyst pairs collaborating, reading, and re-reading the temporary concepts noted during open coding. This process of analysis is called axial coding. That is, taking one data set at a time, the analysts compared, contrasted, and refined their independently noted temporary concepts, resulting in a consensus of emerging themes. Using the first coded data set, the subsequent data sets and temporary concepts were compared to those identified themes within data set one to decide whether certain concepts were consistent with those themes or whether new themes needed to be created (Glaser & Strauss, 1967). This process allowed the analysts to decide whether themes needed to be reduced or expanded to accommodate multiple subthemes. Periodic study team meetings with all 5 analysts and the primary investigators focused on reviewing initial coding. This aided in a checks and balance process to either confirm emerging themes or offer differing viewpoints. The agreed upon axial coding was then entered into the computer database.

After the subthemes were identified, the primary focus of this study was to identify the core themes amongst the subthemes using the third stage of the Constant Comparative Method (selective coding). That is, the primary researcher (thesis student), with appropriate assistance from the research team (committee) reviewed, refined (if needed), and categorized the axial coding (stage 2) in order to arrive at the core themes that emerged from the parents and children's evaluation responses. The following steps were involved when determining and arriving at the core themes: comparing the message within the raw data to the concept and theme to make certain they have parallel meanings, comparing subthemes (axial coding) with their

assigned core themes to validate overall relevance, locating subthemes (axial coding) that may need to be further developed, analyzed, or reduced, and then relating core themes back to the aim of the current study (what constructs should be measured in the future). This process continued until no new core themes emerged. These themes were then used to clarify the specific areas camp was potentially impacting, which aided in identifying quantitative measures for future studies that assess the efficacy of the family bereavement intervention that is Camp Sol. In an exploratory analysis, themes were then separated by language (English versus Spanish), specifically for bereaved parents, in order to identify any potential differences between qualitative responses.

The quantitative analysis utilized a variety of methods to describe the data and assess potential differences between groups according to language, family role, and age of participants. Since the quantitative questions were part of an unvalidated measure, an exploratory factor analysis was conducted to determine if the portions of the parent and child measure that pertained to grief knowledge and social support were unidimensional or bidimensional. Established indices were then used as dependent variables in the analyses in order to evaluate differences between groups according to language, family role, and age of participants. Differences between groups according to parent language (English versus Spanish) were evaluated using an independent samples t-test, while a one-way multivariate analysis of variance (MANOVA) were used to assess differences between groups according to parent family role (mother, father, parent (mother or father role not identified)). Differences between groups according to sibling age (2 to 7, 8 to 11, 12 and older) were evaluated using a one-way analysis of variance (ANOVA). Post hoc analyses (Tukey's HSD) were performed to identify specific differences following analyses between the three types of family roles, as well as between the



three different sibling age groups. Statistical analyses were conducted using IBM SPSS Statistics 23.

## CHAPTER FOUR

### Results

#### Qualitative Results

The following section will discuss the qualitative results of the current study. First, the results of the parent open-ended questions will be reviewed, starting with the question “describe any differences you feel as a result of coming to camp this year.” The parent questions “since coming to camp, what do you think could happen differently in your family once your family gets home,” “what is your favorite aspect of camp,” and “what is your least favorite aspect of camp” will also be reviewed, in that order. An exploratory comparison of the results about themes of English speaking and Spanish-speaking parent open-ended questions will also be reviewed. Secondly, the results of the sibling open-ended questionnaire will be discussed. The questions, including “what did you learn at camp,” “what was your favorite part of camp,” “what did you like least,” and “what would you like different for next year,” will be reviewed, in that order. The responses of each open-ended question, both parent (overall as well as English versus Spanish) and sibling form, are outlined with original comments to provide further reference and are located in the appendices section.

#### Bereaved Parents

**“Describe any differences you feel as a result of coming to camp this year.”** Parent responses regarding differences they felt as a result of coming to camp (373 total meaning units among 226 total parent participants) encompassed 6 core themes, including social support, communication, increased understanding, adjustment, family relationships, and coping skills. In total, 329 parent camp questionnaires were collected. A hundred and three parents failed to provide a response to the question, leaving the total number of participating parents at 226. The

total number of participating parents' comments generated 373 total meaning units. Of the 373 total meaning units, 3 of the responses were "I don't know" and 2 responses were "everything." Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number indicates the number of individual participants endorsing that theme. See Appendix C for a detailed outline of core themes and subthemes.

***Social support.*** Bereaved parents reported that social support was the most common difference they felt as a result of coming to camp (88/80). The two subthemes that emerged were parent social support and child social support. Parents social support yielded more than half of the responses (70/65) among four different categories, including receiving peer/emotional support, appraisal support, providing peer/emotional support, and instrumental support. Bereaved parents described the importance of having the opportunity to meet, bond, and share experiences with other families experiencing the loss of a child (29/24). Through these shared experiences with other bereaved parents, the parents described various accounts of appraisal support (23/19). Although similar to the category of peer/emotional support, appraisal support provides information about how the experience of meeting and interacting with other bereaved parents helped them evaluate their personal grief journey. Comments such as "we are not alone," "I don't feel as alone," and realization that "other families experiencing the same pain" were the most common descriptions of appraisal support. Parents also described the importance of being able to provide support, comfort, and empathy for other grieving families (14/14). The last category in the parent social support subtheme was instrumental support, which refers to aid and services that directly help others in need (House, 1981). Bereaved parents reported feeling

supported and understood by Camp Sol staff, in addition to highlighting the importance of the support of their children's facilitators.

The child social support subtheme yielded 18 total meaning units among 15 total parent participants. Bereaved parents reported perceived differences they felt about the peer/emotional support their children receiving (16/13). Parents highlighted the importance of their children being able to feel supported by other adults, as well as to meet and interact with other children that share the "same experience," "same loss," and "same feelings." Due to the opportunities to meet other bereaved siblings, parents indicated that their children described accounts of appraisal support (2/2) (feelings of not being alone in their grief and universality).

**Communication.** Bereaved parents reported that communication was the second most common difference they felt as a result of coming to camp (87/80). Three subthemes emerged including ease of communication pertaining to the deceased child, emotional expression, and increase in open communication. The majority of parents described feeling that communication would become easier when discussing their deceased child with others (34/32), with surviving children (14/11), and with spouses (1/1), stating that they would feel "more comfortable" and "talk more" about the deceased. Regarding emotional expression, bereaved parents indicated feeling that they would be more comfortable expressing their feelings and/or talking about their grief (21/20). Additionally, parents described wanting a desired change in the emotional expression of their surviving children (9/9) and their family (4/4), as some parents would like to be able to discuss feelings and grief more openly and frequently. Lastly, parents reported perceived changes in the amount of open communication in general they would have with surviving children (4/3).

***Increased knowledge of grief process.*** Bereaved parents reported that increased knowledge of the grief process was the third most common difference they felt as a result of coming to camp (82/73). The majority of bereaved parents reported feeling that they gained knowledge about the developmental stages and grief process of children (39/34). Parents indicated that the ability to understand the “development of children and their grief” and “stages of child grief” will help them better support their surviving children. Parents reported having a better understanding of their personal grief process (19/16). Parents also described gaining knowledge about the family grief process (10/9), resulting in an understanding of how to include a legacy child into the family (2/2), and the individual differences in the grief processes (7/7).

***Adjustment.*** Bereaved parents reported that adjustment was the fourth most common difference they felt as a result of coming to camp (61/52). The subthemes identified were moving forward (16/14), improved mood and negative feelings (38/32), and acceptance (5/5). The majority of the parent responses pertained to the parents perceived ability to move forward with their lives, as the most common phrases were “it gets easier” and “I feel better each time.” The other subtheme was improvements in mood and negative aspects of grief. A portion of bereaved parents discussed a perceived difference in negative aspects of grief (e.g. irritation, impatience, anger, etc.), while others reported a perceived change in how relaxed and at peace they were regarding their painful experience. Lastly, bereaved parents indicated that their experience at camp helped them to be more accepting of their child’s death.

***Family interaction.*** Bereaved parents reported that family interaction was the fifth most common difference they felt as a result of coming to camp (31/25). The parent responses yielded two subthemes: refuge/retreat for the family, as well as family bond and prioritization. The subtheme of refuge/retreat for the family yielded 18 total responses among 14 total participating

parents. After spending time together as a family and away from every day life, bereaved parents described feeling a difference in how their family interacted with each other. Terms such as “retreat,” “solace,” and “sacred place” were used by parents to describe the importance of quality time Camp Sol provided to their families. The other subtheme, family bond and prioritization (13/11), consisted of comments describing the perceived differences parents felt about their family bond, as parents stated that they believed their family would become “closer” and “more united.” Prioritization was also discussed, as one parent insisted on making his family a priority by “not letting them down” and being “a great husband and father figure.”

***Continuing bonds as a coping skill.*** Bereaved parents reported the use of continuing bonds as coping skill as the sixth most common difference they felt as a result of coming to camp (16/13). The two subthemes were honoring/remembering the deceased and discussion of the deceased child. Bereaved parents described the importance of continually remembering and honoring their deceased child (10/8). One parent described how continuing bonds were “vital” to their health and their role as a parent, person, and spouse. In addition, some parents highlighted the importance of continually including their deceased child in topics of conversations as a means to continue bonds with the child (6/5). Although the continuing bond subtheme of *discussion of the deceased* and the communication subtheme of *ease of communication pertaining to the deceased* appear to be the same, there are differences between the two. As parents develop ease of communication and become more comfortable discussing the deceased child, they will be able to utilize these new skills as means to further cope with the death of their child.

***Miscellaneous.*** Aside from the 6 core themes generated by the responses, bereaved parents also provided general comments about Camp Sol. Bereaved parents took the time to

thank Camp Sol for the continued support and respect of their families, as well as comments describing the parents overall experience at Camp Sol. In contrast to positive comments, one parent reported that they did not gain anything while at Camp Sol because of previous “understanding” of certain issues discussed at camp.

**“Since coming to camp, what do you think could happen differently in your family once your family gets home?”** Parent responses regarding the question of what may happen differently in their family once returning home from camp (410 total meaning units among 236 total parent participants) encompassed six core themes, including family interaction, communication, increased knowledge of the grief process, adjustment, social support, and continuing bonds as a coping skills. In total, 329 parent camp questionnaires were collected. Ninety-three parents failed to provide a response to the question, leaving the total number of participating parents at 236. The total number of participating parents’ comments generated 410 total meaning units. Of the 410 total meaning units, 3 of the responses were “I don’t know” and 1 response was “nothing.” Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number indicates the number of individual participants endorsing that theme. See Appendix D for a detailed outline of core themes and subthemes.

***Family interaction.*** Bereaved parents reported that the family interaction was the most common change that could occur in their family once returning home from camp (134/124). The parent responses yielded three subthemes: emotional bond, increased family time, and prioritization. The majority of the responses fell into the subtheme of emotional bond (58/57). As a result of coming to camp, bereaved parents indicated that after returning home their family will be “closer,” “stronger,” and “more united.” The subtheme of increased family time yielded 54

total meaning units among 45 total participating parents. “Spend more time together,” “more family time,” and “more family activities” were the most common responses regarding changes in family interaction once returning from camp. A small portion of the parents (4/3) discussed changes in the amount of electronics they use during family time, indicating an increase in “unplugged” time. The last subtheme, prioritization, consisted of two categories, prioritization of family (11/11) and prioritization of faith and appreciation of life (6/6). By making family a priority, bereaved parents discussed changes, such as “reinforcing their family foundation,” “expressing more love to the children,” and “giving more attention.” In addition, bereaved parents discussed placing priority on faith and appreciation of life by providing comments like “keeping God first,” “little things matter,” and “appreciate where we are today more.”

***Communication.*** Bereaved parents reported that communication was the second most common change that could occur in their family once returning home from camp (84/78). Similar to the responses regarding the question of what can happen differently in their family as a result of coming to camp, three subthemes emerged including increase in open communication, ease of communication pertaining to the deceased child, and emotional expression. After returning home from camp, parents reported that they would like to experience an increase in the amount of communication between family members (26/26), parents and surviving children (11/8), and spouses (2/2). “More open discussion,” “talk more openly,” and “have more communication” were common responses. Regarding communication about the deceased child, a portion of bereaved parents believed that communication would become easier and more comfortable when talking with others in general (11/11), family (3/3) and surviving children (2/2). The last subtheme was emotional expression for families (24/21) and surviving children (5/5). Bereaved parents believed that after returning home their families will be able to



effectively express and identify their grief feelings, including sadness and frustration.

Additionally, parents reported that their surviving children will be able to share more grief related emotions.

***Increased knowledge of the grieving process.*** The third most common change that parents believed could occur in their family once returning home from camp was an increase in knowledge of the grieving process (66/63). The subthemes include individual differences in the grief process, developmental stages and grief process in surviving children, and parental grief process. The majority of responses fell into the category of gaining knowledge about individual differences in the grief process (42/42). Responses' indicated that parents will be able to better understand, accept, and acknowledge that no one person grieves the same. The second subtheme, developmental stages and grief process in surviving children (15/12), described parent's belief that they will have a better understanding of how their child grieves and the emotions that are associated with child mourning. Additionally, bereaved parents indicated that their surviving children will personally be more equipped to understand the death and grief process once returning home from camp. Regarding the parents' personal grief process, bereaved parents indicated that they will have a better understanding of changes in their emotions, non-destructive coping skills, and self-management skills (10/10).

***Adjustment.*** Bereaved parents reported that adjustment was the fourth most common change that could occur in their family once returning home from camp (40/38). The subthemes identified were moving forward (21/19) and improvements in mood and negative feelings (19/18). The majority of the responses pertained to bereaved parents describing adjustment in terms of having the ability move forward with their lives, create new memories, and overcome obstacles (21/19). Additionally, parents discussed adjustment in terms of improvements in their

mood and negative aspects of grief (19/18). After returning home from camp, parents hoped to experience an increase in happiness, relaxation, calmness, and patience, in addition to a decrease in stress, anger, and frustration. Lastly, a portion of bereaved parents indicated that they would have the ability to be more accepting of the death of their child and the grieving process (6/6).

***Social support.*** Bereaved parents reported that social support was the fifth most common change that could occur in their family once returning home from camp (31/27). The 3 subthemes that emerged were parent social support, child social support, and family social support. Parents social support yielded more than half of the responses (21/17) among four different categories, including instrumental support, providing peer/emotional support, receiving peer/emotional support, and appraisal support. The parent responses' indicated that they would participate in more instrumental support (aid and services provided for people in need), such as seeking professional help and support groups, volunteering at Camp Sol, and organizing and participating in fundraisers (7/5). Additionally, bereaved parents described their ability to be more supportive towards others who are grieving and "extend more grace" (5/5). Receiving peer/emotional support was achieved by having the opportunity to interact and share experiences with other bereaved parents, as parents reported being able to continue the friendships even after returning home from camp (4/4). Appraisal support was the last category under the subtheme of parent social support. Although similar to the subtheme of receiving peer/emotional support, appraisal support provides information about how the experience of interacting with other bereaved parents helped them evaluate their personal grief journey. As a result of listening to the experiences and stories of other bereaved families, the parents discussed feelings of peace, normalcy, and universality (5/3).

The child social support subtheme yielded 6 total meaning units among 6 total parent participants and generated two categories: parents providing emotional support and children receiving peer/emotional support. The parents indicated that their ability to offer emotional support to their children will increase once returning home from camp (4/4). Responses also suggest that parents believe their children will be calmer and comfortable after returning home because they will have a support system of other bereaved siblings in which they can communicate (2/2).

The last subtheme was family social support (4/4). Parents' endorsements of family social support were evident as they described how their experience will help their families be more supportive and helpful towards one another once returning home from camp.

***Continuing bonds as a coping skill.*** Bereaved parents reported the use of a specific continuing bonds activity (honoring/remembering the deceased child) as a coping skill as the sixth most common difference they felt as a result of coming to camp (16/14). Bereaved parents described how they will continue to honor and remember their deceased child after returning home from camp. In addition, some of the parents described wanting to instate celebrations (e.g. angel day, birthdays, etc.) and arts and crafts (e.g. scrapbooking) in order to honor their deceased loved one.

***Miscellaneous.*** Aside from the 6 core themes generated by the responses, bereaved parents also provided general comments about Camp Sol. Bereaved parents offered many thanks to the Camp Sol staff and volunteers and commented about the great experience their children had at camp. One mother, however, worried about resources for her surviving child once they age out of the camp program. In addition, some parents offered suggestions regarding family introduction, parent group sessions, scheduling, food, and campfire stories.

**“What was your favorite aspect of camp?”** Parent responses regarding their favorite aspect of camp (550 total meaning units among 275 total participating parents) encompassed five core themes, including camp activities, social support, family relationship, camp environment, and communication. In total, 329 parent camp questionnaires were collected. Fifty-four parents failed to provide a response to the question, leaving the total number of participating parents at 275. The total number of participating parents’ comments generated 550 total meaning units. Of the 550 total meaning units, 38 of the responses were “liked everything” or “liked all of it.” Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number indicates the number of individual participants endorsing that theme. See Appendix E for a detailed outline of core themes and subthemes.

***Camp activities.*** Bereaved parents reported that camp activities were their most common favorite aspect of camp (227/206). The most common subtheme was children and family activities, yielding 134 total unit meanings among 128 total parent participants. In general, 29 parents reported that the family activities and activities for the kids was their favorite aspect of camp. Regarding specific camp activities, the carnival (23/23), ropes course (20/20), and fishing activity (18/17) were the three most commonly reported favorite aspects of camp. Bereaved parents reportedly enjoyed a variety of other camp activities, including cooking (8/8), campfire (8/7), free time (6/5), archery (5/5), sports and games (6/5), arts and crafts (5/5), Saturday night party (1/1), massage (1/1), blackjack (1/1), music therapy (1/1).

The second subtheme was parent activities (78/64). Half of the parents reported that the small group sessions were their favorite aspect of camp (39/33). The comments included a variety of responses related to the parent sessions, such as the parent “morning groups,”

“breakout groups,” and “Saturday groups.” Although parents indicated this was their favorite aspect of camp, a few of the parents mentioned that they wished there was more time in the groups. Parent’s dinner (13/11), mom’s activities (13/10), and dad’s activities (13/10) were the three other favorite aspects of camp reported by the parents. All of these activities provided the parents with opportunities to communicate with other bereaved parents.

Lastly, the subtheme, ‘continuing bond activities’ (15/14) included a few of the parents’ favorite camp activities, such as the remembrance service and remembering the deceased (7/7), stepping stones (4/3), family flag (1/1), quilt squares (1/1), and family introduction (1/1).

***Social support.*** Bereaved parents reported that the social support they received at camp was their second most common favorite aspect of camp (159/139). Parent responses generated three subthemes, with the most common subtheme being parent social support (149/131). The majority of parents (102/91) reported that their favorite aspect of camp was the peer/emotional support they received from other parents and families. Meeting, interacting, and networking with other bereaved parents/families that have experienced the loss of a child, as well as other reports related to the “camaraderie” and “friendship” were the most common responses. In addition, a few of the parents’ discussed that instrumental support (tangible aide and service from camp volunteers) was their favorite aspect of camp (43/37). Parents discussed having the opportunity to “meet and talk” with facilitators about their surviving child. Parent responses also indicated that they were thankful for the staff and volunteers, as they helped provide a safe and fun environment for their children while the parents worked on their own grief. Appraisal support was the last subtheme (6/4). Although similar to the subtheme of receiving peer/emotional support, appraisal supports provides information about how the experience of meeting and interacting with other bereaved parents helped them evaluate their personal grief journey. For

instance, parents discussed how hearing experiences of other families helped them feel a sense of belonging and provided them a sense of universality.

The second subtheme was child social support, which yielded 10 total meaning units among 8 total parent participants. These bereaved parents indicated that their favorite aspect of camp was the peer/emotional support they received from meeting and bonding with other children who have experienced the loss of a sibling.

***Family interaction.*** Bereaved parents reported that the growth in family relationship was their fourth most common favorite aspect of camp (65/54). The responses generated 3 subthemes. The majority of the responses related to family time, which parents commented that having “family time,” “spending time with family,” and “spending time with the kids” were their favorite aspect of camp (50/45). The subtheme refuge/retreat for the family was the second most common subtheme (14/9). These bereaved parent’s favorite aspect of camp was the atmosphere of Camp Sol and the opportunity to “get away from normal life” coupled with the opportunity to spend time with their family. The last subtheme was spousal interaction (2/2). The parents indicated that their favorite aspect of camp was “time away from kids” and spending quality time with their spouse.

***Camp Environment.*** Bereaved parents reported that the camp environment was their third most common favorite aspect of camp (22/19). The responses generated two subthemes, including amenities and structure. The nature (15/12), such as the “serene environment,” “wild life,” and “beautiful scenery,” camp cabins (6/6), and food (1/1) were the amenities that the parents reported as their favorite. The second subtheme, structure, was also mentioned as a favorite aspect of camp, as parents praised the organization of the camp structure.

**Communication.** Bereaved parents reported that the opportunity for communication pertaining to the deceased child was their sixth most common favorite aspect of camp (15/15). Bereaved parents indicated that they enjoyed having the opportunity to discuss topics pertaining to their deceased child with other bereaved parents. In addition, one parent described his wife's ability to open up to others about her experience and communicate more about the deceased child as a result of coming to camp.

**Miscellaneous.** Aside from the 5 core themes the parent's responses generated regarding their favorite aspect of camp, parents also provided general comments about Camp Sol. A few of the parents described improvements that they felt were made to camp, such as improvement in the food and cutting lunch on the last day of camp. In addition, some parents made suggestions related to mixing up the groups during parent sessions and having fewer activities on Saturday of camp. Parents also commented about their overall experience at Camp Sol. In contrast to positive comments, one parent reported that they did not gain anything from attending Camp Sol.

**“What is your least favorite aspect of camp?”** Parent responses regarding their least favorite aspect of camp (198 total meaning units among 166 total participating parents) encompassed three core themes, including camp environment, camp activities, and camp experience. In total, 329 parent camp questionnaires were collected. One hundred and sixty-six parents failed to provide a response to the question, leaving the total number of participating parents at 166. The total number of participating parents' comments generated 198 total meaning units. Of the 198 total meaning units, 53 of the responses were “nothing” or “liked all of it.” Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number

indicates the number of individual participants endorsing that theme. See Appendix F for a detailed outline of core themes and subthemes.

***Camp environment.*** Bereaved parents reported that certain aspects of the camp environment were their least favorite aspect of camp (106/74). Bereaved parent responses generated 3 subthemes, including amenities, nature, and structure. The different amenities that the parents reported as their least favorite was food (26/18/), accessibility (12/11), and cabins (6/4). Regarding accessibility, parent responses indicated that there was excessive walking, low cellular service, and lack of lighting on trails.

The second subtheme, nature, generated 22 total meaning units among 18 total parent participants and consisted of two categories, weather and camp grounds. The comments about the weather were either related to the cold, rain, or mud (21/17), and one parent indicated they did not like “being outdoors.”

The last subtheme was structure (41/24) and consisted of three categories, including schedule, length of camp, and staff. The majority of the parents reported that their least favorite aspect was the scheduling at camp (21/14). “Too little time between activities,” “start and stop times,” and “change things up a little” were the most common responses. In addition, parents indicated that they wanted the camp schedule to be “less structure” and allow more time to explore the camp grounds. Length of camp was another category and generated 5 total meaning units among 5 total parent participants. Parent responses indicated that they would like the camp to be longer than a weekend. Lastly, the parent’s comments regarding the staff indicated that they felt the staff could be more “friendly” and “helpful.”

***Camp activities.*** Bereaved parents reported that some of the camp activities were their least favorite aspect of camp (67/44). The responses generated 3 subthemes: parent activities



(33/19), continuing bond activities (19/12), and children and family activities (16/14). Regarding parent activities, the majority of the responses pertained to small group sessions, as parents reported that the sessions were either not long enough, too large, or did not offer as much discussion as they would have hoped. In addition, 5 fathers mentioned that the dad's activity was their least favorite aspect of camp. Lack of discussion and interaction between the fathers was the main response. The other least favorite aspects of parent activities were parent's dinner and mother's activity.

The two other subthemes are 'children and family activities' and 'continuing bond activities.' The two most common children and family activities are arts and crafts and campfire, which both yielded 3 total meaning units among 3 total participating siblings. Some of the most common least favorite 'continuing bond activities' are family introduction, scrapbooking, and quilt squares. Parents indicated that the family introduction was their least favorite due to the activity being "too quick" and "rushed," as well as a first time camper felt "uncomfortable."

***Camp experience.*** Bereaved parents reported that the experience of Camp Sol was their least favorite aspect of camp (2/4). The subthemes were emotional intensity and first-timers feeling excluded. The one parent that commented on how emotionally intense her camp experience was stated, "all of the crying I did." Lastly, one parent mentioned that they "felt somewhat excluded at times being a first time camper;" however, they added that they felt "reassured" when seeing the interaction between returning families.

***Miscellaneous.*** Aside from the 3 core themes the parent's responses generated regarding their favorite aspect of camp, parents also provided general comments about Camp Sol. In general, two parents commented about the time change while at camp. In addition to general comments, parents offered suggestions about different activities the camp could provide (e.g.

continuing bond activities, alternative activities while raining, and children activities) and open “slots for more families.”

### **Bereaved Siblings**

**“What did you learn at camp?”** Sibling responses regarding what they learned during Camp Sol (252 total meaning units among 236 total participating siblings) encompassed eight core themes, including communication, social support, new activities, adjustment, increased knowledge of the grief process, continuing bonds as a coping skill, and family time. In total, 327 sibling camp questionnaires were collected. Ninety-one siblings failed to provide a response to the question, leaving the total number of participating siblings at 236. The total number of participating siblings’ comments generated 252 total meaning units. Of the 252 total meaning units, 25 of the responses were “I don’t know,” 13 responses were “nothing” or “not a lot,” and 4 responses were “everything” or “a lot.” Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number indicates the number of individual participants endorsing that theme. See Appendix I for a detailed outline of core themes and subthemes.

***Communication.*** Bereaved siblings reported that they learned the most about communicating while at camp (73/68). The siblings’ responses generated three subthemes: communication regarding the deceased (33/32), emotional expression (26/24), and increase in open communication (12/12). The most common responses pertaining to communication about the deceased were, “how to talk about my brother/sister,” “it is okay to talk about your loved one,” and “don’t be afraid to talk about your brother/sister.” Bereaved siblings reported that they also learned about how to express their emotions regarding, as children discussed how their experience helped them “talk about how you feel,” “share our feelings,” and “express yourself,

not to be afraid to talk to other people.” In contrast to the subtheme of communication regarding the deceased, siblings’ endorsements of increase in open communication were more generic. For example, “to talk more” and “to be open to people” were the most common responses.

***Social support.*** Bereaved siblings reported that the second aspect they learned about at camp was the idea of social support (58/55). The two subthemes within this core theme were appraisal support (36/33) and receiving peer/emotional support (22/22). Although similar to the subtheme of receiving peer/emotional support, appraisal supports provides information about how the experience of interacting with other bereaved siblings helped them evaluate their personal grief journey. Siblings’ endorsements of appraisal support were evident as they described how their experience helped them feel “not alone” when dealing with the loss of a sibling. For example, “my sister was not only one who died from cancer or leukemia,” “other people have siblings that have died,” and “that there are people just like me who have lost a brother or sister” are just a few comments made by bereaved siblings. Peer/emotional support was achieved by siblings’ opportunity to make new friends and interact with children who understand what it is like to lose a sibling. Additionally, some of the siblings’ responses described how their experience helped them learn how to be kind, helpful, respectful, and loving towards others.

***New activities.*** Bereaved siblings reported that they learned a variety of different activities at camp (32/32). Siblings indicated that they learned how to do more arts and crafts activities (13/13) than physical activities, including drawing and painting, beadwork, and making slime with “laundry soap and glue.” Siblings’ endorsements of physical activities (12/12) were evident as they described how camp offered them new opportunities to learn different activities, such as bow shooting, rock climbing, zip lining, and cooking.

***Adjustment.*** Bereaved siblings reported that they learned different ways to help adjust to the death of their sibling (21/17). The subthemes within this core theme were hopefulness (13/9) and coping skills (8/8). Siblings' endorsements of hopefulness were evident as they described how their experience at camp helped them be "open minded" and gave them the strength to be optimistic about the future, as children made comments about being "strong" in difficult situations and "never giving up." The other subtheme, coping skills, consisted of siblings' comments describing how camp taught them "how to deal with certain issues," "how to better cope with the sadness of death," and "there are other ways (like tiles and music) to express my feelings about my brother's death."

***Increase knowledge of the grief process.*** Bereaved siblings reported that they learned new information about the grief process (17/14). The responses generated two subthemes: normal grief feelings (12/9) and personal grief process (6/5). The majority of the responses discussed how the children believed that their experience at camp helped them learn about normal feelings related to the grief process, as they discussed how they learned "it is okay to cry" and "it is okay to be sad." In addition, the siblings' endorsements of personal grief process were evident as they described how camp helped them "learn about death," "understand my feelings," and "learn how to grieve." "

***Continuing bonds as a coping skill.*** Bereaved siblings reported that they learned about continuing bonds as a coping skill (7/7). Siblings' endorsements of continuing bonds were evident as they discussed how their experience at camp taught them the importance of continuing to remember, honor, and learn about their siblings.

***Family time.*** Bereaved siblings reported that they learned about the importance of family time (5/4). The children described how their experience at camp taught them that being close to

family is “really important” during hard times, as family “will always be there” and make each other “happy.”

**Miscellaneous.** Aside from the 7 core themes the siblings’ responses generated regarding what they learned at camp, they also provided miscellaneous comments (7/7). General comments about what they learned while at Camp Sol (7/7). The two subthemes were overall experience (6/6) and cabins/sleeping (1/1). The majority of siblings’ indicated that they learned to “have fun,” while one learned how to keep warm while sleeping in the cabins.

**“What is your favorite aspect of camp?”** Sibling responses regarding the question “what is your favorite aspect of camp” (383 total meaning units among 298 total participating siblings) encompassed four core themes, including camp activities, social support, camp environment and family time. In total, 327 sibling camp questionnaires were collected. Twenty-nine siblings failed to provide a response to the question, leaving the total number of participating siblings at 298. The total number of participating siblings’ comments generated 383 total meaning units. Of the 383 total meaning units, 9 of the responses were “liked everything” or “liked all of it,” and 2 responses were “I don’t know.” Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number indicates the number of individual participants endorsing that theme. See Appendix J for a detailed outline of core themes and subthemes.

**Camp activities.** The majority of the siblings’ comments indicated that camp activities were the most common favorite aspect of camp (329/317). The most common subtheme was children and family activities (318/308), followed by continuing bond activities (11/10). Siblings’ endorsed general comments regarding their favorite aspect of camp as evident by response such as “activities” and “family activities.” In contrast to general responses, 291

meaning units among 283 total sibling participants provided more specific responses. The majority of the responses indicated that the carnival (100/99), ropes course (56/54), and camp fire (22/21) were the top three favorite camp activities. Siblings' endorsements of camp activities also indicated that they enjoyed a variety of other camp activities, such as fishing, cooking, fishing, and arts and crafts. Continuing bond activities, including quilt squares (4/4), tiles (3/3), memory boxes (1/1), flag creation (1/1), and the remembrance ceremony (2/1), were also found to be one of the siblings' favorite aspect of camp.

***Social support.*** Bereaved siblings reported that the social support they received at camp was their second favorite aspect of camp (20/20). Sibling responses generated two subthemes: peer/emotional (14/14) and instrumental support (6/6). Peer/emotional support was achieved by siblings' opportunity to "meet new people," "make new friends," "socialize," and "be around families that can relate to my problems." Additionally, siblings' endorsements of instrumental support were evident as they discussed that attending therapy groups with other bereaved siblings was their favorite aspect of camp.

***Camp environment.*** Bereaved siblings reported that the camp environment was their third most common favorite aspect of camp (12/12). The subthemes were amenities (8/8), staff (2/2), and overall experience (2/2). The majority of the responses pertained to the camp amenities, including food (6/6) and cabins (1/1), as siblings' reportedly enjoyed "breakfast time," "eating," and their rooms. In addition, siblings' endorsements of their favorite aspects of the camp environment were evident as they described their how the staff was "friendly and helpful" and their overall experience while at camp.

***Family time.*** Bereaved siblings reported that family time was their fourth most common favorite aspect of camp (11/11). The most frequent comments were "spending time with my

family” and “being with family.” In addition to general comments, a couple of siblings added specific details, such as “sleeping with my mommy” and “playing baseball with my dad.”

**“What is your least favorite aspect of camp?”** Sibling responses regarding the question “what is your least favorite aspect of camp” (280 total meaning units among 261 total participating siblings) encompassed four core themes, including camp activities, camp facilities/environment, family interaction, and emotional experience. In total, 327 sibling camp questionnaires were collected. Sixty-six siblings failed to provide a response to the question, leaving the total number of participating siblings at 261. The total number of participating siblings’ comments generated 280 total meaning units. Of the 280 total meaning units, 90 of the responses were “nothing” or “liked everything,” and 13 responses were “I don’t know.” Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number indicates the number of individual participants endorsing that theme. See Appendix K for a detailed outline of core themes and subthemes.

***Camp activities.*** Bereaved siblings reported that a variety of camp activities were their most common least favorite aspect of camp (100/88). Children and family activities was the most common subtheme, as it yielded 85 total units meaning among 77 total sibling participants. Bereaved siblings reported that their top three least favorite activities were fishing (21/18), music therapy (15/15), and arts and crafts (11/10). Specifically, siblings’ endorsements of fishing were evident as they described how their fishing experience was their least favorite either because of the weather or because they “didn’t catch anything.” Additionally, the children reportedly mentioned 12 other camp activities that they least enjoyed, such as the campfire, foot activity, and ropes course. The second subtheme was continuing bond activities (15/11). The quilt squares

activity (8/5) was the least favorite aspect of the continuing bonds activity, as siblings' described their reasoning behind not enjoying the quilt squares was that the activity seemed "very old now" or they could not "come up with anything." The other least favorite continuing bond activities were stepping stones (2/1), tiles (1/1), remembrance ceremony (1/1), scrapbooking (1/1), and memory chain (1/1).

***Camp environment.*** Bereaved siblings reported that different aspects of the camp environment were their second most common least favorite aspect of camp (70/63). The responses generated 3 subthemes: structure/schedule (26/23), amenities (23/21), and nature (21/19). Siblings' endorsements of structure/schedule of camp being their least favorite aspect of camp were evident as they described not enjoying waking up early, lack of free time, the waiting time between activities, and the length of camp. Siblings' suggested that they camp was "too short" and wanted to stay a longer period of time. The amenities that the siblings liked least were the food (10/8), accessibility (9/9), cabins (3/3), and lack of supplies (1/1). Siblings indicated that the ice cream, snow cones, hamburgers, and/or chicken were their least favorite food items, while showers and pillows cases were their least favorite aspects about the cabins. Siblings' endorsements of accessibility as their least favorite aspect was evident as they described not enjoying "walking a lot" and inability to connect to Wi-Fi. Lastly, siblings' discussed how the weather, including the rain, cold, and/or mud, and camp grounds (i.e. animal poop, cactus) were two of their least favorite aspect of the camp environment.

***Family interaction.*** Bereaved siblings reported that family interaction at camp was their third most common least favorite aspect of camp (4/4). The two subthemes were family time (3/3) and family separation (1). Siblings' indicated that family time was their least favorite aspect of camp; however, it is difficult to know if "time with family" is being portrayed as a



negative aspect or if the siblings misunderstood the question being asked. In contrast, one sibling discussed how they disliked “being away from family” while at camp.

***Emotional experience.*** Bereaved siblings reported that the emotional experience of camp was their fourth most common least aspect of camp (3/2). Although a subtheme with very small responses, the two bereaved children indicated that “being sad most the time” or “hard to see my new friends being scared” was their least favorite aspect of camp.

**“Is there anything that you would like different for next year?”** Sibling responses regarding anything that they would like different next year at camp (289 total meaning units among 245 total participating siblings) encompassed 3 core themes, including camp activities, camp environment, and family time. In total, 327 sibling camp questionnaires were collected. Eighty-four siblings failed to provide a response to the question, leaving the total number of participating siblings at 245. The total number of participating siblings’ comments generated 289 total meaning units. Of the 289 total meaning units, 87 of the responses were “no” or “nothing,” and 5 responses were “I don’t know.” Each core theme with its subthemes will be discussed below. The first number in parenthesis indicates the total number of meaning units for the specific theme, while the second number indicates the number of individual participants endorsing that theme. See Appendix L for a detailed outline of core themes and subthemes.

***Camp activities.*** Bereaved siblings reported that they would mostly likely want to see a difference in camp activities (135/118). The responses generated two subthemes, with the most common relating to changes to current camp activities (103/86). Sibling responses indicating desired changes to the camp carnival (20/18), games (19/16), and arts and crafts (9/8) were the most common. Regarding changes to the camp carnival, comments such as “make carnival longer” and “have cotton candy at carnival” were the most prevalent. The majority of the

responses pertaining to changing camp games described the siblings' desire to have more activities. Similarly, the siblings' discussed how they would like to have participated in "more art stuff" including finger painting and drawing. Bereaved siblings reportedly discussed various changes to other camp activities including ropes course (9/7), archery (9/7), sports (8/6) music therapy (5/4), movie night (6/4), free time (3/3), cooking (3/3), shooting guns (5/3), fishing (3/3) continuing bonds (2/2), and the campfire (1/1). The second subtheme was adding new activities to camp next year (33/32). The top three activities were swimming (13/13), games (8/8), and horseback riding (4/3). Specifically, "duck, duck goose," "paintball," "treasure hunt," and "sack races" are some of the games the siblings' would like to see added to camp next year. In addition, the siblings reportedly would like to see a variety of other camp activities added to camp next year, such as sports (3/3), massage (1/1), teen camp out (2/2), science (1/1), boating (1/1), and girl activities (1/1).

***Camp environment.*** Bereaved siblings reported that they would also like to see a difference in different areas of the camp environment (46/34). The subthemes generated by the responses were amenities (19/17), nature (13/9), and structure (14/8). Siblings' endorsements of camp amenities were evident as they described how they would like to see "different" or "better" food and Wi-Fi, as well as cleaner, less clutter cabins. Although beyond their control, siblings indicated that they would like to see changes in the amount of rain and/or cold weather while at camp. Lastly, bereaved siblings reported that they would like to see a difference in the camp schedule, as they indicated they would like camp to be longer (i.e. a week long). The other siblings' responses pertained to changes to the camp schedule, including changing breakfast time and the month camp is held.

***Family time.*** Bereaved siblings reported that they would like changes to be made in order to increase family relationship (5/5). Three siblings' indicated that they would like to have more family time and family activities, while 2 of the children reportedly would like to bring their cousins to camp next year.

***Miscellaneous.*** Aside from the 3 core themes the siblings' responses generated miscellaneous responses (9/8). A few of the siblings commented on their hopes of having "more fun" at camp the following year. Other responses included "bring a dog" and "I want to come back."

After identifying the most prominent emerging themes in both the parent and siblings qualitative data, it was possible to evaluate if Camp Sol met its stated objectives from the mission statement (Aim 1). As evidenced by the emerging themes, hypothesis 1 is partially supported. In addition to meeting the stated objectives from their mission statement (social support, knowledge of the grief process, and family interactions), Camp Sol appeared to address the following content areas: communication, continuing bonds as a coping skill, adjustment, and camp environment.

### **Differences in Qualitative Themes between Spanish and English Speaking Parents.**

Spanish and English speaking parents' responses for all four questions were examined separately in order to determine potential differences in qualitative responses. There was a total of 368 meaning units for the first question, "describe any differences you feel as a result of coming to camp this year," with English speaking responses totaling 281 and Spanish speaking responses totaling 87. The second question, "since coming to camp, what do you think could happen differently in your family once your family gets home," generated 406 total meaning units with 287 responses from English speaking parents and 119 responses from Spanish

speaking parents. English speaking responses for ‘favorite’ and ‘least favorite’ aspect of camp totaled 442 and 134, while Spanish speaking parents’ responses totaled 70 and 11. Overall, when examining the responses of the four questions as a whole, Spanish speaking parents mainly discussed how their experience at Camp Sol benefited their personal grief journey as evidenced when Spanish speaking parents’ described how camp provided them with social support and information on the grief process, as well as how camp helped increase their communication regarding the deceased child. However, when compared to English speaking parents, Spanish speaking parents’ rarely discussed how the camp experience benefitted their interaction with family and surviving children. See Appendix G (English responses) and Appendix H (Spanish responses) for a detailed outline of core themes and subthemes.

### **Quantitative Results**

The following section will discuss the quantitative results of the current study. First, the results of the Likert scale questions will be reviewed for parents, starting with questions regarding social support and understanding of the grief process. Secondly, the results of the Likert scale questions for siblings, which ask questions regarding communication, will be reviewed.

#### **Bereaved parents**

Because the parent self-reported questionnaire was an unvalidated measure, a principal component analysis (PCA) was conducted to determine if the measure was unidimensional or multidimensional. The PCA results revealed a two-component solution; therefore, 2 indices were created, which included a Support Index and an Understanding Index. Descriptive statistics revealed a parent (N=324) mean score of 5.33 (SD = .685) on the Support Index and a parent (N=323) mean score of 5.05 (SD = .769) on the Understanding Index.

An independent-samples t-test was used to determine if there were differences in scores in the Support Index and the Understanding index between English (N=209) and Spanish (N=112) speaking parents. There were no outliers in the data, as assessed by inspection of a boxplot. Support Index scores and Understanding Index scores were not normally distributed, as assessed by Shapiro-Wilk's test ( $p < .05$ ). There was homogeneity of variances, as assessed by Levene's test for equality of variances ( $p = .110$  and  $p = .142$ ). The results indicated that the Spanish speaking parents' scores on the Support Index were higher ( $M = 5.38$ ,  $SD = .713$ ) than the English speaking parents' scores ( $5.32 \pm .605$ ), but not significantly ( $p > .05$ ). English speaking parents' scores on the Understanding Index were higher ( $5.06 \pm .740$ ) than Spanish speaking parents' score ( $5.04 \pm .817$ ); however, not significantly ( $p > .05$ ).

A one-way multivariate analysis of variance (MANOVA) was completed to determine the difference between family role (mother, father, unspecified parent (mother or father role not identified) scores on the Support Index and the Understanding Index. There were no multivariate outliers, as assessed by boxplot and Mahalanobis distance ( $p > .001$ ), respectively. There was no multicollinearity, as assessed by Pearson correlation ( $r = .326$ ,  $p > .01$ ). Support Index scores and Understanding Index scores for family role were not normally distributed, as assessed by Shapiro-Wilk's test ( $p < .05$ ). There was homogeneity of variance-covariance matrices, as assessed by Box's M test ( $p = .357$ ). Regarding the Support Index, there were 107 mothers, 88 fathers, and 126 unspecified parents. Mothers scored the highest on the Support Index ( $5.37 \pm .626$ ), followed by fathers ( $5.36 \pm .706$ ) then unspecified parents ( $5.29 \pm .690$ ). Regarding the Understanding Index, there were 107 mothers, 89 fathers, and 126 parents. Unspecified parents scored the highest on the Understanding Index ( $5.13 \pm .724$ ), followed by mothers ( $5.12 \pm .719$ ) then fathers ( $4.86 \pm .852$ ). The differences between the family roles on the combined dependent

variables was statistically significant,  $F(4, 634) = 1.675, p = .039$ ; Wilks'  $\Lambda = .969$ ; partial  $\eta^2 = .016$ . Follow-up univariate ANOVAs showed that Understanding Index scores ( $F(2, 318) = 3.76, p < .05$ ; partial  $\eta^2 = .520$ ) were statistically significantly different between the family roles. Tukey post-hoc tests showed that for Understanding Index scores only, fathers had statistically significantly lower mean scores than unspecified parents ( $p < .05$ ).

### **Bereaved siblings**

Because the child self-reported questionnaire was an unvalidated measure, a principal component analysis (PCA) was conducted to determine if the measure was unidimensional or multidimensional. The PCA results revealed a one-component solution; therefore, all 4 questions were examined as a whole, indicating questionnaire cohesiveness regarding communication. Descriptive statistics revealed a sibling ( $N=303$ ) mean score of 3.58 ( $SD = .776$ ) on the questions as a whole.

A one-way analysis of variance (ANOVA) was completed to determine if there were differences between age group (2 to 7, 8 to 11, and 12 years and older) scores on the questionnaire. There were no outliers, as assessed by boxplot. There was homogeneity of variances, as assessed by Levene's test of homogeneity of variances ( $p = .388$ ); but the data was not normally distributed for each group, as assessed by Shapiro-Wilk test ( $p < .05$ ). The responses consisted of 85 siblings ages 2 to 7, 100 siblings ages 8 to 11, and 107 siblings 12 years and older. The difference between age groups on the combined independent variables was statistically significant,  $F(2, 289) = 5.427, p = .005$ . Tukey post hoc tests showed that siblings' ages 8 to 11 (.336, 95% CI [.088, .584],  $p = .005$ ) and 12 and older (.257, 95% CI [.012, .503],  $p = .038$ ) had significantly higher mean scores than siblings' ages 2 to 7 (-.336, 95% CI [-.583, -.088],  $p = .005$ /- .257, 95% CI [-.503, -.012],  $p = .038$ ).

The results of both the parent and sibling quantitative data allows the current study to evaluate if Camp Sol meets its stated objectives from the mission statement (Aim 1). As evidenced by the results, hypothesis 2 is partially supported. Camp Sol appeared to meet the stated objectives from their mission statement as evidenced by quantitative results in the areas of support and knowledge of the grief process. Although the results did not support the content area of family interaction, the content area of communication was identified as being potentially affected by attending camp.

## CHAPTER FIVE

### Discussion

After the death of a child, thousands of parents and surviving siblings are left grieving the loss of their loved one. Each parent and surviving sibling's grief journey is unique. Most parent grief interventions examine changes in complicated grief symptoms or psychopathology and lack research about the social functioning of bereaved parents (Murphy et al., 1998; Murray et al., 2000; Wagner et al., 2006; Videka-Sherman & Lieberman, 1985); however, the majority of parents are not experiencing high levels of distress (McCarthy et al., 2010; van der Houwen et al., 2010; Bonanno & Kaltman, 2001; Lichtenthal et al., 2010; Piper et al., 2001; Aoun et al., 2015). In contrast to parent grief interventions, child and family grief interventions, as well as bereavement camps, examine more aspects of social functioning and are primarily geared towards helping the bereaved children and not specifically designed to encompass the family as a whole. Although a previous study of a bereavement camp (McClatchey & Wimmer, 2013) examined what aspects of camp were perceived by children and their parents as helpful, the camp was specifically for bereaved children and only offered an optional parent retreat (no interaction between children and parents while at camp). Therefore, the literature regarding bereavement camps specifically designed to target grief reactions of bereaved families (*parent* and *sibling*) is absent. The goal of this study was to establish areas reported by parents and sibling campers as being impacted by their experience at Camp Sol. The areas established will then serve as a guide to identify standardized measures that could be implemented in the future evaluation process, thus providing researchers the ability to quantitatively evaluate the efficacy of family bereavement camp for bereaved parents and siblings. Although some previous studies used qualitative data to examine the impact of bereavement camps (Creed et al., 2001; Farber &



Sabatino, 2007; Nabors et al., 2004), these studies neglected to interview or provide evaluations for the children themselves. In contrast to the previous studies, this study contributed to the literature on interventions for bereaved families following the death of a child by examining a bereavement camp experience from both the parent and sibling subjective view. Unlike other studies of bereavement camps, the current study also consisted of a large sample size ( $N = 659$ ) and examined differences in the Likert scale ratings among mothers and fathers, English and Spanish speaking participants, and ages of surviving siblings.

In general, the results reflect Camp Sol's mission ("About Us," 2016): to provide a supportive environment to share experiences with families experiencing the loss of a child/sibling, to learn about the grief process, and to participate in fun, nurturing therapeutic activities, both individually and as a family. Five and a half years of qualitative and quantitative data revealed various aspects being impacted by the camp experience. The following seven core themes will be discussed within the framework of the Camp Sol mission:

1. Social support with the following subthemes: parent social support, child social support, and family social support.
2. Communication with the following subthemes: ease of communication regarding the deceased child/sibling, emotional expression, and increase in open communication.
3. Continuing bonds as a coping skill with the following subthemes: honoring/remember the deceased and discussion of the deceased.
4. Increased knowledge of the grief process with the following subthemes: developmental stages and grief process in surviving children, parent grief process, family grief process, and individual differences in the grief process.

5. Adjustment with the following subthemes: moving forward, improvements in mood and negative aspects, and acceptance.
6. Family interaction with the following subthemes: family time, emotional bond, refuse/retreat for family, prioritization, and spousal interaction
7. Camp environment with the following subthemes: amenities and structure.

Camp Sol's mission to provide a supportive environment to share experiences with other bereaved families was supported by participants' endorsements of various types of social support. Peer/emotional support was achieved through meeting and interacting with other bereaved families, which is consistent with previous literature reporting that grief interventions have provided a safe environment in which experiences can be shared with other bereaved parents (Schwab, 1996; Nair et al., 2006; Feigelman et al., 2008; Umphrey & Cacciatore, 2011; Murphy, 1996; Darbyshire et al., 2012; Murphy et al., 1998), children/siblings (Roberts & McFerran, 2013; Lohens & Kalter, 1994; Swank, 2013; Creed et al., 2001; Bachman, 2013; Schachter, 2007; Farber & Sabatino, 2007; Stokes et al., 1997; Potts et al., 1999; McClatchey et al., 2009) and families (Hopemeyer & Werk, 1994). Appraisal support (i.e. information that bereaved parents may receive and use for self-evaluation purposes) was also found within the shared experiences with other bereaved families at Camp Sol, including feelings of universality and realizations that they are "not alone" in their grief. These findings are consistent with previous reports indicating that grief interventions offered participants the opportunity to use other individuals' experiences of loss as a way to self-assess their own grief journey (Feigelman et al., 2008; Umphrey & Cacciatore, 2011) and learn the importance of not being alone (Hopemeyer & Werk, 1994). Instrumental support (i.e. tangible aid and services directed to help individuals in need) was evident as parents described how their experience at camp helped them

become more comfortable seeking or asking for additional support from peers or professionals, which has been cited in the literature as a positive coping strategy (Schwab, 1990; Wheeler, 2001; Arnold et al., 2005; Thompson et al., 2011). A specific aspect of instrumental support, child care services offered at camp, provided the opportunity for personal grief exploration and processing. In addition to receiving support, a small percentage of parents and siblings reported being able to or wanting to provide peer/emotional support to other bereaved individuals as a result of attending camp, which is consistent with previous literature that indicates interventions have helped families (Hopemeyer & Werk, 1994) and bereaved siblings (Potts et al., 1999; Bachman, 2013; McClatchey et al., 2009) learn how to support other bereaved individuals in their grief.

The supportive environment in which to share experiences appeared to facilitate changes in communication and the use of continuing bonds as a coping skill. First, participants described how Camp Sol increased their comfort and confidence in including the deceased in topics of conversation with friends and family, and this was more salient for older siblings as compared to the youngest siblings. These findings are consistent with previous literature that indicates bereavement camps have helped bereaved children (Creed et al., 2001; Potts et al., 1999; Bachman, 2013; Swank, 2013; Schachter, 2007; Farber & Sabatino, 2007; Stokes et al., 1997) communicate more about the deceased; however, the findings are not consistent with some research on parent grief interventions that indicates mothers and fathers spoke significantly less about the loss of their child with others (Murray et al., 2000). Although the decrease in how frequently parents discuss their deceased child with others may be construed as unfavorable, it may be due to improvements in the adjustment of a parent's grief journey, resulting in less need to talk to others about issues regarding the death. This finding is in contrast to the findings of the

current study that indicate parents are communicating more about the loss of their child; however, due to lack of clarification on specific topics being discussed (positive *versus* negative aspects), it is difficult to identify why the results are in contrast to one another. Second, participants noted improved abilities to openly and appropriately express grief related feelings with friends and family, which is consistent with previous literature that indicates interventions have helped bereaved parents (Schwab, 1996; Nair et al., 2006; Feigelman et al., 2008; Umphrey & Cacciatore, 2011; Murphy, 1996) and siblings (Bachman, 2013; Swank, 2013; Potts et al., 1999; Stokes et al., 1997; Creed et al., 2001; Schachter, 2007; Kalantari et al., 2012; Slyter, 2012; Sandler et al., 2003; Sandler et al., 2013; Roberts & McFerran, 2013) learn how to better express grief emotions.

Involvement in a variety of continuing bonds activities (e.g. quilt squares, remembrance service, scrapbooking, memory box, family flag, small groups, etc.) allowed them to create new memories while discussing and honoring the deceased child/sibling. These findings are consistent with research that indicates that bereavement camps have helped bereaved children establish continuing bonds by promoting increased communication about their deceased sibling (Stokes et al., 1997; Nabors et al., 2004), as well as literature that indicates interventions have helped bereaved parents (Darbyshire et al., 2012; Feigelman et al., 2008; Umphrey & Cacciatore, 2011) and siblings (Bachman, 2013; Swank, 2013; Creed et al., 2001; Schachter, 2007; Farber & Sabatino, 2007; Stokes et al., 1997) establish meaning and memory that facilitated changes in different aspects of communication. In conclusion, the importance of including the deceased child in topics of conversation, as well as being able to express grief emotions, has been linked to reductions in bereaved individuals' stress, anger, and guilt (Walter, 1996), as well as improvements in feelings of isolation, sadness, and anxiety among newly bereaved parents

(Arnold et al., 2005; Walter, 1996; Riley et al., 2007). Furthermore, the ability for parents and surviving children to communicate grief related emotions appears to be important for maintaining a positive parent-child relationship (Creed et al., 2001; Potts et al., 1999; Bachman, 2013; Swank, 2013; Prchal & Landolt, 2009; Farber & Sabatino, 2007; Sandler et al., 2003; Sandler et al., 2010; Black & Urbanowicz, 1987; Stokes et al., 1997; Schachter, 2007), alleviating negative behaviors among bereaved children (Spuij et al., 2012; Prchal & Landolt, 2009; Farber & Sabatino, 2007; Black & Urbanowicz, 1987), and promoting a more dynamic family (Currier et al., 2008; Kissane et al., 2006; Sandler et al., 2003; Sandler et al., 2010; Creed et al., 2001; Potts et al., 1999; Bachman, 2013; Swank, 2013).

The camp experience also appeared to meet the mission of helping families learn about the grief process and progress in their grief journey. Consistent with other interventions (Schwab, 1996; Nair et al., 2006; Feigelman et al., 2008; Umphrey & Cacciatore, 2011; Murphy, 1996; Lohens & Kalter, 1994; Prchal & Landolt, 2009; Bachman, 2013; Creed et al., 2001; Swank, 2013; Potts et al., 1999; Farber & Sabatino, 2007; Stokes et al., 1997; Schachter, 2007; Roberts & McFerran, 2013), participants cited a better understanding of their own grief process, the grief process of other individuals, and the developmental grief process of children. However, while some intervention studies provided parents with information about the family and child grief process (Hopemeyer & Werk, 1994; Black & Urbanowicz, 1987; McClatchey et al., 2009), there are no reports as to how the information benefited them or how the information increased their knowledge of the grief process.

The mission of utilizing fun, nurturing therapeutic activities was supported by this study's results and appeared related to several outcomes. The literature suggests that a family's ability to participate in social activities may provide them with a renewed appreciation for

personal relationships (Wheeler, 2001; Arnold & Gemma, 2008; Arnold et al., 2005), which is consistent with participants' endorsement of prioritization of family (i.e. positive parenting and increased attention to surviving children and family morale), faith, and a renewed appreciation of life. Alternately, the finding that participation in various family camp activities promoted family interaction and enhanced the emotional bond is unique to the literature. Parents specifically highlighted the importance of family time away from "normal" life and everyday stressors, using words such as "solace," "retreat," and "sacred place" to describe their experience at Camp Sol, as well as their expectation that participation in family activities at camp will result in a "better family overall." Previous literature indicates that interventions have improved family well-being and overall family dynamic (Currier et al., 2008; Kissane et al., 2006; Sandler et al., 2003; Sandler et al., 2010; Creed et al., 2001; Potts et al., 1999; Bachman, 2013; Swank, 2013), but these interventions have not been delivered in the context of a camp. Additional enhancements of the spousal relationship were described by a small percentage of the sample, which is consistent with previous literature that indicates that interventions have helped parents (Murphy et al., 1998; Murray et al., 2000) improve their dyadic relationship by communication and social interaction.

The sum total of camp experiences, including the supportive environment with shared experiences and grief education, appears to have the potential to promote adjustment and hopefulness. While not measured quantitatively, as a result of attending camp, parents described perceived improvements in their mood (e.g. happiness, relaxation, patience), reductions in negative emotions (e.g. anger, stress, frustration), and increased ability to continue moving forward with their lives as grieving has become easier. Bereaved siblings described how their experience helped them learn how to be more open minded and hopeful of the future. These

findings are consistent with existing literature that indicates that interventions have helped foster the grief adjustment process of parents (Videka-Sherman & Lieberman, 1985), families (Hopemeyer & Werk, 1994), and siblings (Schachter, 2007; Swank, 2013; Farber & Sabatino, 2007).

In addition to examining parents' camp experience as a whole, the current study was able to examine for potential differences between English and Spanish speaking parents grieving the loss of a child. Overall, the results indicate that Spanish speaking parents primarily discussed how the camp experience benefited their personal grief journey. Spanish speaking parents described how camp helped them increase their communication regarding the deceased child and build continuing bonds, as well as provided them with social support and information on the grief process. When compared to English speaking parents, Spanish speaking parents discussed less about how their camp experience helped them interact with family and surviving children. While individual family members of Hispanic and Latin American cultures may often downplay their own needs, the literature indicates that these cultures traditionally place a strong priority on meeting the needs of the family (Huang, 1994; Fuligni, Tseng, & Lam, 1999; Chilman, 1993), and the family is to provide the primary source of emotional and instrumental support following death of a loved one (Halgunseth, Ispa, & Rudy, 2004). Therefore, it would be expected that Spanish-speaking families participating in Camp Sol would discuss more aspects relating to family relationships, including the dyadic relationship and surviving children, but the current study's results revealed that these parents rarely discussed topics regarding family relationships. It is possible that the Spanish-speaking parents already have a strong family dynamic that allows for open communication between family members, therefore making these kinds of interactions less of a focus for *change* following camp. It is also possible that in day-to-day life, Spanish

speaking parents may have been more focused on providing support to their family and surviving children in lieu of focusing on their personal grief journey, which may explain why these parents more frequently discussed changes in their personal grief journey as a result of camp in contrast to family changes as a result of camp.

In summary, many of the findings are consistent with the literature on grief programs and interventions; however, there are unique benefits to structuring an intervention in the form of a family bereavement camp. The results highlight the specific impact of both receiving and providing various types of social support. While this study found that the camp promoted positive emotional expression, no previous research on family grief interventions or bereavement camps mentions parent emotional expression. Also not previously studied has been insight into the mechanism through which continuing bonds activities may further promote emotional expression, communication, and positive feelings. In addition to simple education about the grief process, the study provides information on how Camp Sol helped parents' use their gained knowledge of the grief process to better understand and manage their family and surviving siblings' grief. The qualitative analysis revealed how the camp environment and therapeutically creative approach to intervention, coupled with the retreat-like atmosphere, promoted positive changes in the amount of family time, the family emotional bond, family well-being, and an enhanced appreciation for life. Additional strengths of a family bereavement camp include the potential cost effectiveness and accessibility of a camp format. For instance, a camp provides an intense therapeutic weekend at a cost that may be less expensive than a support group or individual format that conducts weekly sessions at a fixed rate per session. When providing services for Spanish speaking families, a camp format is also able to provide families with



multiple Spanish speaking professionals, while ongoing individual or group intervention formats may only be able to provide one or two Spanish speaking professionals for multiple families.

In addition to the benefits that a family bereavement camp appears to provide, the current study possesses unique strengths. A strength of the current study is the focus on measuring non-pathological constructs (e.g. social support, communication, family relationships), in contrast to many grief intervention studies that focus on psychopathological or mental health outcomes but fail to find significant outcomes. Additional strengths of the current study include the large sample size and multi-rater report (parent and sibling). For instance, while the number of surveys and/or participants in bereavement camp intervention studies ranged from 18 (Nabors et al., 2004) to 195 (Bachman, 2013), the current study was able to collect 656 surveys to analyze. Lastly, another strength is the ability for the current study to explore differences between English and Spanish speaking parents regarding their camp experience, which has not been previously explored in bereavement camp intervention studies.

Although these findings provide useful qualitative information about how camp may be impacting families, there are limitations to the current study. This study only utilized a self-evaluation generated by Camp Sol and failed to provide any quantitative measures of mental health or social functioning (pre- *or* post-intervention). Given the effort and organization that it may take to plan a family weekend away from home, the structure of a camp is likely a barrier for those families who may be experiencing higher levels of distress. However, there is no way of knowing if this speculation is true because the study failed to provide pre-intervention measures of mental health. In addition, failure to utilize a control group to allow discrimination of the participants' outcomes from outcomes caused by other factors, such as a different intervention (family intervention or support group) or even the natural progression/decline of

grief was also a limitation of the current study. Additional limitations of this study include the limited amount of information solicited on siblings' camp evaluations, resulting in limited information regarding how Camp Sol impacted their grief journey. The study is also limited by the issue of shared variance (potentially having multiple reported from the same family).

Specifically, families can repeat camp over the years, but due to the anonymity of the surveys, it was not possible to determine which responses were from repeating families; therefore, it is possible that certain common themes were cited more often by repeating campers.

This study was a first step in identifying areas potentially impacted by a family bereavement camp. In addition to assessing aspects of mental health, future research should include standardized measures of the impact of camp on social functioning, including family functioning, communication, social support, and adjustment. It would also be beneficial to conduct pre and post-intervention assessment of these constructs. Potential measures of family functioning and communication include Parent-Adolescent Communication Scale (PACS), Parent-Child Communication Scale (PCCS), Family Assessment Devise (FAS), Dyadic Adjustment Scale (DAS), Child Behavior Checklist (CBCL), and Family Assessment Measure-III General Scale (FAM III). In addition, suggested measures of adjustment and social support include Ryff Scales of Psychological Well-Being, Brief COPE Inventory, Multidimensional Scale of Perceived Social Support (MSPSS), and Social Support for Children (SSC). Regarding mental health, suggested measures include Depression Anxiety Stress Scale 21 (DASS-21), Revised Child Depression and Anxiety Scale (RCADS), Beck Depression Inventory II (BDI-II), Children's Depression Inventory (CDI), Perceived Stress Scale (PSS), Clinical Anger Scale (CAS), and Guilt and Shame Proneness Scale (GASP). For information such as the total cost and

administration time of all suggested measures, as well as whether a Spanish form exists for a specific measure, see Table 9.

Although all of the suggested measures would be able to measure aspects of mental health and social functioning discussed in the literature and by Camp Sol participants, it is important to take into consideration the cost and appropriateness of specific measures, as well as the potential burden the administration time may place on the families. Therefore, it is suggested that the following instruments be administered specifically for the purpose of measuring the effectiveness of Camp Sol in future research. After examining the core themes generated by parent and sibling responses in the areas of family interaction and communication, measuring aspects of family functioning (i.e. family communication and emotional expression) may help support parent and siblings' endorsements of how camp has or will help families improve in these specific aspects of family functioning. The suggested measures are the PCCS and PACS, which measures communication between parents and surviving siblings. The PCCS would be appropriate for administration for siblings 7 years to 12 years, while the PACS would be administered to siblings 13 to 17 years old. The parents of surviving siblings will also complete the PCCS and/or the PACS depending on the age of their child(ren). In addition, parents discussed topics regarding spousal interaction/communication, which justifies the use of the Dyadic Adjustment Scale (DAS). Regarding social support, the measures that are recommended for administration are the Multidimensional Scale of Perceived Social Support (MSPSS) (parents *only*) and Social Support Scale for Children (SSSC) (siblings *only*). The suggested instruments both measure social support in the areas of friends and family. The suggested measure of adjustment, including topics such as coping skills, spirituality/religion, acceptance, is the Brief COPE Inventory. While this measure is appropriate for family members as young as 10

years old, it is possible for the parents of younger siblings to read aloud the questionnaire. Lastly, although other aspects of mental health have been reviewed (i.e. anger, guilt, etc.), depression and anxiety appear to be the most commonly discussed throughout the literature. Therefore, the suggested measure of depression and anxiety is the DASS-21, which would be administered to parents only. In addition, the RCADS should be used to measure depression and anxiety in surviving siblings. For information such as the total cost and administration time, as well as age appropriateness of the suggested measures, see Table 10.

## References

- Arnold, J., & Gemma, P. B. (2008). The Continuing Process of Parental Grief. *Death Studies*, 32, 658-673. Retrieved April 1, 2015.
- Arnold, J., Gemma, P., & Cushman, L. (2005). Exploring Parental Grief: Combining Quantitative And Qualitative Measures. *Archives of Psychiatric Nursing*, 19(6), 245-255.
- Ayers, T., Wolchik, S., Sandler, I., Twohey, J., Weyer, J., Padgett-Jones, S., . . . Kriege, G. (2013). The Family Bereavement Program: Description of a Theory-Based Prevention Program for Parentally Bereaved Children and Adolescents. *OMEGA--Journal of Death and Dying*, 68(4), 293-314.
- Bachman, B. (2013). The Development of a Sustainable, Community-Supported Children's Bereavement Camp. *OMEGA--Journal of Death and Dying*, 67(1-2), 21-35.
- Barrera, M., Alam, R., D'agostino, N., Nicholas, D., & Schneiderman, G. (2013). Parental Perceptions of Siblings' Grieving After a Childhood Cancer Death: A Longitudinal Study. *Death Studies*, 37, 25-46.
- Barrera, M., D'agostino, N., Schneiderman, G., Tallett, S., Spencer, L., & Jovcevska, V. (2007). Patterns of Parental Bereavement Following the Loss of a Child and Related Factors. *OMEGA: The Journal of Death and Dying*, 55(2), 145-167.
- Bellali, T., & Papadatou, D. (2006). Parental Grief Following the Brain Death of a Child: Does Consent or Refusal to Organ Donation Affect Their Grief? *Death Studies*, 30, 883-917.
- Black, D., & Urbanowicz, M. (1987). Family Intervention With Bereaved Children. *Journal of Child Psychology and Psychiatry*, 28(3), 467-476.
- Braun, M., & Berg, D. (1994). Meaning reconstruction in the experience of parental bereavement. *Death Studies*, 18, 105-129.

- Callahan, A. (2011). The Parent Should Go First: A Dance/Movement Therapy Exploration in Child Loss. *American Journal of Dance Therapy*, 33, 182-195.
- Clements, P.T., Vigil, G.J., Manno, M.S., Henry, G.C, Wilks, J., Das, S., Foster, W. Cultural perspectives of death, grief, and bereavement. *Journal of Psychosocial Nursing and Mental Health Services*. 2003;41(7):18–26.
- Clute, M., & Kobayashi, R. (2013). Are Children's Grief Camps Effective? *Journal of Social Work in End-of-Life & Palliative Care*, 9, 43-57.
- Creed, J., Ruffin, J., & Ward, M. (2001). A Weekend Camp for Bereaved Siblings. *Cancer Practice*, 9(4), 176-182.
- Currier, J., Neimeyer, R., & Berman, J. (2008). The Effectiveness Of Psychotherapeutic Interventions For Bereaved Persons: A Comprehensive Quantitative Review. *Psychological Bulletin*, 134(5), 648-661.
- Currier, J., Holland, J., & Neimeyer, R. (2007). The Effectiveness of Bereavement Interventions With Children: A Meta-Analytic Review of Controlled Outcome Research. *Journal of Clinical Child & Adolescent Psychology*, 36(2), 253-259.
- Darbyshire, P., Cleghorn, A., Downes, M., Elford, J., Gannoni, A., Mccullagh, C., & Shute, R. (2012). Supporting Bereaved Parents: A Phenomenological Study of a Telephone Intervention Programme in a Paediatric Oncology Unit. *Journal of Clinical Nursing*, 22, 540-549.
- Davies, A. (2001). Death of Adolescents: Parental Grief and Coping Strategies. *British Journal of Nursing*, 10(20), 1332-1342.
- Davies, R. (2004). New Understandings Of Parental Grief: Literature Review. *Journal of Advanced Nursing*, 46(5), 506-513.

- De Groot, M., Neeleman, J., Van der Meer, K., & Burger, H. (2010). The Effectiveness Of Family-Based Cognitive-Behavior Grief Therapy To Prevent Complicated Grief In Relatives Of Suicide Victims: The Mediating Role Of Suicide Ideation. *Suicide and Life-Threatening Behavior*, 40(5), 425-437.
- Dowdney, L. (2005). Children Bereaved By Parent Or Sibling Death. *Psychiatry*, 4(9), 118-122.
- Dyregrov, K., & Dyregrov, A. (2005). Siblings After Suicide-“The Forgotten Bereaved”. *Suicide and Life-Threatening Behavior*, 35(6), 714-724.
- Farber, M., & Sabatino, C. (2007). A Therapeutic Summer Weekend Camp For Grieving Children: Supporting Clinical Practice Through Empirical Evaluation. *Child and Adolescent Social Work Journal*, 24, 385-402.
- Farrugia, D. (1996). The Experience of the Family When a Child Dies. *The Family Journal*, 4(1), 30-36.
- Gentry, J., Kennedy, P., Paul, C., & Hill, R. (1995). Family Transitions During Grief: Discontinuities in Household Consumption Patterns. *Journal of Business Research*, 34, 67-79.
- Gibbons, M. (1992). A Child Dies, A Child Survives: The Impact of Sibling Loss. *Journal of Pediatric Health Care*, (6), 65-72.
- Gilmer, M., Foster, T., Vannatta, K., Barrera, M., Davies, B., Dietrich, M., . . . Gerhardt, C. (2012). Changes in Parents After the Death of a Child from Cancer. *Journal of Pain and Symptom Management*, 44(4), 572-582.
- Hardy-Bougere, M. Cultural Manifestations of Grief and Bereavement: A Clinical Perspective. *Journal of Cultural Diversity*. 2008;15: 66–69.

- Harper, M., O'Connor, R., Dickson, A., & O'Carroll, R. (2011). Mothers Continuing Bonds and Ambivalence to Personal Mortality After the Death of Their Child – An Interpretative Phenomenological Analysis. *Psychology, Health & Medicine, 16*(2), 203-214.
- Heiney, S. (1991). Sibling grief: A Case Report. *Archives of Psychiatric Nursing, 5*(3), 121-127.
- Hendrickson, K. (2009). Morbidity, Mortality, and Parental Grief: A Review of the Literature on the Relationship Between the Death of a Child and the Subsequent Health of Parents. *Palliative and Supportive Care, 7*, 109-119.
- Hopmeyer, E., & Werk, A. (1994). A Comparative Study of Family Bereavement Groups. *Death Studies, 18*, 243-256.
- Horsley, H., & Patterson, T. (2006). The Effects of a Parent Guidance Intervention on Communication among Adolescents Who Have Experienced the Sudden Death of a Sibling. *The American Journal of Family Therapy, 34*, 119-137.
- Hung, N., & Rabin, L. (2009). Comprehending Childhood Bereavement By Parental Suicide: A Critical Review Of Research On Outcomes, Grief Processes, And Interventions. *Death Studies, 33*(9), 81-814.
- Hunt, S., & Greeff, A. (2012). Parental Bereavement: A Panoramic View. *OMEGA--Journal of Death and Dying, 64*(1), 41-63.
- Kalantari, M., Yule, W., Dyregrov, A., Neshatdoost, H., & Ahmadi, S. (2012). Efficacy of Writing for Recovery on Traumatic Grief Symptoms of Afghani Refugee Bereaved Adolescents: A Randomized Control Trial. *OMEGA--Journal of Death and Dying, 65*(2), 139-150.



- Kars, M., Grypdonck, M., Beishuizen, A., Meijer-van Den Bergh, E., & Van Delden, J. (2010). Factors influencing parental readiness to let their child with cancer die. *Pediatric Blood & Cancer*, 54, 1000-1008. Retrieved April 1, 2015.
- Kissane, D., McKenzie, M., Bloch, S., Moskowitz, C., McKenzie, D., & O'Neill, I. (2006). Family Focused Grief Therapy: A Randomized, Controlled Trial In Palliative Care And Bereavement. *American Journal of Psychiatry*, 163(7), 1208-1218.
- Lamberti, J., & Detmer, C. (1993). Model of Family Grief Assessment and Treatment. *Death Studies*, 17, 55-67.
- Li, J., Precht, D., Mortensen, P., & Olsen, J. (2003). Mortality in Parents After Death of a Child in Denmark: A Nationwide Follow-up Study. *The Lancet*, 361(9355), 363-367.
- Lichtenthal, W., Neimeyer, R., Currier, J., Roberts, K., & Jordan, N. (2013). Cause of Death and the Quest for Meaning After the Loss of a Child. *Death Studies*, 37, 311-342.
- Lichtenthal, W., Currier, J., Neimeyer, R., & Keesee, N. (2010). Sense and Significance: A Mixed Methods Examination of Meaning Making After the Loss of One's Child. *Journal of Clinical Psychology*, 66(7), 791-812.
- Litz, B., Schorr, Y., Delaney, E., Au, T., Papa, A., Fox, A., . . . Prigerson, H. (2014). A Randomized Controlled Trial of an Internet-Based Therapist-Assisted Indicated Preventive Intervention for Prolonged Grief Disorder. *Behaviour Research and Therapy*, 61, 23-34.
- Lohnes, K., & Kalter, N. (1994). Preventive Intervention Groups For Parentally Bereaved Children. *American Journal of Orthopsychiatry*, 64(4), 594-603.

- Mancini, A., Prati, G., & Bonanno, G. (2011). Do Shattered Worldviews Lead to Complicated Grief? Prospective and Longitudinal Analyses. *Journal of Social and Clinical Psychology, 30*(2), 184-215.
- McCarthy, M., Clarke, N., Ting, C., Conroy, R., Anderson, V., & Heath, J. (2010). Prevalence And Predictors Of Parental Grief And Depression After The Death Of A Child From Cancer. *Journal of Palliative Medicine, 13*(11), 1321-1326.
- McClatchey, I., & Wimmer, J. (2012). Healing Components of a Bereavement Camp: Children and Adolescents Give Voice to Their Experiences. *OMEGA--Journal of Death and Dying, 65*(1), 11-32.
- McClatchey, I., Vonk, M., & Palardy, G. (2009). Efficacy Of A Camp-Based Intervention For Childhood Traumatic Grief. *Research on Social Work Practice, 19*(1), 19-30.
- McCown, D., & Davies, B. (1995). Patterns Of Grief In Young Children Following The Death Of A Sibling. *Death Studies, 19*, 41-53.
- Murphy, S. (1996). Parent Bereavement Stress and Preventative Intervention Following the Violent Deaths of Adolescent or Young Adult Children. *Death Studies, 20*, 441-452.
- Murphy, S., Baugher, R., Lohan, J., Scheideman, J., Heerwagen, J., Johnson, L., . . . Grover, M. (1996). Parents' Evaluation of a Preventive Intervention Following the Sudden, Violent Deaths of Their Children. *Death Studies, 20*, 453-468.
- Murphy, S., Johnson, C., Cain, K., Gupta, A., Dimond, M., Lohan, J., & Baugher, R. (1998). Broad-Spectrum Group Treatment For Parents Bereaved By The Violent Deaths Of Their 12-To 28-Year-Old Children: A Randomized Controlled Trial. *Death Studies, 22*, 209-235.

- Murray, J., Terry, D., Vance, J., Battistutta, D., & Connolly, Y. (2000). Effects Of A Program Of Intervention On Parental Distress Following Infant Death. *Death Studies*, 24, 275-305.
- Nabors, L., Ohms, M., Buchanan, N., Kirsh, K., Nash, T., Passik, S., . . . Brown, G. (2004). A Pilot Study of the Impact of a Grief Camp for Children. *Palliative & Supportive Care*, 2, 403-408.
- Nair, K., Goodenough, B., & Cohn, R. (2006). Telephone Support Groups for Isolated Bereaved Parents: A Review of the Literature and an Example from Australian Pediatric Oncology. *Illness, Crisis, & Loss*, 14(4), 319-336.
- Neimeyer, R., & Currier, J. (2009). Grief Therapy: Evidence of Efficacy and Emerging Directions. *Current Directions in Psychological Science*, 18(6), 352-356.
- Nolfi, M. (1967). Families in Grief: The Question of Casework Intervention. *Social Work*, 12(4), 40-46.
- Pfeffer, C., Jiang, H., Kakuma, T., Hwang, J., & Metsch, M. (2002). Group Intervention For Children Bereaved By The Suicide Of A Relative. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(5), 505-513.
- Potts, S., Farrell, M., & O'Toole, J. (1999). Treasure Weekend: Supporting Bereaved Siblings. *Palliative Medicine*, 13, 51-56.
- Prchal, A., & Landolt, M. (2009). Psychological Interventions with Siblings of Pediatric Cancer Patients: A Systemic Review. *Psycho-Oncology*, 18, 1241-1251.
- Price, J., Jordan, J., Prior, L., & Parkes, J. (2011). Living Through the Death of a Child: A Qualitative Study of Bereaved Parents' Experiences. *International Journal of Nursing Studies*, 48, 1384-1392.

- Rando, T. (1985). Bereaved Parents: Particular Difficulties, Unique Factors, and Treatment Issues. *Social Work, 30*(1), 19-23.
- Riley, L., LaMontagne, L., Hepworth, J., & Murphy, B. (2007). Parental Grief Responses and Personal Growth Following the Death of a Child. *Death Studies, 31*, 277-299.
- Roberts, M., & McFerran, K. (2013). A Mixed Methods Analysis of Songs Written by Bereaved Preadolescents in Individual Music Therapy. *Journal of Music Therapy, 50*(1), 25-52.
- Rosen, H., & Cohen, H. (1981). Children's reactions to sibling loss. *Clinical Social Work Journal, 9*(3), 211-219.
- Rosner, R., Kruse, J., & Hagl, M. (2010). A Meta-Analysis of Interventions for Bereaved Children and Adolescents. *Death Studies, 34*, 99-136.
- Sandler, I., Ayers, T., Wolchik, S., Tein, J., Kwok, O., Haine, R., . . . Griffin, W. (2003). The Family Bereavement Program: Efficacy Evaluation Of A Theory-based Prevention Program For Parentally Bereaved Children And Adolescents. *Journal of Consulting and Clinical Psychology, 71*(3), 587-600.
- Sandler, I., Ma, Y., Tein, J., Ayers, T., Wolchik, S., Kennedy, C., & Millsap, R. (2010). Long-term effects of the family bereavement program on multiple indicators of grief in parentally bereaved children and adolescents. *Journal of Consulting and Clinical Psychology, 78*(2), 131-143.
- Schachter, S. (2007). Bereavement summer camp for children and teens: A reflection of nine years. *Palliative and Supportive Care, 5*, 315-323.
- Schwab, R. (1996). Gender Differences In Parental Grief. *Death Studies, 20*, 103-113.
- Schwab, R. (1997). Parental Mourning and Children's Behavior. *Journal of Counseling & Development, 75*, 258-265.

- Schwab, R. (1990). Paternal and maternal coping with the death of a child. *Death Studies*, 14, 407-422.
- Slyter, M. (2012). Creative Counseling Interventions for Grieving Adolescents. *Journal of Creativity in Mental Health*, 7, 17-34.
- Spuij, M., Prinzie, P., Dekovic, M., Van den Bout, J., & Boelen, P. (2013). The effectiveness of Grief-Help, a cognitive behavioural treatment for prolonged grief in children: Study protocol for a randomised controlled trial. *Trials*, 14, 395-412.
- Spuij, M., Van Londen-Huiberts, A., & Boelen, P. (2013). Cognitive-Behavioral Therapy for Prolonged Grief in Children: Feasibility and Multiple Baseline Study. *Cognitive and Behavioral Practice*, 20, 349-361.
- Stokes, J., Wyer, S., & Crossley, D. (1997). The Challenge of Evaluating a Child Bereavement Programme. *Palliative Medicine*, 11, 179-190.
- Swank, J. (2013). Obstacles of Grief: The Experiences of Children Processing Grief on the Ropes Course. *Journal of Creativity in Mental Health*, 8, 235-248.
- Thompson, A., Miller, K., Barrera, M., Davies, B., Foster, T., Gilmer, M., . . . Gerhardt, C. (2011). A Qualitative Study of Advice From Bereaved Parents and Siblings. *Journal of Social Work in End-of-Life & Palliative Care*, 7, 153-172.
- Umphrey, L., & Cacciatore, J. (2011). Coping with the Ultimate Deprivation: Narrative Themes in a Parental Bereavement Support Group. *OMEGA--Journal of Death and Dying*, 63(2), 141-160.
- Van der Houwen, K., Schut, H., Van den Bout, J., Stroebe, M., & Stroebe, W. (2010). The Efficacy of a Brief Internet-Based Self-Help Intervention for the Bereaved. *Behaviour Research and Therapy*, 48, 359-367.

- Videka-Sherman, L., & Lieberman, M. (1985). The Effects of Self-Help and Psychotherapy Intervention of Child Loss: The Limits of Recovery. *American Journal of Orthopsychiatry*, 55(1), 70-82.
- Wagner, B., Knaevelsrud, C., & Maercker, A. (2006). Internet-Based Cognitive-Behavioral Therapy For Complicated Grief: A Randomized Controlled Trial. *Death Studies*, 30, 429-453.
- Wagner, B., & Maercker, A. (2007). A 1.5-year Follow-up Of An Internet-based Intervention For Complicated Grief. *Journal of Traumatic Stress*, 20(4), 625-629.
- Wender, E. (2012). Supporting the Family After the Death of a Child. *Pediatrics*, 130(6), 1164-1169.
- Wheeler, I. (2001). Parental Bereavement: The Crisis Of Meaning. *Death Studies*, 25, 51-66.
- Zambelli, G., & DeRosa, A. (1992). Bereavement Support Groups For School-age Children: Theory, Intervention, And Case Example. *American Journal of Orthopsychiatry*, 62(4), 484-493.

**Table 1**

*Comparison Between the First Two Phases of Parental Grief and Symptoms of Complicated Grief*

Phase of Parental Grief (Miles, 1985)	Characteristics of Phases	Overlap with Symptoms of Complicated Grief (Shear et al., 2013)
Immediate Reaction Phase	<ul style="list-style-type: none"> <li>• Shock</li> <li>• Numbness</li> <li>• Disbelief</li> <li>• Reduced cognitive understanding</li> <li>• Sense of unreality</li> </ul>	<ul style="list-style-type: none"> <li>• Intense sorrow and emotional pain</li> <li>• Experiencing disbelief or emotional numbness</li> <li>• Preoccupation with circumstances of the death</li> <li>• Marked difficulty accepting the death</li> </ul>
Intense Grief Phase	<ul style="list-style-type: none"> <li>• Emptiness</li> <li>• Loneliness</li> <li>• Isolation</li> <li>• Anger</li> <li>• Guilt</li> </ul>	<ul style="list-style-type: none"> <li>• Intense sorrow and emotional pain</li> <li>• Feeling alone or detached from other individuals</li> <li>• Feelings that life is empty without the deceased</li> <li>• Diminished sense of one's identity</li> <li>• Reluctance to pursue interests</li> <li>• Bitterness or anger</li> <li>• Maladaptive appraisals (self-blame)</li> </ul>

**Table 2***Unique Grief Reactions of Each Cognitive Developmental Stage*

Cognitive Stage of Development (Piaget, 1963)	Unique Grief Reactions
Sensorimotor Stage (approx. 0 to 2 years old)	<ul style="list-style-type: none"> <li>• Lack knowledge of the concept of death</li> <li>• Start forming attachments with family members</li> <li>• Following a loss: <ul style="list-style-type: none"> <li>◦ Children may be able to sense change in bonds and family environment, potentially resulting in feelings of threats of separation, abandonment, or rejection, which may cause separation anxiety (Jackson, 1982; Trouy &amp; Ward-Larson, 1987; Gibbons, 1986; Gibbons, 1992; Black, 1998)</li> </ul> </li> </ul>
Preoperational Stage (approx. 2 to 7 years old)	<ul style="list-style-type: none"> <li>• Lack understanding of the finality of death</li> <li>• May view death as a temporary or reversible concept <ul style="list-style-type: none"> <li>◦ May experience feelings of increased longing for and preoccupation with the deceased's return (Barrera et al., 2013; Schwab, 1997; Gibbons, 1992; Leon, 1986; Cain, Fast, &amp; Erickson, 1963; Cain, Erickson, Fast, &amp; Vaughan, 1964)</li> </ul> </li> <li>• May develop unrealistic fantasies regarding the deceased's return</li> <li>• May develop own interpretations of how the deceased died (Gibbons, 1992; Wender, 2012; Schwab, 1997; Barrera et al., 2013; Dowdney, 2005; Cain et al., 1964)</li> </ul>
Concrete Operational Stage (approx. 7 to 11 years old)	<ul style="list-style-type: none"> <li>• Begin to develop awareness of finality of death, but continue to struggle with specifics of death <ul style="list-style-type: none"> <li>◦ May consider death to be caused by concrete elements originating outside of the body rather than inside the body (e.g. illness) (Cox, 2005)</li> </ul> </li> <li>• More likely to engage in continuing bonds (Heiney, 1991; Dowdney, 2005; Gibbons, 1992)</li> </ul>
Formal Operational Stage (approx. 11 years and older)	<ul style="list-style-type: none"> <li>• Able to concretely understand the finality and universality of death</li> <li>• In circumstances where parents are intensely grieving or grieving to the point where they no longer can manage specific responsibilities, the children in this stage are more likely than children in other stages to take on parental roles (Wender, 2012)</li> </ul>



**Table 3***Common Manifestations of Grief Across Different Developmental Stages*

Common manifestation	Preoperational and concrete operational Stage	Concrete and formal operational Stage	Formal operational stage	All stages (except sensorimotor stage)
Impact of communication on avoidance	Parents may believe siblings aren't affected due to age and developmental (Gibbons, 1992; Schwab, 1997), resulting in failure to discuss the death	May avoid communication about the death in an attempt to protect parents from further distress (Gibbons, 1992; Dowdney, 2005; Barrera et al., 2013; Heiney, 1991)		
Impact of communication on placing personal blame				Lack of communication between parents and surviving children may lead to feelings of guilt and personal blame (Gibbons, 1992), long-lasting grief, maladaptive coping skills, internalization of problems (Gibbons, 1992; Dowdney, 2005; Barrera et al., 2013; Heiney, 1991), and anxiety (Lyles, 2004)
Acting out of negative behaviors	Tantrums, crying, disobeying rules, hitting, slapping, and/or slamming doors (Barrera et al., 2013; McCown & Davies, 2001; Heiney, 1991; Lyles, 2004; Dowdney, 2005)	School problems (Gibbons, 1992; Barrera et al., 2013; Lyles, 2004)	Risky behaviors (e.g. understand drinking, use of drugs, skipping school, tattoos/piercings) (Gibbons, 1992; Barrera et al., 2013; Lyles, 2004; McCown & Davies, 2001; Dowdney, 2005)	

**Table 4***Demographics and Characteristics of Parent Intervention Studies*

Author(s)	Study Details	Modality	Measures	Results for Mental Health	Results for Social Functioning
Videka-Sherman & Lieberman (1985)	Longitudinal N = 667 No Control	Self-Help & Psychotherapy	Survey at post-intervention and follow-up	<ul style="list-style-type: none"> <li>• <i>Non-significant</i> Improvements in depression, anxiety, physical health, self-esteem, psychotropic medication use, masterful orientation</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Non significant</i> increase in parent's attitude toward devastation of losing a child life satisfaction</li> </ul>
Murphy et al. (1996, 1998)	Longitudinal N = 261 Control	Self-Help & Psychoeducation	BSI, TES, PBS, GES, HHB, DAS at pre/post-intervention and 6M follow-up	<ul style="list-style-type: none"> <li>• Significant improvements in physical health, posttraumatic stress symptoms, mental distress (high risk mothers)</li> <li>• <i>Non significant</i> improvements in posttraumatic stress symptoms ('high' risk fathers)</li> </ul>	<ul style="list-style-type: none"> <li>• Significant improvements in avoidance coping, seeking support, marital cohesion (high risk fathers)</li> <li>• <i>Non significant</i> improvements overtime in marital satisfaction (high risk parents)</li> <li>• <i>Non significant</i> increase in taking direct action, support seeking, adaptive behaviors</li> </ul>

**Table 4 (cont.)***Demographics and Characteristics of Parent Intervention Studies*

Author(s)	Study Details	Modality	Measures	Results for Mental Health	Results for Social Functioning
Wagner et al., (2006) / Wagner & Maercker (2007)	Longitudinal 1 N = 55 Control	Internet-Based CBT & Therapeutic Writing	IES, BSI, SF-12, Failure to Adapt Scale at pre/post intervention, and 3M and 18M follow-up	<ul style="list-style-type: none"> <li>• Significant improvements in intrusion, avoidance, failure to adapt</li> <li>• <i>Non-significant</i> improvements in depression, anxiety, physical health</li> </ul>	
Murray et al., (2000)	Longitudinal 1 N = 144 Control	Self-Help & Psychoeducation	DSSI/sAD, HDLFM, DAS at pre intervention, and 6M and 15M post-loss	<ul style="list-style-type: none"> <li>• Significant improvements in anxiety ('high-risk' fathers) and depressive symptoms ('high-risk' mothers)</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Non significant</i> improvements in dyadic relationship (low and high risk mothers)</li> <li>• <i>Non significant</i> reduction in avoidance coping, cognitive coping, support seeking</li> </ul>

**Table 4 (cont.)***Demographics and Characteristics of Parent Intervention Studies*

Author(s)	Study Details	Modality	Measures	Results for Mental Health	Results for Social Functioning
Darbyshire et al., (2012)	Longitudinal N = 6 No Control	Telephone Support Group	Interview at post intervention and 12M follow up		<i>(Qualitative Data)</i> <ul style="list-style-type: none"> <li>• Helped establish offered meaning and memory around the death of their child</li> <li>• Satisfied with the accessibility and cost effectiveness of the intervention.</li> </ul>
Schwab (1996)	Cross-Sectional N = 43 No Control	Self-Help	Interview at post intervention		<i>Qualitative Data)</i> <ul style="list-style-type: none"> <li>• Qualified group leaders and good group structure</li> <li>• Provided safe environment to share feelings and experiences with other bereaved parents</li> <li>• Provided information regarding parental grief and the death process</li> </ul>

**Table 4 (cont.)***Demographics and Characteristics of Parent Intervention Studies*

Author(s)	Study Details	Modality	Measures	Results for Mental Health	Results for Social Functioning
Nair et al., (2006)	Longitudinal 1 N = 10 No Control	Telephone Support Group	Interview at 6M follow-up		<p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Qualified group leaders and good group structure</li> <li>• Provided safe environment to share feelings and experiences with other bereaved parents</li> <li>• Provided information regarding parental grief and the death process</li> <li>• Satisfied with the accessibility and cost effectiveness of the intervention</li> </ul>

**Table 5***Demographics and Characteristics of Child Intervention Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results for Mental Health	Results for Social Functioning
Pfeffer et al. (2002)	Longitudinal N=39 Psychoeducation Control	Various	BDI, CPTSRI, CDI, RCMAS, SAICA at pre and post intervention	<ul style="list-style-type: none"> <li>• Significant reductions in anxiety and depression</li> <li>• No improvement in PTSS</li> </ul>	
Currier et al. (2007)	Meta-Analysis N=13 Psychoeducation Control	Various	Unspecified	<ul style="list-style-type: none"> <li>• <i>Non significant</i> small to moderate improvements in grief symptoms</li> </ul>	
Spuij et al. (2012)	Longitudinal N=5 CBT No Control	Various	Grief Checklist, IPG-C, CPSS, CDI, CBCL at pre and post intervention	<ul style="list-style-type: none"> <li>• Significant reductions in anxiety, depression, prolonged grief, and posttraumatic grief</li> </ul>	<ul style="list-style-type: none"> <li>• Significant improvements in internalizing and externalizing behaviors, and child's social and behavioral functioning</li> </ul>
Kalantari et al. (2012)	Longitudinal N=61 Creative Therapy Control Group	Parent	TGIC at pre and post intervention	<ul style="list-style-type: none"> <li>• Significant reductions in childhood traumatic grief symptoms</li> </ul>	

**Table 5 (cont.)***Demographics and Characteristics of Child Intervention Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results for Mental Health	Results for Social Functioning
Rosner et al. (2010)	Systemic Review N=15 (w/ controls) N=12 (w/o controls)	Various	Various	<ul style="list-style-type: none"> <li>• <i>Non significant</i> small to moderate improvements in grief symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Non significant</i> small to moderate increase in social adjustment</li> </ul>
Roberts & McFerran (2013)	Cross-Sectional N=14 Creative Therapy No Control	Sibling	Self evaluation at post intervention		<p>(Qualitative Data)</p> <ul style="list-style-type: none"> <li>• Aided in the outward expression of specific emotions</li> <li>• Provided an age appropriate way to discover feelings</li> <li>• Helped establish continuing bonds &amp; coping strategies</li> <li>• Provided safe environment to talk to other bereaved siblings</li> <li>• Helped process &amp; understand grief-related issues</li> <li>• Music helped connect feelings associated with the lyrics to personal feelings regarding death</li> </ul>

**Table 5 (cont.)***Demographics and Characteristics of Child Intervention Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results for Mental Health	Results for Social Functioning
Prchal & Landolt, (2009)	Systemic Review N=14 Various Interventions	Sibling	Various	<ul style="list-style-type: none"> <li>• Significant improvements in depression and/or negative mood states, health-related quality of life, and knowledge about death by cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Small number of reviewed studies found small, significant improvement</li> <li>• <i>Non significant</i> small increase in self-esteem (all)</li> </ul>
Lohnes & Kalter (1994)	Cross-Sectional N=49 Process Group No Control	Parent	Interview at post intervention		<p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Helped establish continuing bonds &amp; coping strategies</li> <li>• Provided safe environment to talk to other bereaved siblings</li> <li>• Helped process &amp; understand grief-related issues</li> </ul>



**Table 5 (cont.)***Demographics and Characteristics of Child Intervention Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results for Mental Health	Results for Social Functioning
Slyter (2012)	Descriptive N= Not Reported Creative Therapy No Control	Parent	Interview at post intervention		<i>(Qualitative Data)</i> <ul style="list-style-type: none"> <li>• Aided in the outward expression of specific emotions</li> <li>• Provided an age appropriate way to discover feelings</li> <li>• Music helped connect feelings associated with the lyrics to personal feelings regarding death</li> </ul>

**Table 6***Demographics and Characteristics of Family Intervention Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results for Mental Health	Results for Social Functioning
Black & Urbanowicz (1987)	Longitudinal N=45 In-home Counseling Control	Parent	Interview at pre intervention, and 12M and 24M follow up	<ul style="list-style-type: none"> <li>• <i>Non significant</i> Improvements (ns) in physical health (parents only) and emotional/psychological state</li> <li>• No improvements on scores of physical health when compared to the control group (younger children)</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Non significant</i> small improvements in communication regarding the deceased sibling</li> <li>• <i>Non significant</i> improvements in children's behavior, school performance, ease of communication with surviving parent</li> <li>• <i>Non significant</i> decrease in behavioral and emotional problems for children who reportedly cried more</li> </ul>
Groot et al., 2010	Longitudinal N=122 CBT Control	Various	EPQ, Pearlin Scale, RSES, ITG, CES-D, PSI, SCAN 2.1, TRGR2L at 2.5M and 13M pre-loss	<ul style="list-style-type: none"> <li>• <i>Non significant</i> improvements in complicated and maladaptive grief, suicide risk for "suicide ideators"</li> </ul>	

**Table 6 (cont.)***Demographics and Characteristics of Family Intervention Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results for Mental Health	Results for Social Functioning
Sandler et al. (2003)	Longitudinal N=156 In-home counseling Control	Parent	CRPBI, C-CDRS, SPES, SFS, CEEQ, ODS, CCSC-R, CDI, R-CMAS at pre and post intervention and 11M follow up	<ul style="list-style-type: none"> <li>• Small significant reduction in distress</li> <li>• <i>Non significant</i> improvements in intrusive negative thoughts about stressful events (children)</li> </ul>	<ul style="list-style-type: none"> <li>• Significant improvements in positive parenting, parent's communication about feelings, parent's adaptive control beliefs, coping skills (parents and young girls, externalizing behaviors (parents and children), internalizing behaviors (young girls), and parent-child relationships</li> <li>• <i>Non significant</i> Improvements in internalizing behaviors (young boys), feelings of social detachment and insecurity, and children's self-esteem</li> </ul>
Kissane et al., (2006)	Longitudinal N=86 Family Focused Grief Therapy Control	Various	BSI, BDI, SAS at pre intervention, and 6M and 13M follow up	<ul style="list-style-type: none"> <li>• Small significant reduction in distress and depression</li> </ul>	

**Table 6 (cont.)***Demographics and Characteristics of Family Intervention Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results for Mental Health	Results for Social Functioning
Horsley & Patterson (2006)	Longitudinal N=5 Parent Guided Intervention No Control	Sibling	PACI at pre and post intervention		<i>Non significant</i> improvements in communication regarding the deceased sibling, sharing stories and memories about the deceased, children's self-esteem
Hopmeyer & Werk (1994)	Comparative N=3 Self-help Groups No Control	Various	SSPQ (time point not reported)		<p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Well-led, ideal for specific situation, helpful, and provided knowledge on the grief process</li> <li>• Helped families learn the importance of not being alone, sharing experiences of personal grief, supporting other bereaved individuals in their grief, increasing one's hope, strength, and developing coping strategies</li> <li>• Mothers reported dissatisfaction with negative and abrasive individuals in the group</li> </ul>

**Table 7***Demographics and Characteristics of Selected Bereavement Camp Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results
Stokes et al. (1997)	Longitudinal N = 65 6 to 14 years No Control	Parent Sibling	CBQ and interview at pre intervention and 12M follow up	<p>(Qualitative Data)</p> <ul style="list-style-type: none"> <li>• Allowed children to make lasting friendships with other children</li> <li>• Helped children feel a sense of normalcy and express importance of meeting other bereaved children</li> <li>• Children began to understand their feelings more, share feelings with others and communicate more about the deceased</li> <li>• Children's gained knowledge of the grief process</li> </ul>
Nabors et al. (2004)	Longitudinal N = 18 12 to 18 years No Control	Parent Grandparent	Survey at pre and post intervention and 6M follow up	<p>(Mental Health)</p> <ul style="list-style-type: none"> <li>• Failed to report changes in children's sadness and anxiety</li> <li>• Some parents indicated a continuation of grief related symptoms and intense sadness</li> </ul> <p>(Qualitative Data) Helped increase communication about the deceased</p>
Potts et al. (1999)	Cross-Sectional N = 24 5 to 16 years No Control	Sibling	Interview at post intervention	<p>(Qualitative Data)</p> <ul style="list-style-type: none"> <li>• Interaction with other bereaved siblings was greatly beneficial and provided opportunity to help other bereaved children</li> <li>• Allowed children to express feelings in a safe environment and helped increase communication about the deceased</li> <li>• Children's gained knowledge of the grief process</li> </ul>

**Table 7 (cont.)***Demographics and Characteristics of Selected Bereavement Camp Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results
Creed et al. (2001)	Cross-Sectional N = 19 6 to 18 years No Control	Sibling (cancer)	Survey at post intervention	<p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Helped children feel a sense of normalcy, express importance of meeting other bereaved children, and how to ask for support from others</li> <li>• Helped them share feelings and gain an understanding of experienced emotions and increase communication about the deceased</li> <li>• Children's gained knowledge of the grief process</li> </ul>
Bachman (2013)	Cross-Sectional N = 195 7 to 15 years No Control	Parent Sibling Grandparent	Survey at post intervention	<p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Helped them express importance of meeting other bereaved children and feel a sense of normalcy</li> <li>• Provided the opportunity to help other bereaved children and how to ask for support from others</li> <li>• Helped them express, talk, and share about feelings and helped increase communication about the deceased</li> <li>• Children's gained knowledge of the grief process</li> </ul>
Schachter (2007)	Cross-Sectional N = Not Reported 6 to 17 years No Control	Parent Sibling	Survey at post intervention	<p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Bereaved children expressed importance of meeting other bereaved children</li> <li>• Learned new coping skills that may help regulate emotions and gained knowledge of the grief process</li> <li>• Helped them express negative emotions appropriately and increase communication about the deceased</li> </ul>

**Table 7 (cont.)***Demographics and Characteristics of Selected Bereavement Camp Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results
McClatchey et al. (2009)	Longitudinal N = 100 6 to 16 years Control	Parent Sibling	UCLA PTSD Index and EGI at pre and post intervention and follow up	<p><i>(Mental Health)</i></p> <ul style="list-style-type: none"> <li>• Significant decrease in traumatic grief symptoms and significant reductions in the control group's posttraumatic stress symptoms</li> <li>• <i>Non significant</i> reduction in posttraumatic stress symptoms</li> </ul> <p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Allowed children to make lasting friendships with other children and helped children feel a sense of normalcy</li> <li>• Helped facilitate positive interactions between bereaved children and provided the opportunity to help other bereaved children</li> </ul>
Farber & Sabatino (2007)	Longitudinal N <sub>2003</sub> = 49 N <sub>2004</sub> = 46 6 to 15 years No Control	Parent Sibling Grandparent	BRIC, interview, CECTA (time point unknown)	<p><i>(Social Functioning)</i></p> <ul style="list-style-type: none"> <li>• Small significant increases in social and behavioral problems (1<sup>st</sup> year)</li> <li>• Significantly lower degrees of problems regarding social functioning and negative behaviors functioning (2<sup>nd</sup> year)</li> </ul> <p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Helped them express importance of meeting other bereaved children</li> <li>• Learned new coping skills that may help regulate emotions and helped increase communication about the deceased</li> <li>• Children's gained knowledge of the grief process</li> </ul>

**Table 7 (cont.)***Demographics and Characteristics of Selected Bereavement Camp Studies*

Author(s)	Study Details	Relation to Deceased	Measures	Results
Swank (2013)	Cross-Sectional N = 29 6 to 17 years No Control	Parent Sibling Grandparent Extended Family Member	Interview at post intervention	<p><i>(Qualitative Data)</i></p> <ul style="list-style-type: none"> <li>• Helped facilitate positive interactions between bereaved children</li> <li>• Helped children learn how to ask for support from others</li> <li>• Helped them express and talk about their feelings and children reportedly understood their feelings more</li> <li>• Learned new coping skills that may help regulate emotions, helped them express negative emotions appropriately and helped increase communication about the deceased</li> <li>• Children's gained knowledge of the grief process</li> </ul>



**Table 8***Camp Sol Demographics*

Term/Year	Number of Campers	Parents	Children	English Speaking Parents	Spanish Speaking Parents
Spring 2009	63	52.4%	47.6%	65.1%	34.9%
Fall 2009	45	44.4%	55.6%	95.6%	4.4%
Spring 2010	65	49.2%	50.8%	81.5%	18.5%
Fall 2010	54	44.4%	55.6%	87%	13%
Spring 2011	70	50%	50%	80%	20%
Fall 2011	53	45.3%	54.7%	94.3%	5.7%
Spring 2012	66	57.6%	42.4%	69.7%	30.3%
Fall 2012	71	50.7%	42.3%	88.7%	11.3%
Spring 2013	55	49.1%	50.9%	76.4%	23.6%
Fall 2013	58	53.4%	46.6%	94.8%	5.2%
Spring 2014	56	51.8%	48.2%	69.6%	30.4%

**Table 9***Information About Suggested Instruments for Future Research*

Suggested Measure	Cost	Parent / Time to Administer	Child / Time to Administer	Spanish Form	Construct(s) Being Measured
Parent-Adolescent Communication Scale (PACS)	\$30	Yes / 5-10 min.	Yes / 5-10 min.	Yes	• Communication
Parent-Child Communication Scale (PCCS)	\$30	Yes / 5-10 min.	Yes / 5-10 min.	Yes	• Communication
Family Assessment Device (FAS)	Free	Yes / 15-20 min.	Yes / 15-20 min.	Yes	• Family Functioning
Dyadic Adjustment Scale (DAS)	Free	Yes / 5-10 min.		Yes	• Communication
Child Behavior Checklist (CBCL)	\$45	Yes / 25-30 min.	Yes / 30-35 min.	Yes	• Child behaviors
Family Assessment Measure-III-General Scale (FAM III)	\$60 (25/pack)	Yes / 10-15 min.	Yes / 15-20 min.	Yes	• Family communication • Affective expression • Involvement
Ryff Scales of Psychological Well-Being	Free	Yes / 10-15 min.		Yes	• Acceptance • Growth • Purpose of Life • Well-being

**Table 9 (cont.)***Information About Suggested Instruments for Future Research*

Suggested Measure	Cost	Parent / Time to Administer	Child / Time to Administer	Spanish Form	Construct(s) Being Measured
Brief COPE Inventory	Free	Yes / 5-10 min.	Yes / 10-15 min.	Yes	<ul style="list-style-type: none"> <li>• Coping skills</li> <li>• Acceptance</li> </ul>
Multidimensional Scale of Perceived Social Support (MSPSS)	Free	Yes / 5-10 min.		Yes	<ul style="list-style-type: none"> <li>• Social Support</li> </ul>
Social Support for Children (SSC)	Free		Yes / 10-15 min.	Yes	<ul style="list-style-type: none"> <li>• Social Support</li> </ul>
Depression Anxiety Stress Scale 21 (DASS-21)	Free	Yes / 5-10 min.		Yes	<ul style="list-style-type: none"> <li>• Depression</li> <li>• Anxiety</li> <li>• Stress</li> </ul>
Revised Child Depression and Anxiety Scale (RCADS)	Free		Yes / 15-20 min.	Yes	<ul style="list-style-type: none"> <li>• Depression</li> <li>• Anxiety</li> </ul>
Beck Depression Inventory II (BDI-II)	\$58 (25/pack)	Yes / 5 min.		Yes	<ul style="list-style-type: none"> <li>• Depression</li> </ul>
Children's Depression Inventory (CDI)	\$55 (25/pack)		Yes / 5-10 min	Yes	<ul style="list-style-type: none"> <li>• Depression</li> </ul>
Perceived Stress Scale (PSS)	Free	Yes / 5 min.		Yes	<ul style="list-style-type: none"> <li>• Stress</li> </ul>

**Table 9 (cont.)***Information About Suggested Instruments for Future Research*

Suggested Measure	Cost	Parent / Time to Administer	Child / Time to Administer	Spanish Form	Construct(s) Being Measured
Clinical Anger Scale (CAS)	Free	Yes / 5-10 min.		Yes	• Anger
Guilt and Shame Proneness Scale (GASP)	Free	Yes / 5-10 min.		Yes	• Guilt • Shame
Total:	Estimated \$218	Estimated 110-160 min	Estimated 110-155 min		

**Table 10***Suggested Measures for Future Research*

Suggested Instrument	Cost	Parent / Time to Administer	Child / Time to Administer	Age Range	Construct (s) being measured
Parent-Adolescent Communication Scale (PACS)	\$30	Yes / 5-10 min.	Yes / 5-10 min.	13 yrs & older	• Communication
Parent-Child Communication Scale (PCCS)	\$30	Yes / 5-10 min.	Yes / 5-10 min.	7 yrs & older	• Communication
Dyadic Adjustment Scale (DAS)	Free	Yes / 5-10 min.		17 yrs & older	• Spousal Communication
Multidimensional Scale of Perceived Social Support (MSPSS)	Free	Yes / 5-10 min.		13 yrs & older	• Social Support
Social Support for Children (SSC)	Free		Yes / 10-15 min.	8 yrs & older	• Social Support
Brief COPE Inventory	Free	Yes / 5-10 min.	Yes / 10-15 min.	10 yrs & older	• Coping Skills • Acceptance
Depression, Anxiety, and Stress Scale 21 (DASS-21)	Free	Yes / 5-10 min.		14 yrs & older	• Depression • Anxiety • Stress
Revised Child Depression and Anxiety Scale (RCADS)	Free		Yes / 5-10 min.	10 yrs & older	• Depression • Anxiety
Total:	\$60	Estimated 30-60 min.	Estimated 35-60 min.		

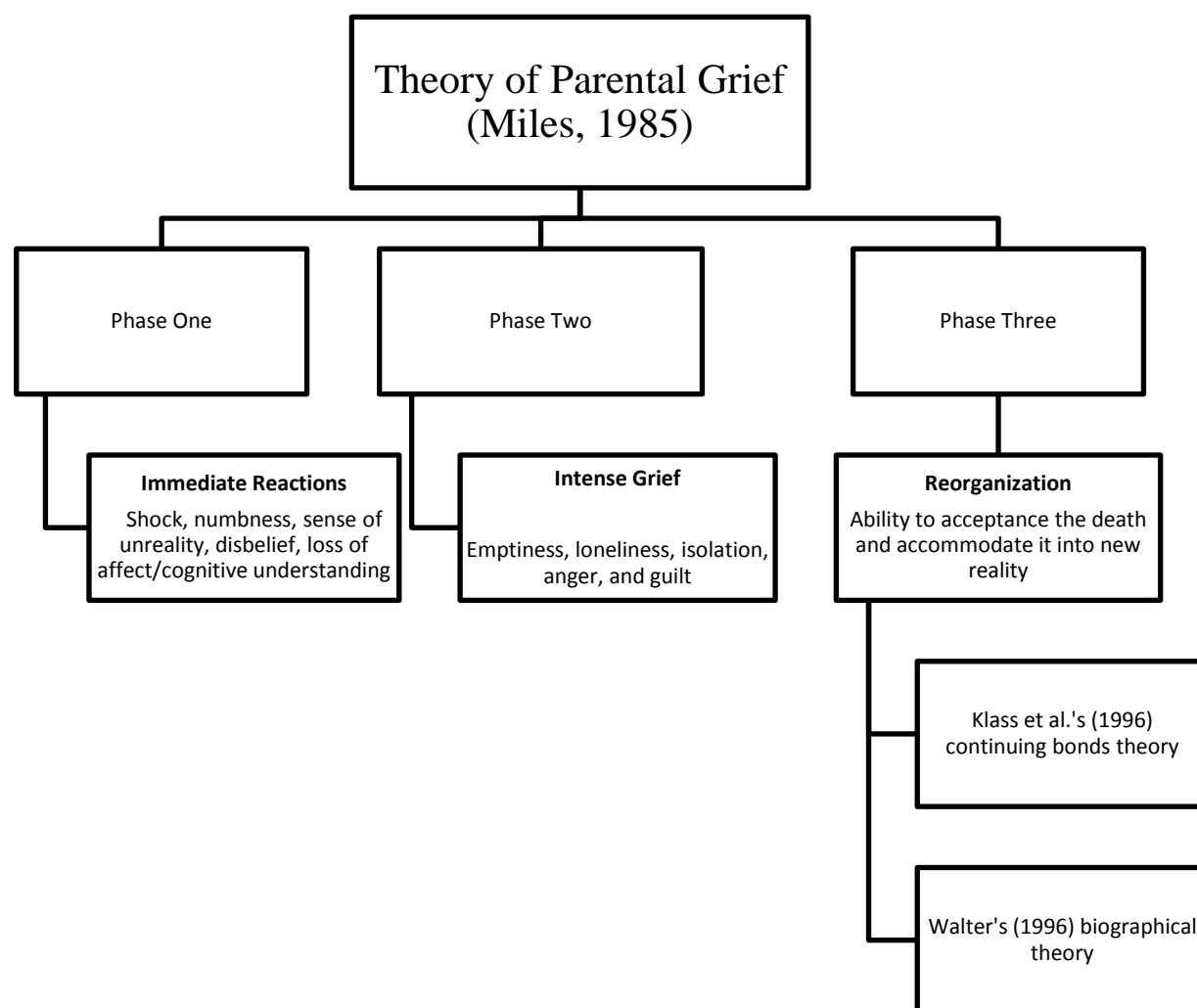


Figure 1.

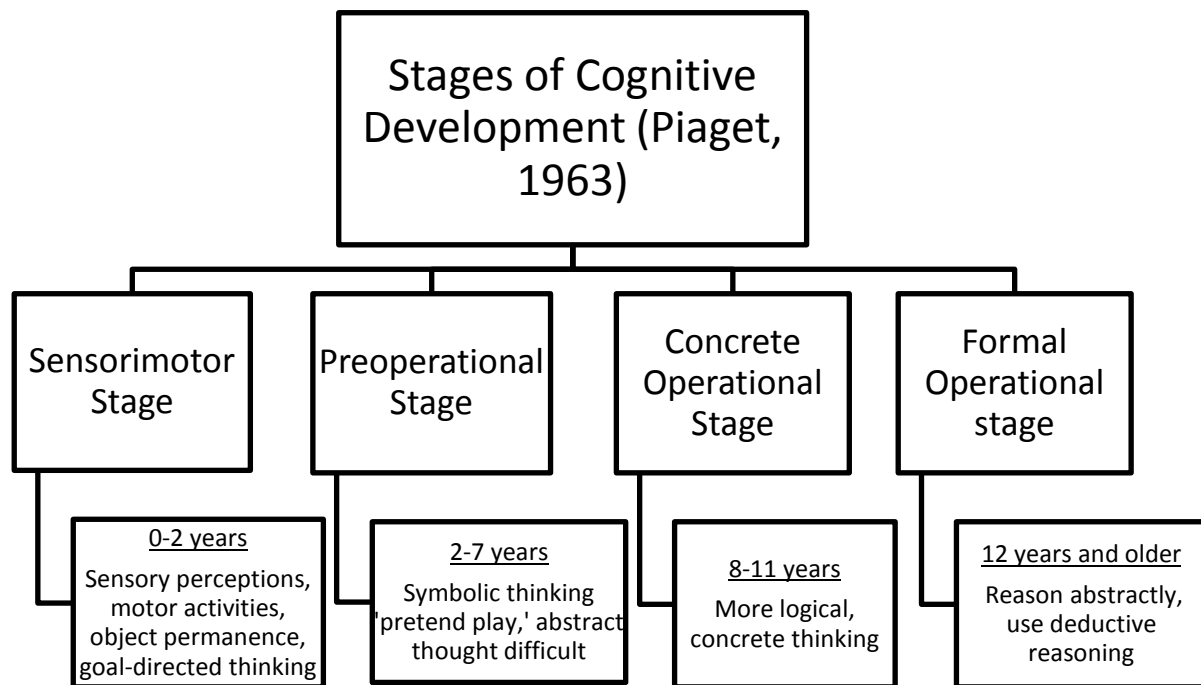


Figure 2.

## Appendix A

*Example of Parent Evaluation Form***CAMP SOL 2015  
Parent Evaluation**

NAME (Optional): \_\_\_\_\_

**Thank you very much for attending Camp Sol's Family Retreat Weekend. Please take a few minutes to give us your thoughts and feedback. Your input helps us to continue to improve our programs to best meet you and your family's supportive needs.**

- 1. How well do you feel that you understand the grief process?  
 Not very well                      Well                      Extremely Well  
 1       2                      3       4                      5       6
- 1. 2. After attending the family retreat weekend, how comfortable are you communicating about the death with your family?  
 Not Comfortable              Comfortable              Extremely Comfortable  
 1       2                      3       4                      5       6
- 1. 3. How well do you feel the weekend gave you an opportunity to network with other grieving parents?  
 Not very well                      Well                      Extremely Well  
 1       2                      3       4                      5       6
- 1. 4. How well do you feel that the adult processing groups were in meeting your support needs?  
 Not very well                      Well                      Extremely Well  
 1       2                      3       4                      5       6
- 5. Circle the number that best describes how much you liked that particular activity, 1 being didn't like to 3 being liked okay to 5 being liked a lot.

Activity						Comments
Cooking	1	2	3	4	5	N/A
Family Introduction activity	1	2	3	4	5	N/A
Campfire	1	2	3	4	5	N/A
Quilt Squares	1	2	3	4	5	N/A
Family fishing	1	2	3	4	5	N/A
Family barn games	1	2	3	4	5	N/A
Family ropes course	1	2	3	4	5	N/A
Family carnival	1	2	3	4	5	N/A
Parent Dinner	1	2	3	4	5	N/A
Morning parent group (Sat.)	1	2	3	4	5	N/A



Moms Art Activity	1	2	3	4	5	N/A
-------------------	---	---	---	---	---	-----

<b>Activity</b>						<b>Comments</b>
Dads Activity	1	2	3	4	5	N/A
Large parent meeting (Sun.)	1	2	3	4	5	N/A
“Ask a Facilitator”	1	2	3	4	5	N/A
Remembrance Service	1	2	3	4	5	N/A
Meals	1	2	3	4	5	N/A
Cabins	1	2	3	4	5	N/A
Camp Sol Staff	1	2	3	4	5	N/A
Camp John Marc Staff	1	2	3	4	5	N/A
Other:_____	1	2	3	4	5	N/A

**6. Assuming that you would like to come back to Camp Sol,**

a. a. What would you like to try next year that you didn't try this year at camp?

a. b. What would you rather not do again next year that you did this year at camp?

**7. Has your family been to Camp Sol previously?\_\_\_\_\_**

**If so, how many years has your family attended?\_\_\_\_\_**

a. Are there any activities that you enjoyed in the past that we have discontinued?

b. b. Are there activities that we continue to do that you feel are no longer effective because of the repetitiveness?

**8. What was your:**

**\* favorite aspect of camp? (or if you had several aspects you liked, please describe)**

**\* least favorite aspect of camp? (or if you had several aspects you didn't like, please describe)**

**9. Describe any differences you feel as a result of coming to camp this year?**

(i.e. "it will be easier for me to express my feelings and to talk about my child openly with my family," "it will be easier for me to allow my children to talk about their brother or sister who died," "I have a better understanding about family mourning.")

**10. Since coming to camp, what do you think could happen differently in your family once your family gets home?**

(i.e. "we may spend more time together," "we may feel closer as a family," "we may be more accepting of each other's individual grief and mourning needs.")

**11. a. Would it be acceptable to publish your comments on our website or in print? (please check appropriate answer)**

\_\_\_\_\_ Yes  
\_\_\_\_\_ No

**b. If you answered yes, would you prefer to be quoted:**

\_\_\_\_\_ Anonymously  
\_\_\_\_\_ First Name Only  
\_\_\_\_\_ Full Name  
\_\_\_\_\_ No Preference

## Appendix B

*Example of Child Evaluation Form***Children's Evaluation-Camp 2015****Age** \_\_\_\_\_

1. After having come to camp this weekend, do you feel it is easier to talk about your brother or sister who died?

1-*I don't know*      2-*No*      3-*Some*      4-*Yes*      5-*A lot*

2. Did it help to be around other kids who have also had a brother or sister that has died?

1-*I don't know*      2-*No*      3-*Some*      4-*Yes*      5-*A lot*

3. Would you tell other kids who have had a brother or sister that has died to come to a camp like this one?

1-*I don't know*      2-*No*      3-*Some*      4-*Yes*      5-*A lot*

4. After having come to camp this weekend do you think it will be easier to talk to your mom or dad about your brother or sister who died?

1-*I don't know*      2-*No*      3-*Some*      4-*Yes*      5-*A lot*

**Did you like the following activities?****Camp Fire**

1-*I don't know*      2-*No*      3-*Some*      4-*Yes*      5-*A lot*      6-*Did not do*

**Time together with just your family**

1-*I don't know*      2-*No*      3-*Some*      4-*Yes*      5-*A lot*      6-*Did not do*

**Music Therapy**

1-*I don't know*      2-*No*      3-*Some*      4-*Yes*      5-*A lot*      6-*Did not do*

**Puzzle Pieces (Family Activity)**

*1-I don't know                      2-No                      3-Some                      4-Yes                      5-A lot                      6-Did not do*

**Craft Activity (Forest of Fears/Path of Peace projects)**

*1-I don't know                      2-No                      3-Some                      4-Yes                      5-A lot                      6-Did not do*

**Carnival on Saturday Night**

*1-I don't know                      2-No                      3-Some                      4-Yes                      5-A lot                      6-Did not do*

**Remembrance Service on Sunday Morning**

*1-I don't know                      2-No                      3-Some                      4-Yes                      5-A lot                      6-Did not do*

**What did you learn at camp?**

**What was your favorite part of camp?**

**What did you like least?**

**Is there anything that you would like different for next year? If so, please describe:**

## Appendix C

*Parents' Qualitative Raw Data for Differences as a Result of Coming to Camp*

## I. Social support

## a. Parent social support

## i. Receiving peer/emotional support

1. F10-ECS12D: [grieve as a family] with others who understand where we are at (2)
2. UN5-ECS11P:
  - a. Good to spend another year with friends who have similar experiences (1)
  - b. Good to spend another year with newcomers who have similar experiences (2)
3. UN17-ECS10P: feeling the support from other parents who have been through this process (2)
4. F11-ECF13D:
  - a. I feel better when talking to other parents about my loss (1)
  - b. Because I feel like this is something I cannot easily do outside (2)
5. F16-ECF12M: Got to talk to another mom about guilt over the relief I felt after my son's death (2)
6. UN3-SCF09P:
  - a. I like to come and share my grief with other families (1)
  - b. And I feel better. (2)
7. F10-SCS09M: ever year, we meet new families (1)
8. F19-SCS12D: it is very nice to share our experience with other families (1)
9. F4-SCS13D: I liked meeting more people with similar problems that one has (1)
10. F11-ECF11M: feel more connected with the families this year (1)
11. F12-ECF10: Felt more connected with other families (1)
12. UN14-ECS10P: new friends (1)
13. F8-SCS14D: it helps me to talk with the other families in camp so (1)
14. F4-ECS12M: I was able to connect with some of these families through social media (1)
15. UN9-ECS11P:
  - a. It has been very beneficial to get to know the other families better (1)
  - b. It allows us to communicate more deeply because we know each other better (2)
16. UN6-SCS13P: talking with other families help me (1)
17. F1-ECF13D: nice to meet other parents/fathers (1)
18. UN6-ECS12P: great feeling to be around others [1]

19. F1-ECF13M: I feel my family made friends who will be supportive for years to come (1)
  20. UN11-ECS09P:
    - a. connect with other families outside of camp (2)
    - b. and others in similar situations (3)
  21. F2-ECF13M: I know that is it a safe place among friends to talk about their feelings and bond with each other
  22. F9-ECF13M: and get to meet and understand people with the same feelings we have (2).
  23. F18-SCS11M: [I am better to express my feelings] with the families that have experience the same pain (2)
  24. F9-ECF10: I love being able to grieve with others who understand (1)
- ii. Appraisal support
1. F5-ECF09D: It's so unfortunate, but I realize that we are not alone in our story [2]
  2. F15-ECS09D: I realized that we are not alone in our loss (1)
  3. F4-ECS12D: I feel like we are not alone (1)
  4. F4-ECS12D: That there are more families that I thought that share the same feelings [2]
  5. F11-ECF09D: It's good to know each year that we are not alone (1)
  6. UN16-ECS10P: It was a good reminder of how our family is not the only one dealing with the loss of a child (1)
  7. F8-ECS11M: others are experiencing the same things (2)
  8. F4-ECS12D:
    - a. I feel like we are not alone (1)
    - b. ...that there are more families that share the same feelings (2)
  9. F5-SCS12M: [I feel a little bit better] because I know other families that have experiences the same pain I have (2)
  10. UN13-ECS09P:
    - a. Being at camp helps to remind me that we are doing okay (2)
    - b. and that we are normal (3)
  11. UN9-SCS12P: There are other families that have gone through the same as me (2)
  12. UN14-SCS09P:
    - a. I feel that I'm not the only one with this grief (1)
    - b. And there are those who understand me (2)
  13. UN9-SCS12P: ...knowing that I'm not alone (1)
  14. UN3-ECS09P: don't feel as alone in my grief (1)
  15. F3-ECF10D: not as alone as I thought (1)
  16. F2-ECF10D: It also help you to have hope when you see other couples that have made it through their tragedy (4)
  17. F10-ECF09D:

- a. Helpful to hear from families in similar situations (1)
  - b. I will feel more comfort in knowing that (2)
- 18. UN7-ECF11P: I felt more comfortable this year because I know/or knew of each families' story (1)
- 19. F8-ECS11M: It is easier for me when I learn from other families that we are not crazy (1)
- iii. Providing peer/emotional support
  - 1. F11-ECF09D: we love helping other families too (2)
  - 2. F12-ECF10: Enjoyed being a host family (2)
  - 3. F16-ECF10: it is good to mentor new families through their grief (1)
  - 4. UN1-ECF10P: it feels great to be able to help other families (1)
  - 5. F11-ECF11M: I'd like to be a host family next year (3)
  - 6. F12-ECF11P: I feel like I can be there to help new families (1)
  - 7. F15-ECF12D: I look forward to coming in the future to help other families (2)
  - 8. F20-SCS11P: I now feel that I am able to help other families (2)
  - 9. F1-ECS12M: meeting with a new family that I could offer some guidance to (1)
  - 10. F2-ECS09D: [it's our 3<sup>rd</sup> year and it is much easier to explain our personal grief process] to help others (2)
  - 11. F4-ECS12M: [I was able to] give and offer support that we all may not have in our lives as much as we would like (2)
  - 12. F4-ECF10M: I felt more of a desire to comfort other new families (3)
  - 13. F3-ECF13D: a shift from having a focus solely on my own honor child and more onto the other families (1)
  - 14. F1-ECF12D: more empathy (2)
- iv. Instrumental support
  - 1. UN17-ECS10P: feeling the support from staff (1)
  - 2. F8-SCS09M: I liked the understanding towards us and other families (1)
  - 3. F9-ECF10: [I love that my son was able to talk to the facilitators since he won't talk to me) ...and hearing that he is doing okay from them [facilitators] (2)
  - 4. UN11-ECS09P: ...things from facilitators to follow up with kids (1)
  - 5. F10-ECF13M: even though we have been coming a long time. I still hear new ideas, suggestions and view points (1)
- b. Child social support
  - i. Receiving Peer/emotional support
    - 1. UN4-ECF13P: Nice for them to meet other kids with the same experience (2)
    - 2. F4-ECS12D: It also gave me insight into the fact that our boys (3 1/2) will have chances to make friends and grow up with kids that share the same loss (3)

3. F15-ECS09M: It really helps my daughter to find friends her age that have experienced what she is going through (1)
4. F12-ECF09D: my son relates very well with kids with similar situations (1)
5. UN5-ECS09P: give them this time to share their loss (2)
6. F2-ECF11M:
  - a. Camp sol helps my children to be around others like them (3)
  - b. There is a precious almost strange connection they make with these children. They just understand. (4)
7. F2-ECF13M: I knew and continue to know that my children needed to be around other children that were experiencing the same feelings as them (2)
8. F10-ECF13D:
  - a. Adrienne started by not jumping into the mix of things (1)
  - b. But by Saturday morning, she couldn't help herself. (2)
  - c. I'm not complaining at all; this is why I love her so much (3)
9. F3-ECS13M: with our son almost being a teenager, I hope this was a small part of reminding him that we have his back no matter what happens and that we are always here for him (1)
10. F9-ECS11M: We continue to need support for our daughter to make sure that she is continuing to process everything ok (1)
11. UN8-ECS09P: I'm glad all had an opportunity for our children to share their experience with another caring person other than us (1)
12. F9-ECF10: I love that my son was able to talk to the facilitators since he won't talk to me
13. F8-ECF10D: good for them to understand that their grief is important to me (2)
- ii. Appraisal support
  1. UN3-ECS14P: my kids feel like their not alone in the process (1)
  2. UN5-ECF11P: love that my kids know they are not alone in experiencing the death of a sibling (1)

## II. Communication

- a. Ease of communication pertaining to the deceased child
  - i. with others in general
    1. F8-SCS13P: it's easier to talk about my daughter (1)
    2. UN37-SCF12P: I am able to better talk about my children that died (1)
    3. F13-SCF09D:
      - a. Every time we come, I find it easier to talk with other families of the camp regarding the death of our children (1)
      - b. And also with other people outside of camp (2)
    4. UN4-ECF10: it will be easier for me to talk about my deceased children (1)
    5. F11-ECF12M: it is easier for me to discuss the loss of my child (1)



6. UN11-ECS10P: it was a little easier this year to talk about things (1)
7. F9-SCS12M: each year that passes is much easier to talk (1)
8. UN13-ECS09P:
  - a. I think more we come the easier it gets for all of us to share our loss with others (1)
  - b. And to talk to others about their loss (2)
9. F6-SCS09D: easier for me to share my experience with new families (2)
10. F14-SCS12D: it will be easier talking with my family about my deceased son (1)
11. F14-SCS12M: it's easier for me to talk about my child (2)
12. F13-SCS12M: I feel much better talking about my daughter with my family (1)
13. F11-ECS12M: the experience made it easier to discuss the death with others who understand (1)
14. UN7-SCS12P: we were able to talk about our daughter without the moment being too difficult (1)
15. UN11-SCS14P: easier to talk about my daughter (1)
16. F14-SCS11M: I feel better to talk about my children (1)
17. F4-ECF10M: I felt more comfortable and wanting to talk about my experience (2)
18. UN9-ECS09P: I feel more comfortable talking to others about our experiences (1)
19. F4-ECS10D: easier for me to talk with other parents (1)
20. F9-SCS12M: also, I am able to talk more easily and communicate with other parents (2)
21. F14-SCS13D: That I feel more comfortable talking about my child here (1)
22. UN4-SCS13P: for me, now I talk about death with other people and tell them that this is something we have to prepare for (1)
23. UN7-ECS11P: although still hard, it got a little easier to talk about my child (1)
24. F15-SCF13M: It's easier for the family to know that it's not important how much time has passed since the death, we are able to talk to freely (1)
25. UN15-SCS09P: I will be more open in talking with more people about my babies (1)
26. UN4-ECS12P: more openness as a family about our loss (1)
27. F2-ECF09M: ...and talk more freely about baby [my son] (2)
28. F13-ECF12P: talk about my daughter more openly (1)
29. F15-SCS11P: we feel more open to talk about the loss of our baby (1)
30. F10-ECS13M: Talking openly about the death of my daughter (1)
31. F10-SCS09M: and yes, I can speak more about the death of my daughter (2)

32. F1-ECF12D: Learning to be more comfortable with others (1)
  - ii. With surviving children
    1. F8-ECF11D: it will be easier for me to talk to the kids (1)
    2. F8-SCF12D: it's easier to discuss the subject of the deceased with my [surviving] child (1)
    3. UN10-ECF12P: I think this weekend will help us and her to talk about it better (2) [the loss of sibling]
    4. F13-ECF13M: it will be easier for my husband and I to talk about our child with our surviving daughter (2)
    5. F12-SCS14D: it will be easier to talk with my child about his brother who died (1)
    6. F8-SCS12D: it's easier for me to talk with my children (1)
    7. F6-ECF13D:
      - a. I'm excited about a connection point for my daughter (1)
      - b. Something in common with her (2)
      - c. I think it could provide a focus or direction for our conversations (3)
    8. UN6-ECS11P: Learned it is easier for my child to talk without being face to face (2)
    9. F10-ECS11D: more confidence between parents and children (1)
    10. UN7-ECF13P: better understanding of how to talk to my son (1)
    11. F9-ECF11M:
      - a. I have a better understanding about how to speak with my children (1)
      - b. And I understand if they don't feel like speaking about the deceased, just to leave them alone (2)
  - iii. With Spouse
    1. F13-ECF13M: It will be easier for my husband and I to talk about our child with each other (1)
- b. Emotional expression
  - i. Parents
    1. UN8-ECF12P: comfortable sharing feelings (1)
    2. UN8-SCF13P: it's easier to share what I feel about my child (1)
    3. F16-SCS11D: it will be easier for me to express my feelings (1)
    4. F18-SCS11M: it is easier and I am better to express my feelings (1)
    5. F2-ECF11M: I'm so thankful that this camp helps me to get that stuff out (2)
    6. UN10-ECS09P: it may be a little easier to express my feelings with the kids (1)
    7. UN13-SCS14P: it is easier to talk about the grief (1)
    8. F7-ECS09M:
      - a. Everyone here is used to and not afraid of tears. [3]
      - b. At home people try so hard to keep me from crying. They watch what they say and do, so afraid of my tears. [4]
    9. F6-SCS09D: easier for me to express my feelings (1)

10. F15-SCS12D: it's easier to express feelings (1)
11. UN6-SCS14P: I feel more confidence in sharing my pain with more people (1)
12. F2-ECS09D: it's our 3<sup>rd</sup> year and it is much easier to explain our personal grief process (1)
13. F14-SCS12M: it is easier for me to express my feelings (1)
14. F4-SCS13M: and talking about my feelings (2)
15. F12-SCS13D: it's easier to express my mourning/grief to my family (1)
16. F9-SCS14M: it will be easier for me to express my feelings (1)
17. F10-SCS14D: it is easier to express my feelings (1)
18. F1-ECF11M: Or I don't feel I have to keep certain feelings at bay (3)
19. UN10-SCS14P: express my feelings more toward my children (1)
20. F11-ECS10G: it is okay to still grieve my child (1)

ii. Surviving Children

1. F1-ECF09M: It will give me an opportunity to talk to my son about grief feelings [1]
2. UN5-ECS09P: it gave my children this weekend to grieve if they haven't (1)
3. F11-ECS12M: Most important camp sol allowed my child to express her feelings of loss of her sister with other her age that along is priceless [2].
4. F2-ECF09M: ...and let him know that it's okay for him to express whatever feelings he has (3)
5. UN10-ECF12P: my youngest (legacy child) has been very expressive about missing their brother (1)
6. F6-ECF12M: a chance for my child to grieve more openly (1)
7. UN7-ECF12P: I feel that it will help my children cope with the loss of their sister (1)
8. F1-ECF10M: and it is safe to talk about and be in their grief at any time. (2)
9. UN10-SCS14P: [children expressing emotions] and in the same way them towards me (2).

iii. Family

1. F10-ECS12D: it allowed us time to grieve as a family (1)
2. F1-ECF11M: I am more open with my husband and kids as a family regarding my feelings at different times (4)
3. F5-ECF13D: having the family open up more about grief (1)
4. UN11-SCS12P: more confidence with my family (1)

c. Open communication

i. With surviving children

1. F2-ECF09M: I'm going to be more open with my oldest son (1)
2. F1-ECF10M: ensuring with my kids that the door is always open (1)
3. F17-ECF12M:

- a. Look forward to hearing more from kids (1)
  - b. an opening for us to ask (2)
- III. Increased knowledge of grieving process
  - a. Developmental stages and grief process in surviving children
    1. F8-ECF11M: I have a better understanding about children's mourning (1)
    2. F2-ECS10D: Better understanding of children's grief process (1)
    3. F2-ECS10M: better understanding of the kid's grief (1)
    4. UN12-SCS14P: I am better able to understand the grieving process in different ages of my daughter (1)
    5. F1-ECF13M: I also understand a bit more of my children's age group level of grieving and understanding (2)
    6. F9-ECS13M:
      - a. I feel better about helping my child (1)
      - b. Understand her feelings better (child) (2)
    7. F5-ECF12M: I have a better understanding how my kids deal with the loss of their sister (1)
    8. F12-ECS09D: I have learned to expect differences in the way my child deals with grief as age groups [1]
    9. F13-ECS11M: understand how my children process as they grow (2)
    10. F6-SCF10M: Understanding that it is healthy that my youngest daughter sometimes is sad even though she was only a year and a half old when her sister died (1)
    11. F1-ECS12D: I think that it will help me understand better my children's grieving process [1]
    12. F10-ECS12M: gained more insight into how children continue to grieve through the years [1]
    13. UN1-ECS12P:
      - a. I hope to remember what my kid is going through (1)
      - b. And to have more patience with her (2)
    14. UN1-ECS09P: camp helps me identify where my children are in their individual grief journeys (1)
    15. UN3-ECS11P: Better understanding on development of children and their grief (2)
    16. F14-ECF13M: I have a better understanding of how to help my son through this devastation (2)
    17. F12-ECF13M: I have a better understanding about kids mourning at a certain age (1)
    18. UN1-ECF09P: More understanding of my child's emotions [1].
    19. F4-ECF10D: understanding phases of children's grieving process
    20. F8-ECF09M: Easier to understand a 7 year old child's way of handling grief [1]
    21. UN2-ECF10P: Also the stages that children go through [2]
    22. UN2-ECF12P:

- a. I had more understanding of behavior issues with my children (1)
  - b. I could recognize the areas of grief (2)
  - c. I can recognize the struggles rather than thinking its just bad behavior instead of it being grief (3)
- 23. UN12-ECS09P: it helps us know where our child is today emotionally and what things they need (1)
- 24. F6-ECF13M: realizing that even though our 5-year-old (and eventually our 2 year old) doesn't talk a lot about the deceased child, she is on her own grief journey (1)
- 25. F10-ECF10:
  - a. I discovered that the young people act differently due to the change of the grief process (1)
  - b. And I can help them more (2)
- 26. UN6-ECF11P: I like the insight into what my kids are feeling (1)
- 27. UN12-ECS10P: I feel like I have better insight on how my child is thinking and feeling (1)
- 28. F13-ECS11M: understand how my children process as they grow (2)
- 29. F5-ECF13M: it is helping my understanding of grieving as my son is growing and developing (1)
- 30. F8-ECF10D: It is good the kids understand that I can also grieving (1)
- 31. UN4-ECF13P: my kids keep getting more comfortable with understanding losing their brother (1).
- 32. F12-ECF11D: hope my children can process better (1)
- 33. F2-ECS13D: that even with our legacy child he is continually processing the loss of his sister that he never met (2)
- 34. F3-ECF10D: I can walk my daughter down this path of grief with more confidence, understanding, love, wisdom, etc. (3)
- b. Parents/spouses
  - 1. F12-SCS14M: and understand each other (2)
  - 2. UN5-SCS13P: I have a better understanding of mourning (1)
  - 3. F12-SCS13M: I have a better understanding of mourning (1)
  - 4. F4-SCS13M: I am better able to understand each stage of grief (1)
  - 5. UN8-SCS12P: it has helped me better understand (1)
  - 6. UN8-SCS12P: it helped me understand more (1)
  - 7. UN1-ECS09P: camp helps me identify where I am individual grief journey (1)
  - 8. F11-SCS14D:
    - a. It has always helped me to understand (1)
    - b. And recognize that it is part of life (2)
  - 9. UN9-SCS12P: this helps me understand the loss of my son (3)
  - 10. F13-ECF10M: I now understand why it can be healing to come for several years [1]
  - 11. F1-ECS13D: I feel that I can understand her better each time (2)

12. F1-ECS09M:
    - a. My fiancé gets a glimpse of my thought process [1]
    - b. During everything through meeting everyone else and talking to others (2)
  13. F1-ECF10M: I have the tools to now work with my husband to ensure that he is moving on and dealing with grief in a healthy way and not suppressing. (4)
  14. F2-ECF13M: I think I had a good grasp of handling/understanding/communicating the grief process as a couple
  15. F5-ECS10M:
    - a. I feel a deeper appreciation for the depth of the grief my husband is keeping inside (1)
    - b. and wish he would express it more to me and my daughter in appropriate ways (2)
  16. F19-ECF12D: I've been impatient this year not understanding how my wife grieves (2)
- c. Family grief process
1. UN10-ECS10P: I have a better understanding about the family mourning (1)
  2. F15-SCS12M: I have a better understanding about family mourning (1)
  3. F11-SCS09P: I have a better understanding of my family's mourning (1)
  4. F7-ECF12M:
    - a. I understand my family mourning better (1)
    - b. We all grieve differently (2)
  5. F5-ECF09D: I have a better understanding about family mourning [1].
  6. F3-ECF09M: Better understanding of our family grief (1)
  7. F7-SCS14D: I have a better understanding about family mourning (1)
  8. F6-ECF13M: and it is a family process, not just me and my husband (2)
  9. F9-SCS14M: I have a better understanding of family mourning (2)
- ii. Inclusion of legacy child
1. F3-ECF13M: A better understanding of how to include a legacy child (2)
  2. UN2-ECS12P: easier to bring our youngest child (born after death of sibling) in to the fold [1]
- d. Individual differences in the grief process
1. F14-ECF13M: I have a better understanding how people all grieve differently (1).
  2. F3-ECF09M: better understanding of how each one of us mourns differently (2)
  3. UN2-ECF10P: understanding how differently people grieve [1]

4. F8-SCF12M: Understanding that we all have ways to feel and express our pain and mourning that we carry and knowing how to understand it (1)
5. F2-ECS13D: camp is a reminder that we are grieving differently (1)
6. F1-ECF10M: There is no right or wrong time to grieve (3)
7. F19-ECF12D: I will have a better attitude towards the grieving process with those around me (1)

#### IV. Adjustment

##### a. Moving forward

1. UN1-ECF10P: I can see where I was before and how far I've come with my grief (2)
2. F1-ECF11M: I truly feel that I am at a different place now regarding my child's death (1).
3. F7-ECF13D: I do feel that after 4 years I am in a better place than I was after 1 year (2)
4. F13-ECS11M: truly being able to grow (1)
5. F5-SCS12M: I feel a little bit better (1)
6. F17-SCS12D: each year it is easier (1)
7. F11-ECS13M: every year seems to get a little easier (1)
8. F3-ECF11P: each year it is getting easier to come (1)
9. F4-ECS14D: better adjusted (2)
10. UN1-ECS14P: it does seem to get easier with time (1)
11. UN13-SCS14P: I am able to comment on my grief without fear (2)
12. F11-ECF09M: grief has gotten easier (1)
13. F15-ECF10: it will be easier to order my son's headstone (1)
14. F12-SCS13D: and be better (3)
15. UN2-ECF11P: Camp seemed easier for me this year compared to past years (1)
16. F3-ECF12M:
  - a. I feel maybe time will help make it easier (1)
  - b. 8 months is not enough (2)
17. F15-ECF12D: I feel like our family is doing well in the grieving process (1)
18. F3-ECF13M: realizing how far we have come as a family (1)
19. F3-ECS11M: It helps our family to know that in several years we will continue to survive (1)
20. F9-SCS09P: it will be easier to continue moving forward (1)
21. UN2-ECF09P: The doctor pointed out several things that will help our family relationships grow in a more positive way [1]
22. F2-ECF10M:
  - a. I am able to see each year perspective on my healing (1).
  - b. I look back to exactly one year before at camp and am able to use that as a marker to see growth, healing, etc.(2)
  - c. Healing is so gradual, so slow sometimes you feel like you are not even moving (4).

- d. But camp reminds me that I am different than the year before! (5)
- 23. F2-ECF10D: It helps me to be mindful of where we have been, where we are and where we are headed in the grief process (3)
- 24. F2-ECF11M: Each year reminds me that there is still healing to be done (1)
- 25. F6-ECF11M: continue to learn how to live and not simply exist
- 26. UN6-ECS09P: easier for me next time
- 27. F3-ECS09M: I feel better this year than last year (1)
- 28. F20-SCS11P: Each time better (1)
- 29. UN5-ECF13P:
  - a. Being further out on this journey (1)
  - b. And being here made it easier knowing what to expect from camp (2)
- 30. F14-ECF12M:
  - a. Just the fact to know that it doesn't get easier (1)
  - b. It's just learning to live with this hurt (2)
- 31. F6-ECF11M: continue our grief work (1)
- 32. F4-ECF09M:
  - a. A little piece of me has been tended to, and a little piece has been healed! (1)
  - b. I hope it is the same for my son! Thank you! (2)
- b. Improved mood and negative feelings
  - 1. F10-ECF12M: I feel more peace in my heart
  - 2. UN14-ECS10P: feel more peace (4)
  - 3. UN13-ECS10P: relaxed (1)
  - 4. F13-ECS09D: I feel kind of relaxed (1) [where as I have experienced a lot of stress lately]
  - 5. UN7-SCS12P: I felt more peaceful (1)
  - 6. F10-ECF13D: we had a really stress free start (2)
  - 7. F5-SCS12D: I feel that you helped us to relieve a little stress that we had (1)
  - 8. F1-ECF11M: I do not feel overwhelmed with grief (2)
  - 9. UN14-ECS10P:
    - a. Leave more comfortable (1)
    - b. More ensure (2)
    - c. Less irritated
  - 10. F5-SCS12D: I feel that you helped us to relieve a little stress that we had (1)
  - 11. F3-ECS09M: it has really help me with my anger (2)
  - 12. UN1-ECS10P: lighter, almost like relief at letting go of a lot of stuff clouding me (1)
- c. Acceptance of death of child
  - 1. F7-SCS13P: it's a little easier to accept the loss of my child (1)
  - 2. F3-ECF09M: we are all more accepting this year (3)
  - 3. UN8-SCS12P: it helped me accept (2)



4. F4-SCS13M: only acceptance (3)
5. F1-ECF12M: simply to accept that this is a lifelong journey (1)

## V. Family interaction

### a. Refuge/retreat for family

1. F5-ECF10: Camp Sol is our solace (1)
2. F13-ECS09D: I think getting out in the woods can be great for you (2)
3. F1-ECF11M: Camp sol has truly made an impact on my life and my kids and now... my husband (5)
4. F4-ECF13M: camp sol is truly a retreat for me and my boys (1)
5. F5-ECF10: Camp Sol is our place to heal every year (2)
6. F5-ECF10: Camp Sol is a sacred place to our family (3)
7. F2-ECF10D: coming to camp sol helps me to personally focus my thoughts on our children both living and in heaven (1)
8. F2-ECF13M: that is how this camp greatly benefited us. Allow us some great time away to focus on our grieving away from the business of life! (4)
9. F4-ECF13M: We feel that we have a place to go that no one else does and that makes us feel special (2)
10. F9-ECF13M: it's a magical place where my family feels very comfortable and loved (1)
11. F1-ECS13M: We just had a loss of our niece- cousin this week so it was nice to come release from that for us and the kids (2)
12. F10-ECF13D: We came as a family this time (1)
13. F3-ECS13D:
  - a. Allow you to take time out to reflect back (1).
  - b. Remember what's important (2)
  - c. And be grateful (3).
14. UN8-ECF11P:
  - a. Camp is a great "reset button" for our whole family (1).
  - b. We come to camp to reflect on the past year (2)
  - c. And plan for the next (3)

### b. Family bond and prioritization

1. F10-ECF11D: I think it always brings us closer together (1)
2. F15-ECF12M: more connected as a family (1)
3. F7-ECS11M: I'll be closer to my family (1)
4. F2-ECS12M:
  - a. We connected more with less frustration with on another (1)
  - b. I feel our family trying to connect with each other more (2)
5. F7-ECS09M: this experience really helps draw our family together (1)
6. UN1-ECS13P: feel that reconnected with family (1)
7. F2-ECS14D: I feel that each year I become close to my family through this experience (1)

8. F12-SCS14M: it makes us more united (1)
9. F1-ECS13D: I always feel closer to my wife after these weekends (1)
10. F4-ECS14D: better with each other (3)
11. F1-ECS09D:
  - a. I feel that this camp will help me to be a great husband and father figure (1)
  - b. Because I got to see another side of the family and the other families and it make me want to not let them down (2)

#### VI. Continuing bonds as a coping skill

##### i. Honoring/Remembering the deceased

1. F15-ECF12D: [I look forward] to remember and dedicate time for our own son we lost (3)
2. F7-ECS09M: it is safe place to remember our son (2)
3. F6-SCS13M: My children will keep on remembering their sister (1)
4. UN5-SCS14P: I feel as if she were with us and very happy to attend (1)
5. F12-SCS12M: We continue to remember everything that happened (1)
6. UN9-ECF11P: One more year that I am able to honor my child in a way that is indescribable and vital to my continuous health as a man, person and parent (1)
7. UN1-SCS11P: we were able to watch our videos (1)
8. F5-ECS14D:
  - a. I learn that I don't grieve my daughter (1)
  - b. I refuse to allow her memory to be a sad one (2)
  - c. She gives my life meaning and purpose and for that she will always be with me (3)

##### ii. Discussion of the deceased

1. F13-SCS14M: we will continue to talk about our deceased daughter (1)
2. UN36-SCF12P: I continue talking openly about my children (1)
3. F9-SCS12M: we continue to talk about our deceased daughter openly (1)
4. F13-SCS14M: [continue talking about child] with more confidence (2)
5. F1-ECS14M:
  - a. I feel validated and encouraged to continue sharing my deceased child with the boys on such a regular basis (1)
  - b. I had been encouraged by my personal counselor to intensely pull back on "deceased child talk" with my sons, my heart disagrees (2)

#### VII. Miscellaneous

- a. General evaluation comments about Camp Sol
  - i. Thank you

1. F9-ECF13M: Thank you so much for the support (3)
  2. F8-SCS09M: Thank you. God take care of them. For this foundation and in my opinion and the respect toward us. Thank you very much.
  3. F12-SCS12M: Thousand Thousand thanks for helping us Camp sol (2)
- ii. Accomplishments
1. F5-ECF10: and (camp sol) accomplishes all the goals it sets out to do (4)
  2. F5-ECF09D: I also recognize the love + charity that are involved in running a camp such as this [3]
- iii. Camp experience
1. F7-ECF12M: it was a great experience (3)
  2. UN1-ECF13P: I believe this experience has been great for my boys (2)
  3. F8-SCF12D: since coming to camp sol, it helped my family a lot (2)
- iv. Honored to be a part of camp
1. F4-ECF13M: we feel honored and privileged to be a part of camp sol history (1)
- v. Did not gain anything from camp
1. UN1-ECF13P: I feel I had a good understanding before camp and continue to have a good understanding. I didn't gain anything from the experience (1)

## Appendix D

*Parents' Qualitative Raw Data for Differences in the Family Once Returning Home from Camp*

## I. Family interaction

## a. Emotional bond

1. F14-SCS11M: a stronger union (1)
2. F8-ECF11D: closer as a family (1)
3. F12-ECF11D: closer as a family (1)
4. UN5-ECF11P: feel closer as a family (1)
5. UN3-ECF11P: feeling more like a family unit (1)
6. F1-ECS12D: I believe it makes us closer every year (1)
7. UN33-SCF12P: I feel closer to my family (1)
8. UN5-SCS14P: I feel closer to my family (1)
9. F5-ECF12M: I hope we become closer as a family (1)
10. F10-ECF11D: I think it always brings us closer together (1)
11. UN10-ECS09P: I would hope it would help us to be closer as a family (1).
12. F18-SCS11M: become closer as a family (2)
13. UN6-ECS09P: more closer (1)
14. UN3-ECS13P: bring us closer together (2)
15. F6-SCS12M: be more in family (1)
16. F16-SCS11D: we are able to feel closer as a family (1)
17. F1-ECF12D: we are closer as a family unit
18. F14-SCS12M: we feel closer as a family (1)
19. F8-SCS13P: we feel closer as a family (1)
20. UN8-SCF13P: we feel closer (1)
21. F6-ECF12M: we may feel closer as a family (1)
22. F12-ECF13M: we may feel closer as a family (1)
23. UN11-ECS09P: we may feel closer as a family (1)
24. F1-ECS14M: we may feel closer as a family (1)
25. F9-SCS14M: We will be able to feel closer as a family
26. F3-ECF11P: we may feel more together (1)
27. UN14-SCS09P: we will be closer (1)
28. F2-ECF10D: it reminds us that we are a team (5)
29. UN15-SCS09P: we will be closer as a family (1)
30. F10-ECF09M: how we can grow together as a family (2)
31. F10-ECF12M: we will feel closer (1)
32. UN5-ECS09P: we'll become closer as family as we already are (1)
33. F4-ECF10M: I think this helps us to become a closer family (1)
34. U10-ECS10P: more unity (1)
35. F1-ECS13D: make my kids stronger (2)
36. F11-SCS09P: we can feel more united as a family (1)
37. F12-SCF12D: it keeps us united as a family (1)

38. U17-ECS10P: pulls everyone together as a family unit to strengthen our bonds as we face a different road today (1)
39. F14-SCS12D: we are able to feel more united as a family (1)
40. F13-SCS12M: we are united (1)
41. UN8-SCF13P: we feel united (2)
42. F4-SCS13M: we feel connected as a family with similar feelings (1)
43. F8-SCF12D: I think there will be more union as a family (1)
44. UN1-ECS10P: we will continue to be a strong family (1)
45. U1-ECS13P: make us stronger (1)
46. UN1-ECS10P: we will continue to be a strong family (1)
47. F1-ECS13D: I think that this will make my kids closer (1)
48. F1-ECF09M: Being in camp will make us feel closer (1)
49. F15-ECF12D: Camp always brings us closer together (1)
50. UN12-ECS09P: camp help brings us back together including the child we lost (1)
51. F13-SCF09D:
  - a. The camp has helped us a lot to come together more as a family (2)
  - b. No other activity has united us as much as this (3).
52. UN9-ECF11P: Camp Sol creates memories and strength in us as a family that otherwise would not be there (2)
53. F9-ECF13M: we have been more united since we have been coming (1)
54. UN1-ECS12P: we always feel closer to each other after camp (1)
55. UN9-ECF11P: Continued bond that we share as a result of Camp sol (1)
56. UN2-ECF12P: We are closer as a family because of camp (2)
57. F1-ECF09M: The whole experience of driving here, together, spending this time together with the memory of lost child will definitely make us closer (2)
- b. Increased family time
  1. F6-SCS09D: Have more time together (1)
  2. F11-ECF12M: Definitely bond more as a family in different activities we can all do as a family (1)
  3. F2-ECF09M: Definitely spend a lot more time together (1)
  4. F9-ECS13M: Do more family things together (1)
  5. F5-SCS12D: spend more time together (2)
  6. UN10-ECS09P: We want to spend more time together (2)
  7. F2-ECF10D: spending more time together (3)
  8. F3-ECF09M: hopefully more family time (2)
  9. F19-ECF12D: more time together (1)
  10. UN9-ECS09P: spend more quality time together (1).
  11. F7-ECF09M: Spend more time together (1)
  12. F11-ECF09M: Spend more time together (1)
  13. UN3-ECS13P: Spend more time together (1)

14. F13-ECF12P: Spend more time together (1)
15. F9-ECF11M: Spend more quality time with them at home (1)
16. UN9-SCS12P:
  - a. Spending more time together (1)
  - b. And enjoying each other more as a family each second (2)
17. F13-SCS14M: we are able to dedicate more time together (1)
18. UN1-SCS11P: we are able to dedicate more time together (1)
19. F8-SCS12D: we are able to dedicate more time together (1)
20. F12-ECS11P:
  - a. Spend time together (1)
  - b. And share more time (2)
21. UN3-SCF09P:
  - a. We can be more together as a family (1)
  - b. This gives me more strength when I arrive home (2)
22. F7-SCF20D: we can dedicate more time together (1)
23. F9-ECF09M: we may try to spend more time together doing something (1)
24. UN7-ECS11P: we plan on doing more things together as a family (1)
25. U11-ECS10PL: we try to do more things together (1)
26. F9-SCS12M: We will be able to dedicate more time together (1)
27. F7-ECS11M: we'll spend more time together (1)
28. F19-SCS12D: being a family (1)
29. F15-SCF13M: It's marvelous that we are together like a family honoring our baby that died (1)
30. F9-ECS13D: Plan more family functions together (1).
31. F3-ECS13M: reinstate family night (2).
32. UN4-ECF12P: Do more activities together (1)
33. F6-ECF13M: more family activities (2)
34. UN2-ECF13P: family game time (1)
35. UN9-ECS09P: Do more family activities (2)
36. F4-ECS12M: we may be open to more family activities (1)
37. F17-SCS12D:
  - a. Yes, now we are together a little more (1)
  - b. ...Sharing (2)
  - c. Making crafts (3)
  - d. Or playing (4)
38. F1-ECF11M: we will do it together with everybody's touch (make continuing bond) (2)
39. UN4-ECS11P: charades (1)
40. F11-ECS12M: we will spend more time together as a family as a result of attending Camp sol. (1)
41. F16-ECF12M: less electronics (1)
42. F11-ECF11M:
  - a. Hopefully less electronics in our house- we tend to turn to TV too much (1)

- b. Really enjoyed the "unplugged" time (2)
  - 43. F14-ECF13M:
    - a. We need more family quality time without electronics (1)
    - b. I loved disconnecting from everything outside of camp (2)
  - 44. F2-ECS10M: try to work on something as a family (1)
  - 45. F3-ECS09M:
    - a. Laugh and giggle more about camp. (1)
    - b. Reminisce about old time and the time we shared when we were here (2)
  - c. Prioritization
    - i. Of family
      1. F5-ECF09D: it reinforces that we must put priority on the foundation of our family (1)
      2. UN2-ECF09P: We will work on our relationship as a couple (1)
      3. F15-ECF12D: reminds me as a dad what is important (2)
      4. F2-ECF10D: it always helps me to take inventory of our day-to-day lives and helps me to refocus or tweak areas to benefit our whole family. (1)
      5. F3-ECF11P: help us to realize the importance of family time (2)
      6. F3-ECF13D: for me, a realization of needing/giving more attention
      7. UN11-SCS14P: to be better in every aspect (1)
      8. F8-SCS09M: It helps me to be better with my family and my children (1)
      9. F2-ECF09M: we need to cherish every moment w/ our children (3)
      10. F10-ECS13M: Expressing the love for my children (1)
      11. F7-ECF13D: I hope (and plan) to work hard at showing more love to my children (2)
    - ii. Faith and appreciation of life
      1. F2-ECF09M: Listening to everyone's story on how their child died is a reminder that life is not always a guarantee (2)
      2. F1-ECF10M: still keeping God first in this journey (2)
      3. UN1-ECF12P: little things matter (2)
      4. UN1-ECF12P: appreciate things more (1)
      5. UN5-ECS11P: appreciate where we are today more (1)
      6. UN11-SCS12P: we enjoy each day because tomorrow we don't know if we will be together (2)
- II. Communication
  - a. Increase in open communication
    - i. With family
      1. F13-ECS11M: Talk more about our new "family member" and how he fits in (1)
      2. F19-SCS12D: sharing as a family (2)
      3. F14-SCS13D: sharing more as a family (1)
      4. UN1-ECF10P: share more (1)
      5. F15-ECF12M: Try to encourage them to share in their journals and with each other (1)

6. F12-SCS13D: To be able to share more with my family (1)
  7. F6-SCS09D: and we can have more communication (3)
  8. F9-ECS11M: Hopefully open more doors for communication (1)
  9. F4-ECS11D: I think we will talk more (1)
  10. F7-ECF12M: we might spend more time together talking
  11. F3-ECS13M: make more time to just talk (1)
  12. UN6-ECS12P: talk to each other more (1)
  13. UN37-SCF12P: There is more communication in the family (1)
  14. UN8-SCS12P: we communication with each other what we think (2)
  15. UN6-ECS12P: talk to each other (1)
  16. F5-ECS14D: we will listen to each other a little more (1)
  17. F2-ECF10D: this means talking more about what we've experienced as a family (2)
  18. UN9-ECS11P: it is helpful to discussed changes (in grieving)
  19. F13-ECF10M: will reopen the discussion of having another child after seeing how a legacy child can be a blessing and source of healing (1)
  20. F10-ECS12D: Be more open towards each other (1)
  21. F2-ECS14M: it just gives us more opportunity to openly talk (1)
  22. F2-ECS14D: just continuing to be more open with each other (1)
  23. F11-ECS13M: more open discussion (1)
  24. F5-ECF13D: being able to open up more (1)
  25. F1-ECS13M: talk more openly (1)
  26. F1-ECF10M: talk more openly
- ii. With surviving children
1. F11-ECS11M: maybe talk more with our surviving child (1)
  2. F6-ECF13M: encourage my child to talk more (1)
  3. F9-SCS12D: I hope that he will have communication with us (2)
  4. U5-SCS13P: talking more about her sister with my oldest daughter (2)
  5. F2-ECF10M:
    - a. It just opens up the airway to talk with out little daughter (surviving child) (1)
    - b. She isn't closed to talking (2)
    - c. We talk about the deceased children all the time but talking about how they are doing, how their little heart is, is sometimes hard. (3)
    - d. You hate to bring that part up sometimes, but camp just leads you there. (4)
  6. F14-ECF12M: As for my children they will be more open with me. (2)
  7. UN2-SCS11P: we talk more openly with our children (2)
  8. F9-ECF10M: hopefully my child will feel a little better about opening up (1)
- iii. With spouse



1. F14-ECF12M: I am hoping for my husband to speak more openly with me (1)
2. F13-ECF13D: I personally don't talk cause I don't know what to say to my wife but I now know I can talk to her and say things about our son that passed away (2)
- b. Ease of communication pertaining to the deceased child
  - i. With others in general
    1. UN3-ECS14P: as always an openness to discuss Ian (1)
    2. F10-ECF09M: we will continue to grow in our ability to talk openly about the deceased (1)
    3. F8-SCF12M: we will be able to talk more about the loss of our child (1)
    4. UN2-ECS12P: open discussion of death (1)
    5. F8-ECF09M: Talk and include more of our son who has gone to be with the Lord (2)
    6. F6-SCS09M: To be able to talk a little more about our child without pain (1)
    7. F6-SCS13M: We will be able to talk about our daughter without too much sadness (1)
    8. U15-ECS10P: talk more comfortably about child (1)
    9. UN5-ECS12P: we don't worry about sharing how we feel and talking about what's happened in our lives (1)
    10. F12-SCS14D: able to talk with more confidence (2)
    11. F14-SCS11D: it is going to be easier to talk with more people (1)
  - ii. With family
    1. F8-ECF11M: we may talk about our daughter more as a family (1)
    2. UN7-SCS12P: asking ourselves things about our daughter without making a knot in our throat (2)
    3. F1-ECF13M: Not be so protective of each others feelings/hurting them by talking about the child who passed (2)
  - iii. With surviving children
    1. F12-ECF13M: The kids may speak more about their sister (2)
    2. F5-ECF12M: hope the kids find it easier to talk to me about their sister (2)
- c. Emotional expression
  - i. Family
    1. F3-ECF09M: more open about feelings and sadness
    2. UN16-ECS10P: I hope we can be more open about our feelings of grief (1)
    3. F15-SCS12D: Feel better because talking our feelings (1)
    4. F5-ECS10M: I'm hoping we can all share more openly about or grief (1)
    5. UN1-ECS13P:
      - a. Have mix emotions that we have to talk about (1)
      - b. To make us stronger (2)
    6. UN6-SCS14P: sharing my grief more (1)

7. F15-SCS12D: we vented our feelings (2)
  8. UN2-SCS11P: we talk more calmly about the sorrow
  9. F1-ECF09M: hopefully will be easier for everyone to share there feelings (2)
  10. F5-SCS12D: I hope that it helps us know how to express ourselves better (1)
  11. UN2-ECF11P: we should be able to express our feelings easier (1)
  12. F4-ECF10M: I think this helps us to become a more emotional family (2)
  13. F12-ECF11M: more grieving (3)
  14. F16-ECF10D: we can communication our feelings more effectively (1)
  15. F15-ECS09M: we will communicate our grieving to each other better (1)
  16. F18-ECS12M: I feel that allows all of us as a family to talk about our feelings that we may not always talk about (2)
  17. F4-ECS12M: exploring our grief journey as a family
  18. F6-ECF13D:
    - a. The camp provided me with a chance to include the kids in my grieving process (1)
    - b. Prior to how I've felt pretty alone and separate (2).
    - c. I want to include them and this kind of broke the cycle of seclusion and frustration for me (3)
  19. F3-ECS13D: able to grieve together as one (2)
  20. F7-ECF12M: we might spend more time together grieving as a family (2)
  21. UN5-SCS13P: Sharing our mourning more (1)
  - ii. Surviving Children
    1. F4-ECF10D: Asking more questions to our son on his feelings of deceased child (1)
    2. F8-ECF13M: hopefully my kids will feel more open to talk with us about their feelings (1)
    3. F13-ECS09D: I have hopes that my big girls will be a little more open in sharing their grief-based feelings.
    4. UN7-ECF12P: our children will express their emotions (1)
    5. UN7-ECF11P: we may hear from the kids about their individual feelings (1)
- III. Increased knowledge of grieving process
- i. Individual differences in the grief process
    1. F8-ECF10D: an understanding that each of us has his own process to go through (2)
    2. UN12-SCS14P: I hope that we will be able to understand that we each have a different grief process (1)
    3. UN12-SCS14P: I hope that we will be able to understand that we each have a different grief process (1)

4. F7-ECS09M: I will respect the fact that children and adults grieve differently (1).
5. F4-ECF13M: more mindful of each others struggles (1)
6. F8-ECF09M: more understanding of everyone's grief
7. F10-ECF09D: More understanding of each others feelings (1) and what is happening in the process (2)
8. F3-ECF13M: we are always more aware of another's grieving process (1)
9. F13-ECF13M: we may be able to understand the way each one of us grieves (1)
10. F12-ECF09D: we may be more understanding of others and their feelings (1)
11. F5-ECF13M: we may understand each other as it pertains to our own grief (2)
12. UN5-ECS09P: And understand more on how each of us grieve (2)
13. F6-ECF11M: Understanding that every parent and child grieves differently.
14. F10-ECF11M: Understanding each others needs better (1)
15. F13-ECS13D: understanding us better (1)
16. F12-SCS14M: understand each other (1)
17. F4-SCS13D: I understand more the pain of others (1)
18. F2-ECS13D: Remembering that we all still struggle at different times (1) may help to consciously keep talking and checking in on each other's journey.
19. F10-SCF10P: We can understand each other more for what is happening to us (1)
20. F2-ECF10D: recognizing that we are all grieving and that is okay (4)
21. F16-ECS12M: accepting each others grief (1)
22. F16-ECS12D: accepting each others individual grief (1)
23. F10-ECS12M: Be more accepting of the difference in our grief (3)
24. F1-ECF13M: I hope we will all be more accepting of each others individual's grief needs (1).
25. UN11-SCS12P: We are more accepting of each other's individual grief and mourning needs (1)
26. F12-SCS13M: We may be more accepting of each other's individual grief and mourning needs (1)
27. UN4-SCS13P: we are able to accept the need of one another (1)
28. F6-SCS12D: we may be more accepting of each other's individual grief and mourning needs. (1)
29. UN6-ECF11P: we may be more accepting of each other's individual grief and mourning needs. (1)
30. F7-SCS14D: we may be more accepting of each other's individual grief and mourning needs. (1)
31. F3-ECF10D: we may be more accepting of each other's individual grief and mourning needs. (1)

32. F15-ECF10M: we may be more accepting of each other's individual grief and mourning needs. (1)
33. UN11-ECS09P: we may be more accepting of each others individual grief and mourning needs (2)
34. F2-ECS12M: we will continue to accept each other's differences better (1)
35. F5-ECF10M: more understanding (2)
36. F1-ECS11D: we can understand grief (1)
37. F9-SCS09P: we had a lot of answers to questions about our grief (1)
38. UN8-SCS12P: we understand more the mourning of our son (2)
39. UN9-ECS11P: grief process changes over time (1)
40. F10-SCS14D: we understanding each other better (1)
41. UN6-SCS13P: We understand each other more (1)
42. F10-SCS09M: yes, my family understands (1)
- ii. Developmental stages and grief process in surviving children
  1. UN8-ECS11P:
    - a. Ability to understand my children's needs (1)
    - b. And respond to them (2)
  2. F15-ECS09D: I could be more aware of how my daughter is coping with her loss (1)
  3. UN1-ECF09: I will understand my child's emotions (1)
  4. F2-ECS10D: invest more time in understanding our kid's feelings (1)
  5. F11-ECF13D:
    - a. We may understand more how our kids grieve (1)
    - b. And how to deal with it (2)
  6. F1-ECF13D: understand that my kid's behavior may be a result of their grief (1)
  7. F7-ECS09M: I won't worry about my girls just because they don't cry as much as I do (2)
  8. F9-SCS12D:
    - a. That my son can assimilate (1)
    - b. And understand the death of his sister (2)
  9. UN10-ECF12P: I think the other kids will understand a little better. (2)
  10. F10-SCS09M: and I think it was a good experience for him to understand better (2) (child coming to camp)
  11. F7-ECS10P: That our daughter has grown up and has many more questions (2)
  12. F13-ECF10M: Also comforts me to know that my legacy child has not forgotten about her brother (2)
- iii. Parent grief process
  1. F1-ECF12M: understand our individual grieving processes (2)
  2. UN8-ECS09P: continue to effectively manage grief especially with 1st anniversary in a few weeks (1)

3. U15-ECS10P: understand the grieving process (2)
4. UN2-ECF12P: I am better prepared for this next phase of our grief journey (1)
5. UN1-ECS09P: I feel more capable of coping with my own grief (2)
6. F11-ECS10M: It's ok how I've chosen to grieve as long as its not destructive (2)
7. UN13-SCS14P: understand more of what happened to us (2)
8. F4-ECS10D: this camp helps me to understand the death of my daughter (2).
9. UN36-SCF12P: understanding the changes of emotions (1)
10. F10-SCS14D: And understand the pain of grief (2)

#### IV. Adjustment

##### a. Moving forward

1. F4-ECS11D: begin facing our loss (2)
2. F12-ECF11M: more healing (2)
3. UN6-SCS14P: moving forward (2)
4. F11-SCS09P: That we have people around us that need us to continue moving forward (3).
5. F8-SCS14D:
  - a. When we leave camp sol we are ready to move forward with our grief for a time (1)
  - b. But suddenly the sadness comes back (2)
  - c. UN11-ECS09P: making new memories (3)
6. F11-SCS14D: at the same time, making or thinking and preparing ourselves for the next year
7. F10-SCS09M: and above all, my husband improves every time (2)
8. F18-SCS11M: yes, camp always helps us overcome (1)
9. F4-ECF09M: Camp Sol gives us hope again that our lives can be ok (1)
10. F4-ECS14D: anything (1), but we are prepared for it
11. UN12-ECS09P: It gives us an ability to start the next year fresh again (2)
12. F4-ECF09M: it also gives us something to look forward to! (2)
13. F12-ECF11M: more hope (1)
14. F12-SCS14D: We are better able to live together as a family (1)
15. F12-ECS11P: we are going to be better as a family (1)
16. UN13-SCS14P: we are going to be better as a family (1)
17. F17-SCS12D: better in general (2)
18. F4-ECF09M: Camp Sol gives us hope again that our lives can be ok (1)
19. F10-SCS14D: Thank you for helping us handle our pain more easily (1)

##### b. Improvements in mood and negative feelings

1. UN3-SCF10P: content (2)
2. F20-SCS11P: I am better for my family (1)

3. F22-SCS11P: I feel much better (1).
4. UN1-ECF09P: and not get frustrated with him (child) (2)
5. F18-ECS12M: camp just makes me happy (1)
6. F21-SCS11M: we are happy about coming (1)
7. F11-SCS14D: we return home very happy (1)
8. F15-SCS12D: you feel better (1)
9. F3-ECF13D: being less grumpy (3)
10. UN3-SCF10P: I come home more relaxed (1)
11. UN3-SCF09P: more calm (3)
12. F4-ECS10D:
  - a. We come back to my home more relaxed (1)
  - b. We spend a week without stress (2)
13. F3-ECS13D: family more relax (1)
14. F15-SCS11P: we feel more relaxed (1)
15. F3-ECF13D: for me, a realization of needing/giving more patience (1)
16. F5-ECF10M: more patience towards each other (1)
17. F12-SCS14M: more patience with each other (2)
18. UN9-ECS09P: try and relax and enjoy life more (1)
- ii. Accepting the death of the child
  1. F5-SCS12M: we will accept that the mourning is real (1)
  2. F6-SCS12M: accept the mourning more (2)
  3. F3-ECS11M: more accepting (1)
  4. UN4-SCS13P: It is okay to grieve however we do (2)
  5. UN3-ECS09P: may not feel that we have to get over it as quickly (1)
  6. F12-ECF10M: dad might be more accepting and willing to talk about walker (1)

## V. Social support

### a. Parent social support

#### i. Instrumental support

1. UN9-ECS10P: able to get more help (1)
2. F11-ECS10M: will seek to join other grief support (1)
3. F8-ECS11M: We will participate in the Run (1)
4. F1-ECF10M:
  - a. I want and plan to do more in the success and longevity of this camp (3)
  - b. I've been praying to God to put me where I'm suppose to be (4)
  - c. So many families need this! (5)
5. F4-ECS12D: we will have an actual organization or "place" to pour our fundraising and energy into (1)

#### ii. Providing peer/emotional support

1. F4-ECF13M: being more supportive of the others difficult times
2. F3-ECF13M: we are always more supportive of another's grieving process (1)

3. F5-ECF13M: we may extend more grace (1)
  4. F10-ECS12M: grace, grace, grace (1)
  5. F8-SCS09M: It helps me to be better with other families that experienced the same (1)
  - iii. Receiving Peer/emotional support
    1. F4-SCS13M: more friendships with other families (2)
    2. F9-SCS09P: speaking with other parents (2)
    3. UN7-ECS11P: also get together with other families from camp (2)
    4. UN3-SCF10P: I enjoyed camp with other people, and we could talk to each other about our children who passed (1)
  - iv. Appraisal support
    1. F7-SCS13P:
      - a. We felt peace (1)
      - b. Because we know there are other families with the same pain (2)
    2. F11-SCS09P: It helps us to know there are other people who have had a loss as great as ours (2)
    3. F18-ECS12M:
      - a. I really enjoy being with families who just get it (2)
      - b. I feel somewhat normal here (3)
  - b. Child social support
    - i. Parents providing peer/emotional support
      1. UN2-ECF10P: provide more helpful support during this process (2)
      2. F11-ECS11M: and find a different way to help her talk about things. (2)
      3. F2-ECS10M: focus on kids needs as being different and changing (1)
      4. UN2-ECF10P: I will be able to better meet my child's needs (1)
    - ii. Receiving peer/emotional support
      1. F2-ECS09D: it's good for the kids to have someone to talk to that understands loss (2)
      2. F6-SCS09D: My son is who worries me the most, because he is so quiet and doesn't talk a lot about the death of his sister, and I hope that he feels more calm knowing more children his own age (2)
  - c. Family social support
    1. F8-ECF10D: an understanding that we are there for each other (1)
    2. F1-ECF12M: being able to support each other (1)
    3. UN6-SCS14P: supporting each other as a family (3)
    4. F10-SCF10P: and try to help each other as a family and as parents (2)
- VI. Continuing bonds as a coping skills
- i. Honoring/remembering deceased child
    1. UN3-ECF13P:
      - a. Nice having a refreshed sense of honoring the child we lost (1)

- b. Have ideas and materials of things we could/can do at home to honor our child, etc. (2)
- 2. UN12-ECS09P: celebrate our family including the ones we've lost (2)
- 3. F1-ECS13M: let the kids make more choices for her Angel day or birthday celebrations
- 4. F21-SCS11M: (happy to come to camp) to honor our daughter (1)
- 5. UN7-SCS12P: for us, now we are able to have her keepsakes in whatever part of the house and we look at them like it is something normal (1)
- 6. F1-ECF11M:
  - a. We can now take out all of our pictures and do the scrapbooking pages for 2010 and 2011 (1).
  - b. It was so hard to complete 2010's page (2)
- 7. UN10-ECF12P: we will continue to honor our missing son (1)
- 8. UN8-ECF11P: We will talk more about our loved ones that passed away because we talked so much about them over the camp weekend (1)
- 9. F6-ECF10: continue remembering the little girl who died openly (1)
- 10. F2-ECF11M: we have precious memories together + they are because of our deceased children (1).
- 11. UN14-SCS09P: we will not forget our babies (2)
- 12. F6-SCS09M: remember her with more affection (2)
- 13. F6-SCF10M: Continue remembering the little girl who died openly (1)
- 14. UN9-ECF11P: continued bond that we share as a result of Camp sol (1)

## VII. Miscellaneous

- a. General evaluation comments about Camp Sol
  - i. Thank you
    - 1. F19-SCS11M: No but thank you for having us in mind and giving us your support (1)
    - 2. F14-ECF13M: thank you for everything (3)
    - 3. F4-ECF09M:
      - a. And it also gives us something to look forward to! (2)
      - b. I am so grateful and so thankful to everyone at Camp Sol and CJM, we feel privileged to be a part of something so powerful and important! (3)
      - c. Thank you! (4)
    - 4. F13-SCF09D:
      - a. Every time we come to camp the children feel like staying and always want to return (1)
      - b. Then the notice of the camp arrives, they begin to count the days until they'll return (2)
      - c. Thank you Camp Sol!! (4)



5. UN3-SCF10P: thank you for helping us share with all of you.
  6. F18-SCS11M: thousand thanks (3)
  7. F8-SCS09M:
    - a. That can I say to you all...Continue doing the same (2)
    - b. That it is very important for the families that lose a loved one (3)
    - c. I am going to pray that Camp Sol never ends (4)
  8. F22-SCS11P: Thank you for helping us in cope with our grief a little better (2)
  9. F11-ECF10D: staff was great (1)
  10. F9-ECF10M: hopefully we can talk his father into coming next year (2)
- ii. Suggestions
1. F3-ECS09M: maybe next year as a family introduction we could make a dream catcher or letter descriptions of our children who have died with their name (3) (example: t- talented, r-respectful, e-excellent, v-vibrant, o-outstanding, n-never giving up)
  2. F4-ECS12M: I really would have loved it if all the camp sol volunteers could have just been very briefly introduced at the beginning, especially the younger volunteers. Having my kids in their care, I would have loved to have a name/face/voice connection very early on (3)
  3. U13-ECS10P: for families that have been here 5+ years it may be valuable to have a session where they go 1-1 with new folks to keep them involved
  4. UN3-ECS09P:
    - a. Give out tissues in welcome bags (2)
    - b. Send agenda ahead of time (3)
    - c. Give more history on camp in packet (4)
    - d. Better intro activity on 1st night (5)
    - e. More ways to meet other families (6)
    - f. Camp songs at meal time to entertain kids/help parents loosen up (7)
  5. F13-ECF10:
    - a. Hot dogs, not burgers for kids (3)
    - b. List more info in directory so parents can seek each other out (4) (i.e. where they live/how child died, confidentiality, I know, but only have people share if they want to, maybe assign seating for meals and switch families around? seems hard to meet all the families. mom's groups...should be some structure sharing time)
    - c. Add to list to bring: nightlight (5)
  6. UN1-ECF10: Suggestion: maybe have a breakout group for legacy kids (2)
  7. F2-ECF10M: I'm sure you probably already heard a few people talk about the "coffin story" at the campfire. I know for sure the

young guys meant nothing by their story, but it just wasn't good. Our little girl does know what a cemetery is, but during the story she asked what a coffin is. My little girl has had to see two of her siblings in a coffin. How do you explain, you know those boxes, those sad little boxes that we put your brother and sister in and then put them in the ground and left...those boxes? that is what this joke is about. I just told her he is talking about a box and because she is her mother's daughter she said, "oh the box can talk" haha. It just wasn't a good taste. If I heard that story in a mixed crowd it wouldn't have been so bad. I don't expect or want people to walk on eggshells around me but everyone here has had to deal with a coffin. That's why we are here. This year we are a host family and it was hard to hear one of our families that are new talk about this story too. They loved everything, but the story just wasn't the best pick. We know they are young and camp john marc staff; they didn't mean to be insensitive. We still like them haha (3)

iii. Bereaved siblings' experience at camp

1. F11-ECS11M: Note: worried about what happens once my daughter turns 18. Place for her at camp (3)
2. F2-ECF11M: It is hard knowing that they have bad memories too because of losing Emma + John Michael, but this is a good one (3)
3. F11-ECS13D: it is great for our kids (1)

## Appendix E

*Parents' Qualitative Raw Data for Favorite Aspect of Camp*

## I. Camp Activities

## a. Children and family activities

## i. General activities

1. UN3-ECF11P: Fun activities to do as a family (3)
2. U4-ECF11P: family activities (2)
3. F1-ECS12M: doing the family activities (2)
4. F3-ECF13M: all family activities (1)
5. UN2-ECS09P: family activities (1)
6. F8-ECF09M: family activities (1)
7. F13-ECF10: family activities (1)
8. F15-ECF12M: family activities (2)
9. F19-ECF12D: family activities (2)
10. F1-ECS13M: I love the family activities (1)
11. F12-ECF10: the family activities (1)
12. F6-ECF11M: family activities (2)
13. F3-ECF13D: family activities (1)
14. F6-ECF09D: family night at silo (2)
15. UN1-ECS13P: the activities (3)
16. F1-ECF13M: family activities (1)
17. F12-ECF09D: the various activities
18. F13-ECF12P: activities (2)
19. F1-ECS12M: I liked all the activities (1)
20. F3-ECF09M: I like how regular camp activities are included so the weekend is not all sadness and crying (3)
21. F6-ECF10P: the activities (1)
22. F12-ECF13M: activities (3)
23. F7-SCS14D: the diverse activities (3)
24. F18-SCS11M: having activities that my kids enjoyed (1)
25. F9-ECS13M: children activities (2)
26. F7-ECF12M: activities for the kids (4)
27. UN3-ECS11P: kids groups (1)
28. F6-SCS09D: children's activities (2)
29. F2-ECF10M: Loved the little music kids did at service, so sweet (4)

## ii. Carnival

1. F3-ECF11P: carnival (1)
2. F6-ECF11M: carnival (1)
3. UN5-ECF12P:
  - a. Carnival (1)
  - b. Engaged all kids and most adults (2)
4. F3-ECS13D: carnival dance (5)
5. F10-ECF13D: carnival (1)

6. F4-ECF10D: family carnival (1)
  7. F2-ECS12M: I enjoyed the carnival (1)
  8. F8-SCS14D: I liked the carnival (1)
  9. F11-ECF13D: carnival (1)
  10. F7-ECS11M: carnival (2)
  11. F17-SCS11P: carnival (2)
  12. F8-SCS13P: carnival (3)
  13. UN1-ECS13P: carnival (1)
  14. F12-SCS13M: carnival (2)
  15. F8-ECF11D: kid's carnival (1)
  16. F8-ECF11M: kid's carnival (1)
  17. UN13-SCS14P: carnival (1)
  18. F9-ECS13M: carnival (1)
  19. F2-ECS09D: carnival (2)
  20. UN4-ECS09P: carnival (2)
  21. F10-ECF11M: bingo at the carnival (2)
  22. F6-ECF10P: the carnival (3)
  23. F3-ECS13D: family carnival (2)
- iii. Ropes course
1. F5-ECS11M: rope climbing (2)
  2. F1-ECF12M: ropes (2)
  3. F19-SCS12D: ropes (1)
  4. F8-SCS13P: ropes (1)
  5. F17-SCS11P: ropes (3)
  6. F6-ECF09M: ropes course (1)
  7. F15-ECF10: ropes course (1)
  8. F2-ECF13M: ropes course (1)
  9. UN12-ECS10P: ropes course (1)
  10. F7-ECS11D: ropes course (1)
  11. F12-SCS14D: ropes course (2)
  12. UN5-SCS14P: ropes course (1)
  13. UN12-ECS09P: ropes course (2)
  14. F3-ECS13D: ropes (3)
  15. F3-ECS13M: ropes course (2)
  16. UN4-SCS13P: ropes (1)
  17. F12-ECS09D: ropes/climbing (2)
  18. UN2-ECS14P: love the ropes (2)
  19. F6-ECF09D: ropes course for dads (1)
  20. F15-ECS09D: I enjoyed doing the ropes course with the dads (1)
- iv. Fishing
1. F5-ECS11M: fishing (1)
  2. F16-SCS11D: fishing (2)
  3. F9-ECS13D: fishing (1)
  4. F13-ECS13D: fishing (1)
  5. F11-SCS09P: fishing (1)
  6. F12-SCS14D: fishing (1)

7. F10-ECF09D: fishing (1)
8. F16-ECF10: fishing (1)
9. F1-ECF12M: fishing (1)
10. F8-SCF13D: fishing (1)
11. F8-SCS13P: fishing (1)
12. UN5-ECS09P:
  - a. Fishing (2)
  - b. Eased my mind a lot (3)
13. F4-SCS13D: I really liked fishing (1)
14. F14-ECF13D: the fishing (1)
15. UN4-ECF12P: fishing (2)
16. F7-SCS13P: fishing is very relaxing (2)
17. UN5-SCS14P: fishing (2)
- v. Cooking
  1. F2-ECF09M: cooking (1)
  2. F12-ECF10: and loved the cooking activities (2)
  3. F12-ECF11P: cooking (1)
  4. F13-SCS14M: cooking (1)
  5. F13-ECS13D: cooking (2)
  6. UN8-SCS12P: cooking (2)
  7. F11-SCS09P: cooking (2)
  8. UN17-ECS10P: family cooking (3)
- vi. Camp fire
  1. F5-ECF13D: camp fire (1)
  2. F8-ECF11M: camp fire (2)
  3. UN12-ECS09P: camp fire (3)
  4. F9-ECS13M: and the song at fireside (6)
  5. F12-ECF11P: wood burning (2)
  6. F1-ECF12D: I like how the children know the songs at the campfire because of repetitiveness (1)
  7. F9-ECS13M:
    - a. Roasting marshmallows and smores (4)
    - b. Great family activity my child loved (5)
- vii. Free time
  1. F10-ECF13D: free time- started playing farkel (2)
  2. F3-ECF13M: we enjoyed jump ropes, balls, etc. being available for free play
  3. F4-SCS13D: free time to relax (2)
  4. UN1-ECF13P:
    - a. Break time (1)
    - b. This allowed free time for my boys to do what they wanted (2)
  5. F8-ECF13M: thank you for adding the free family time! (2)
- viii. Archery
  1. F12-ECF11D: archery (1)
  2. F19-ECF12D: archery (2)

3. F6-ECF09M: the archery this year (3)
4. UN4-ECF12P: archery (3)
5. F14-ECF13D: archery (3)
- ix. Sports and games
  1. F1-ECF13M: sports and games (2)
  2. F14-SCS11D: sports (2)
  3. F15-SCS12D: sports (2)
  4. F4-ECS14D: playing (2)
  5. UN13-ECS09P:
    - a. The games that camp sol leaves in the cabins are great (1)
    - b. We have played ours many times over the weekend (2)
- x. Arts and crafts
  1. F1-ECF13M: arts and crafts (1)
  2. F12-ECS11P: arts and crafts (1)
  3. F15-SCS12D: arts and crafts (4)
  4. UN17-ECS10P: family arts and crafts (2)
  5. U14-ECF09C-10: I like making the T-shirt (1)
- xi. Saturday night party
  1. F5-ECF13D: Saturday night party (2)
- xii. Massage
  1. F1-ECS11D: massage (1)
- xiii. Blackjack table
  1. F19-ECF12D: blackjack table (5)
- xiv. Music therapy
  1. UN5-ECF12P:
    - a. The music truly helped energize everyone (3)
    - b. The energy created an environment such that people moved out of their comfort zones (4)
- b. Parent Activities
  - i. Small group sessions
    1. F11-ECF09M: parent breakout groups (2)
    2. U3-ECF11P: small group sharing (2)
    3. F1-ECF12M: parent morning group (3)
    4. F12-ECF11D: facilitated discussion (2)
    5. F1-ECS14M: Morning parent group (1)
    6. UN7-ECF11P: morning parent group was the only time we were given to express our situation to other families and hear from 2 families about their story (1)
    7. UN2-ECS12P: open discussion (3)
    8. F6-ECF12M: parent group on Saturday morning (2)
    9. F7-ECF12M: loved parent group session (2)
    10. F9-ECF12M: sharing in small groups (1)
    11. UN11-ECS09P: Saturday morning parent session (1)
    12. F14-ECF12M:
      - a. The parents meeting (1)

- b. The division of moms and dads to get together and work on different crafts (2)
- 13. F19-ECF12D: Saturday morning share (1)
- 14. UN4-ECF12P: parent group (1)
- 15. F1-ECS10M:
  - a. I liked our small parent break out group (1)
  - b. Wished we had more time (2)
- 16. UN5-ECF13P:
  - a. I really like that it seem either the parent groups were small or the time was longer (1)
  - b. It felt we had more time/opportunity to share (2)
- 17. UN17-ECS10P: parent breakout (1)
- 18. F3-ECS11M: our parent small group was good (1)
- 19. F7-ECS11D: parent breakout (2)
- 20. F8-ECS11M: 1<sup>st</sup> therapy/parent session (2)
- 21. F15-ECS09M: I liked the way you made our groups for the parent breakout session
- 22. UN6-ECS11P: parent small group (1)
- 23. UN9-ECS11P: adult breakout (1)
- 24. F6-SCS12M: parent time in discussion is my favorite (1)
- 25. F4-ECS12M:
  - a. Breakout group was great (1).
  - b. I would have liked another session, continuing with my same group, to go even further (2)
- 26. UN4-ECS12P: group time (1)
- 27. F2-ECS13D:
  - a. Parents break out group (3)
  - b. Parent time (1)
- 28. F6-ECS14D: parent time in discussion is my favorite (1)
- 29. UN7-ECS09P: parents group (sat) (1)
- 30. UN3-ECS09P:
  - a. Parent group (1)
  - b. I would like more of these (2)
- 31. UN2-ECS14P: the parent group on Saturday (1)
- 32. UN5-ECS09P: the 1<sup>st</sup> group (1) because I haven't basically discussed my child's death until asked (2)
- 33. UN7-ECF11P: morning parent group (1) was the only time were given to express our situation to other families and hear from 2 families about their story
- ii. Parent dinner
  - 1. F4-ECF10M: esp. parents dinner (2)
  - 2. F3-ECF11P: parent dinner (1)
  - 3. F19-ECF12D: parent dinner (4)
  - 4. F5-ECF13D: parents dinner (3)
  - 5. UN2-ECS14P: parents dinner (3)
  - 6. F2-ECS13D: parents dinner (2)

7. F12-ECF13M: Saturday night dinner (2)
8. F12-SCS13M: parents' dinner (1)
9. F10-ECF13M:
  - a. Great parent dinner (1)
  - b. Like the addition of music (2)
10. F7-ECS11M: parent dinner (1)
11. F11-ECS13M:
  - a. Love that parent meal (1)
  - b. Great time to talk with other parents (2)
- iii. Mom's activities
  1. Scrap booking
    - a. UN1-ECF10:
      - i. Mom's activity with my child (2)
      - ii. Mosaic was awesome (3)
    - b. F6-ECF12M: the mom's activity (1)
    - c. F14-ECF12M: the division of moms to get together and work on different crafts (2)
    - d. F9-ECS13M: mom's group (3)
    - e. UN7-ECS09P: scrapbooking (2)
    - f. F2-ECF09M:
      - i. I think its great that you've utilized the mom's group to incorporate making the scrapbook page for camp sol (3)
      - ii. As opposed to just having them laid out in the saddle room (4)
    - g. UN2-ECF10: scrapbooking was unexpectedly fun (4)
  2. Yoga
    - a. F11-ECF11M: loved the yoga (2)
    - b. F17-SCS11P: yoga (1)
    - c. F1-ECF11M:
      - i. Yoga was literally an out of body experience for me (2)
      - ii. I participate in the yoga away from camp, but the energy in the room with the "Like" mothers during the session was exhilarating (3)
- iv. Dad's activity
  1. F13-ECF10: men's activities (1)
  2. UN4-ECS09P: dad's activity (1)
  3. F14-ECF12M: the division of dads to get together and work on different crafts (2)
  4. F15-ECF12D:
    - a. The time the dads spend together is great also (2)
    - b. Helps the guys in being comfortable together (3)
  5. F10-ECF13D: dad's activity (1)
  6. F11-ECF13D: dad's activity (1)
  7. F4-ECS11D:



- a. The activities with other dads are very important (2)
      - b. As it is a frame to "be dads" (3)
      - c. And express our thoughts in our own way (4)
    - 8. UN4-ECS12P: dad time (2)
    - 9. F4-ECS14D: fellowship with other men who could relate to my loss (4)
    - 10. UN12-ECS09P: men's activity (1)
  - c. Continuing bond activities
    - i. Remembrance service
      - 1. F6-ECF09M: remembrance service (2)
      - 2. F7-ECF12M: remembrance service (3)
      - 3. UN9-ECF12P: remembrance (1)
      - 4. F3-ECS13D: remembrance service (1)
      - 5. UN13-SCS14P: remembrance ceremony (2)
      - 6. F6-SCS09D: remembrance (1)
      - 7. F7-ECF09M: remembering my son (3)
    - ii. Stepping stones
      - 1. UN11-ECS09P: stepping stones (2)
      - 2. F2-ECF09M: loved the stepping stones (2)
      - 3. F11-ECF09D:
        - a. Stepping stones (1)
        - b. Each stone from each year is like a step in the process that I can now take home (2)
    - iii. Family flag
      - 1. F5-ECF12M: making the family flag (1)
    - iv. Quilt squares
      - 1. UN6-ECS12P: art for the blanket (1)
    - v. Family introduction
      - 1. F10-ECF11M: enjoyed the family introduction activity (1)
    - vi. Memory boxes
      - 1. UN3-ECS13P: it was so much fun making our boxes (1)
- II. Social Support
  - a. Parent social support
    - i. Peer/emotional support
      - 1. F10-ECF09M: meeting other families (1)
      - 2. F10-ECF11D: meeting the other families (1)
      - 3. F12-ECF13M: communicating with other families (1)
      - 4. U2-ECS13P: reconnecting with families (1)
      - 5. 7-ECS09M:
        - a. Meeting and talking with the volunteers (2)
        - b. Also we loved meeting a young woman, a "towny", who was so kind and compassionate (3)
      - 6. UN11-ECS09P: meeting other families (3)
      - 7. F10-ECF09D: parent interaction (1)
      - 8. F7-ECF09M: the openness and feeling comfortable (2)

9. UN1-ECS09P: Enjoy meeting with and communicating with other parents (2)
10. F1-ECS12D: just being here with families that have become like family for us over the years (1)
11. F1-ECS12M: seeing all the friends (families) from past years (1)
12. F3-ECF13D:
  - a. Meeting new families (3)
  - b. Seeing recurring ones (4)
13. F15-ECF12D: Really enjoy meeting new parents and families (1)
14. F10-ECF12M: seeing the other families again (1)
15. F11-ECF09M: meeting new families (1)
16. F11-ECS13D: talking with other families (1)
17. UN5-SCS13P: living with the other families (2)
18. F1-ECF10M: being in the company of family who were impacted by a child's death (1)
19. F15-ECF12M: meeting other families (1)
20. F18-ECS12M: time with other families (2)
21. UN1-ECS12P:
  - a. Being with other families (1)
  - b. Getting to know new families (2)
22. F13-ECF13M: how great it was to meet other families that are accepting and understanding (1)
23. F2-ECF10D: networking with other families (1)
24. F4-ECS12D: my favorite part is hearing the stories of other families (1)
25. F2-ECS10M: networking/talking/sharing with other families (1)
26. F4-ECF10M: meeting with other parents (1)
27. F9-ECS13D: how family's talk to each other
28. F8-ECF10: just being around other families (1)
29. F13-ECF13D: I enjoyed speaking with families that understand (1)
30. F9-ECF10: talking with other families (2)
31. UN2-ECF13P: dinners/meals with other families (2)
32. F13-ECF10: sharing with other parents (1)
33. UN6-ECF13P: meeting other families (1)
34. F11-ECS11M: meeting families (1)
35. UN1-ECF10: networking with other families (1)
36. UN2-ECS12P: common friends (2)
37. F11-ECF11M: I felt more comfortable this year knowing sever families (1)
38. UN3-ECF11P: being with other families (1)
39. F7-SCS14D: the companionship that there is (2)
40. UN4-ECF11P: meeting the other families (1)
41. F14-ECF13D: also getting to know people that is going through the same thing that I'm going through (3)
42. UN5-ECF11P: networking with other families (1)
43. UN6-ECF11P: meeting with parents who have lost a child (1)

44. UN8-ECF11P: connecting with other families (1)
45. UN8-ECF12P: sharing (2)
46. F14-SCS12D: Being able to live with families that feel the same pain that I do (1)
47. UN1-ECS10P: families (2)
48. F4-ECF13M: just having the opportunity to be amongst so many loving people with similar paths in such a beautiful setting!
49. F6-ECF13M: talking with other parents (1)
50. F8-SCS14D: meeting with the other parents (2)
51. F6-ECF13D: us as parents connecting with other parents (3)
52. F7-ECF13D: meeting and communicating with other bereaved parents (1)
53. F9-ECF13M: we got to meet families (1)
54. UN13-ECS09P: getting to visit with the other families who have experienced the same loss (1)
55. UN5-ECS12P: people (1)
56. UN12-ECS10P: getting to be with the other families and getting to know the new ones (2)
57. F7-ECS10P: being around similar families (1)
58. F11-ECS10G: meeting other families that lost a child (1)
59. F13-ECS10G: meeting families (2)
60. UN10-ECS10P: friendliness of the participants (1)
61. UN14-ECS10P: comradery (1)
62. F7-ECS09M: meeting other families (1)
63. F13-ECS11M: seeing all of my “veteran families” (2)
64. F15-SCS11P: to meet various families (1)
65. F23-SCS11D: being with other people suffering the same pain (1)
66. UN4-ECS11P: time with families with similar experiences (1)
67. UN5-ECS11P: families (1)
68. F3-ECS09M:
  - a. Meeting other parents (1)
  - b. Seeing/meeting new parents (2)
69. UN7-ECS11P: we love that we get to be with other families like ours (1)
70. UN8-ECS11P: all here for the same reason (2)
71. F1-ECF09D: meet other families (2)
72. F1-ECS09D: the camaraderie that everyone shows (1)
73. F3-ECF09M:
  - a. Meeting other families (1)
  - b. Sharing stories (2)
74. F3-ECF10D: the XX family (4)
75. F1-ECF12D: Similarity w/ others despite all the possible differences (no one cares or broaches/breeches religious or vocation differences) (3)
76. F3-ECF12M: getting to meet and talk to other families (1)
77. UN6-ECS12P: being with other families (1)

- 78. F13-ECS09D: meeting new friends (3)
- 79. UN1-ECS14P:
  - a. We love hat we get to see our old friends (1)
  - b. But we love meeting new ones as well (2)
- 80. F12-ECS09D: Meeting other parents/sharing (1)
- 81. UN4-ECS14P: the people (1)
- 82. F2-ECF10M:
  - a. I think the very best thing about the camp is the people (1)
  - b. The families, they feel like an extension of ours now. We are here because we have lost and yes because we are here and because of yall...
  - c. Our family feels like they have grown in number (3)
- 83. F5-ECF13M: connecting with other moms (1)
- 84. F4-SCS13M: sharing like a family with the mothers (2)
- 85. UN7-ECF11P: opportunity to hear from 2 families about their story (3)
- 86. F15-SCS12M: helping other families in mourning (1)
- 87. F1-ECS09D: the way everyone helps each other (2)
- 88. F10-ECS12M:
  - a. Meeting families who truly understand what we are dealing with (1)
  - b. Who have additional insight on how our child will process grief as he grows up (2)
- 89. F14-ECF13M: being able to relate and talk to other without being judged (1)
- 90. UN6-SCS14P: most of all I met more parents that have problems like mine (2)
- 91. F5-ECS10M:
  - a. Being able to talk to other parents whose children had struggled and battled illnesses (1)
  - b. This is different for me than those who lost children in other different circumstances (2). Ex: car accidents, suicide, etc.
  - c. A lot to exclude them but the opportunity to hear from these parents was very nice (3)
- ii. Instrumental support
  - 1. UN7-ECS09P: meeting kids facilitators (3)
  - 2. F6-ECF09D: meeting with facilitators of our boys different age groups (3)
  - 3. F9-ECF10: talking with the facilitators (4)
  - 4. F8-SCS09M: the help that you give to the children (1)
  - 5. F1-ECF13M: the care shown for our children (4)
  - 6. F4-SCS13M: and even more, the care of our children (3)
  - 7. F9-ECF09M: child care for parents to have a chance to do something without worrying about our children or chasing them around (1)

8. F11-ECF10: child care (1)
9. UN2-ECF10: I truly trusted the staff with my child (2)
10. UN10-ECF12P:
  - a. I love how you have the kids totally covered (1)
  - b. I don't have to worry about them and can concentrate on what I'm doing (3)
11. F3-ECF13D:
  - a. Safety of children (1)
  - b. And their level of freedom provided them (2)
12. F4-ECS12D: knowing my kids are safe (4)
13. F1-ECS14D:
  - a. I like that so many staff are assigned to each age group (1)
  - b. I feel my boys are safe because they are playing with others not too old or too little for them (3)
14. F3-ECF10D: safety and security (1)
15. UN2-ECF10P: the safe environment (1)
16. F13-ECF12P: great staff! (1)
17. F10-ECF12M: seeing the staff who I love too again (2)
18. F13-ECF13M: also how wonderful the staff was for us and our daughter (2)
19. UN1-ECS10P: volunteers (1)
20. F19-SCS11M: the people that help the families (1)
21. F5-SCS12D: the staff was very attentive to the families (1)
22. F9-SCS12D: That there are many people and volunteers that donate their time so that this reunion is possible (1)
23. F10-ECS12D:
  - a. The staff was very thoughtful of everything (1)
  - b. And they tried to make sure all our needs were met (2)
24. F16-ECS12M: enjoyed every staff member (2)
25. F14-SCS13D: the staff (3)
26. F4-SCS13M: my son's group leader (3)
27. F3-ECF10D: staff (3)
28. F11-ECF10: Staff (2)
29. UN16-ECS10P: it is apparent that the camp staff are patient about the camp's purpose (2)
30. F1-ECS14D: the staff is wonderful (4)
31. F12-ECS09D:
  - a. Staff/volunteers (4)
  - b. The volunteers and directors were so attentive to the needs of the families and delivered satisfaction with smiles and such a degree of professionalism all the time (5)
  - c. The Camp John Marc staff were an inspirational group of young men and women too (6)
32. UN11-SCS14P: all the staff (2)
33. UN9-SCS14P: the kindness of staff (1)

34. F2-ECF10M: I can't express how thankful we are to yall for all the work and time you put into this (2)
35. F2-ECF11M: I wish the volunteers understood how much it means to us. We are so thankful. I just can't say enough about how you ALL go above and beyond!!! (6)
36. UN9-ECS10P: Friendliness of the camp (1)
37. F7-ECS10P: friendliness (2)
- iii. Appraisal support
  1. UN2-ECF09P:
    - a. I liked hearing all the stories (although they were so sad) (1)
    - b. It helps to be with others experiencing the same feelings (2)
  2. UN15-ECS10P:
    - a. The favorite thing is that we got to understand better the grieving process (1)
    - b. And know that we all suffer (2)
  3. F10-ECF09M: feeling of belonging (2)
  4. F15-ECS09M: it helped to be with other brain tumor parents (2)
- b. Child Social Support
  - i. Peer/emotional support
    1. F2-ECS10D: kids chance to bond with kids of like experience (1)
    2. F6-ECF13M: groups for kids to talk and be with other grieving kids (2)
    3. F6-ECF13D:
      - a. Kids getting to connect with a purpose (1)
      - b. The kids being involved (2)
    4. F18-ECS12M: kid having time with other children (3)
    5. UN13-ECS09P: the fact that our child gets to be part of a group where she isn't different (2)
    6. F9-ECF10: peers for my son (3)
    7. F1-ECS09M:
      - a. My daughter getting to see old friends (2)
      - b. And meet new ones (3)
    8. UN12-ECS10P: I love that my child is getting therapy and doesn't even know it (3)
- III. Family interaction
  - a. Family time
    1. F1-ECF09D: time with my family (1)
    2. F2-ECF10D: setting aside time to connect as a family (2)
    3. F6-ECF10P:
      - a. Playing together (1)
      - b. And also eating together as a family (4)
    4. F9-ECF10: family togetherness (1)
    5. F12-ECF11M: family time (1)
    6. UN1-ECS13P: family meals (2)
    7. UN8-ECS11P: the togetherness (1)

8. F8-ECS11M: family time (1)
9. F11-ECS12M: Due to busy schedules we don't spend much family time (2)
10. F13-ECS10G: family time (1)
11. U2-ECF11P: spending time with family (1)
12. F17-ECF12M: time together (1)
13. UN2-ECF12P: family time (1)
14. UN6-ECS11P:
  - a. Family time (2)
  - b. All of us going to sleep in the same room at the same time (3)
  - c. Quiet time to talk (4)
15. F11-ECS11M: family time (2)
16. UN3-ECF12P: family time (1)
17. UN8-ECF12P: family time (1)
18. F2-ECF13M: (ropes course)...good family encouragement time (2)
19. F6-ECF13M: time as a family (5)
20. F8-ECF13M: Family time...(1)
21. U11-ECS10P: we just love what you guys let us do as a family (1)
22. F18-ECS12M: family time (1)
23. UN2-ECS12P: family time (1)
24. F1-ECS13D: quality family time (1)
25. F3-ECS13D: family dinner (4)
26. F2-ECS14M: I just love the family time (1)
27. F1-ECS09M: the family spending time together (1)
28. F2-ECS09D: time with family (1)
29. UN8-ECS09P: time spent as a family (1)
30. F8-SCS09M: to be together (2)
31. F13-ECS09D: being with my family (2)
32. UN10-ECS09P: we just love that we get to do these fun things together as a family (1)
33. UN9-ECS09P: Just being away from home (1)
34. UN1-ECS12P: watching my child laugh and play at camp (3)
35. UN7-ECF13P: watching the kids have fun (1)
36. UN3-ECF13P:
  - a. Loved the break (1)
  - b. We walked through camp in places that we don't typically get to walk through during scheduled events...saw 2 deer as a family, walked through 3 tree houses (2)
  - c. Was most fun family bonding time we had (3)
37. F15-SCS12M: sharing fun times with my children (2)
38. F9-ECF11M: just seeing my boys smile and having so much fun (1)
39. UN1-ECS09P: the time to focus on and enjoy my kids is primary (1)
40. F3-ECS13M: time with kids (1)

41. UN2-ECF13P: spending time with my kids (1)
  42. F1-ECF13D: time with my kids (1)
  43. F11-ECF12M: being able to do many activities with my children (1)
  44. F11-ECS12M: Doing family activities with my child (1)
  45. F11-ECS12M: the time I had here with my daughter was priceless (3)
  - b. Refuge/retreat for family
    1. UN8-ECF11P: having a weekend set aside to focus on our loved ones (1)
    2. UN7-ECF12P: a chance for our family to get away from everyday life (1)
    3. UN4-ECF13P: enjoy the get away down time from "normal" life like the opportunity to do some things as a family (1)
    4. UN17-ECS10P: overall: formal time to take a break from normal life to remember and honor our son (2)
    5. F13-ECS11M: away from life...no phone!! (1)
    6. F13-ECS09D: getting away from home and normal stress (1)
    7. F2-ECF11M:
      - a. There are too many to say- but I think the main thing is that camp Sol is a refuge for us (1)
      - b. Even though it was so hard I remember looking around and seeing others smile and laugh (2)
      - c. Looking back I see that I felt freedom here to be happy even though it still hurt so bad (3).
      - d. I was with others that were not watching me- trying to see if I was ok or wondering how I could be happy at such a time (4)
      - e. I felt freedom to be happy or sad- whenever I wanted (5)
      - f. Being here heals me (6).
    8. UN9-ECS09P: it was a peaceful and relaxing time to remember our daughter/sibling (1)
    9. UN1-ECF09P: peacefulness away from the normal day to day stuff (1)
  - c. Spousal interaction
    1. F4-ECS12D: I enjoyed being able to share the weekend with my wife (3)
    2. F6-ECF13M: time away from kids (1)
- IV. Camp environment
- a. Amenities
    - i. Nature
      1. F14-SCS11M: nature (1)
      2. F14-SCS11D: nature (2)
      3. F16-ECS12D: I enjoyed the atmosphere (1)
      4. UN14-SCS09P: nature (1)
      5. UN15-SCS09P: nature (1)



6. F14-SCS13D:
  - a. The trees (1)
  - b. Lake (2)
7. F8-ECF09M: the serene environment (2)
8. F12-ECF09D:
  - a. The peace and quiet (2)
  - b. The wild life (3)
9. F2-ECF10D: enjoying the peaceful setting at Camp John Marc (4)
10. UN16-ECS10P: the peaceful setting of the camp (1)
11. F12-ECS09D: Camp John Marc (3)
12. F12-SCS14M:
  - a. The location makes you feel you are in vacation (1)
  - b. Camp is beautiful (2)

#### ii. Facilities

1. UN8-ECF11P: the facilities (we love camp sol!) (4)
2. F13-SCF09D: I really like the cleanliness of the camp (1)
3. F3-ECF10D: cabins (2)
4. F10-ECF10: clean (1)
5. F4-SCS09M: cabins (1)
6. UN11-SCS14P: cabins (1)

#### iii. Food

1. F4-ECS14D: eating (1)

#### b. Structure

##### i. Organization

1. F10-ECS11D: everything very organized (1)
2. F13-SCF09D: the organization (2)
3. F10-ECF10: well-organized (2)
4. F7-SCS14D: I like the order that there is (1)
5. UN3-ECS11P: that things are optional—not forced (2)

#### V. Communication pertaining to the deceased child

1. UN8-ECF11P: talking about our lost children with our family and others (2)
2. F9-ECF13M: talk about our child that we lost (2)
3. F11-ECS10G: talking about child (2)
4. F4-ECS11D: talking about loss (1)
5. F4-ECS12D: and of being able to speak of our loss without having reservation (2)
6. F2-ECF10D: talking/thinking about the children we lost (3)
7. F11-SCS09P: sharing in group (3)
8. UN12-SCS14P: sharing with families (1)
9. F5-ECF09D: sharing in formation with other fathers and families about our deceased children's journey (1)
10. F5-ECS14D: pushing myself out of my comfort zone to talk about my deceased daughter (1)
11. UN7-ECF11P: the only time were given to express our situation to other families (1)

12. F14-ECF12M: You are given the opportunity to speak about your feelings. (3)
13. F1-ECF09M: giving us the time to think/talk focus on our grief in a supportive network (1)
14. F5-ECF09D: sharing our feelings regarding this journey (2)
15. F13-ECF13D: my wife open up and face what had happened finally (1)

#### VI. Miscellaneous

##### a. General evaluation of Camp Sol

##### i. Overall experience

1. UN9-ECS10P: Good experience (1)
2. F13-ECF13D: I would like and love to come every year! (f4)
3. F16-ECS12M: good experience (1)
4. F4-ECS10D: my kids loved camp (2)
5. F16-ECF12M: my daughter loves it, smile on her face the whole time (1)
6. F3-ECS14D: being catered to (1)
7. F1-ECS14M:
  - a. Thank you, camp sol, for always being so laid back and encouraging with us high-anxiety parents (4)
  - b. You put us at ease and love on us, and love on our kids (5)
  - c. We are grateful for you in our lives, and we love you guys (6)

##### ii. Suggestions

1. F6-ECS14D:
  - a. A suggestion would be to mix up the groups if possible. (2)
  - b. My group this year was many of my friends. (3)
  - c. It worked, but there was no need to really ever introduce ourselves (4)
2. F3-ECF12M: I feel maybe less activities on Saturday so to be able to get to know more families (2)
3. F1-ECS14M: I wish we had another parents group on Sunday morning (with the same group as Saturday with an opportunity to go deeper) instead of the Saddle room parent meeting. (2)
4. F5-ECF13M: I think it might be a good idea for camp sol to have its own private Facebook group that families could join and keep connected throughout the year (1)

##### iii. Camp improvements

1. F10-SCS09M: camp improves every year (1)
2. UN3-ECS12P: good idea about cutting lunch on Sunday (1)
3. F18-ECS12M: I thought food was better (4)

##### iv. Personal improvements

1. F12-SCS14M: looking forward to changes (3)

## Appendix F

*Parents' Qualitative Raw Data for Least Favorite Aspect of Camp*

- I. Camp environment
  - a. Amenities
    - i. Food
      1. F6-ECS10M: food (1)
      2. F16-SCS11D: food (1)
      3. F13-ECF10:
        - a. Meals (1)
        - b. Need alternate to hamburger on kids meal night (2)
      4. UN5-ECS11P: meals (1)
      5. F4-ECS12D:
        - a. I would have been ok with being asked to bring more of our own food (1)
        - b. The meals (understandably) were less than appetizing (2)
        - c. Better coffee (3)
      6. F5-ECF10: thanks for the food, but this sadly was my least favorite part of camp...sorry (1)
      7. F1-ECF12M: food (1)
      8. F1-ECF12D: food (1)
      9. F16-ECF12M:
        - a. Meals (1)
        - b. No high chair so meals very stressful (2)
        - c. Didn't get to talk to other families (3)
      10. UN3-ECF12P: food (1)
      11. UN8-ECF12P: food (1)
      12. F1-ECF13M: food (1)
      13. F1-ECF13D: food (1)
      14. F10-ECF13M: meals are still kind of goofy (1)
      15. UN1-ECF13P:
        - a. The food (1)
        - b. I normally eat a lot of protein and good complex carbs. There were only simple sugars to eat (2)
      16. UN2-ECF13P: the food change...but that is so minor (1)
      17. F6-ECF09D:
        - a. Meals were better (1)
        - b. I would have liked to have more "beef" (2)
        - c. Chicken was ok (3)
      18. F5-ECF13D: need more coffee (1)
    - ii. Cabins
      1. F13-ECF10: beds (1)
      2. F3-ECF12M: beds (1)
      3. F3-ECF13M:
        - a. Lack of tissues in cabins (1)

- b. Soggy pillows (2)
  - 4. F3-ECF13D:
    - a. Tissues need to be in rooms (1)
    - b. Bottled water as well (2)
- iii. Accessibility
  - 1. UN1-ECS10P: Hard walking for my girls (we need to think more about mobility issues as a family) (1)
  - 2. F7-ECS11D: walking but that's not your fault (1)
  - 3. F14-SCS12D: too much walking (1)
  - 4. F2-ECS09D: walking (1)
  - 5. UN11-ECS09P: lots of walking (1)
  - 6. F11-ECF11M: Just a comment on safety; I know the staff were trying to reach Dr. Bob and couldn't find him- shouldn't he have a radio? (1)
  - 7. UN2-ECS14P: I didn't know how to contact medical staff in the middle of the night! (1)
  - 8. UN4-ECF11P: no cell signal :)
  - 9. UN15-SCS09P: no light in path ways at night time (1)
  - 10. F12-ECF09D:
    - a. Dark at night (1)
    - b. Lit pathways would have been nice (2)
  - 11. F23-SCS11D: there isn't much lightning (1)
- b. Nature
  - i. Weather
    - 1. UN8-ECF11P:
      - a. Rain (1)
      - b. We definitely needed it, but it made a mess! We survived though!
    - 2. UN1-ECF12P: cold (1)
    - 3. F13-ECS11M: weather (1)
    - 4. UN4-ECS11P: cold wind (1)
    - 5. F1-ECS12M: this year...the weather!!! (1)
    - 6. F5-SCS12D: the rain (1)
    - 7. F10-ECS12M:
      - a. Rain (1)
      - b. And cold (2)
    - 8. F10-ECS12D:
      - a. The rain (1)
      - b. And cold (2)
    - 9. F19-SCS12D:
      - a. The rain (1)
      - b. It did not let us enjoy outdoor activities (2)
    - 10. UN1-ECS12P: the rain (1)
    - 11. UN4-ECS12P: rain! (1)
    - 12. F4-SCS13M: the weather (1)
    - 13. UN1-ECS13P: rain (1)

14. UN1-ECS14P: it was cold (1)
15. UN13-SCS14P: only the cold (1)
16. UN2-ECF09P: wish the weather was warmer (1)
17. F3-ECF12M: cold (2)
- ii. Camp grounds
  1. F8-ECS11M: being outdoors (1)
- c. Structure
  - i. Schedule
    1. UN12-ECS09P:
      - a. Not clear enough on meeting places and start/stop times. (1)
      - b. They are listed but we had a lot of time this year where people were sitting around not knowing what to do or when something was going to start (2)
    2. F10-ECF12M: getting up so early (1)
    3. F6-ECS10M: knowing when it's time to stop and move on (2)
    4. F1-ECF13M: need more time between activities (2)
    5. F1-ECF13D: too little time between activities (2)
    6. F2-ECF13M: needs to have more family time together incorporated into the schedule (1)
    7. UN4-ECF13P:
      - a. It would be nice to change things up a little (1)
      - b. It is essentially the same camp each year (2)
      - c. Most of that is ok, but maybe some different plans would be nice (3)
    8. UN3-ECF13P: just that it was very much the same as last year (1)
    9. F10-ECF13D:
      - a. Structure...too much is not good (1)
      - b. Camp john marc staff advice- flexibility of just being there to help, staff, its ok if something doesn't start on time or is everything isn't covered in that time slot (2)
    10. F10-ECS12M: no mid-day down time for a power nap (1)
    11. F5-ECF12M:
      - a. I would like to maybe have one less activity (1)
      - b. Get to spend that time with family walking around (2)
      - c. Taking pictures (3)
    12. UN10-ECF12P:
      - a. I would like to have a little bit of free time in the schedule (1)
      - b. So the whole family can walk around and enjoy the ground (2)
    13. F1-ECS09M: would like more "free" time to explore! (1)
    14. UN5-ECF12P: But it was tough eating a lot of sweets between a big breakfast and a big lunch (3)
  - ii. Length of camp
    1. F1-ECS13D: only 2 days (1)

2. UN2-ECF10: it's too short! (1)
3. F7-ECF13D: it's not long enough (1)
4. F13-ECF13M: leaving (1)
5. F7-ECS09M: saying goodbye (1)
- iii. Staff
  1. F6-ECF09D:
    - a. Past camp directors were great, but I wasn't crazy about this year's camp director. (1)
    - b. He seemed a little too consumed w/ himself, and it was like it was "all about me." (2)
    - c. The past directors were more "short, brief to the point." Left more time for parents to meet w/ other parents and lead, quietly, by example + were more gracious. (3)
    - d. This director either openly delegated too much, or it wasn't very 2013 to do this or that... I didn't see any of this w/ the past directors (4)
    - e. Past camp directors seemed more helpful, and went out of their way to assimilate others (5)
  2. UN9-ECF11P:
    - a. The only complaint I have this year is the group of volunteers (excepting our familiar and beloved volunteers) were not as friendly or even helpful (1)
    - b. I had a couple of different occasions where my children were asked to find their parent, even though I was standing right there (2)
    - c. I was sad to see the emphasis on keeping the kids "corralled" instead of allowing them the freedom typically found at camp sol (3)
    - d. This approach I also found at the carnival, to the point where my youngest child was actually brought to tears (4)
    - e. It's important that the volunteers working with our children and us are empathetic, compassionate and understanding. (5)
  3. UN1-ECS09P:
    - a. Also, someone (probably a child) altered our paving stone.
    - b. Minor but upsetting. (2)
    - c. Not enough supervising of the kids at times (3)
  4. UN1-ECF13P: I had several workers ask how camp is going when I told them they all replied with its normal to feel overwhelmed your first year...I don't feel overwhelmed (2)

## II. Camp activities

### a. Parent activities

#### i. Small group sessions

##### 1. F2-ECS10M:

- a. Also, needed more time in our groups (1)
- b. We really only got to introduce ourselves (2)

- c. Needed another session probably (3)
- 2. F2-ECS10D:
  - a. Parent break out groups were too large (1)
  - b. Not as effective (2)
- 3. UN7-ECS11P: mom and dad's group on sat (1)
- 4. F10-ECF11D: could have used more time in parent group as in one group together (2)
- 5. F15-ECF12D:
  - a. I normally enjoy the parent breakout group meeting, but felt that the groups were less effective due to size (1)
  - b. 3-4 parents in a group is a good number (2)
  - c. I think people don't express themselves as much or as well in the larger groups, and I missed that connection. (3)
- 6. UN2-ECF12P: group therapy (1)
- 7. F10-ECF11D: didn't feel there was much discussion of everyone's individual experiences with their loss (1)
- 8. UN7-ECF11P: There wasn't really enough time to hear from other families about their grief.
- 9. F19-ECF12D:
  - a. I think Dads need to be asked questions to get them talking about grief (4)
  - b. What they say may help them find more in common about other grieving Dads, creates more ties to ongoing relationships beyond camp (5)
- 10. F10-ECF09M:
  - a. I would like to see more specific discussion regarding the grieving process (1)
  - b. And what to expect (2)
- 11. F1-ECS09D:
  - a. There is really nothing offered for someone who is marrying into a family who has had a death (1).
  - b. In some meetings I felt out of place because I have not experienced what the other parents have. (2)
- ii. Dad's activities
  - 1. F4-ECS14D: dad's activity where there is no formal networking or getting to know you (1)
  - 2. UN2-ECS09P: dad time (1)
  - 3. F8-ECF11D:
    - a. Wood burning (1)
    - b. It was good but did not involve cooperation or interaction among fathers (2)
  - 4. F19-ECF12D:
    - a. Dad's craft (1)
    - b. Cabin with no supplies (2)
  - 5. F4-ECS12M:

- a. My husband really came searching for connection with other dads (1).
    - b. I think the dad's activity was a miss for him (2)
    - c. And a dads breakout group was what he was yearning for (3)
    - d. And discussion going deeply (4)
  - 6. F4-ECS14D: It would be good to have a questions facilitated that elicit a response from some of the guys (3)
- iii. Parent's dinner
  - 1. F11-ECS12M: parents dinner (1)
  - 2. F11-ECS12M:
    - a. Parent's dinner (1)...
    - b. When you have no husband here with you UGH that was no fun (2).
- iv. Mothers activity
  - 1. UN2-ECF12P: spending time with other mothers (4)
- b. Continuing bond activities
  - i. Family introduction
    - 1. F11-ECS11M: introduction (1)
    - 2. F3-ECF11P: feel like introducing the other families was too quick and rushed (2)
    - 3. F15-ECF12M: introduction (1)
    - 4. F5-ECF09D:
      - a. I was uncomfortable when I knew my time was coming to talk about our child the first night, (1)
      - b. Knowing that it was going to be emotional (2)
      - c. If it had been our 2nd year, I believe it would have been easier (3)
      - d. Although I'm not suggesting that the process change (4)
    - 5. UN3-ECS09P:
      - a. 1st night was awkward (1)
      - b. Would have liked more guidance on what was going on (2)
  - ii. Scrapbooking
    - 1. F1-ECS13M:
      - a. The scrapbook time (1)
      - b. Only because I didn't have this year! (2)
    - 2. F3-ECS09M: scrapbooking
    - 3. UN1-ECS09P: scrapbooking (1)
  - iii. Quilt squares
    - 1. F9-ECS13M: quilt squares (1)
    - 2. UN3-ECS13P:
      - a. Quilt squares (1)
      - b. Nice, but no one gets to see them only here at camp (2)
  - iv. Remembrance service
    - 1. UN5-ECF11P:
      - a. Write up for remembrance service (1)



- b. I love the service (2)
      - c. But write up is so difficult (3)
    - 2. UN9-ECF12P: remembrance (1)
  - c. Family activities
    - i. Arts and crafts
      - 1. F12-ECS09D: arts and crafts (I'm a guy) (1)
      - 2. F12-ECF11D: having to be creative during the arts and crafts (1)
      - 3. F2-ECS10M: lots of time spent on crafts (1)
    - ii. Campfire
      - 1. F1-ECS14M: campfire (1)
      - 2. F3-ECF10D: campfire "coffin" story was inappropriate (1)
      - 3. F13-ECF10: campfire...no more coffin stories (3)
    - iii. Cooking
      - 1. UN5-ECS12P:
        - a. Cooking (1)
        - b. Too many people in our session (2)
    - iv. Dancing
      - 1. F5-ECS14D:
        - a. Just the dancing (1)
        - b. The too small costumes (2)
    - v. Massage
      - 1. F12-SCS13M: I would have liked massage (1)
    - vi. Yoga
      - 1. F12-SCS13M: I would have liked to have yoga (2)
    - vii. Carnival
      - 1. U15-ECS10P: carnival should end at 11pm (1)
    - viii. Fishing
      - 1. F19-ECF12D: fishing...would have liked to fish in the morning (3)
    - ix. General activities
      - 1. UN2-ECF12P: family activities (2)
    - x. Pottery:
      - 1. UN2-ECF12P: pottery (3)
- III. Camp experience
  - a. Emotionally Intense
    - 1. F9-ECF10:
      - a. All of the crying I did (1)
      - b. Not sleeping well...my common problem (2)
  - b. First-timers feeling excluded
    - 1. F5-ECS10M:
      - a. Felt somewhat excluded at time being a first timer (1)
      - b. Yet it was reassuring to know we can come back and hear of the kinship among families (2)
- IV. Miscellaneous
  - a. General evaluation comments
    - i. Suggestions
      - 1. UN1-ECS12P: small parent group have parents bring a picture (2)

2. F10-ECF11M: no alternative activities for the kids while raining during the last family activity (1)
3. UN5-ECF12P:
  - a. We really enjoyed the cooking (1)
  - b. And the volunteers who led it (2)
  - c. Maybe only do cooking in the afternoon. (4)
4. UN5-ECF13P:
  - a. I think have 3 activities with young kids is still hard (1)
  - b. It would be nice to have sitters so the older kids don't miss out on some of the fun activities because of three toddler siblings (2)
5. F6-ECF11M: Perhaps having the 13+ movie night on Friday night rather than Saturday night due to exhausted children from the day of activities as well as exhausted volunteers! (1)
6. F2-ECF09M:
  - a. Maybe make the stepping-stones an arts and craft activity instead of something else to do after making quilt (1)
  - b. I think some families didn't get a chance to make one (2)
7. F11-ECS12M: Only suggestion...maybe give the moms a stuffed animal as well as children (3)
8. F19-ECF12D: Slots for more families (2)
9. F3-ECF12M:
  - a. Maybe talk about 1 & 2 year olds (3)
  - b. Our son's age group wasn't even mentioned on Sunday (4)
- ii. Time change
  1. UN3-ECS14P: losing an hour (1)
  2. UN15-SCS09P: time change (1)

## Appendix G

*English Speaking Parents' Qualitative Raw Data***Differences as a Result of Coming to Camp****I. Social support****a. Parent social support****i. Receiving peer/emotional support**

1. F10-ECS12D: [grieve as a family] with others who understand where we are at (2)
2. UN5-ECS11P:
  - a. Good to spend another year with friends who have similar experiences (1)
  - b. Good to spend another year with newcomers who have similar experiences (2)
3. UN17-ECS10P: feeling the support from other parents who have been through this process (2)
4. F11-ECF13D:
  - a. I feel better when talking to other parents about my loss (1)
  - b. Because I feel like this is something I cannot easily do outside (2)
5. F16-ECF12M: Got to talk to another mom about guilt over the relief I felt after my son's death (2)
6. F11-ECF11M: feel more connected with the families this year (1)
7. F12-ECF10: Felt more connected with other families (1)
8. UN14-ECS10P: new friends (1)
9. F4-ECS12M: I was able to connect with some of these families through social media (1)
10. UN9-ECS11P:
  - a. It has been very beneficial to get to know the other families better (1)
  - b. It allows us to communicate more deeply because we know each other better (2)
11. F1-ECF13D: nice to meet other parents/fathers (1)
12. UN6-ECS12P: great feeling to be around others [1]
13. F1-ECF13M: I feel my family made friends who will be supportive for years to come (1)
14. UN11-ECS09P:
  - a. connect with other families outside of camp (2)
  - b. and others in similar situations (3)
15. F2-ECF13M: I know that is it a safe place among friends to talk about their feelings and bond with each other
16. F9-ECF13M: and get to meet and understand people with the same feelings we have (2).

17. F9-ECF10: I love being able to grieve with others who understand (1)
- ii. Appraisal support
  1. F5-ECF09D: It's so unfortunate, but I realize that we are not alone in our story [2]
  2. F15-ECS09D: I realized that we are not alone in our loss (1)
  3. F4-ECS12D: I feel like we are not alone (1)
  4. F4-ECS12D: That there are more families that I thought that share the same feelings [2]
  5. F11-ECF09D: It's good to know each year that we are not alone (1)
  6. UN16-ECS10P: It was a good reminder of how our family is not the only one dealing with the loss of a child (1)
  7. F8-ECS11M: others are experiencing the same things (2)
  8. F4-ECS12D:
    - a. I feel like we are not alone (1)
    - b. ...that there are more families that share the same feelings (2)
  9. UN13-ECS09P:
    - a. Being at camp helps to remind me that we are doing okay (2)
    - b. and that we are normal (3)
  10. UN3-ECS09P: don't feel as alone in my grief (1)
  11. F3-ECF10D: not as alone as I thought (1)
  12. F2-ECF10D: It also help you to have hope when you see other couples that have made it through their tragedy (4)
  13. F10-ECF09D:
    - a. Helpful to hear from families in similar situations (1)
    - b. I will feel more comfort in knowing that (2)
  14. UN7-ECF11P: I felt more comfortable this year because I know/or knew of each families' story (1)
  15. F8-ECS11M: It is easier for me when I learn from other families that we are not crazy (1)
- iii. Providing peer/emotional support
  1. F11-ECF09D: we love helping other families too (2)
  2. F12-ECF10: Enjoyed being a host family (2)
  3. F16-ECF10: it is good to mentor new families through their grief (1)
  4. UN1-ECF10P: it feels great to be able to help other families (1)
  5. F11-ECF11M: I'd like to be a host family next year (3)
  6. F12-ECF11P: I feel like I can be there to help new families (1)
  7. F15-ECF12D: I look forward to coming in the future to help other families (2)
  8. F1-ECS12M: meeting with a new family that I could offer some guidance to (1)

9. F2-ECS09D: [it's our 3<sup>rd</sup> year and it is much easier to explain our personal grief process] to help others (2)
10. F4-ECS12M: [I was able to] give and offer support that we all may not have in our lives as much as we would like (2)
11. F4-ECF10M: I felt more of a desire to comfort other new families (3)
12. F3-ECF13D: a shift from having a focus solely on my own honor child and more onto the other families (1)
13. F1-ECF12D: more empathy (2)
- iv. Instrumental support
  1. UN17-ECS10P: feeling the support from staff (1)
  2. F9-ECF10: [I love that my son was able to talk to the facilitators since he won't talk to me) ...and hearing that he is doing okay from them [facilitators] (2)
  3. UN11-ECS09P: ...things from facilitators to follow up with kids (1)
  4. F10-ECF13M: even though we have been coming a long time. I still hear new ideas, suggestions and view points (1)
- b. Child social support
  - i. Receiving Peer/emotional support
    1. UN4-ECF13P: Nice for them to meet other kids with the same experience (2)
    2. F4-ECS12D: It also gave me insight into the fact that our boys (3 1/2) will have chances to make friends and grow up with kids that share the same loss (3)
    3. F15-ECS09M: It really helps my daughter to find friends her age that have experienced what she is going through (1)
    4. F12-ECF09D: my son relates very well with kids with similar situations (1)
    5. UN5-ECS09P: give them this time to share their loss (2)
    6. F2-ECF11M:
      - a. Camp sol helps my children to be around others like them (3)
      - b. There is a precious almost strange connection they make with these children. They just understand. (4)
    7. F2-ECF13M: I knew and continue to know that my children needed to be around other children that were experiencing the same feelings as them (2)
    8. F10-ECF13D:
      - a. Adrienne started by not jumping into the mix of things (1)
      - b. But by Saturday morning, she couldn't help herself. (2)
      - c. I'm not complaining at all; this is why I love her so much (3)
    9. F3-ECS13M: with our son almost being a teenager, I hope this was a small part of reminding him that we have his back no matter what happens and that we are always here for him (1)

10. F9-ECS11M: We continue to need support for our daughter to make sure that she is continuing to process everything ok (1)
  11. UN8-ECS09P: I'm glad all had an opportunity for our children to share their experience with another caring person other than us (1)
  12. F9-ECF10: I love that my son was able to talk to the facilitators since he won't talk to me
  13. F8-ECF10D: good for them to understand that their grief is important to me (2)
  - ii. Appraisal support
    1. UN3-ECS14P: my kids feel like their not alone in the process (1)
    2. UN5-ECF11P: love that my kids know they are not alone in experiencing the death of a sibling (1)
- II. Communication
- a. Ease of communication pertaining to the deceased child
    - i. with others in general
      1. UN4-ECF10: it will be easier for me to talk about my deceased children (1)
      2. F11-ECF12M: it is easier for me to discuss the loss of my child (1)
      3. UN11-ECS10P: it was a little easier this year to talk about things (1)
      4. UN13-ECS09P:
        - a. I think more we come the easier it gets for all of us to share our loss with others (1)
        - b. And to talk to others about their loss (2)
      5. F11-ECS12M: the experience made it easier to discuss the death with others who understand (1)
      6. F4-ECF10M: I felt more comfortable and wanting to talk about my experience (2)
      7. UN9-ECS09P: I feel more comfortable talking to others about our experiences (1)
      8. F4-ECS10D: easier for me to talk with other parents (1)
      9. UN7-ECS11P: although still hard, it got a little easier to talk about my child (1)
      10. UN4-ECS12P: more openness as a family about our loss (1)
      11. F2-ECF09M: ...and talk more freely about baby [my son] (2)
      12. F13-ECF12P: talk about my daughter more openly (1)
      13. F10-ECS13M: Talking openly about the death of my daughter (1)
      14. F1-ECF12D: Learning to be more comfortable with others (1)
    - ii. With surviving children
      1. F8-ECF11D: it will be easier for me to talk to the kids (1)
      2. UN10-ECF12P: I think this weekend will help us and her to talk about it better (2) [the loss of sibling]
      3. F13-ECF13M: it will be easier for my husband and I to talk about our child with our surviving daughter (2)
      4. F6-ECF13D:
        - a. I'm excited about a connection point for my daughter (1)

- b. Something in common with her (2)
    - c. I think it could provide a focus or direction for our conversations (3)
  - 5. UN6-ECS11P: Learned it is easier for my child to talk without being face to face (2)
  - 6. F10-ECS11D: more confidence between parents and children (1)
  - 7. UN7-ECF13P: better understanding of how to talk to my son (1)
  - 8. F9-ECF11M:
    - a. I have a better understanding about how to speak with my children (1)
    - b. And I understand if they don't feel like speaking about the deceased, just to leave them alone (2)
- iii. With Spouse
  - 1. F13-ECF13M: It will be easier for my husband and I to talk about our child with each other (1)
- b. Emotional expression
  - i. Parents
    - 1. UN8-ECF12P: comfortable sharing feelings (1)
    - 2. F2-ECF11M: I'm so thankful that this camp helps me to get that stuff out (2)
    - 3. UN10-ECS09P: it may be a little easier to express my feelings with the kids (1)
    - 4. F7-ECS09M:
      - a. Everyone here is used to and not afraid of tears. [3]
      - b. At home people try so hard to keep me from crying. They watch what they say and do, so afraid of my tears. [4]
    - 5. F2-ECS09D: it's our 3<sup>rd</sup> year and it is much easier to explain our personal grief process (1)
    - 6. F1-ECF11M: Or I don't feel I have to keep certain feelings at bay (3)
    - 7. F11-ECS10G: it is okay to still grieve my child (1)
  - ii. Surviving Children
    - 1. F1-ECF09M: It will give me an opportunity to talk to my son about grief feelings [1]
    - 2. UN5-ECS09P: it gave my children this weekend to grieve if they haven't (1)
    - 3. F11-ECS12M: Most important camp sol allowed my child to express her feelings of loss of her sister with other her age that along is priceless [2].
    - 4. F2-ECF09M: ...and let him know that it's okay for him to express whatever feelings he has (3)
    - 5. UN10-ECF12P: my youngest (legacy child) has been very expressive about missing their brother (1)
    - 6. F6-ECF12M: a chance for my child to grieve more openly (1)
    - 7. UN7-ECF12P: I feel that it will help my children cope with the loss of their sister (1)

8. F1-ECF10M: and it is safe to talk about and be in their grief at any time. (2)
- iii. Family
  1. F10-ECS12D: it allowed us time to grieve as a family (1)
  2. F1-ECF11M: I am more open with my husband and kids as a family regarding my feelings at different times (4)
  3. F5-ECF13D: having the family open up more about grief (1)
- c. Open communication
  - i. With surviving children
    1. F2-ECF09M: I'm going to be more open with my oldest son (1)
    2. F1-ECF10M: ensuring with my kids that the door is always open (1)
    3. F17-ECF12M:
      - a. Look forward to hearing more from kids (1)
      - b. an opening for us to ask (2)
- III. Increased knowledge of grieving process
  - a. Developmental stages and grief process in surviving children
    1. F8-ECF11M: I have a better understanding about children's mourning (1)
    2. F2-ECS10D: Better understanding of children's grief process (1)
    3. F2-ECS10M: better understanding of the kid's grief (1)
    4. F1-ECF13M: I also understand a bit more of my children's age group level of grieving and understanding (2)
    5. F9-ECS13M:
      - a. I feel better about helping my child (1)
      - b. Understand her feelings better (child) (2)
    6. F5-ECF12M: I have a better understanding how my kids deal with the loss of their sister (1)
    7. F12-ECS09D: I have learned to expect differences in the way my child deals with grief as age groups [1]
    8. F13-ECS11M: understand how my children process as they grow (2)
    9. F1-ECS12D: I think that it will help me understand better my children's grieving process [1]
    10. F10-ECS12M: gained more insight into how children continue to grieve through the years [1]
    11. UN1-ECS12P:
      - a. I hope to remember what my kid is going through (1)
      - b. And to have more patience with her (2)
    12. UN1-ECS09P: camp helps me identify where my children are in their individual grief journeys (1)
    13. UN3-ECS11P: Better understanding on development of children and their grief (2)
    14. F14-ECF13M: I have a better understanding of how to help my son through this devastation (2)



15. F12-ECF13M: I have a better understanding about kids mourning at a certain age (1)
16. UN1-ECF09P: More understanding of my child's emotions [1].
17. F4-ECF10D: understanding phases of children's grieving process
18. F8-ECF09M: Easier to understand a 7 year old child's way of handling grief [1]
19. UN2-ECF10P: Also the stages that children go through [2]
20. UN2-ECF12P:
  - a. I had more understanding of behavior issues with my children (1)
  - b. I could recognize the areas of grief (2)
  - c. I can recognize the struggles rather than thinking its just bad behavior instead of it being grief (3)
21. UN12-ECS09P: it helps us know where our child is today emotionally and what things they need (1)
22. F6-ECF13M: realizing that even though our 5-year-old (and eventually our 2 year old) doesn't talk a lot about the deceased child, she is on her own grief journey (1)
23. F10-ECF10:
  - a. I discovered that the young people act differently due to the change of the grief process (1)
  - b. And I can help them more (2)
24. UN6-ECF11P: I like the insight into what my kids are feeling (1)
25. UN12-ECS10P: I feel like I have better insight on how my child is thinking and feeling (1)
26. F13-ECS11M: understand how my children process as they grow (2)
27. F5-ECF13M: it is helping my understanding of grieving as my son is growing and developing (1)
28. F8-ECF10D: It is good the kids understand that I can also grieving (1)
29. UN4-ECF13P: my kids keep getting more comfortable with understanding losing their brother (1).
30. F12-ECF11D: hope my children can process better (1)
31. F2-ECS13D: that even with our legacy child he is continually processing the loss of his sister that he never met (2)
32. F3-ECF10D: I can walk my daughter down this path of grief with more confidence, understanding, love, wisdom, etc. (3)

b. Parents/spouses

1. UN1-ECS09P: camp helps me identify where I am individual grief journey (1)
2. F13-ECF10M: I now understand why it can be healing to come for several years [1]
3. F1-ECS13D: I feel that I can understand her better each time (2)
4. F1-ECS09M:
  - a. My fiancé gets a glimpse of my thought process [1]

- b. During everything through meeting everyone else and talking to others (2)
      - 5. F1-ECF10M: I have the tools to now work with my husband to ensure that he is moving on and dealing with grief in a healthy way and not suppressing. (4)
      - 6. F2-ECF13M: I think I had a good grasp of handling/understanding/communicating the grief process as a couple
      - 7. F5-ECS10M:
        - a. I feel a deeper appreciation for the depth of the grief my husband is keeping inside (1)
        - b. and wish he would express it more to me and my daughter in appropriate ways (2)
      - 8. F19-ECF12D: I've been impatient this year not understanding how my wife grieves (2)
    - ii. Acceptance of death of child
      - 1. F3-ECF09M: we are all more accepting this year (3)
      - 2. F1-ECF12M: simply to accept that this is a lifelong journey (1)
  - c. Family grief process
    - 1. UN10-ECS10P: I have a better understanding about the family mourning (1)
    - 2. F7-ECF12M:
      - a. I understand my family mourning better (1)
      - b. We all grieve differently (2)
    - 3. F5-ECF09D: I have a better understanding about family mourning [1].
    - 4. F3-ECF09M: Better understanding of our family grief [1]
    - 5. F6-ECF13M: and it is a family process, not just me and my husband (2)
  - ii. Inclusion of legacy child
    - 1. F3-ECF13M: A better understanding of how to include a legacy child (2)
    - 2. UN2-ECS12P: easier to bring our youngest child (born after death of sibling) in to the fold [1]
  - d. Individual differences in the grief process
    - 1. F14-ECF13M: I have a better understanding how people all grieve differently (1).
    - 2. F3-ECF09M: better understanding of how each one of us mourns differently (2)
    - 3. UN2-ECF10P: understanding how differently people grieve [1]
    - 4. F2-ECS13D: camp is a reminder that we are grieving differently (1)
    - 5. F1-ECF10M: There is no right or wrong time to grieve (3)
    - 6. F19-ECF12D: I will have a better attitude towards the grieving process with those around me (1)
- IV. Adjustment of the grief journey

## a. Moving forward

1. UN1-ECF10P: I can see where I was before and how far I've come with my grief (2)
2. F1-ECF11M: I truly feel that I am at a different place now regarding my child's death (1).
3. F7-ECF13D: I do feel that after 4 years I am in a better place than I was after 1 year (2)
4. F13-ECS11M: truly being able to grow (1)
5. F11-ECS13M: every year seems to get a little easier (1)
6. F3-ECF11P: each year it is getting easier to come (1)
7. F4-ECS14D: better adjusted (2)
8. UN1-ECS14P: it does seem to get easier with time (1)
9. F11-ECF09M: grief has gotten easier (1)
10. F15-ECF10: it will be easier to order my son's headstone (1)
11. UN2-ECF11P: Camp seemed easier for me this year compared to past years (1)
12. F3-ECF12M:
  - a. I feel maybe time will help make it easier (1)
  - b. 8 months is not enough (2)
13. F15-ECF12D: I feel like our family is doing well in the grieving process (1)
14. F3-ECF13M: realizing how far we have come as a family (1)
15. F3-ECS11M: It helps our family to know that in several years we will continue to survive (1)
16. UN2-ECF09P: The doctor pointed out several things that will help our family relationships grow in a more positive way [1]
17. F2-ECF10M:
  - a. I am able to see each year perspective on my healing (1).
  - b. I look back to exactly one year before at camp and am able to use that as a marker to see growth, healing, etc.(2)
  - c. Healing is so gradual, so slow sometimes you feel like you are not even moving (4).
  - d. But camp reminds me that I am different than the year before! (5)
18. F2-ECF10D: It helps me to be mindful of where we have been, where we are and where we are headed in the grief process (3)
19. F2-ECF11M: Each year reminds me that there is still healing to be done (1)
20. F6-ECF11M: continue to learn how to live and not simply exist
21. UN6-ECS09P: easier for me next time
22. F3-ECS09M: I feel better this year than last year (1)
23. UN5-ECF13P:
  - a. Being further out on this journey (1)
  - b. And being here made it easier knowing what to expect from camp (2)
24. F14-ECF12M:

- a. Just the fact to know that it doesn't get easier (1)
    - b. It's just learning to live with this hurt (2)
  - 25. F6-ECF11M: continue our grief work (1)
  - 26. F4-ECF09M:
    - a. A little piece of me has been tended to, and a little piece has been healed! (1)
    - b. I hope it is the same for my son! Thank you! (2)
  - b. Improved mood and negative feelings
    - 1. F10-ECF12M: I feel more peace in my heart
    - 2. UN14-ECS10P: feel more peace (4)
    - 3. UN13-ECS10P: relaxed (1)
    - 4. F13-ECS09D: I feel kind of relaxed (1) [where as I have experienced a lot of stress lately]
    - 5. F10-ECF13D: we had a really stress free start (2)
    - 6. F1-ECF11M: I do not feel overwhelmed with grief (2)
    - 7. UN14-ECS10P:
      - a. Leave more comfortable (1)
      - b. More ensure (2)
      - c. Less irritated
    - 8. F3-ECS09M: it has really help me with my anger (2)
    - 9. UN1-ECS10P: lighter, almost like relief at letting go of a lot of stuff clouding me (1)
- V. Family interaction
  - a. Refuge/retreat for family
    - 1. F5-ECF10: Camp Sol is our solace (1)
    - 2. F13-ECS09D: I think getting out in the woods can be great for you (2)
    - 3. F1-ECF11M: Camp sol has truly made an impact on my life and my kids and now... my husband (5)
    - 4. F4-ECF13M: camp sol is truly a retreat for me and my boys (1)
    - 5. F5-ECF10: Camp Sol is our place to heal every year (2)
    - 6. F5-ECF10: Camp Sol is a sacred place to our family (3)
    - 7. F2-ECF10D: coming to camp sol helps me to personally focus my thoughts on our children both living and in heaven (1)
    - 8. F2-ECF13M: that is how this camp greatly benefited us. Allow us some great time away to focus on our grieving away from the business of life! (4)
    - 9. F4-ECF13M: We feel that we have a place to go that no one else does and that makes us feel special (2)
    - 10. F9-ECF13M: it's a magical place where my family feels very comfortable and loved (1)
    - 11. F1-ECS13M: We just had a loss of our niece- cousin this week so it was nice to come release from that for us and the kids (2)
    - 12. F10-ECF13D: We came as a family this time (1)
    - 13. F3-ECS13D:
      - a. Allow you to take time out to reflect back (1).

- b. Remember what's important (2)
      - c. And be grateful (3).
    - 14. UN8-ECF11P:
      - a. Camp is a great "reset button" for our whole family (1).
      - b. We come to camp to reflect on the past year (2)
      - c. And plan for the next (3)
  - b. Family bond and prioritization
    - 1. F10-ECF11D: I think it always brings us closer together (1)
    - 2. F15-ECF12M: more connected as a family (1)
    - 3. F7-ECS11M: I'll be closer to my family (1)
    - 4. F2-ECS12M:
      - a. We connected more with less frustration with on another (1)
      - b. I feel our family trying to connect with each other more (2)
    - 5. F7-ECS09M: this experience really helps draw our family together (1)
    - 6. UN1-ECS13P: feel that reconnected with family (1)
    - 7. F2-ECS14D: I feel that each year I become close to my family through this experience (1)
    - 8. F1-ECS13D: I always feel closer to my wife after these weekends (1)
    - 9. F4-ECS14D: better with each other (3)
    - 10. F1-ECS09D:
      - a. I feel that this camp will help me to be a great husband and father figure (1)
      - b. Because I got to see another side of the family and the other families and it make me want to not let them down (2)
- VI. Continuing bonds as a coping skill
- a. Honoring/Remembering the deceased
    - 1. F15-ECF12D: [I look forward] to remember and dedicate time for our own son we lost (3)
    - 2. F7-ECS09M: it is safe place to remember our son (2)
    - 3. UN9-ECF11P: One more year that I am able to honor my child in a way that is indescribable and vital to my continuous health as a man, person and parent (1)
    - 4. F5-ECS14D:
      - a. I learn that I don't grieve my daughter (1)
      - b. I refuse to allow her memory to be a sad one (2)
      - c. She gives my life meaning and purpose and for that she will always be with me (3)
  - ii. Discussion of the deceased
    - 1. F1-ECS14M:
      - a. I feel validated and encouraged to continue sharing my deceased child with the boys on such a regular basis (1)

- b. I had been encouraged by my personal counselor to intensely pull back on “deceased child talk” with my sons, my heart disagrees (2)

## VII. Miscellaneous

- a. General evaluation comments about Camp Sol
  - i. Thank you
    - 1. F9-ECF13M: Thank you so much for the support (3)
  - ii. Accomplishments
    - 1. F5-ECF10D: and (camp sol) accomplishes all the goals it sets out to do (4)
    - 2. F5-ECF09D: I also recognize the love + charity that are involved in running a camp such as this [3]
  - iii. Camp experience
    - 1. F7-ECF12M: it was a great experience (3)
    - 2. UN1-ECF13P: I believe this experience has been great for my boys (2)
  - iv. Honored to be a part of camp
    - 1. F4-ECF13M: we feel honored and privileged to be a part of camp sol history (1)
  - v. Did not gain anything from camp
    - 1. UN1-ECF13P: I feel I had a good understanding before camp and continue to have a good understanding. I didn’t gain anything from the experience (1)

## Differences in the Family Once Returning Home from Camp

- Family interaction
  - Emotional bond
    - F8-ECF11D: closer as a family (1)
    - F12-ECF11D: closer as a family (1)
    - UN5-ECF11P: feel closer as a family (1)
    - UN3-ECF11P: feeling more like a family unit (1)
    - F1-ECS12D: I believe it makes us closer every year (1)
    - F5-ECF12M: I hope we become closer as a family (1)
    - F10-ECF11D: I think it always brings us closer together (1)
    - UN10-ECS09P: I would hope it would help us to be closer as a family (1).
    - UN6-ECS09P: more closer (1)
    - UN3-ECS13P: bring us closer together (2)
    - F1-ECF12D: we are closer as a family unit
    - F6-ECF12M: we may feel closer as a family (1)
    - F12-ECF13M: we may feel closer as a family (1)
    - UN11-ECS09P: we may feel closer as a family (1)
    - F1-ECS14M: we may feel closer as a family (1)
    - F3-ECF11P: we may feel more together (1)
    - F2-ECF10D: it reminds us that we are a team (5)

- F10-ECF09M: how we can grow together as a family (2)
- F10-ECF12M: we will feel closer (1)
- UN5-ECS09P: we'll become closer as family as we already are (1)
- F4-ECF10M: I think this helps us to become a closer family (1)
- U10-ECS10P: more unity (1)
- F1-ECS13D: make my kids stronger (2)
- U17-ECS10P: pulls everyone together as a family unit to strengthen our bonds as we face a different road today (1)
- UN1-ECS10P: we will continue to be a strong family (1)
- U1-ECS13P: make us stronger (1)
- UN1-ECS10P: we will continue to be a strong family (1)
- F1-ECS13D: I think that this will make my kids closer (1)
- F1-ECF09M: Being in camp will make us feel closer (1)
- F15-ECF12D: Camp always brings us closer together (1)
- UN12-ECS09P: camp help brings us back together including the child we lost (1)
- UN9-ECF11P: Camp Sol creates memories and strength in us as a family that otherwise would not be there (2)
- F9-ECF13M: we have been more united since we have been coming (1)
- UN1-ECS12P: we always feel closer to each other after camp (1)
- UN9-ECF11P: Continued bond that we share as a result of Camp sol (1)
- UN2-ECF12P: We are closer as a family because of camp (2)
- F1-ECF09M: The whole experience of driving here, together, spending this time together with the memory of lost child will definitely make us closer (2)
- Increased family time
  - F11-ECF12M: Definitely bond more as a family in different activities we can all do as a family (1)
  - F2-ECF09M: Definitely spend a lot more time together (1)
  - F9-ECS13M: Do more family things together (1)
  - UN10-ECS09P: We want to spend more time together (2)
  - F2-ECF10D: spending more time together (3)
  - F3-ECF09M: hopefully more family time (2)
  - F19-ECF12D: more time together (1)
  - UN9-ECS09P: spend more quality time together (1).
  - F7-ECF09M: Spend more time together (1)
  - F11-ECF09M: Spend more time together (1)
  - UN3-ECS13P: Spend more time together (1)
  - F13-ECF12P: Spend more time together (1)
  - F9-ECF11M: Spend more quality time with them at home (1)
  - F12-ECS11P:
    - Spend time together (1)

- And share more time (2)
- F9-ECF09M: we may try to spend more time together doing something (1)
- UN7-ECS11P: we plan on doing more things together as a family (1)
- U11-ECS10PL: we try to do more things together (1)
- F7-ECS11M: we'll spend more time together (1)
- F9-ECS13D: Plan more family functions together (1).
- F3-ECS13M: reinstate family night (2).
- UN4-ECF12P: Do more activities together (1)
- F6-ECF13M: more family activities (2)
- UN2-ECF13P: family game time (1)
- UN9-ECS09P: Do more family activities (2)
- F4-ECS12M: we may be open to more family activities (1)
- F1-ECF11M: we will do it together with everybody's touch (make continuing bond) (2)
- UN4-ECS11P: charades (1)
- F11-ECS12M: we will spend more time together as a family as a result of attending Camp sol. (1)
- F16-ECF12M: less electronics (1)
- F11-ECF11M:
  - Hopefully less electronics in our house- we tend to turn to TV too much (1)
  - Really enjoyed the "unplugged" time (2)
- F14-ECF13M:
  - We need more family quality time without electronics (1)
  - I loved disconnecting from everything outside of camp (2)
- F2-ECS10M: try to work on something as a family (1)
- F3-ECS09M:
  - Laugh and giggle more about camp. (1)
  - Reminisce about old time and the time we shared when we were here (2)
- Prioritization
  - Of family
    - F5-ECF09D: it reinforces that we must put priority on the foundation of our family (1)
    - UN2-ECF09P: We will work on our relationship as a couple (1)
    - F15-ECF12D: reminds me as a dad what is important (2)
    - F2-ECF10D: it always helps me to take inventory of our day-to-day lives and helps me to refocus or tweak areas to benefit our whole family. (1)
    - F3-ECF11P: help us to realize the importance of family time (2)
    - F3-ECF13D: for me, a realization of needing/giving more attention
    - F2-ECF09M: we need to cherish every moment w/ our children (3)
    - F10-ECS13M: Expressing the love for my children (1)



- F7-ECF13D: I hope (and plan) to work hard at showing more love to my children (2)
- Faith and appreciation of life
  - F2-ECF09M: Listening to everyone's story on how their child died is a reminder that life is not always a guarantee (2)
  - F1-ECF10M: still keeping God first in this journey (2)
  - UN1-ECF12P: little things matter (2)
  - UN1-ECF12P: appreciate things more (1)
  - UN5-ECS11P: appreciate where we are today more (1)
- Communication
  - Increase in open communication
    - With family
      - F13-ECS11M: Talk more about our new "family member" and how he fits in (1)
      - UN1-ECF10P: share more (1)
      - F15-ECF12M: Try to encourage them to share in their journals and with each other (1)
      - F9-ECS11M: Hopefully open more doors for communication (1)
      - F4-ECS11D: I think we will talk more (1)
      - F7-ECF12M: we might spend more time together talking
      - F3-ECS13M: make more time to just talk (1)
      - UN6-ECS12P: talk to each other more (1)
      - UN6-ECS12P: talk to each other (1)
      - F5-ECS14D: we will listen to each other a little more (1)
      - F2-ECF10D: this means talking more about what we've experienced as a family (2)
      - UN9-ECS11P: it is helpful to discussed changes (in grieving)
      - F13-ECF10M: will reopen the discussion of having another child after seeing how a legacy child can be a blessing and source of healing (1)
      - F10-ECS12D: Be more open towards each other (1)
      - F2-ECS14M: it just gives us more opportunity to openly talk (1)
      - F2-ECS14D: just continuing to be more open with each other (1)
      - F11-ECS13M: more open discussion (1)
      - F5-ECF13D: being able to open up more (1)
      - F1-ECS13M: talk more openly (1)
      - F1-ECF10M: talk more openly
    - With surviving children
      - F11-ECS11M: maybe talk more with our surviving child (1)
      - F6-ECF13M: encourage my child to talk more (1)
      - F2-ECF10M:
        - It just opens up the airway to talk with out little daughter (surviving child) (1)
        - She isn't closed to talking (2)

- We talk about the deceased children all the time but talking about how they are doing, how their little heart is, is sometimes hard. (3)
  - You hate to bring that part up sometimes, but camp just leads you there. (4)
- F14-ECF12M: As for my children they will be more open with me. (2)
- F9-ECF10M: hopefully my child will feel a little better about opening up (1)
- With spouse
  - F14-ECF12M: I am hoping for my husband to speak more openly with me (1)
  - F13-ECF13D: I personally don't talk cause I don't know what to say to my wife but I now know I can talk to her and say things about our son that passed away (2)
- Ease of communication pertaining to the deceased child
  - With others in general
    - UN3-ECS14P: as always an openness to discuss Ian (1)
    - F10-ECF09M: we will continue to grow in our ability to talk openly about the deceased (1)
    - UN2-ECS12P: open discussion of death (1)
    - F8-ECF09M: Talk and include more of our son who has gone to be with the Lord (2)
    - U15-ECS10P: talk more comfortably about child (1)
    - UN5-ECS12P: we don't worry about sharing how we feel and talking about what's happened in our lives (1)
  - With family
    - F8-ECF11M: we may talk about our daughter more as a family (1)
    - F1-ECF13M: Not be so protective of each others feelings/hurting them by talking about the child who passed (2)
  - With surviving children
    - F12-ECF13M: The kids may speak more about their sister (2)
    - F5-ECF12M: hope the kids find it easier to talk to me about their sister (2)
- Emotional expression
  - Family
    - F3-ECF09M: more open about feelings and sadness
    - UN16-ECS10P: I hope we can be more open about our feelings of grief (1)
    - F5-ECS10M: I'm hoping we can all share more openly about or grief (1)
    - UN1-ECS13P:
      - Have mix emotions that we have to talk about (1)
      - To make us stronger (2)
    - F1-ECF09M: hopefully will be easier for everyone to share there feelings (2)

- UN2-ECF11P: we should be able to express our feelings easier (1)
- F4-ECF10M: I think this helps us to become a more emotional family (2)
- F12-ECF11M: more grieving (3)
- F16-ECF10D: we can communicate our feelings more effectively (1)
- F15-ECS09M: we will communicate our grieving to each other better (1)
- F18-ECS12M: I feel that allows all of us as a family to talk about our feelings that we may not always talk about (2)
- F4-ECS12M: exploring our grief journey as a family
- F6-ECF13D:
  - The camp provided me with a chance to include the kids in my grieving process (1)
  - Prior to how I've felt pretty alone and separate (2).
  - I want to include them and this kind of broke the cycle of seclusion and frustration for me (3)
- F3-ECS13D: able to grieve together as one (2)
- F7-ECF12M: we might spend more time together grieving as a family (2)
- Surviving Children
  - F4-ECF10D: Asking more questions to our son on his feelings of deceased child (1)
  - F8-ECF13M: hopefully my kids will feel more open to talk with us about their feelings (1)
  - F13-ECS09D: I have hopes that my big girls will be a little more open in sharing their grief-based feelings.
  - UN7-ECF12P: our children will express their emotions (1)
  - UN7-ECF11P: we may hear from the kids about their individual feelings (1)
- Increased knowledge of grieving process
  - Individual differences in the grief process
    - F8-ECF10D: an understanding that each of us has his own process to go through (2)
    - F7-ECS09M: I will respect the fact that children and adults grieve differently (1).
    - F4-ECF13M: more mindful of each others struggles (1)
    - F8-ECF09M: more understanding of everyone's grief
    - F10-ECF09D: More understanding of each others feelings (1) and what is happening in the process (2)
    - F3-ECF13M: we are always more aware of another's grieving process (1)
    - F13-ECF13M: we may be able to understand the way each one of us grieves (1)
    - F12-ECF09D: we may be more understanding of others and their feelings (1)

- F5-ECF13M: we may understand each other as it pertains to our own grief (2)
- UN5-ECS09P: And understand more on how each of us grieve (2)
- F6-ECF11M: Understanding that every parent and child grieves differently.
- F10-ECF11M: Understanding each others needs better (1)
- F13-ECS13D: understanding us better (1)
- F2-ECS13D: Remembering that we all still struggle at different times (1) may help to consciously keep talking and checking in on each other's journey.
- F2-ECF10D: recognizing that we are all grieving and that is okay (4)
- F16-ECS12M: accepting each others grief (1)
- F16-ECS12D: accepting each others individual grief (1)
- F10-ECS12M: Be more accepting of the difference in our grief (3)
- F1-ECF13M: I hope we will all be more accepting of each others individual's grief needs (1).
- UN6-ECF11P: we may be more accepting of each other's individual grief and mourning needs. (1)
- F3-ECF10D: we may be more accepting of each other's individual grief and mourning needs. (1)
- F15-ECF10M: we may be more accepting of each other's individual grief and mourning needs. (1)
- UN11-ECS09P: we may be more accepting of each others individual grief and mourning needs (2)
- F2-ECS12M: we will continue to accept each other's differences better (1)
- F5-ECF10M: more understanding (2)
- F1-ECS11D: we can understand grief (1)
- UN9-ECS11P: grief process changes over time (1)
- Developmental stages and grief process in surviving children
  - UN8-ECS11P:
    - Ability to understand my children's needs (1)
    - And respond to them (2)
  - F15-ECS09D: I could be more aware of how my daughter is coping with her loss (1)
  - UN1-ECF09: I will understand my child's emotions (1)
  - F2-ECS10D: invest more time in understanding our kid's feelings (1)
  - F11-ECF13D:
    - We may understand more how our kids grieve (1)
    - And how to deal with it (2)
  - F1-ECF13D: understand that my kid's behavior may be a result of their grief (1)
  - F7-ECS09M: I won't worry about my girls just because they don't cry as much as I do (2)
  - UN10-ECF12P: I think the other kids will understand a little better. (2)

- F7-ECS10P: That our daughter has grown up and has many more questions (2)
  - F13-ECF10M: Also comforts me to know that my legacy child has not forgotten about her brother (2)
- Parent grief process
  - F1-ECF12M: understand our individual grieving processes (2)
  - UN8-ECS09P: continue to effectively manage grief especially with 1st anniversary in a few weeks (1)
  - U15-ECS10P: understand the grieving process (2)
  - UN2-ECF12P: I am better prepared for this next phase of our grief journey (1)
  - UN1-ECS09P: I feel more capable of coping with my own grief (2)
  - F11-ECS10M: It's ok how I've chosen to grieve as long as its not destructive (2)
  - F4-ECS10D: this camp helps me to understand the death of my daughter (2).
- Adjustment
  - Moving forward
    - F4-ECS11D: begin facing our loss (2)
    - F12-ECF11M: more healing (2)
    - F4-ECF09M: Camp Sol gives us hope again that our lives can be ok (1)
    - F4-ECS14D: anything (1), but we are prepared for it
    - UN12-ECS09P: It gives us an ability to start the next year fresh again (2)
    - F4-ECF09M: it also gives us something to look forward to! (2)
    - F12-ECF11M: more hope (1)
    - F12-ECS11P: we are going to be better as a family (1)
    - F4-ECF09M: Camp Sol gives us hope again that our lives can be ok (1)
  - Improvements in mood and negative feelings
    - UN1-ECF09P: and not get frustrated with him (child) (2)
    - F18-ECS12M: camp just makes me happy (1)
    - F3-ECF13D: being less grumpy (3)
    - F4-ECS10D:
      - We come back to my home more relaxed (1)
      - We spend a week without stress (2)
    - F3-ECS13D: family more relax (1)
    - F15-SCS11P: we feel more relaxed (1)
    - F3-ECF13D: for me, a realization of needing/giving more patience (1)
    - F5-ECF10M: more patience towards each other (1)
    - UN9-ECS09P: try and relax and enjoy life more (1)
  - Accepting the death of the child
    - F3-ECS11M: more accepting (1)
    - UN3-ECS09P: may not feel that we have to get over it as quickly (1)

- F12-ECF10M: dad might be more accepting and willing to talk about walker (1)
- Social support
  - Parent social support
    - Instrumental support
      - UN9-ECS10P: able to get more help (1)
      - F11-ECS10M: will seek to join other grief support (1)
      - F8-ECS11M: We will participate in the Run (1)
      - F1-ECF10M:
        - I want and plan to do more in the success and longevity of this camp (3)
        - I've been praying to God to put me where I'm suppose to be (4)
        - So many families need this! (5)
      - F4-ECS12D: we will have an actual organization or "place" to pour our fundraising and energy into (1)
    - Providing peer/emotional support
      - F4-ECF13M: being more supportive of the others difficult times
      - F3-ECF13M: we are always more supportive of another's grieving process (1)
      - F5-ECF13M: we may extend more grace (1)
      - F10-ECS12M: grace, grace, grace (1)
    - Receiving Peer/emotional support
      - UN7-ECS11P: also get together with other families from camp (2)
    - Appraisal support
      - F18-ECS12M:
        - I really enjoy being with families who just get it (2)
        - I feel somewhat normal here (3)
  - Child social support
    - Parents providing peer/emotional support
      - UN2-ECF10P: provide more helpful support during this process (2)
      - F11-ECS11M: and find a different way to help her talk about things. (2)
      - F2-ECS10M: focus on kids needs as being different and changing (1)
      - UN2-ECF10P: I will be able to better meet my child's needs (1)
    - Receiving peer/emotional support
      - F2-ECS09D: it's good for the kids to have someone to talk to that understands loss (2)
  - Family social support
    - F8-ECF10D: an understanding that we are there for each other (1)
    - F1-ECF12M: being able to support each other (1)
- Continuing bonds as a coping skills
  - Honoring/remembering deceased child
    - UN3-ECF13P:
      - Nice having a refreshed sense of honoring the child we lost (1)

- Have ideas and materials of things we could/can do at home to honor our child, etc. (2)
- UN12-ECS09P: celebrate our family including the ones we've lost (2)
- F1-ECS13M: let the kids make more choices for her Angel day or birthday celebrations
- F1-ECF11M:
  - We can now take out all of our pictures and do the scrapbooking pages for 2010 and 2011 (1).
  - It was so hard to complete 2010's page (2)
- UN10-ECF12P: we will continue to honor our missing son (1)
- UN8-ECF11P: We will talk more about our loved ones that passed away because we talked so much about them over the camp weekend (1)
- F6-ECF10: continue remembering the little girl who died openly (1)
- F2-ECF11M: we have precious memories together + they are because of our deceased children (1).
- UN9-ECF11P: continued bond that we share as a result of Camp sol (1)
- Miscellaneous
  - General evaluation comments about Camp Sol
    - Thank you
      - F14-ECF13M: thank you for everything (3)
      - F4-ECF09M:
        - And it also gives us something to look forward to! (2)
        - I am so grateful and so thankful to everyone at Camp Sol and CJM, we feel privileged to be a part of something so powerful and important! (3)
        - Thank you! (4)
      - F11-ECF10D: staff was great (1)
      - F9-ECF10M: hopefully we can talk his father into coming next year (2)
    - Suggestions
      - F3-ECS09M: maybe next year as a family introduction we could make a dream catcher or letter descriptions of our children who have died with their name (3) (example: t- talented, r-respectful, e-excellent, v-vibrant, o-outstanding, n-never giving up)
      - F4-ECS12M: I really would have loved it if all the camp sol volunteers could have just been very briefly introduced at the beginning, especially the younger volunteers. Having my kids in their care, I would have loved to have a name/face/voice connection very early on (3)
      - U13-ECS10P: for families that have been here 5+ years it may be valuable to have a session where they go 1-1 with new folks to keep them involved
      - UN3-ECS09P:

- Give out tissues in welcome bags (2)
  - Send agenda ahead of time (3)
  - Give more history on camp in packet (4)
  - Better intro activity on 1st night (5)
  - More ways to meet other families (6)
  - Camp songs at meal time to entertain kids/help parents loosen up (7)
- F13-ECF10:
  - Hot dogs, not burgers for kids (3)
  - List more info in directory so parents can seek each other out (4) (i.e. where they live/how child died, confidentiality, I know, but only have people share if they want to, maybe assign seating for meals and switch families around? seems hard to meet all the families. mom's groups...should be some structure sharing time)
  - Add to list to bring: nightlight (5)
- UN1-ECF10: Suggestion: maybe have a breakout group for legacy kids (2)
- F2-ECF10M: I'm sure you probably already heard a few people talk about the "coffin story" at the campfire. I know for sure the young guys meant nothing by their story, but it just wasn't good. Our little girl does know what a cemetery is, but during the story she asked what a coffin is. My little girl has had to see two of her siblings in a coffin. How do you explain, you know those boxes, those sad little boxes that we put your brother and sister in and then put them in the ground and left...those boxes? that is what this joke is about. I just told her he is talking about a box and because she is her mother's daughter she said, "oh the box can talk" haha. It just wasn't a good taste. If I heard that story in a mixed crowd it wouldn't have been so bad. I don't expect or want people to walk on eggshells around me but everyone here has had to deal with a coffin. That's why we are here. This year we are a host family and it was hard to hear one of our families that are new talk about this story too. They loved everything, but the story just wasn't the best pick. We know they are young and camp john marc staff; they didn't mean to be insensitive. We still like them haha (3)
- Bereaved siblings' experience at camp
  - F11-ECS11M: Note: worried about what happens once my daughter turns 18. Place for her at camp (3)
  - F2-ECF11M: It is hard knowing that they have bad memories too because of losing Emma + John Michael, but this is a good one (3)
  - F11-ECS13D: it is great for our kids (1)

## Parents' Favorite Aspect of Camp

- I. Camp Activities
  - a. Children and family activities



## i. General activities

1. UN3-ECF11P: Fun activities to do as a family (3)
2. U4-ECF11P: family activities (2)
3. F1-ECS12M: doing the family activities (2)
4. F3-ECF13M: all family activities (1)
5. UN2-ECS09P: family activities (1)
6. F8-ECF09M: family activities (1)
7. F13-ECF10: family activities (1)
8. F15-ECF12M: family activities (2)
9. F19-ECF12D: family activities (2)
10. F1-ECS13M: I love the family activities (1)
11. F12-ECF10: the family activities (1)
12. F6-ECF11M: family activities (2)
13. F3-ECF13D: family activities (1)
14. F6-ECF09D: family night at silo (2)
15. UN1-ECS13P: the activities (3)
16. F1-ECF13M: family activities (1)
17. F12-ECF09D: the various activities
18. F13-ECF12P: activities (2)
19. F1-ECS12M: I liked all the activities (1)
20. F3-ECF09M: I like how regular camp activities are included so the weekend is not all sadness and crying (3)
21. F6-ECF10P: the activities (1)
22. F12-ECF13M: activities (3)
23. F9-ECS13M: children activities (2)
24. F7-ECF12M: activities for the kids (4)
25. UN3-ECS11P: kids groups (1)
26. F2-ECF10M: Loved the little music kids did at service, so sweet (4)

## ii. Carnival

1. F3-ECF11P: carnival (1)
2. F6-ECF11M: carnival (1)
3. UN5-ECF12P:
  - a. Carnival (1)
  - b. Engaged all kids and most adults (2)
4. F3-ECS13D: carnival dance (5)
5. F10-ECF13D: carnival (1)
6. F4-ECF10D: family carnival (1)
7. F2-ECS12M: I enjoyed the carnival (1)
8. F11-ECF13D: carnival (1)
9. F7-ECS11M: carnival (2)
10. UN1-ECS13P: carnival (1)
11. F8-ECF11D: kid's carnival (1)
12. F8-ECF11M: kid's carnival (1)
13. F9-ECS13M: carnival (1)
14. F2-ECS09D: carnival (2)

15. UN4-ECS09P: carnival (2)
16. F10-ECF11M: bingo at the carnival (2)
17. F6-ECF10P: the carnival (3)
18. F3-ECS13D: family carnival (2)
- iii. Ropes course
  1. F5-ECS11M: rope climbing (2)
  2. F1-ECF12M: ropes (2)
  3. F6-ECF09M: ropes course (1)
  4. F15-ECF10: ropes course (1)
  5. F2-ECF13M: ropes course (1)
  6. UN12-ECS10P: ropes course (1)
  7. F7-ECS11D: ropes course (1)
  8. UN12-ECS09P: ropes course (2)
  9. F3-ECS13D: ropes (3)
  10. F3-ECS13M: ropes course (2)
  11. F12-ECS09D: ropes/climbing (2)
  12. UN2-ECS14P: love the ropes (2)
  13. F6-ECF09D: ropes course for dads (1)
  14. F15-ECS09D: I enjoyed doing the ropes course with the dads (1)
- iv. Fishing
  1. F5-ECS11M: fishing (1)
  2. F9-ECS13D: fishing (1)
  3. F13-ECS13D: fishing (1)
  4. F10-ECF09D: fishing (1)
  5. F16-ECF10: fishing (1)
  6. F1-ECF12M: fishing (1)
  7. UN5-ECS09P:
    - a. Fishing (2)
    - b. Eased my mind a lot (3)
  8. F14-ECF13D: the fishing (1)
  9. UN4-ECF12P: fishing (2)
- v. Cooking
  1. F2-ECF09M: cooking (1)
  2. F12-ECF10: and loved the cooking activities (2)
  3. F12-ECF11P: cooking (1)
  4. F13-ECS13D: cooking (2)
  5. UN17-ECS10P: family cooking (3)
- vi. Camp fire
  1. F5-ECF13D: camp fire (1)
  2. F8-ECF11M: camp fire (2)
  3. UN12-ECS09P: camp fire (3)
  4. F9-ECS13M: and the song at fireside (6)
  5. F12-ECF11P: wood burning (2)
  6. F1-ECF12D: I like how the children know the songs at the campfire because of repetitiveness (1)
  7. F9-ECS13M:

- a. Roasting marshmallows and smores (4)
  - b. Great family activity my child loved (5)
- vii. Free time
  - 1. F10-ECF13D: free time- started playing farkel (2)
  - 2. F3-ECF13M: we enjoyed jump ropes, balls, etc. being available for free play
  - 3. UN1-ECF13P:
    - a. Break time (1)
    - b. This allowed free time for my boys to do what they wanted (2)
  - 4. F8-ECF13M: thank you for adding the free family time! (2)
- viii. Archery
  - 1. F12-ECF11D: archery (1)
  - 2. F19-ECF12D: archery (2)
  - 3. F6-ECF09M: the archery this year (3)
  - 4. UN4-ECF12P: archery (3)
  - 5. F14-ECF13D: archery (3)
- ix. Sports and games
  - 1. F1-ECF13M: sports and games (2)
  - 2. F4-ECS14D: playing (2)
  - 3. UN13-ECS09P:
    - a. The games that camp sol leaves in the cabins are great (1)
    - b. We have played ours many times over the weekend (2)
- x. Arts and crafts
  - 1. F1-ECF13M: arts and crafts (1)
  - 2. F12-ECS11P: arts and crafts (1)
  - 3. UN17-ECS10P: family arts and crafts (2)
  - 4. U14-ECF09C-10: I like making the T-shirt (1)
- xi. Saturday night party
  - 1. F5-ECF13D: Saturday night party (2)
- xii. Massage
  - 1. F1-ECS11D: massage (1)
- xiii. Blackjack table
  - 1. F19-ECF12D: blackjack table (5)
- xiv. Music therapy
  - 1. UN5-ECF12P:
    - a. The music truly helped energize everyone (3)
    - b. The energy created an environment such that people moved out of their comfort zones (4)
- b. Parent Activities
  - i. Small group sessions
    - 1. F11-ECF09M: parent breakout groups (2)
    - 2. U3-ECF11P: small group sharing (2)
    - 3. F1-ECF12M: parent morning group (3)
    - 4. F12-ECF11D: facilitated discussion (2)
    - 5. F1-ECS14M: Morning parent group (1)

6. UN7-ECF11P: morning parent group was the only time we were given to express our situation to other families and hear from 2 families about their story (1)
7. UN2-ECS12P: open discussion (3)
8. F6-ECF12M: parent group on Saturday morning (2)
9. F7-ECF12M: loved parent group session (2)
10. F9-ECF12M: sharing in small groups (1)
11. UN11-ECS09P: Saturday morning parent session (1)
12. F14-ECF12M:
  - a. The parents meeting (1)
  - b. The division of moms and dads to get together and work on different crafts (2)
13. F19-ECF12D: Saturday morning share (1)
14. UN4-ECF12P: parent group (1)
15. F1-ECS10M:
  - a. I liked our small parent break out group (1)
  - b. Wished we had more time (2)
16. UN5-ECF13P:
  - a. I really like that it seem either the parent groups were small or the time was longer (1)
  - b. It felt we had more time/opportunity to share (2)
17. UN17-ECS10P: parent breakout (1)
18. F3-ECS11M: our parent small group was good (1)
19. F7-ECS11D: parent breakout (2)
20. F8-ECS11M: 1<sup>st</sup> therapy/parent session (2)
21. F15-ECS09M: I liked the way you made our groups for the parent breakout session
22. UN6-ECS11P: parent small group (1)
23. UN9-ECS11P: adult breakout (1)
24. F4-ECS12M:
  - a. Breakout group was great (1).
  - b. I would have liked another session, continuing with my same group, to go even further (2)
25. UN4-ECS12P: group time (1)
26. F2-ECS13D:
  - a. Parents break out group (3)
  - b. Parent time (1)
27. F6-ECS14D: parent time in discussion is my favorite (1)
28. UN7-ECS09P: parents group (sat) (1)
29. UN3-ECS09P:
  - a. Parent group (1)
  - b. I would like more of these (2)
30. UN2-ECS14P: the parent group on Saturday (1)
31. UN5-ECS09P: the 1<sup>st</sup> group (1) because I haven't basically discussed my child's death until asked (2)

32. UN7-ECF11P: morning parent group (1) was the only time were given to express our situation to other families and hear from 2 families about their story
- ii. Parent dinner
  1. F4-ECF10M: esp. parents dinner (2)
  2. F3-ECF11P: parent dinner (1)
  3. F19-ECF12D: parent dinner (4)
  4. F5-ECF13D: parents dinner (3)
  5. UN2-ECS14P: parents dinner (3)
  6. F2-ECS13D: parents dinner (2)
  7. F12-ECF13M: Saturday night dinner (2)
  8. F10-ECF13M:
    - a. Great parent dinner (1)
    - b. Like the addition of music (2)
  9. F7-ECS11M: parent dinner (1)
  10. F11-ECS13M:
    - a. Love that parent meal (1)
    - b. Great time to talk with other parents (2)
- iii. Mom's activities
  1. Scrap booking
    - a. UN1-ECF10:
      - i. Mom's activity with my child (2)
      - ii. Mosaic was awesome (3)
    - b. F6-ECF12M: the mom's activity (1)
    - c. F14-ECF12M: the division of moms to get together and work on different crafts (2)
    - d. F9-ECS13M: mom's group (3)
    - e. UN7-ECS09P: scrapbooking (2)
    - f. F2-ECF09M:
      - i. I think its great that you've utilized the mom's group to incorporate making the scrapbook page for camp sol (3)
      - ii. As opposed to just having them laid out in the saddle room (4)
    - g. UN2-ECF10: scrapbooking was unexpectedly fun (4)
  2. Yoga
    - a. F11-ECF11M: loved the yoga (2)
    - b. F1-ECF11M:
      - i. Yoga was literally an out of body experience for me (2)
      - ii. I participate in the yoga away from camp, but the energy in the room with the "Like" mothers during the session was exhilarating (3)
- iv. Dad's activity
  1. F13-ECF10: men's activities (1)
  2. UN4-ECS09P: dad's activity (1)

3. F14-ECF12M: the division of dads to get together and work on different crafts (2)
4. F15-ECF12D:
  - a. The time the dads spend together is great also (2)
  - b. Helps the guys in being comfortable together (3)
5. F10-ECF13D: dad's activity (1)
6. F11-ECF13D: dad's activity (1)
7. F4-ECS11D:
  - a. The activities with other dads are very important (2)
  - b. As it is a frame to "be dads" (3)
  - c. And express our thoughts in our own way (4)
8. UN4-ECS12P: dad time (2)
9. F4-ECS14D: fellowship with other men who could relate to my loss (4)
10. UN12-ECS09P: men's activity (1)
- c. Continuing bond activities
  - i. Remembrance service
    1. F6-ECF09M: remembrance service (2)
    2. F7-ECF12M: remembrance service (3)
    3. UN9-ECF12P: remembrance (1)
    4. F3-ECS13D: remembrance service (1)
    5. F7-ECF09M: remembering my son (3)
  - ii. Stepping stones
    1. UN11-ECS09P: stepping stones (2)
    2. F2-ECF09M: loved the stepping stones (2)
    3. F11-ECF09D:
      - a. Stepping stones (1)
      - b. Each stone from each year is like a step in the process that I can now take home (2)
  - iii. Family flag
    1. F5-ECF12M: making the family flag (1)
  - iv. Quilt squares
    1. UN6-ECS12P: art for the blanket (1)
  - v. Family introduction
    1. F10-ECF11M: enjoyed the family introduction activity (1)
  - vi. Memory boxes
    1. UN3-ECS13P: it was so much fun making our boxes (1)
- II. Social Support
  - a. Parent social support
    - i. Peer/emotional support
      1. F10-ECF09M: meeting other families (1)
      2. F10-ECF11D: meeting the other families (1)
      3. F12-ECF13M: communicating with other families (1)
      4. U2-ECS13P: reconnecting with families (1)
      5. F7-ECS09M:
        - a. Meeting and talking with the volunteers (2)

- b. Also we loved meeting a young woman, a “towny”, who was so kind and compassionate (3)
- 6. UN11-ECS09P: meeting other families (3)
- 7. F10-ECF09D: parent interaction (1)
- 8. F7-ECF09M: the openness and feeling comfortable (2)
- 9. UN1-ECS09P: Enjoy meeting with and communicating with other parents (2)
- 10. F1-ECS12D: just being here with families that have become like family for us over the years (1)
- 11. F1-ECS12M: seeing all the friends (families) from past years (1)
- 12. F3-ECF13D:
  - a. Meeting new families (3)
  - b. Seeing recurring ones (4)
- 13. F15-ECF12D: Really enjoy meeting new parents and families (1)
- 14. F10-ECF12M: seeing the other families again (1)
- 15. F11-ECF09M: meeting new families (1)
- 16. F11-ECS13D: talking with other families (1)
- 17. F1-ECF10M: being in the company of family who were impacted by a child’s death (1)
- 18. F15-ECF12M: meeting other families (1)
- 19. F18-ECS12M: time with other families (2)
- 20. UN1-ECS12P:
  - a. Being with other families (1)
  - b. Getting to know new families (2)
- 21. F13-ECF13M: how great it was to meet other families that are accepting and understanding (1)
- 22. F2-ECF10D: networking with other families (1)
- 23. F4-ECS12D: my favorite part is hearing the stories of other families (1)
- 24. F2-ECS10M: networking/talking/sharing with other families (1)
- 25. F4-ECF10M: meeting with other parents (1)
- 26. F9-ECS13D: how family’s talk to each other
- 27. F8-ECF10: just being around other families (1)
- 28. F13-ECF13D: I enjoyed speaking with families that understand (1)
- 29. F9-ECF10: talking with other families (2)
- 30. UN2-ECF13P: dinners/meals with other families (2)
- 31. F13-ECF10: sharing with other parents (1)
- 32. UN6-ECF13P: meeting other families (1)
- 33. F11-ECS11M: meeting families (1)
- 34. UN1-ECF10: networking with other families (1)
- 35. UN2-ECS12P: common friends (2)
- 36. F11-ECF11M: I felt more comfortable this year knowing sever families (1)
- 37. UN3-ECF11P: being with other families (1)
- 38. UN4-ECF11P: meeting the other families (1)

39. F14-ECF13D: also getting to know people that is going through the same thing that I'm going through (3)
40. UN5-ECF11P: networking with other families (1)
41. UN6-ECF11P: meeting with parents who have lost a child (1)
42. UN8-ECF11P: connecting with other families (1)
43. UN8-ECF12P: sharing (2)
44. UN1-ECS10P: families (2)
45. F4-ECF13M: just having the opportunity to be amongst so many loving people with similar paths in such a beautiful setting!
46. F6-ECF13M: talking with other parents (1)
47. F6-ECF13D: us as parents connecting with other parents (3)
48. F7-ECF13D: meeting and communicating with other bereaved parents (1)
49. F9-ECF13M: we got to meet families (1)
50. UN13-ECS09P: getting to visit with the other families who have experienced the same loss (1)
51. UN5-ECS12P: people (1)
52. UN12-ECS10P: getting to be with the other families and getting to know the new ones (2)
53. F7-ECS10P: being around similar families (1)
54. F11-ECS10G: meeting other families that lost a child (1)
55. F13-ECS10G: meeting families (2)
56. UN10-ECS10P: friendliness of the participants (1)
57. UN14-ECS10P: comradery (1)
58. F7-ECS09M: meeting other families (1)
59. F13-ECS11M: seeing all of my "veteran families" (2)
60. UN4-ECS11P: time with families with similar experiences (1)
61. UN5-ECS11P: families (1)
62. F3-ECS09M:
  - a. Meeting other parents (1)
  - b. Seeing/meeting new parents (2)
63. UN7-ECS11P: we love that we get to be with other families like ours (1)
64. UN8-ECS11P: all here for the same reason (2)
65. F1-ECF09D: meet other families (2)
66. F1-ECS09D: the camaraderie that everyone shows (1)
67. F3-ECF09M:
  - a. Meeting other families (1)
  - b. Sharing stories (2)
68. F3-ECF10D: the XX family (4)
69. F1-ECF12D: Similarity w/ others despite all the possible differences (no one cares or broaches/breeches religious or vocation differences) (3)
70. F3-ECF12M: getting to meet and talk to other families (1)
71. UN6-ECS12P: being with other families (1)
72. F13-ECS09D: meeting new friends (3)



- 73. UN1-ECS14P:
  - a. We love hat we get to see our old friends (1)
  - b. But we love meeting new ones as well (2)
- 74. F12-ECS09D: Meeting other parents/sharing (1)
- 75. UN4-ECS14P: the people (1)
- 76. F2-ECF10M:
  - a. I think the very best thing about the camp is the people (1)
  - b. The families, they feel like an extension of ours now. We are here because we have lost and yes because we are here and because of yall...
  - c. Our family feels like they have grown in number (3)
- 77. F5-ECF13M: connecting with other moms (1)
- 78. UN7-ECF11P: opportunity to hear from 2 families about their story (3)
- 79. F1-ECS09D: the way everyone helps each other (2)
- 80. F10-ECS12M:
  - a. Meeting families who truly understand what we are dealing with (1)
  - b. Who have additional insight on how our child will process grief as he grows up (2)
- 81. F14-ECF13M: being able to relate and talk to other without being judged (1)
- 82. F5-ECS10M:
  - a. Being able to talk to other parents whose children had struggled and battled illnesses (1)
  - b. This is different for me than those who lost children in other different circumstances (2). Ex: car accidents, suicide, etc.
  - c. A lot to exclude them but the opportunity to hear from these parents was very nice (3)
- ii. Instrumental support
  - 1. UN7-ECS09P: meeting kids facilitators (3)
  - 2. F6-ECF09D: meeting with facilitators of our boys different age groups (3)
  - 3. F9-ECF10: talking with the facilitators (4)
  - 4. F1-ECF13M: the care shown for our children (4)
  - 5. F9-ECF09M: child care for parents to have a chance to do something without worrying about our children or chasing them around (1)
  - 6. F11-ECF10: child care (1)
  - 7. UN2-ECF10: I truly trusted the staff with my child (2)
  - 8. UN10-ECF12P:
    - a. I love how you have the kids totally covered (1)
    - b. I don't have to worry about them and can concentrate on what I'm doing (3)
  - 9. F3-ECF13D:

- a. Safety of children (1)
  - b. And their level of freedom provided them (2)
- 10. F4-ECS12D: knowing my kids are safe (4)
- 11. F1-ECS14D:
  - a. I like that so many staff are assigned to each age group (1)
  - b. I feel my boys are safe because they are playing with others not too old or too little for them (3)
- 12. F3-ECF10D: safety and security (1)
- 13. UN2-ECF10P: the safe environment (1)
- 14. F13-ECF12P: great staff! (1)
- 15. F10-ECF12M: seeing the staff who I love too again (2)
- 16. F13-ECF13M: also how wonderful the staff was for us and our daughter (2)
- 17. UN1-ECS10P: volunteers (1)
- 18. F10-ECS12D:
  - a. The staff was very thoughtful of everything (1)
  - b. And they tried to make sure all our needs were met (2)
- 19. F16-ECS12M: enjoyed every staff member (2)
- 20. F3-ECF10D: staff (3)
- 21. F11-ECF10: Staff (2)
- 22. UN16-ECS10P: it is apparent that the camp staff are patient about the camp's purpose (2)
- 23. F1-ECS14D: the staff is wonderful (4)
- 24. F12-ECS09D:
  - a. Staff/volunteers (4)
  - b. The volunteers and directors were so attentive to the needs of the families and delivered satisfaction with smiles and such a degree of professionalism all the time (5)
  - c. The Camp John Marc staff were an inspirational group of young men and women too (6)
- 25. F2-ECF10M: I can't express how thankful we are to yall for all the work and time you put into this (2)
- 26. F2-ECF11M: I wish the volunteers understood how much it means to us. We are so thankful. I just can't say enough about how you ALL go above and beyond!!! (6)
- 27. UN9-ECS10P: Friendliness of the camp (1)
- 28. F7-ECS10P: friendliness (2)
- iii. Appraisal support
  - 1. UN2-ECF09P:
    - a. I liked hearing all the stories (although they were so sad) (1)
    - b. It helps to be with others experiencing the same feelings (2)
  - 2. UN15-ECS10P:
    - a. The favorite thing is that we got to understand better the grieving process (1)
    - b. And know that we all suffer (2)

3. F10-ECF09M: feeling of belonging (2)
4. F15-ECS09M: it helped to be with other brain tumor parents (2)
- b. Child Social Support
  - i. Peer/emotional support
    1. F2-ECS10D: kids chance to bond with kids of like experience (1)
    2. F6-ECF13M: groups for kids to talk and be with other grieving kids (2)
    3. F6-ECF13D:
      - a. Kids getting to connect with a purpose (1)
      - b. The kids being involved (2)
    4. F18-ECS12M: kid having time with other children (3)
    5. UN13-ECS09P: the fact that our child gets to be part of a group where she isn't different (2)
    6. F9-ECF10: peers for my son (3)
    7. F1-ECS09M:
      - a. My daughter getting to see old friends (2)
      - b. And meet new ones (3)
    8. UN12-ECS10P: I love that my child is getting therapy and doesn't even know it (3)
- III. Family interaction
  - a. Family time
    1. F1-ECF09D: time with my family (1)
    2. F2-ECF10D: setting aside time to connect as a family (2)
    3. F6-ECF10P:
      - a. Playing together (1)
      - b. And also eating together as a family (4)
    4. F9-ECF10: family togetherness (1)
    5. F12-ECF11M: family time (1)
    6. UN1-ECS13P: family meals (2)
    7. UN8-ECS11P: the togetherness (1)
    8. F8-ECS11M: family time (1)
    9. F11-ECS12M: Due to busy schedules we don't spend much family time (2)
    10. F13-ECS10G: family time (1)
    11. U2-ECF11P: spending time with family (1)
    12. F17-ECF12M: time together (1)
    13. UN2-ECF12P: family time (1)
    14. UN6-ECS11P:
      - a. Family time (2)
      - b. All of us going to sleep in the same room at the same time (3)
      - c. Quiet time to talk (4)
    15. F11-ECS11M: family time (2)
    16. UN3-ECF12P: family time (1)
    17. UN8-ECF12P: family time (1)
    18. F2-ECF13M: (ropes course)...good family encouragement time (2)

19. F6-ECF13M: time as a family (5)
20. F8-ECF13M: Family time...(1)
21. U11-ECS10P: we just love what you guys let us do as a family (1)
22. F18-ECS12M: family time (1)
23. UN2-ECS12P: family time (1)
24. F1-ECS13D: quality family time (1)
25. F3-ECS13D: family dinner (4)
26. F2-ECS14M: I just love the family time (1)
27. F1-ECS09M: the family spending time together (1)
28. F2-ECS09D: time with family (1)
29. UN8-ECS09P: time spent as a family (1)
30. F13-ECS09D: being with my family (2)
31. UN10-ECS09P: we just love that we get to do these fun things together as a family (1)
32. UN9-ECS09P: Just being away from home (1)
33. UN1-ECS12P: watching my child laugh and play at camp (3)
34. UN7-ECF13P: watching the kids have fun (1)
35. UN3-ECF13P:
  - a. Loved the break (1)
  - b. We walked through camp in places that we don't typically get to walk through during scheduled events...saw 2 deer as a family, walked through 3 tree houses (2)
  - c. Was most fun family bonding time we had (3)
36. F9-ECF11M: just seeing my boys smile and having so much fun (1)
37. UN1-ECS09P: the time to focus on and enjoy my kids is primary (1)
38. F3-ECS13M: time with kids (1)
39. UN2-ECF13P: spending time with my kids (1)
40. F1-ECF13D: time with my kids (1)
41. F11-ECF12M: being able to do many activities with my children (1)
42. F11-ECS12M: Doing family activities with my child (1)
43. F11-ECS12M: the time I had here with my daughter was priceless (3)
- b. Refuge/retreat for family
  1. UN8-ECF11P: having a weekend set aside to focus on our loved ones (1)
  2. UN7-ECF12P: a chance for our family to get away from everyday life (1)
  3. UN4-ECF13P: enjoy the get away down time from "normal" life like the opportunity to do some things as a family (1)
  4. UN17-ECS10P: overall: formal time to take a break from normal life to remember and honor our son (2)
  5. F13-ECS11M: away from life...no phone!! (1)
  6. F13-ECS09D: getting away from home and normal stress (1)

7. F2-ECF11M:
    - a. There are too many to say- but I think the main thing is that camp Sol is a refuge for us (1)
    - b. Even though it was so hard I remember looking around and seeing others smile and laugh (2)
    - c. Looking back I see that I felt freedom here to be happy even though it still hurt so bad (3).
    - d. I was with others that were not watching me- trying to see if I was ok or wondering how I could be happy at such a time (4)
    - e. I felt freedom to be happy or sad- whenever I wanted (5)
    - f. Being here heals me (6).
  8. UN9-ECS09P: it was a peaceful and relaxing time to remember our daughter/sibling (1)
  9. UN1-ECF09P: peacefulness away from the normal day to day stuff (1)
  - c. Spousal interaction
    1. F4-ECS12D: I enjoyed being able to share the weekend with my wife (3)
    2. F6-ECF13M: time away from kids (1)
- IV. Camp environment
- a. Amenities
    - i. Nature
      1. F16-ECS12D: I enjoyed the atmosphere (1)
      2. F8-ECF09M: the serene environment (2)
      3. F12-ECF09D:
        - a. The peace and quiet (2)
        - b. The wild life (3)
      4. F2-ECF10D: enjoying the peaceful setting at Camp John Marc (4)
      5. UN16-ECS10P: the peaceful setting of the camp (1)
      6. F12-ECS09D: Camp John Marc (3)
    - ii. Facilities
      1. UN8-ECF11P: the facilities (we love camp sol!) (4)
      2. F3-ECF10D: cabins (2)
      3. F10-ECF10: clean (1)
    - iii. Food
      1. F4-ECS14D: eating (1)
  - b. Organization
    1. F10-ECS11D: everything very organized (1)
    2. F10-ECF10: well-organized (2)
    3. UN3-ECS11P: that things are optional—not forced (2)
- V. Communication pertaining to the deceased child
- a. UN8-ECF11P: talking about our lost children with our family and others (2)
  - b. F9-ECF13M: talk about our child that we lost (2)
  - c. F11-ECS10G: talking about child (2)
  - d. F4-ECS11D: talking about loss (1)

- e. F4-ECS12D: and of being able to speak of our loss without having reservation (2)
  - f. F2-ECF10D: talking/thinking about the children we lost (3)
  - g. F5-ECF09D: sharing in formation with other fathers and families about our deceased children's journey (1)
  - h. F5-ECS14D: pushing myself out of my comfort zone to talk about my deceased daughter (1)
  - i. UN7-ECF11P: the only time were given to express our situation to other families (1)
  - j. F14-ECF12M: You are given the opportunity to speak about your feelings. (3)
  - k. F1-ECF09M: giving us the time to think/talk focus on our grief in a supportive network (1)
  - l. F5-ECF09D: sharing our feelings regarding this journey (2)
  - m. F13-ECF13D: my wife open up and face what had happened finally (1)
- VI. Miscellaneous
- a. General evaluation of Camp Sol
    - i. Overall experience
      - 1. UN9-ECS10P: Good experience (1)
      - 2. F13-ECF13D: I would like and love to come every year! (f4)
      - 3. F16-ECS12M: good experience (1)
      - 4. F4-ECS10D: my kids loved camp (2)
      - 5. F16-ECF12M: my daughter loves it, smile on her face the whole time (1)
      - 6. F3-ECS14D: being catered to (1)
      - 7. F1-ECS14M:
        - a. Thank you, camp sol, for always being so laid back and encouraging with us high-anxiety parents (4)
        - b. You put us at ease and love on us, and love on our kids (5)
        - c. We are grateful for you in our lives, and we love you guys (6)
    - ii. Suggestions
      - 1. F6-ECS14D:
        - a. A suggestion would be to mix up the groups if possible. (2)
        - b. My group this year was many of my friends. (3)
        - c. It worked, but there was no need to really ever introduce ourselves (4)
      - 2. F3-ECF12M: I feel maybe less activities on Saturday so to be able to get to know more families (2)
      - 3. F1-ECS14M: I wish we had another parents group on Sunday morning (with the same group as Saturday with an opportunity to go deeper) instead of the Saddle room parent meeting. (2)
      - 4. F5-ECF13M: I think it might be a good idea for camp sol to have its own private Facebook group that families could join and keep connected throughout the year (1)
    - iii. Camp improvements
      - 1. UN3-ECS12P: good idea about cutting lunch on Sunday (1)
      - 2. F18-ECS12M: I thought food was better (4)

**Parents' Least Favorite Aspect of Camp****I. Camp environment****a. Amenities****i. Food**

1. F6-ECS10M: food (1)
2. F13-ECF10:
  - a. Meals (1)
  - b. Need alternate to hamburger on kids meal night (2)
3. UN5-ECS11P: meals (1)
4. F4-ECS12D:
  - a. I would have been ok with being asked to bring more of our own food (1)
  - b. The meals (understandably) were less than appetizing (2)
  - c. Better coffee (3)
5. F5-ECF10: thanks for the food, but this sadly was my least favorite part of camp...sorry (1)
6. F1-ECF12M: food (1)
7. F1-ECF12D: food (1)
8. F16-ECF12M:
  - a. Meals (1)
  - b. No high chair so meals very stressful (2)
  - c. Didn't get to talk to other families (3)
9. UN3-ECF12P: food (1)
10. UN8-ECF12P: food (1)
11. F1-ECF13M: food (1)
12. F1-ECF13D: food (1)
13. F10-ECF13M: meals are still kind of goofy (1)
14. UN1-ECF13P:
  - a. The food (1)
  - b. I normally eat a lot of protein and good complex carbs. There were only simple sugars to eat (2)
15. UN2-ECF13P: the food change...but that is so minor (1)
16. F6-ECF09D:
  - a. Meals were better (1)
  - b. I would have liked to have more "beef" (2)
  - c. Chicken was ok (3)
17. F5-ECF13D: need more coffee (1)

**ii. Cabins**

1. F13-ECF10: beds (1)
2. F3-ECF12M: beds (1)
3. F3-ECF13M:
  - a. Lack of tissues in cabins (1)
  - b. Soggy pillows (2)
4. F3-ECF13D:
  - a. Tissues need to be in rooms (1)
  - b. Bottled water as well (2)

## iii. Accessibility

1. UN1-ECS10P: Hard walking for my girls (we need to think more about mobility issues as a family) (1)
2. F7-ECS11D: walking but that's not your fault (1)
3. F2-ECS09D: walking (1)
4. UN11-ECS09P: lots of walking (1)
5. F11-ECF11M: Just a comment on safety; I know the staff were trying to reach Dr. Bob and couldn't find him- shouldn't he have a radio? (1)
6. UN2-ECS14P: I didn't know how to contact medical staff in the middle of the night! (1)
7. UN4-ECF11P: no cell signal :)
8. F12-ECF09D:
  - a. Dark at night (1)
  - b. Lit pathways would have been nice (2)

## b. Nature

## i. Weather

1. UN8-ECF11P:
  - a. Rain (1)
  - b. We definitely needed it, but it made a mess! We survived though!
2. UN1-ECF12P: cold (1)
3. F13-ECS11M: weather (1)
4. UN4-ECS11P: cold wind (1)
5. F1-ECS12M: this year...the weather!!! (1)
6. F10-ECS12M:
  - a. Rain (1)
  - b. And cold (2)
7. F10-ECS12D:
  - a. The rain (1)
  - b. And cold (2)
8. UN1-ECS12P: the rain (1)
9. UN4-ECS12P: rain! (1)
10. UN1-ECS13P: rain (1)
11. UN1-ECS14P: it was cold (1)
12. UN2-ECF09P: wish the weather was warmer (1)
13. F3-ECF12M: cold (2)

## ii. Camp grounds

1. F8-ECS11M: being outdoors (1)

## c. Structure

## i. Schedule

1. UN12-ECS09P:
  - a. Not clear enough on meeting places and start/stop times. (1)



- b. They are listed but we had a lot of time this year where people were sitting around not knowing what to do or when something was going to start (2)
- 2. F10-ECF12M: getting up so early (1)
- 3. F6-ECS10M: knowing when it's time to stop and move on (2)
- 4. F1-ECF13M: need more time between activities (2)
- 5. F1-ECF13D: too little time between activities (2)
- 6. F2-ECF13M: needs to have more family time together incorporated into the schedule (1)
- 7. UN4-ECF13P:
  - a. It would be nice to change things up a little (1)
  - b. It is essentially the same camp each year (2)
  - c. Most of that is ok, but maybe some different plans would be nice (3)
- 8. UN3-ECF13P: just that it was very much the same as last year (1)
- 9. F10-ECF13D:
  - a. Structure...too much is not good (1)
  - b. Camp john marc staff advice- flexibility of just being there to help, staff, its ok if something doesn't start on time or is everything isn't covered in that time slot (2)
- 10. F10-ECS12M: no mid-day down time for a power nap (1)
- 11. F5-ECF12M:
  - a. I would like to maybe have one less activity (1)
  - b. Get to spend that time with family walking around (2)
  - c. Taking pictures (3)
- 12. UN10-ECF12P:
  - a. I would like to have a little bit of free time in the schedule (1)
  - b. So the whole family can walk around and enjoy the ground (2)
- 13. F1-ECS09M: would like more "free" time to explore! (1)
- 14. UN5-ECF12P: But it was tough eating a lot of sweets between a big breakfast and a big lunch (3)
- ii. Length of camp
  - 1. F1-ECS13D: only 2 days (1)
  - 2. UN2-ECF10: it's too short! (1)
  - 3. F7-ECF13D: it's not long enough (1)
  - 4. F13-ECF13M: leaving (1)
  - 5. F7-ECS09M: saying goodbye (1)
- iii. Staff
  - 1. F6-ECF09D:
    - a. Past camp directors were great, but I wasn't crazy about this year's camp director. (1)
    - b. He seemed a little too consumed w/ himself, and it was like it was "all about me." (2)

- c. The past directors were more "short, brief to the point." Left more time for parents to meet w/ other parents and lead, quietly, by example + were more gracious. (3)
  - d. This director either openly delegated too much, or it wasn't very 2013 to do this or that... I didn't see any of this w/ the past directors (4)
  - e. Past camp directors seemed more helpful, and went out of their way to assimilate others (5)
- 2. UN9-ECF11P:
  - a. The only complaint I have this year is the group of volunteers (excepting our familiar and beloved volunteers) were not as friendly or even helpful (1)
  - b. I had a couple of different occasions where my children were asked to find their parent, even though I was standing right there (2)
  - c. I was sad to see the emphasis on keeping the kids "corralled" instead of allowing them the freedom typically found at camp sol (3)
  - d. This approach I also found at the carnival, to the point where my youngest child was actually brought to tears (4)
  - e. It's important that the volunteers working with our children and us are empathetic, compassionate and understanding. (5)
- 3. UN1-ECS09P:
  - a. Also, someone (probably a child) altered our paving stone.
  - b. Minor but upsetting. (2)
  - c. Not enough supervising of the kids at times (3)
- 4. UN1-ECF13P: I had several workers ask how camp is going when I told them they all replied with its normal to feel overwhelmed your first year...I don't feel overwhelmed (2)

## II. Camp activities

- a. Parent activities
  - i. Small group sessions
    - 1. F2-ECS10M:
      - a. Also, needed more time in our groups (1)
      - b. We really only got to introduce ourselves (2)
      - c. Needed another session probably (3)
    - 2. F2-ECS10D:
      - a. Parent break out groups were too large (1)
      - b. Not as effective (2)
    - 3. UN7-ECS11P: mom and dad's group on sat (1)
    - 4. F10-ECF11D: could have used more time in parent group as in one group together (2)
    - 5. F15-ECF12D:
      - a. I normally enjoy the parent breakout group meeting, but felt that the groups were less effective due to size (1)

- b. 3-4 parents in a group is a good number (2)
    - c. I think people don't express themselves as much or as well in the larger groups, and I missed that connection. (3)
  - 6. UN2-ECF12P: group therapy (1)
  - 7. F10-ECF11D: didn't feel there was much discussion of everyone's individual experiences with their loss (1)
  - 8. UN7-ECF11P: There wasn't really enough time to hear from other families about their grief.
  - 9. F19-ECF12D:
    - a. I think Dads need to be asked questions to get them talking about grief (4)
    - b. What they say may help them find more in common about other grieving Dads, creates more ties to ongoing relationships beyond camp (5)
  - 10. F10-ECF09M:
    - a. I would like to see more specific discussion regarding the grieving process (1)
    - b. And what to expect (2)
  - 11. F1-ECS09D:
    - a. There is really nothing offered for someone who is marrying into a family who has had a death (1).
    - b. In some meetings I felt out of place because I have not experienced what the other parents have. (2)
- ii. Dad's activities
  - 1. F4-ECS14D: dad's activity where there is no formal networking or getting to know you (1)
  - 2. UN2-ECS09P: dad time (1)
  - 3. F8-ECF11D:
    - a. Wood burning (1)
    - b. It was good but did not involve cooperation or interaction among fathers (2)
  - 4. F19-ECF12D:
    - a. Dad's craft (1)
    - b. Cabin with no supplies (2)
  - 5. F4-ECS12M:
    - a. My husband really came searching for connection with other dads (1).
    - b. I think the dad's activity was a miss for him (2)
    - c. And a dads breakout group was what he was yearning for (3)
    - d. And discussion going deeply (4)
  - 6. F4-ECS14D: It would be good to have a questions facilitated that elicit a response from some of the guys (3)
- iii. Parent's dinner
  - 1. F11-ECS12M: parents dinner (1)
  - 2. F11-ECS12M:

- a. Parent's dinner (1)...
    - b. When you have no husband here with you UGH that was no fun (2).
  - iv. Mothers activity
    - 1. UN2-ECF12P: spending time with other mothers (4)
- b. Continuing bond activities
  - i. Family introduction
    - 1. F11-ECS11M: introduction (1)
    - 2. F3-ECF11P: feel like introducing the other families was too quick and rushed (2)
    - 3. F15-ECF12M: introduction (1)
    - 4. F5-ECF09D:
      - a. I was uncomfortable when I knew my time was coming to talk about our child the first night, (1)
      - b. Knowing that it was going to be emotional (2)
      - c. If it had been our 2nd year, I believe it would have been easier (3)
      - d. Although I'm not suggesting that the process change (4)
    - 5. UN3-ECS09P:
      - a. 1st night was awkward (1)
      - b. Would have liked more guidance on what was going on (2)
  - ii. Scrapbooking
    - 1. F1-ECS13M:
      - a. The scrapbook time (1)
      - b. Only because I didn't have this year! (2)
    - 2. F3-ECS09M: scrapbooking
    - 3. UN1-ECS09P: scrapbooking (1)
  - iii. Quilt squares
    - 1. F9-ECS13M: quilt squares (1)
    - 2. UN3-ECS13P:
      - a. Quilt squares (1)
      - b. Nice, but no one gets to see them only here at camp (2)
  - iv. Remembrance service
    - 1. UN5-ECF11P:
      - a. Write up for remembrance service (1)
      - b. I love the service (2)
      - c. But write up is so difficult (3)
    - 2. UN9-ECF12P: remembrance (1)
- c. Family activities
  - i. Arts and crafts
    - 1. F12-ECS09D: arts and crafts (I'm a guy) (1)
    - 2. F12-ECF11D: having to be creative during the arts and crafts (1)
    - 3. F2-ECS10M: lots of time spent on crafts (1)
  - ii. Campfire
    - 1. F1-ECS14M: campfire (1)
    - 2. F3-ECF10D: campfire "coffin" story was inappropriate (1)

- 3. F13-ECF10: campfire...no more coffin stories (3)
  - iii. Cooking
    - 1. UN5-ECS12P:
      - a. Cooking (1)
      - b. Too many people in our session (2)
  - iv. Dancing
    - 1. F5-ECS14D:
      - a. Just the dancing (1)
      - b. The too small costumes (2)
  - v. Carnival
    - 1. U15-ECS10P: carnival should end at 11pm (1)
  - vi. Fishing
    - 1. F19-ECF12D: fishing...would have liked to fish in the morning (3)
  - vii. General activities
    - 1. UN2-ECF12P: family activities (2)
  - viii. Pottery:
    - 1. UN2-ECF12P: pottery (3)
- III. Camp experience
  - a. Emotionally Intense
    - 1. F9-ECF10:
      - a. All of the crying I did (1)
      - b. Not sleeping well...my common problem (2)
  - b. First-timers feeling excluded
    - 1. F5-ECS10M:
      - a. Felt somewhat excluded at time being a first timer (1)
      - b. Yet it was reassuring to know we can come back and hear of the kinship among families (2)
- IV. Miscellaneous
  - a. General evaluation comments
    - i. Suggestions
      - 1. UN1-ECS12P: small parent group have parents bring a picture (2)
      - 2. F10-ECF11M: no alternative activities for the kids while raining during the last family activity (1)
      - 3. UN5-ECF12P:
        - a. We really enjoyed the cooking (1)
        - b. And the volunteers who led it (2)
        - c. Maybe only do cooking in the afternoon. (4)
      - 4. UN5-ECF13P:
        - a. I think have 3 activities with young kids is still hard (1)
        - b. It would be nice to have sitters so the older kids don't miss out on some of the fun activities because of three toddler siblings (2)
      - 5. F6-ECF11M: Perhaps having the 13+ movie night on Friday night rather than Saturday night due to exhausted children from the day of activities as well as exhausted volunteers! (1)
      - 6. F2-ECF09M:

- a. Maybe make the stepping-stones an arts and craft activity instead of something else to do after making quilt (1)
  - b. I think some families didn't get a chance to make one (2)
- 7. F11-ECS12M: Only suggestion...maybe give the moms a stuffed animal as well as children (3)
- 8. F19-ECF12D: Slots for more families (2)
- 9. F3-ECF12M:
  - a. Maybe talk about 1 & 2 year olds (3)
  - b. Our son's age group wasn't even mentioned on Sunday (4)
- ii. Time change
  - 1. UN3-ECS14P: losing an hour (1)

## Appendix H

*Spanish Speaking Parents' Qualitative Raw Data***Differences as a Result of Coming to Camp****I. Social support****a. Parent social support****i. Receiving peer/emotional support****1. UN3-SCF09P:**

a. I like to come and share my grief with other families (1)

b. And I feel better. (2)

**2. F10-SCS09M: ever year, we meet new families (1)****3. F19-SCS12D: it is very nice to share our experience with other families (1)****4. F4-SCS13D: I liked meeting more people with similar problems that one has (1)****5. F8-SCS14D: it helps me to talk with the other families in camp sol (1)****6. UN6-SCS13P: talking with other families help me (1)****7. F18-SCS11M: [I am better to express my feelings] with the families that have experience the same pain (2)****ii. Appraisal support****1. F5-SCS12M: [I feel a little bit better] because I know other families that have experiences the same pain I have (2)****2. UN9-SCS12P: There are other families that have gone through the same as me (2)****3. UN14-SCS09P:**

a. I feel that I'm not the only one with this grief (1)

b. And there are those who understand me (2)

**4. UN9-SCS12P: ...knowing that I'm not alone (1)****iii. Providing peer/emotional support****1. F20-SCS11P: I now feel that I am able to help other families (2)****iv. Instrumental support****1. F8-SCS09M: I liked the understanding towards us and other families (1)****II. Communication****a. Ease of communication pertaining to the deceased child****i. with others in general****1. F8-SCS13P: it's easier to talk about my daughter (1)****2. UN37-SCF12P: I am able to better talk about my children that died (1)****3. F13-SCF09D:**

a. Every time we come, I find it easier to talk with other families of the camp regarding the death of our children (1)

b. And also with other people outside of camp (2)

4. F9-SCS12M: each year that passes is much easier to talk (1)
5. F6-SCS09D: easier for me to share my experience with new families (2)
6. F14-SCS12D: it will be easier talking with my family about my deceased son (1)
7. F14-SCS12M: it's easier for me to talk about my child (2)
8. F13-SCS12M: I feel much better talking about my daughter with my family (1)
9. UN7-SCS12P: we were able to talk about our daughter without the moment being too difficult (1)
10. UN11-SCS14P: easier to talk about my daughter (1)
11. F14-SCS11M: I feel better to talk about my children (1)
12. F9-SCS12M: also, I am able to talk more easily and communicate with other parents (2)
13. F14-SCS13D: That I feel more comfortable talking about my child here (1)
14. UN4-SCS13P: for me, now I talk about death with other people and tell them that this is something we have to prepare for (1)
15. F15-SCF13M: It's easier for the family to know that it's not important how much time has passed since the death, we are able to talk to freely (1)
16. UN15-SCS09P: I will be more open in talking with more people about my babies (1)
17. F15-SCS11P: we feel more open to talk about the loss of our baby (1)
18. F10-SCS09M: and yes, I can speak more about the death of my daughter (2)
- ii. With surviving children
  1. F12-SCS14D: it will be easier to talk with my child about his brother who died (1)
  2. F8-SCS12D: it's easier for me to talk with my children (1)
  3. F8-SCF12D: it's easier to discuss the subject of the deceased with my [surviving] child (1)
- b. Emotional expression
  - i. Parents
    1. F16-SCS11D: it will be easier for me to express my feelings (1)
    2. F18-SCS11M: it is easier and I am better to express my feelings (1)
    3. UN13-SCS14P: it is easier to talk about the grief (1)
    4. UN8-SCF13P: it's easier to share what I feel about my child (1)
    5. F6-SCS09D: easier for me to express my feelings (1)
    6. F15-SCS12D: it's easier to express feelings (1)
    7. UN6-SCS14P: I feel more confidence in sharing my pain with more people (1)
    8. F14-SCS12M: it is easier for me to express my feelings (1)
    9. F4-SCS13M: and talking about my feelings (2)



- 10. F12-SCS13D: it's easier to express my mourning/grief to my family (1)
- 11. F9-SCS14M: it will be easier for me to express my feelings (1)
- 12. F10-SCS14D: it is easier to express my feelings (1)
- 13. UN10-SCS14P: express my feelings more toward my children (1)
- ii. Surviving Children
  - 1. UN10-SCS14P: [children expressing emotions] and in the same way them towards me (2).
- iii. Family
  - 1. UN11-SCS12P: more confidence with my family (1)
- III. Increased knowledge of grieving process
  - a. Developmental stages and grief process in surviving children
    - 1. UN12-SCS14P: I am better able to understand the grieving process in different ages of my daughter (1)
    - 2. F6-SCF10M: Understanding that it is healthy that my youngest daughter sometimes is sad even though she was only a year and a half old when her sister died (1)
  - b. Parents/spouses
    - 1. F12-SCS14M: and understand each other (2)
    - 2. UN5-SCS13P: I have a better understanding of mourning (1)
    - 3. F12-SCS13M: I have a better understanding of mourning (1)
    - 4. F4-SCS13M: I am better able to understand each stage of grief (1)
    - 5. UN8-SCS12P: it has helped me better understand (1)
    - 6. UN8-SCS12P: it helped me understand more (1)
    - 7. F11-SCS14D:
      - a. It has always helped me to understand (1)
      - b. And recognize that it is part of life (2)
    - 8. UN9-SCS12P: this helps me understand the loss of my son (3)
  - ii. Acceptance of death of child
    - 1. F7-SCS13P: it's a little easier to accept the loss of my child (1)
    - 2. UN8-SCS12P: it helped me accept (2)
    - 3. F4-SCS13M: only acceptance (3)
  - c. Family grief process
    - 1. F15-SCS12M: I have a better understanding about family mourning (1)
    - 2. F11-SCS09P: I have a better understanding of my family's mourning (1)
    - 3. F7-SCS14D: I have a better understanding about family mourning (1)
    - 4. F9-SCS14M: I have a better understanding of family mourning (2)
  - d. Individual differences in the grief process
    - 1. F8-SCF12M: Understanding that we all have ways to feel and express our pain and mourning that we carry and knowing how to understand it (1)
- IV. Adjustment of the grief journey
  - a. Moving forward

1. F5-SCS12M: I feel a little bit better (1)
2. F17-SCS12D: each year it is easier (1)
3. UN13-SCS14P: I am able to comment on my grief without fear (2)
4. F12-SCS13D: and be better (3)
5. F9-SCS09P: it will be easier to continue moving forward (1)
6. F20-SCS11P: Each time better (1)
- b. Improved mood and negative feelings
  1. UN7-SCS12P: I felt more peaceful (1)
  2. F5-SCS12D: I feel that you helped us to relieve a little stress that we had (1)
- V. Family interaction
  - a. Family bond and prioritization
    1. F12-SCS14M: it makes us more united (1)
- VI. Continuing bonds as a coping skill
  - a. Honoring/Remembering the deceased
    1. F6-SCS13M: My children will keep on remembering their sister (1)
    2. UN5-SCS14P: I feel as if she were with us and very happy to attend (1)
    3. F12-SCS12M: We continue to remember everything that happened (1)
    4. UN1-SCS11P: we were able to watch our videos (1)
  - b. Discussion of the deceased
    1. F13-SCS14M: we will continue to talk about our deceased daughter (1)
    2. UN36-SCF12P: I continue talking openly about my children (1)
    3. F9-SCS12M: we continue to talk about our deceased daughter openly (1)
    4. F13-SCS14M: [continue talking about child] with more confidence (2)
- VII. Miscellaneous
  - a. General evaluation comments about Camp Sol
    - i. Thank you
      1. F8-SCS09M: Thank you. God take care of them. For this foundation and in my opinion and the respect toward us. Thank you very much.
      2. F12-SCS12M: Thousand Thousand thanks for helping us Camp sol (2)
    - ii. Camp experience
      1. F8-SCF12D: since coming to camp sol, it helped my family a lot (2)

### **Differences in the Family Once Returning Home from Camp**

- I. Family interaction
  - a. Emotional bond
    1. F14-SCS11M: a stronger union (1)

2. UN33-SCF12P: I feel closer to my family (1)
  3. UN5-SCS14P: I feel closer to my family (1)
  4. F18-SCS11M: become closer as a family (2)
  5. F6-SCS12M: be more in family (1)
  6. F16-SCS11D: we are able to feel closer as a family (1)
  7. F14-SCS12M: we feel closer as a family (1)
  8. F8-SCS13P: we feel closer as a family (1)
  9. UN8-SCF13P: we feel closer (1)
  10. F9-SCS14M: We will be able to feel closer as a family
  11. UN14-SCS09P: we will be closer (1)
  12. UN15-SCS09P: we will be closer as a family (1)
  13. F11-SCS09P: we can feel more united as a family (1)
  14. F12-SCF12D: it keeps us united as a family (1)
  15. F14-SCS12D: we are able to feel more united as a family (1)
  16. F13-SCS12M: we are united (1)
  17. UN8-SCF13P: we feel united (2)
  18. F4-SCS13M: we feel connected as a family with similar feelings (1)
  19. F8-SCF12D: I think there will be more union as a family (1)
  20. F13-SCF09D:
    - a. The camp has helped us a lot to come together more as a family (2)
    - b. No other activity has united us as much as this (3).
- b. Increased family time
1. F6-SCS09D: Have more time together (1)
  2. F5-SCS12D: spend more time together (2)
  3. UN9-SCS12P:
    - a. Spending more time together (1)
    - b. And enjoying each other more as a family each second (2)
  4. F13-SCS14M: we are able to dedicate more time together (1)
  5. UN1-SCS11P: we are able to dedicate more time together (1)
  6. F8-SCS12D: we are able to dedicate more time together (1)
  7. UN3-SCF09P:
    - a. We can be more together as a family (1)
    - b. This gives me more strength when I arrive home (2)
  8. F7-SCF20D: we can dedicate more time together (1)
  9. F9-SCS12M: We will be able to dedicate more time together (1)
  10. F19-SCS12D: being a family (1)
  11. F15-SCF13M: It's marvelous that we are together like a family honoring our baby that died (1)
  12. F17-SCS12D:
    - a. Yes, now we are together a little more (1)
    - b. ...Sharing (2)
    - c. Making crafts (3)
    - d. Or playing (4)
- c. Prioritization

- i. Of family
      - 1. UN11-SCS14P: to be better in every aspect (1)
      - 2. F8-SCS09M: It helps me to be better with my family and my children (1)
    - ii. Faith and appreciation of life
      - 1. UN11-SCS12P: we enjoy each day because tomorrow we don't know if we will be together (2)
- II. Communication
  - a. Increase in open communication
    - i. With family
      - 1. F19-SCS12D: sharing as a family (2)
      - 2. F14-SCS13D: sharing more as a family (1)
      - 3. F12-SCS13D: To be able to share more with my family (1)
      - 4. F6-SCS09D: and we can have more communication (3)
      - 5. UN37-SCF12P: There is more communication in the family (1)
      - 6. UN8-SCS12P: we communication with each other what we think (2)
    - ii. With surviving children
      - 1. F9-SCS12D: I hope that he will have communication with us (2)
      - 2. U5-SCS13P: talking more about her sister with my oldest daughter (2)
      - 3. UN2-SCS11P: we talk more openly with our children (2)
  - b. Ease of communication pertaining to the deceased child
    - i. With others in general
      - 1. F8-SCF12M: we will be able to talk more about the loss of our child (1)
      - 2. F6-SCS09M: To be able to talk a little more about our child without pain (1)
      - 3. F6-SCS13M: We will be able to talk about our daughter without too much sadness (1)
      - 4. F12-SCS14D: able to talk with more confidence (2)
      - 5. F14-SCS11D: it is going to be easier to talk with more people (1)
    - ii. With family
      - 1. UN7-SCS12P: asking ourselves things about our daughter without making a knot in our throat (2)
  - c. Emotional expression
    - i. Family
      - 1. F15-SCS12D: Feel better because talking our feelings (1)
      - 2. UN6-SCS14P: sharing my grief more (1)
      - 3. F15-SCS12D: we vented our feelings (2)
      - 4. UN2-SCS11P: we talk more calmly about the sorrow
      - 5. F5-SCS12D: I hope that it helps us know how to express ourselves better (1)
      - 6. UN5-SCS13P: Sharing our mourning more (1)
- III. Increased knowledge of grieving process
  - a. Individual differences in the grief process

1. UN12-SCS14P: I hope that we will be able to understand that we each have a different grief process (1)
  2. UN12-SCS14P: I hope that we will be able to understand that we each have a different grief process (1)
  3. F12-SCS14M: understand each other (1)
  4. F4-SCS13D: I understand more the pain of others (1)
  5. F10-SCF10P: We can understand each other more for what is happening to us (1)
  6. UN11-SCS12P: We are more accepting of each other's individual grief and mourning needs (1)
  7. F12-SCS13M: We may be more accepting of each other's individual grief and mourning needs (1)
  8. UN4-SCS13P: we are able to accept the need of one another (1)
  9. F6-SCS12D: we may be more accepting of each other's individual grief and mourning needs. (1)
  10. F7-SCS14D: we may be more accepting of each other's individual grief and mourning needs. (1)
  11. F9-SCS09P: we had a lot of answers to questions about our grief (1)
  12. UN8-SCS12P: we understand more the mourning of our son (2)
  13. F10-SCS14D: we understanding each other better (1)
  14. UN6-SCS13P: We understand each other more (1)
  15. F10-SCS09M: yes, my family understands (1)
  - b. Developmental stages and grief process in surviving children
    1. F9-SCS12D:
      - a. That my son can assimilate (1)
      - b. And understand the death of his sister (2)
    2. F10-SCS09M: and I think it was a good experience for him to understand better (2) (child coming to camp)
  - c. Parent grief process
    1. UN13-SCS14P: understand more of what happened to us (2)
    2. UN36-SCF12P: understanding the changes of emotions (1)
    3. F10-SCS14D: And understand the pain of grief (2)
- IV. Adjustment of the grief process
- a. Moving forward
    1. UN6-SCS14P: moving forward (2)
    2. F11-SCS09P: That we have people around us that need us to continue moving forward (3).
    3. F8-SCS14D:
      - a. When we leave camp so we are ready to move forward with our grief for a time (1)
      - b. But suddenly the sadness comes back (2)
      - c. UN11-ECS09P: making new memories (3)
    4. F11-SCS14D: at the same time, making or thinking and preparing ourselves for the next year
    5. F10-SCS09M: and above all, my husband improves every time (2)

6. F18-SCS11M: yes, camp always helps us overcome (1)
  7. F12-SCS14D: We are better able to live together as a family (1)
  8. UN13-SCS14P: we are going to be better as a family (1)
  9. F17-SCS12D: better in general (2)
  10. F10-SCS14D: Thank you for helping us handle our pain more easily (1)
  - b. Improvements in mood and negative feelings
    1. UN3-SCF10P: content (2)
    2. F20-SCS11P: I am better for my family (1)
    3. F22-SCS11P: I feel much better (1).
    4. F21-SCS11M: we are happy about coming (1)
    5. F11-SCS14D: we return home very happy (1)
    6. F15-SCS12D: you feel better (1)
    7. UN3-SCF10P: I come home more relaxed (1)
    8. UN3-SCF09P: more calm (3)
    9. F15-SCS11P: we feel more relaxed (1)
    10. F12-SCS14M: more patience with each other (2)
  - c. Accepting the death of the child
    1. F5-SCS12M: we will accept that the mourning is real (1)
    2. F6-SCS12M: accept the mourning more (2)
    3. UN4-SCS13P: It is okay to grieve however we do (2)
- V. Social support
- a. Parent social support
    - i. Providing peer/emotional support
      1. F8-SCS09M: It helps me to be better with other families that experienced the same (1)
    - ii. Receiving Peer/emotional support
      1. F4-SCS13M: more friendships with other families (2)
      2. F9-SCS09P: speaking with other parents (2)
      3. UN3-SCF10P: I enjoyed camp with other people, and we could talk to each other about our children who passed (1)
    - iii. Appraisal support
      1. F7-SCS13P:
        - a. We felt peace (1)
        - b. Because we know there are other families with the same pain (2)
      2. F11-SCS09P: It helps us to know there are other people who have had a loss as great as ours (2)
  - b. Child social support
    - i. Receiving peer/emotional support
      1. F6-SCS09D: My son is who worries me the most, because he is so quiet and doesn't talk a lot about the death of his sister, and I hope that he feels more calm knowing more children his own age (2)
  - c. Family social support
    1. UN6-SCS14P: supporting each other as a family (3)

2. F10-SCF10P: and try to help each other as a family and as parents (2)
- VI. Continuing bonds as a coping skills
  - a. Honoring/remembering deceased child
    1. F21-SCS11M: (happy to come to camp) to honor our daughter (1)
    2. UN7-SCS12P: for us, now we are able to have her keepsakes in whatever part of the house and we look at them like it is something normal (1)
    3. UN14-SCS09P: we will not forget our babies (2)
    4. F6-SCS09M: remember her with more affection (2)
    5. F6-SCF10M: Continue remembering the little girl who died openly (1)
- VII. Miscellaneous
  - a. General evaluation comments about Camp Sol
    - i. Thank you
      1. F19-SCS11M: No but thank you for having us in mind and giving us your support (1)
      2. F13-SCF09D:
        - a. Every time we come to camp the children feel like staying and always want to return (1)
        - b. Then the notice of the camp arrives, they begin to count the days until they'll return (2)
        - c. Thank you Camp Sol!! (4)
      3. UN3-SCF10P: thank you for helping us share with all of you.
      4. F18-SCS11M: thousand thanks (3)
      5. F8-SCS09M:
        - a. That can I say to you all...Continue doing the same (2)
        - b. That it is very important for the families that lose a loved one (3)
        - c. I am going to pray that Camp Sol never ends (4)
      6. F22-SCS11P: Thank you for helping us in cope with our grief a little better (2)

### **Parents' Favorite Aspect of Camp**

- I. Camp Activities
  - a. Children and family activities
    - i. General activities
      1. F7-SCS14D: the diverse activities (3)
      2. F18-SCS11M: having activities that my kids enjoyed (1)
      3. F6-SCS09D: children's activities (2)
    - ii. Carnival
      1. F8-SCS14D: I liked the carnival (1)
      2. F17-SCS11P: carnival (2)
      3. F8-SCS13P: carnival (3)
      4. F12-SCS13M: carnival (2)
      5. UN13-SCS14P: carnival (1)

- iii. Ropes course
      - 1. F19-SCS12D: ropes (1)
      - 2. F8-SCS13P: ropes (1)
      - 3. F17-SCS11P: ropes (3)
      - 4. F12-SCS14D: ropes course (2)
      - 5. UN5-SCS14P: ropes course (1)
      - 6. UN4-SCS13P: ropes (1)
    - iv. Fishing
      - 1. F16-SCS11D: fishing (2)
      - 2. F11-SCS09P: fishing (1)
      - 3. F12-SCS14D: fishing (1)
      - 4. F8-SCF13D: fishing (1)
      - 5. F8-SCS13P: fishing (1)
      - 6. F4-SCS13D: I really liked fishing (1)
      - 7. F7-SCS13P: fishing is very relaxing (2)
      - 8. UN5-SCS14P: fishing (2)
    - v. Cooking
      - 1. F13-SCS14M: cooking (1)
      - 2. UN8-SCS12P: cooking (2)
      - 3. F11-SCS09P: cooking (2)
    - vi. Free time
      - 1. F4-SCS13D: free time to relax (2)
    - vii. Sports and games
      - 1. F14-SCS11D: sports (2)
      - 2. F15-SCS12D: sports (2)
    - viii. Arts and crafts
      - 1. F15-SCS12D: arts and crafts (4)
  - b. Parent Activities
    - i. Small group sessions
      - 1. F6-SCS12M: parent time in discussion is my favorite (1)
    - ii. Parent dinner
      - 1. F12-SCS13M: parents' dinner (1)
    - iii. Mom's activities
      - 1. Yoga
        - a. F17-SCS11P: yoga (1)
  - c. Continuing bond activities
    - i. Remembrance service
      - 1. UN13-SCS14P: remembrance ceremony (2)
      - 2. F6-SCS09D: remembrance (1)
- II. Social Support
  - a. Parent social support
    - i. Peer/emotional support
      - 1. UN5-SCS13P: living with the other families (2)
      - 2. F7-SCS14D: the companionship that there is (2)
      - 3. F14-SCS12D: Being able to live with families that feel the same pain that I do (1)



4. F8-SCS14D: meeting with the other parents (2)
5. F15-SCS11P: to meet various families (1)
6. F23-SCS11D: being with other people suffering the same pain (1)
7. F4-SCS13M: sharing like a family with the mothers (2)
8. F15-SCS12M: helping other families in mourning (1)
9. UN6-SCS14P: most of all I met more parents that have problems like mine (2)
- ii. Instrumental support
  1. F8-SCS09M: the help that you give to the children (1)
  2. F4-SCS13M: and even more, the care of our children (3)
  3. F19-SCS11M: the people that help the families (1)
  4. F5-SCS12D: the staff was very attentive to the families (1)
  5. F9-SCS12D: That there are many people and volunteers that donate their time so that this reunion is possible (1)
  6. F14-SCS13D: the staff (3)
  7. F4-SCS13M: my son's group leader (3)
  8. UN11-SCS14P: all the staff (2)
  9. UN9-SCS14P: the kindness of staff (1)
- III. Family interaction
  - a. Family time
    1. F8-SCS09M: to be together (2)
    2. F15-SCS12M: sharing fun times with my children (2)
- IV. Camp environment
  - a. Amenities
    - i. Nature
      1. F14-SCS11M: nature (1)
      2. F14-SCS11D: nature (2)
      3. UN14-SCS09P: nature (1)
      4. UN15-SCS09P: nature (1)
      5. F14-SCS13D:
        - a. The trees (1)
        - b. Lake (2)
      6. F12-SCS14M:
        - a. The location makes you feel you are in vacation (1)
        - b. Camp is beautiful (2)
    - ii. Facilities
      1. F13-SCF09D: I really like the cleanliness of the camp (1)
      2. F4-SCS09M: cabins (1)
      3. UN11-SCS14P: cabins (1)
  - b. Organization
    1. F13-SCF09D: the organization (2)
    2. F7-SCS14D: I like the order that there is (1)
- V. Communication pertaining to the deceased child
  - a. F11-SCS09P: sharing in group (3)
  - b. UN12-SCS14P: sharing with families (1)
- VI. Miscellaneous

- a. General evaluation of Camp Sol
  - i. Camp improvements
    - 1. F10-SCS09M: camp improves every year (1)
  - ii. Personal improvements
    - 1. F12-SCS14M: looking forward to changes (3)

### **Parents' Least Favorite Aspect of Camp**

- I. Camp environment
  - a. Amenities
    - 1. Food
      - a. F16-SCS11D: food (1)
    - 2. Accessibility
      - a. F14-SCS12D: too much walking (1)
      - b. UN15-SCS09P: no light in path ways at night time (1)
      - c. F23-SCS11D: there isn't much lightning (1)
  - b. Nature
    - 1. Weather
      - a. F5-SCS12D: the rain (1)
      - b. F19-SCS12D:
        - a. The rain (1)
        - b. It did not let us enjoy outdoor activities (2)
      - c. F4-SCS13M: the weather (1)
      - d. UN13-SCS14P: only the cold (1)
- II. Camp activities
  - a. Family activities
    - 1. Massage
      - a. F12-SCS13M: I would have liked massage (1)
    - 2. Yoga
      - a. F12-SCS13M: I would have liked to have yoga (2)
- III. Miscellaneous
  - a. Time change
  - b. UN15-SCS09P: time change (1)

## Appendix I

*Siblings' Qualitative Raw Data for What Siblings Learned at Camp*

## I. Communication

## a. Communication regarding the the deceased

1. UN33-ECS09C-12: how to talk about my brother (1)
2. UN29-ECS09C-11: I learned that its ok sometimes to talk about your brother or sister who died (1)
3. U28-ECS13C-13: how to talk to people about my brother (1)
4. UN26-ECS14C-15: to talk about it more to other friends about your sister or brother (1)
5. UN27-ECS14C-15: to be able to talk about it (1)
6. U15-ECS13C-16: that you shouldn't feel afraid to talk about your sibling (1)
7. U16-ECS13C-14: to talk about my little brother who passed away (1)
8. U12-ECS13C-12:
  1. That you can talk about your siblings (1)
  2. And not feel shy (2)
9. UN24-ECS12C-13: to talk to other people about our brother or sister that died (1)
10. UN21-ECS12C-12: you don't need to be afraid to talk about your sister or brother (1)
11. F9-ECS12C1-6B: talking to other kids that lost their sister or brother (1)
12. UN30-ECS11C-14: to share more about my loved one (1)
13. UN31-ECS11C-14: to be able to talk to other people about my brother (1)
14. UN15-ECS11C-9: not to be afraid to talk about my deceased brother (1)
15. F6-ECS11C1-10G: I learned that you don't have to be afraid to tell people that someone died (1)
16. U37-ECS10-13: how to talk about my brother more (1)
17. U30-ECS10-9: it's ok to talk about your loved ones (1)
18. U26-ECS10C-10: to talk about your loved ones (1)
19. UN25-ECF13C-11: it's ok to talk about your dead relative (1)
20. UN28-ECF13C-12: don't be scared about to talk about your family (1)
21. F15-ECF12C1-10G: that it is good to talk about my brother with people (1)
22. F2-ECF12C1-12G: it's ok if you don't want to talk about your lost one (1)
23. F10-ECF11C2-G8: that it was okay to talk about it sometimes (1)
24. UN25: you don't have to talk about your brother or sister if its too hard for you (1)
25. UN19: that it is ok to talk about our brothers or sisters that have died (1)
26. UN13: that talking about your brother or sister who has died is okay (1)
27. UN9: that talking about it is okay (1)
28. U16-ECF09C-8: I learned that its easier to talk about my sister (1)
29. U14-ECF09C-10: that is ok to talk about your sister or brother (1)
30. U9-ECF09C-12: it's ok to talk about it (1)

31. F7-ECF09C1-12B: it's ok to talk about your siblings (1)
32. UN10: don't be afraid to talk to someone about your loved one (1)
- b. Emotional expression
  1. UN19-ECS12C-11: you can talk about your feelings (1)
  2. UN39-ECS09C-16: I don't need to be afraid to talk about how I'm feeling (1)
  3. UN22-ECS11C-14: to talk about how you feel (1)
  4. UN17: it's good to express your feelings about your sibling (1)
  5. F18-ECF12C1-11G: that you can tell people about your feelings (1)
  6. UN16-ECF12C-14: learned to express yourself, not to be afraid to talk to other people (1)
  7. UN30-ECF13C-14: that its okay to let people know how you feel (1)
  8. UN35-ECS09C-13: that I can express my feelings about my sister (1)
  9. UN32-ECS09C-12: to share my feelings (1)
  10. UN24-ECS09C-9:
    1. That don't keep your feelings inside (1)
    2. You need to share them with friends (2)
  11. UN14-ECS14C: to talk about my feels (1)
  12. U25-ECS13C-12: don't be afraid to tell people what your feeling (1)
  13. UN30-ECS14C-17: that you shouldn't be afraid to talk about your feelings (1)
  14. UN25-ECS12C-13: I learned how it helps to share our feelings about our loved one (1)
  15. UN38-ECS11C-10: how we shared feelings (1)
  16. UN32-ECS11C-14: express your feelings (1)
  17. U13-ECS13C-13: I can tell people how I feel about my sibling (1)
  18. UN36-ECS11C-11: I learned that it is ok to share feelings with each other (1)
  19. UN39-ECS11C-10: to not be afraid to talk about your feelings (1)
  20. UN14-ECS11C-8: talk about my feelings (2)
  21. UN16-ECS11C-9: that it's ok to let your feelings out (1)
  22. UN21-ECS11C: how to express myself about my brother (1)
  23. U26-ECS13C-13:
    1. I learned that its better let your feelings out in different ways (1)
    2. Other than keeping them inside (2)
  24. U25-ECS10C-10: that you don't have to be embarrassed about your sister or brother (1)
- c. Increase in open communication
  1. U8-ECS13C-5: I learned about sharing (1)
  2. UN23-ECS09C-9: I learned how to kind of talk more (1)
  3. UN37-ECS09C-14: I learned how to kind of talk more (1)
  4. U22-ECS13C-12: to talk (1)
  5. U15-ECF09C-9: I learned how to talk to other kids (1)
  6. UN17-ECS12C-11: to talk (1)
  7. U43-ECS10-10: to be open to people (1)
  8. U44-ECS10-10: to be open and share your differences (1)

9. U36-ECS10-13: to be open (1)
10. UN18-ECF13C-8: that is okay to talk to other people if you need to (1)
11. UN30-ECF12C-16: talking eases grief (1)
12. F2-ECF11C1-G8: that I can talk better with you all (1)

## II. Social support

### a. Appraisal support

1. F15-ECF09C2-12B: how everyone has to cope through death not just me (1)
2. U7-ECF09C-14: that it isn't just me who feels sad after the loss of my sister (1)
3. U8-ECF09C-13: that there is other people my age going through the same thing (1)
4. U11-ECF09C-12:
  1. I learned that just because you lost a brother or sister it doesn't make you different (1)
  2. It just makes you feel different (2)
5. UN18:
  1. That other people had lost siblings (1)
  2. So I won't have to be the only one (2)
6. UN29: that there is people my age that have experienced the same thing as me (lost a sibling) (1)
7. F6-ECF12C1-11G: about other kids who have lost their siblings (1)
8. UN15-ECF12C-9: I learned that everything that happens you are usually not alone (1)
9. F12-ECF13C1-9B: my sister was not only one who died from cancer or leukemia (1)
10. UN18-ECS12C-11: that there is other people who have lost a person in their life (1)
11. UN29-ECS11C-17:
  1. I'm not alone (1)
  2. There are others who are going through the same thing I am (2)
12. UN19-ECS11C-13: that there's always someone with you by your side (1)
13. U39-ECS10-12: that you're never alone (1)
14. U22-ECS10C-14: that you are not the only one who has lost someone (1)
15. UN32-ECF13C-15: that there is always other people that have gone through what you have gone through also (1)
16. UN33-ECF13C-18: that you aren't alone and there is more people who have gone through the same stuff (1)
17. UN38-ECS09C-15: some kids deal the same about losing someone they love (1)
18. UN30-ECS09C-11: other people have siblings that have died (1)
19. UN40-ECS11C-11: that I'm not alone (1)
20. F6-ECS12C1-13G: what I learn in camp is that there were more kids that went through the same thing that I went (1)
21. UN29-ECS12C-17: that there is other people out there on what we are going through that are the same (1)

22. F5-ECS13C1-14G: that there is more people, kids that went through the same thing (1)
23. U18-ECS13C-15: there are people out there going through almost the same as you are (1)
24. U24-ECS13C-17: that there are other people who understand what I am going through (1)
25. U27-ECS13C-13: I'm not the only one who has gone through this (1)
26. U29-ECS13C-14: it is easier to be with other kids who've gone through the same thing (1)
27. UN31-ECS14C-18: that everyone has lost someone too (1)
28. UN25-ECS09C-10: how other people lost their brother or sister died (1)
29. UN28-ECS09C-11: that I'm not the only one who has lost someone (1)
30. UN39-ECS09C-16: that I am not alone (1)
31. U17-ECS13C-16: that they are people just like me who has lost a brother or sister (1)
32. U28-ECS10-8: everyone went through the same thing (1)
33. UN22-ECS09C-8: every person has somebody died in their family (1)
- b. Peer/emotional support
  1. F5-ECF11C2-B8.5: talk to other kids who have lost a brother or sister (1)
  2. F13-ECS12C1-11B: that I can talk with other kids that I can talk to (1)
  3. U12-ECF09C-11: that being with other kids, we learn more (1)
  4. F1-ECF12C1-6G: making friends is good (1)
  5. UN31-ECS14C-18: that all of these people will help me through my grief journey (2)
  6. UN28-ECF12C-15: new people (1)
  7. UN23-ECS12C-13: to be together with each other (1)
  8. F6-ECS12C1-13G: made new friends (2)
  9. UN27-ECS14C-15: it is a lot easier to be around other kids who lost a loved one and (1)
  10. UN22-ECS14C-14: that it can be really fun new people (1)
  11. U24-ECF11C-12: that I can talk to more kids that knows what I am going through (1)
  12. U14-ECS13C-8: to be kind to other friends that have a brother or sister that died (1)
  13. UN25-ECS11C-5: to be nice to everybody (1)
  14. UN12-ECS11C-7: that we can help other people (1)
  15. UN25-ECF12C-8: to be nice (1)
  16. F12-ECF10C1-5b: to be nice (1)
  17. UN11: to help (1)
  18. F5-ECF11C1-B8: helpful (1)
  19. U25-ECF11C-15: be friendly (1)
  20. UN37-ECS11C-11: respect others (1)
  21. U41-ECS10-11: to be respectful to others (1)
  22. UN28-ECS12C-14: we can share love with others (1)

### III. New activities

- a. Arts and crafts

1. UN24-ECS11C-6: how to do arts and crafts (1)
  2. F19-ECF12C1-5G: drawing (1)
  3. U47-ECS10-7: to paint (1)
  4. U20-ECS13C-9: how to make secret bags (1)
  5. U30-ECS13C-7: make secret bags (1)
  6. U21-ECF11C-12: how to make beads (1)
  7. UN14-ECS11C-8: how to make a bead necklace (1)
  8. U15-ECF11C-5: rolling the beads (1)
  9. F10-ECF11C3-G9: how to make beads (1)
  10. UN26: I learned how to make umbrella (1)
  11. U24-ECF09C-5: how to color (1)
  12. UN23-ECF12C-7: flowers/feathers (1)
  13. UN16-ECF13C-7: that you can make slime with laundry soap and glue (1)
  - b. Physical activities
    1. UN28: how to shoot with a bow (1)
    2. F10-ECF11C3-G9: rock climbing (1)
    3. UN24: let your fishing hook drop to the bottom (1)
    4. UN25-ECS14C-15: how to shoot a bow (1)
    5. U10-ECF09C-12: how to rock climb (1)
    6. U14-ECF11C-4: skipping rocks (1)
    7. UN12-ECF12C-6: how do a nature walk (1)
    8. UN17-ECS14C-5: how to be a superhero (1)
    9. UN14: how to do peoples hair (1)
    10. UN26-ECF12C-7: how to ride the zip line (1)
    11. U21-ECS10C-16: balloons do not like to be shot at with arrows (they will not pop) (1)
    12. F4-ECF10C1-4B: astronaut food (cooking) (1)
  - c. Continuing bond activities
    1. UN13-ECF12C-4: write in activity (1)
    2. U16-ECF11C-4: some new songs (1)
    3. F12-ECF11C1-B10: how to write a song (1)
    4. UN21-ECS09C-8: sing a lot of songs (1)
    5. UN13-ECS12C-7: how to make a remembrance journal (1)
    6. UN16-ECS14C-5: learned to make a stepping stone... "I love her" (1)
    7. F4-ECS14C1-5B: memory box (1)
- IV. Adjustment in the grieving process
- a. Hopefulness
    1. F10-ECF11C1-B6: I learned that whoever dies in my family will be resurrected (1)
    2. UN22:
      1. That losing a sister is like the seasons. (1)
      2. The seasons are beautiful while they last (2)
      3. But sooner or later they have their bad times (3)
    3. UN29-ECF12C-16: good things happen (1)
    4. UN23-ECS11C-15: how to be open minded (1)
    5. UN29-ECS14C-16: there'll always be a light at the end of every tunnel (1)

6. U23-ECS13C-13: no matter what happened, you should never give up on your life (1)
7. UN23-ECS14C-14: not everything is easy, you just have to be strong about it (1)
8. U19-ECS13C-12:
  1. To not be sad all the time (1)
  2. But be grateful for the time that you had them (2)
9. UN22-ECF13C-10:
  1. I learned that you should have joy and sadness when they die (1)
  2. Because they are in a better place (2)
- b. Coping skills
  1. U4-ECF09C-19: how to deal with certain issues (1)
  2. UN21: how to deal with what's in my heart a little more (1)
  3. UN13-ECS11C-9: how to have fun without my big brother (1)
  4. U20-ECF11C-14: how to cope (1)
  5. U22-ECF11C-12: that you can deal with your grief in a unharmed way (1)
  6. UN31-ECS09C-11: that you can deal with that your sibling had died (1)
  7. UN36-ECS09C-13: I learned how to better cope with the sadness of death (1)
  8. UN14-ECF12C-7: there are other ways (like tiles and music) to express my feelings about my brother's death (1)
- V. Increased knowledge of the grieving process
  - a. Normal grief feelings
    1. F15-ECF09C1-9B: that it is okay to be sad that somebody died (1)
    2. U21-ECF09C-6: that it's okay to cry (1)
    3. UN16-ECF13C-7: to show people it is okay to be sad (1)
    4. UN20: it's okay to cry somewhere (1)
    5. UN23:
      1. You can cry (1)
      2. And let your feeling go (2)
      3. Don't keep them in (3)
    6. F1-ECF11C2-11B:
      1. I learned that it's okay to cry (1)
      2. Because you're not the only one (2)
    7. F9-ECF11C1-B11: do not be afraid to cry (1)
    8. UN34-ECS11C: to be happy (1)
    9. U28-ECS10-8: you don't have to feel sad anymore (1)
  - b. Personal grief process
    1. F1-ECF11C1-9B: about death (1)
    2. UN17-ECS11C-7: I learned that my sister died many years ago because she couldn't breathe very well (1)
    3. UN19-ECS14C-6:
      1. Some people have died (1)
      2. Some people have not (2)
    4. U17-ECS13C-16: I also learned how to grieve (1)
    5. U32-ECS13C-12: how to understand my feelings (1)



## VI. Continuing bonds as a coping skill

1. UN21-ECF13C-9: to still remember your sibling (1)
2. U23-ECS10C-14: That there is good way to remember your sibling (1)
3. U34-ECS10-13: remembrance (1)
4. U42-ECS10-10: the memory of the person who died (1)
5. UN28-ECS14C-16: to remember about your loved one (1)
6. UN34-ECS09C-13: that my sisters always with me (1)
7. UN12-ECS12C-7: to learn about our brothers and sisters (1)

## VII. Family time

1. U18-ECS10C-4:
  1. That is really important to be close to your family (1)
  2. And be happy (2)
2. UN13-ECS11C-9: have family time! (2)
3. UN22-ECS14C-14: that it can be really fun to be with our family (1)
4. UN20-ECS11C-12: that with family beside you, they will always be there (1)

## VIII. Miscellaneous

## a. Overall experience

1. U23-ECF11C-14: to have fun (1)
2. UN16-ECS12C-10: just to have fun (1)
3. U22-ECF09C-6: you get to play (1)
4. F14-ECF12C1-6B: playing (1)
5. UN24-ECS14C-14: I learned that you can have fun without reception and internet (1)
6. U42-ECS10-10: that camp sol is all about having fun (1)

## b. Cabins/sleeping

1. UN23-ECS14C-14: you have to bring blankets to sleep warm (1)

## Appendix J

*Siblings' Qualitative Raw Data for Favorite Aspect of Camp*

- I. Camp activities
  - a. Children and family activities
    - i. Carnival
      1. U13-ECF09C-10: carnival (1)
      2. U16-ECF09C-8: it was the carnival (1)
      3. U6-ECF09C-16: carnival (1)
      4. U7-ECF09C-14: carnival (1)
      5. U8-ECF09C-13: carnival (1)
      6. U19-ECF09C-7: the carnival (1)
      7. U20-ECF09C-6: carnival (1)
      8. UN5: carnival (1)
      9. UN8: carnival (1)
      10. UN10: carnival (1)
      11. UN11: carnival (1)
      12. UN12: carnival (1)
      13. UN13: the carnival (1)
      14. F10-ECF11C2-G8: The carnival (1)
      15. F2-ECF11C1-G8: when the carnival happen (1)
      16. F4-ECF11C1-B10: carnival (1)
      17. UN29: carnival (1)
      18. UN25: carnival (1)
      19. UN21: carnival (1)
      20. UN22: carnival (1)
      21. UN14: carnival (1)
      22. UN17: carnival (1)
      23. F5-ECF11C1-B8: carnival (1)
      24. F14-ECF12C1-6B: carnival (1)
      25. F1-ECF12C1-6G: carnival (1)
      26. F2-ECF12C1-12G: carnival (1)
      27. F4-ECF12C1-5G: carnival (1)
      28. U20-ECF11C-14: carnival (2)
      29. U18-ECF11C-13: the carnival (2)
      30. U21-ECF11C-12: carnival (1)
      31. U22-ECF11C-12: the carnival (1)
      32. U25-ECF11C-15: the carnival dance (1)
      33. U24-ECF09C-5: getting the purple bear at the carnival (1)
      34. UN23: the carnival (1)
      35. U29-ECS13C-14: the carnival (2).
      36. F4-ECS14C1-5B: carnival (1)
      37. UN18-ECS12C-11: the carnival (1)
      38. UN30-ECS11C-14: carnival (1)
      39. U44-ECS10-10: the carnival (1)

40. U48-ECS10-11: carnival (1)
41. U38-ECS10-12: the carnival (1)
42. U39-ECS10-12: carnival (1)
43. F6-ECS10C1-11B: carnival (1)
44. UN27-ECF13C-12: carnival (1)
45. U34-ECS10-13: carnival (2)
46. F12-ECF13C1-9B: the carnival (1)
47. UN21-ECF12C-10: carnival (1)
48. UN14-ECF12C-7: carnival (1)
49. UN23-ECF12C-7: carnival (1)
50. UN17-ECF13C-7: carnival (1)
51. U37-ECS10-13: the carnival (1)
52. UN16-ECF13C-7: going to the carnival (1)
53. UN28-ECF13C-12: carnival (1)
54. U20-ECS10C-16: carnival (2)
55. U21-ECS10C-16: carnival (2)
56. U22-ECS10C-14: the carnival (1)
57. UN25-ECS11C-5: going to the parade (1)
58. U24-ECS10C-11: carnival (1)
59. U27-ECS10C-9: carnival (1)
60. U28-ECS10-8: the carnival (1)
61. U30-ECS10-9: carnival (1)
62. UN10-ECS11C-13: carnival (1)
63. UN19-ECS11C-13: carnival (1)
64. UN20-ECS11C-12: the carnival (1),
65. UN21-ECS11C: the carnival (2)
66. UN32-ECS11C-14: the carnival (1)
67. UN34-ECS11C: carnival (1)
68. UN38-ECS11C-10: carnival (1)
69. F3-ECS12C1-4G: carnival (1)
70. F9-ECS12C1-6B: carnival (1)
71. UN12-ECS12C-7: the carnival (1)
72. UN24-ECS12C-13: the carnival (1)
73. UN25-ECS12C-13: the carnival (1)
74. UN28-ECS12C-14: the carnival (1)
75. F12-ECS13C1-10G: the carnival (1)
76. U8-ECS13C-5: carnival (1)
77. U11-ECS13C-5.5: carnival (1)
78. U14-ECS13C-8: the carnival (1)
79. U16-ECS13C-14: carnival (1)
80. U13-ECS13C-13: the carnival (2)
81. U17-ECS13C-16: the carnival (3)
82. U18-ECS13C-15: carnival (1)
83. U27-ECS13C-13: carnival (1)
84. U25-ECS13C-12: the carnival (1)
85. U22-ECS13C-12: carnival (1)

86. F6-ECS14C1-6G: carnival (1)
87. F12-ECS14C1-9B: carnival (1)
88. UN14-ECS14C: carnival (1)
89. UN15-ECS14C-5: carnival (1)
90. UN25-ECS14C-15: the carnival (1)
91. UN27-ECS14C-15: the carnival (1)
92. UN30-ECS14C-17: carnival (1)
93. UN31-ECS14C-18: carnival (1)
94. UN28-ECS09C-11: carnival (1)
95. UN26-ECS09C-10: the carnival (1)
96. UN31-ECS09C-11: the carnival (1)
97. UN34-ECS09C-13: the carnival (1)
98. UN18-ECS09C-7:
  - a. My favorite part of camp is at the carnival (1)
  - b. When we got to dance and stuff like that (2)
99. UN15-ECF12C-9: I liked going to the carnival (1)
- ii. Ropes
  1. F15-ECF09C1-9B: ropes (1)
  2. U20-ECF11C-14: ropes (1)
  3. UN30: ropes course (1)
  4. UN24: ropes course (1)
  5. U22-ECS10C-14: ropes (4)
  6. UN18: doing the ropes course (1)
  7. UN19: the ropes (1)
  8. UN13: ropes (2)
  9. U15-ECF09C-9: ropes course (1)
  10. U10-ECF09C-12: ropes course (1)
  11. U12-ECF09C-11: ropes course (1)
  12. U11-ECF09C-12:
    - a. I liked the ropes the best (2)
    - b. I wish I could climb it more than once (3)
  13. F8-ECF12C1-11B: ropes (1)
  14. F6-ECS12C1-13G: ropes (1)
  15. UN21-ECS12C-12: the ropes
  16. U37-ECS10-13: the ropes course (1)
  17. UN15-ECF13C-6: the ropes (1)
  18. UN19-ECF12C-7: ropes course (1)
  19. UN19-ECF12C-7: ropes course (1)
  20. UN28-ECF12C-15: ropes course (1)
  21. UN19-ECF13C-8: ropes (1)
  22. UN22-ECF13C-10: ropes (1)
  23. UN24-ECF13C-10: my favorite part of camp was ropes (1)
  24. UN25-ECF13C-11: ropes (1)
  25. U20-ECS10C-16: ropes course (1)
  26. U21-ECS10C-16: ropes course (1)
  27. U22-ECS10C-14: ropes (3)

28. U25-ECS10C-10: ropes (1)
29. U40-ECS10-11: ropes (1)
30. U41-ECS10-11: the ropes (1)
31. U42-ECS10-10: the ropes (1)
32. U43-ECS10-10: the ropes (1)
33. U44-ECS10-10: ropes (2)
34. UN10-ECS11C-13: ropes (2)
35. UN16-ECS11C-9: ropes course (1)
36. UN18-ECS11C-9: ropes (1)
37. UN35-ECS11C-6: getting down from ropes course (1)
38. UN36-ECS11C-11: ropes (1)
39. UN40-ECS11C-11: ropes (1)
40. UN41-ECS11C-10: ropes (1)
41. UN37-ECS11C-11: ropes (1)
42. UN38-ECS11C-10: ropes (2)
43. UN23-ECS12C-13: the rope climbing (1)
44. U19-ECS13C-12: ropes (1)
45. U23-ECS13C-13: the ropes (1)
46. U24-ECS13C-17: ropes (1)
47. U28-ECS13C-13: ropes (1)
48. UN21-ECS14C-9: the ropes course (1)
49. UN27-ECS09C-10: ropes (1)
50. UN31-ECS14C-18: ropes course (1)
51. UN25-ECS09C-10: ropes (2)
52. UN24-ECS09C-9:
  - a. When we went to the ropes course (1)
  - b. Because my friends my parents and my friends parents went on it (2)
53. UN33-ECS09C-12: ropes (2)
54. UN36-ECS09C-13: my favorite part was probably the ropes (1)
- iii. General activities
  1. U4-ECF09C-19: activities (1)
  2. U12-ECF09C-11: activities (2)
  3. U11-ECF09C-12: my favorite part was the family activities (1)
  4. UN23: family activities (1)
  5. F5-ECF11C2-B8.5:
    - a. Family activity 1
    - b. 2
    - c. 3
    - d. 4
  6. F10-ECF11C3-G9: the family activities (1)
  7. F6-ECF12C1-11G: family activities (1)
  8. UN30-ECF12C-16: family activities (1)
  9. UN30-ECF13C-14: the family activities (1)
  10. U23-ECS10C-14: family activities
  11. F6-ECS11C1-10G: the activities (1)

12. UN16-ECF12C-14: when we did activities in our groups (1)
  13. UN16-ECS12C-10: family activity (1)
  14. U33-ECS10-9: family activities (1)
  15. UN33-ECF13C-18: family activities (1)
  16. U17-ECS13C-16: the family activities (2)
  17. U12-ECS13C-12: family activities (1)
  18. UN33-ECS09C-12: all the activities (1)
  19. UN13-ECF12C-4: marching like animals to activity (1)
  20. UN38-ECS09C-15: the activities (1)
  21. UN20-ECS11C-12: activities (2)
  22. U24-ECF11C-12: doing different activities (1)
  23. UN23-ECS14C-14: family activities with my family (2)
  24. F1-ECF11C2-11B: the recreation barn (1)
- iv. Camp fire
1. U16-ECF11C-4: camp fire (1)
  2. UN12-ECF12C-6: sitting by camp fire (1)
  3. UN26: the camp fire (1)
  4. U23-ECF09C-5: roasting marshmallows (1)
  5. U21-ECF09C-6: camp fire (1)
  6. U14-ECF11C-4: camp fire (1)
  7. UN24-ECS11C-6: the camp fire (1)
  8. UN21-ECS11C: the camp fire (1)
  9. U46-ECS10-5: marshmallows (1)
  10. U28-ECS10-8: camp fire (2)
  11. U18-ECS10C-4: the camp fire (1)
  12. UN21-ECF13C-9: camp fire (1)
  13. UN22-ECF12C-7:
    - a. Camp fire (1)
    - b. Marshmallows (2)
  14. UN26-ECF12C-7: camp fire (1)
  15. UN29-ECS11C-17: camp fire (1)
  16. UN39-ECS11C-10: camp fire (1)
  17. F9-ECS12C1-6B: camp fire (1)
  18. F5-ECS13C1-14G: the camp fire (1)
  19. UN27-ECS12C-14: camp fire (1)
  20. U10-ECS13C-5.5: marshmallows (1)
  21. F6-SCS09C1-5B: camp fire (2)
- v. Fishing
1. U5-ECF09C-17: fishing (1)
  2. U17-ECF09C-8: fishing (1)
  3. UN28: fishing (2)
  4. F8-ECF12C1-11B:
    - a. Fishing (2)
    - b. A bass baby that almost pulls me in to the water (3)
  5. U18-ECF11C-13: I guess it was fishing (1)
  6. U11-ECF11C-4: caught a fish (1)

7. F9-ECF11C1-B11: fishing (1)
8. F1-ECF11C1-9B: fishing!! (1)
9. U20-ECS13C-9: going fishing (1)
10. U9-ECS13C-6: going fishing (1)
11. UN29-ECF12C-16: fishing (1)
12. UN18-ECF13C-8: fishing (2)
13. F14-ECF13C1-10B: fishing (1)
14. U31-ECS10-8: fishing (1)
15. U45-ECS10-6: fishing
16. U29-ECS13C-14: I liked fishing (1)
17. F13-ECS14C1-8B: fishing (1)
18. UN20-ECS14C-7: fishing (1)
19. UN25-ECS09C-10: going fishing (1)
- vi. Arts and crafts
  1. F13-ECF12C1-5B: crafts (1)
  2. F19-ECF12C2-6B: crafts (1)
  3. UN29-ECS12C-17: the crafts
  4. UN33-ECS09C-12: arts and crafts (3)
  5. UN17-ECS11C-7: making beads (1)
  6. UN12-ECS11C-7: the beads! (1)
  7. U17-ECF11C-5: beads (1)
  8. UN25-ECS09C-10:
    - a. T-shirts (4)
    - b. Tie-dye (5)
  9. F6-SCS09C1-5B: T-shirt (1)
  10. U22-ECF11C-12: the poster (2)
  11. UN20: making the storm poster (1)
  12. UN24-ECF12C-9: making journal? (1)
  13. UN43-ECS11C-4: face painting (1)
- vii. Games and sports
  1. U26-ECS13C-13: my favorite part was playing 21 (1)
  2. UN31-ECF13C-14:
    - a. Sports (1)
    - b. Games (2)
  3. F12-ECF10C1-5b: playing games (1)
  4. UN31: playing soccer (1)
  5. UN17-ECS14C-5: games (1)
  6. U10-ECF11C-5: when we got to play (1)
  7. F5-ECS12C1-5B: the limbo (1)
  8. UN20-ECF13C-8: scavenger hunt (1)
  9. UN15-ECF12C-9: cup stacking (2)
  10. U31-ECS13C-11: a couple of years back we did a egg drop (2)
  11. F3-ECS14C2-5B: dinosaur bones (1)
  12. F12-ECS13C1-10G: science (2)
- viii. Archery
  1. F15-ECF09C1-9B: archery (2)

2. U25-ECF11C-15: the archery (2)
  3. UN28: archery (1)
  4. UN23-ECF13C-10: archery (1)
  5. UN19-ECF13C-8: archery (2)
  6. UN29-ECF12C-16: archery (2)
  7. U24-ECS13C-17: archery (3)
  8. U31-ECS13C-11: the archery (1)
  9. F7-ECS14C1-15B: archery because I like shoot at objects (1)
  10. UN22-ECS14C-14: I like archery, it was really awesome (1)
  11. UN25-ECS09C-10: archery (3)
- ix. Cooking
1. UN18-ECF13C-8: cooking (1)
  2. UN31-ECF12C-9: my favorite part was cooking it was really fun (1)
  3. U37-ECS10-13: cooking (3)
  4. U30-ECS13C-7: making snacks (1)
  5. UN22-ECS11C-14: the cooking (1)
  6. UN36-ECS11C-11: cooking (2)
  7. U7-ECS13C-5: cooking (1)
  8. UN13-ECS12C-7: cooking
  9. UN19-ECS12C-11: cooking (2)
  10. F4-ECF10C1-4B: cooking cookies (1)
- x. Zip line
1. UN9: the zip line (1)
  2. U23-ECF11C-14: the zip line (1)
  3. F11-ECF11C1-G6: zip line! (1)
  4. UN32-ECF12C-12: zip line (1)
  5. UN14-ECF13C-6: zip line (1)
  6. UN25-ECF12C-8: the zip line (1)
  7. UN26-ECF12C-7: zip line (2)
  8. UN28-ECF13C-12: zip line (2)
  9. UN18-ECS11C-9: zip line! (2)
  10. U26-ECS13C-13: zip line (3)
- xi. Dance party
1. U21-ECS13C-12: doing the harlem shake (1)
  2. F4-ECS14C2-7B: the dance (1)
  3. U29-ECS13C-14: the dance with the dads was funny (4).
  4. UN26-ECS14C-15: the dance lol (1)
  5. F13-ECS09C1-4G: the best part was the party we had (1)
  6. UN23-ECS09C-9: the party (1)
  7. F11-ECS09C1-6G: the dancing (1)
  8. UN18-ECS09C-7: when we got to dance and stuff like that (2)
  9. UN19-ECS14C-6: the party (1)
- xii. Music therapy
1. F10-ECF11C2-G8: music therapy (2)
  2. U13-ECS13C-13: making my own CDs (1)



3. U17-ECS13C-16: music therapy (4)
4. U26-ECS13C-13: also music therapy (2)
5. U32-ECS13C-12:
  - a. When we made the paper to pick music that you liked or how ever your feelings were (1)
  - b. And then the teacher made that music into a disc (2).
6. F9-ECS09C1-5G: singing (1)
7. F12-ECF11C1-B10: writing and singing the song we made (1)
8. U15-ECf11C-5: singing (1)
- xiii. Movie
  1. U34-ECS10-13: movie (1)
  2. UN35-ECS10-13: movie (1)
  3. UN28-ECS14C-16: the movie (1)
  4. U14-ECF11C-4: movie (2)
  5. U37-ECS10-13: the movie night (4)
  6. UN27-ECS11C-15: my favorite part was the movie (1)
  7. UN29-ECS11C-17: the teen movie (2)
- xiv. Free time
  1. F15-ECF09C2-12B: break activities (1)
  2. U14-ECF09C-10: my favorite part at camp was going on a hike (1)
  3. UN16-ECF13C-7: chasing deer this morning (2)
  4. UN23-ECS14C-14: 3 walking all over the woods (3)
  5. UN24-ECS14C-14: being able to walk around and having freedom (1)
  6. UN26-ECS14C-15: walking around (2)
- xv. Rock climbing
  1. UN14-ECS11C-8: my favorite part of camp was when I did rock climbing (1)
  2. F7-ECF09C1-12B: silo (1)
  3. UN27-ECS11C-15: the rock climbing at the silo (2)
  4. F18-ECF12C1-11G: rock-climbing (1)
- b. Continuing bond activities
  - i. Quilt squares
    1. U47-ECS10-7: the quilt (1)
    2. UN17-ECS12C-11: the quilt (1)
    3. UN19-ECS12C-11: quilt squares (1)
    4. UN20-ECS12C-11: making the quilt squares (1)
  - ii. Tiles
    1. UN10-ECF13C-5: coloring tiles (1)
    2. UN20-ECF12C-7: when we did the tiles (1)
    3. F13-ECS12C1-11B: when we did the tiles (1)
  - iii. Remembrance ceremony
    1. UN13-ECS11C-9:
      - a. At the remembrance chapel (1)
      - b. Because I like to remember my brother (2)
  - iv. Memory box

1. UN27-ECS14C-15: making memory boxes
- v. Family flag
  1. F6-ECS12C1-13G: making flags (2)
- II. Social support
  - a. Peer/emotional support
    - i. UN7: liked playing with all the other kids (1)
    - ii. UN9-ECF09C-12: making new friends (1)
    - iii. U22-ECS10C-14: making friends (2)
    - iv. U12-ECF11C-5: seeing all the camp sol friends (1)
    - v. F20-ECF12C1-11B: socializing (1)
    - vi. UN15-ECS12C-10: being with my friends (1)
    - vii. UN39-ECS09C-16: meeting new people (1)
    - viii. UN22-ECS09C-8: meeting other people (1)
    - ix. U36-ECS10-13: friends (2)
    - x. U17-ECS13C-16: spending time with kids my age (1)
    - xi. UN15-ECS11C-9: being able to see all of my friends (1)
    - xii. UN15-ECS12C-10: and being around people who have gone through what I have (2)
    - xiii. UN29-ECS14C-16: getting together with families that can relate to problems I've faced when losing a sibling of mine (1)
    - xiv. U24-ECF11C-12: talking about my sister and brother (2)
  - b. Informational support
    - i. UN20-ECS11C-12: groups (3)
    - ii. UN23-ECS11C-15: groups (1)
    - iii. F8-ECS12C1-11G: being in groups (1)
    - iv. U24-ECS13C-17: group (2)
    - v. F5-ECF12C1-12G: going with groups (1)
    - vi. UN27-ECF12C-14: group time with facilitators (1)
- III. Camp environment
  - a. Amenities
    - i. Food
      1. UN32-ECF13C-15: eating (2)
      2. UN29-ECF13C-13: the food (1)
      3. F19-ECF12C1-5G: eating here (1)
      4. U22-ECF09C-6: breakfast time (1)
      5. F10-ECF11C1-B6: lunch (1)
      6. U12-ECF11C-5: ringing the bell (2)
    - ii. Cabins
      1. UN16-ECS14C-5: I sure did love my room (1)
      2. UN22-ECS12C-12: to sleep (1)
  - b. Staff
    - i. UN23-ECS14C-14: 3 cute staff guys lol (1)
    - ii. UN24-ECS14C-14: also the staff members were friendly and helpful (2)
  - c. Overall experience
    - i. UN30-ECS09C-11: the whole camp (1)
    - ii. F2-ECS12C2-4G: having fun (1)

## IV. Family interaction

## a. Family time

- i. U13-ECF11C-5: "sleeping with my mommy" (1)
- ii. U7-ECF09C-14: spending time with my family (2)
- iii. UN17-ECF12C-17: was spending time with my family (1)
- iv. F2-ECS12C1-4G: spending time with family (1)
- v. UN42-ECS11C-4: being with family (1)
- vi. UN32-ECF13C-15: my favorite was getting to spend time with my family in activities (1)
- vii. UN26-ECF13C-11: playing baseball with my dad (1)
- viii. UN29-ECS09C-11: my favorite part was probably just hanging out with my family (1)
- ix. UN21-ECS09C-8: family time (1)
- x. UN26-ECS14C-15: spending time with my family (3)
- xi. UN18-ECS14C-5: we had fun times together (1)

## Appendix K

*Siblings' Qualitative Raw Data for Least Favorite Aspect of Camp*

- I. Camp activities
  - a. Children and family activities
    1. Fishing
      1. F12-ECS13C1-10G:
        - a. Fishing (1)
        - b. Because I got wet (2)
      2. U7-ECS13C-5: fishing (1)
      3. F18-ECS12C1-6B: fishing
      4. UN29-ECS11C-17: fishing (1)
      5. U21-ECS10C-16: fishing
      6. UN29-ECF13C-13: fishing (1)
      7. UN27-ECF12C-14: fishing (1)
      8. UN20-ECF12C-7: when we went fishing (1)
      9. UN25-ECF12C-8: fishing (1)
      10. F14-ECF12C1-6B: fishing in cold (1)
      11. F12-ECF10C1-5b: fishing (1)
      12. UN31-ECF13C-14:
        - a. Fishing (1)
        - b. Didn't catch anything (2)
      13. UN32-ECS11C-14: fishing (didn't catch 1) (1)
      14. U11-ECF09C-12: not being able to catch any fish (1).
      15. UN36-ECS11C-11:
        - a. Fishing (1)
        - b. Because I didn't catch any fish (2)
      16. F8-ECS12C1-11G: fishing in the star lab (1)
      17. U27-ECS13C-13: fishing (1)
      18. UN20-ECS09C-8: fishing (1)
    2. Music therapy
      1. UN34-ECS09C-13: music therapy (1)
      2. UN36-ECS09C-13: I liked music therapy the least (1)
      3. UN23-ECS12C-13: music therapy (1)
      4. UN27-ECS11C-15: musical therapy (1)
      5. UN21-ECS11C: music therapy (1)
      6. F6-ECS10C1-11B: music therapy
      7. UN26-ECF13C-11: music therapy (1)
      8. U21-ECF11C-12: music Therapy
      9. UN10: song (1)
      10. UN12: singing the song (1)
      11. U8-ECF09C-13: music therapy (1)
      12. U6-ECF09C-16: music therapy (1)
      13. UN27-ECS12C-14: music therapy (1)
      14. U28-ECS13C-13: singing (1)

15. UN23-ECF12C-7: music (2)
3. Arts and crafts
  1. U30-ECS13C-7: the art and crafts (1)
  2. UN25-ECS11C-5: play doh (1)
  3. UN30-ECS11C-14: arts and crafts (2)
  4. U43-ECS10-10: arts and craft (1)
  5. U40-ECS10-11: arts and craft (1)
  6. UN28-ECF12C-15: arts and crafts (1)
  7. U20-ECF11C-14: art + craft
  8. UN16-ECF12C-14: arts and crafts (1)
  9. UN16-ECS11C-9:
    - a. Crafts (1)
    - b. Cause my sister was doing all the work (2)
  10. U18-ECS13C-15: arts and crafts (1)
4. Campfire
  1. UN20-ECS14C-7: camp fire (1)
  2. UN34-ECS11C: fire (1)
  3. UN17-ECS11C-7:
    - a. Marshmallows (1)
    - b. I just make a little (2)
  4. UN12-ECS11C-7: s'mores (1)
  5. UN32-ECF12C-12: campfire (1)
  6. F19-ECF12C1-5G: the fire (1)
  7. U25-ECF11C-15:
    - a. Campfire (1)
    - b. Because no fire (2)
  8. F12-ECF11C1-B10:
    - a. Camp fire (1)
    - b. Because of the fire hand it was not your fault (2)
  9. UN9: s'mores night (1)
5. Foot activity
  1. F6-SCS09C1-5B: foot activity (1)
  2. U12-ECF09C-11: the foot activity (1)
  3. UN26-ECS09C-10: foot activity (1)
  4. U15-ECF09C-9: Foot painting (1)
6. Ropes course
  1. UN20-ECS12C-11: the ropes because it was not out side in that cable like last year because of the rain (1)
  2. F3-ECS14C1-6G: the zip line (1)
  3. F1-ECF11C1-9B: zip line (1)
  4. F1-ECF11C2-11B: zip line (1)
7. T-shirt making
  1. F13-ECS09C1-4G: painting the shirt is boring (1)
  2. UN21-ECS09C-8: t-shirt (1)
  3. UN30-ECS09C-11: t-shirt (1)
8. Sports/Games

1. F11-ECS09C1-6G: when the dominos fell (1)
2. F10-ECF11C2-G8: sports and games (1)
3. U17-ECF09C-8: sports / games (1)
9. General activities
  1. U25-ECS13C-12: Only having 3 activities (1)
  2. UN18-ECS12C-11: some of my family activities (1)
10. Cooking
  1. U31-ECS13C-11: cooking (1)
  2. UN23-ECF13C-10: cooking (1)
11. Swimming
  1. UN26-ECS11C-4: pool was closed (1)
  2. UN8: not going to the pool (1)
12. Interaction with other campers
  1. U37-ECS10-13: playing with the little kids at the beginning of camp on Friday (1)
  2. U5-ECF09C-17: Screaming kids (1)
13. Rock climbing
  1. UN14-ECF13C-6: rock climbing...hard (1)
14. Star gazing
  1. U7-ECF09C-14:
    - a. Star gazing (1)
    - b. B/c there were no stars (2)
15. Massage
  1. UN23-ECS11C-15: teens get no massage (1)
- b. Continuing bonds activities
  1. Quilt squares
    1. UN41-ECS11C-10: quilt making (1)
    2. U24-ECS13C-17:
      - a. Doing the same family craft activity (quilt square) (1)
      - b. It is fun and I love seeing the end project, but it seems very old to do now (2)
    3. UN31-ECF12C-9:
      - a. The quilt part (1)
      - b. We could not come up with anything (2)
    4. F20-ECF12C1-11B: quilt squares (1)
    5. U17-ECS13C-16:
      - a. I really didn't like doing the quilt squares (1)
      - b. Because doing it every year you have to come up with ideas (2)
  2. Stepping stones
    1. U20-ECF09C-6:
      - a. Stepping stone (1)
      - b. I was standing around watching my mom do all the work (2)
    2. F8-ECF12C1-11B: making a block (1)
  3. Tiles

1. UN16-ECS12C-10: making the tiles (1)
4. Remembrance ceremony
  1. U13-ECF09C-10: remembrance at the chapel (1)
5. Scrapbooking
  1. UN28: scrapbook (1)
6. Memory chain
  1. UN15: memory chain activity (1)
- II. Camp environment
  - a. Structure/schedule
    1. Too early
      1. UN22-ECS09C-8: getting up in the morning (1)
      2. UN28-ECS14C-16: the time (1)
      3. UN29-ECF12C-16: the fact that breakfast is so early (1)
      4. UN30-ECF12C-16: waking up at 7:30 (1)
      5. UN25-ECS14C-15: daylight savings time (1)
      6. F18-ECF12C1-11G: waking up (1)
      7. UN29: waking up really early (1)
    2. Leaving camp
      1. F6-ECS11C1-10G: leaving camp (1)
      2. UN15-ECF12C-9: camp ending (1)
      3. UN22: have to leave and getting here late on Friday (1)
      4. UN25: leaving (1)
      5. U33-ECS10-9: leaving (1)
    3. Length of activities/camp
      1. U22-ECF09C-6: waiting for parents after parent group (1)
      2. UN12-ECF12C-6: waiting in cabin (1)
      3. F5-ECF12C1-12G: that eating time is so long (1)
      4. UN10-ECS11C-13: too short (1)
      5. U11-ECF09C-12: also I wish we had more time during our groups (2)
    4. Lack of free time
      1. F15-ECF09C2-12B: how we were not allowed to "roam" (1)
      2. UN29-ECS09C-11: umm...I guess I would like a little more free time to go explore or play (1)
      3. F7-ECS12C1-5G: when I couldn't play (1)
    5. Nap time/bedtime
      1. U32-ECS13C-12:
        - a. When we went back to the cabin for a hour to rest (1)
        - b. I didn't like that that much because I was bored (2)
        - c. Maybe they could send only the parents to rest because they are the ones that get tired
        - d. The kids don't so we can do something instead (4)
      2. F2-ECS12C1-4G: nap time (1)
      3. U26-ECS10C-10: bedtime (1)
  - b. Amenities
    1. Food

1. UN8-ECS13C-5:
  - a. The ice cream/snow cones (1)
  - b. No taste (2)
2. UN11-ECS13C-5.5: ice cream (1)
3. F2-ECS12C2-4G: to eat the chicken (1)
4. U41-ECS10-11: the snow cones (1)
5. UN22-ECF13C-10: eating (1)
6. F11-ECF11C1-G6:
  - a. Hamburgers for dinner- yuck!
  - b. Want hot dogs
7. U15-ECf11C-5: food (1)
8. U16-ECF11C-4: food (1)
2. Accessibility
  1. UN27-ECS09C-10: the hike (1)
  2. UN38-ECS09C-15: walking a lot (1)
  3. UN30-ECF13C-14: walking (1)
  4. U18-ECS10C-4: walking (1)
  5. U22-ECS10C-14: walking (1)
  6. UN26-ECS14C-15: wifi lol (1)
  7. UN28-ECF13C-12: service (1)
  8. UN27-ECF13C-12: the drive up here (1)
  9. F5-ECS12C1-5B: driving...the drive to camp (1)
3. Cabins
  1. UN30-ECS14C-17: showers (1)
  2. U22-ECS13C-12: pillow cases (1)
  3. UN26-ECF12C-7: My house (1)
4. Lack of supplies
  1. U42-ECS10-10: share chairs (1)
- c. Nature
  1. Weather
    1. UN31-ECS14C-18: the weather (1)
    2. UN22-ECS14C-14: it was really cold (1)
    3. UN23-ECS14C-14: the weather, it was cold (2)
    4. UN24-ECS14C-14: the weather (1)
    5. UN25-ECS12C-13: rain (1)
    6. UN28-ECS12C-14:
      - a. The rain (1)
      - b. And cold (2)
    7. UN17-ECS12C-11:
      - a. The mud (1)
      - b. And rain (2)
    8. F9-ECS12C1-6B: weather (1)
    9. U17-ECF11C-5: the storm (1)
    10. U14-ECF11C-4: rain (1)
    11. F10-ECF11C3-G9: that it rained (1)
    12. F4-ECF11C1-B10: the rain storm (1)



13. F9-ECF11C1-B11: the rain (1)
  14. F10-ECF11C1-B6: rain (1)
  15. U9-ECF09C-12: the cold weather (1)
  16. UN30: the storm cycle (1)
  2. Camp grounds
    1. F7-ECF09C1-12B: the ground (2)
    2. U36-ECS10-13: animal poop
    3. UN23-ECF12C-7: the cactus (1)
- III. Family interaction
- a. Family time
    1. U14-ECS13C-8: time together with just your family (1)
    2. U31-ECS10-8: family (1)
    3. UN39-ECS09C-16: family time (1)
  - b. Family separation
    1. UN42-ECS11C-4: Being away from family (1)
- IV. Emotional experience
1. UN15-ECS11C-9: being sad most of the time (1)
  2. UN16-ECF13C-7:
    - a. Friday (1)
    - b. ...It was hard to see new friends being scared (2)

## Appendix L

*Siblings' Qualitative Raw Data for What Siblings Would Like to See Different at Camp*

- I. Camp activities
  - a. Change activities
    - i. Carnival
      - 1. U14-ECS13C-8: and have 3 hours for carnival (2)
      - 2. UN13-ECS12C-7: yes, cotton candy at the carnival
      - 3. UN15-ECS12C-10: yes, have cotton candy at the carnival
      - 4. UN36-ECS11C-11: to have more games at the carnival
      - 5. UN31-ECF13C-14: more activities at carnival
      - 6. UN27-ECF13C-12: cotton candy at the carnival
      - 7. UN16-ECF13C-7:
        - a. At the carnival, she does not want to contest...(1)
        - b. She wants to put on a show (2)
      - 8. F12-ECF13C1-9B: cotton candy machine
      - 9. UN18-ECF12C-8: a cotton candy machine for the carnival
      - 10. U20-ECF11C-14: make carnival longer
      - 11. F8-ECF11C1-B7: cotton candy at the carnival
      - 12. UN24: make the carnival longer
      - 13. UN25: way longer time at the carnival
      - 14. UN10: prizes for the carnival and bumper cars
      - 15. U23-ECF09C-5: make the carnival outside
      - 16. U22-ECF09C-6: candies at the carnival
      - 17. UN12: I don't know, carnival would want bumper cars
      - 18. F2-ECF11C1-G8:
        - a. Having cotton candy (1)
        - b. Because did not have it this year (2)
    - ii. Games
      - 1. F1-ECF11C2-11B: I would like to do the games (2)
      - 2. UN20-ECF12C-7: to play more games
      - 3. UN23-ECF12C-7: yes, more games
      - 4. F14-ECF13C1-10B: more activities (2)
      - 5. U18-ECS10C-4: that they would put more games hard and easy
      - 6. U14-ECS13C-8: dress up more and more (1)
      - 7. UN22-ECS09C-8: playing more games
      - 8. U32-ECS13C-12:
        - a. I wish we could have 4 family activities instead of 3 (1)
        - b. Because then I would be bored in the extra time if we have 3 (2)
      - 9. U25-ECS13C-12:
        - a. We need more activates (1)
        - b. Because we need more to do (2).
      - 10. U23-ECS13C-13: let us have 4 actives instead of 3.
      - 11. U17-ECS13C-16: more activities! (2)

12. UN32-ECS11C-14: more activities during the breakout sessions
13. U40-ECS10-11: more camp activity
14. F5-ECF12C1-12G:
  - a. more activities (1)
  - b. More time to do them (2)
15. U22-ECF11C-12: do more activities in class
16. UN23: to have more activities
- iii. Arts and crafts
  1. UN17-ECS11C-7: I want to make a surprise for my Mom
  2. UN20: draw something else
  3. F11-ECS09C1-6G: do sticker and marker work all day long
  4. F5-ECS12C1-5B: draw a house with a slife
  5. U24-ECS13C-17:
    - a. Maybe paint a mural (1)
    - b. Or some fancy art activity (2).
  6. UN21-ECF12C-10: finger painting
  7. UN29-ECS12C-17: more art stuff
  8. UN17-ECS13C-16: I think we should make more stuff to take home! (1)
- iv. Ropes course
  1. UN22-ECS14C-14:
    - a. I didn't get to do the rope (1)
    - b. But I want to do it next year (2)
  2. U21-ECS10C-16:
    - a. The teens should either do the swing (1)
    - b. Or the pamper pole/leap of faith (2)
  3. UN17-ECF13C-7: yes, did not like ropes
  4. UN19-ECF13C-8: maybe on the ropes to have a rope to climb up
  5. F8-ECF12C1-11B: make 20 times the rope
  6. UN23: let all activities for the rope course to be open
  7. F18-ECS12C1-6B: rock wall
- v. Archery
  1. UN16-ECS11C-9:
    - a. Archery to be bigger (1)
    - b. Lots of bows (2)
  2. U11-ECF11C-4:
    - a. Archery (1)
    - b. Next year old enough (2)
  3. UN26: more archery (1)
  4. U28-ECS10-8: bow and arrow should start at 8 years old (1).
  5. UN13-ECS11C-9: archery (1)
  6. UN14-ECS11C-8: archery (1)
  7. UN30-ECS11C-14: no except archery (1)
- vi. Sports
  1. UN42-ECS11C-4:
    - a. Sports (1)

- b. Love soccer (2)
  - 2. F6-ECS10C1-11B:
    - a. Get a better soccer ball (1)
    - b. And actual soccer nets (2)
  - 3. UN31: soccer balls that are not flat (1)
  - 4. U13-ECF09C-10: a soccer field (1)
  - 5. U10-ECF09C-12: indoor football (1)
  - 6. F1-ECF11C2-11B: I would like to do the sports (1)
- vii. Music therapy
  - 1. U6-ECF09C-16:
    - a. The songs in music therapy are too sad (1)
    - b. And when they give us the lyrics, there's no need to discuss it because, I can read them one time and instantly know what message they expect us to get from them (2)
  - 2. UN30: need instruments for music (1)
  - 3. UN14-ECS11C-8: to play the piano (3)
  - 4. F3-ECS12C1-4G: different music (1)
- viii. Movie night
  - 1. U44-ECS10-10: kids being able to watch the movie
  - 2. U36-ECS10-13:
    - a. Movie time (1)
    - b. But it was good (2)
  - 3. U23-ECS10C-14:
    - a. Friday night movie for Saturday night (1)
    - b. Movie night for girls (2)
  - 4. F15-ECF09C2-12B: movies for 12 & up (1)
- ix. Free time
  - 1. UN11: free time
  - 2. UN28-ECF13C-12: more free time at the gym
  - 3. UN29-ECS09C-11: I guess I would like a little more free time
  - 4. UN25-ECS09C-10: play time, barn all day
- x. Cooking
  - 1. UN31-ECS11C-14: to change to food in the class
  - 2. UN10-ECS11C-13: different food during cooking
  - 3. U21-ECF11C-12: make different foods in cooking (1)
- xi. Shooting BB guns
  - 1. UN22-ECF13C-10: begun shooting ally near the barn or tree houses
  - 2. UN23-ECF13C-10:
    - a. Yes, I would like to do BBs (1)
    - b. You get little BB bullets and air soft gun and shoot targets (2)
    - c. You can get BBs and air soft guns at academy (3)
  - 3. UN26-ECF13C-11: shot gunning
- xii. Fishing
  - 1. U17-ECF09C-8: to be able to do fishing 4 times!

2. UN20-ECS14C-7: fishing
3. UN37-ECS09C-14: more fishing time
- xiii. Continuing bond activities
  1. U28-ECS13C-13: do something other than the quilt square
  2. U29-ECS13C-14: I think we should do something else beside the quilt squares.
- xiv. Campfire
  1. UN32-ECF12C-12: I don't like the campfire song
- b. Add activities
  - i. Swimming
    1. UN38-ECS11C-10: to open the pool
    2. F3-ECS14C1-6G: I want the swimming pool
    3. F4-ECS14C2-7B: the pool
    4. F13-ECS14C1-8B: I want the pool
    5. F4-ECF11C1-B10: a water slide
    6. UN17: adding water slide
    7. UN8: being able to go in the pool
    8. U14-ECF09C-10: going swimming next year
    9. UN18: I would like a time in march when we could go to the pool
    10. UN15-ECS11C-9: swimming in the swimming pool
    11. UN28-ECF13C-12: let us in the pool
    12. UN14-ECS11C-8: to go swimming (4)
    13. UN36-ECS11C-11: I would like for the pool to be open
  - ii. Games
    1. F5-ECF11C2-B8.5: yes Angry Birds
    2. UN12-ECS12C-7: play duck, duck, goose
    3. U31-ECS13C-11: egg drop in the Barn.
    4. UN30: paintball
    5. UN25-ECS11C-5: go on treasure hunt
    6. UN20-ECS12C-11: I would like to be different is if we could have a race with sacks on our feet
    7. F1-ECF11C1-9B: races
    8. U17-ECF11C-5: tell stories
  - iii. Horseback riding
    1. F10-ECF11C2-G8:
      - a. I would like there to be horse back riding for 9 and up
      - b. Because I take lessons and I know how to canter (2)
    2. F19-ECF12C1-5G: ride horses
    3. F15-ECF09C1-9B: horse back riding
  - iv. Sports
    1. UN24-ECS09C-9: would like a bowling course because I like bowling
    2. UN18-ECS14C-5: golf
    3. U22-ECS13C-12: bike riding
  - v. Massage
    1. UN23-ECS11C-15: kids get massage (teens)

- vi. Teen camp out
  - 1. U23-ECS10C-14: add a teen camp out (2)
- vii. Science
  - 1. F12-ECS14C1-9B: I want the weird science next year
- viii. Boating
  - 1. UN19: we get to use the boats
- ix. Activities for girls
  - 1. U31-ECS10-8: more girl things
- II. Camp environment
  - a. Amenities
    - i. Food
      - 1. UN9: hot dogs instead of hamburgers (1)
      - 2. F6-SCS09C1-5B: the food (1)
      - 3. U41-ECS10-11: no snow cones (1)
      - 4. F1-ECF12C1-6G: would like to bring our own snacks (1)
      - 5. U16-ECF11C-4: different food (1)
      - 6. UN14: have a cookie fight (1)
      - 7. U21-ECF11C-12: keep the astronaut food (2).
      - 8. UN14-ECS11C-8: ice cream (2)
      - 9. UN13-ECS11C-9: ice cream (2)
      - 10. UN20-ECS11C-12: ice cream machine (1)
      - 11. U9-ECS13C-6: better food (1)
      - 12. U11-ECS13C-5.5: ice cream (1)
      - 13. UN17-ECS14C-5: pizza! (1)
    - ii. Accessibility
      - 1. UN24-ECS14C-14:
        - a. And if there was wi-fi (2)
        - b. That'd be nice (3)
      - 2. UN26-ECS14C-15: wifi, lol (1)
    - iii. Cabins
      - 1. U28-ECS10-8:
        - a. The bathrooms should be cleaner (1)
        - b. And rooms should be cleaner (2)
      - 2. U42-ECS10-10: too many beds in the cabin (1)
  - b. Nature
    - i. Weather
      - 1. UN24-ECS14C-14:
        - a. Yes, I would like if this camp was arranged when there is warm weather (1)
        - b. So we could enjoy it more (2)
      - 2. UN23-ECS14C-14:
        - a. Yes, we should do it in warm days (1)
        - b. And probably it'll be funner to be outside (2)
        - c. And do outside things (3)
        - d. But other than that it was good (4)
      - 3. UN23-ECS12C-13: not the rain

4. UN29-ECS11C-17: can you make it warmer outside
5. UN25-ECF12C-8: for it to be warm fishing
6. F11-ECF11C1-G6: no rain :)
7. UN14-ECS11C-8: rain at all unless I say so (5)
8. UN13-ECS11C-9: no rain at all (3)
9. UN21-ECS12C-12: next time let it be sunny

c. Structure

i. Length of camp

1. U11-ECF09C-12:
  - a. I think it would be so much more fun to have this camp longer (1).
  - b. If you did it over Labor Day kids don't have school on Monday so we could be here longer (2)
  - c. It was so much fun I would stay here forever (3)
2. UN17-ECS12C-11:
  - a. It to be long (1)
  - b. Like a week long (2)
3. UN37-ECS11C-11: be for a whole week (1)
4. U43-ECS10-10: to have more days of camp (1)
5. UN15-ECF12C-9:
  - a. More days at camp (1)
  - b. And not just weekends (2)
6. UN41-ECS11C-10:
  - a. So it can be longer (1)
  - b. Maybe a week (2)

ii. Schedule

1. U21-ECF09C-6:
  - a. Breakfast be at 9:00 (1)
  - b. So we can sleep more (2)
2. UN18: I would like a time in March to touch the reindeers (1)

III. Family time

- a. UN21-ECS12C-12: you should also let us bring one of our cousins
- b. F8-ECS12C1-11G: we could bring a cousin
- c. UN18-ECF13C-8: for us to have more time to spend time with are families
- d. F1-ECF11C2-11B: family activity (3)
- e. F14-ECF13C1-10B: more family activity time (1)

IV. Miscellaneous

- a. F12-ECF10C1-5b: I want to come back (1)
- b. UN28-ECF12C-15: the same stuff like I did this year (1)
- c. UN16-ECS14C-5: he wishes we could come to his birthday party (1)
- d. UN23-ECS09C-9:
  - i. I hope it is much more fun then this year (1)
  - ii. And more fun (2)
- e. F14-ECF12C1-6B: Something more fun (1)
- f. UN35-ECS09C-13: I hope it be a lot more fun than this year (1)
- g. UN37-ECS09C-14: I hope it is much funnier than this year (1)

U8-ECS13C-5: to bring a dog (1)



**BIOGRAPHICAL SKETCH**

Melissa Anne Carawan  
M.Carawan09@gmail.com

**EDUCATION/TRAINING** *(Begin with baccalaureate or other initial professional)*

INSTITUTION AND LOCATION	DEGREE (if applicable)	YEAR(s)	FIELD OF STUDY
University of North Texas	B.S.	2012	Rehabilitation Studies
The University of Texas Southwestern School of Allied Health Sciences	M.R.C.	2016	Clinical Rehabilitation Counseling

**Positions and Employment**

January 2010-December 2012  
December 2012-April 2014  
August 2015- Present

Student Assistant-University of North Texas  
Clerk I- Denton County Tax Office  
Behavior Specialist Teacher- Pathfinder Achievement  
Center in Garland Independent School District

**Clinical Experience**

August 2012-December 2012  
August 2014-February 2015  
February 2015-August 2015

Denton County Juvenile Detention Center  
Dr. Housson and Associates  
University Rehabilitation Services-UTSouthwestern School  
of Allied Health Sciences

**Presentations and Publications**

July 2015                      Thesis Proposal  
June 2016                      Thesis Defense