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Therapeutic Camps and their Impact on the Family of Children with Special Health Care Needs: A Mixed Method Study

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Therapeutic Camps and their Impact on the Family of Children with Special Health Care Needs: A Mixed Method Study

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ABSTRACT

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Children with a chronic illness or disability can encounter many difficulties throughout their lifetimes. Respite care through therapeutic summer day camps is a service used to relieve the physical and mental strains placed on caregivers while also creating unique opportunities to benefit the child. There are gaps in the literature surrounding therapeutic camps and their benefit for the family and their ability to manage the child's special health care need. The purpose of this study is to determine how respite care in the form of a therapeutic summer day camp for children with special needs impacts a family's ability to manage their child's special health care needs within their family. This research study used mixed methodology combining quantitative data collection through pre- and postsurveys and qualitative data collection through interviews that work to answer questions relating to the effects of a therapeutic summer day camp on parents' perspective and management of their child's condition. The theoretical framework used to guide the study is the Family Management Style Framework. Twenty-two parents completed The Family Management Measure that was administered prior to and at the conclusion of an 8-week therapeutic summer day camp program. Qualitative interviews with 11 parents helped to better understand specific interventions and experiences of the therapeutic camp that benefitted their child and family. Although the quantitative analysis did not yield statistically significant changes in the family's ability to manage their child's condition as a result of attendance at the camp, the qualitative interviews demonstrated robust evidence that the camp provided meaningful

experiences for the campers and parents while alleviating stress within the family. Themes that emerged from the interviews include: (1) Family-Child themes of *loss of normalcy, relationships affected, increased stress, family adaptations, and love for the child*; (2) Camp-Child themes of *meets individual needs, creates happiness, and behavior changes*; and (3) Camp-Parent themes of *improved perception of the child, decreased stress, parent involvement with staff, and need for specific environment at camp*. Implications of the results are discussed, along with recommendations for future research.

DEDICATION

I dedicate my dissertation research first and foremost to my family. To my husband Josh who has given so much while I sit at the computer for hours on end. You have been a constant encourager to me and taught me so much patience and understanding. Also, to my sweet girls Eva, Kaetlyn, and Gracie Jo who have given me so much joy during this time in my life, and I know will continue to provide laughter and happiness for many years. Also, to my parents, Linda and Calvin, who have tirelessly supported me and given so much of their life to help me succeed. I have learned to be a hard worker and be so disciplined because of you. I also want to give a special dedication to my grandparents, Eleanor and Ken, who taught me so much about love and finding enjoyment in life and who I know would be proud of this work.

Lastly, I want to dedicate this work to all the families that have children with special needs. Your tireless efforts to care for and love your children are a true inspiration to me. I hope that I can love my family as I have seen so many of you love yours. My experiences with you and your children have enriched my life.

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CHAPTER 1

BACKGROUND AND SIGNIFICANCE

Background of the Research Problem

Children with a chronic illness or disability can encounter many difficulties throughout their lifetimes. Hardships may include physical, mental, developmental, and social issues that not only impact the child but also may increase demands and burdens experienced within the family unit. Caring for a child with a chronic illness or disability can cause many challenges within the family and may contribute to poor family functioning, inadequate management of the child's condition, negative perceptions of the child's disability, and a lack of integration of the child's condition into family life resulting in caregiver burden (Aitken et al., 2009). Families of children who have a chronic illness or disability may encounter certain issues that make family management more difficult than other families in a typical situation.

The consequences of a chronic condition in children may include physical disabilities, cognitive and academic deficits, school performance issues, behavioral adjustment, adaptive functioning, and socialization (Morse, Wilson, & Penrod, 2000; Yeates, Walz, Taylor, Stancin, & Wade, 2010). The child and family must learn to cope with daily medical tasks, doctor's appointments, and financial stress and overcome other psychological and medical aspects of the child's condition (McClellan & Cohen, 2007). For these reasons it is clear that a child's chronic illness or disability may have a negative impact on the child's emotional, physical, and developmental health that can last a lifetime.

These difficulties faced by families of children with chronic disabilities need to be understood so health care professionals can assist these families in achieving optimal functioning and incorporate strategies into their daily life that increase their ability to manage their child's

condition. Because these obstacles can affect the everyday life of the child and family, it is important that support services are identified and understood to meet the needs of these children and their families. Respite care is used to relieve the physical and mental strains placed on caregivers while also creating unique opportunities to benefit the child. Cowen and Reed (2002) showed a statistically significant decrease in parental stress with a p value of 0.03 after families received respite care. This reduction in parental stress resulted in a decreased risk for further development of dysfunctional parental behavior. Parenting distress was also decreased after the participation in respite care for their child with a p value of < 0.05 in a study by Mullins, Aniol, Boyd, Page, and Chaney (2002). Meltzer and Johnson (2007) reported a reduction in stress levels that improved psychological functioning of mothers, and Sherman (1995) reported a reduction in somatic complaints by primary caregivers after their child's attendance at respite care.

The literature demonstrates evidence that respite care is considered a valuable support intervention to assist families with the daily struggles of caring for a child with special health care needs. Therapeutic camps have been identified as a way to meet the needs of the child and the family (Meltzer & Johnson, 2007; Michalski, Mishna, Worthington & Cummings, 2003; Shelton & Witt, 2011; Swallow, Forrester, & Macfadyen, 2011). Research must be aimed at discerning what aspects of the camp are beneficial to the family's ability to function and manage their child's special health care needs. As this concept is further analyzed, explored, and researched, nurses and other health care providers can seek ways to use respite care and therapeutic camps to improve the wellbeing of the child, caregiver, and overall family functioning.

Statement of the Problem

The problem to be addressed in this study is the lack of evidence surrounding the benefits of therapeutic camps as respite care on the family and their ability to manage their child's special health care need. Therapeutic camps have been shown to provide valuable experiences for the child while also meeting the needs of the caregivers (Greenberg, 2011; Meltzer & Johnson, 2004; Michalski et al., 2003; Shelton & Witt, 2011; Swallow et al., 2011; Woods, Mayes, Bartley, Fedele, & Ryan, 2013). There is research that supports these outcomes, but there is little evidence that shows how therapeutic camps assist the family in managing their child's special health care needs. There is scant research that identifies the specific components of therapeutic camps as respite care that are meaningful to the families' view of the child and their ability to manage the condition. Most of the current studies examine how respite care and/or therapeutic camps affect the child or parent, but they do not examine how these camps impact the family's ability to function within the context of managing the child's condition (Greenberg, 2011; Meltzer & Johnson, 2004; Michalski et al., 2003 Shelton & Witt, 2011; Swallow et al., 2011; Woods et al., 2013). A deeper understanding of specific experiences and interventions that occur at therapeutic camps that impact the family unit must be explored through research. Woods et al. (2003) determined that therapeutic camps can provide hope to youth with chronic illnesses, but the specific components of the camp that increased hope were not identified. There are gaps in the literature surrounding therapeutic camps as respite care and its benefit on the family and their ability to manage the child's special health care needs. Specific interventions of therapeutic camps must be identified to create experiences for families and children that are beneficial to their well-being.

The purpose of this study was to explore how respite care in the form of a therapeutic summer day camp for children with special needs influences a family's ability to manage their child's special health care need within their family. The researcher sought to understand the implications of attendance at a summer therapeutic camp on the parent's perspective of the child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parental mutuality. These components are all in accordance with the theoretical framework used to guide the study, the Family Management Style Framework (Knafl & Deatrick, 2003) and the instrument used in the study, the Family Management Measure (FaMM) by Knafl et al. (2011) (see Appendix K). Specific interventions and/or experiences at the camp that benefitted the family and improved their management styles were explored through interviewing the parents. The information gathered from the interviews supplemented data obtained through the administration of the FaMM. The researcher also made visits to the camp to gather field notes regarding specific interventions and experiences discussed by the parents in the interviews. The qualitative portion of the data included analysis of the field notes. This added to the understanding of specific interventions and experiences at camp that may assist the parents' ability to manage their child's condition and increase family functioning.

Research Approach

A sequential, exploratory mixed methods approach was used to obtain data that explores the effect of a therapeutic summer camp on the family's ability to manage their child's condition. Statistical data were combined with data collected by qualitative interviews to give a more complete understanding of the research purpose. This was a multistrand design because more than one phase was employed to collect data throughout the research process (Teddlie & Tashakkori, 2009). Mixed method research allows the combining of qualitative and quantitative

data to provide a more accurate overall picture of the data (Johnson & Onwuegbuzie, 2004; Teddlie & Tashakkori, 2009). Sequential designs are used when the quantitative and qualitative strands occur in chronological order and the conclusions from the first strand lead to the formulation of the design components for the next strand (Teddlie & Tashakkori, 2009). Mixed method research is considered, "research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry" (Tashakkori & Creswell, 2007, p. 4). This method is used as an alternative to the qualitative and quantitative traditions because it uses whatever methodological approach that answers the research questions in the most complete way (Johnson & Onwuegbuzie, 2004). Mixed method research emerged as a way to explain discrepancies that occurred in a research study by Trend (1979) at one site between the quantitative and qualitative components (Teddlie & Tashakkori, 2009). The mixed method approach was used to explain these discrepancies and provided the opportunity for divergent views to be heard. This combination of methods also served as a catalyst for a more complete and balanced evaluation of the data (Trend, as cited in Teddlie & Tashakkori, 2009). Mixed method research is the only research approach that can simultaneously be used to answer a range of research questions that are rooted in both quantitative and qualitative approaches (Johnson & Onwuegbuzie, 2004). Mixed method research provides stronger inferences from the data through the combination of the qualitative and quantitative data (Onwuegbuzie & Leech, 2004).

Research Questions

A combination of confirmatory and exploratory questions can be used with both the quantitative and qualitative approaches in mixed method research to give a greater breadth and depth to the research questions (Teddlie & Tashakkori, 2009) and enhance the strength of the

study (Creswell & Plano Clark, 2007). The first seven research questions in this study are quantifiable and confirmatory, and the last two research questions are exploratory in nature. A variety of data sources including a questionnaire, field notes, and interviews were used to answer these questions, which is in accordance with mixed method research (Teddlie & Tashakkori, 2009). The research questions for this study are:

1. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to the child's condition?
2. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to condition management ability?
3. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to the child's condition management effort?
4. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to family life difficulty?
5. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to the view of the condition's impact?
6. In families that have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to parental mutuality?

7. Are there differences in the family's ability to manage their child's condition (according to the FaMM) prior to and at the conclusion of the child's attendance at an 8-week therapeutic summer day camp?
8. What are the perceptions of parents of children with special health care needs of the interventions and experiences at a therapeutic summer day camp program?
9. What interventions or experiences (if any) impacted the parents' perceptions regarding the management of their child's condition?

The specific aims of the reseracher are:

1. To understand and evaluate the outcomes that respite care through a therapeutic summer day camp program has on family management styles of families of a child with a special health care need
2. To understand and examine any specific interventions or experiences at camp that assisted parents in improving their perspective of the child's condition on their family life and ability to function as a family
3. To use the findings to develop specific interventions or create experiences at therapeutic camps that camp organizers can use to promote positive family outcomes and improve family management styles

Importance of the Study

This study regarding the impact of therapeutic camps on the families of children with special health care needs was valuable for several reasons. First, understanding how a family's view of their child's condition, its impact on their family life, and their ability to manage their child's condition is imperative to create better health outcomes for these families and children with special health care needs. If attendance at a therapeutic camp impacts these components,

families can improve their functioning as a unit. The findings from this study will potentially benefit therapeutic camps in several ways. Quantifiable data that demonstrate an improvement in family management styles may assist camps with funding for their programs in order to provide care to families that may not have the financial resources to allow their child to participate in a therapeutic camp. Specific guidelines and interventions for what works best to assist families may also be determined from the results of the study. These may be incorporated into camps and other respite care services to benefit the families of children with special health care needs.

CHAPTER 2

LITERATURE REVIEW

Childhood Disability and Chronic Illness

A child's chronic disability or special need may negatively impact the child's emotional, physical, and developmental health. The consequences of a chronic condition in children may include physical disabilities, cognitive and academic deficits, school performance issues, behavioral adjustment, adaptive functioning, and socialization (Yeates et al., 2010). These changes and disabilities can adversely influence the child's family functioning by increasing family caregiver burden (Aitken et al., 2009). The family burden encountered after a child's diagnosis of a chronic disability can be related to the stress associated with the management of the child's conditions, perceptions of those close to the child, and the disruption to the normal family processes (Wade, Taylor, Drotar, Stancin, & Yeates, 1998). Raina et al. (2005) also wrote that demands placed on the caregiver of a child with special needs contribute directly to both the psychological and the physical health of the caregivers. The family's ability to function affected health directly and influenced the concepts of self-perception, social support, and stress management.

It is important to clarify the definition of children in this population to better understand the health care needs of these children. According to the Federal Maternal and Child Health Bureau (2006) a broad and inclusive definition that classifies children with a chronic illness or disability as a child with special health care needs has been developed. This definition is intended to encompass the characteristics held in common by children with a wide range of diagnoses. The definition states that children with special health care needs are, " those who have or are at an increased risk for a chronic physical, developmental, behavioral, or emotional

condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). This definition is useful in understanding the wide range of disabilities or illnesses that impact a child's well-being. This is the definition that was used for this study to identify children with special health care needs.

The child with special health care needs struggles with physical and psychological impairment and is also at a disadvantage within the health care system. According to the Child and Adolescent Health Measurement Initiative (2012) the needs and difficulties of these children within the health care system are magnified. It is estimated that 14.6 million children or 19.8% of children nationally have special health care needs with 65% of these children needing complex services that go beyond a primary health care need for prescription medications to manage their condition. The Child and Adolescent Health Measurement Initiative (2012) reports that 24.5% of families of children with special needs indicated they had difficulty getting referrals for the services they need with 43.6% not receiving the effective coordination of care when needed. Inadequate health insurance was reported by 29.2% of families resulting in a decrease in access to services. These data reinforce the idea that children with special health care needs face many physical, psychological, and medical difficulties.

Although these children and their families face many obstacles, recent advances in medical technology have resulted in significant improvements in the health care of this population, enhancing survival and health related quality of life (Varnie, Limbers, & Burwinkle, 2007). The transference of the burden of care from the hospital and /or residential setting to the home setting has occurred through a shift towards better development of in home care and other community-based services (Hockenberry & Wilson, 2011). This change led to the parent becoming the primary care giver and taking on many more medical and nursing responsibilities

for their child, which significantly impacted their parenting role and the ability of the family to function as a unit.

Impact of the Child's Special Health Care Needs on the Caregiver

Because the child with special health care needs faces so many challenges, the demands of caring for this child can be daunting. The practical day-to-day needs of the child create challenges for parents, and these demands placed on the caregiver contribute directly to both the psychological and physical health of the caregivers (Kuster & Merkle, 2004; Raina et al., 2005). These demands can consequently increase caregiver burden (Aitken et al., 2009; Meltzer & Johnson, 2007), result in a great strain on the family causing physical and emotional stress (Thomas & Price, 2011; Yantzi, Rosenberg, & NcKeever, 2007), increase somatic complaints (Sherman, 1995), and possibly lead to depressive symptoms (Baker et al., 2003; Sullivan-Bolyai, Sadler, Knafl, Gilliss, & Ahmann, 2003). Parents experience caregiver burden from the physical and mental stress associated with caring for their child, and they may also feel social isolation (Johnson, O'Reilly, & Vostanis, 2006; Yantzi et al., 2007), a sense of imprisonment and disconnection from others (Eaton, 2008), and a limitation of current lifestyle (Johnson et al., 2006).

Family caregivers are often overwhelmed with the stress of caring for their child's needs, and they express frustrations with the uncertainties of their child's care (Eaton, 2008; MacDonald & Callery, 2003). The distress faced by the caregiver is magnified as they seek to manage medical tasks, responsibilities, access to educational and medical services, emotional grieving, and stigmatizing reactions from the community and other family members (Hockenberry & Wilson, 2011). The primary caregiver is usually the parent, so the child's care responsibilities are often accompanied by other tasks such as working, caring for other children

in the home, and completing household duties that may increase the burden of care giving. Fathers may be considered primary caregivers, but mothers of children with disabilities have received the most attention in the literature (Meltzer & Johnson, 2007). Negative behaviors exhibited by the child with special health care needs can lead to the mother's feelings of self-blame and conflict (Johnson et al., 2006). Parents who serve as primary caregivers may suffer higher levels of distress and need greater support throughout the life of their child (Baker, Blacher, Crnic, & Edelbrock, 2002). The stress experienced in caring for a child with special health care needs can affect the family's ability to function and achieve normalization (Knafl, Darney, Gallo, & Angst, 2010).

Impact of the Child's Special Health Care Needs on the Family

Caring for a child with special health care needs can have an overwhelming impact on all aspects of family life (Thomas & Price, 2011). The family burden that is encountered after a child's diagnosis of a chronic disability can be related to the stress associated with the management of the child's condition, perceptions of those close to the child, and the disruption to the normal family processes (Wade et al., 1998). Evidence has demonstrated that families with a child with a chronic illness or disability are at a greater risk for problems with family cohesion, parent-child interactions, problem solving skills, family conflict (McClellan & Cohen, 2007), and lower family functioning (Baker et al., 2003).

Caring for a child with special health care needs may negatively affect parents and others in the family. The impact on siblings of children with special health care needs has not been widely researched, but there is some evidence that they face difficulties as they watch their brother's or sister's health deteriorate (Thomas & Price, 2011). Parents express concern that

caring for the child with special health care needs takes time away from interacting with the other children in the home, which can adversely affect their wellbeing (Sherman, 1995).

Based on the these findings, it is important that health care providers assist families to overcome the challenges they face as they care for their child with special health care needs in order to create a functioning, viable family unit. The current trend to keep children at home for much of their care has led to an increased need to support families through various programs that help prevent family dysfunction and burnout (Sherman, 1995). For families of children with special health care needs to function normally, they must be able to integrate their child's condition into daily family life, see their child's life and their family life as normal, and manage their stress through social support (Knafl et al., 2010). There are many services that seek to provide interventions for these families and children. Respite care is an intervention that can provide valuable support for families and children with special health care needs.

Respite Care

Respite care is identified as a way to alleviate the family's burden of caring for a child with a disability or chronic illness (Cowen & Reed, 2002; Eaton, 2008; Ling, 2012; Shelton & Witt, 2011; Wilkie & Barr, 2008). Respite care has also been identified as a very positive experience for both the child and the family (Thomas & Price, 2011). Respite care can provide relief from the emotional and physical strains that are prevalent while providing care, and respite care can provide opportunities for the child to gain new experiences and interact socially. Occasionally, this service includes additional child-focused support that allows the family to engage in activities with the child that would not have been possible otherwise (Robertson et al., 2011). Respite care can occur inside the home, a residential facility, hospice setting, community

setting, therapeutic day camp, or summer camp program. Respite care is extremely diverse and varies in location, duration, and the person or organization that provides the service.

There is substantial evidence that respite care is beneficial to the child and family. Respite is often the most frequently requested support service by families. This assistance is considered a preventative strategy that strengthens families, allows individuals to remain in their home, and protects family health and wellbeing. Respite care can reduce the risk of abuse or neglect and keep all family members stable and safe (ARCH, 2006). This type of support is a necessity to maintain the family unit (MacDonald & Callery, 2003). Families may seek respite care when feelings of helplessness and anxiety regarding their child's behavior become overwhelming (Wilkie & Barr, 2008). Hoare, Harris, Jackson, and Kerley (1998) suggest that respite care services should be provided early to prevent physical and emotional burnout. In a qualitative study by Eaton (2008), all families that participated in some form of respite care felt that they were close to "cracking up" before respite care began. The literature has shown that respite care allows families to keep caring for their child in the home (Eaton, 2008), provides a break from the tasks of everyday life (Ling, 2012), allows the family to function normally while also caring for other children within the home (MacDonald & Callery, 2003), and reduces caregiver stress (Cowen & Reed, 2002; Meltzer & Johnson, 2007; Robertson et al., 2011). Respite care can provide a valuable support system for the family that is caring for the child with special health care needs.

Not only does respite care have an effect on the family, but it can also influence the child. Respite care can maintain positive family functioning, offer normal opportunities for children to encourage independence, increase social experiences, and allow the child to become more involved in the community (Swallow et al., 2011; Wilkie & Barr, 2008). This review outlined

and explored the research documenting the effects of respite care on the caregiver, family, and child.

Definitions

There is a wide variety of definitions of respite care present in the current literature. Defining respite care can be difficult because there is such a broad range of services that may create a lack of consistency among terms. MacDonald and Callery (2003) wrote that respite care can have different meanings for different people. The ambiguity in the definitions involves variations in the location of respite, who is providing respite, the services being offered, and the purpose of the respite care. According to the ARCH National Respite Network (2011) respite care is defined as, "planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult" (para 1). Respite care should provide a break to parents and benefit the child by offering the opportunity for social interaction development of other life skills (Ling, 2012). This benefit is apparent through evidence-based research, but it is still lacking in the majority of the literature. Wilkie and Barr (2008) found that parents felt respite care provided their child with the opportunity to interact with peers, increase social skills, and have more social and physical interaction through leisure activities. Although Swallow et al. (2011) did not present a clear definition of respite care, they did conclude that the purposes of respite care should be geared towards the needs of the child as well as the family. Robertson et al. (2011) define short breaks or respite care as being designed for families to have a break from the responsibilities incurred from parenting a disabled child and also give the child opportunities for new experiences with other people. The weight of the current evidence pertaining to respite care services supports the idea that care should be focused on meeting the needs of the child along with providing relief to

the caregiver (Shelton & Witt, 2011; Swallow et al., 2011; Wilkie & Barr, 2008). Therapeutic camps can provide this specialized respite care that alleviates the burden of care for the caregiver while also meeting the needs of the child.

Location of Respite Care

Although a wide array of respite care services have been studied, the evidence surrounding the best location and type of respite care is inconsistent. MacDonald and Callery (2007) concluded that the needs of families and children with disabilities are dynamic and evolve over time, which may result in various types of respite care needed throughout the child's lifetime. Respite services can include inpatient care for a few days or up to 30 days or more at a residential facility (Mullins et al., 2002). Respite can be given in the home, residential setting, or hospice setting. The time frame for respite care can range from several hours per week to 24-hour nursing care for a specified number of days (Eaton, 2008). Respite care can also be classified as overnight care at a therapeutic camp for a period of several days (Meltzer, 2002; Meltzer & Johnson, 2007; Shelton & Witt, 2011). The literature demonstrates that there is a wide range of locations for respite care, but the literature is lacking in evidence regarding which location provides the best outcomes for the child and family. Certain studies demonstrate that parents and children preferred overnight care that occurred outside the home, but in home care also has benefits to consider and may be preferred by some families (Hartrey & Wells, 2003; Sherman, 1995). In home care may provide a more consistent environment and release the burden of transporting the child and the medical equipment (Ling, 2012). There is some evidence supporting the benefits of in home care, but the literature reveals a greater amount of evidence that out-of-home respite care is advantageous.

It is clear from the literature that families need a variety of respite offerings due to difficult family scheduling and the need for planned breaks from caregiver responsibilities (Eaton, 2008; Thomas & Price, 2011; Wilkie & Barr, 2008), but there are inconsistencies in the methods that evaluate the best location for respite care. Evidence-based research will provide a greater understanding of the type of respite that imparts the greatest impact on the caregiver, family, and child with special health care needs. In particular, therapeutic camps must be evaluated so that providers can better understand the needs of this population and assist with enhancing health outcomes and promoting normalization of the family.

Therapeutic Camps as Respite Care

Therapeutic camps are created to give children with special health care needs opportunities to participate in activities that other typical children may experience in the camp setting. Activities focus on children's abilities instead of their disabilities. Camps provide children with social interaction and time to experience fun activities that they might not have been able to experience otherwise. Camps can range from overnight weekly camps to day camps in the summer. Counselors are specially trained to meet each child's individual needs. Therapeutic camp programs for children with special needs are unique because they are designed to create goals and experiences for the children with disabilities in order to help them achieve their maximum potential. Therapeutic camps often focus on increasing self-management skills, enhancing emotional adjustment, enhancing self-esteem, and engaging in one-on-one and group social activities (Hunter, Rosnov, Koontz, & Roberts, 2006; Michalksi et al., 2003). Morse et al. (2000) conducted a study of medically fragile children who attended a summer camp program. They concluded that as the children with disabilities became more accustomed to the outside world, they developed attributes that helped them "fit in" with the outside world. They worked to

develop their own capabilities, and they stretched the limits of their disability by maximizing these capabilities. This helped change the perceptions of others in regards to their disability and assisted family members to adapt to the child's ever-changing disability. From this research, it is clear that therapeutic camps are considered an effective avenue of respite care that benefits the child and the family.

Impact of Respite Care

Impact of Respite Care on Caregiver Well Being

The impact of respite care to the caregiver's wellbeing is the most commonly studied concept in the literature. Although there are a small number of studies that have been designed to measure the impact on the caregiver, the evidence within these studies demonstrates there are benefits from respite services for the caregiver (Cowen & Reed, 2002; Eaton, 2008; MacDonald & Callery, 2003; Meltzer & Johnson, 2007; Mullins et al., 2002; Shelton & Witt, 2011; Sherman, 1995; Swallow et al., 2011; Wilkie & Barr, 2008). After families had received respite care, there was a decrease in parental stress (Cowen & Reed, 2002; Mullins et al., 2002). Reported reduction in stress levels, improved psychological functioning of mothers (Meltzer & Johnson, 2007), and reduction in somatic complaints by primary caregivers (Sherman, 1995) were also apparent.

Quantitative studies using a pre- and postdesign found that mothers' stress levels were reduced at 1 week and at 1 month after their child attended a therapeutic respite camp (Meltzer & Johnson, 2007). A reduction in somatic complaints by parents 6 months after receiving in home respite care was documented in the study by Sherman (1995). Although Mullins et al. (2002) found an improvement in stress levels amongst parents immediately following respite

interventions of short-term (3-7 days) and long-term care lasting 30 days at an inpatient facility, the parenting stress level scores had returned to baseline levels 6 months after the intervention.

There is a significant amount of qualitative literature providing a rich description of the lived experiences and valuable perspectives of the caregivers concerning respite care. These benefits include emotional and physical relief (MacDonald & Callery, 2003; Shelton & Witt, 2011; Swallow et al., 2011; Wilkie & Barr, 2008), increased time to participate in leisure and social activities (Eaton, 2008; Wilkie & Barr, 2008), the ability to complete household tasks (Shelton & Witt, 2011), and an improved sense of confidence in caring for their child (Wilkie & Barr, 2008).

Therapeutic Camps

Based on the current literature, therapeutic camps are designed to help children with special health care needs achieve similar experiences that other children receive through summer camps (Meltzer & Johnson, 2007; Michalski et al., 2003; Shelton & Witt, 2011; Swallow et al., 2011). The camp staff provides a range of therapeutic and recreational activities in a safe environment that are used to enhance social skills, self-confidence, and self-esteem of the campers (Michalski et al., 2003). Based on the studies of therapeutic camps for children, the camp experience was enjoyable for the parent and the child (Shelton & Witt, 2011) and provided relief from their caregiving demands and psychological distress (Meltzer & Johnson, 2007). Swallow et al. (2011) found that when teenagers with life limiting conditions participating in an overnight respite care program enjoyed the activities at the respite service, the parents had greater peace of mind that enhanced their psychological wellbeing and perceptions of respite care.

Shelton and Witt (2011) and Swallow et al. (2011) demonstrate a clear picture of the benefits to the caregiver during the child's participation in a therapeutic camp. This is documented by specific examples given by the research participants that resulted in specific themes obtained through precise coding methods leading to data saturation.This type of respite care provided the caregivers with needed breaks and peace of mind. Specific qualities of the camps that contributed to the benefits of respite also emerged in the data, which increases the robustness of the findings. The quality of these studies is measured in their methodological description. Thorough documentation of the interview and coding process, careful explanation of apparent themes, explicit summary of interview questions, and discussion of possible biases enhanced the rigor of these studies (Shelton & Witt, 2008; Swallow et al., 2011) through documented credibility, demonstrated dependability, and triangulation through the use of various data collection methods (Thomas & Magilvy, 2011). There is no current research in the literature that implements mixed methodology using quantitative data that are augmented with qualitative data to better understand how therapeutic camps affect the child and family.

Impact of Respite Care on Family Unit and Family Functioning

There is scarce literature that evaluates the impact of respite care on the family unit and family functioning. Studies that measured this concept concluded that respite care provided the parents with more time to spend together as a couple and with other children in the home (Shelton & Witt, 2011; Swallow et al., 2011; Wilkie & Barr, 2008). Respite care also gave them time to be a normal family (MacDonald & Callery, 2003). Thomas and Price (2011) and Eaton (2008) discuss how respite care improved the quality of life of the family, but there was a lack of discussion regarding the reasons for the improvements. Quantifiable measures that were used to obtain these data were not discussed, which diminished the credibility of the findings.

Therapeutic Camps

Therapeutic camps affected family functioning because they provided the family with more time to spend together (Shelton & Witt, 2011; Swallow et al., 2011; Wilkie & Barr, 2008) and increased time spent with friends (Shelton & Witt, 2011). These outcomes describe benefits that the family may have experienced as a result of respite care, but they do not specifically measure family functioning. Shelton and Witt (2011) found evidence that respite care through a therapeutic camp improved family functioning, but the specific components of family functioning were not identified.

Further research using qualitative and quantitative methods needs to be conducted to examine short-term and long-term effects of respite care on the family's ability to function as a unit. Comprehensive measurement tools with established validity and reliability need to be used to evaluate benefits of respite care for the family as a unit and the individual perceptions of others within the family. Among both qualitative and quantitative studies, there is a lack of evidence surrounding the perceptions of the father and the siblings in regards to the impact of respite care on the family. The involvement of fathers and siblings has been addressed minimally in the literature that does not fully explore the impact of respite care, specifically therapeutic camps on the family unit and family functioning.

Instrumentation

The evidence-based studies that were included in this review implemented a small number of measurement tools to better understand the impact of respite care on the caregiver and the child with special health care needs. There are some limitations with these tools. None of these instruments involve the full range of complexities seen in assessing the impacts of respite care, including the impact on family functioning. There is an inconsistent use of instruments

pertaining to caregiver stress, and many of the instruments do not account for the intricate psychological components that are directly related to caring for the child with special health care needs.

Reliability and validity of all of the instruments are not discussed, and some studies have limitations in their documentation of reliability and validity. There were a few studies that mentioned the use of Cronbach's alpha for reliability of questionnaires; however, the number fell below 0.70. This may indicate a small number of questions or poor interrelatedness between items requiring further evaluation thereby diminishing the reliability of the questionnaire (Tavakol & Dennick, 2011). In addition, some of the measurement tools used to assess impact on caregiver wellbeing only evaluated global stress levels and general psychological distress levels that may also be present in the general population. These tools neglect the importance of stress that is indirectly or directly related to caring for a child with special health care needs (Meltzer, 2002). Mullins et al. (2002) concluded that the use of unstandardized parent-report measures that lack established reliability and validity to understand the impact of respite services creates methodological errors (Meltzer & Johnson, 2007; Radcliffe & Turk, 2007). Although self-report questionnaires may be seen as reliable, the specific self-report questionnaires in these studies had no documentation of reliability. None of the measurement tools examined various aspects of mothers as compared to fathers, and variations in parent mutuality and its effect on the impact of respite care within the family were also excluded.

The effectiveness of respite services through high quality research with measurable data is crucial due to the high financial cost of services and need for services by many families. There is a need to incorporate methodology that employs tools that assess physical and psychological stress specifically related to caregiver demands, family functioning, parent mutuality, and

caregiver burden. The Family Management Measure (FaMM) by Knafl et al. (2011) was used for this study. This instrument addresses issues that are pertinent to families of children with special health care needs and their ability to manage their child's condition.

Only three quantitative studies examined pre- and postdata around the intervention of respite care (Meltzer & Johnson, 2007; Mullins et al., 2002; Sherman, 1995). These studies did find statistically significant results including: a decrease in mothers' stress and psychological distress (Meltzer & Johnson, 2007), reduction in somatic complaints by caregivers, a decrease in number of hospitalization days required by the child (Sherman, 1995), a reduction in psychological distress for the caregiver, and improved functional ability of the child (Mullins et al., 2002). Although these longitudinal studies increase the knowledge surrounding respite care services, none of these studies used the same measurement tools or employed the use of control groups, and there was variation in all three studies regarding the type of respite care that was being researched. The lack of consistency among these longitudinal designs creates a gap in the current literature. More quasi-experimental designs need to be undertaken that use standard measurement tools to better understand the long-term impact of respite care on children and families. For this study the FaMM was administered prior to therapeutic camp attendance and immediately following the camp experience to better determine the effects of a therapeutic camp on the family's ability to function.

Theoretical Models and Frameworks

The review of literature yielded a significant lack of theoretical models or conceptual frameworks to guide the studies surrounding respite care. From the studies that were included in this paper, there were only two research studies that used theoretical models to enhance the research process and findings (Meltzer, 2002; Cowen & Reed, 2002). In a dissertation by

Meltzer (2002) regarding mothers of children with chronic illnesses and their experience with summer camp respite care, Pearlins's model of caregiver burden (Pearlin, as cited in Meltzer, 2002) was used to describe the stressors involved with caring for a child with special health care needs. Meltzer (2002) further classified the stresses involved in care giving as objective and subjective stress in accordance with the model by Pearlin. Objective stress involved stress associated with medical tasks, doctor's visits, etc; whereas, subjective stress involved the mother's perceptions of the stress in relation to each of the objective stressors. This model does incorporate specific stresses that are encountered during the experience of caring for a child with a chronic disability or illness, and it also accounts for mediators that might affect stresses and outcomes. The use of this model was implemented throughout the study, and modifications were suggested at the conclusion of the dissertation based on the evidence demonstrating a complete underpinning of the model throughout the research. This model is specific to the stresses associated with caregiver burden, but there are still some inadequacies with this model in regards to the impact of respite care. This model does not incorporate concepts related to family functioning, family management, or outcomes of the objective and subjective stress experienced by the mother on the child.

The conceptual framework, The Ecological Model of Child Maltreatment Prevention by Garbarino (1977), was used in the study by Cowen and Reed (2002) regarding the effects of respite care for children with developmental disabilities. This model was chosen because it provides a framework for understanding relationships between stress, social support systems, and child maltreatment (Cowen & Reed, 2002). Respite care programs are considered a part of child maltreatment prevention programs within the model proposed by the authors. The framework was outlined at the beginning of the study, but it was not implemented throughout the findings

and conclusion, which contributes to the lack of consistency within the organizing framework of the study. This model does discuss prevention of child maltreatment, which was a component of the data related to the outcomes of respite care in the study, but this model did not address the other issues that were presented in the study such as parenting stress, coping, and family functioning. The Ecological Model of Child Maltreatment Prevention by Garbarino (1977) did not discuss cultural influences that were pertinent to the study. These gaps demonstrate that the framework was not used to guide the entire study, which does not enhance the findings based on the theoretical model.

The lack of integration of theoretical models in the current literature has created poor use of theories to guide evidence-based practice. When the theoretical model or framework is used to undergird the research questions, methods, instrumentation, and conclusions, conceptual and empirical efforts can be combined to further the advancement of evidence based practice. A theoretical model that encompasses all of the complex concepts surrounding the impact of respite care may not be available, but there are certain principles that must be included within the model. There is a definite need to integrate theoretical models that include how stress in the caregiver is directly related to caregiver responsibilities of the child with special health care needs along with perspectives of siblings and the concept of parent mutuality. A model must be chosen to understand the entire family's response to childhood illness or disability to assess family functioning. This may include how the family defines the child's illness, medical management, and the impact of the child's needs on family functioning within the context of daily family life. A model clearly defining various components and classifications of family functioning may provide a greater depth of knowledge surrounding the influence that respite care has on the

family unit. For this study the Family Management Style Framework (Knafl & Deatrick, 2003) was used to undergird the research process.

Family Management Style Framework

The theoretical framework that was selected and used for this research is the Family Management Style Framework (Knafl & Deatrick, 2003). This framework was chosen because it describes how families manage their child's chronic condition, and it seeks to explain how a family's perspective may change throughout the course of their child's condition. In this study the Family Management Style Framework (FMSF) was used to better understand the impact of a therapeutic summer camp on the family's ability to manage their child's condition. It was developed through numerous qualitative studies and integrative reviews. This framework includes views of each family member to further understand overall family response to a health-related condition and to enhance understanding of how families incorporate the work of managing a child's chronic condition within family life (Deatrick, Knafl, & Havill, 2012). This framework is narrower in scope because it addresses the family's response to childhood chronic illness specifically. Other theoretical frameworks address family's response to stressors (Symbolic Interaction Framework, Blumer, 1969; Pearlins's model of caregiver burden, (Pearlin, cited in Meltzer, 2002), but they do not specifically address stressors that are related to childhood illness or chronic conditions. These models also do not address the family's interaction and response to each other, which are important components for this study. The Family Management Style Framework includes aspects of decision making and specific responses to chronic illnesses. This framework has been used in 46 published journal articles and includes 13 in nursing journals and 12 in other interdisciplinary sectors (Knafl et al., 2012). The major components of the framework include definition of the situation, management behaviors, perceived

consequences, and contextual influences. The FMS framework identifies five management styles that include: thriving, accommodating, enduring, struggling, and floundering (Knafl, Breitmayer, Gallo, & Zoeller, 1996). These management styles can be seen through adjustments that the family makes while adapting to the child's disability or chronic condition (Deatrick, Knafl, & Walsh, 1988). Another component of the framework includes the perspective of the family caring for the child with the chronic condition. This corresponds to the family management styles leading to the outcomes of individual and family unit functioning. Sociocultural influences on family management of childhood chronic conditions include social networks and response to the child and family, health care, education, social service professionals and systems, and resources. The framework also accounts for parental mutuality and parenting philosophy. Family focus and future expectations of the child are also accounted for within this framework (Knafl et al., 2012). Three attributes are included that are definition of the situation, management behaviors, and perceived consequence (Knafl & Deatrick, 2003). This framework is built on the concept that the family's response is based on how they define and manage certain aspects of their child's health related condition. This framework is directly aligned with the Family Management Measure, which is the quantitative instrument used in this study.

Conclusion of Respite Care Review

Gaps in the Current Literature

The current literature surrounding the impact of respite care has some significant gaps and limitations specifically in regards to the exploration of therapeutic summer camp programs. There is a consistency in the small amount of evidence that respite care through the use of therapeutic camps has a positive impact on the caregiver, family unit, and the child's wellbeing. There must be a greater breadth and quality of literature that covers this concept within the

specific population to expand the knowledge surrounding respite care. There is perpetual ambiguity in regards to the definition of respite care creating contradictions in the meaning and purpose of respite care that must be addressed through further concept analysis and theoretical literature. Certain methodological issues that limit rigor and robustness of the findings include: lack of research on the impact and effectiveness of various types of respite care services, specifically therapeutic camps, lack of consistent use of documented valid and reliable instrumentation, minimal insight into family perception and functioning, and negligible use of longitudinal studies measuring long-term outcomes of respite care. Outcome measures of respite care and specific standards of care have not been documented within the literature leading to inconsistencies in the best location and most recommended types of respite care across disciplines. This may be attributed to meager explanations of activities offered and protocols enforced within the various types of respite care. The current evidence also yielded problems with measuring the impact of respite care on family functioning and child outcomes. There is a major lack of theoretical models and/or conceptual frameworks to guide current studies. This study used quantitative and qualitative methods to answer research questions regarding the effects of therapeutic camps on the family's ability to manage their child's condition. An instrument was used (FaMM) that had documented reliability and validity, and the Family Management Style Framework was used to guide the study. This researcher sought to explore, provide evidence, and fill some of the existing gaps in the current literature regarding the benefits of therapeutic camps.

CHAPTER 3

METHODS

Introduction

An exploratory mixed methods design with a sequential approach was used to collect data. This method was chosen to combine both quantitative and qualitative approaches to create a design that provides the best understanding of the phenomenon being studied. The mixed method uses both qualitative and quantitative approaches to establish types of questions, research methods, data collection, data analysis, and inferences. Research questions can be answered, modifications can be made, and new meanings from the previous strand can be explored through the use of the sequential design (Newman & Benz, 1998). The qualitative and quantitative strands of this study occurred in chronological order, so a sequential design was used. The design implemented between-strategies data collection. This method for data collection involves research that gathers qualitative and quantitative data with more than one data collection strategy (Newman & Benz, 1998; Teddlie & Tashakkori, 2009). The use of various data collection strategies in mixed method research has been identified as a form of triangulation that enhances the findings of the research (Teddlie & Tashakkori, 2009). Johnson and Turner (as cited in Teddlie & Tashakkori, 2009) list a fundamental principle of mixed method research as using methods that are mixed in a way that has "complementary strengths and nonoverlapping weaknesses" (p. 238). A quantitative instrument was used by the researcher to measure family management styles. This tool does not specifically address the effects of a therapeutic camp on family management styles, so interviews addressing this specific concept were added to the research to explain and augment the findings from the quantitative instrument. Both of these

types of data collection complement each other and minimize weaknesses to create robust information regarding the phenomenon being studied.

Ethical Considerations

The researcher followed ethical guidelines by obtaining IRB permission from the researcher's educational institution. The camp director provided a letter of support that indicated his enthusiastic approval for the research to be conducted in the summer camp (see Appendix H). A meeting was held with the camp director to discuss the sampling plan, recruitment, questionnaire, interviews, data collection, and analysis.

The parents were invited to participate and were made aware that there would be no penalty for their child at camp if they chose not to participate. The researcher stressed that participation was voluntary, and each parent was given the opportunity to sign the informed consent document. They were given ample time to read the document and ask any questions of the researcher. Each questionnaire was assigned a number by the researcher in order to maintain confidentiality of the participants. The questionnaires were given to each parent and then returned to the researcher who then placed them in a sealed envelope and kept them in a locked cabinet. Initials were used to identify the participants to the researcher in order to maintain organization of the number system for the questionnaires. Once the data had been entered into SPSS version 21, the files remained in the locked cabinet in the researcher's office. The document that correlated the initials with the number on the questionnaire was kept in a separate locked cabinet.

A private room was used at the camp to conduct the interviews, and parents were given the option to decline participation in the interviews. The interviews were scheduled at a time that was convenient for the parents in order to meet their needs. The interviews were audiorecorded

and transcribed verbatim by the researcher. Initials were used to identify the participants and protect anonymity. The files were kept on a password protected hard drive in order to protect participant confidentiality. All raw data will be kept for five years after publishing in Proquest and then they will be destroyed. There was no correspondence with the participants through email.

In the observation phase the researcher only observed parents who had signed the informed consent document. Children over the age of 17 were not included in the observations. Children who may have been present in the observation had consent documents signed by their parents. Any observations that occurred with children who were capable of understanding an assent document would have been given the opportunity to sign the form. However, no children met this criterion in the observation, so no assent forms were signed.

Philosophical Worldview

The worldview underlying this study is a pragmatic worldview (Cherryholmes, 1992), which is a commonly used philosophical orientation in mixed methods research (Johnson & Onwuegbuzie, 2004; Newman & Benz, 1998). Pragmatism focuses on what works regarding the research questions under investigation. This worldview grounds this study. The research was focused on what interventions from the therapeutic camp assisted the families in providing better care for their child with special health care needs. Pragmatism supports the idea for mixed methods research because truth is seen as what works best at the time (Creswell, 2009). A mixed methods approach was used for this study to provide a better understanding of what works for families of children with special health care needs to help them manage their child's condition as a result of the therapeutic camp. This is in congruence with the ideas of the pragmatic worldview.

The pragmatic worldview acknowledges that the values of the researcher may play a role in the interpretation of the results of the study (Johnson & Onwuegbuzie, 2004). In this study the researcher's experience of working with children with special health care needs and their families within a therapeutic camp setting assisted with the planning for the study. The researcher believes deeper insight into the parents' perspective on the effects of a therapeutic camp and their ability to manage their child's condition is very important. Based on the researcher's experiences with this population and camp setting, it is vital to understand and consequently create interventions and experiences that benefit both the child and the family.

In a pragmatic worldview both objective and subjective viewpoints are taken into consideration within the participant-researcher relationship. Mertens (2003) wrote that in mixed method research, objective data in the form of a questionnaire are important to limit bias that can be present with subjective data. For this study objective data though a questionnaire were coupled with subjective data from interviews. It is important for the researcher to be present in the field setting to better understand the participant's subjective experience (Teddlie & Tashakkori, 2009). For this study objective data were obtained through the questionnaire, and subjective viewpoints were obtained through the interviews in which the researcher was a coparticipant.

Theoretical Framework

The theoretical framework used to guide this study is the Family Management Style Framework (Knafl & Deatrick, 2003). The major components of the framework include definition of the situation, management behaviors, perceived consequences, and contextual influences (see Figure 1). The FMS framework identifies five management styles that are thriving, accommodating, enduring, struggling, and floundering (Knafl et al., 1996). These

management styles can be seen through adjustments that the family makes while also adapting to the child's disability or chronic condition (Deatrick et al., 1988). The framework describes the family's reponse to health callenges and explains how families "incorporate the work of managing a child's chronic condition within family life" (Kanfl, Deatrick & Havill, 2012). This framework was used to develop the FaMM, which is the measurement tool used for the quantitative portion of this study. The framework describes how families manage their child's condition, the underlying purpose of this study.

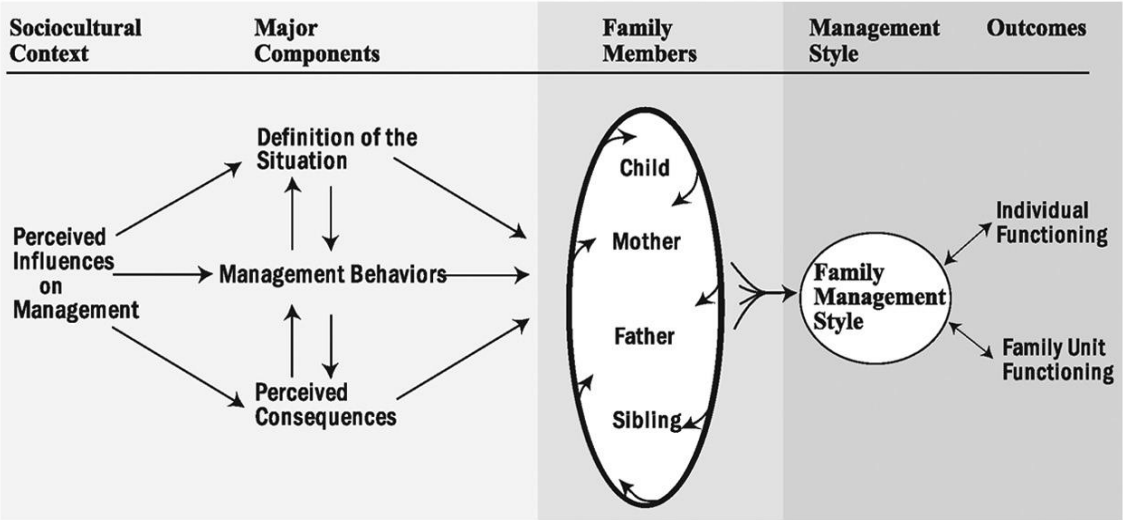

Figure 1. The Family Mangement Style Framework Conceptual Model (Knafl, Deatrick, & Havill, 2012)

Quantitative Instrument

The measure used for this study derived from the FMS framework was the Family Management Measure (FaMM). The FaMM is an experiential condition specific measure that includes six family management factors that were identified in a quantitative validation study. These are (1) the child's daily life, (2) the impact of the condition on family life, (3) the difficulty of family life, (4) the effort managing the condition, (5) the ability to manage the condition, and (6) parental mutuality (Knafl et al., 2011). The instrument has 53 items for

partnered parents and 45 items for nonpartnered parents. Research was conducted to assess the psychometric properties of the FaMM including factor structure, internal consistency, test-retest reliability, and construct validity. The FaMM was initially tested with 579 parents from 417 families with a wide array of chronic conditions. (Knafl et al., 2011). There were 162 families in the sample that had two parents participating. The parents responded to the 65-item FaMM along with measures of family functioning (Family Assessment Device, child adaptation (Eyeberg Child Behavior Inventory), and child functional status (Functional Status Measure II). In order to evaluate construct validity, hypotheses testing was used and reliability assessment was also completed. The calculations of reliability and validity were modified to account for variations in which both parents were in the home. Based on this analysis, internal consistency reliability for the scales ranged from 0.72 – 0.90. Sixty-five parents were also retested within 2-4 weeks, and this retest reliability was calculated at 0.75-0.94 (Knafl et al., 2011).

The FaMM was developed to understand family management over time and compare family management styles at different points in the child's life while assessing interventions that change the problematic aspects of family management and promote other interventions that strengthen child and family outcomes (Knafl et al., 2011). The instrument was used for this study to measure how a therapeutic summer day camp for children with special needs affects a family's ability to manage their child's condition. It was also one component used to determine if the camp can be identified as an intervention that promotes optimal child and family outcomes. This measurement was chosen because it was specifically developed to assist the practitioner in understanding how families are able to manage their child's chronic condition. The components of the measurement are directly related to a family's ability to normalize their child and family situation, and it correlates with the items outlined in the Family Management Style Framework.

This tool provided a description of each family's management abilities prior to and at the completion of camp. This offered the researcher insight into the outcomes that the camp had on the family's ability to manage their child's illness and family life.

This measurement was chosen for its ease and convenience of administration. It is not a lengthy questionnaire, and it can be administered and returned via email if needed to enhance convenience to the participant and prevent attrition. It has already demonstrated reliability and validity, which enhances the validity of the findings from the questionnaire for the study. One of the limitations of this tool is its lack of questions specific about interventions that occur at camp that may impact family management. In order to fill this gap, qualitative interviews were conducted with parents. This approach helped the researcher better understand specific interventions that occurred at camp that promoted the family's ability to manage their child's special health care needs.

Research Site

The therapeutic camp in which the study was conducted is located in the southeastern region of the United States. This camp is a Christian, summer day camp for children with special health care needs 6-25 years of age. The camp is designed to allow children with special needs to participate in an interactive, social, and fun environment during the summer months each year. The counselors focus on the children's abilities rather than disabilities. Campers are encouraged to participate in all activities, and the staff seeks to adapt each activity to the child's need. It is divided into two sessions that occur individually in June and in July. Campers are able to attend one or both sessions depending on a family's need. Campers are divided into groups of about 8-12 campers based on age groups to better meet their developmental needs. In each classroom there is one lead counselor and two or more support counselors that gives a ratio of one

counselor to every three campers. A nurse is on site at all times, and volunteers participate in camper groups with more involved activities when needed.

There is an average of about 40 children at camp. They may come to one or both sessions. The disabilities include children with autism, Down Syndrome, cerebral palsy, and other mental and/or physical disorders. The camp is held from 8:00 am to 3:00 pm Monday through Friday in the summer. Many of the participants have attended camp in previous years, but there are always new campers. Activities are all geared towards children with special needs. The campers participate in art, music, puppets, various recreation activities, and field trips. The older campers participate in life skills training such as cooking, cleaning, and other activities that will help prepare them to be more independent and function better in society.

The typical schedule for the day at camp is as follows:

8:00 to 8:30 = Group Welcome

8:30 to 9:00 = Bible Study

9:00 to 9:30 = Craft

9:30 to 11:30 = Field Trip

11:30 to 12:30 = Lunch

12:30 to 1:30= Organized play in the gym

1:30 to 2:30 = Activities

2:30 to 3:00 = Pack up and go home

This site was chosen for this study because it is similar to many other therapeutic camps that occur in this region of the United States (Easter Seals, 2014; EmpowerMeDayCamp, 2014). Children of various ages and special health care needs are present, and they are typical of the population at these types of camps. This site was chosen because it provided an opportunity to

learn how to help meet the needs of children with special health care needs and their families. This camp is one of the few respite therapeutic camps in this area, and the researcher wanted to learn more about how this camp's activities and interventions are able to affect how families manage their child's condition.

Sampling Plan

Recruitment

The initial contact with families that participated in the research study occurred within the first week of camp. Each camper and the parent or guardian arrived at camp on the first day. Parents had already met with the director and counselors to identify special needs and establish goals for the camper for the summer sessions. The camp nurse was available on the first day to provide assessments and obtain medications. The researcher set up a table near the nurse and camp director at the beginning of the camp day and at the end of the camp day to meet with the parents and discuss the possibility of participation in the research. All of the information in regards to the research was given to the parents of campers at this time.

The researcher had worked in the camp before (full time for 1 year and part time for 2 years) as a nurse and was familiar with the counselors, director, and many of the parents and campers. As the parents and campers entered the camp for the day, they passed by the nurse and director, so the researcher was able to interact with them at this time. This occurred prior to checking the campers in for the day. There was a designated room on this hallway that was used for privacy to fill out the questionnaire. As the parents interacted with the nurse and director, the researcher approached them in a friendly manner that invited conversation about the well-being of their child and family. This provided an opportunity for the researcher to explain to the parents about the research study and discuss the consent form. The researcher was present at the

table at the close of camp when parents were passing by to pick up their children from the camp. Many of the families know the researcher, so trust was already established. The researcher explained that although she has worked in the camp before, her role would be exclusively to obtain research data throughout the summer camp experience.

At the initial contact with the participants, the researcher presented them with a flyer that explained the importance of the research study and gave a brief description of the procedure for obtaining data. The flyer also contained the researcher's information and goals of the research study along with a discussion of both the qualitative and quantitative portions of the study. If they decided to participate, the researcher then initiated the consent procedure. At this time consent was explained and the consent form was presented. Once parents signed the consent form, the researcher asked if they would like to fill out the questionnaire in a private room at the camp or if they would like to take the questionnaire home with them and return it to camp that week. All parents chose to take the questionnaire home.

In this study convenience sampling was used. Because the number of eligible participants was small, all eligible participants were recruited. Participants came from the same camp to limit confounding variables that may have occurred from including other camps in the area such as differing schedules, types of interventions, and overall environment. Specific inclusion and exclusion criteria were implemented for this study. All participants had children enrolled in the chosen respite summer day camp program at least 5 days a week. Inclusion and exclusion criteria included the following characteristics: (1) parents of campers between the ages of 6 and 25 at the time of camp participation; (2) parents were excluded if they have children with a comorbid, possibly terminal illness such as cancer, because this may alter the parent's perspective on the child's condition; (3) families of children with a special health care need must include at least

one parent who resides in the same household as the child and speaks English; (4) chronic conditions or disabilities may include autism, down syndrome, cerebral palsy, or any child who has or is at risk for a chronic physical, developmental, behavioral, or emotional condition and requires additional health services; (5) only parents of children between the ages of 6 and 17 may participate in the interviews; (6) only children ages 6 through 17 whose parents had consented may be observed in the camp setting during the field note collection. Only one parent from each household was recruited for participation in the study to complete the FaMM. In accordance with the research design, recruitment occurred at the camp setting and only one parent was present at the camp and able to discuss participation in the study with the researcher. Because both parents were not present at the camp to obtain consent, only the parent who brought the child to camp was recruited for the study.

Purposive sampling was used to recruit participants for the qualitative strand of the study. Teddlie and Yu (2007) wrote that purposive sampling is used to address specific components of the research questions, so the researcher selects cases that are robust in information regarding the research questions. Purposive samples can also be selected using the expert judgment of the researcher. The researcher chose participants using theoretical sampling. According to Charmaz (2000) theoretical sampling is used to develop categories and make them more useful during the research process. It is used to redefine ideas and helps identify conceptual boundaries and understand the relevance of certain categories. With this sampling the researcher is able to examine certain aspects of the phenomenon to elaborate on current manifestations. The cases that were chosen by the researcher lead to other logical cases (Teddlie & Tashakkori, 2009). In this study the sample for interview was chosen based on the number of participants who completed the pretest FaMM. All participants who met the inclusion criteria were invited to participate.

These parents were contacted by the researcher via phone and invited to participate in qualitative interviews.

The sampling for interview began once the first strand of data collection was completed. When the researcher obtained consent, information was provided to the parents about the possibility of participating in an interview regarding the impact of the therapeutic camp on their family management and their view of their child's condition. The interview process was explained to the prospective participants.

Prospective participants for the interviews were contacted via phone to describe the interview, discuss the importance of the interview to the study, and establish trustworthiness with the participants. The researcher conveyed how interested she was in hearing their story and their experience with the therapeutic camp and its effect on their family and child. Interviews were conducted on site at the camp after approximately 7 weeks of participation in the camp activities. Interviews were scheduled prior to parents picking up their children or after they were dropped off in the morning.

Data Collection

In the first strand of data collection a demographic questionnaire was attached to the FaMM that documented the special health care needs of the child, age of the child, length of time since diagnosis, age of parents, race, previous participation in camp, participation in other respite care activities, and number of people in the household (see Appendix D). One question pertaining to whether or not the child had been diagnosed with a terminal illness was also included in accordance with the inclusion criteria. A child's terminal illness may affect the parent's perspective differently than the general perspective of caring for a child with special health care needs. This possible variation in perspective was not accounted for in the study. The

FaMM and the first demographic questionnaire were administered at the beginning (within 1 week) of attending the camp.

The second strand (qualitative phase) was used to provide further explanation of the findings from the quantitative portion with the final inferences from the data based on the results from both strands (Tashakorri & Teddlie, 2003). Qualitative data were obtained through semistructured interviews with participants and observation of interventions occurring at camp. The results from the quantitative phase led to the sampling and design of the qualitative portion of the study in accordance with a sequential design. The qualitative portion occurred approximately 7 weeks after the beginning of camp. In order to keep with the sequential mixed methods design, the pretest FaMM (Appendix K) was used to assist in formulating some open-ended guiding questions for the qualitative data strand. Field notes were taken while the researcher observed therapeutic interventions or other experiences at the camp described by the families in the interviews. Field notes were used to supplement the qualitative data.

Once the pretest results were analyzed and the interviews had occurred, the researcher saw a need to further investigate characteristics of the family that possibly compounded parental stress related to caring for their child with special health care needs. Demographic data pertaining to possible sources of parental stress were added to the posttest questionnaire based on data that emerged from the qualitative interviews and the expert advice from the dissertation committee. The demographic questions given to the parents along with the posttest questionnaire included items pertaining to number of hours spent caring for the child, parental education, hours spent working, and income (see Appendix E).

The researcher implemented several techniques to control for extraneous influences during data collection. All participants attended the same camp in the Southeast area of the

United States. They were all enrolled in the camp for at least five days a week for both sessions in June and July to control for variances in camp attendance that may pose a threat to validity. The participants varied in age, gender, and disability or special need, but this is typical of the variety of children that are present in therapeutic camps in other areas that offer services to a diverse population of children. Attrition is also considered a threat to internal validity (Polit & Beck, 2012). In order to prevent attrition the researcher made face-to-face contact with the families during the last week of camp and gave them the opportunity to fill out the questionnaire. The use of the same measurement tool for pre- and postcamp data collection strengthened the study design.

Quantitative Strategies

The quantitative portion of this study used a quasi-experimental, within-subjects design. This type of design is appropriate because the study included an intervention (therapeutic camp) without randomization or a control group (Creswell, 2009; Munro, 2005; Polit & Beck, 2012). This design was also chosen because it is economical and will produce a rapid turnaround of data collection and results (Creswell, 2009). The FaMM (Knafl et al., 2011) was administered to the same group of participants within 1 week at the start of camp and within 1 week prior to the conclusion of camp. Randomization was not used because the sample consisted of all consenting participants who have children enrolled at the chosen therapeutic camp for the summer of 2014.

Qualitative Strategies

A descriptive phenomenological approach was used for the qualitative strand of this research. This approach was used to understand people's everyday experiences and grasp the essence of the phenomenon while learning what their experiences mean (Polit & Beck, 2012). Descriptive phenomenology was developed by Husserl (1962) to describe the human experience.

Descriptive phenomenology is used to understand the most essential meaning of a phenomenon of interest from the perspective of those who are directly involved in it while exploring their lived experiences, which gives meaning to their perception of what is true in his or her life. (Giorgi, 1997). This method was chosen for this research because it is used when there is little known about the phenomenon. The impact of a therapeutic camp on the parents' perception of caring for their child is not widely discussed in the literature. Phenomenology is used to analyze descriptions given by the participants and divide them into statements with meaning without making interpretations (Giorgi, 1997).

This approach was chosen by the researcher because she desired to learn about the parents' experiences of caring for the child with special health care needs and the impact that camp had on their perception of caring for their child. Van Manen (1990) concluded that phenomenology must focus on common everyday life experiences. In this study the guiding open-ended questions were made to better understand the specific life experiences of the parent as they care for their child. Descriptions were made from the data in accordance with phenomenological methods. The researcher remained open to the meanings given by the participants throughout the interview process. This was accomplished through the use of open-ended questions, listening to the views of the participants, and being aware of any biases by the researcher that may have played a role in the interviews and data analysis.

Interviews consisted of the researcher and participant being coparticipants. The researcher asked the participants to describe their overall experiences of caring for their child within the context of family life. Benefits of camp and specific interventions that occurred at camp were also explored.

Interviews occurred at the camp site at a convenient time mutually agreed upon with the parents. Permission to use a private room at the camp setting was obtained from the camp director. This room provided a neutral location that was consistently available to each family. In this study only mothers consented to participate in the interviews. Because the researcher had already met all of the parents at the initial meeting and she had worked at the camp before, trust between the researcher and the participants was established. Once consent was obtained for participation, the researcher spent time at the camp interacting with the parents to demonstrate her care and concern for the child and family to continue to build trust.

Prior to the interviews open-ended questions were formulated by the researcher. Open-ended interviews are useful because they may lead to reconceptualization of the issues under study (Teddlie & Tashakkori, 2009). This type of interview may assist the researcher in uncovering certain unexpected aspects of camp that were beneficial to the family. Open ended questions were developed using the Family Management Style Framework as a guiding principle for question development. According to Deatrick et al. (2006) the FMSF has three components that are the definition of the situation, management behaviors, and perceived consequences. Through the interviews the researcher sought to assess how these principles are perceived within the family to better understand the family's ability to manage their child's condition. A sample of the guiding questions follows:

- How has your child's condition affected your daily life? Your family life? Your social life?
- What are some things that help you manage your child's condition within your family?
- How does the camp help you better manage your child's condition?

- Are there certain experiences at the camp that impact your ability to care for your child's special health care needs?
- How does the camp help you better manage your family?
- What are some specific things that occur at the camp that help you view your child's special need in a different way?
- How does the camp affect your family when camp is over?
- Is there anything else you would like to tell me about how the camp has affected your child and family's ability to manage your child's special needs?

After the interviews began a common thread of parental stress related to the child's condition began to emerge. Applying hermeneutical reasoning along with the expert advice from the dissertation committee, the researcher added the following guiding questions to the interview:

- How does managing your child's condition create stress in your family?
- What aspects of camp (if any) help alleviate the stress surrounding caring for your child?

Once the interviews were completed, some specific interventions that were discussed in the interview process were observed by the researcher in the natural field setting. The field notes were used to complement the interview data. Creswell (2009) states that observations may be useful in exploring topics that participants may have a hard time articulating in the interview process. Specific interventions were documented and led to a clearer understanding of certain aspects of camp that benefitted the family. This strand of data collection offered a deeper understanding of the subjective interview data that is important to mixed method research (Teddlie & Tashakkori, 2009).

Data Analysis and Management

Quantitative Data Analysis

In order to answer research questions 1-7, a paired sample t-test was performed. These research questions are:

In families who have a child with a special health care need, what are the effects of respite care through a therapeutic summer day camp program on parental perceptions in regard to:

1. The child's condition?
2. Condition management ability?
3. Condition management effort?
4. Family life difficulty?
5. View of the condition's impact?
6. Parent mutuality?
7. Are there differences in the family's ability to manage their child's condition (according to the FaMM) prior to and at the conclusion of the child's attendance at an 8-week therapeutic summer day camp?

The paired samples *t*- test was used to compare the mean differences of the data. The results of this test are discussed in Chapter 4. The instrument scoring of the FaMM was based on a Likert-type Scale with values ranging from 1 to 5 with 1 being *Strongly Disagree* and 5 being *Strongly Agree*. The sample was described using demographic and statistical data that included frequencies and percentages of the sample participants as shown in Appendix A, Tables 12 and 13.

Qualitative Data Analysis

Interviews with the participants were audio recorded and transcribed verbatim. The transcription was cross-checked against the recording to ensure accuracy. Transcribed interviews described the meaning of the camp experience to the family's management styles. With qualitative data analysis a back-and-forth process between the data collection and the data analysis was used to analyze the data (Lincoln & Guba, 1985). Qualitative software for data analysis was not implemented in this study. The interviews were studied holistically to determine possible themes from the data. Themes were identified as the dominant feature of the data from the interviews that define or describe the mother's experiences. The researcher used contextualizing strategies to analyze the data collected from the interviews. This strategy interprets the narrative data within the context of the whole text that includes interconnections between statements, events, experiences, and other occurrences (Teddlie & Tashakkori, 2009). Moustakas (1994) wrote that this will involve looking for patterns across the connecting narratives and will seek to focus on the wholeness of the experiences rather than fracturing into parts. This approach allowed the researcher to better understand the description by the participant in the particular situation or specific setting (Moustakas, 1994). In this study the setting was the therapeutic camp. Similarities and contrasting ideas were compared from the interviews to look for similarities and differences within the data. Codes were developed from these comparisons through a contextualizing coding process that led to a more detailed analysis. This included the development of categories and subsequent themes from the initial codes. A codebook was kept to assist the researcher in keeping detailed and consistent codes. Initial codes were general statements of the therapeutic camp experiences, management efforts, perspective of the child's condition, and any changes that may have occurred as a result of the camp. Codes became more

specific as the data were continually compared until categories were formed and themes were clearly identified from the data. The coding process involved revisiting the data very frequently to continue to understand the data and identify specific themes. Van Manen's method for phenomenological research was implemented in the study to better understand the lived experiences of parents who have a child with special health care needs. This approach to thematic analysis for phenomenological research was used to attribute meaning to the data (Van Manen, 1990). The codes, categories, and themes developed from this method were used to describe the family's experience caring for a child with special health care needs and their experiences at the camp and its effect on their family. The researcher also collaborated with an expert in qualitative methods on the dissertation committee and an outside expert to check the accuracy of the categories and themes to enhance confirmability (i.e. process check). The expert checked the codes against the transcripts to ensure they were representative of the original data. The categories and themes were also checked by the expert along with the researcher to ensure consistency and dependability of the development of these components.

Throughout the interview process, data collection, and analysis phase of the research data saturation was the goal of the researcher. Saturation in purposive sampling occurs when the addition of more interviews does not result in any new information used in the development of the themes that emerged from the research. Through the data collection and analysis of the interviews, if unique cases were discovered, further interviews would have been conducted to determine the possible cause of this varying data. Stand out cases were not found in the data collection.

Credibility and Trustworthiness – Qualitative Validation

Trustworthiness is a global term that is used to describe measurement quality issues in qualitative research (Lincoln & Guba, 1985). The researcher implemented techniques throughout the data collection and analysis to establish trustworthiness of the data. Teddlie and Tashakkori (2009) wrote that prolonged engagement, persistent observation, triangulation, member checks, and thick descriptions can be used to enhance the trustworthiness of the data. The researcher has spent long periods of time in the camp setting and was involved in every aspect of the study to enhance credibility. She has worked at the camp in some capacity since 2009, and she has been involved with the care of children with special health care needs at other outpatient and inpatient facilities. The researcher spent time in the field setting to obtain field notes through persistent observation regarding the interactions and experiences of the participants within the camp. The interview process was lengthy and allowed the researcher to have more interaction with the participants while observing characteristics of the phenomenon being studied.

Triangulation was practiced to enhance the validity of the findings. This method is helpful in overcoming biases that may occur from a single method or single observer study (Denzin, 1989). Triangulation was used in this study through the use of quantitative data collection (FaMM), qualitative interviews with mothers of children with special health care needs, and field notes at the camp setting. Triangulation was used to converge different sources of data and different perspectives of parents (Crewell, 2009; Teddlie & Tashakkori, 2009). Because the parents have extremely busy lives and the children were no longer attending camp once the interviews were transcribed, member checking was not performed. However, the researcher herself transcribed the audiorecorded interview diligently and made sure data were transcribed accurately. Confirmability audit, which examines the product of inquiry to create

confidence that the interpretations of the data are supported by the results, was used to enhance confirmability of the results and inferences (Lincoln & Guba, 1985). Confirmability was established through the repeated examination of the data and results by the researcher. The researcher was diligent to be aware of any biases that she may have while collecting and analyzing data. The results were also congruent with findings in the literature surrounding this topic, so credibility of the findings was demonstrated. The transcription was rechecked continuously and themes were verified repetitively to ensure accuracy of the transcription and coding. A journal was kept to record field notes to contribute to a clear and thick description of the camp. These findings were included in the report to give a rich understanding of the setting where the research occurred. This will increase the transferability of the study.

Mixed Method Data Analysis

Mixed method data analysis involves the process of combining, connecting, or integrating qualitative and quantitative data analysis strategies. The type of data analysis used for this study was iterative sequential mixed analysis because the research is a sequential design with more than two phases: quantitative pretest with FaMM, qualitative interviews, and quantitative posttest with FaMM (Creswell & Plano Clark, 2007; Teddlie & Tashakkori, 2009). With this form of data analysis it is possible that some of the questions for the interviews may be developed based on the first strand of data collection. The results from each phase of data collection may be used to confirm or describe the results from the previous phase (Johnson & Onwuegbuzie, 2004; Teddlie & Tashakkori, 2009). The data can be linked because the components from the FaMM were discussed in the interviews along with supplementary data regarding the specific experiences at the therapeutic camp. This type of design creates flexibility

in the data collection and analysis process while using each phase to complement the previous phase as shown in Table 1.

Table 1

Iterative Sequential Mixed Method Design

First Phase

First phase of study – QUANT Demographic questionnaire and FaMM pretest administered first week of camp	Original study design Select participants for the interview based on FaMM scores	Changes to study based on data All participants recruited for interviews

Second Phase

Second phase of study - QAUL Interview with consenting participants and field notes at camp	Original study design Guided interview questions based on FaMM and Family Management Style Framework	Changes to study based on data Guided interview questions added: - Does managing your child's condition create stress in your family? - Does camp help alleviate the stress surrounding caring for your child?

Third Phase

Third phase of study - QUANT FaMM posttest administered the last week of camp with	Original study design Administer posttest with no demographic data	Changes to study based on data Administer FaMM posttest with separate demographic statements regarding factors that may influence parental stress

Another important component to mixed method research involves inferences. An enhanced understanding of the phenomenon is possible as areas of disagreement or agreement are identified through comparisons of results and inferences from the data (Teddlie & Tashakkori, 2009). "Inferences are conclusions and interpretations that are made on the basis of

collected data in a study" (Teddlie & Tashakkori, 2009, p. 287). Inference quality was determined through the quantitative internal validity and the qualitative trustworthiness of the study are described in the following section. Inference transferability is the degree to which the conclusions may be applied to other settings or people and is described as the generalizability and transferability in the following section of the proposal.

The inferences for this study included the researcher's construction of the relationships between the parents, their child, their ability to manage their child's condition, and the therapeutic camp. This began in the data collection phase as the researcher tried to understand these relationships through each strand of data collection. Teddlie and Tashakkori (2009) wrote that one important component of making inferences is to know the participants. The researcher has worked with this population for 3 years in the camp setting and in outpatient settings, and she understands the culture of the phenomenon and the research setting. The researcher continuously referred to the research purposes and questions throughout the data collection and analysis to enhance the credibility of inferences. The researcher stated each research question and then examined all the results from the data (instrument, field notes, and interviews) that were pertinent to that question (Teddlie & Tashakkori, 2009). After this was done the researcher compared and contrasted the answers to the questions and tried to combine the answers with hopes of explaining similarities and differences. After each strand of data collection results were analyzed and revisited within the context of the research questions. Modifications or changes to the following strand were made after each strand based on these results from the previous data analysis. After the first strand of pretest data collection, demographic questions were added to the posttest to better understand possible situations that create more stress in relation to caring for the child with special health care needs. During the qualitative strand questions were added to

the interviews regarding parental stress in accordance with themes that were emerging from the data collection. This assisted in connecting the data and led to more credible inferences. The linking of data throughout the research process is important to create credible inferences (Onwuegbuzie & Johnson, 200). The quality of the inferences was based on the credibility and trustworthiness of the data. This is discussed in the next section.

CHAPTER 4

RESULTS

Introduction

The purpose of this study was to understand how respite care in the form of a therapeutic summer day camp for children with special needs impacts a family's ability to manage their child's special health care needs within their family. The researcher sought to understand the implications that attendance of respite care through a summer therapeutic camp has on the parent's perspective of the child's daily life, condition management ability, condition management effort, family life difficulty, parental mutuality, and view of condition impact. The results from a pre- and posttest using the Family Management Measure were analyzed. The analysis of quantitative data was discussed and compared with qualitative data from semistructured interviews that were conducted after about 7 weeks of attendance at the camp. The information presented in this chapter shows the demographics of the participants for both quantitative and qualitative portions, statistical analysis of the quantitative data, and coding and thematic analysis of the qualitative data including summary of field notes.

Participants

Quantitative Sample

A demographic questionnaire was added to the pretest and posttest to better understand the characteristics of the population (see Appendix D and Appendix E). All of the demographic questions were deemed important by the researcher to understand the situations that may improve or hinder the family's ability to manage their child's condition, their perception of the child's daily life, condition management ability, condition management effort, view of the

impact of the child's condition on the family, and family life difficulty in accordance with the FaMM and the FMSF.

Based on the sampling criteria, 30 primary caregivers from 30 different families were eligible to participate. In the study primary care givers were defined as the primary parent or grandparent who lived with the child and provided the main care for the child in the home setting. The quantitative sample could have included mothers or fathers, but in this study it was mostly mothers (20 mothers, 1 grandmother, and 1 father) who were present at the camp and able to provide consent. Each of these parents gave formal consent to participate in the study. The collection of the FaMM resulted in 23 usable questionnaires. The final collection of the Family Management Measure posttest yielded 22 questionnaires resulting in a final sample of 22 participants for the quantitative strand of data collection. A demographic questionnaire was given to the participants along with the FaMM. The demographic data for the quantitative sample are shown in Appendix A, Table 12. Demographic data showed 20 participants were Caucasian and 2 participants were African American. The age of parents ranged from 25 years to 73 years (M=46.6, SD = 10.1). Twelve of the parents reported other children living in the same home as the child with special health care needs. At the beginning of the study 16 parents indicated they were partnered. In this study partnered was defined as living with a partner in the same household as the child. At the conclusion of the study 17 parents indicated they were partnered. Participant educational levels are as follows: 2 with high school diploma, 1 with technical or trade school, 10 with some college or 2-year degree, 5 with a bachelor's degree, and 3 with a graduate degree with one not reporting. Hours of employment per week are as follows: less than 10 hours =3; 11-20 hours =2; 21-30 hours =2; 31-40 hours =6; 41-50 hours =5; Over 50 hours =3 with one not reporting. Income ranges are as follows: $10,000 to $14,999 =1, $15,000

to $19, 999 =2, $25,000 to $34,999 =1, $35,000 to $49,999 =3, $50,000 to $74,999 =5, Greater than $75,000 =9 with one not reporting. Parents indicated they spent a range of 4.5 hours a day to 24 hours a day provided care for their child (*M* = 12.7). The participants' children enrolled in the camp were 11 boys and 11 girls ranging in age from 6 years to 23 years of age (*M* = 13.8). For 6 children, it was their first time at camp. The number of diagnosis for each child ranged from 1 to 6 (*M*=2.09), and the length of time since diagnosis ranged from 3 years to 23 years or since birth (*M*=11.25). Diagnosis included autism, hydrocephalus, Down Syndrome, developmental delay, PTSD, reactive attachment disorder, seizures, Angelman syndrome, ADHD, craniosynostosis, blindness, Partial Trisomy 18, and Fetal Alcohol Syndrome with a larger number (10) diagnosed with autism. Twelve of the children had siblings ranging in ages from newborn to 23 years. None of the families participated in any other respite care services.

Qualitative Sample

The participants for the interviews were recruited using purposive sampling techniques. The original sample size for the quantitative strand was 22 (*N=22*), and all participants who were eligible for interviews were recruited. Only 16 parents who completed questionnaires had children who met the inclusion criteria (i.e. child must be under the age of 18 while attending camp) for interviews. Out of all the parents who were recruited whether in person or via phone, 11 consented to participate in the interviews. The demographic data for the qualitative sample are shown in Appendix A, Table 13. The participants were all Caucasian females and mothers of the campers. The mothers ranged in age from 35 to 57 (*M*= 44.5). The children (6 boys and 5 girls) ranged in age from 7-17 years (*M*=10.4). The children had a variety of diagnosis including autism, developmental delay, seizures, fetal alcohol syndrome, cerebral palsy, and Angelman syndrome. The years passed since the child's initial diagnosis ranged from 4 years to 17 years

(*M*=9.8). Eight parents indicated they were partnered and 8 indicated they had other children living at home. Only one parent indicated it was their child's first time to attend camp. Parents indicated they spent a range of 7 hours a day to 24 hours a day providing care for their child (*M*=12.8). Participant educational levels are as follows: 1 with high school diploma, 1 with technical or trade school, 4 with some college or 2 year degree, 3 with a bachelor's degree, and 2 with a graduate degree. Hours of employment per week are as follows: less than 10 hours =2; 11-20 hours =2; 21-30 hours =1; 31-40 hours =2; 41-50 hours =3; Over 50 hours =1. Income ranges are as follows: $10,000 to $14,999 =1, $15,000 to $19, 999 =1, $25,000 to $34,999 =1, $35,000 to $49,999 =1, $50,000 to $74,999 =2, Greater than $75,000 =5.

Quantitative Results

For data analysis of the FaMM, each response for the questionnaires was entered into SPSS version 21. Each of the scales was scored according to the instructions provided by Knafl et al. (2009). These scales included the child's daily life, condition management ability, condition management effort, family life difficulty, view of condition impact, and parent mutuality. In this research study internal consistency was affirmed through the calculation of Cronbach's alpha. Internal consistency values ranged between 0.66 and 0.93 for the scales of the FaMM in this sample as shown in Table 2.

Table 2

Description of Cronbach's Alpha

Scale	Number of Items	Pretest Cronbach's alpha	Posttest Cronbach's alpha
Child's Daily Life	5	.73	.66
Condition	12	.87	.74
Management Ability			
Condition	4	.68	.89
Management Effort			
Family Life Difficulty	14	.93	.92
Condition Impact	10	.67	.75
Parent Mutuality	8	.93	.90

All participants completed the first five scales and 15 of the parents completed the scale on parent mutuality. Analysis included resulting scores for each scale prior to and at the conclusion of camp. Table 3 presents the mean scores for each scale pretest and posttest.

Table 3

Description of Scales and Scoring

Description of Scale	Scoring	Min	Max	Pretest Mean	Posttest Mean	t	Significance P value
Child's Daily Life (5 items) - Parent perceptions of the child's everyday life	Higher values indicate a more normal life for the child	5	25	11.59	11.45	0.2	0.81
Condition Management Ability (12 items) - Parent perceptions of overall manageability of child's condition	Higher values mean the condition is seen as more easily managea ble	12	60	38.77	39.09	-0.4	0.69
Condition Management Effort (4 items) - Addresses the time and work needed to manage the condition	Higher values mean more work is needed to manage the condition	4	20	13.64	14.18	-0.8	0.42
Family Life Difficulty (14 items) - Parent perception of the extent that having a child with a chronic condition makes family life difficult	Higher values indicate more difficulty managing the condition	14	70	46.27	45.18	0.8	0.42

Table 3 (continued)

View of Condition Impact (10 items) - Parent perception of the seriousness of the condition and its implications for their child and their family's future	Higher scores indicate greater concern in managing the condition	10	50	30.05	30.41	-0.3	0.70
Parent Mutuality (8 items) - Addresses perceptions of support, shared views, and satisfaction with how the partners work together to manage the child's condition	Higher values indicate a more shared response and greater satisfacti on with working together	8	40	32.4	32.67	-0.3	0.77

Note. $df = 21$ for all tests except Parent Mutuality, which as $df = 14$.

The alpha level selected for this study was 0.05 in accordance with guidelines by Teddlie and Tashakkori (2009) and Polit and Beck (2012). Because the researcher expected the sample size to be small due to convenience sampling, a medium effect size of 0.5 was determined to be adequate (Cohen, 1988). In order for this to occur a sample of 50 was needed for the study. Because the final sample was 22, the effect size was not met. An effect size of 0.3 could be used for the study with the number of participants, but this would not yield clinically significant results (Cohen, 1988).

Once the data were put into SPSS version 21, it was analyzed using a paired sample *t*-test because the *t*-test assumptions of normality were met. The normality assumption of the *t*-test is based on the difference scores, so the differences of the pre- and posttest were evaluated for

normality using the Shapiro-Wilk test in SPSS version 21. The Shapiro-Wilk test is used to test normality in small samples ranging from 3 to 200 (Shapiro & Wilk, 1965). The significance level for all scales was p >0.05 indicating nonsignificance or normal distribution. Table 4 shows that the data were approximately normally distributed, indicating the paired samples *t*-test was the appropriate analysis. Histograms depicting normal distribution of the difference scores are shown in Appendix M.

Table 4

Normality Scores for FaMM

	Shapiro-Wilk		
	Statistic	Df	Sig.
DailyLifeDifference	.957	15	.632
CMADifference	.963	15	.743
CMEDifference	.907	15	.124
LifeDiffDifference	.968	15	.820
PMDifference	.961	15	.712
ImpactDifference	.919	15	.184

Tests for normality were conducted on the pretest and posttest data that also showed normality. The skewness and kurtosis data for the pretest, posttest, and difference data are included in Appendix M. The paired sample *t*-test compared the results from the same groups at the appointed time intervals. This analysis yielded no significant changes (p >0.05) in any of the scales from the beginning of camp to the end of the 8-week camp.

Child's Daily Life

There was no significant difference in the scores for the Child's Daily Life pretest (*M*=11.59, *SD* = 3.5) and the Child's Daily Life posttest (*M* = 11.45, *SD* = 3.051*); t*(21*)* = 0.2, *p* = 0.81. The mean increase in the child's daily life scores was 0.136 with a 95% confidence

interval ranging from -1.059 to 1.332. The *eta squared statistic* (0.003) indicated a small effect size.

Condition Management Ability

There was no significant difference in the scores for Condition Management Ability pretest (M = 38.77, SD = 8.485) and the Condition Management Ability posttest (M = 39.09, SD = 6.817*);* $t(21) = -0.4$, $p = 0.69$. The mean increase in the condition management ability scores was -0.318 with a confidence interval ranging from -1.962 to 1.326. The *eta squared statistic* (0.007) indicated a small effect size.

Condition Management Effort

There was no significant difference in the scores for Condition Management Effort pretest (M = 13.64, SD = 3.710) and the Condition Management Effort posttest (M = 14.18, SD = 4.787); $t(21) = -0.8$, $p = 0.42$. The mean increase in the condition management effort scale was -0.545 with a confidence interval of -1.946 to 0.855. The *eta squared statistic* (0.03) indicated a small effect size.

Family Life Difficulty

There was no significant difference in the scores for Family Life Difficulty pretest (M = 46.27, SD = 11.997) and the Family Life Difficulty posttest (M = 45.18, SD = 11.206); $t(21) = 0.8$, $p = 0.42$. The mean decrease in the family life difficulty scale was 1.091 with a confidence interval -1.673 and 3.854. The *eta squared statistic* (0.03) indicated a small effect size.

View of Condition Impact

There was no significant difference in the scores for View of Condition Impact pretest (M = 30.05, SD = 5.420) and the View of Condition Impact posttest (M = 30.41, SD = 6.139); $t(21) = -0.3$, $p = 0.70$. The mean increase in the view of condition impact scale was -0.364 with a

confidence interval of -2.358 to 1.631. The *eta squared statistic* (0.004) indicated a small effect size.

Parent Mutuality

There was no significant difference in Parent Mutuality pretest (M = 32.40, SD = 7.744) and the Parent Mutuality posttest (M = 32.67, SD = 7.471); $t(14) = -0.3$, $p = 0.77$. The mean increase in the parent mutuality scale was -0.267 with a confidence interval of -2.257 to 1.724. The *eta squared statistic* (0.004) indicated a small effect size. The statistical analysis of the data is shown in Table 5 and Table 6.

Table 5

Statistical Analysis – Paired Sample Statistics

Scale	Mean	N	Std. Deviation	Std. Error Mean
dailylifepre	11.59	22	3.500	.746
dailylifepost	11.45	22	3.051	.650
CMApre	38.77	22	8.485	1.809
CMApost	39.09	22	6.817	1.453
CMEpre	13.64	22	3.710	.791
CMEpost	14.18	22	4.787	1.021
Lifediffpre	46.27	22	11.997	2.558

Table 5 (continued)

Lifediffpost	45.18	22	11.206	2.389
Impactpre	30.05	22	5.420	1.156
Impactpost	30.41	22	6.139	1.309
PMpre	32.40	15	7.744	2.000
PMpost	32.67	15	7.471	1.929

Note. df = 21 for all tests except Parent Mutuality, which is *df* = 14.

Table 6

Paired Samples t-test – Paired Differences

Scale	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		t	Sig. (2 tailed
dailylifepre - dailylifepost	.136	2.696	.575	-1.059	1.332	.237	.815
CMApre - CMApost	-.318	3.708	.791	-1.962	1.326	-.402	.691
CMEpre - CMEpost	-.545	3.158	.673	-1.946	.855	-.810	.427
Lifediffpre - Lifediffpost	1.091	6.233	1.329	-1.673	3.854	.821	.421
Impactpre - Impactpost	-.364	4.499	.959	-2.358	1.631	-.379	.708
PMpre-PMpost	-.267	3.595	.928	-2.257	1.724	14	.778

Note. df = 21 for all tests except Parent Mutuality, which is *df* = 14.

Qualitative Results

A descriptive phenomenological approach was used for the qualitative portion of the study. This approach allows the researcher to explore and describe the lived experiences of the participants through various data collection procedures and analysis. This research approach was used to guide the interviews of the participants. Data analysis was performed to answer the following research questions:

1. What are the perceptions of parents of children with special health care needs of the interventions and experiences at a therapeutic summer day camp program?
2. What interventions or experiences (if any) impacted the parents' perceptions regarding the management of their child's condition?

The qualitative strand included semistructured interviews consisting of guiding open-ended questions with selected parents. The first part of the interview followed the principles outlined in the Family Management Style Framework that seek to better understand the experiences of families of children with special health care needs. The researcher used the second part of the interview to discover the effects of camp attendance on the participants' stress level, family life, and perception of the child. Interventions or activities that occurred at camp were also explored in the interviews. Through the expert advice from the dissertation committee prior to data collection, the component of parental stress was added to the interviews. This emerging concept of parental stress was affirmed once the interviews began. Teddlie and Tashakkori (2009) wrote that "in exploratory research, data collection techniques may be modified based on ideas or results discovered in each data collection phase." (p.207). Therefore, questions regarding stress in the family as a result of the child's special health care needs were

added. Questions aimed at understanding how camp affected parental stress were also included in the interviews. These questions are:

- How does managing your child's condition create stress in your family?
- What aspects of camp (if any) help alleviate the stress surrounding caring for your child?

The researcher began the interview with a welcome to the participant and an ice breaker question to help the participant feel more at ease. Silence or pauses were used to allow the participant to elaborate on their responses. The interview was audio-recorded and then transcribed verbatim. The researcher took notes during the interview process. Measures were taken to protect the anonymity of the participants. The data from the interviews and field notes were kept in a locked cabinet in the researcher's office. Computer files were kept on a password protected computer in the researcher's office. Once the data were collected and analyzed, the files were destroyed. After completion of the data collection, the audio was deleted.

After transcription had been finalized, each interview was repeatedly analyzed separately to increase reliability, and the interviews were searched for codes within the data. The codes were closely examined and refined in accordance with the constant comparative method outlined by Lincoln and Guba (1985). The researcher began to look for meanings within the codes and placed the codes into categories that were broad in nature but also meaningful. Throughout this process the researcher continuously went back to the transcribed interviews to verify the codes and information presented. All interviews were read, reviewed, and examined sentence by sentence for insight into the phenomenon of interest. The researcher sought to define which statement was most revealing about the phenomenon. This allowed the researcher to formulate meanings from the interviews and organize the meanings into clusters of themes while referring

to the data. Once the data had been organized into categories the results were integrated into an exhaustive description of the phenomenon to better understand and identify the characteristics of the population being studied. All phases of this project were subject to scrutiny through the use of a research expert through the dissertation committee. Transcripts were checked throughout the process for any discrepancies. Codes were checked and compared with the data constantly to ensure accuracy and consistency of the findings. An expert in qualitative methods outside of the dissertation committee from the researcher's institution also checked the categories and themes to ensure accuracy of the findings. These measures taken by the researcher ensured that the findings and inferences from the study maintained credibility. This is based on the degree of fit between the participants' realities with their child with special health care needs and their experiences at a therapeutic camp compared with the researcher's representations of those realities (Teddlie & Tashakkori, 2009).

Categories derived from the participants' response to each question were placed into different broader categories that were titled: Family-Child categories, Camp-Child categories, and Camp-Parent categories. This was done in order to provide a more meaningful broader category for each of the assigned categories and subsequent themes to provide a classification system that made creating themes a more streamlined process. Once the categories were developed the researcher analyzed each category and its codes and grouped them into similar sections. Once this had been done the researcher began to discover emergent themes. These emerging themes evolved from the data that had been collected through the interview process, which is characteristic of this type of data analysis according to Lincoln and Guba (1985). The data collected from these participants in the interviews led to data saturation.

Identification of Themes

At the conclusion of the coding and categorizing process there were several themes that emerged. The themes for Family-Child categories are:

1) loss of normalcy

2) relationships affected

3) increased stress

4) family adaptations, and

5) love for the child.

The themes for Camp-Child categories are:

1) meets individual needs

2) creates happiness, and

3) behavior changes.

The themes for Camp-Parent categories are*:*

1) improved perception of the child

2) decreased stress

3) parent involvement with staff, and

4) need for specific environment at camp.

These themes are discussed below with examples from the codes and categories present in interviews. They are presented with meaningful quotes from the participants to provide a richer description of the data. The themes are shown in Table 7.

Table 7

Identification of Themes

Family-Child Themes	**Camp-Child Themes**	**Camp-Parent Themes**
1. Loss of Normalcy • Family life – everyday activities • Relationships • Shattered idea of normal family • Eventual acceptance 2. Relationships Affected • Marriage • Friendships • Their other children • Improved family closeness 3. Increased Stress • Caring as a job • Strained relationships • Increased financial burden • Inability to find sitters • Parental sense of guilt 4. Family Adaptations • Family limitations • Modifying the family routine • Shared responsibilities • Coping mechanisms 5. Love for the Child • Sacrifices made • Being together • Child's needs	1. Meets Individual Needs • Consistent routine • Socialization • High energy activities 2. Creates Happiness • Excitement • Enjoyment of activities • Friendships 3. Behavior Changes • Improvement in behaviors • Different behaviors at camp vs home	1. Improved Perception of Child • Seeing the child participate in typical activities • Broadening their view of the child • Seeing other with greater needs • Discussing activities with the child 2. Decreased Stress • Parents have time for other activities • Time for rest • Communication with other parents at camp • Relieving parental guilt • Time to spend with others in the family • Decreased financial burden • Peace of mind 3. Parent Involvement with Staff • Counselors listen to parent's needs regarding child • Need for more communication with counselors 4. Need for Specific Environment at Camp • Need for routine

Table 7 (continued)

• come first	• Need for socialization • Need for organized activities • Sense of security • Special training of counselors • Distinctive environment

Family-Child Themes

This broad category was created to delineate the parents' experience with caring for a child with special health care needs within the context of their family. These codes, categories, and themes do not pertain to the findings discussed from the attendance at the therapeutic camp. These themes provided the researcher with a better understanding of the lived experience of the family and their response to caring for a child with special health care needs.

Theme 1 - Loss of Normalcy. Throughout the interviews each parent discussed a *loss of normalcy* (*n=11*) since the child had been diagnosed with a special health care need. This loss was apparent in family life and outside relationships. Participant 20 concluded,

> It affects everything that you do, you know, from your other kids, I mean we have older kids, you know, it affects them, it affects them, we were big campers and stuff and she can't sweat, so we don't do anything outdoors now you know, from every aspect it affects your life.

The loss was evident in the lost dream for a normal family. Participant 18 stated,

> Well you never expect to have a child with special needs, um, that was a tough blow, and then since my boys are older they have been able to help some but they get super

> frustrated with her autism behaviors, they don't get it, it's just different than what we expected but I guess that is true with any special needs family. Um, I am a lot busier than I expected to be at my age, I am a lot more tired, it's just harder than I expected it be at this stage in my life.

Mothers reported a complete change in their normal routine since they began caring for their child, which created a sense of loss. Although this loss of normalcy was not always associated with grief or perceived as completely negative by the mothers, it was experienced by all participants. Participant 22 stated, "You can't have a family unit with autism, you know, even a family meal can be really difficult." Participant 20 concluded,

> I don't know if it's (the child's condition) not become our lives, everything revolves around it – if it's too hot you can't go somewhere, if it's too cold you can't go somewhere, she has to be in bed at a certain time, have her meds at a certain time – I think for the most part it has (become our life).

The participants discussed the loss of normalcy within the context of their family life due to the demands of caring for the child. Simple everyday tasks at home were identified as challenging by the participants. The loss of a typical home environment was also a recurring concept for some mothers ($n = 3$). Participant 16 stated,

> Your house is like a therapy house and not a living space really…its very routine and monotonous and I hate it, it's the same thing at the same time every day and it's not fun. I feel like the elephants on the jungle book where its march, march all the time, its redundant to the point of you want to scream because you know at 7:00 the dishes have to be done and the trash has to go out or we are going to have a fit… It has to be that way – it's just not fun – there is no fun in it, the planning that goes into it, you can't throw a

> monkey wrench in there, it's planning for everything, what time you do the laundry, what time everybody gets a shower, it's all around his little world.

Caring for the child was described repeatedly as a complete life change that was different from the previous way of life. This created a lost sense of normalcy compared to other families. Participant 3 concluded, "We can't do everything like a typical family would do." Participant 21 stated, "We can't ever have what we had (prior to child's diagnosis)." All of these statements reinforce that families experienced a loss of normalcy within their family when caring for their child with special health care needs.

The *loss of normalcy* theme (*n=11*) was also discussed within the context of relationships. The mothers expressed a change in their relationships with their friends, spouses, extended families, and other children because of caring for their child. Four of the mothers reported that they had lost the ability to have normal relationships with their friends and families because of their child's condition. This isolation from others was deemed as a loss. Participant 16 stated, "Initially it was the isolation because I don't know if everybody from the outside world thought it was contagious or what but everybody just disappeared." Participant 23 concluded that most people she had associated with prior to the diagnosis of her child's PTSD chose not to spend time with them anymore leading to a sense of isolation that had not been previously normal for their family. The inability to participate in certain family functions, activities with friends, or job opportunities was described as a loss from their previous normal relationships. Participant 28 stated,

> It has made life really hard and it has played a huge factor in the loss of my job, failure of my marriage, and lack of being able to get new employment…. we can't go to my sister's

house anymore because it is not child proofed, and they are not very patient; they are not mean to him but they can't deal with the meltdowns, the screaming, the crying.

The theme of *loss of normalcy* was seen throughout the discussions regarding the mother's relationships.

Another way that loss of normalcy was recognized was through the shattered idea of a normal family. Participant 21 said, "We have our families in this beautiful box, maybe I shared that with you, and when she (the child) came home it was like everything exploded." This was described as a loss when the families realized their child was not "normal" anymore, and their life was not going to be the same again. Traditional ideas of family life were shattered for some mothers (*n=6*) when they realized the care that was needed for their child. Participant 22 stated, "My thought of what the family life should be is very traditional. And that has been a dream that shattered, you can't do it." Mothers reported chaos at home leading to exhaustion that is not typical of other families. A sense of a constantly changing life with their child caused a loss of normalcy for the mothers. It was very clear through the discussions that a loss of normalcy regarding shattered dreams of family life was common.

Although mothers (*n=7*) reported a loss of a certain dream for their family, a sense of adaptation, realization, and acceptance of the way their life had turned out with their child was apparent. This life they were living was their reality and they had come to better understand their life with their child and family. Mothers who expressed these ideas had gone through an initial adjustment period with their child's diagnosis and accepted their new "normal" reality with their child. Participant 16 stated, "And then you reach that point of acceptance, and there is still the isolation. So then the gears changed to the acceptance and living with it." Several of the mothers (*n=4*) reported a sense of optimism and hope as they had "gotten better" at caring for their child.

Theme 2 – Relationships Affected. The mothers reported a sense of affected relationships (*n=10*) because of caring for their child. Relationships affected included marriages, friendships, and relationships with their other children. There was a recurring sense of strained relationships throughout the interviews, but some mothers (*n=4*) reported improved family relationships as they all grew closer to one another to help care for the child.

All but one married mother (*n=8*) reported a strain on their marriage due to the care demands of their child. Although the participants said there was added stress, only one participant reported a separation from her husband because of the needs of her child. The husband and wife relationships were affected due to increased stress in caring for the child, lack of alone time, a change in day-to-day scheduling, and an inability to find sitters for their child.

Although the mothers did report stress within their family because of their child's special health care needs, five mothers reported an overwhelming sense of closeness and togetherness occurring in the family because of their child's condition. They tried to continuously focus on the positive aspects of caring for their child to help them cope with the stressful times. A sense of appreciation, gratitude, and patience was present in the families. Participant 3 discussed this,

> It has affected our family life, but in a positive way, it brings us together….Oh yeah, there is always a positive side to it too, and it has helped us recognize the needs around us too. It's a humbling experience to have a special needs child sometimes you see things differently. So, it definitely has a positive side too.

Families learned to focus on the positive side of caring for their child instead of always focusing on the negative.

The mothers reported that they felt some degree of isolation from their friends and acquaintances. There was an overwhelming sense of "feeling different" that the mothers

expressed. Four of the mothers felt that others just "don't understand" what it is like for their family. Participant 15 described,

> And a lot of people are like oh you make it look easy, it's not easy, and I make it look easy, no, you're not at home seeing all the back work that goes into it, you know what I tell people all the time that I feel like I am running a marathon , up, dressed, changed, med and fed, I call it, you can't just say Johnny go put that on , go get your cereal, go get the bus, it's an hour of just him getting ready, braces, and he's still in diapers, you know people say oh you make it look easy, I don't know, well that's because you have grace, yeah well they don't see me changing poopy diapers and having poop everywhere.

Because many of the children require one-on-one care, one mother felt that it was hard for her and her husband to socialize at gatherings because they had to care for their child making it difficult for them to be part of the adult group. Two mothers stated they had no social life because there was no one to help them watch their child while they went out with their friends. Although many mothers reported a loss in friendships, three of the mothers discussed making it a point to go out with their friends often to cope and decrease their stress level. A sense of socialization was apparent in their lives even though their relationships were not the same as they once were. All of the mothers who did report having friends were in a marriage relationship, and the father watched the children so she was able to socialize. The negative effect on friendships seemed to be directly correlated with a lack of ability to find help caring for the child. Participant 28, a single mother, stated,

> What few friends that I have if we try to get together I have to do it after he is in bed because he is so dependent on me… I have to be there to put him to bed, there is no way that I can have a girls night out it has to be at my house before he goes to bed because he

> doesn't sleep all through the night…. so there really are no family or friends, (her child) and I pretty much stay at home, there is no social life….there is no sitter.

Another recurring problem for these mothers involved making time for their other children. In the summer months mothers felt there was an added stress because of the constant demands of caring for their child that left them very little time to spend with their other child/children. Some mothers (*n=4*) discussed a sense of guilt over the loss of time with their other children and reported that the other children felt neglected. This added to the mother's stress level because she was unable to divide her time equally among the children. Participant 22 stated,

> How do you explain all of the attention that this child is getting and to them (the other child) no matter what you do it is still deprivation to some degree. Then you don't have a normalcy because my (other) child is 15 and I need to be letting him go but because I spend all my time with this child it's so hard for me to switch to be a caregiver. For years and years and years excessive amounts of attention and then over here (the other child) letting go and when he needs me and it's just tough.

The special needs of the child inhibited some families from doing certain things with the other children because the special needs child was unable to do those things. This occasionally created anger and frustration from the other children. Parenting was also difficult because parents did not use the same parenting techniques on each child within the home. Overall, the participants felt that it was very difficult to meet the needs of the other children in the home while caring for their child with special needs.

Theme 3 – Increased Stress. The third theme that emerged from the data was a sense of increased stress (*n=10*) within the family. Although the concept of stress was not specifically

included in the initial guiding interview questions, it was added once the researcher saw the concept emerging from the data. This is in accordance with the sequential mixed method design that concludes that one phase of the data collection can change or modify another phase (Creswell & Plano Clark, 2007; Teddlie & Tashakorri, 2009). The concept of stress was noted throughout the interviews with the mothers. Increased stress was experienced by all the mothers as they worked to care for their child within their family. The theme of *increased stress* was apparent through the difficult "job" of caring for the child, strained relationships, increased financial burden, inability to find sitters, and a parental sense of guilt. Participant 28 stated,

> I never know when the school is going to call. I have to be on call for the school because I never know when I am going to have to go pick him up. Even though I put extra clothes in his backpack, he has gone through those and they call that he needs more clothes, they don't always let me know in advance that he is going to run out of meds so I might have to run medicine over to the school, so I am pretty much just on standby whenever the school needs me –so yes it's pretty much, he is my job.

Several of the mothers (*n=6*) reported that caring for their child was like a job. There was never a break and no time to rest. This constant demand of meeting the needs of the child was seen as exhausting and challenging. Participant 22 stated, "It is a job and you are always in a job and how do you just sit back and relax which is some of what family should be." This sense of "caring as a job" created a stressful environment within the home. One mother reported that she felt like there was no fun in her family because there was so much work involved in caring for the child. Mothers felt an urgency to take breaks and to get help to minimize the job like status of caring for their child.

Stress within the family was magnified by the various fractured relationships that were discussed previously. The strain on relationships that led to feelings of isolation added stress within the home. The financial burden of doctor's visits, special equipment, therapies for the child, and loss of jobs because of caring for the child all contributed to the added stress within the family. Three of the mothers had lost their jobs due to the high demands of caring for their child that led their families to a significant loss in income. Participant 23 stated,

> For the first three years that he was home, I was literally unemployable because I lost multiple opportunities to work because his needs were so great that it kept me…. a 9 to 5 job isn't going to get it, so we have lived on very little and you know but you know when you have a child, special needs or not, you go, child… things…. And from my perspective it goes child… things… and you just have to pick which ones wins out.

A problem experienced by all mothers was an inability to find caregivers or sitters for their child. Mothers were unable to acquire help that would allow them to complete household chores, spend time with their friends, other children, or spouse, and take a break. When these tasks were not completed, the mothers felt a sense of increased stress. The demanding care needs of the child made it difficult to find reliable, trustworthy, energetic sitters. Participant 22 concluded, "With a child that would run around the table for 2 hours and then sit down and eat, people will say this isn't worth 10 to 15 dollars an hour; and even if you paid them $25 an hour, agencies may say we could find somebody to work with you but they (the sitter) will say no." Mothers reported that sitters would quit because they did not feel equipped to care for the child. The inability to find sitters made life more complicated for the parents, which increased their stress.

The mothers discussed that their child was unable to stay at home during the summers because the child would get bored, so they needed socialization and activities. Because the mothers were unable to meet these needs due to other responsibilities, a sense of guilt followed. The children in the study needed extra attention, interaction, and high energy activities. When the mothers were not able to give the child these experiences, it left them feeling guilty. The mothers' inability to provide all that the child needed magnified their stress within their family. Participant 13 stated,

> The whole family feels better (while child is at camp) knowing that because part of our stress is that we know she needs that social interaction and we know that she has a high energy level and she needs to burn the energy, so when you know you have to run errands and do housework and do things for the other children, we feel like we are not meeting her needs because she needs to go to the park for several hours or swim for several hours, so that you do have a little guilt like she (the child) should have been at the park for two hours or swam for two hours in order for her to be in her happy place and calmer you know so we do have a little bit of guilt sometimes so in camp she gets all that met and we get all of our other stuff done.

Theme 4- Family Adaptations. One of the predominant themes within the Family-Child category was the idea of the family adapting (*n=10*) to the child's special health care needs. All of the mothers reported they had to learn to adapt in order to have a successful family unit. The predominant categories within this theme include family limitations and modifying the family routine, shared responsibilities, and coping mechanisms.

The mothers identified changes they had made in their family that limited what they could do because of the needs of their child. Many mothers reported that certain activities such

as camping, hiking, or swimming were no longer part of their family routine because their child could not participate in these activities. There was also a significant modification in the family routine in order to care for their child. Therapy schedules, house design, sleep routines, and other normal activities were modified to meet the needs of the child. Several of the mothers reported that the child's needs came first, so the family had to learn to adapt to the child's needs. Participant 21 stated, "She is paramount, for her well-being, her emotional, mental, security well-being."

The category of shared responsibilities was seen as a common thread as the mothers discussed changes in the family routine. Sharing the care burden for the child gave each parent opportunities to take breaks from the demands of caring. Several mothers stated that life got easier once they (parents) decided to work together and share responsibilities. A couple of the mothers stated that it was necessary for the family to work together to meet the needs of the child. As parents shared responsibilities, each parent was given an opportunity to individually take some breaks. This may have helped decrease stress and increase coping. The mothers who did not report a strong sense of shared responsibilities had less time for themselves and reported less time to accomplish other tasks.

The concept of coping was also apparent within the theme of *family adaptations* (n=10*)*. Some of the predominant mechanisms for coping included talking to other parents of children with special health care needs, taking breaks, spiritual influences, and spending time with friends. Several of the mothers (*n=4*) felt that expressing their emotions to other parents validated their feelings and helped them cope with the stress of caring for their child. Many of the moms referenced prayer and being with friends at church as a way of coping. All of the

parents reported a need for breaks to allow them time to rest and relax away from the demands of caring for their child. Participant 13 stated,

> I think that is the first thing that we have had to kind of say ok we need more help and I think just knowing when the other person needs a break, so we just really say ok you know I'll take the kids to my mom's house and give my husband some time by himself and he does the same for me.

Summer was seen as an especially difficult time because the children were not in school, which created less time for the mothers to have breaks. Every mother did not have the same coping mechanisms, but all mothers reported that they needed breaks in order to decrease stress.

Theme 5 – Love for the Child. There was an overwhelming sense of the mother's love for her child (n=8). Some of the sacrifices that were made for the child included quitting a job, loss of friendships, loss of sleep, inability to participate in previous activities, monotonous routine, household modifications, and strained marriages. All of these sacrifices demonstrate the love that each mother had for her child. Several of the mothers reported that their family seeks out specific things that the family can do because they enjoy being together as a unit. Being together as a family was seen as valuable to the mothers. Participant 3 stated, "It's just finding the right niche for him each time so he can be a part of what we are doing because that is always important to us you know to let him be involved too if possible." One mom reported that although her son is blind and has cerebral palsy and severe developmental delays, she and her husband are just, "grateful to have him with us". Even though the mothers reported difficulty in caring for their child, they also expressed a sense of love for their child.

Camp-Child Themes

These themes emerged from the discussion with the mothers during the interviews regarding the impact of camp on their child. This broad category was created to specifically examine how camp affected or benefitted the child based on the codes that were categorized from the interviews. The themes that emerged include:

1) meets individual needs

2) creates happiness, and

3) behavior changes.

Because these themes emerged from the activities at camp, any field notes that were taken at the camp setting were analyzed and are discussed after certain themes are described. The field notes taken by the researcher were used to support the data obtained from the qualitative strand to create a nearly complete picture of the experiences described by the parents.

The field notes were documented based on beneficial experiences at the camp mentioned by the mothers in the interviews. Only parents and children ages 6 through 17 whose parents had signed the informed consent document were eligible to be observed in accordance the exclusion criteria in the study and in compliance with IRB approval.

Theme 1 – Meets Individual Needs. The mothers were very consistent in discussing the idea that camp met their child's individual needs (n=10). Every mother stated that their child needed a consistent routine, socialization, and high energy activities to be happy and have their needs met. The camp schedule addressed all of these needs for the child. After the interview process the researcher met with the director of the camp to go over the camp schedule to better understand the routine, socialization, and activities that occurred at camp. The camp day starts at 8:30 am and ends at 3:00 pm to coincide with the school schedule. Camp begins the week after

school is out for the summer and ends the week before school is back in session to streamline the transition. The schedule for each day is written on the board in every classroom, so the children know exactly what to expect. Field trips and swimming occur on the same day each week. The counselors discuss the schedule with the children numerous times throughout the day.

The child's needs of socialization were met while they were at camp. The children are placed in classrooms according to age, so they can socialize with other children. Many of the children know each other from school and other activities, so they are able to be with their friends. There are special activities each day at camp. These activities include but are not limited to art, puppet shows, music, swimming, recreation, Bible study, and life skill training for the older children. Field trips include but are not limited to home project at Lowes, Bounce U, basketball games, and bowling. Special guests also visit camp and include sports teams from the local college, local professional football team, therapy dogs, and karate instructors. The schedule and activities at camp are designed to meet the social and routine needs of the child. The activities are designed to cater to each of the child's abilities. Participant 3 stated,

> Just having organized activities for him makes all the difference and he feels like he is doing something and enjoying being here because he is very social. It's like the music up here, he loves that, and I didn't even realize they had that going on here and I knew he would think that was just awesome because music is his favorite thing.

Many of the children have high energy needs that require special care in the camp setting. The mothers also reported that the counselors have a high energy level to meet the needs of the child and give one-on-one care. This was deemed important by the mothers because they do not feel that they can always meet these high energy needs at home. In the camp setting the researcher sought to observe one counselor interact with a child who had mental disabilities and

an extremely high energy level. The counselor walked with the child up and down the hall numerous times while the child ran alongside the counselor. The counselor gave this child one-on-one attention during the morning session and continuously walked with the child as needed. During this interaction with the child the counselor talked lovingly to the child and was very compassionate. This field observation affirmed that the counselors are able to give one-on-one care and attend to the child's high energy needs.

Theme 2 – Creates Happiness. Most of the mothers indicated that they believed their child enjoyed camp (n=8). Even though some of the children were nonverbal, the mothers felt that they could tell their child looked forward to camp and/or enjoyed being there. Four of the mothers stated that their child became excited and looked forward to attending camp. The mothers concluded that camp made their child happy because it met their needs of socialization, routine, and participation in activities. Participant 20 expressed,

> She is a social butterfly, so she would like let's say the week before camp starts and they are out of school she has to go to work with us, you know, or we split it up, you know, and we will go home with her half a day, she is not happy with that, she likes to be around people, she likes to be involved, and we own our own business, so it's not like we can just take vacation whenever we want and just take her somewhere, so with that, um, honestly I think that that is probably the main thing that camp does. It gives her something to look forward to and gives us something to look forward to in the summer because we don't want her to be bored.

Participant 3 stated, "He talks about camp and I know they have some sessions throughout the year and occasionally we go to those and when I mention it he gets excited, I think his experiences here carry over." Participant 18 stated, " So it's just very structured and I wanna say

that right now it is like a one on one ratio right now, um, so I think all those things, she likes all the attention and I think it helps for someone to give her all that attention." Participant 9 stated, "The 2 weeks we brought her last summer, she was always happy, and that has been this way this year too." This sense of happiness was attributed to the child's interaction with friends, enjoyment of activities, and the ability to succeed at camp. Participant 21 discussed this concept, "It gives her an opportunity to excel, she wants it, she is excited, and she is anticipating it. It makes a difference with her."

Over half of the mothers stated that camp gave their child somewhere to go instead of being bored at home during the summer. Half of the mothers reported that when camp makes their child happy, the mothers are happy as well. Even though the children may not be able to articulate why they enjoy camp, the participants were sure that their child was happy to be at camp.

Theme 3 – Behavior Changes. Another important theme identified was *behavior changes* (n=9) with the child as a result of camp. The two categories that are part of this theme are parents seeing specific improvements and presentation of behavior at camp versus behavior at home. Both of these categories include behavior changes that are a direct result of attendance at camp. Five of the mothers reported that there were noticeable improvements in their child's behavior. Some of these improvements include increased independence, lifestyle activities, behavior changes, and social improvements. At the beginning of camp parents have an interview time with the camp director where goals for their child are discussed. Many of the goals include modifications in behavior and improvement in social areas. The counselor for that child works with the child throughout the summer on these skills. For several of the children this resulted in

meaningful changes in behavior. According to the camp director the counselors focus on teaching the children social skills, and each lesson is aimed at teaching important life skills.

On one occasion the researcher observed an interaction with a parent and counselor prior to picking up her child and documented this interaction within the field notes. The parent discussed a behavior at home that they were working on, and the counselor agreed to work on it with them. This was discussed by Participant 18, "They [the counselors] do go along with the goals I am trying to work with her on which is using her whole sentences instead of just one word, and they have taught her some things, she comes home and says something and I think where did she learn that and will have been at camp, so that is good." It was apparent that the counselors made time to discuss issues with the parents regarding their child's needs.

Changes in behavior also occurred because of the activities and opportunities that the children were given at camp. Participant 23 stated,

> The fact that he gets the opportunities to do the things that he does, it opens doors for these kids and I think it allows them to grow on every level, emotionally, socially, physically, um, every year that I take him back to school, camp is two months, and every year that I take him back, they always say, 'wow, how much he has grown over the summer', they are always amazed, and where is he? He is at camp.

The mothers commented on how the child's behavior at home was different from their behavior at camp. Four of the mothers reported their child does not respond well to activities at home, but they will perform activities at camp with enthusiasm. Participant 3 stated, "So just having activities to do, when I try to get him an activity to do on his own he is very resistance, but when he is here in a group setting with the other kids and seeing what they are doing, he is more willing to participate." Other mothers shared that the child's performance at camp allowed

the mother to expect more from their child at home. The new things their child was doing at camp gave them a different perspective on what their child could accomplish. There were only two mothers who did not notice a change in behaviors from their child being at camp. These mothers did not report any negative behavior changes, but there were no positive changes noted either.

Camp-Parent Themes

This broad category of themes was created to delineate the outcomes of camp for the parent versus the child. The themes correlate with the themes identified in the Family-Child category. Many of the needs, experiences, and stressors that were identified in the Family-Child category are addressed and remedied by the child's attendance at camp. The complete comparison of these themes is analyzed further in the discussion portion of the paper. The themes identified in this broad category are

1) improved perception of the child

2) decreased stress

3) parent involvement with staff, and

4) need for specific environment at camp.

Theme 1 – Improved Perception of the Child. The first theme in this category is the *improved perception of the child* (n=7). The mothers reported a sense of enjoyment and excitement as they saw their child participate in certain activities at camp. If the mothers were unable to see their child directly participate at camp, they discussed how they enjoyed listening to the child recall what he or she had done at camp. As the mothers saw or heard the changes that were occurring in their child, some of their perceptions of the child and his/her abilities began to change. Five of the mothers indicated that they enjoyed seeing the changes in their child, and one

mother noted that she enjoyed seeing her child do "typical" things. Participant 15 said, "The things he does here makes me look at him like he is growing up and he is progressing, that's always a good thing." Participant 28 stated,

> It is for me the activities, the karate, when I can see the pictures where he interacts with ballplayers, on the field trips, hearing how well he does on those things, because these are things that we can't do at home, he gets so overstimulated, being able to see him do things like that that we can't do that those are things seeing him act like a typical child, he is having a good time and playing – he seems to be able to adapt to this better at camp and I don't get to see him do these things at home.

Two of the mothers also indicated that their child was able to understand the Bible stories that were taught at camp. This began to change their idea that the child could now understand Bible stories, which was meaningful to the parents. These mothers reported great enjoyment from talking about the stories and praying with their child. Three of the mothers conveyed that seeing children at camp who were worse off than their child improved their view of the child's special health care needs. Overall, most of the mothers felt that seeing their child do certain activities at camp broadened their view and changed their perspective of what the child could do.

Theme 2 – Decreased Stress. The theme of *decreased stress* (n=10) is important to this study because it shows that camp provided a remedy to the theme of *increased stress* (n=10) in the discussion of Family-Child themes. The mothers discussed that caring for a child with special health care needs increased stress within their family, but the attendance at camp decreased stress within their family. One of the most prevalent reasons that camp decreased stress was that it filled a void of something for their child to do for the summer. One mother expressed, "Let me tell you what happened after we started going to camp – I became not desperate, that is what I

became because you have to understand from the end of May until August, there is no help." Seven of the mothers directly reported that camp decreased stress for their family. The decrease in stress was a result of extra time for the mothers to participate in other activities and rest, communicating with other parents at camp, relief of parental guilt, extra time to spend with others in the family, and decreased financial burden due to the affordability of camp. Camp also decreased stress because it gave the mothers peace of mind knowing their child was safe and happy at camp.

The mothers noted that camp gave them time to accomplish other activities. While their child was at camp, the mothers were able to finish tasks at home, work a part time job, or participate in activities with their friends. When mothers were able to do this, they were happy and encountered less stress. Participant 21 stated, "This morning when I leave here (camp), I have until 2 o'clock to give my attention to what I have to do…. when I walk out the door, I'm like whew". Participant 3 concluded,

> I think it makes a big difference for us – it really does, it frees me up to be able to do things- get some things done at home and errands that I can't take him to like shopping besides grocery shopping, and it frees me up to do activities with friends, so it makes me a happier person, and it makes him a happier person because he gets to go somewhere and do something.

Participant 23 said,

> I am behind in things, crucial things, that I am trying to get caught up now, when I found out about camp, then the fact that I was able to leave him in a safe and secure environment where people understood his limitations that that has given me more time to actually start working part time, and if I hadn't had camp I couldn't have done that.

Not only did camp provide the mothers with time to accomplish tasks, but it also provided two of them with the ability to work part time. Only one mother reported that it did not give her additional time in her daily routine, but it did give her child something to do and somewhere to go that alleviated her burden of finding activities for him. It was clear that the mothers were able to accomplish something important to them while their child was at camp.

Three of the mothers reported that interacting with other mothers at camp helped them cope with their emotions regarding their child, which may have decreased their stress. One mother expressed that she learned certain behavioral interventions to try with her child while communicating with other mothers at camp. One mother reported that her feelings regarding her child were validated when she was able to share some of her emotions with a mother at camp. Participant 21 stated,

> I was tight lipped about how I felt about that (child staying at camp) until I talked to other mothers that said they felt the same way, you know, I had a mom and her son goes here, I asked her 'are you sending him that last day' and she said 'oh yes!' and she would be a mom that I would expect wouldn't (send him) and she said 'oh no, one more day that I can (send him), so yeah!' I have never been validated verbally that is something that has come later (at camp).

In the field setting the researcher observed the interaction of the mothers during pick-up and drop-off times. The classrooms at camp are located on a long hallway, and everyone comes in one door and goes out that same door. As certain mothers passed by each other in the hallway, they would stop and talk about how their child was doing. Some mothers would talk for 15 minutes and others just spoke briefly. This drop off and pick up time created an environment for parents to see each other and encourage one another. One mother suggested that the camp should

provide more opportunities for interaction with other parents. Interventions for this topic are recommended in the discussion section.

Camp also relieved parental guilt felt by some of the mothers (n=4). As mentioned in the Child-Family themes, several of the mothers felt guilty because they were not able to always give their child one on one attention or meet the high energy demands of the child. The mothers knew that their child's needs were being met, and they were growing and learning in a safe environment while they were at camp. One mother reported that it made her family "feel good" knowing that her child was at camp doing the things that he loved to do.

One category within this theme that was important to several of the mothers was that camp gave them time to spend with others in the family, especially their other children. The inability of the mothers to spend time with their other children was noted within the Family-Child themes; however, mothers reported that while their child was at camp, they were able to have more time to spend with others. Participant 21 stated, "It is essential, she has to be somewhere, and serenity or peace of mind and it gives me an opportunity to be with the boys in the summer."

Some of the mothers (*n= 5)* noted that they were unable to give attention or do certain activities with the other children in the home during the summer months because they had to devote constant care to the child with special needs. Because their child attended camp, they were able to do many activities with their other children. Participant 13 stated,

> I have been able to do things with my other two that we have never been able to do, we have gone hiking, the waterfalls, swimming with the water slides, because with her, I have to stay in the baby side and I couldn't go with them and do things, and now I can do all that, so he (other child) has had the best summer and the older ones that is going away

> to college, I have spent way more time with him than I normally can get to, so it has been awesome. Very awesome – the best thing ever!

Some of the parental guilt may have been relieved because the mothers were able to spend time with their other children. One mother reported that she was able to spend more time with her husband while her child was at camp. Camp allowed most of the mothers extra time to choose what they wanted to do in their daily routine.

The final category that decreased stress for the parents was the affordability of camp. Many of the mothers reported that camp was much less expensive than hiring sitters. Camp also gave the child opportunities to do activities that the family could not afford on their own. Participant 15 concluded,

> And just doing all the activities, for the price, we couldn't do that as a family, it costs $40 to just go bowling and swimming, just the activities that keep him enriched and new experiences, we really want him to have all the life experiences he can even if he can't see them, it's a memory that we can do because we spend so much time in the hospital, you gotta have some fun sometimes.

Some of the parents require help financially to get their child access to the resources they need, and camp provides them with an affordable outlet for their child. When the researcher discovered this theme, she talked about this concept with the camp director. The camp in this study is a nonprofit Christian based camp that raises funds throughout the year and receives grants to assist with funding. This allows them to provide very inexpensive respite care for these children. The camp director responded that the average cost per week for each child to attend camp is $226, but through grants and other funding, each family is only charged $100 per week. Most of the parents pay on a sliding scale, so the average amount that is paid by the parents is

only $60 per week. This includes 5 days a week of camp from 8:30 am to 3:00 pm, so camp is very affordable to the parents.

Theme 3 – Parent Involvement with Staff. There were two different perspectives pertaining to this theme of *parent involvement with staff* (n=8). Many mothers enjoyed the interaction they had with the camp counselors and appreciated their communication with them. Some of the mothers felt that they needed more interaction with the camp counselors, and they were unaware of exactly what their child was doing at camp (*n=3).* Four of the mothers reported that the counselors listened to their needs and worked with them to better care for their child. One mother called her child's counselors, "her counselors" as they taught her special interventions to help with her child's behavior at home. She stated,

> Like I said, his counselors have been my counselors because you know you are just trying to understand why things are the way they are or what happens about this or what are some other techniques, what are you trying, when we first came, (the counselor) helped a lot, I would listen to her about things she would do to try to get him focused with things, because, I mean, that relationship is different than mine is with him, but still it was helpful to me to try to implement some of that at home a little bit in our environment, so, just seeing what was working.

Several of the mothers (*n=3*) also enjoyed hearing the counselors tell them what their child had done for the day. Because their child was nonverbal, they were unable to communicate with the child regarding the activities done at camp. Participant 28 stated,

> They are able to tell me. I can ask him 'did you have fun at camp today?' and he will usually say yes or no but as far as being able to get out of him what you do, you can't

always get that, but they are able to tell you 'oh yeah he had a great time at bounce u or the discover center', so yes that really helps!

According to three of the mothers the counselors created certain activities for the child based on their goals and needs of the child. One mother stated, "At camp they say "ok parent" we will do this, so they provide for their needs." In the field setting the researcher observed the parent's interaction with the counselors prior to picking up their child at the end of the day. Each parent came to the room to sign the child out of camp, and the parent was greeted by a counselor at the door. The counselors discussed any special activities that the child had done that day and any behaviors that they were working on with the child. The counselor took time to listen to the parents if they had any questions or concerns about their child. Many parents asked, "How did he/she do today?", and the counselors responded with an account of certain things the child had done throughout the day. This was considered meaningful by the mothers. One mother reported that she enjoyed the consistency of the same counselors that were present at camp. She felt that the counselors knew her child's needs and were able to provide a consistent relationship with her child. The researcher discussed this with the director, and he said they try to use the same counselors year after year to keep the same routine and consistency for the child.

The other perspective regarding communication with the staff involved a need for more communication with the counselors. Some of the parents reported that they did not fully understand what their child was doing at camp (*n=2*). They were unsure what their child did during certain times of the day (e.g. movie time) because they knew their child might not participate in that activity. This demonstrated a need for better and more proactive communication to occur between the counselors and the parents. Interventions to assist with this concern are recommended in the discussion section.

Theme 4 – Need for Specific Environment at Camp. There were several characteristics mentioned by the mothers in regards to creating a specific environment at the camp (*n=11*) to help the child succeed. The categories present with this theme included a need for routine, socialization, organized activities, a sense of security, special training of the counselors, and a distinctive environment at camp. All of these concepts related to the uniqueness of camp that made it a positive and thriving environment for the child.

The most recurring component in relation to the child's needs throughout the interviews included the child's requirement for routine, socialization, and organized activities. The mothers stated that these aspects were important to helping their child succeed and be happy at camp. As mentioned in the Family-Child themes, these three concepts were all mandatory in the child's daily life. At camp all of these needs were met for the child. The parents appreciated the variety of activities, the daily routine that was similar to school, and the friends their child was able to make at camp. Participant 16 stated,

> His routine is askew, you know, school breaks and stuff, cause he doesn't seem to have this schedule, he wants to eat, eat, he doesn't know when to eat, he needs something to fill up his dead space, he doesn't know what order to do anything….. it fills up his dead space during the day.

Although the parents did not mention many specific interventions that occurred at camp that promoted these attributes, they all knew that their child experienced routine, socialization, and activities while at camp. This helped relieve their stress and created an enjoyable experience for their child.

Camp also provided a very secure and safe environment for the children from the parents' perspective. Several of the mothers (*n=6*) mentioned that they were not always able to trust

sitters and other care providers, but they were able to trust the counselors and staff at camp. Three of the mothers concluded that camp gave them peace of mind, and they didn't have to even think about their child once they left the child at camp because they felt so safe. Participant 20 stated,

> Just the fact that we don't have to worry about where she is going to be, peace of mind, with her being nonverbal if we didn't have camp and had to try and find a sitter for her, the fact that she is nonverbal and you don't know who to trust, whereas you know you can trust these people, just all around peace of mind. I don't think about her from the minute I drop her off till the minute I pick her up.

The safe environment was noted in the loving and positive attitude of the staff at camp. Some of the mothers reported they felt the counselors truly cared for their children which made them feel good about leaving their children at camp. Participant 18 stated,

> They (the counselors) always, always, are just so happy to see her and she just had surgery 2 weeks ago and they were genuinely glad when she came back, and it wasn't just 'oh she had surgery lets maker her a card,' it was genuine. When I went to pick her up before her surgery, her counselor was holding her with tears in his eyes because she wasn't going to be there the next few days.

All of the counselors are uniquely equipped to care for children with special health care needs, which was a distinctive attribute to this camp. All of the lead teachers in the classrooms work with children with special health care needs in the local school system throughout the year. Ninety percent of the counselors have worked at the camp previously and have cared for children with special health care needs on a regular basis. The researcher inquired about the special training of the staff with the director. Prior to the start of camp there are numerous meetings that

prepare the counselors to care for the children in the best way possible. There are training sessions and team building work that occur to prepare the counselors. The camp director has been in the lead role for the past five years adapting the camp environment and preparing the camp staff to meet the needs of the children. Three of the parents noted specifically that the counselors focus on what the child can do instead of what the child can't do. All of these characteristics regarding the counselors create a specific environment at the camp that is meaningful to the parents.

Camp has a unique environment that is different from the school system most of the children attend. The environment at camp is specifically designed for children with special health care needs. The mothers (*n=7)* noted this unique environment and mentioned it in the interviews. Participant 21 stated,

> When I walked in (to camp) like the first day or so, I told everybody that I wish school was like this, I saw sensory stuff, I saw kids walking around or kind of not doing their own thing, but doing what they need, not everyone was in their room with the door shut, if they needed to walk, like if a student had to circle for 10 or 15 minutes walking, that is what I saw – I saw equipment specifically for what our kids need. It's all about them you know.

One mother stated that other camps her child attended did not have as many activities as this camp, and three of the mothers reported they appreciated the Bible stories and Christian influence of the camp. The loving environment sets camp apart from other places. Participant 15 stated,

> If camp opened a Christian school we would be the first to enroll, because it is such a different environment, don't get me wrong, we love our school, but it's just different,

there is just a love and so positive, it's just a refreshing break to not hear all the 'don't do this and don't do that'.

All of these special attributes at camp created an encouraging environment for the children and parents that provided meaningful experiences.

The researcher collected field notes at camp regarding topics mentioned in the interviews. During this time the researcher noticed certain equipment present in each of the rooms geared towards the child with special needs. A few sensory toys that created vibrating pulses or flashing lights were available for the children who might need them. The researcher was expecting to see many more toys and games specially designed for these children, but few were apparent. The researcher began to try to understand what activities or toys at camp were created specifically for the child with special health care needs. As the researcher reviewed the interviews, there was a common thread that became evident. The things about camp that created a successful environment for the campers was not special toys or high tech equipment, but it was the experiences with the counselors and other children, the group activities, and the general positive spirit that was present at camp that made a difference to these parents. When the parents were asked to define what interventions were most helpful to their child at camp, most of them did not mention very specific activities. Their responses centered on relationships at camp, having fun, and the encouragement from the counselors and staff. When this research study began, the researcher thought she would observe specific activities and interventions that occurred at camp that made a difference in the child's life. This was not the case. Although certain activities were mentioned as fun and important to the children (swimming, Bounce U, etc), these were general activities and were not specifically designed for the child with special health care needs. The things that mattered most to the parents and the children were not always observable activities.

They were built on relationships, loving and positive attitudes, and a genuine care and concern for the child. These are the attributes that created this theme of a *specific environment at camp*.

CHAPTER 5

DISCUSSION

Introduction

In this section the researcher interprets results of both quantitative and qualitative explorations as they relate to relationships between the parents, their child, their ability to manage their child's condition, and the therapeutic camp. The steps outlined by Teddlie and Tashakkori (2009) for interpreting the data were followed. The research questions and purposes were examined separately and all of the results that pertained to a question were summarized. Tentative interpretations were created, and those interpretations were analyzed to compare, contrast, and combine the data. Recommendations are made for activities to enhance therapeutic camps for the parent and the child based on the data from this study.

Throughout the data collection and analysis process, the value of using a mixed methods study became apparent. Based on the findings from the quantitative strand of data collection, the results were not significant, demonstrating no significant improvements in the parent's perceptions of the child's condition, condition management ability, condition management effort, family life difficulty, view of condition impact, and parent mutuality after attending the summer therapeutic camp for 8 weeks. If this was the only phase of the study, the results would demonstrate no significant benefit from the child's attendance at camp. The researcher was not certain if the FaMM would yield results to measure the true benefits of the camp, so the qualitative strand of data collection was added to the study from the outset, as part of the study design to understand the specific benefits from camp as perceived by the parents. The results from these interviews demonstrated that parents and children indeed benefitted from attending the camp as evidenced by the themes that emerged in the data-collection phase. The results were

compared and synthesized to make meaning of the data to formulate recommendations for future research, implications for nursing, camp organizers, and camp staff, and to suggest specific activities and interventions for this camp and other similar camps. This study was unique in comparison to other studies that research the benefits of therapeutic camps because it identified certain interventions that benefitted the child and family. The benefits from the longer duration of the camp also demonstrate the uniqueness of these study results.

Discussion of Quantitative Analysis

The data from the pretest FaMM administered within the first week of camp and the posttest FaMM administered within the last week of camp for a total of 8 weeks duration yielded no significant changes ($p > 0.05$) in any of the scales (child's condition, condition management ability, condition management effort, family life difficulty, view of condition impact, and parent mutuality). The small sample size was a threat to statistical conclusion validity. Although this sample was less than the original desired number, it was 73% of the eligible participants based on inclusion and exclusion criteria and 47% of the total participants at camp. The researcher chose one camp site in order to control for varying degrees of schedule changes, other activities, and time variations that may be present in other camps. These variations across other camps may have created confounding variables. Although the sample was small, it is typical of the variety of special health care needs and disabilities at other camps similar to this one in southeast area of the United States.

There were several reasons that may help to explain the lack of significant results from the FaMM in addition to the small sample size. The children in the study had been diagnosed with their chronic condition for an average of 9.8 years. There were no children in the study with

a time since diagnosis of less than 4 years. Many of the families may have become adjusted to their current way of life with their child. Knafl et al. (2010) concluded that condition management becomes easier and less time consuming as the time since diagnosis is increased. MacDonald and Callery (2004) found that as children grow older, life becomes routinized, but there is still a need for quality respite care. The established routine and longer time since diagnosis may make it difficult to assess changes in perception of the child's condition and the impact of the condition on family life.

Although this camp lasted an entire summer (8 weeks) this may be considered a short time to measure any changes in the family's ability to manage their child's condition. The current literature regarding respite care concludes that the benefits of respite care are transitory in nature because parents must resume their caregiving activities once the child comes home (Meltzer & Johsnon, 2004; Mullins et al., 2002). The scales measured in the FaMM including condition management effort, condition management ability, and family life difficulty may not have significant changes because they measure the parent's perception of the demands of caring for their child that resume immediately when the child returns home from camp each day. The mothers' return to caring for their child once camp is over may have contributed to a lack of statistical significance.

Any changes occurring at home or changes in the child's health care needs during the summer that possibly added to the parent's stress level could not be accounted for in this study because they were not part of the measurement instrument. A child with a chronic condition or disability has health needs that are constantly changing, and it is hard to quantify specific changes that affect the family's ability to manage the condition.

One of the most important reasons that the FaMM may not have yielded significant results is that it did not measure any interventions or occurrences that are specific to camp that benefitted the family. The researcher sought to understand what aspects of camp would be meaningful to the participants and determine if camp would affect the family and/or the child in a positive way. After conducting the interviews and analyzing the data, the emerged themes clearly showed that many of the benefits of participating in the camp discussed by the mothers were not specifically addressed by the FaMM. The themes under the categories of Camp-Child and Camp-Parent were not adequately measured by the FaMM. This instrument is a general questionnaire created to measure how families manage caring for a child with a chronic condition or illness and the extent to which they are able to incorporate that in their everyday family life (Knafl et al., 2011). It does not assess interventions (from camp) that may impact a family's ability to manage their child's condition. Some of the components in the questionnaire assess categories and themes mentioned by the parents, but there were many factors that were not included in the FaMM pertaining to the attendance of the camp.

The major benefits of attending the camp for the parents included an improved perception of the child's condition and abilities, a perceived decrease in stress level due to increased time for other activities, more time for rest, being involved with other parents at camp, relief of parental guilt, increased time to spend with others in the family, decreased financial burden, and a peace of mind from the sense of security at camp. The benefit regarding the parent's perception of the child mostly included the parent's improved view of the child's independence or a sense of "growing up" or maturing in certain areas. Although the FaMM does address some of these components in the Child's Daily Life scale and the View of Condition Impact scale, the exact

concepts identified in the interviews are not thoroughly explored in the FaMM as shown in Table 8. The mother's discussion of activities with the child was not included in the FaMM.

Table 8

Statements from FaMM Assessing the Theme, Improved Perception of the Child (n=7)

Child's Daily Life Scale
• Our child's everyday life is similar to that of other children his/her age.
• Our child takes part in activities he/she wishes to despite the condition.
• Our child enjoys life less because of the condition.
• Our child is different from other children his/her age because of the condition.
View of Condition Impact Scale
• Despite the condition, we expect our child to live away from home in the future.
• Our child's condition will be harder to take care of in the future
• It is hard to know what to expect of our child's condition in the future
• People with our child's condition have a normal length of life.
• Many conditions are more serious than our child's

Each of the items mentioned by the parents that decreased their stress as a result of their child's attendance at camp was not clearly measured in the FaMM. The idea of increased time for other activities, more time for rest, being involved with other parents at camp, relief of parental guilt, increased time to spend with others in the family, and a peace of mind from the sense of security were not items clearly identified within the FaMM. The financial burden that contributed to stress was assessed in the FaMM scale of Condition Management Ability. The effect on family relationships was generally assessed in the Family Life Difficulty scale and the Parent Mutuality scale, but specifics regarding time spent with others in the family were not a part of this scale as shown in Table 9.

Table 9

Statements from FaMM Assessing the Theme, Decreased Stress (n=10)

Condition Management Ability Scale
• We have enough money to manage our child's condition
Family Life Difficulty Scale
• Our child's condition gets in the way of family relationships.
• Taking care of our child's condition is often overwhelming.
• It is very hard for us to take care of our child's condition.
• A condition like the one our child has makes family life very difficult.
• It seems as if our child's condition controls our family life.
• It is hard to get anyone else to help us with our child's condition.
• We are sometimes undecided about how to balance the condition and family life.
• It is difficult to fit care of our child's condition into our usual family routine.
• Dealing with our child's condition makes family life more difficult.
• A condition like the one our child has makes it very difficult to lead a normal family life.
• Our child's condition rarely interferes with other family activities.
• Even though our child has the condition, we have a normal family life
Parent Mutuality Scale
• We are a closer family because of how we deal with our child's condition.
• I am pleased with how my partner and I work together to manage our child's condition.

There were no specific items on the FaMM scales that discuss and elaborate on the idea of time spent with friends, time spent with other children or spouses, parental guilt, or having a sense of security about outside care for the child.

The major benefits of attending the camp for the child included a change in behaviors and meeting their social, routine, and activity needs. Behavior changes were not adequately evaluated by the FaMM because it did not asses changes based on interventions specific to camp. The Child's Daily Life scale has statements pertaining to friendships and the Condition Management Ability scale has statements that generally refer to the child's behavior or maturing, but there are no specific items that assess behavior changes or modifications as shown in Table 10.

Table 10

Statements from FaMM Assessing the Theme, Behavior Changes for the Child (n=9)

Child's daily Life Scale
• Our child's friendships are different because of the condition.
Condition Management Ability scale
• In the future we expect our child to take care of the condition.
• Despite the condition, we expect our child to live away from home in the future.

The FaMM was unable to evaluate whether camp met the social, routine, and activity needs of the child because it does not measure the characteristics specific to camp.

The scales of the FaMM were useful for measuring certain aspects of caregiving, but they did not capture all of the different dimensions of caring for the child that were important to the mothers. The importance of time spent with friends and others in the family, time for rest, relief from parental guilt, inability to find sitters, the importance of seeing the child mature in certain areas, and the desire to communicate with the child regarding certain activities were not addressed specifically in the FaMM. Although some components may have been discussed, it was not able to fully measure all of the aspects mentioned by the mothers.

Meaning Making – Quantitative Data

Although the analysis of the quantitative data did not yield statistically significant results, there are some points that can be speculated from the data. The length of time for participating in the camp (8 weeks) may not be long enough to show any significant changes in a family's ability to manage their child's condition. The study was designed in a way that explored and measured any possible changes after completion of the program as measured by the FaMM. Longer time periods for administering the posttest, for example after 1 year, was not considered for this study due to possible occurrence of confounding factors such as the child's return to school, variations

in the child's health status, changes within the family unit, and the conclusion of camp resulting in a return to school routine. Because the children would not be participating in camp after the summer session ended, it would be difficult to determine if any changes in family management could be attributed to the camp. In order to gain possibly significant statistical results, the researcher recommends administering the posttest 6 months to 1 year after attending and completing the summer camp activities. The instrument could also be modified to include the specific components identified by the mothers in the interviews to reflect benefits from the camp that affected their ability to manage their child's special health care needs.

Discussion of Qualitative Analysis

Meaning Making - Qualitative Data

The descriptions and interpretation of the data are rooted in the researcher's knowledge of the participants. Teddlie and Tashakkori (2009) concluded that the researcher's familiarity of the specific population is a valuable asset in making inferences. The researcher has been involved with the camp in this study for 5 years, and she has worked full time as a nurse at this camp in the past that provided many opportunities to interact with the parents of the children at the camp. The researcher is also involved with a local outpatient center that provides skilled nursing care to children with special health care needs, and she has worked in some capacity at this facility for the past 4 years. The researcher's knowledge of the time and effort that parents dedicate to care for these children has been enhanced through her role at the camp and the outpatient center. The time spent in the field setting also gave her a better awareness of this population. The use of multiple data sources including interviews, field notes, and the investigator's expertise with the population contributed to the trustworthiness and rich

descriptions of the results. Prolonged engagement, prolonged observation, and triangulation were all part of the data collection and analysis.

Discussion of Themes in Relation to the Current Literature

Family-Child Category

Based on the themes that emerged from this study, it is clear that parents with a child with special health care needs experience a loss of normalcy, encounter affected relationships, experience stress, and make adaptations within their family in order to care for their child. A love for the child was evident in the sacrifices made by the mothers. These themes are in accordance with and support those presented in the current literature surrounding the impact of caring for a child with a chronic condition or disability. This adds to the trustworthiness of the data through confirmability of the results to other research studies. Difficulties and changes in family life that caused a loss of normal routine and activities apparent in the theme *loss of normalcy* are evident in the literature (Eaton, 2008; Gravelle, 2012; Knafl et al., 2010; McClellan & Cohen, 2007; Wade et al., 1998). Several of the mothers in this research described their eventual acceptance of their reality with their child resulting in their ability to incorporate those differences into family life. This supports the current body of knowledge concluding that over time parents learn to make their child's condition part of their normal family routine leading to a more satisfying life (Gravelle, 2012; Knafl et al., 2010; MacDonald et al., 2006; Rehm & Bradley, 2012).

The second theme of *affected relationships* is supported by current findings in the literature. The constant care of the child affects parent-child interactions due to a decreased amount of time to spend with the other children in the family (McClellan & Cohen, 2007; Sherman, 1995; Swallow et al., 2011; Thomas & Price, 2011). These findings from other studies

are similar to the affected parent-child relationships as reported by the mothers in this study. Mothers discussed a significant decrease in the amount of time spent with their other children and a loss of certain normal activities due to the demanding care of their child with special health care needs. Thomas and Price (2011) concluded that mothers struggled to divide their time between all the children, which was evident in this study. Swallow et al. (2011) discussed that the parents in their study felt sorry for their other children because they knew that they were neglected at times. The mothers in this study also reported that they knew their children felt a sense of neglect even if they did not voice this need. The findings from this study support the knowledge surrounding the impact on the parent-child relationship as a result of caring for the child with special health care needs.

Friendships are also affected resulting in social isolation (Eaton, 2008; Hockenberry & Wilson, 2011; Thomas & Price, 2011). This research confirms these findings, but it also adds to the limited body of knowledge regarding isolation from other family members due to the child's condition. A couple of mothers in this study described a disconnection from certain family members because they were not equipped to help care for the child that limited their ability to spend time with them. This lack of support resulted in fragmented family relationships. Adequate support systems are an important component to parental stress (Baker et al., 2002; Cowen & Reed, 2002; Garbarino, 1977; Johnson et al., 2006; Kuster & Merkle, 2004; Rehm & Bradley, 2005) and normalization (Knafl et al., 2010). This study affirmed that lack of support from family contributed to an increase in parental stress; however, some mothers reported they gained support at the camp through interaction with the counselors and other mothers. It is important that environments to increase support for families occur within respite care settings because this is a component to decrease parental stress. Therapeutic camps can foster this

support by creating opportunities for parent interaction with other parents and counselors. Although negative relationships were discussed in the interviews, an improved family closeness was apparent in some of the families. Several of the mothers felt their family was closer as a unit because of their child's condition. Knafl et al. (2010) concluded that parents who are seeking normalization within their family can identify positive aspects on family life because of their child's condition. In this study improved closeness as a family ensued when everyone accepted the changes that occurred as a result of the child's condition.

The theme *increased stress* related to caring for a child with special health care needs is also supported in the literature. Studies conclude that holiday times present increase stress because of the lack of availability of respite care services (Damiani et al. 2004; MacDonald & Callery, 2003; Swallow et al., 2011; Thomas & Price, 2008; Wilkie & Barr, 2008). The summer was noted in this research as an especially stressful time because of the long period away from the care provided though school attendance. This supported the idea that respite care throughout the summer can lead to decreased stress because it meets the parents' needs for extra help during this time.

The idea expressed by the mothers that caring for their child was seen as a job increased stress. This specific theme is not widely discussed in the literature, so this study adds to the identification of "caring seen as a job" as a component of parental stress. The literature depicting the constant demands of caring for a child with special health care needs explains why mothers might see their role of caring as a job (Aitken et al. 2009; Kuster & Murkle, 2004; Meltzer & Johnson, 2007; Raina et al., 2005; Thomas & Price, 2011; Wade et al., 1998; Yantzi et al., 2007). Cowen and Reed (2002) discuss parenting stress as a result of the normal caregiving demands of the child, but this stress was not described as a result of "caring as a job". The attendance at this

camp provided some relief from "caring as a job" because it provided day time respite for an entire summer; however, this is most likely a transient relief based on the current literature. Mullins et al. (2002) and Meltzer and Johnson (2007) measured parental stress during respite services and found a decrease in parental stress, but the stress returned to baseline after the service was over, which is most likely attributed to the mother's return to the demands of caring for the child. Mullins et al. (2002) concluded that respite care may diminish general distress felt by parents over time, but the specific type of stress that is associated with parenting a child with special health care needs is only temporarily relieved through respite care. Two of the mothers reported this finding in the qualitative portion of data. They concluded that when their child returned home from camp, the demands and time that they must devote to caring for their child stays the same.

Another component of parental stress related to caring for the child with special health care needs includes financial burden. This is a component in the literature related to parental stress included in parental stress measures such as The Parenting Stress Index (Loyd & Abidin, 1985). Many of the mothers in this study identified increased stress from financial burdens due to a loss of job, expense of equipment and medical care, and other more expensive respite services. The literature concerning respite care does not discuss a reduction in parental stress because of decreased financial costs. This is most likely because the majority of respite services, especially therapeutic camps, are expensive forms of respite care. This study demonstrated that when camp costs are kept low, parental stress regarding financial burden of care is alleviated. This study demonstrates the importance of seeking outside funding to assist with the cost of respite services to decrease the financial burden of caring for the child.

The parent's inability to meet the child's needs due to the demands of daily life resulted in an increase in parental guilt as evidenced by this study. Parental guilt is not readily discussed in the current respite care literature, but many of the mothers in this study reported guilt that contributed to their stress level. Aitken et al. (2009) concluded that parents who felt that their child's health care needs were not being met, experienced greater family burden, but this finding was not directly discussed in regards to parental stress.

It is important to consider financial burden, caring as a job, isolation from family members, and parental guilt as sources of parental stress from the findings in this study. Camp attendance alleviated some factors of stress for the mothers, so these components must be implemented when designing camps to help reduce parental stress. Some of the findings related to stress discussed by the mothers in this study can be explained by the current literature regarding parental stress. Different components of stress identified in the literature include social isolation lack of support services, perceived competence of caring for the child, acceptability of the child's condition, degree of impairment, behavior problems, and spouse or partner support (Aitken et al, 2009; Baker et al., 2002; Loyd & Abidin, 1985; Meltzer, 2002; Mullins et al., 2002). The mothers in this study reported some degree of social isolation and a need for support from their friends, family, spouse, and professional sources. The time of acceptance of the child's condition also revolved around their reported stress levels. These findings are all in accordance with the current literature discussing parental stress.

The theme of *family adaptations* (n=10) is supported with findings in the current literature. In this study mothers discussed modifying the family routine and making adjustments to family life to meet the needs of their child. Gravelle (1997) found that mothers rearranged their lives to care for their child resulting in family adaptations. This was apparent in this study

as mothers changed jobs, modified their home environment, and modified family activities for their child. Limitations on family activities along with the creation of normal activities were also discussed in the literature (Lee & Rempel, 2011; Rehm & Bradley, 2012; Thomas & Price, 2011). Shared care responsibilities between parents was identified in this study and adds to the current body of knowledge surrounding caring for children with special health care needs. Knafl et al. (2012) discussed that parents' perceptions of the impact of the condition on the family can be improved if they share the same perspective on caring for the child, but the idea of relieving one another from the care demands is not discussed. This study demonstrates the value of sharing responsibilities and giving breaks from care demands to promote family adaptation and coping.

One coping mechanism identified in this study that is evident in the literature includes parents taking time for themselves (MacDonald et al., 2006, MacDonald & Callery, 2007). This research also identified time spent with friends and talking with other parents as specific coping mechanisms that are not prominently discussed in the literature concerning respite care. As mentioned previously, support systems are important to successfully decreasing parental stress, so this is an important component to consider when designing a therapeutic camp.

This study also identified spiritual practices as a coping mechanism. Lee and Rempel (2011) found that spiritual aspects led parents to a positive appraisal of their experiences with their child. Several of the mothers in this study determined that prayer and spiritual components helped them cope with their child's condition. The findings from this study demonstrate the value of spiritual components in the mothers' ability to cope with the struggles of caring for their child. Spiritual influences on a family's ability to manage their child's condition is significantly lacking in the literature and needs to be further researched to understand its specific effect on

family management. The spiritual component of the camp in this research that was meaningful to some of the mothers sets it apart from other camps in the current literature.

The final theme discussed in this section is *love for the child (n=8).* This theme is prominent in the literature including the parent's deep care for the child (Gravelle, 1997), the parent's focus on creating a good life for their child (Knafl et al. 2010), and sacrifices made for their child (Knafl et al., 2010; MacDonald & Callery, 2007; Meltzer & Johnson, 2004; Swallow et al., 2011), which are all in accordance with the findings from this research.

Camp-Child Category

The findings in this study regarding the benefits of the camp to the child significantly add to the body of knowledge surrounding respite care for children with special health care needs. The majority of the literature discussing respite care focuses on the benefits of respite care for the parents (Cowen & Reed, 2002; Eaton, 2008; Ling, 2012; Meltzer & Johnson, 2007; Mullins et al., 2002; Robertson et al., 2011; Shelton & Witt, 2011). There is little evidence demonstrating the benefits of respite care to the child. This study demonstrated that the child's attendance at the therapeutic camp met their individual needs, created happiness, and promoted behavior changes. Meeting the child's needs of socialization, leisure activities, and promoting enjoyment for the child are apparent in the literature surrounding therapeutic camps (Shelton & Witt, 2011; Swallow et al., 2011; Wilkie & Barr, 2008). There were no studies that demonstrated any behavior changes with the child as a result of respite care. Radcliffe and Turk (2007) found that only 11% of their sample (N=35) had any changes in behavior after attending an overnight respite care program. In this study nine of the mothers noted improvements in behavior as a result of the attendance at camp. This may be attributed to the longer duration of this therapeutic camp (8 weeks). In particular, this camp works with the parent to establish goals surrounding

behaviors that can be worked on throughout the summer. The counselors are mindful of the goals and prioritize them each day. Measurable goals and longer duration that are unique to this camp may increase the changes in behavior reported by the parents as compared to other types of respite services in the current literature. The benefits to the child from attendance at a therapeutic camp are well documented in this research and add to the body of knowledge regarding specific components at camp (i.e. camp duration and goal setting) that may promote these changes. It is important that recommendations for camp organization include goal setting with parents and continued development of these goals in regards to the child's behavior.

Camp-Parent Category

A perceived decrease in parental stress as a result of respite care is documented in the literature and paralleled in this research. The mothers' increased time to complete other activities, rest, and spend time with others in the family contributed to their perceived decreased stress. These are all components of the benefits of respite care discussed in the current literature (Cowen & Reed, 2002; Meltzer & Johnson, 2007; Shelton & Witt, 2011; Thomas & Price, 2011; Wilkie & Barr, 2008). This study demonstrated that stress was also decreased as mothers were able to talk with other parents at the camp setting. This benefit may be specific to this type of camp because it is a day camp that occurs throughout the entire summer as opposed to a 1-week overnight camp that is the type of camp predominantly included in the literature (Meltzer & Johnson, 2007; Shelton & Witt, 2011; Swallow et al., 2011) Only one study identified the idea that parents valued meeting others who were involved in a respite service, but this did not occur on a daily basis because the children were left at the camp for a week and then picked up by the parents at the conclusion of the camp (Shelton & Witt, 2011). Mothers in this research saw each other every day as they dropped off and picked up their child from camp, and they enjoyed

discussing issues related to their child with other parents at the camp to relieve some of their care burden. This is a unique feature to this camp that fostered support relationships between the mothers. This intervention is not widely discussed in the literature as a component to decrease stress regarding respite care. Further research should be aimed at discovering specific ways to implement greater parent interaction at therapeutic camps to decrease stress and promote coping.

This study adds to the current body of literature surrounding the improved perception of the child as a result of the attendance at respite care. This is currently not discussed in the literature, and this research confirms that camp positively affects the mothers' overall perception of the child through seeing the child participate in typical activities, broadening their view of the child, seeing others with greater needs, and discussing camp activities with the child. Many respite services are overnight services or camps that prevent the parent from seeing the child participate in camp activities. This camp was a day camp, but because it extended throughout the entire summer, mothers were able to see their child interact within the camp setting over a long period of time. The mothers were also able to interact with the camp staff for a prolonged period of time that may have fostered closer relationships and increased trust with the counselors. This study can be used to show the value of a prolonged day camp as respite care in order to affect the mother's overall perception of the child and have prolonged engagement with the counselors in regards to communication and trust.

Some of the components of the specific environment at camp that were discovered in this study are also apparent in the literature. The expertise and loving attitude of the staff was a prevalent factor in the study by Swallow et al. (2011). Although the staff was seen as helpful in the literature and in this study, the need for greater communication from the staff was paralleled in the literature (Eaton, 2008; Swallow et al., 2011; Thomas & Price, 2008). Respite care must

include trustworthy staff that helps the parents feel safe and secure about leaving their child at the respite care facility. The gratefulness felt by parents participating in respite care services was noted in several of the studies because it gave them peace of mind (Eaton, 2008; MacDonald & Callery, 2003; Meltzer & Johnson, 2004; Mullins et al. 2002; Shelton & Witt, 2011; Swallow et al., 2011; Thomas & Price, 2008; Wilkie & Barr, 2008).

There are many findings in the current literature that support the themes from this study. This study is important because most of the studies in the current literature assess general respite services, not therapeutic camps. This study affirms that therapeutic camps should be seen as beneficial respite care for the child and the family. The length of time for the camp in this study (8 weeks) demonstrated benefits regarding prolonged relationships with the staff and other parents, increased time for change in child behaviors, and improved perception of the child. This study also adds to the body of knowledge regarding decreased parental stress as a result of attendance at an 8-week therapeutic summer day camp. Aspects of stress discussed in this research that are not prevalent in the literature regarding therapeutic camps include communication with other parents at camp, a relief of parental guilt, and decreased financial burden. All of these components add to the minimal body of knowledge surrounding the benefits of respite care through a summer camp program for children with special health care needs.

Discussion of Conceptual Model

It is apparent that the stressful components or "loss" aspects of the themes from the Family-Child category were addressed through the child's attendance at camp. Some of the stresses and needs described by the mothers in the interviews were relieved when their child was at camp. The inability to find sitters, loss of normalcy in everyday activities, loss of time spent with others, and lack of time for completing everyday tasks were all negative aspects of caring

for their child. Camp provided the mothers with a secure environment for their child where they could have their individual needs met. It also provided the mother with time to engage in outside activities, rest, and spend time with others in the family. The benefits from the child's attendance at camp clearly demonstrate that camp is a valuable experience for the child and the parent.

The child's attendance at camp addressed many of the issues and needs that were identified in the Family-Child category. This is described in the conceptual model created by the researcher as shown in Figure 2. The components described in the themes from the Family-Child category are at the top of the model, and they are highlighted in green to correspond with the color depicting the benefits of the child's attendance at camp form the Camp-Parent and Camp-Child categories. Several characteristics and benefits from the camp identified by the mothers improved the sense of loss of normalcy. In the Family-Child category everyday activities within the family were a struggle, the idea of a normal family was shattered, and relationships were affected. In the Camp-Parent category, mothers identified that their perception of their child was improved as they saw their child progress and participate in certain camp activities. Mothers were able to accomplish tasks at home and spend time with friends and family members. Some of the participants commented that they enjoyed seeing the counselors and staff interact with their child in a genuine way. Seeing the counselors view their child in a positive manner may have helped them view their child in a more "typical" way. All of the benefits from camp that target negative aspects of caring for the child with special health care needs are highlighted in green, so the reader can see the direct benefits of camp on the family's ability to manage their child's condition.

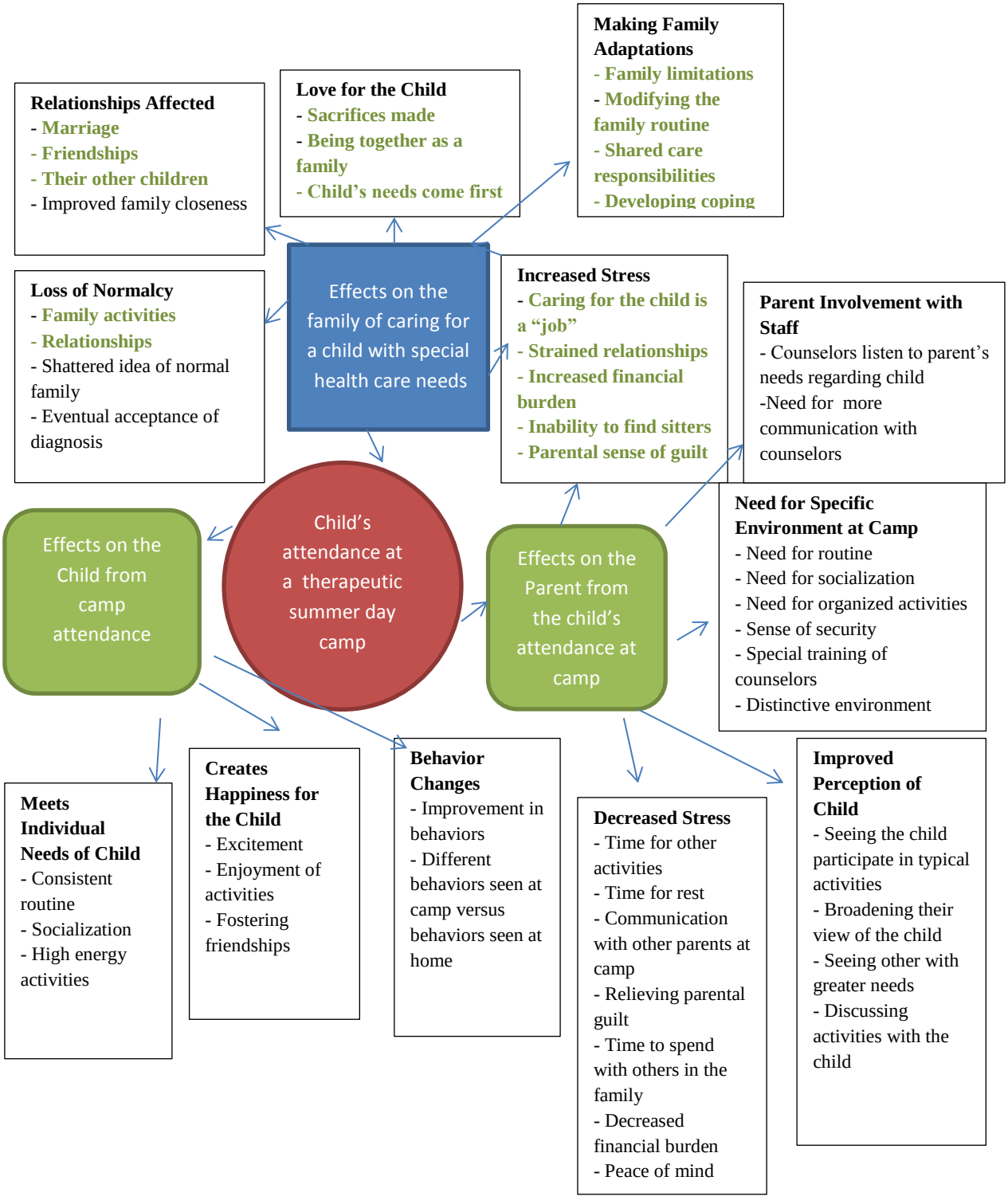

Figure 2. Conceptual model describing the benefits of therapeutic camp attendance on the family's ability to manage their child's condition within their family.

The theme of *increased stress* in the family resulted from certain struggles within family life that were improved through the child's attendance at camp. In the Family-Child category stress was increased through the idea of "caring as a job" and strained relationships. This was alleviated by the specific components of the *decreased stress* theme in the Camp-Parent category. Camp gave the mothers the opportunity to rest, spend time with others, and experience quiet time to themselves throughout the entire summer while their child was at camp that may have briefly decreased their feelings of "caring as a job". The stress associated with increased financial burden from the Family-Child category was also improved through the child's attendance at camp. The affordability of camp and the ability of some of the mothers to work part time during the summer decreased financial burden in the Camp-Parent category and resulted in a decrease in stress. The stress associated with an inability to find sitters from the Family-Child category was significantly remedied through the child's attendance at camp. The mothers reported that they were able to trust the staff, and the camp met the social, routine, and high energy activity needs of their child. *Parental guilt* was also alleviated through the attendance of camp because the mothers were able to spend time with their other children. Camp was able to meet their child's needs while the mothers accomplished other tasks, which decreased parental guilt. Coping mechanisms under the theme of *family adaptations* included taking breaks, talking with other parents, and having time to rest and relax. In the Camp-Parent category some of the mothers were allowed to have breaks and rest while their child was at camp. The child's attendance at camp met the mother's needs that were identified in the theme of *family adaptations* under the Family-Child category. All of these corresponding themes are depicted in the model as shown in Figure 2. This model can be used to show the benefits of camp to prospective parents. Nurses and camp organizers should identify families that are in need of

respite care services and use the model to explain the benefits of camp on their family and child to promote participation in the camp. The model can also be used for funding purposes to show guarantors the benefits of camp.

Discussion of Themes in Relation to the Research Questions

The research questions aimed at answering the qualitative phase of data collection included:

1. What are the perceptions of parents of children with special health care needs of the interventions and experiences at a therapeutic summer day camp program?
2. What interventions or experiences (if any) impacted the parents' perceptions regarding the management of their child's condition?

The first research question was comprehensively explored and elaborated on in the interviews. According to the themes identified in the study the parents perceived the therapeutic summer day camp program as beneficial to their family. It met vital needs that they had regarding care of their child in the summer. All of the parents concluded that their child was unable to stay at home when they were out of school for the summer. The mothers expressed the routine, socialization, and activities at camp benefitted their child in greater ways than other child care options such as a sitters, other camps, and daycare.

Camp changed some of the parent's perceptions of their child as they saw them participate in activities and mature in certain areas. Parents appreciated the group activities for their child, Bible stories, and one-on-one interaction of the counselors with the children. They felt that camp met certain needs of their child that they, as mothers, were unable to fulfill. This included the child's high energy needs and participation in other outside activities such as

recreation and other group activities. The mothers expressed that their child excelled at camp in ways they would not perform at home. There was an overwhelming sense of gratitude and happiness that their child was able to attend camp. One mother stated, "I was so happy when she got old enough to come to camp." Participant 15 expressed her sadness about camp coming to an end for the summer when she said, "And I can't believe next week is the last week, yeah, I hate to see it end. It gives us good memories, and I told my husband that we are going to send him (their child) to camp until he ages out of it." Another mother stated, "We love it. We will be back. We love it. It's just good respite for her and for you and your family – it gives her what she needs." Participant 18 concluded, "It has been a wonderful thing for her – we wouldn't trust them at a regular day care but we do at camp so that is good – it has been great for her."

Participants did not express any negative points about the camp but have made a few suggestions. The main area that needed improvement as discussed by the mothers involved more communication between parents and staff. Some of the mothers reported they did not know exactly what their child was doing at camp, and they weren't sure how their child responded to certain activities. This could be alleviated if there was more interaction and clear communication between the counselors and the parents. Although most of the mothers felt that they were able to communicate with other parents, there were a few mothers who desired more opportunities to interact with other parents at the camp.

The second research question regarding specific interventions and experiences at camp that impacted the parents' perspective of managing their child's special health care need was also clearly expanded on and explored in the interviews. The stresses surrounding managing their child's condition were alleviated through the child's attendance at camp. Communication with others, providing time for other activities and time with family, seeing their child mature at

certain tasks, and supporting their child's routine, socialization, and high energy activity needs were the most important aspects of camp that assisted the parents in managing their child's health care needs.

Although parents mentioned certain activities their child enjoyed such as swimming, bowling, and Bounce U, it was the overall specific camp environment that impacted the parent's perspective of managing their child's needs. The camp staff's love and concern for the child impacted the parents in a positive way. The unique environment of camp geared towards meeting their child's individual needs and focusing on their abilities instead of their disabilities was refreshing to the parents. There were not clearly identified interventions that the parents experienced that could be observed in the field setting. The researcher was able to observe some parent interaction between the camp staff and other parents, but the secure, consistent, and loving environment of camp seemed to matter most to the parents. The interviews with the mothers clearly demonstrate that the parent perceptions of camp were very positive and the overall experience of camp impacted their perspective on managing their child's health care needs. Participant 15 stated,

> And to see him come (to camp) and do this, they said he has been in his walker, I think he is maturing by being here, I just – yeah, the things he does here, makes me look at him like he is growing up and he is progressing, that's always a good thing. We really want him to have all the life experiences he can even if he can't see them, it's a memory that we can do because we spend so much time in the hospital, you gotta have some fun sometimes.

Participant 21 concluded, “This camp is wonderful, yes, everything, because this camp, they attend to our kid’s needs.” Participant 22 stated, “This is the only place that knows my kid’s needs.” Participant 28 commented on how camp affects her view of her child,

> It is for me the activities, the karate, when I can see the pictures where he interacts with ballplayers, on the field trips, hearing how well he does on those things, because these are things that we can’t do at home….. being able to see him do things like that that we can’t do- those are things- seeing him act like a typical child, he is having a good time and playing – he seems to be able to adapt to this better at camp and I don’t get to see him do these things at home.

These examples from the interviews reveal the positive feelings that mothers had about camp.

Implications for Research

Implications Regarding the Family Management Style Framework

The components of the FMSF include the definition of the situation, management behaviors, perceived consequences, and perceived influences on management. The interviews with the mothers included a discussion of all of these components. The definition of the situation in regards to how the family defines their child’s illness, identity, and management mindset were all prevalent themes in the interviews from this study. The mothers mentioned each of these components as important aspects of caring for their child. They defined the care of their child’s condition as overwhelming and stressful at times, but many of them had adapted and modified their family routing to accommodate their life with the child. Management behaviors included making modifications to their family life and seeking out professional sources of help through the therapeutic camp. The perceived consequences of caring for their child’s condition included

stress within the family due to strained relationships, lack of time for other activities, and financial burden.

Knafl et al. (2012) wrote that the parent's management mindset reflects their assessments of the demands they are going to face as parents and their ability to face those demands. In this study the parents were aware of the constant caring demands that they encountered every day, and these demands created stress within their family. Their inability to meet those demands resulted in stress and parental guilt. When those demands were met through attending camp, their management mindset was alleviated.

One aspect of the management behaviors in this framework revolves around the parents establishing and modifying the routine within their family to meet their needs (Kanfl et al., 2012). This was echoed in this study through the themes of *family adaptations* (n=10) and meeting the child's individual needs. Mothers reported an extreme need for routine in the care of their child, and they also saw the value in modifying what they do as a family in order to better manage their child's needs.

The perceived consequences component of the FMSF includes the idea of the family's focus on caring for their child's condition while balancing other aspects of family life (Knafl et al., 2012). Throughout the interviews mothers concluded that they struggled to balance the needs of their child with other needs that were prevalent in their family life. This included spending time with other children, making time for their husbands and friends, and the lack of the ability to accomplish everyday tasks. The theme of *loss of normalcy* (n=11) indicated the mother's thoughts on the perceived consequences of caring for their child's condition.

The FMSF identifies the family's social network, healthcare professionals, and resources as factors that contribute to a family's ease or difficulty in managing their child's condition

(Kanfl, Deatrick, & Havill, 2012). It was evident in this study that the family needed support from their friends and family to help them manage their child's condition effectively. The mothers concluded they also needed help from healthcare professionals and other resources, such as camp, in order to help them manage their child's condition within their family. The themes that emerged from this study directly support the components of the FMSF.

Implications for Nursing

The results from this study can be used by nurses to improve their understanding and care of this population. The themes identified in the study demonstrate that parents caring for children with special health care needs experience a major life change and need support from health care professionals. Nurses must be aware of the struggles that these families face in order to better meet the care needs of the child, parent, and family. Based on the data from the study, one of the most important things that nurses can do for these families is to support and encourage them. Nurses need to be aware of the benefits of respite care, specifically summer therapeutic camps, and encourage parents to participate in this form of respite care. Nurses can identify families that may have an increased stress level based on the components in that theme from the study. These families need intervention and respite in order to create a less stressful environment for their family.

Nurses who work within these camp settings can also enact practices based on the recommendation from this study in order to create a better environment for the children and parents at camp. One-on-one time with the parents and increased communication are paramount to creating a successful camp environment. The nurse must be aware of the child's needs and listen attentively to the parents' concerns. The nurse should also strive to ensure that the camp is

incorporating activities that promote a consistent routine, socialization, and high energy leisure activities. It is also imperative that the nurse educate the staff on how to provide excellent and individualized care for the child with special health care needs. When nurses can understand the specific needs of these families, they can influence others to provide excellent care to these families.

Nurses can use the conceptual model created by the researcher to demonstrate the need for therapeutic camps to the family of children with special health care needs. The model demonstrates that common struggles and hardships faced by these families can be alleviated through the attendance of camp. When nurses are aware of the benefits of this type of respite care, they can share this information with families to assist them at locating a therapeutic camp that will benefit them. It can also be used to show camp organizers the benefits of therapeutic camps while demonstrating important components to include within the camp design.

Implications for Camp Organizer

The interviews yielded very specific results about the best practices at a summer camp for children with special health care needs. Parents reported a need for consistent routine, socialization, and high energy activities. Because the summer time brings difficulty in finding care for the child, it is important that these camps maintain a cohesive routine and begin when school is out and continue until school begins in order to meet the needs of the parent and the child. Parents felt that the socialization their child experienced was paramount. Camps should provide an environment where children can be with other children their age and have one-on-one time with the counselors. High energy and fun activities are also very important at camp. Field trips were valuable to the mothers because they allowed their child to do things they may not be

able to afford at home. The low cost of camp was also imperative to the mothers. Because there are so many high costs involved with caring for a child with special health care needs, the affordability of camp was a relief to the mothers. Camps should strive to keep costs down through external funding if possible.

A secure and loving environment was also vital at the camp. Parents must be able to trust the counselors and staff. This rapport was established at this camp through the use of the same counselors and staff consistently. A 'meet and greet' time was also conducted prior to the start of camp that allowed the parents to meet the counselor and see the room where their child would be in class. A nurse was always on site at this camp, which also gives parent peace of mind while their child is at camp. The nurse met with the parents individually at the 'meet and greet' time in order to speak one-on-one with the parents and interact with the child. There was open communication between the staff, camp director, and parents that also contributed to a sense of trust between the parents and the staff. Parents were able to set goals with the counselors and director prior to the start of camp to determine their child's needs. These goals were focused on throughout the entire summer. Some of the parents were able to see progress that also confirmed the secure and loving environment at camp.

The 8-week duration of camp is an important factor for the camp organizer to consider. Attending camp for an entire summer as opposed to 1 week in the summer possibly contributed to the positive benefits of camp on the child and mothers. The camp provided continuous childcare during the summer months, which is noted to be a stressful time for parents (MacDonald & Callery, 2003; Damiani et al. 2004; Swallow et al., 2011; Thomas & Price, 2008; Wilkie & Barr, 2008). Longer duration also allowed the counselors at the camp to work with the child to change certain behaviors and achieve specific goals with the child. The consistency

of seeing the counselors daily for 8 weeks may have contributed to the trust and open communication between the parents and the counselors. Mothers were able to have more time for friends, family, part time jobs, and rest due to the length of camp. Because camp lasted for the entire summer, the families did not have to hire any sitter or find other services to care for their child in the summer. For these reasons it is important for the camp organizer to consider conducting the camps for the entire summer if possible.

Because camp decreased stress for the parents, it is important to implement interventions at the camp that can continue to reduce stress. Based on the findings from this study, camps should be used for social support and an emphasis should be placed on decreasing costs and providing care for the entire summer. These benefits to the parent have not been identified in the literature as part of the design of therapeutic camps, but camp organizers should consider these findings when planning therapeutic camps as respite care.

Implications for Camp Staff

Camp improvements were discussed by the mothers. Some of them wanted more communication with the staff and a more detailed description of what their child was doing each day. This could be accomplished with a daily progress note filled out by the counselors and given to the parent at the end of each day. This would allow time for the parent to ask any questions to the staff and also learn about what their child did at camp that day. Through the use of a progress report, the parents would know more about their child's behaviors at camp. At this camp, they have instituted a praise board. This is used to display any accomplishments or good behaviors that the child shows during the day at camp. Parents are able to see the praise board at drop off and pick up. Although this was not mentioned by the parents in the interviews, it is a

great tool for parents to see what their child is doing at camp. Children also can feel very proud of their accomplishments that are written on the praise board.

Mothers also stated that they enjoyed talking with other parents. For some of the mothers this was a coping mechanism for them to share their thoughts and feelings with other parents. Although some mothers expressed they were able to converse with other parents while at camp, there was a need to create more time for parents to get together at the camp setting. A parent social time where all of the children are kept at the camp for an extra hour 1 day a week or every other week is suggested by the researcher. This would allow parents the opportunity to talk and spend time with each other prior to picking their child up from camp. Mothers and fathers could participate in meeting other parents and sharing their experiences with them. According to the data in this study this would be meaningful for the parents.

Recommendations for Future Research

Both phases of this study provided data that can be used for future nursing research. In regard to the quantitative phase, the FaMM needs to be used in other studies to understand the family's perspective and ability to manage their child's condition. For this study the 8-week time frame for the summer camp was not long enough to demonstrate any statistical significance as measured by the FaMM. The time frame suggested by the researcher for future studies using the FaMM is 6 months to a year with the child completing the entire summer session at the therapeutic camp along with attendance at the respite care days offered throughout the year. Another recommendation for future research includes using a larger sample to increase the power and effect size of the quantitative portion of data collection. The use of a larger camp or several similar camps in the same area may be useful for future research endeavors. Future

research should also include questionnaires from both parents with comparisons from each viewpoint in order to see any statistical difference based on the various parent perspectives.

In the future demographic characteristics that are related to parental stress should be examined. Because the idea of stress within the family was a predominant theme in the study, a scale that measures stress along with demographic questions that assess possible stress factors should be included in future research studies with this population. The Parenting Stress Index (Abidin, as cited in Mullins et al., 2002) is a scale that has been used within this population to measure the stress associated with caring for a child with special health care needs (Cowen & Reed, 2002; Mullins et al., 2002). This type of scale along with the use of the FaMM may contribute to a greater understanding of the impact that camp has on the parental stress associated with caring for a child with special health care needs. It may also be beneficial to add components of the themes that emerged from the qualitative strand of data collection to the FaMM. This would give quantitative data that are based on the emergent themes from the study.

For the qualitative phase of the study, the data showed that families of children with special needs indeed benefit from a respite therapeutic summer camp. Future research should be aimed at understanding the exact interventions that are meaningful to the parents, the specific training of the counselors, and behavior changes that are apparent within the child as a result of camp. All of these areas were mentioned in the interviews, but they were not fully explored. It would also be beneficial to conduct interviews with both parents to determine the perspective of the father in comparison to the mother. Future interview questions should be developed to determine the specific components of camp that are meaningful for the parents and the child. A sample of these questions include:

1. What is the difference in the environment at camp vs the environment at school?

2. What does your child learn while at camp?
3. Does camp impact the way you and your partner are able to care for your child's condition?
4. What activities are the most meaningful to your child at camp?
5. What can be done better at camp to help meet your needs and your child's needs?
6. How do the counselors help your child at camp?

Each of these questions targets a specific area that needs to be further explored to make more specific recommendations for the structure of the camp.

Limitations

This study was limited by the small number of participants recruited for the quantitative strand based on the inclusion and exclusion criteria. A larger sample that encompasses one or two more camps may be beneficial for future research. Convenience sampling was employed in the quantitative strand of the study; therefore, the results are not generalizable. The fact that mostly mothers filled out the questionnaires and only mothers participated in the interviews is also a limitation of the study. Future research should be aimed at recruiting more fathers and parent pairs to participate in the research. The time frame for the study was also only 8 weeks, which could have contributed to a lack of statistical significance. The camp setting was a nonprofit Christian camp that may diminish the transferability to other camps that are not similar in setting or philosophy. The specific training of the counselors and special needs of the children at camp could also lead to varying results.

Personal Reflection on the Research Process

This process was a wonderful learning experience for me. Seeing the progression unfold from the beginning to the end was an amazing process. I felt overwhelmed at times and inundated with information that I hoped I would be able to disseminate correctly. Because I am so passionate about this population, that passion carried over in my drive to use sound research techniques and give a voice to the mothers who participated in the interviews for my study. After my interviews I would go home and my heart would feel so full as I thought about the deep love and care that these mothers have for their children. I was overwhelmed at their sense of "doing whatever it takes" to meet the needs of their child. I learned the value in mixed methods research during this study, but I also learned the large amount of work that is involved in conducting this type of research. I think that my past relationship with the camp, the staff, and some of the parents helped me build rapport with the families. Each day that I was at camp I felt closer to the children whose parents were participating in the interviews.

After the interviews I conducted observations at the camp setting to create meaningful field notes regarding specific interventions and activities that occurred at the camp. The communication with the staff, one-on-one care of the children by the staff, and general observation of parents during the drop off and pick up time of camp were part of the observations and field notes. I also met with the camp director to discuss certain techniques they used at camp to create an environment that promoted consistent routine, socialization, leisure activities, specially trained staff, and the decreased financial costs of camp. The field notes and meeting with the director helped provide recommendation for other camps to enhance their program based on the interviews from the mothers. After conducting this research I am more prepared to care for and serve these special families. This has increased my empathy,

compassion, and knowledge surrounding this population. I hope that this research will serve to enhance their experiences at camp and provide better respite for the parents and children who participate in camp.

Conclusion

This mixed method study used a sequential design imploring both quantitative and qualitative strands to better understand the perceptions of parents of children with special health care needs after the attendance of a therapeutic summer camp. The researcher also sought to determine the effects of the camp on the parent's perspective in regards to the child's condition, condition management ability, condition management effort, parental mutuality, and family life difficulty.

These themes supported the theoretical framework used for this study, the Family Management Style Framework, and they were supported by the current literature surrounding the benefits of respite care. Although the quantitative phase did not yield significant results, the study overall yielded very significant results and provided insight into the lived experiences of parents caring for a child with a special health care need and the effects on their child and family from attending a therapeutic camp. The qualitative phase of the data collection demonstrated important results concerning the positive outcomes of camp for the child, the family, and the parents. The benefits of the camp on the parent's stress level and family management were paramount in the interviews. Camp also benefitted the children through meeting their individual needs, changing some of their behaviors, and creating happiness for them while at camp. Camp was seen as beneficial to the families and children because it met their emotional and social needs while giving the parents time to rest and spend time doing other activities and being with their families.

The results of the study helped provide recommendations for future research and identify camp activities and interventions that were meaningful to parents. These activities can be implemented in other camps to enhance the overall experience for the child and family. Better communication between the parents and staff along with increased time for parents to socialize with other parents at camp were identified as important modifications to future camps. Future research should be aimed at using larger sample sizes and using both qualitative and quantitative data collection techniques to assess the impact of therapeutic summer camps on parental stress.

This population of parents is a very special group that has specific needs nurses and other health care providers should seek to meet. This research demonstrated their extreme care and compassion for their children as they sought to provide the best care possible and gave up so much within their families to care for their child. I hope that this research will serve them well and be meaningful to them as I continually strive to offer them better experiences through nursing and respite care. I hope to always look on the positive side of life and never take for granted the things that I hold dear. One mother stated in the interviews,

> It has affected our family life, but in a positive way, it brings us together. Oh yeah, there is always a positive side to it too, and it has helped us recognize the needs around us too. It's a humbling experience to have a special needs child sometimes you see things differently. So, it definitely has a positive side too.
>
> May we as nurses always look on the positive side and strive each day to "see things differently".

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APPENDICES

Appendix A: Supplemental Tables

Table 11
Instruments Used to Measure Impacts of Respite Care

Instrument	Measured Concept	Characteristics and Psychometric Properties
Parenting Stress Inventory- Long Form (Cowen & Reed, 2002) and Short Form (Mullins et al., 2002)	Levels of stress related to the parenting role	• 101 items questionnaire with four subscales of The Child Domain, The Parent Domain, Life Stress, and Total Stress • Combined scores identify families at risk for dysfunctional behavior • Validity established in over 40 studies with parents of children with various disabilities • Not specific to children with disabilities or chronic illness • Reliability indicated by Cronbach's α for various scales of 0.90, 0.93. 0.95, and 0.70; internal reliability also discussed
Development Behavior Checklist (Hoare et al., 1998)	Behavior and emotional disturbances	• Specifically used for children and adolescents with intellectual disability • 96 item checklist for parents to complete • No reliability or validity discussed • No report of use in other studies
General Health Questionnaire (Hoare et al., 1998)	Psychological morbidity within the community	• Subscales include: Somatic, anxiety and insomnia, social dysfunction, and severe depression • Completed by caregivers • Not specific to children with disabilities or chronic illness • No reliability or validity discussed • No report of use in other studies
Robson Self-Esteem Questionnaire (Hoare et al., 1998)	Self-esteem	• Subscales include: Attractiveness, contentment, self-regard, competence, and the value for existence • Not specific to children with disabilities or chronic illness • No reliability or validity discussed • No report of use in other studies
Questionnaire on	Impact of a	• Subscales include: Parent and family,

Resources and Stress (Hoare et al., 1998)	developmentally delayed or mentally retarded child on the family	pessimism, child characteristics, physical incapacitation • No reliability or validity discussed • No report of use in other studies
The Coping Inventory for Stressful Situations (Hoare et al., 1998)	Coping styles in stressful situations	• 48 item questionnaire • Not specific to children with disabilities or chronic illness • No reliability or validity discussed • No report of use in other studies
Pearlin's Measure of Psychological Distress (Meltzer & Johnson, 2007)	Overload in terms of fatigue, burnout, and the relentless nature of caring for a person with a chronic condition	• 4 point Likert scale • Utilized in another study with Alzheimer's patients and two studies with pediatric patients • Cronbach's $\alpha = 0.80$ with internal reliability stated
Langner Screening Inventory for Depression and Anxiety (Meltzer & Johnson, 2007)	Depression and anxiety	• 6 item screening inventory • Only utilized previously with members of a health maintenance organization • Cronbach $\alpha = 0.67$ with internal reliability
Maternal Stress Scale (Meltzer & Johnson, 2007)	Distress related to being a parent	• 7 item scale • Utilized in other populations of children with chronic illness and disability • Not specifically created for use with children with chronic illness or disability • Cronbach $\alpha = 0.89$ with internal reliability
Brief Symptom Inventory (Sherman, 1995; Mullins et al., 2002)	Anxiety, depression, and somatization	• 4 point Likert scale • Not specific to children with disabilities or chronic illness • Cronbach α = ranging from 0.37 to 0.72 for various scales with internal reliabilty • Validity discussed
Impact on Family Scale (Sherman, 1995)	Stress in families of children with a chronic illness	• Subscales include: Financial, social/family, sibling strain, and personalities • 4 point Likert scale • Cronbach's α = ranging from 0.72 to 0.86 for various scales with internal reliability
Functional Ability Scale (Mullins et	Child's ability to engage in various functional	• Utilized previously only with patients with juvenile rheumatoid arthritis

al., 2002)	tasks and activities of daily living	• Cronbach's $\alpha = 0.98$

Table12

Description of Demographic Variables

Quantitative Strand (N=22)

Variable	N	%
Participant Relationship to Child	20	91%
Mother	1	4.5%
Father	1	4.5%
Grandmother		
Participant Race		
Caucasian	20	91%
African American	2	9%
Gender of Child	11	50%
Females	11	50%
Males		
Number of families with other children in the home	12	55%
Partnered – pretest	16	73%
Partnered - posttest	17	77%
Education		
High School Diploma	2	9.5%
Technical or Trade School	1	4.8%
Some College of 2 year Degree	10	47.6%
Bachelor's Degree	5	23.8%
Master's Degree	3	14.3%
Hours of Employment Per Week		
Less than 10 hours	3	14.3%
11-20 hours	2	9.5%
21-30 hours	2	9.5%
31-40 hours	6	28.6%
41-50 hours	5	23.8%
Over 50 hours	3	14.3%
Income		
$10,000-$14,999	1	4.8%
$15,000 - $19,999	2	9.5%
$25,000 - $34,999	1	4.8%
$35,000 - $49,000	3	14.3%

$50,000 - $74,999	5	23.8%
Over $75,000	9	42.9%
First Time to Attend Camp	6	27.3%

Variable	M
Age of Parents	46.6
Age of Child	13.8
Years Since Initial Diagnosis	11.25
Hours Spent Daily Caring for Child	12.7

Table 13

Description of Demographic Variables

Qualitative Strand (n=11)

Variable	N	%
Participant Relationship to Child		
Mother	11	100%
Participant Race		
Caucasian	11	100%
Gender of Child		
Females	5	45.5%
Males	6	54.5%
Number of families with other children in the home	8	72.7%
Partnered	8	72.7%
Education		
High School Diploma	1	9.1%
Technical or Trade School	1	9.1%
Some College of 2 year Degree	4	36.4%
Bachelor's Degree	3	27.3%
Master's Degree	2	18.2%
Hours of Employment Per Week		
Less than 10 hours	2	18.2%
11-20 hours	2	18.2%
21-30 hours	1	9.1%
31-40 hours	2	18.2%
41-50 hours	3	27.3%
Over 50 hours	1	9.1%
Income		
$10,000-$14,999	1	9.1%
$15,000 - $19,999	1	9.1%
$25,000 - $34,999	1	9.1%
$35,000 - $49,000	1	9.1%
$50,000 - $74,999	2	18.2%
Over $75,000	5	45.5%
First Time to Attend Camp	1	9.1%

Variable	M
Age of Parents	44.5
Age of Child	10.4
Years Since Initial Diagnosis	9.8
Hours Spent Daily Caring for Child	12.8

Appendix B: Nursing Research Flyer

Are you excited about Camp?

Is your child enrolled in camp at least 5 days a week?

Are you willing to help?

If so, then I need you!

My name is Brandi Lindsey and I am conducting some research this summer at Camp that will help me learn more about how your child's attendance at camp impacts your family. This research will help me better understand the specific experiences and interventions that occur at camp that help you manage your child's special health care need within your daily life. Your participation in this research is so valuable! If you decide to participate, there are two components that you may be asked to complete:

1. A survey questionnaire at the beginning and end of camp – starting this week!
2. Possibly an interview in the middle of camp– not all participants will be asked to complete the interviews
3. If you complete an interview, you may be briefly observed by the researcher within the camp setting

All of this data will may be used to create better experiences in the future for your child at Camp. Your perspective on your child's special health care need in your family and the experiences at camp will be extremely useful to enhance this program and other camp programs like it in this area.

Interested? Then contact Brandi Lindsey, RN, MSN, CPNP, PhD I at 615-812-1724

Appendix C: Exclusion Criteria Form

Eligibility criteria for participation in the research study

1. Is your child enrolled in camp at least 5 days a week?
2. Is your child between the ages of 6 and 25?
3. Do you live in the same house as your child that is attending camp?
4. Do you speak English?
5. Does your child have a special health care need that puts them at risk for a chronic physical, developmental, behavioral, or emotional condition that requires additional health services?
6. Has your child recently been diagnosed with a terminal illness such as cancer?

If you answered yes to questions 1-5 and no to answer 6, then you are eligible to participate!

Appendix D: Pretest Demographic Questionnaire

Supplemental form to the Family Management Measure questionnaire

What is your child's special health care need at time of Camp Ability?_____

How old is your child that is attending Camp Ability?

Has your child been recently diagnosed with a terminal illness, such as cancer?_____

How long has your child been diagnosed with the special health care need?_____

Is this your first time to attend Camp Ability?_____ If no, how many times have you attended previously?_____

What is your age?_____

Are you currently living with a spouse or partner in the same house as your child?_____

How many other children are living in the same home?_____

What are the ages of the other children in your home?_____

Do you and/or your child participate in any other respite care activities?_____

Appendix E: Posttest Demographic Questionnaire

How many hours a day on average do you spend caring for your child?

Education

What's the last educational experience you had? Was it:

1 No Formal Schooling	2 Completed 8th grade or less	3 Some High school
4 High School graduate	5 GED	6 some college or 2 yr degree
7 Technical or trade school	8 Bachelor's degree	9 Graduate or Professional

Employment

In an average week during the past few months, how many hours per week do you work? If you stay at home, how many hours does your partner/spouse work?

0-10 hrs 11-20 hrs 21-30 hrs 31-40 hrs 41-50 hrs Over 50 hrs

Income

Thinking about your income and the income of everyone who lives in your household, what was your total household income before taxes in the past 12 months?

Under $5,000	1
$5,000 to $9,999	2
$10,000 to $14,999	3
$15,000 to $19,999	4
$20,000 to $24,999	5
$25,000 to $34,999	6
$35,000 to $49,999	7
$50,000 to $74,999	8
Greater than $75,0000	9

Appendix F: Sample of Guided Interview Questions

Sample of the Guided Interview Questions

- How has your child's condition affected your daily life? Your family life? Your social life?
- What are some things that help you manage your child's condition within your family?
- How does the camp help you better manage your child's condition?
- Are there certain experiences at the camp that impact your ability to care for your child's special health care needs?
- How does the camp help you better manage your family?
- What are some specific things that occur at the camp that help you view your child's special need in a different way?
- How does the camp affect your family when camp is over?
- Is there anything else you would like to tell me about how the camp has affected your child and family's ability to manage your child's special needs?
- How does managing your child's condition create stress in your family?
- What aspects of camp help alleviate the stress surrounding caring for your child?

Appendix G: Coding Sheet

Coding Sheet

Family-Child Categories	Family-Child Themes	Camp – Child Categories	Camp – Child Themes	Camp – Family Categories	Camp – Family Themes
Complete Life Change **-** Life is not what she expected **-** Dramatic life change – taking care of child (13, 20, 21, 23, 28, 18) - Los of what they once had (21, 22) -Family dream shattered (21, 22, 18) - Effects everything within the family (13, 15, 16, 20, 21, 22, 23, 28) - Everyday tasks are difficult (22, 23, 28) - Life changing to give up career to take care of child (15, 23, 28) - Child's condition has become reality (15, 21) - Life is monotonous – loss of normalcy (16, 23) - Must have same routine (all) - Mom hates the routine – loss of	**Loss of Normalcy** **Loss of Normalcy**	**Catered to Child's Needs** - Socialization is most important (3, 13, 15, 20) - In home sitters do not give her socialization (9) - Requires one on one activity (13) - Child is tired from all activities; has social needs met (13) - Child needs routine (all) - Child needs socialization (all) - Inability to stay at home during the summer (21, 15, 16, 20, 28) - Counselors have high energy to care for child (22, 23) **Enjoyment** - Child enjoys camp (3, 9, 28) - Child needs socialization (3, 9, 13, 15, 20, 21) - Child remembers camp throughout the year (3, 28) - Excitement	**Meets Individual Needs** **Creates Happiness**	**Enjoyment from Seeing Child Participate in Camp** - Family enjoys talking to child about what he does at camp (3, 21, 22) - Family enjoys seeing child be excited (3, 23) - Mom enjoys seeing the changes (13, 15, 21, 23, 28) - Growing independence / maturity excites mom (13, 15, 23) - Camp gives him new experiences (15, 23) - Enjoys discussing Bible stories with child (21, 22) - Enjoys seeing child do "typical" things (28) **Camp Decreases Stress** - Unsure of what they would do if they didn't have camp (3, 22)	**Improved Perception of Child** **Decreased stress**

fun and normalcy (16) - Taking care of child is their life (20, 23, 28) - Let go of "normal" dream (22, 18) - Mom must do everything for child (28) **Initial Encounter – Adjustment Period** **-** Manage better over time (9, 21, 20, 22, 23, 18) - Initially thought the problems were temporary (9) - Parents not prepared to care for a long term disability (9) - Have gotten better at managing over time (13) - Stressful at first, then learned to work together (13, 23) -The first year of life was chaotic-unsure of diagnosis created stress (13, 16, 23) - Tried numerous treatments and doctors (13, 16) - Financial stress (13, 23) - First year – really bad (13)	**Loss of Normalcy** **Loss of Normalcy**	about camp (3, 20, 21, 28) -Loves camp 166cc coo of activities and getting to go somewhere (3, 9, 13, 15, 23, 28) - Camp makes mom and child happier (3, 13, 20, 21, 23) - Camp provides her with activities to do, enjoys Bounce U, swimming, enjoys being with other kids (9, 20, 21) - Camp keeps child busy (20, 21, 28) After camp, she is glad to be home (13) - Camp gives more friends and increases his skills (15, 20, 21) - Camp gives child purpose (16) - Child is able to succeed at camp (21) **Parents See Specific Improvements** - Increased independence with camp activities (3) - Mom is amazed at certain things child does at	**Behavior Changes** **Behavior Changes** **Behavior Changes**	- Camp alleviates stress for family (3, 9, 20, 21, 22, 23, 28) - Thankful for camp (3) - Camp helps them manage(9, 20, 22, 23, 28) - Mom very happy when child old enough for camp (13) - Summers are stressful because the child is at the house more, lack of sleep (13, 21) - Alleviates stress to get things accomplished at home (13, 20, 21, 22, 23) - Camp provides time for mom to relax and be quiet (13, 15, 20, 23, 18) - Camp helps alleviate guilt burden (13, 22, 23) - Camp is wonderful (13, 20, 21, 18) - Camp provides them with good memories (15, 23) - Loss of routine when school is out (16, 21) - Camp alleviates the stress of finding something for child to do (16) - Provides time	**Improved Perception of Child**

- Unexpected changes (15, 18) - Unexpected outcome with pregnancy (15) - Felt thrown into the world of special needs (15) - Sink or swim mentality (15) - Not knowledgeable about special needs before (15) - People disappeared from their life (16, 23) - Mom finally accepted diagnosis (16) Acceptance – then living with the diagnosis – (16) **Constant Changes in Child's Behavior** - Constantly working on issues (3, 23, 28, 18) - Medication changes common (3, 23, 28) - Medications regulated (3) - Medications are helpful (3, 23) - Life is constantly changing (15, 23, 28) - Interruption in routine causes	**Loss of Normalcy** **Loss of Normalcy** **Increased Stress**	camp (3, 13) - Mom values lifestyle activities at camp (3) - Child learns from activities at camp (3, 23, 18) - Certain behaviors are improving from camp (13, 20, 21, 22, 23) - Emotional and social improvements (23) **Behavior at Camp vs Behavior at Home** - Does more things in a group setting than at home (3, 15) - Does not respond as well to activities at home initiated by mom (3, 21, 28, 18) - Child acts different at camp than at home (13, 21, 28, 18) - Performance at camp allows mom to expect other things from the child (13, 20, 18) - No change in behaviors at home from camp (16, 18)		for mom to get part time job (23, 18) **Change in Parent Perspective** - Changes mom's view of what child can do (broadens view) (3, 15) - Mom does have a different perspective when she sees children worse off than her child (9, 15, 20) - Allows her to view her child in a different way (13, 15, 18) **Need for Communication with Other Parents** **-** Talking to other moms at camp helps (15, 21, 22, 23) - Being friends with moms with special needs kids benefits mom (15, 21) - Feelings are validated (21) - Learns from others at camp (23) - Desires more opportunities for communication with other parents(22) **Increased Time**	**Decreased Stress** **Decreased Stress**

child to throw a fit (16) - Inability for child to wait (3,16) - Mom feels like she is “on call” (28) **Care of Child Increase Stress in Family** - Loss of normalcy (3, 15, 21, 22, 23, 18) - Stressful situations within family (3, 20, 22, 23, 28, 18) -Concern about child’s abilities in the future (9) - Worried about child because nonverbal (9, 21) - Difficult meeting the needs of all the children in the home during the summer (13, 22, 18) - Caring for a special needs child is stressful (all) - Constant battle with insurance and education (15) - Mom feels she has to constantly be on top of the teachers at school with the IEP (15) - Mom unable to sleep(15) - Stressful on	**Loss of Normalcy** **Loss of Normalcy** **Increased stress**			**for Other Activities** - Camp allows mom to do other things at home (3, 13, 21, 22, 23) - Camp allows mom to interact with friends (3) - Free time for mom makes her happy (3) - Mom is able to do things with the other children while child is at camp (13, 20, 21) - Other children have done lots of activities they have never done before since child is at camp (13) - Mom is unable to do certain activities with the other children when she is with child (13) - Other children have had the best summer, Mom and two other children have been together during the summer (13) - Mom and Dad are able to spend time together in the summer because of camp (15) **Decreased Financial Burden**	**Decreased Stress**

marriage due to work schedule (15) - Mom must anticipate child's needs to prevent frustration (16, 23) - Mom must divide time between children (21, 20, 22, 18) - Issues with adolescent period (3) - Worsening behaviors (3) - Adolescence is difficult time (3) - Child more defiant (3) - Mom unable to lift child and provide total care (15, 20) **Loss of Time with Other Children** **-** Mom is unable to do certain activities with the other children when she is with child (13, 22) - Affects other children in the home (20, 22) - Other children are neglected (21, 22) - Other family members are unwilling to help (28)	**Relationships Affected** **Loss of normalcy** **Loss of normalcy** **Increased Stress**			- Camp is affordable (3, 13, 15, 22, 23) - Camp is affordable, less expensive than a sitter (9, 13) **Increased Hope** - Camp makes a big difference in family life (3, 23) - Performance at camp allows mom to expect other things from the child (13, 23) - Plan to send child to camp as long as possible (15, 23) - Offers hope for the future (23) **Need for Communication with Counselors** - Mom is unaware of certain things that occur at camp (3, 16, 20) - Mom unsure if child gets one on one care - Mom worries about them watching movies bc of short attention span (9) - Mom is unaware what child does during movie time (9) - Mom enjoys getting reports from counselors	**Parent Involvement with Staff** **Need for Specific Environment**

Family Dream Shattered - Recognizes that she does have dark times (15) - Loss of fun for family (16) **Complicated Life** - Life is a challenge with child (3, 15, 20, 21, 22, 23, 28, 18) - Parents have to help with all ADLs (9, 15) - Family already has a very busy lifestyle (9) - Life is challenging and exhausting (15, 16, 23, 23, 18) - No change in home routine while at camp (16, 28) **Loss of Previous Lifestyle** - Family is limited to what they can do together (3, 20, 22) - Difficult to go to church together (3, 22) - Very strict schedule (16) - Everything in family revolves around child's needs (16, 20, 21, 22, 23, 18) - Will never be like it was before	**Loss of normalcy** **Relationships Affected** **Loss of normalcy** **Family Adaptations** **Relationships Affected**			(13, 28) - Counselors listens to mom's needs for child (21, 23, 28, 18) - Counselors "counsel" mom (23) - Counselors create activities based on the child's needs (21, 28, 18) - Consistency of counselors **Camp Environment** - Child has routine at home – gets bored (3, 15, 16, 21, 18) - Need for organized activities for the child (3, 15, 16, 21, 23) - Child does more things at camp he would not do at home (3, 15, 21) - Hesitant at first to let child participate in all activities (3) - Camp director encouraged mom to participate with child in activities (3) - Mom feels safe about camp activities (3, 21, 23) - Other camps didn't give what	**at Camp** **Need for Specific Environment at Camp**

(21) - Does what works for her family – (22) - Divorce as a result of caring for child – (28) **Chaos at Home** - Child has behavior problems within family (3, 21, 22, 23, 18) **Family Limitations** - Family is limited to what they can do together (3, 20, 28) - Must adapt to child (3, 20, 21, 22, 23, 28) **Parent Isolation** **-** Parents feel isolated at gatherings (9) - Parents feel isolated from friends (9, 16, 23, 28) **Outside World Perspective of Family** - Needs other to be accommodating to child's condition (3) - Others are curious about child (15) - Mom and dad feel he is a ministry to tell	**Relationships Affected** **Relationships Affected**			she needed (9) - Other camps don't have as many activities as this camp (9) - Mom desires after school program like camp (9) - Other places are not equipped to handle special needs children like camp (9, 21, 22) - Mom notices the counselors play with her a lot (13, 18) - Mom appreciates the one on one time with the counselors and her child (13, 22, 23, 18) - They do things the child likes (13, 23) - Family has peace of mind from camp (13, 20, 21, 23) - Camp is a loving environment (15, 23, 18) - Camp is different from school because of the love and positive attitude (15, 21, 22, 23) - They focus more on what child can do, not what he can't do (15, 21, 23) -Counselors give	**Need for Specific Environment at Camp**

others about God (15) -Stares from others (15) - Unable to cope with stares some days (15) - Sense of educating others (15) - Others don't understand (15, 16, 22, 23) - Others don't see the hard parts of caring for child (15, 22, 23) -Others perceive them as different (15, 23) - Confused by diagnosis (16) **Other Children in Family Affected** - Older child may not be able to do certain things because of child (3) - Older daughter may get upset (9) - Other children don't understand what child can and can't do (9, 21, 18) - Stress comes out with anger in family at times (9, 22, 18) - Siblings do not get along (22) **Peer Relationships**	**Increased Stress** **Relationships Affected** **Increased Stress** **Increased Stress**			encouragement to child (23) - Teaches child how to behave (23) - Importance of having fun (15) - Learns life skills (20) - Bible stories (20, 22) - Art (20) - Parents trust counselors (20, 21, 22, 23, 18) - Has specific sensory games, equipment at camp (21) - Camp is all about the children (21, 22, 23) - Counselors are specially trained (23, 28, 18) - Counselors genuinely love the children (18)	

Affected **-** Child's condition affects relationships with other families (9) - Makes it difficult for parents to socialize (9, 28) **Work Relationships Affected** **-** Mom gave up job to care for child (15, 23, 28) - Loss of corporate job Mom and Dad decided together who would quit work (15) - Mom gave up career, education (15, 23) - Inability to work (23, 28) **Extreme Need for Sitters** - Seeks assistance from sitters (3, 13, 23, 28) - Finds sitters on vacation and other times so they can do certain things without child (3, 13) - Mom has to have help during	**Increased Stress** **Increased Stress** **Increased Stress**				

the summer (3, 20, 21, 22) - Parents have some outside help (9, 22) - Difficult to ask for help -Reliance on friends, family, and church (13, 22, 23) - Realization that they need help as a family (13) - Cannot put child in daycare (15) - Sitter must be trustworthy and safe (23, 22)					
Inability to Find help - Difficulty finding help (3, 22, 28, 18) - Difficulty finding a sitter (9, 20, 28) - Have to be able to trust the sitter (9) - Feelings of desperation (22)	**Increased Stress**				
Financial Burden - Financial changes life changing (15, 23, 28) - Currently living on teacher's salary – one income (15) - Dad has additional jobs to pay for care (15)	**Family Adaptations**				

- Increased stress from living on one income (15) - There is significant financial burden (15, 22, 23, 18) - Mom considered getting a part time job (15, 23) - Financial impact due to rising costs (15) - Therapies are expensive (21) - Broken items from bad behavior (21) - Sitters are expensive (22)	**Increased Stress**				
Parental Sense of Guilt - Family feels like they can't always meet her needs; Child needs lots of interaction and high energy activities (13, 22, 23 - Mom unable to give all things to child bc mom has other responsibilities (housework, etc) (13, 23 - Sense of guilt that family can't meet all of child's needs (13 - Child must participate in activities in order to be happy (13, 15, 20, 21, 22, 28	**Family Adaptations**				

- Stressful having to discipline other children because of child (18) **Parents' Need for Breaks** **-** Parents spend time by themselves to help cope (9, 22, 18 - Understand that they need breaks from caring for child (13, 15, 22, 18 - Mom and dad give each other breaks from childcare as needed (13, 20 - Extra Sleep (15 - Parents miss having alone time - Very little time to rest with parenting (22 **Coping** - Talking to other moms at camp helps (15, 23 - Being friends with moms with special needs kids benefits mom (15 - Goes out to lunch with the moms (15 - Involved in Christian ministry for special needs parents (15	**Family Adaptations** **Family Adaptations** **Family Adaptations**				

- Mom needs to "vent" sometimes (15 - Spiritual influences, venting, and massage help mom cope (15 - Involved in social media (15 - Massage (22, 15 - Spends time with friends (20, 18 **Constant Care of Child** **-** Parents have to constantly be focused on child (9, 23, 28 - Child can't be left unattended (9 - Parenting feels like a job (16, 22, 28, 23, 28, 18 - Mom takes on the burden of care (28) **Making Time for Each Child** - Does things as a family w/o child to meet needs of the family (3 - Parents allot time for each child (9, 13, 20, 21 - Child is jealous of parents spending time with other children (13 - Mom and dad work together to	**Family Adaptations** **Family Adaptations** **Family Adaptations**				

spend time with each child (13 - Can't do things with both parents with each child (13 - Does not discuss issue with other children (21 - Different parenting techniques with each child (21, 22 - Uses the situation to teach other children about serving and God (21 **Desire to be Together as a Family** - Seeks out activities to do as a family (3, 23 - Seeks out activities that work for them (3 - Mom finds things that child likes to do (3, 22,23 - Seeks out trips that the whole family can do together (3 - Seeks out opportunities for H to participate with family (3 - Family values doing things that child can do with them (3 **Family Must Work Together**	**Love for the Child** **Love for the Child**				

- Family must work together (3, 13, 20, 22 - Decisions are made together (3 - Family modifies activities to make him happy (3 - Mom and dad work together to share responsibilities (9, 20 - Difficult for one parent to care for all children by themselves (9, 20 - Important to share responsibilities (9, 20 - Mom unsure how single parents are able to manage (9 **Positive Influence** - Family is closer because of child's condition (3, 13, 15, 20) - Child's condition has positive effect on family (3, 20) - Mom tries to find the positive aspects (3, 21, 23) - Allowed to see things from another viewpoint (3) - Focus on the positive aspects (3) - Learned to appreciate things	**Love for the Child** **Family Adaptations** **Love for the child** **Family Adaptations** **Love for the Child**				

more (13) Family doesn't take things for granted (13 - Always try to focus on child and loving him (15) - Gained patience **Seeking Optimism** - Family is aware of others' needs (3) - Family has learned from experience (3) - Mom understands the child tries to behave normally (3) - Mom reports not a lot of stress in the family because of child (9) - Grateful that he is alive at all (15) - Mom notices other typical children, but doesn't compare child to other children (15) - Strong support systems (15) **Family Adaptation to Child** - Family must adapt and change to child's needs (3, 16) - Family makes	**Family Adaptation**				

adjustments to sleep schedule to accommodate child (13) - Adjustments made to house to accommodate child (13, 16, 28) - Everything is childproofed (13, 28) - Family rearranged schedules for therapies (13, 28) - Child's needs come first (21, 22, 23, 28) **Need for Spiritual Influences** **-** Prayer (15, 21, 22, 23) - Sense of God's will for the family (15, 21) **Utilization of Outside Resources** - Use of professional resources for help (3, 13, 21, 22, 23, 28, 18					

Appendix H: Camp Facility Approval Letter

changing hv s througn Jews Chris

April 29, 2014

To Whom It
May Concern,

Brandi' Lindsey has been approved to conduct research at

Camp during our 2014

season.

Camp Director

Appendix I: ETSU Informed Consent Letter for Participants

PRINCIPAL INVESTIGATOR: Brandi Lindsey

TITLE OF PROJECT: Therapeutic Camps and their Impact on the Family of Children with Special Health Care Needs: A Mixed Method Study

EAST TENNESSEE STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
INFORMED CONSENT DOCUMENT

PRINCIPAL INVESTIGATORS: Brandi Lindsey, RN, MSN, CPNP, PhD(c), Doctoral student, Dissertation Advisor: Dr. Masoud Ghaffari

TITLE OF PROJECT: Therapeutic Camps and their Impact on the Family of Children with Special Health Care Needs: A Mixed Method Study

This Informed Consent will explain about being a participant in a research study. It is important that you read this material carefully and then decide if you wish to be a volunteer.

PURPOSE:

The purpose of this study is to understand how respite care in the form of a therapeutic summer day camp for children with special needs impacts a family's ability to manage their child's special health care need. This research will identify any specific interventions or experiences at the camp that assisted parents in improving their perspective of the child's condition on their family life and ability to function as a family The findings from the study will be used to develop specific interventions or create

experiences at therapeutic camps that camp organizers can use to promote positive family outcomes and improve family management styles.

DURATION

The study will be ongoing throughout the duration of the summer camp. Participants will complete one survey at the beginning of the camp, and they will complete one survey at the end of the camp. The survey has 45 questions for non partnered parents and 53 questions for partnered parents. This survey will take approximately 15-20 minutes.

Some participants may be asked to participate in an interview that will be audio recorded that will occur about 4-6 weeks after camp has started. These interviews will last approximately 45 minutes to 1 hour. After the interviews towards the end of camp, some participants that participated in interviews may be asked to be observed for a short period of time as they engage in certain experiences and/or interventions within the camp setting.

PROCEDURES

You will be asked to complete one survey at two different time periods and possibly participate in an interview that will be audio recorded. Those participating in the APPHOVED interview procedure may possibly be briefly observed in the camp setting as they intedbt[1]hc ETSl[1] ,.,,1R1(with their child co unsel rs, other parents etc. t:A· . . B_t · ugh 17 wi ll ha / 11 //JM

MAY 9- 9 2015

Appendix J: ETSU Informed Assent

PRINCIPAL INVESTIGATOR: Brandi Lindsey

TITLE OF PROJECT: Therapeutic Camps and their Impact on the Family of Children with Special Health Care Needs: A Mixed Method Study

EAST TENNESSEE STATE
UNIVERSITY INSTITUTIONAL
REVIEW BOARD RESEARCH
ASSENT DOCUMENT

What is a research study?

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about our research and the choice that you have to take part in it. We want you to ask us any questions that you have. You can ask questions any time.

Important things to know...

- You get to decide if you want to take part.
- You can say 'No' or you can say 'Yes'.
- **No one will be upset if you say 'No'.**
- If you say 'Yes', you can always say 'No' later.
- You can say 'No' at anytime.
- We would still take good care of you no matter what you decide.

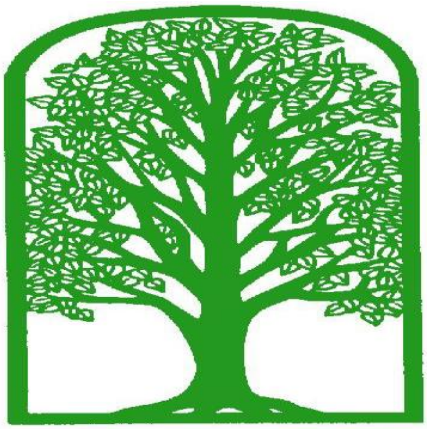
Why are we doing this research?

We are doing this research to find out more about Campo Ability and how it helps you and your family.

(J) What would happen if I join this research?

We might watch you do some things at camp that you enjoy doing with your parents or your friends to learn more about what helps you and your family at camp.

Appendix K: Family Management Measure



FAMILY MANAGEMENT MEASURE

Kathleen Knafl, PhD Janet Deatrick, RN, PhD Agatha Gallo, RN, PhD Jane Dixon, PhD Margaret Grey, RN, PhD

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FAMILY MANAGEMENT MEASURE

This questionnaire is about how your family manages caring for a child with a chronic condition.

INSTRUCTIONS

For each statement in this questionnaire, you are asked to rate your response to the statement on a scale of 1 to 5, with 1 indicating "Strongly disagree" and 5 indicating "Strongly agree". Please respond to each statement in this questionnaire based on what you think, not on how you think others might respond. If your child has more than one chronic condition the word "condition" refers to all of their diagnoses together. Also, many of these questions use the word "family". This refers to those people living in your household that you think of as family.

Section 1: to be completed by everyone Please check the boxes with your answers.

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**
1. Our child's everyday life is similar to that of other children his/her age.					
2. Our child's condition gets in the way of family relationships.	☐	☐	☐	☐	☐
3. Our child's condition requires frequent visits to the clinic.	☐	☐	☐	☐	☐
4. In the future we expect our child to take care of the condition.	☐	☐	☐	☐	☐

5. Our child enjoys life less because of the condition.					
6. Taking care of our child's condition is often overwhelming.					
7. Our child's condition is like a roller coaster with lots of ups and downs.					

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**
8. Our child's condition is the most important thing in our family.					
9. It is very hard for us to take care of our child's condition.					
10. Our child takes part in activities he/she wishes to despite the condition.					
11. Because of the condition, we worry about our child's future.					
12. Our child's condition doesn't take a great deal of time to manage.					
13. We have some definite ideas about how to help our child live with the condition.					
14. Despite the condition, we expect our child to live away from home in the future.					
15. We have enough money to manage our child's condition.					
16. Our child is different from other children his/her age because of the condition.					

17. It is difficult to know when our child's condition must come first in the family.					
18. We are looking forward to a happy future with our child.					
19. When something unexpected happens with our child's condition, we usually know how to handle it.					
20. Our child's friendships are different because of the condition.					

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**
21. We expect to be devoting less time to our child's condition in the future.					
22. A condition like the one our child has makes family life very difficult.					
23. Our child's condition rarely interferes with other family activities.					
24. Our child's condition requires frequent hospital stays.					
25. We feel we are doing a good job taking care of our child's condition.					
26. People with our child's condition have a normal length of life.					
27. It's often difficult to know if we need to be more protective of our child.					
28. We often feel unsure about what to do to take care of our child's condition.					

29. Our child's condition will be harder to take care of in the future.					
30. We think about our child's condition all the time.					
31. It seems as if our child's condition controls our family life.					
32. Many conditions are more serious than our child's.					
33. It is hard to get anyone else to help us with our child's condition.					
34. We have not been able to develop a routine for taking care of our child's condition.					

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**
35. It takes a lot of organization to manage our child's condition.					
36. We are sometimes undecided about how to balance the condition and family life.					
37. It is hard to know what to expect of our child's condition in the future.					
38. Even though our child has the condition, we have a normal family life.					
39. Our child would do better in school if he/she didn't have the condition.					
40. We are confident that we can take care of our child's condition.					

41. We have goals in mind to help us manage our child's condition.					
42. It is difficult to fit care of our child's condition into our usual family routine.					
43. Dealing with our child's condition makes family life more difficult.					
44. We know when our child needs to be a child.	☐	☐	☐	☐	☐
45. A condition like the one our child has makes it hard to live a normal life.	☐	☐	☐	☐	☐

This ends Section 1.

If you currently have a partner, please proceed to the next page. If you do not have a partner, please stop here.

Section 2

The questions in the next section relate to you and your partner. For each statement in this section, rate your response to the statement on a scale of 1 to 5, with 1 indicating "Strongly disagree" and 5 indicating "Strongly agree". Again, please respond to each statement in this questionnaire based on how YOU feel, not on how you think your partner or others might respond.

	Strongly Disagree **1**	**2**	**3**	**4**	**Strongly Agree** **5**

46. We are a closer family because of how we deal with our child's condition.					
47. My partner and I have different ideas about how serious our child's condition is.					
48. I am pleased with how my partner and I work together to manage our child's condition.					
49. My partner and I argue about how to manage our child's condition.					
50. My partner and I consult with each other before we make a decision about our child's care.					
51. My partner and I have similar ideas about how we should be raising our child.					
52. I am unhappy about the way my partner and I share the management of our child's condition.					
53. My partner and I support each other in taking care of our child's condition.					

Appendix L: Scoring Instructions for FaMM

Scoring Instructions for the FaMM

The FaMM questionnaire has two sections. The items from Section 1 are answered by all parents and are used to calculate five scales: Child's Daily Life, Condition Management Ability, Condition Management Effort, Family Life Difficulty, and View of Condition Impact. The items from Section 2 are answered only by parents who have adult partners in the household and are used to calculate a sixth scale: Parental Mutuality. Item numbers are given by the order in which they are listed on the FaMM questionnaire. Reverse coded items are indicated with an asterisk.

Calculation of Scale Scores and Scoring Template

Follow these steps to compute the FaMM scales.

1. Determine the number of items in a scale with valid responses (i.e., values of 1-5).
2. Compute a scale score from the valid responses as instructed in steps 3-7, **but only if at least seventy percent of the items for that scale have valid responses** (minimum numbers for the scales are provided below). If less than 70% of the items are answered, the scale cannot be computed.
3. Reverse code the negative item responses (indicated by asterisks) by subtracting those item responses from the value 6.
4. Sum the positive item responses and the reverse coded negative item responses.
5. Divide by the number of valid responses.
6. Multiply by the total number of items for the scale.
7. Round to the nearest integer.

Scoring Template

Download the scoring template here (.xls format)

Child’s Daily Life Scale

This scale addresses parents’ perception of the everyday life of the child. Higher values indicate more normal life for the child despite the condition.

1. Our child’s everyday life is similar to that of other children his/her age.
10. Our child takes part in activities he/she wishes to despite the condition.
5. *Our child enjoys life less because of the condition.
16. *Our child is different from other children his/her age because of the condition.
20. *Our child’s friendships are different because of the condition.

Total number of items = 5.
Minimum number of valid responses required to compute the scale score = 4.

Condition Management Ability Scale

This scale addresses parents’ perception of their ability to manage their child’s condition. Higher values indicate that the condition is viewed as more readily manageable.

4. In the future we expect our child to take care of the condition.
13. We have some definite ideas about how to help our child live with the condition.
14. Despite the condition, we expect our child to live away from home in the future.
15. We have enough money to manage our child’s condition.
18. We are looking forward to a happy future for our child.
19. When something unexpected happens with our child’s condition, we usually know how to handle it.

25. We feel we are doing a good job taking care of our child’s condition.

41. We have goals in mind to help us manage our child’s condition.
17. *It is difficult to know when our child’s condition must come first in our family.
27. *It’s often difficult to know if we need to be more protective of our child.
28. *We often feel unsure about what to do to take care of our child’s condition.
34. *We have not been able to develop a routine for taking care of our child’s condition.

Total number of items = 12.
Minimum number of valid responses required to compute the scale score = 9.

Condition Management Effort Scale

This scale addresses parents’ perception of the time and work required to manage their child’s condition. Higher values indicate more time and work expended in managing the illness

3. Our child’s condition requires frequent visits to the clinic.
7. Our child’s condition is like a roller coaster with lots of ups and downs.
35. It takes a lot of organization to manage our child’s condition.
12. *Our child’s condition doesn’t take a great deal of time to manage.

Total number of items = 4.
Minimum number of valid responses required to compute the scale score = 3.

Family Life Difficulty Scale

This scale addresses parents' perception of the extent to which their child's condition makes their life difficult. Higher values indicate more difficulty in dealing with the condition.

2. Our child's condition gets in the way of family relationships.
6. Taking care of our child's condition is often overwhelming.
9. It is very hard for us to take care of our child's condition.
22. A condition like the one our child has makes family life very difficult.
31. It seems as if our child's condition controls our family life.
33. It is hard to get anyone else to help us with our child's condition.
36. We are sometimes undecided about how to balance the condition and family life.
39. Our child would do better in school if he/she didn't have the condition.
42. It is difficult to fit care of our child's condition into our usual family routine.
43. Dealing with our child's condition makes family life more difficult.
45. A condition like the one our child has makes it very difficult to lead a normal family life.
23. *Our child's condition rarely interferes with other family activities.
38. *Even though our child has the condition, we have a normal family life.
44. *We know when our child needs to be a child.

Total number of items = 14.
Minimum number of valid responses required to compute the scale score = 10.

Parental Mutuality Scale

This scale is calculated from the items in Section 2 of the FaMM questionnaire, answered only by parents with an adult partner living in the home. It addresses parents' satisfaction with how the couple works together to manage their child's condition and their perception of the degree to which

they receive support from their partner and share views on the management of their child's condition. Higher values indicate that the condition is viewed as more readily manageable.

46. We are a closer family because of how we deal with our child's condition.
48. I am pleased with how my partner and I work together to manage our child's condition.
50. My partner and I consult with each other before we make a decision about our child's care.
51. My partner and I have similar ideas about how we should be raising our child.
53. My partner and I support each other in taking care of our child's condition.
47. *My partner and I have different ideas about how serious our child's condition is.
49. *My partner and I argue about how to manage our child's condition.
52. *I am unhappy about the way my partner and I share the management of our child's condition.

Total number of items = 8.
Minimum number of valid responses required to compute the scale score = 6

View of Condition Impact Scale

This scale addresses parents' perception of the seriousness of the condition and its implications for the future. Higher values indicate a higher level of concern about the condition.

8. Our child's condition is the most important thing in our family.
11. Because of the condition, we worry about our child's future.
24. Our child's condition requires frequent hospital stays.
29. Our child's condition will be harder to take care of in the future.
30. We think about our child's condition all the time.
37. It is hard to know what to expect of our child's condition in the future.

21.*We expect to be devoting less time to our child’s condition in the future.
26. *People with our child’s condition have a normal length of life.
32. *Many conditions are more serious than our child’s.
40. *We are confident that we can take care of our child’s condition.

Total number of items = 10.
Minimum number of valid responses required to compute the scale score = 7.

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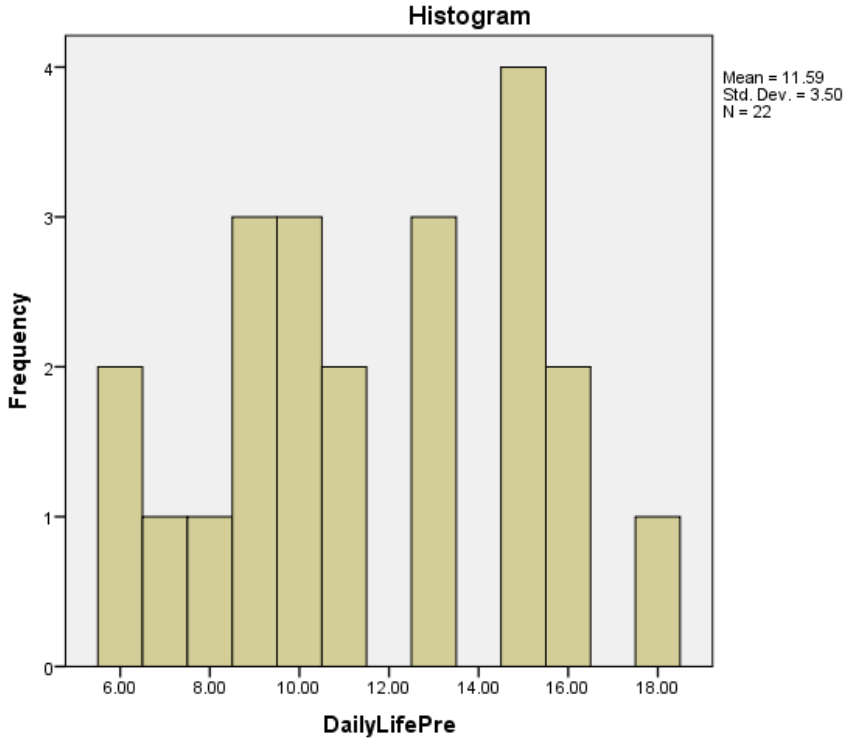
Appendix M: Histograms, Skewness, and Kurtosis

Tests of Normality

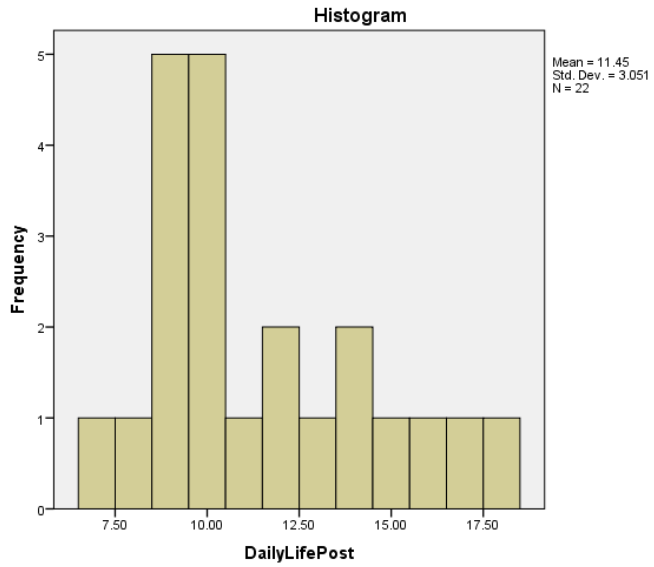
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
DailyLifePre	.153	22	.196	.950	22	.319
DailyLifePost	.229	22	.004	.914	22	.057
CMAPre	.146	22	.200*	.976	22	.835
CMAPost	.144	22	.200*	.977	22	.857
CMEPre	.147	22	.200*	.948	22	.290
CMEPost	.197	22	.027	.919	22	.073
LifeDiffPre	.108	22	.200*	.969	22	.685
LifeDiffPost	.112	22	.200*	.978	22	.875
PMPre	.245	15	.016	.769	15	.002
PMPost	.242	17	.009	.799	17	.002
ImpactPre	.156	22	.172	.956	22	.417
ImpactPost	.143	22	.200*	.960	22	.499
DailyLifeDifference	.155	22	.184	.947	22	.278
CMADifference	.142	22	.200*	.927	22	.106
CMEDifference	.204	22	.018	.919	22	.074
LifeDiffDifference	.086	22	.200*	.988	22	.993
PMDifference	.136	15	.200*	.961	15	.712
ImpactDifference	.118	22	.200*	.959	22	.478

*. This is a lower bound of the true significance.

DailyLifePre



DailyLifePost



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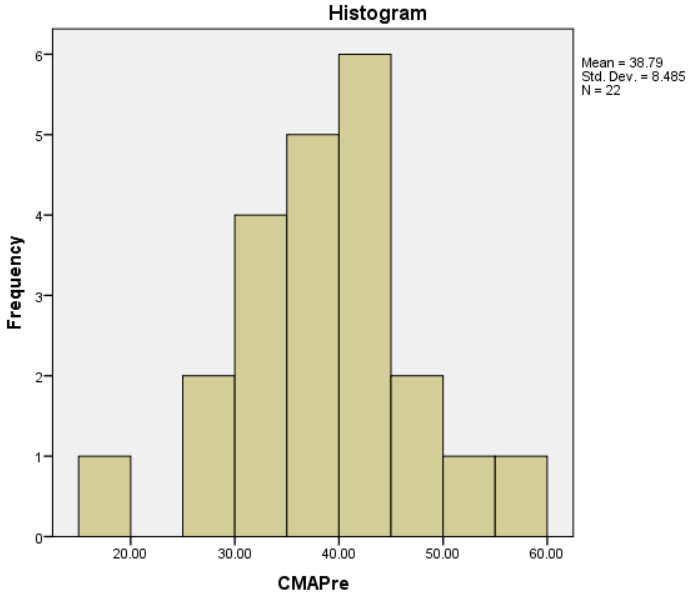
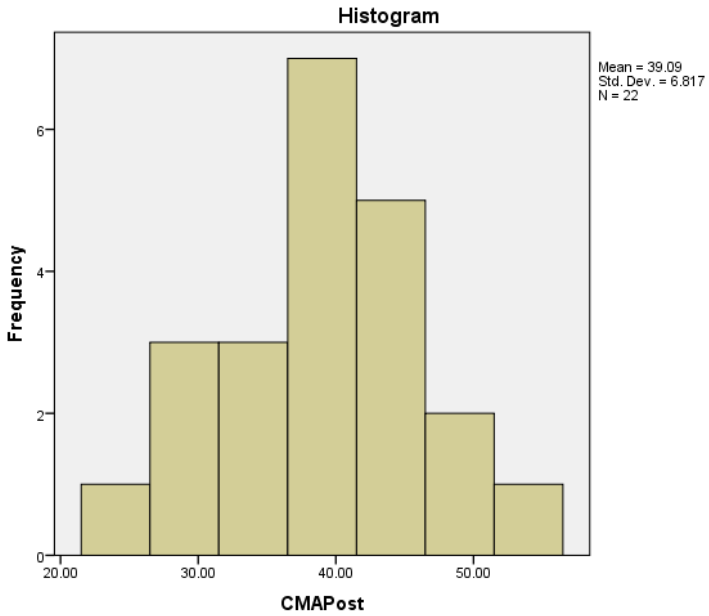
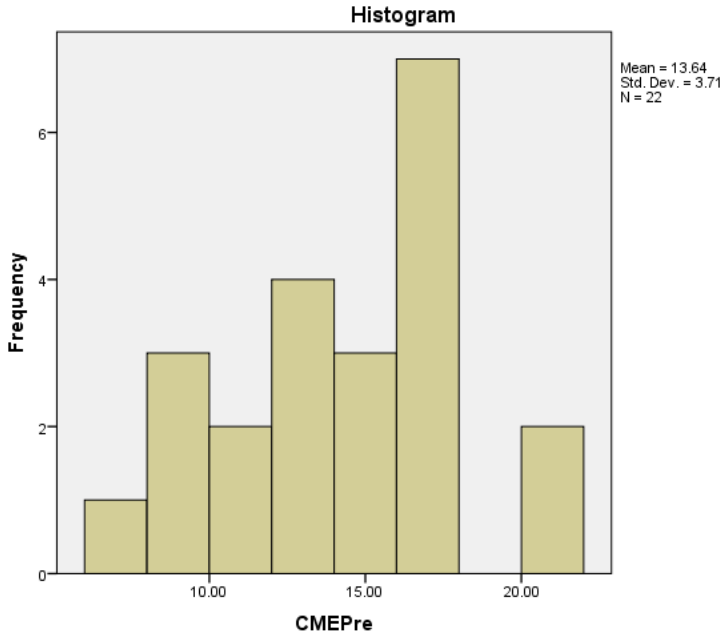


CMAPost



CMEPre



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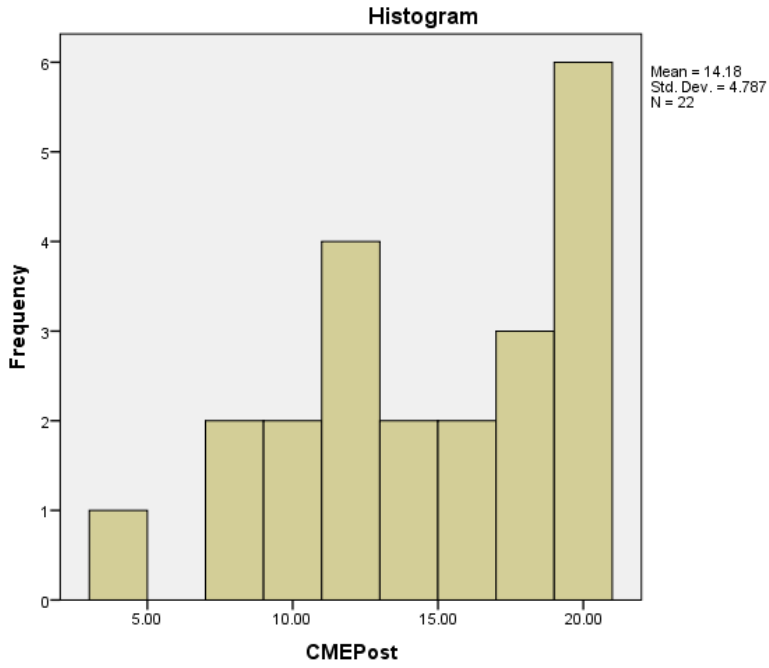

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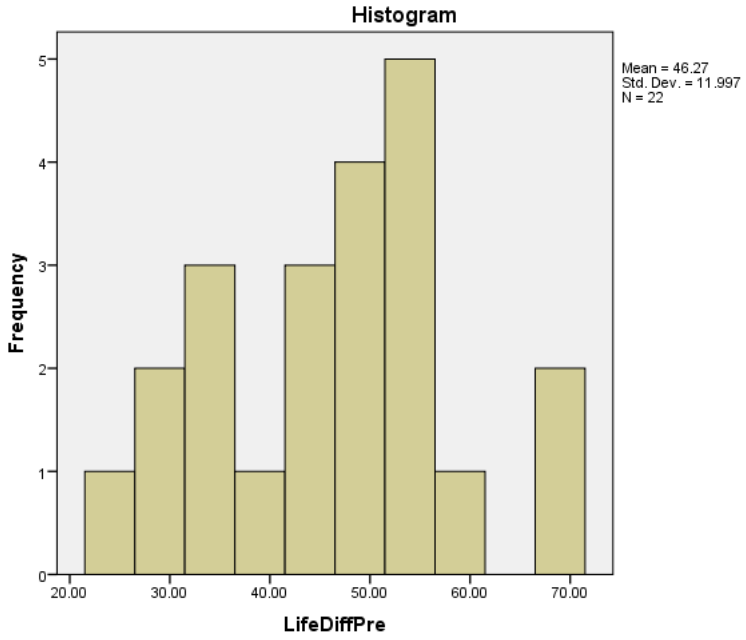
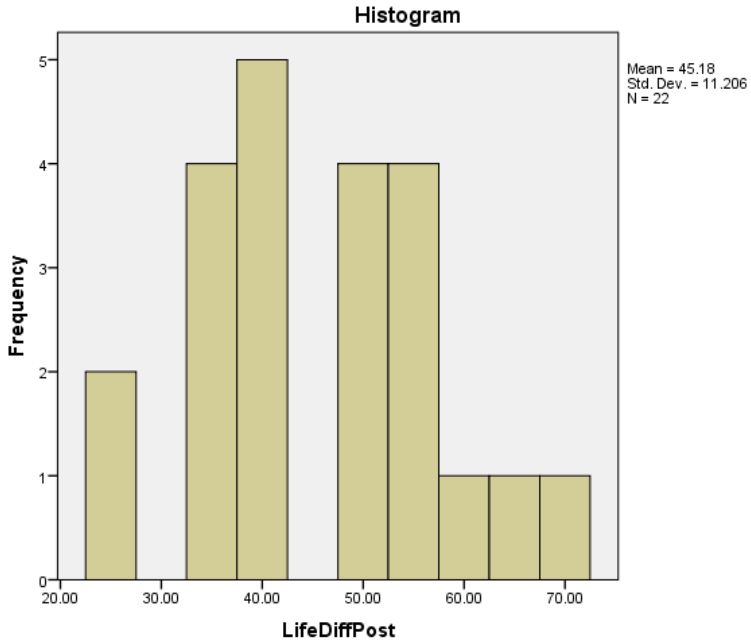
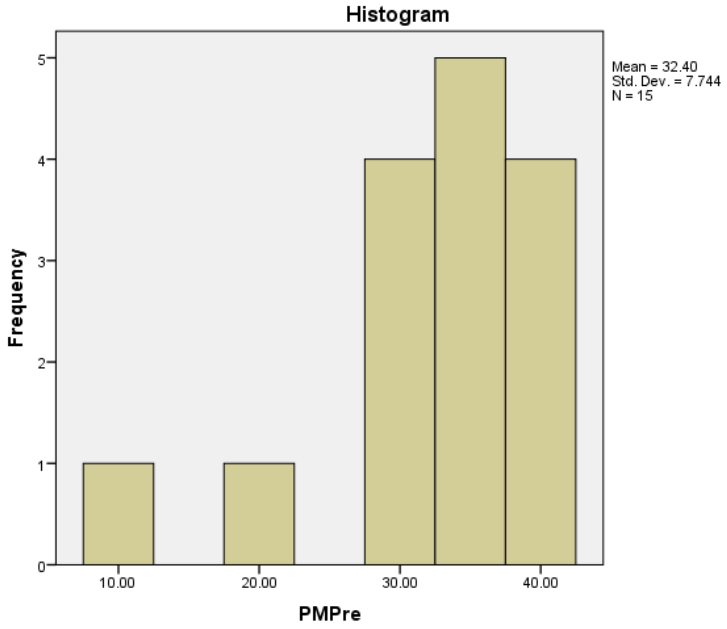


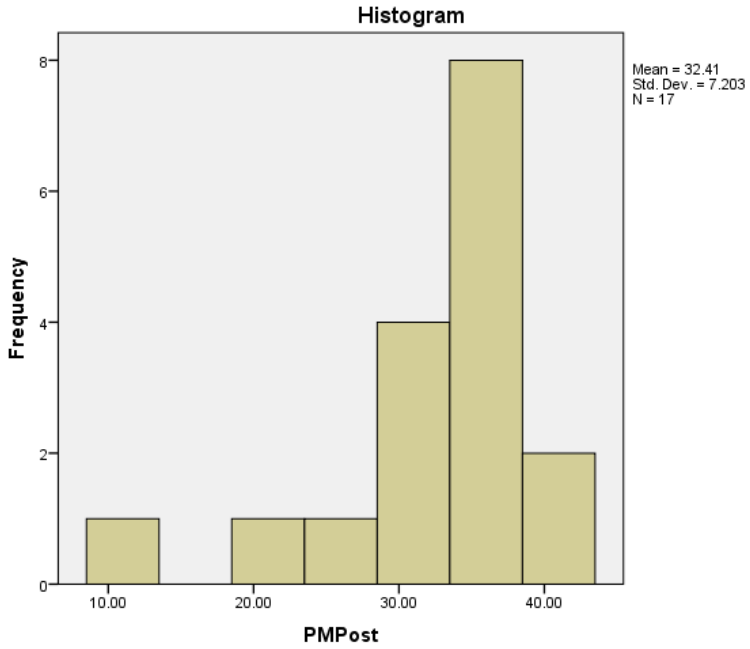
LifeDiffPost



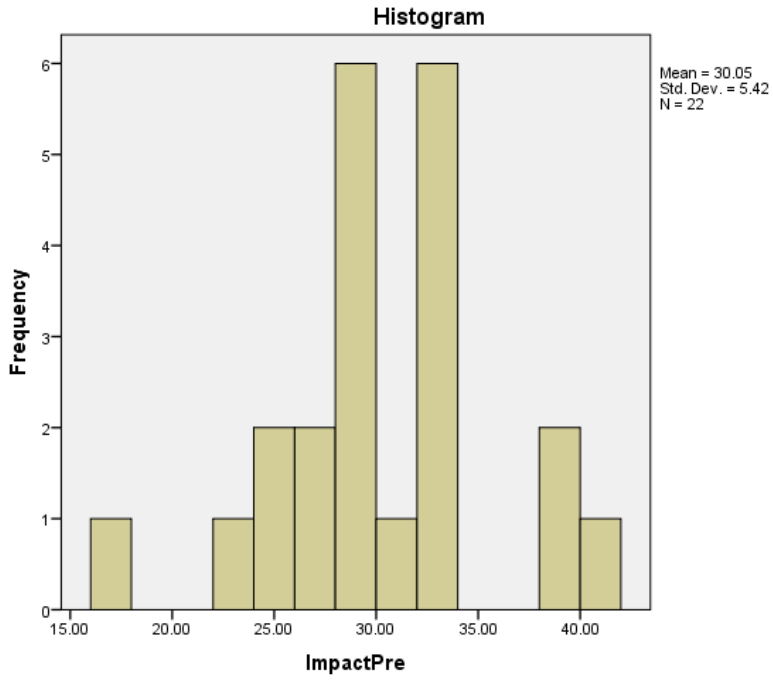
PMPre



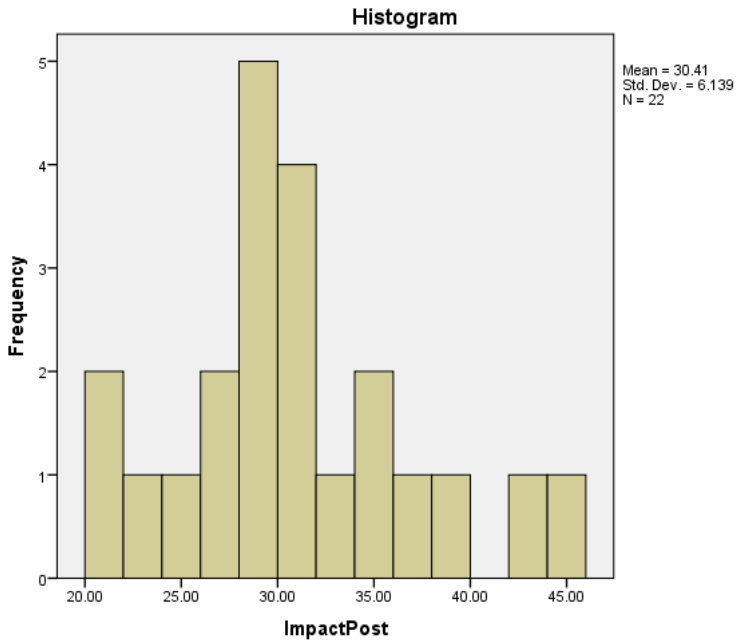
PMPost



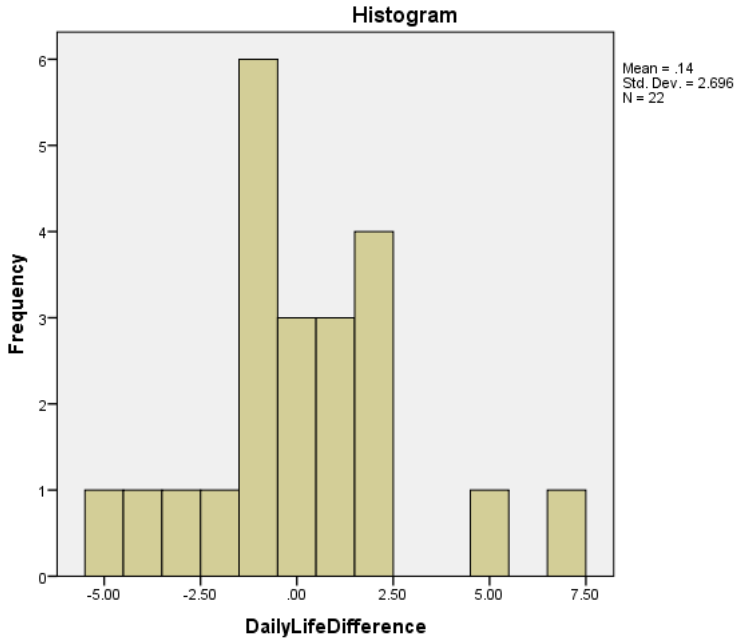
ImpactPre



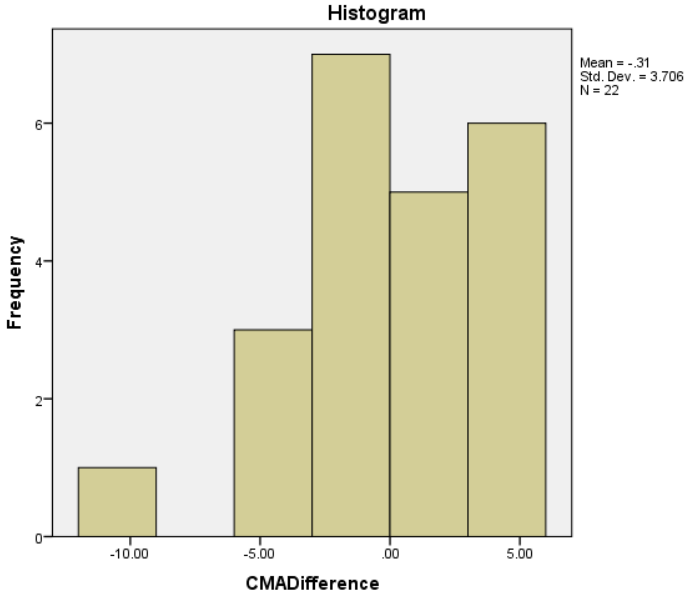
ImpactPost



DailyLifeDifference



CMADifference



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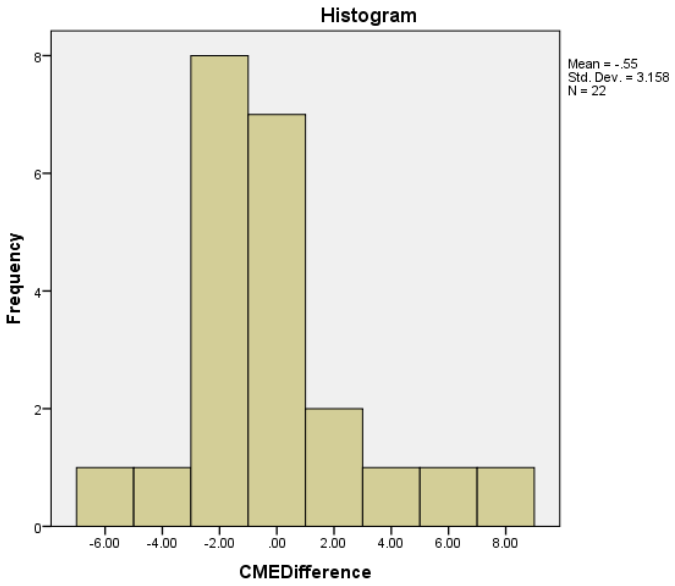
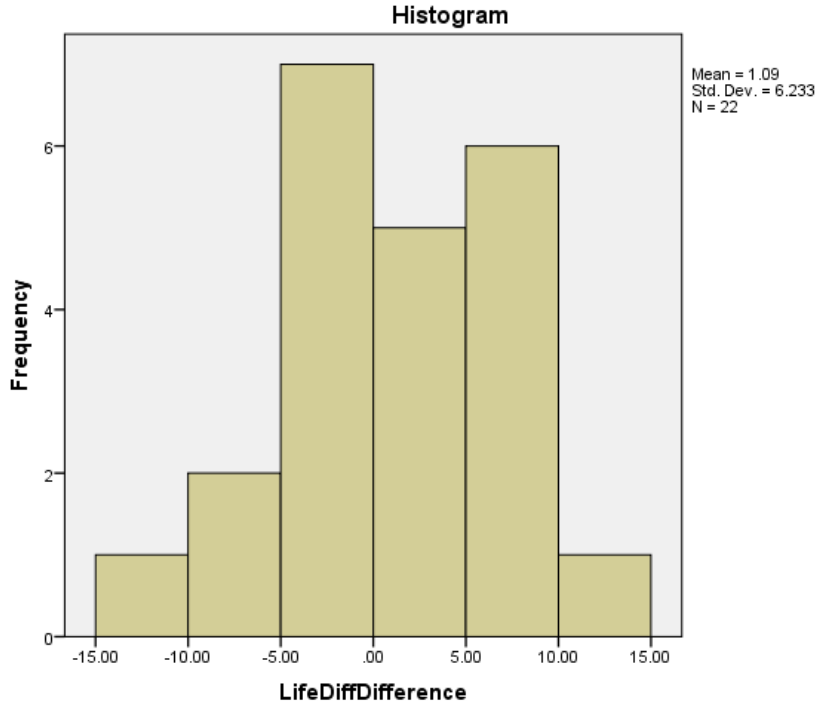


LifeDiffDifference



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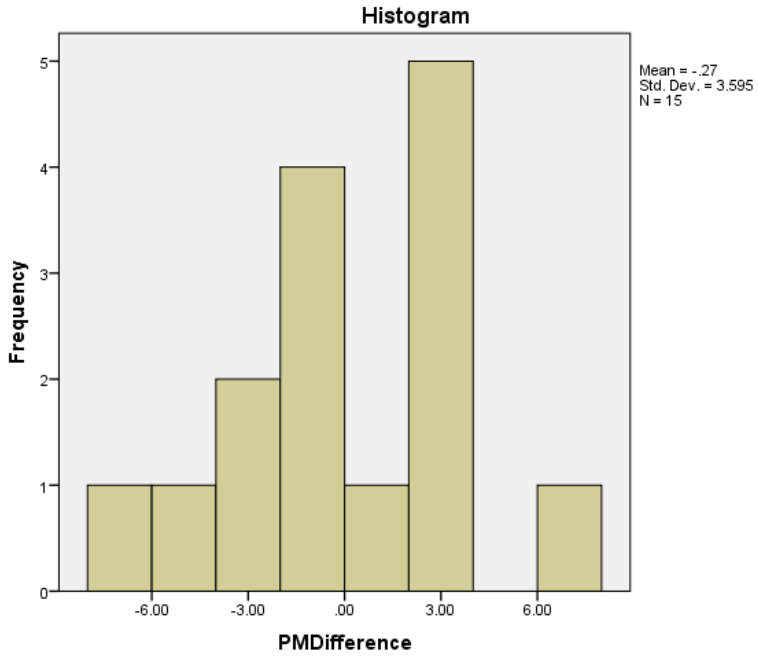

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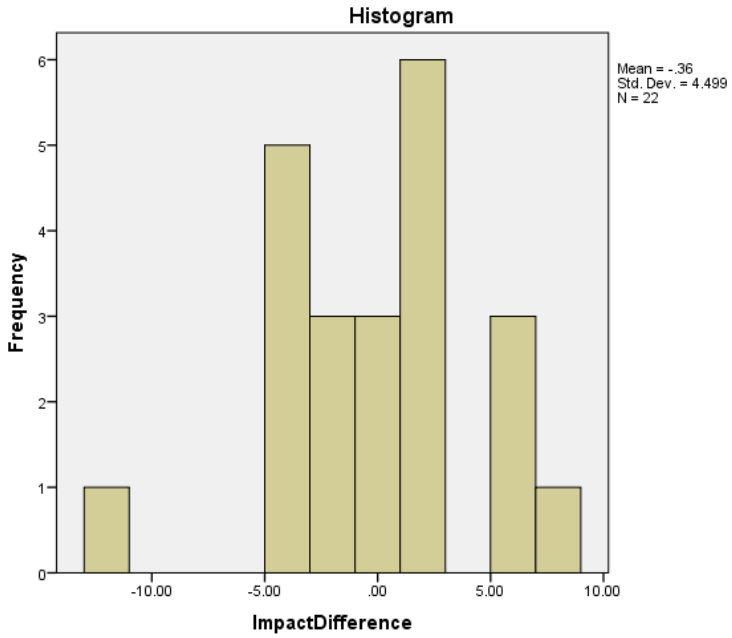

VITA

BRANDI LINDSEY

Education:	Public High School, Knoxville, TN 1999 BSN Bryan College, Dayton, TN, 2003 MSN Vanderbilt School of Nursing, Nashville, TN, 2004 PhD Nursing, East Tennessee State, Johnson City, TN, 2014
Professional Experience:	Pediatric Nurse Practitioner, Middle Tennessee Pediatrics and Adolescent Medicine - Lebanon, TN, 2004-2009 Registered Nurse, Camp, Murfreesboro, TN, 2009-2012 Assistant Professor, Middle Tennessee State University, Murfreesboro, TN, 2009-present
Publications:	Lindsey, B. (2011). Caring for parents who are preparing for a child with special needs. *International Journal of Childbirth Education. p.* 14-18. Lindsey, B. (2012). Transracial adoption: Current literature and one mother's perspective. *International Journal of Childbirth Education,* 27 (4), p. 55-60 Lindsey, B. & Driskill, C. (2013). The Psychology of Infertility. International Journal of Childbirth Education, 28(3), p. 41-45. Wilson, D. R. & Lindsey, B. (2011). Book Review: *On Duty: Power, Politics, and the History of Nursing in New Jersey* by F. Ward. Assigned by the *Journal of Health Care for the Poor and Underserved.* Lindsey, B. (2012) Book Review: Disorders of Sex Development: A guide for parents and physicians by A. Wisniewski, S. Chernausek, and B. Kropp. Assigned by the *International Journal of Childbirth Education.* Nehring, W. & Lindsey, B. (2014). History of health care for people with intellectual and developmental disabilities. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan* (3rd ed.) edited by Rubin, Merrick, Greydanus, and Patel
Presentations:	Cooper, C., Wilson, D. R., Frizzell, J., Lindsey, B., Harris, J., & Moore, S. (2011). *Women's Health: Prevention, Promotion, and Wellness: A Panel of Health Care Experts.* Accepted by peer

review to present at Western Social Science Association's 53rd Annual National Conference April 13-16, 2011 in Salt Lake City, Utah.

Lindsey, B., (2011). *Cystic Fibrosis: Diagnosis, Treatment, and Management*. Accepted by peer review to present at Western Social Science Association's 53rd Annual National Conference April 13-16, 2011 in Salt Lake City, Utah.

Lindsey, B. (2012). Understanding the Concepts of Chronic Sorrow as Lived by Families of Children with Chronic Disabilities. Accepted by peer review to present at Western Social Science Association's 54th Annual National Conference April 11-14, 2012 in Houston, TX.

Lindsey, B. (2013). Assessing family management styles within the family of a child with special needs. Accepted by peer review to present at Western Social Science Association's 55th Annual National Conference April 10-13, 2012.

November 11, 2011 – Presentation on Critical Social Theory and Implications for Nursing and Teaching (off campus at East Tennessee State University

November 6, 2012 – Presentation with students to the Xi Alpha Chapter of STTI and District 15 TNA members about the medical mission trip to Kenya and how to implement this into nursing education

October 8, 2012 – presentation to peers at East Tennessee State University regarding current health policies and problems in regards to nursing care

Summer 2013 – Presentation on implementing teaching strategies to foster collaboration between public health officials and nursing students and faculty to peers at East Tennessee State University

Certifications:

Certified pediatric nurse practitioner – current since November 2004

RN Tennessee Licensure – current since 2004
BLS certified – current