

EXPLORING SUPPORT SYSTEMS OF FATHERS OF CHILDREN WITH CHRONIC MEDICAL CONDITIONS

by

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(Under the Direction of Charlotte Wallinga)

ABSTRACT

A review of previous research reveals that parents of children with chronic medical conditions are usually represented by the mother or a combined parental report (Goble, 2004; Grootenhuis & Last, 1997). These research methods are based on outdated assumptions that fathers are less influential in children's development than mothers (May, 1996). With a new understanding of the significant roles that fathers have within the family, it is necessary to explore how fathers can be uniquely supported in parenting children with chronic medical conditions. This qualitative study used indepth interviews so fathers could define support using their own words. Five fathers of children with serious illnesses participated in a series of two interviews. Interview themes included: stress related to disappointing expectations for fatherhood, support that assists fathers in managing stress, and barriers to receiving and requesting support. Participants also made recommendations for improvement of male support services.

INDEX WORDS: Qualitative study, Fathers, Children, Chronic medical conditions, Support systems

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MEDICAL CONDITIONS

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DEDICATION

This is dedicated to the children who are battling chronic medical conditions with more energy and enthusiasm that I ever thought possible. I am grateful to learn from their stories and hope that this research will impact them and their families in positive ways.

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First, I want to thank my gracious participants who took time out of their busy lives to share their stories with me. I am appreciative of their willingness to speak so openly about their experiences in a way that truly expands our understanding of how the *entire* family is influenced by a chronic medical condition. I was inspired by the strength of these men and am forever grateful for their participation.

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CHAPTER 1

INTRODUCTION

There have been multiple debates over the last four decades about the way that childhood chronic medical conditions or special healthcare needs should be defined (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). European researchers in the 1970s introduced a definition that describes a chronic medical condition as: “a physical, usually nonfatal condition which lasted longer than three months in a given year or necessitated a period of continuous hospitalization of more than one month; [condition must also be] of sufficient severity to interfere with the child’s ordinary activities to some degree” (Pless & Douglas, 1971, p. 407). These earliest definitions focused primarily on the duration of the illnesses and the impact it has on the child’s daily activities (van der Lee et al., 2007). As researchers in the United States in the early 1990s attempted to refine definitions of chronic medical conditions, their focus shifted to the types and extent to which the child’s condition impacted the child’s functioning and daily needs (Perrin et al., 1993; Stein, Baumen, Westbrook, Coupey, & Ireys, 1993).

Definitions of chronic medical conditions gradually became broader in order that more children might be included in interventions and receive specialized services. One of the most recent definitions was developed by a committee from the Maternal and Child Health Bureau and adopted by the American Academy of Pediatrics (McPherson et al., 1998). In this definition, children with special healthcare needs are children who “have or are at 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).

Using the Maternal and Child Health Bureau definition of special health care needs, researchers attempted to estimate the prevalence of children with special health care needs in the United States using a national telephone survey. Families were randomly selected from each of the 50 states and the District of Columbia to see if any of their children met the criteria described in the definition of special health care needs constructed by the Maternal and Child Health Bureau. The results indicated that 12.8% of children in the United States had a special health care need in the year 2001 (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). The prevalence was highest for boys, school-aged children, and children from lower-income families. Since so many children in the United States meet the criteria for special health care needs, it is becoming increasingly important to explore the psychosocial needs of the families of which they are a part.

Along with the issue of determining an appropriate definition of chronic medical conditions, there is controversy over the appropriateness of grouping all chronic medical conditions together when studying the impact of pediatric health care needs on families. Some researchers advocate studying each illness separately arguing that every illness has unique demands and impacts. Other researchers have discovered that there is actually more variability within a particular diagnosis than between distinct diagnoses when investigating psychological and social impact of chronic childhood illnesses on families (Stein & Jessop, 1989). Medical professionals suggest that all parents of children with chronic medical conditions will share certain experiences, even if they may vary in intensity depending on severity of the child's illness (Canam, 1993; Stein & Jessop, 1989).

While researchers agree that caring for a child with any special health care need can be demanding, many of these families also have to cope with periodic crises and hospitalizations.

Examination of hospitalization patterns of children with chronic health conditions (asthma, diabetes, cystic fibrosis, muscular dystrophy, cerebral palsy, chronic respiratory disease, spina bifida, and malignant neoplasms) over the 10 year period of 1987 to 1996 revealed a significant decline in hospitalization rates and length of stay for all conditions combined; however, an increase was reported in the number of repeated hospitalizations (Valentine et al., 2000). While this pediatric population appears to be visiting the hospital less frequently than in the past, the children who are admitted into the hospital are more likely to return. It is important to recognize families that are facing repeated hospitalizations and learn how best to support them during periods of hospitalization.

Rationale of Study

Considering the prevalence of children with chronic medical conditions and the repeated hospitalizations children are experiencing, there is a need to investigate how best to support the caregivers of these children. A review of the past research reveals that parents of children with chronic medical conditions are usually represented by the mother or by a combined parental report that does not separate the different gendered perspectives (Goble, 2004; Grootenhuis & Last, 1997). These ideas are based on outdated assumptions that fathers were less influential in their children's development than mothers (May, 1996).

There has been an increased interest in research on families with children with chronic medical conditions specifically focusing on identifying parental needs, not only of mothers, but also of fathers. As researchers discover a variety of parental needs, many researchers are growing increasingly invested in learning more about how each parent meets his/her own needs and finds support.

Several quantitative researchers have included mother-father couples when exploring parental supportive resources used in coping with a child's chronic medical condition (Garwick, Patterson, Bennett, & Blum, 1998; Katz, 2002; Perrin, Lewkowicz, & Young, 2000; Tak & McCubbin, 2002). The results from these studies highlight some of the different needs of fathers and mothers; however, the results are far from conclusive. Some quantitative studies have found fathers use support less frequently than mothers (Schilling, Schinke, & Kirkham, 1985). Others, however, have found that it might not only be the frequency of social support usage, but the satisfaction with social support networks that could be most significant. For example, Katz (2002) compared fathers and mothers and discovered new patterns involving social support. Katz included both frequency of use and satisfaction with social support to investigate the relationships between parents' social support and their use of coping behaviors (including family problem solving, emotional coping behaviors, and use of medical services). Katz's discovered social support influences the coping behaviors of fathers more significantly than mothers. These results contradict previous findings by Schilling et al. (1985) drawing attention to the need for qualitative research that allows fathers to define support and acknowledges the unique perspective of fathers. Even though previous studies about parents of children with chronic medical conditions have included fathers through interview methods such as couple interviews (e.g. Kerr & McIntosh, 2000; Garwick et al., 1998), father-only focus groups (e.g. Neil-Urban & Jones, 2002), and fathering workshops (e.g. Chesler & Parry, 2001), it seems as though fathers have had limited opportunities to talk about their experiences independent of their spouses or peers (Goble, 2004; Grootenhuis & Last, 1997; Katz, 2002).

One study of parents of children with special health care needs found that a wife's view of her child tends to gravitate in the same direction as her husband's, whether positive or

negative (Frey, Fewell, Vadasy, & Greenberg, 1989). Even though these results require corroboration, James May (1996) makes a general conclusion based on these findings and his own work with fathers that neglecting to focus attention on struggling fathers could consequently place the entire family at risk.

Judith Hovey (2005) introduced a more positive spin on this theory. Hovey discusses how empowering fathers (e.g. providing them with first-hand medical information to increase their knowledge bases\)) strengthens the father's role in the family. She proposes that paternal confidence could have a positive influence on the mother-child dyad and improve the entire family unit's ability to adapt and cope to the chronic medical condition. This indirect relationship is significant enough to warrant further exploration of the accessibility and utilization of male support. Researchers must continue asking questions and seeking more information about how fathers of children with special healthcare needs establish support systems and how those systems influence family coping.

Purpose of Study

The purpose of this study was to explore the support systems that fathers use in coping with the chronic medical condition of a child, during both daily management of the illness and during periods of hospitalization. Using open-ended interviewing techniques, fathers participating in this study have the opportunity to define support from a male perspective and identify the types and timing of support that are most beneficial to them as fathers. Another goal was to help fathers establish a voice of their own, distinct from their wives.

Although the terms *chronic medical conditions (CMC)* and *special health care needs* are often used interchangeably, the term CMC is used throughout the remainder of this paper to refer to *chronic medical conditions*. CCMC is used to refer to *children with chronic medical*

conditions. The definition used to define CMC for this study are children who “have or are at 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).

Research Questions

The following research questions are at the center of this study:

1. How do fathers of CCMC define support?
2. What types of support are helpful to fathers of CCMC and under what circumstances?
3. What types of support are unhelpful to fathers of CCMC and under what circumstances?

CHAPTER 2

LITERATURE REVIEW

The following chapter includes a review of the relevant literature involving parents of children with chronic medical conditions (CCMC). Specifically, this review includes research under the following headings: (a) parents of CCMC, (b) the role of fathers in the modern American family, (c) commonly reported stressors of fathers of CCMC, (d) defining social support systems, and (e) fathers of CCMC and their use of support systems.

Parents of CCMC

Reported Demands

Parents of CCMC experience stress from illness-related demands, repeated hospitalizations, anxieties about child's present and future vulnerability, and the unpredictability of the disease (Canam, 1993). Through interviews with parents of CCMC over the course of a five year longitudinal study, Cohen (1995) discovered seven triggers that parents report as causing increased levels of uncertainty. These parental triggers include: (a) routine medical appointments, especially awaiting exams and test results, (b) minor symptoms or variations from the child's norm, (c) specific medical words and phrases, which occur as harsh reminders of the severity of their child's condition (d) changes in therapeutic regime, which threaten the emotional equilibrium of parents, (e) evidence of negative outcomes for other children, (f) changes in developmental stages, which cause anxiety because of the need to relinquish some elements of control either to the child or to others, and (g) night-time absence because of the lack of distraction from reality.

Any of these demands and triggers can appear at any time, and often occur simultaneously. McCubbin and Patterson (1983) explain that coping with co-existing demands

can ultimately end in a variety of ways. At one end of the spectrum, the family can manage demands effectively and become strengthened as a result. On the other hand, other families become overwhelmed and discover that the pile-up of demands exceed their resources.

Parental Needs

A critical aspect of relieving stress and demands is recognizing and meeting the needs of family members. Researchers working with families of CCMC have identified several fundamental parental needs (Sterken, 1996). Sterken (1996) outlined the following basic needs, which include the need for (a) information about the child's illness, (b) guidance and support during this learning process, (c) developing trust in themselves and the healthcare team, (d) discovering available resources, and (e) establishing normalcy. Sterken proposes the more parental needs that are met, the more prepared parents are to alleviate the stress that results from their children's medical conditions.

Several of these parental needs were confirmed in a review of the literature on parents of CCMC (Fisher, 2001). Fisher (2001) discovered three main needs throughout her review including: (a) the need for normality and certainty, (b) the need for information, and (c) the need for partnership. While the first two needs are similar to Sterken's (1996) findings, the need for partnership is an additional need identified by fathers in Fisher's review. The opportunity to participate in caring for their children is seen as a means of maintaining some semblance of control and making an effort to reduce uncertainty (Fisher, 2001).

Adaptive Tasks

In addition to parental needs, nursing professionals have identified a series of adaptive tasks for parents of CCMC (Canam, 1993). One of the most basic steps is acceptance of the child's condition. This acceptance often involves the stress of comprehending the diagnosis and

coping with any uncertainty associated with the illness (Melnik, Feinstein, Moldenhouer, & Small, 2001). At some point, the family learns to manage the child's condition by seeking information and working with healthcare professionals to learn about how to interact in the healthcare culture (Canam, 1993). Along the way, parents are also faced with the challenge of meeting the continuing developmental needs of CCMC. Periods of developmental transitions are often a source of stress and sorrow as parents struggle to assist their children with challenging developmental tasks and recognize the disparities between their child's abilities and those of their healthy peers (Melnik et al., 2001).

Canam (1993) suggests that parents must also accomplish the task of meeting the developmental needs of all other family members, such as well siblings. As healthy siblings mature, they will not only need guidance in typical developmental tasks, but they will also have the additional challenge of coping with the variety of emotions they experience regarding their brother or sister's illness.

Whether parents are dealing with daily management of their children's medical conditions or coping with periods of crises such as exacerbations and hospitalizations, parents need to develop support systems in order to adapt successfully (Canam, 1993; Melnik et al., 2001). A support system can aid parents in learning how to cope with their own feelings and how to be supportive of the feelings of other family members (Canam, 1993). Interacting with other parents of CCMC may also assist parents in accomplishing the task of learning how to talk to others about their children's conditions (Canam, 1993).

While this series of adaptive tasks seems to flow in a sequence, they can be accomplished in any order, and many families will be working on multiple tasks at once. Canam (1993) explains that professionals who work with families of CCMC need to be cognizant of periods

when a family is experiencing a crisis and be sure to offer help managing the crisis before they provide assistance with completing additional adaptive tasks.

Periods of Hospitalization

Periods of hospitalization impact the needs of parents caring for children with chronic conditions. When a child has to be admitted to the hospital, parents suddenly have to shift into a new routine and a different type of caregiver role. According to Horn, Feldman, and Ploof (1995), parents' most significant stressors involve managing their own emotions, such as fear that their child might die, as well as communicating with hospital staff and coordinating care. Many of these parents are unsure about their role as the secondary caregiver to their child in the hospital setting.

Even when parents are involved in the caregiving role, they often feel they have inadequate time and resources to make decisions. Patterson, Holm, and Gurney (2004) found that parents of children with cancer described frustratingly long waits for diagnoses and tests results that left them with very short amounts of time for making important decisions about their children's medical treatments. In order for parents to work through these sudden changes, parents report several coping strategies. The most helpful strategies reported were gathering information and gaining support from hospital staff. Other strategies included reprioritizing, normalizing the experience, depending on support from family and friends, forming supportive relationships with families going through similar experiences, and relying on inner strength or beliefs. While these strategies may also be used in periods of non-hospitalization, they are especially useful to parents during the experience of an extended hospital stay (Horn et al., 1995).

The Role of Fathers in the Modern American Family

Changing trends in fatherhood of the twenty-first century American families are well documented (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Carlson, 2006; Lamb, 2000; Marsiglio, Amato, Day, & Lamb, 2001; Pleck & Masciadrelli, 2004; Yeung, Sandberg, Davis-Kean, & Hofferth, 2001). Knowing what the general population expects of fathers provides the necessary background for understanding the world in which fathers of CCMC are living.

Cabrera et al. (2000) described four significant social trends that are influencing the modern family. The first and most significant trend is the growing percentage of women participating in paid-labor. With more wives in the workforce, husbands and wives are renegotiating parenting responsibilities and children are spending more time in non-parental care, such as daycares. A second trend is the lack of involvement nonresidential fathers have with their children. This trend is especially significant in light of research that reveals increased quality interactions between children and their nonresidential fathers are associated with fewer negative child outcomes, such as lower rates of depression and fewer externalizing behavior as adolescents (Carlson, 2006; Marsiglio et al., 2001). On the other hand, a third trend shows that fathers of intact families are increasing their general involvement with their children (Cabrera et al., 2000; Pleck & Masciadrelli, 2004). The fourth and last trend is cultural. As the United States continues to attract people from other cultures, their cultural traditions are undeniably impacting the way that fathers are parenting and defining their roles within the family as they are exposed to alternative parenting roles and behaviors. Together, these four trends are causing a shift from the traditional view of separate male breadwinners and female caregivers, to co-parenting families (Pleck & Pleck, 1997).

The trend of fathers' increased involvement in intact families seems the most germane to this study, and is examined more closely here. Researchers have explored how the amount of time that mothers versus fathers spend with their children has changed over the years (Yeung et al., 2001). In the 1970s and 1980s, fathers spent 30-40% as much time with children as mothers (Pleck, 1997). In 1997, Yeung et al. conducted a nationwide study and found that fathers reported spending 67% as much time in direct engagement with their children as their wives on weekdays, and 87% as much time as their wives on weekends. These findings indicate that the gap is closing between the amounts of time that fathers and mothers spend with their children comparatively. Some of the societal factors that have been associated with the increase in fathers' responsibility for childcare in intact families are increased maternal employment, periods of societal economic decline, increased flexibility in the workplace including flexible hours, part-time position availability, opportunities for job sharing and the increase in home-based work options (Cabrera et al., 2000).

As speculative theorists and researchers have attempted to learn more about the involvement of fathers, they have recognized that paternal involvement is a complex role that must be examined on a deeper level (Lamb, Pleck, Charnov, & Levine, 1985, 1987). While much of the research before the 1980s had negatively focused on paternal absence, a new trend in thinking emerged in the mid-1980s. This perspective involved researchers asking new questions about the relationship between parents and their children and exploring new dimensions of parenting that researchers hoped would become a better model for explaining the unique relationship between fathers and their children (Pleck & Masciadrelli, 2004). Lamb et al. (1985, 1987) initiated a new perspective that moved beyond the traditional methods of measuring involvement based solely on the amount of time and physical presence a parent spends with a

child. They devised three distinct dimensions of parenting involvement: engagement, accessibility, and responsibility. Engagement is the most obvious type of involvement and is described as direct contact, caregiving, and shared interactions. Accessibility is a less intense dimension of involvement referring to the parent's presence and availability both physically and psychologically. Responsibility is the most abstract dimension of involvement that is much less direct than the other dimensions. Lamb (2000) defines responsibility as participation in making arrangements for the welfare and care of the child, such as selecting childcare, monitoring children, making appointments, or developing contingency plans. Responsibility may or may not be happening in the presence of the child. The responsibility dimension of parenting allows researchers to define and quantify the worry, anxiety, and planning that requires so much time and effort of a parent (Lamb, 2000).

With a broader understanding of parental involvement, there have been major adjustments in the conceptualization of family roles (McBride et al., 2005; Pleck and Masciadrelli, 2004). Cabrera et al. (2000) suggest that while historically mothers have held the role of the family gatekeepers, more recent family models reflect a shift towards a partnership in parenting between mothers and fathers. It is also necessary to reconstruct the traditional views of mothers being the central influence on children's lives in order to account for the increasing influence of fathers. The next step is to talk to fathers about these changing roles and expectations and consider how they apply to families of CCMC.

Commonly Reported Stressors of Fathers of CCMC

Although this researcher makes every effort to allow fathers participating in this study to define stress in their own words, this section will include descriptions of the sources of stress of fathers who have previously been involved in research of parents of children with chronic

medical conditions (CCMC). This brief review will consist of stressors that fathers of CCMC experience in both their daily management of the illness as well as during periods of crisis, specifically hospitalization.

In one of the first qualitative interviews of fathers of CCMC, 10 fathers of children receiving home-care shared their concerns surrounding their children's illnesses (McKeever, 1981). McKeever (1981) found that communication with health professionals was a point of stress for fathers. Fathers reported that they had less contact with the healthcare team than their wives, in addition to perceiving professional support as inadequate to meet their needs. Fathers also explained how their children's illnesses affected them personally. They felt deep shock and grief at times, but also felt the need to appear strong in order to support their wives. Fathers reported that their lifestyles required sacrifices, such as leisure activities and time with their spouses, which has had a significant impact on their marital relationships.

Another theme McKeever (1981) discovered was stress from the fathers' relationships with their ill children. Fathers struggled with knowing how to talk to their children about their illnesses. In addition, fathers said they still felt a responsibility to contribute to the direct care of their children despite working full-time. Through McKeever's (1981) interviews, fathers shared that one of the major coping mechanisms they used was denial. Most of the fathers reported that they would allow their feelings to build up rather than sharing them with anyone, which often resulted in their own health problems. Habitual denial prevented these particular fathers from reaching the point where they could admit the need for support and participate in support groups.

Research focused on fathers of CCMC continued to gain momentum during the 1990s. Cayse (1994) questioned fathers of children with cancer about stressors they encountered. The most commonly reported stressors included the future of their children, the health of their

children, the health of their spouses, and the lack of time available to spend with their spouses. Sterken (1996) continued research with fathers of children with cancer and recognized differences between the stressors experienced by younger and older fathers. The younger fathers reported stress related to receiving vague and ill-defined information about their children's treatment, the system of care, and the seriousness of their children's illnesses more frequently than did older fathers. In addition, fathers whose children had been diagnosed for the shortest amount of time reported the most uncertainty and lack of clarity (Sterken, 1996). This finding reflects the importance of communicating and supporting fathers at the time of diagnosis and the months to follow.

In a recent phenomenological study of five fathers of CCMC, Goble (2004) found themes similar to those of previous studies as well as additional findings. Living with financial strain was something that fathers expressed as a source of stress. In order to be available to care for their children, all of their wives quit their jobs, which resulted in a reduction in the total household income. This was significant since all of the fathers also experienced the burden of immense medical expenses, and some grappled with the added expense of having to travel in order to receive proper care for their children.

Fathers also described how raising a child with a CMC has affected and limited their social lives. Fathers explained that they did not have time to spend in social activities, but would feel too guilty to enjoy social activities even if they did have the time. Fathers also shared a desire to remain isolated since they could not imagine others being able to understand the stress and worry that they experience in their daily lives.

Living with lack of intimacy was another theme fathers expressed. Intimacy with their well children and their wives was less possible as fathers were forced to run their families like

businesses, focusing on efficiency and accuracy rather than personal relationships. Because of the complex needs of their children, fathers found very few people who are willing and able to care for their children and give parents relief from caregiving. As a result, many fathers experienced a lack of one-on-one time with their wives.

Still another theme was the burden of being the primary caregiver to the well child. Fathers struggled with giving their well children as much attention as their sick children. As fathers spend time with their well children, they experienced disappointment that they could not share the same types of interactions with their ill children because of their medical situations (Goble, 2004).

Several studies have shed light on the common fears and concerns that cause stress for fathers of CCMC. Fathers reported feeling psychologically unprepared to care for sick children; many fathers felt uncomfortable being left alone with their sick children for fear that something would happen that they could not manage themselves (Goble, 2004; Sabbeth, 1984). Fathers also live with worry over the future. A major source of stress is the uncertainty of their children's conditions and fear for both their ill and well children's futures (McKeever, 1981). Fathers described a lack of confidence about their abilities to care for their children as adults, especially considering the fathers' decreasing physical strength with age. They are worried about children's quality of life and whether they will reach milestones such as marriage (Goble, 2004).

Considering the numerous stressors fathers have identified related to raising CCMC, researchers have explored how fathers react to the accumulation of stressors. In a qualitative study of 13 fathers of children with acute lymphoblastic leukemia, McGrath and Chesler (2004) identified trends in the way that fathers respond to their children's CMC. In response to the lack

of intimacy and business-like family interactions as described above, McGrath and Chesler (2004) found that fathers felt the pressure to maintain a sense of normalcy, meaning that they attempted to conduct life as it was before the child's diagnosis. In the midst of their children's illnesses, these fathers felt deep grief and shock, but they revealed how they experienced less restriction in the way they expressed their emotions than they had anticipated. These fathers report that there is a growing understanding of fathers' emotional needs and growing acceptance of men crying publicly. In a few situations, fathers even took on the role of the primary caregiver to the child while the wives worked. This study supports the idea that new roles are emerging for fathers.

In response to their findings, McGrath and Chesler (2004) hypothesized that the way fathers cope with their children's CMC may be linked to the role that fathers have within their marriages. McGrath and Chesler suggest that couples may choose their roles and responses to the child's illness in a complementary fashion, meaning that there is often one partner who appears more stoic and another partner who is more expressive within each couple. While males have traditionally been stereotyped as the stoic partners, a male may be more likely to be expressive if he is married to a woman with more stoic tendencies.

While the daily management of a child's CMC is extremely stressful for fathers, there are times of increased demands when a child's health needs require advanced, hospitalized care. During periods of hospitalization, parents' stress is often amplified as they attempt to adjust daily routines and cope with feelings of helplessness and fear for their child's health (Melnik et al., 2001). After conducting small focus group sessions, Neil-Urban and Jones (2002) reported that fathers of children with cancer express that the hospital environment produced unique stressors such as the reminder of the severity of their children's illnesses and the possibility of their own

children dying. Throughout hospital stays, fathers described how the appearances of other sick children, intimidating equipment, disturbing noises such as crying, other anxious parents and even dying children are challenges they faced when trying to maintain a positive attitude.

In his work with fathers of CCMC through the National Fathers' Network, May (1996) discovered that many men do not feel welcomed by female care-providers to participate in their children's care. Often these fathers worked during the day and were not able to receive first hand medical information from medical staff, leaving them with unanswered questions and confusion regarding their children's health.

Defining Social Support Systems

This researcher will make every attempt to avoid making assumptions about how fathers define and conceptualize support systems. It is necessary, however, to include some of the definitions of support commonly used throughout the literature in order to have a reference point for formulating research questions.

Caplan (1974) defines support systems as both the formal and informal relationships that provide an individual with emotional, cognitive, and material supports necessary to cope with stressful experiences. Emotional support refers to actions of others that promote feelings of comfort and offers the individual admiration, respect and love. This dimension of support also involves a sense of security and the reassurance that others are available for assistance. Cognitive support includes the information, knowledge, and/or advice that aid the individual in understanding his/her changing world and to make adjustments in thinking accordingly. Finally, material support encompasses the resources and services that help to solve practical problems such as money, transportation, or caregiving. Several studies examining parents of CCMC have

used models that incorporate these three dimensions of support (Garwick et al., 1998; Tak & McCubbin, 2002).

Researchers interested in families of CCMC have extended Caplan's (1974) definition of support to include additional dimensions that have helped create a more comprehensive understanding of how individuals manage stress through relationships. The appraisal of support, which can be defined as the satisfaction and confidence individuals hold concerning their supportive resources, is one of the additional aspects of support that has been explored.

Hentinen & Kyngas (1998) measured the appraisal of support by asking parents of CCMC about their satisfaction with the cooperation and availability of support from healthcare staff. Another extension of the concept of social support is the inclusion of a companionship dimension. Nagy and Ungerer (1990) included a social companionship dimension of support in their study of parents of children with cystic fibrosis. In contrast to emotional support, which has a focus on the stressful situation, companionship does not necessarily directly relate to the individual's stress. Companionship is often diversional and involves spending time in social or recreational activities.

Although theorists agree that support is a means of coping with stress, multiple models explain this process. According to the *needs model of stress*, interactions that take place within social relationships are the means through which individual needs are met and stress is reduced (Jacobson, 1986). Within this model, theorists explain that each type of relationship is specialized in order to meet a unique need. For example, marriage accomplishes the need for attachment while friendships fulfill the need for social integration (Jacobson, 1986). An alternative model developed by stress theorists is called the *transactional model of stress* (Jacobson, 1986). Within this model, stress is considered an imbalance between perceived

demands and perceived resources with negative consequences for an individual's well-being. Support is conceptualized by the way in which individuals cope with these imbalances and their consequences. More specifically, support serves one of two purposes. On one hand, it can address the imbalance between demands and resources by decreasing demands and/or by increasing resources. On the other hand, support can alter the consequences of failure to meet those demands (Jacobson, 1986).

Defining Support for Families of CCMC

In a study of parents of children with congenital heart disease, Tak and McCubbin (2002) utilize the needs model of stress and define social support as any resource that meets the needs of family members. Tak and McCubbin included emotional, cognitive, and material dimensions of support in order to capture the larger picture of support. In addition, they measured family stressors in an attempt to recognize the way life events affect the manner in which support offered by others will be perceived and received by parents of CCMC.

Garwick et al. (1998) narrowed their focus on support in a study of parents of preadolescents with CMC receive. While using the three types of support delineated by Caplan (1974), emotional, cognitive, and material support, Garwick et al. investigated the types and sources of support that are both most and least helpful to parents. Since unsupportive resources are a relatively new area of study within CMC research, they used open-ended interviews in order to investigate this exploratory topic.

Looking specifically at parents of children with profound disabilities, Brett (2004) used phenomenological interviewing to develop a more comprehensive understanding of the steps parents take towards accepting support that include a point of change, loss of autonomy and pride, and viewing the acceptance of support as a positive choice. Because many of these parents

described their initial views about accepting support as admitting they have failed, many parents expressed feelings of anxiety and distress about receiving support and losing a sense of autonomy. In addition, through their research, Tak and McCubbin (2002) recognized the multiple facets of accepting support that complicate our understanding of how families use support systems. They suggest that the complexities of social support may best be understood within a contextual setting.

Fathers of CCMC and Their Use of Support Systems

In a review of literature and theory, Canam (1993) suggests that developing support systems can be viewed as an important adaptive task facing families of children diagnosed with a CMC. Families receiving poor emotional and instrumental support from family members and healthcare professionals have shown poor adaptation to the CMC of a child (Hentinen & Kyngas, 1998). In addition, researchers have recognized that the extent to which a specific resource will be supportive and aid family members in adaptation depends on a variety of other factors, such as the individual's current circumstances, other resources, values, and perceptions (Hobfoll, 1985). Knowing that each person will interpret resources independently is evidence for seeking the perspective of each individual family member rather than allowing one parent to represent the entire family or parental unit.

Research focusing on the perspective of fathers of CCMC has revealed some specific patterns about the ways in which fathers use support systems. Past findings suggest that men rely on and use support networks less frequently than their wives (McKeever, 1981; Schilling et al., 1985). Although it was recognized that fathers use support resources differently than mothers, it was unclear whether there is an equal availability of resources for mothers and fathers. A study of parents of children with cystic fibrosis found that the reported amounts of informational,

emotional, and social support available to parents was not significantly different for fathers and mothers (Nagy & Ungerer, 1990). Nagy and Ungerer explain that fathers may recognize the availability of resources but choose not to use them to the same extent as their wives.

Interestingly, other studies have included fathers who perceive support as being geared primarily towards women in a way that does not make them feel included or meet their unique needs as fathers of CCMC (Chesler & Parry, 2001; Davis & May, 1991). The contradicting results from past research suggest the need for additional studies that allow fathers to explain this phenomenon in a way that furthers our understanding of how fathers perceive support availability.

Since fathers of CCMC sometimes feel excluded from support resources available to their wives, fathers often learn to become self-reliant (Sterken, 1996). Self-reliance is a coping strategy that involves fathers taking complete responsibility for their needs and emotions rather than turning to others for assistance and support. While self-reliance may be a successful strategy temporarily, what happens during a crisis, such as a hospitalization, when self-reliance proves ineffective? Sterken (1996) suggests that fathers often seek external support during these difficult times; however, support that is not geared towards their needs often proves unproductive and may cause fathers to revert to their previous self-reliant coping techniques.

Researchers suggest that a powerful way fathers have overcome barriers to support has been through participation in support groups geared solely toward fathers. Chesler and Parry (2001) conducted interviews and open-workshops with over 160 fathers of children with cancer. They learned that because fathers have difficulty expressing the need for support or finding appropriate means of support in their everyday relationships, fathers have benefited from gatherings made up exclusively of fathers who have also experienced raising a child with cancer.

Fathers reported that these men were better able to understand and respond to their needs than those people who have not had similar experiences (Chesler & Parry, 2001; Kerr & McIntosh, 2000). Fathers in the supportive workshops felt comfortable asking for specific types of assistance, such as continued contact or prayers from fellow fathers (Chesler & Parry, 2001). Fathers participating in other father-to-father support groups have described their experiences as opportunities to share advice and give emotional support that was grounded in their own experiences. Facilitators noted that support group meetings established a process in which fathers' attitudes were transformed from defeat and anger to camaraderie and hope (Neil-Urban & Jones, 2002).

Additional evidence to suggest that fathers may benefit from social support more than previous researchers have implied is found in a study conducted with parents of CCMC using the Double ABCX Model of Family Stress (Katz, 2002). When considering the family's pile up of stressors, such as life events and the severity of the child's illness, and their relationship with the father's use of coping behaviors, Katz found that social support was the most significant intervening variable. Comparatively, the impact of social support for fathers was actually greater than it was for mothers in this stress model (Katz, 2002).

Need for Qualitative Study

While interest in research on fathers has increased over the last few decades (Day, Lewis, O'Brien, & Lamb, 2005), a very small percentage of these studies have focused on fathers who are raising CCMC. Even fewer studies have been conducted that address the topic of support systems of fathers of CCMC. There is a need to continue searching for more information about how fathers uniquely view and utilize supportive resources, especially in light of changing cultural expectations of fathers in modern society. It must be noted, however, that the literature

reviewed is merely a guide that will aid this researcher in deriving explanations from the participants' data. These findings must be held in abeyance and must not be used to force theories that are not grounded in the current research study.

CHAPTER 3

METHODOLOGY

The following chapter contains a description of this study's design as well as a description of the methods by which the study was conducted. The methods section is divided into subsections that outline: (a) participant eligibility and recruitment, (b) instrumentation, and (c) data analysis of this study.

Design

Epistemology

It is important to acknowledge this researcher's epistemological stance since it influences the way in which the researcher's questions are explored. This researcher's epistemology can be classified as constructionism because she believes that individuals come to know the world through their engagement with it. As Crotty (1998) suggests, researchers operating with constructionist beliefs do not believe that there is an objective truth to be found. Instead, they believe there is interdependence between the subject and the world that allows meaning to be continuously and bi-directionally constructed. As a constructionist, this researcher acknowledges the social structures and sign-systems that are constantly influencing the consciousness, language, and contexts that mediate individual realities. Specific to this study, fathers are constantly constructing meaning within their multiple contexts such as family, work, and healthcare.

Purpose Orientation

Just as the epistemological stance influences the methodology of this study, the goals for this study also inform the approach this researcher utilizes in answering the research questions. Borrowing from Marshall and Rossman (2006), this study can be categorized as primarily

exploratory because the researcher seeks to investigate a phenomenon that has received very little attention in the literature. In addition, it is exploratory in purpose since it seeks to reveal important themes and categories of meaning from the participants. The study is also descriptive since it attempts to describe the experiences and support systems fathers encounter during the daily care and hospitalizations of a child with a chronic medical condition (CMC).

Theoretical Perspective

The exploratory nature of this study lends itself to an interpretive theoretical perspective. In contrast to the positivist approach in which researchers seek universal truths about humanity or society that lead toward predictability, researchers under the interpretive perspective seek to make interpretations that are both culturally and historically situated (Crotty, 1998). This study is an intentional attempt to listen to and capture the emic voice of the participants rather than imposing any personally derived terms on their experiences. Although it requires tremendous effort and patience, there is a belief within interpretivism that it is possible for an outsider to understand the experiences of a culture of which he/she is not a member. This researcher attempted to capture the emic voice of fathers of children with chronic medical conditions (CCMC) during the interview process.

Interpretivism encompasses multiple theoretical perspectives including phenomenology, which focuses on the meaning, structure and essence of individuals' lived experiences (Patton, 2002). A main assumption, which is fundamental both to phenomenology and to this study, is that essential meanings exist and create a shared sense of familiarity of the world (Lindseth & Norberg, 2004). Phenomenological researchers seek to reinterpret these meanings in a fresh way that results in a fuller understanding of the world (Crotty, 1998). A phenomenological approach operates under the assumption that this researcher can find essential meanings within the stories

fathers tell that can be added to previous meanings created solely from the perspectives of mothers.

Fathers' experiences receiving support cannot be separated from the meaning that support has for fathers. In contrast to a quantitative approach, which would involve operationalizing variables and imposing a limited worldview on fathers, a qualitative approach recognizes the role of the specific context of parenting a child with a CMC and attempts to reveal the thoughts, feelings, beliefs, and values that are behind fathers' behaviors. Qualitative research allows the researcher to pose questions that are general enough to allow for sufficient exploration but narrow enough to create necessary boundaries for the study (Marshall & Rossman, 2006). Specifically, this researcher used a grounded theory approach (Strauss & Corbin, 1998) to inductively build new theory about fathers' use of support based on the data rather than previous theoretical assumptions.

While specific theories were not used to formulate theoretical expectations prior to interviewing participants, the researcher acknowledges that several theories informed the development of this study. The researcher's background in child and family development has created a lens through which she approached research with fathers of CCMC. An example of a family theory that has influenced the researcher is the family systems theory, which consists of several principles that are essential to family research. Principles of family systems theory that are applicable to this study include (a) the family is characterized by wholeness and order and (b) at times, family order is interrupted and influenced by change (Pinquart & Silbereisen, 2005). Family systems theorists explain that "changes can arise at any level of the family system and change at any one level can stimulate change in an individual member." (Pinquart & Silbereisen, 2005, p. 368). Understanding that fathers' participation in other systems, such as social support

systems, will influence the order of the family unit is a motivation to explore fathers' support systems.

In addition to family systems theory, the Double ABCX Model of Family Stress and Adaptation (Lavee, McCubbin, & Patterson, 1985) has influenced the researcher's perspective. This model allows theorists to describe family adaptation to stress by addressing the mediating influences of family resources and processes. Family processes are defined as the ways family members come to perceive their circumstances and develop levels of confidence in the predictability of their environments. The Double ABCX Model of Family Stress and Adaptation accounts for how these processes influence a family's utilization of resources (Lavee, McCubbin, & Patterson, 1985). With the knowledge of this stress theory, the researcher was motivated to explore the unique perceptions of fathers and their relationship to family adaptation to a CMC. In addition, this theoretical perspective gave the researcher confidence that family resources, such as support, are significant to the family's ability to cope with stress and that this is an area worthy of exploration. The researcher's adoption of qualitative research methods has the potential to verify family systems and family stress theoretical principles or add to the current understanding of these theories.

Method

Participants

Recruitment. In an attempt to locate fathers who have at least minimal access to supportive resources, fathers for this study were recruited through Starlight Starbright Children's Foundation. The foundation is a non-profit organization that provides services to children who are seriously ill and their families. Families who desire to enroll in Starlight Starbright programs go through an application process, which requires documentation from a doctor that the child has

a serious medical condition requiring ongoing treatment or monitoring. Families attend all events sponsored by Starlight Starbright free of charge. Events include holiday parties, sporting events, theater tickets, and many other local attractions.

The Georgia chapter of Starlight Starbright, located in Atlanta, collaborated with this researcher in order to recruit participants for this study. As a former intern at this foundation, this researcher established rapport with many of the families. Starlight Starbright employees provided this researcher with a list of names and phone numbers of Starlight Starbright families so that eligible fathers could be called to set up interviews. The time and location of the initial interviews were arranged over the telephone by the researcher according to the father's schedules. The researcher attempted to locate a quiet, public space such as a coffee shop or quiet restaurant that was convenient for the father as the interview location. A second, follow-up interview with participants was conducted over the phone. The average time between initial and follow-up interview was nine months. The researcher took care to summarize the initial interview in order to clarify any misconceptions and remind fathers of the initial conversation since there was a significant time lapse between interviews due to scheduling difficulties of the fathers. In one situation, a father was interested but unable to meet in person, so a phone interview was conducted for both the initial and follow-up interviews.

Eligibility. In order that the results of this study might lead to meaningful development of theory, criterion sampling (Marshall & Rossman, 2006) was used in order to recruit fathers of school-aged children who have at least minimal access to support through Starlight Starbright Children's Foundation. To be eligible for this study, a father had to meet the following criteria: (a) is between the ages of 25 and 50-years-old, (b) has a child between the ages of 5 and 11-years-old who is currently enrolled in the Starlight Starbright program, (c) the same child has

been hospitalized for a minimum of 3 days over the past 18 months, and (d) the father lives within Atlanta and surrounding metro-Atlanta counties. The rationale for recruiting fathers of school-aged children was based on findings from a previous study that revealed significant differences in the types and amounts of support that families have developed and still need to establish when comparing families of preadolescents/adolescents and those of elementary school-aged children (Garwick et al., 1998). A total of five fathers participated in this study. After the fifth interview, this researcher reached a point of saturation. According to Strauss and Corbin (1998), this is the point when no new or relevant data emerges and the relationship between categories is well defined.

Instrumentation

Semi-Structured Interviews. Considering the purpose of this study, the researcher developed a series of open-ended questions to initiate a conversation with participants about their experiences with developing support systems as fathers of CCMC. The interview style was semi-structured in that the researcher did not necessarily ask the questions in a specific order or ask every question of each father. The questions were merely a starting point for discussion, but the researcher did not allow the questions to dictate the direction of the conversation or force fathers to talk about issues that were uncomfortable or irrelevant to his circumstances. (See Appendix A for Interview Guide). In addition to the interview questions, fathers completed a short demographic questionnaire. (See Appendix B for Demographic Questionnaire). Fathers signed a consent form that acknowledges the voluntary nature of their participation and reminded fathers that they can remove themselves from this study at any point in time without penalty. (See Appendix C for the Consent Form).

Researcher as Instrument. In contrast to the objective role of the researcher in quantitative data collection, the qualitative researcher is dynamically involved in the collection of data. According to Marshall and Rossman (2006), the qualitative researcher conducting interviews must be a careful listener, able to interact on a personal level with participants, as well as be skilled at framing questions and probing for more information when clarification or elaboration is needed. While attempting all of this, the qualitative researcher still allows the participants to guide the conversation and reveal their experiences as it makes sense to the participants, rather than the researcher imposing his/her own views on the participants.

Inevitably, there are limitations to the researcher serving as the instrument of inquiry. Because the interview is basically a conversation, the participant may or may not be cooperative or respond to the researcher's personal style (Marshall & Rossman, 2006). In addition, the researcher's own biases and subjectivities have the potential to taint the way in which the participants' responses are heard and understood. This researcher took multiple steps in order to assure that the effects of these limitations were minimized. First, this researcher kept a journal documenting her thoughts and biases as well as any immediate feelings or reactions that she experienced throughout the research process. Second, this researcher used peer reviews from her graduate committee members that involved reviews of the general interview process and assistance in recognizing any intruding biases. Last, member checks were conducted so that participants had the opportunity to review the research findings and correct any misinterpretations or misrepresentations that appeared in the interview summaries or discussion.

Grounded Theory.

Although specific theoretical influences have been acknowledged as influencing this researcher, the true goal of this study is to reveal fresh theory that is rooted in the experiences of

the fathers participating in the study. Grounded theory is a method of analysis that requires researchers to collect data and analyze it simultaneously from the beginning of the research process so data is both significant to participants and relevant to creating new theoretical frameworks (Charmaz, 2003). Grounded theory analysis is exploratory and interpretive in that, "...the interviewer starts with the participant's story and fills it out by attempting to locate it within a basic social process" (Charmaz, 2003, p. 314). Grounded theory allows the researcher to then take the individual experiences of each father and attempt to formulate a collective story through theoretical comparisons. Strauss and Corbin (1998) describe theoretical comparisons as the tools that researchers use objectively to identify the properties and dimensions of the data so that relationships can be identified and can be used to formulate new theories rather than merely reinforcing preconceived explanations.

Several different types of coding were used throughout the analysis of data to formulate grounded theory in this study. *Open coding* involves labeling the phenomena according to their properties and dimensions as well as classifying these phenomena into categories and subcategories. *Axial coding* was also used to form more complete explanations of phenomena by relating categories to their subcategories according to the dimensions and properties of the phenomena. It is the subcategories that allow the researcher to learn more about the "when, where, why, who, how, and with what consequences" of the phenomena (Strauss & Corbin, 1998, p. 125). In addition, *selective coding* was used to identify the main theme/central category of the study. This step allows the researcher to integrate and refine categories in order that theory may develop with internal consistency and logic (Strauss & Corbin, 1998).

CHAPTER 4

PARTICIPANT PROFILES

The purpose of this chapter is to describe the participants in a way that captures the unique characteristics of fathers and their families. The following sections include a brief background on the participating fathers and their children's medical conditions. Information about the medical conditions is reported as the fathers shared it with the researcher. In some cases, the researcher added additional information for the reader's understanding of the diagnosis. All the names of participants and their family members have been changed and any identifying information has been altered to respect the privacy of the families.

Profiles of fathers and their children are presented from the viewpoint of the fathers to represent the perceptions of fathers most accurately. According to the Double ABCX Model of Family Stress and Adaptation (Lavee, McCubbin, & Patterson, 1985), fathers perceptions are essential to their use of resources and their adaptation to stress. How fathers perceive their children's CMC and their family circumstances is the foundation for understanding fathers' support systems.

Overview of Participants

Fathers in this study ranged in age from 41- to 49-years-old. Four of the fathers were Caucasian and one was Hispanic. Each of the fathers was in his first marriage. Family sizes ranged from three to five members. Fathers ranged in educational backgrounds from a high school education to graduate degrees. Family incomes ranged from \$25,000 to more than \$75,000. When asked about their families' religious affiliations, two of the families affiliated with Judaism and the other three with Christian traditions.

The target children with the chronic medical conditions (CMC) ranged from 7- to 11-years-old. There were three male and two female children. Four children were biological and one was adopted into the participant's home when he was just a few years old. The chronic medical conditions included Cystic Fibrosis, liver transplantation, Neurofibromatosis, heart transplantation, and Acute Lymphocytic Leukemia. (See Table 1 for table of participant and child demographics).

Table 1

Participant and Child Demographics

Participant Name	George	Jeff	Brian	Bruce	Scott
Age (years)	49	46	41	48	44
Ethnicity	Hispanic	Caucasian	Caucasian	Caucasian	Caucasian
Highest level of Education	High School Equivalent	Some college	Masters Degree	Bachelors Degree	Bachelors Degree
Annual Income	\$25,000-50,000	\$50,000-75,000	\$75,000+	\$75,000+	\$75,000+
Religious Affiliation	Christian	Christian	Christian	Jewish	Jewish
Child's Diagnosis	Neurofibromatosis	Cystic Fibrosis	Liver Transplant	Heart Transplant	Acute Lymphocytic Leukemia
Age of Child with CMC (years)	9	11	7	11	9
Gender of Child with CMC	Male	Female	Male	Male	Female

Participant and Child Profiles

George

George is a 49-year-old Hispanic male who is deeply committed to his family and his faith. George was eager to participate in this study and suggested that the researcher meet him at one of his son's little league baseball games for his initial interview. George explained that his recommendation for the interview location was so that the researcher would have the opportunity to meet his whole family rather than just himself. The temperature was pleasant and the sun shinning when the researcher met George on the day of the interview. After facilitating introductions between his family and the researcher, George led the researcher to a deck area away from the ball fields. Although this area was the most quiet and private area available, there was still a significant amount of noise from children playing nearby and several parents who entered this area to make phone calls. Despite the chaotic atmosphere, George remained focused throughout the interview. George displayed some nervous and shy behaviors, such as looking down and avoiding eye contact towards the beginning of the interview. These behaviors also could be attributed to the sun shinning in his direction. Whether he became more comfortable with the researcher or the sun changed positions, George initiated more eye contact as the interview progressed. Several months later, George participated in a follow-up interview over the phone. This interview consisted of George confirming themes the researcher had identified from his first interview as well as answering clarification questions about his son's medical history.

George has been married to his 46-year-old wife for 27 years. Together, they have had two children, ages 9- and 20-years-old. Although George was not raised in the United States, he has estimated that his education is equivalent to a high school degree. He is currently

self-employed in a construction business that allows him to be flexible in his scheduling; however, his self-employment also produces great amounts of stress including issues of obtaining insurance for his family. He explains the frustration he has encountered regarding insurance:

It's really tough. It has to come out of my pocket. At this point, I mean, we've got insurance just in case of an emergency or something. But honest to God, we can't even use our insurance because our primaries are so high...but we've got to have it. It's really hard to find one that [will] take you in and [make you less] worried. I don't think there's one out there.

George understood that he could not risk going without insurance in case of an emergency, but he has been frustrated because he has been unable to afford an insurance policy that he could utilize routinely.

Insurance has been such an important issue for George because his 9-year-old son, Thomas, has been diagnosed with Neurofibromatosis. Neurofibromatosis includes a set of genetic conditions that cause tumors to grow along various types of nerves. Neurofibromatosis can cause tumors to grow anywhere on or in the body, sometimes affecting non-nervous tissues such as bones and skin (The Children's Tumor Foundation, 2008). As the tumors increase in size, they can press on vital areas of the body, causing problems in the way the body functions. Neurofibroma tumors are often removable. Although usually benign, an estimated 5% of Neurofibroma tumors are cancerous (Kids Health, 2008). There is a spectrum of Neurofibromatosis that ranges from mild to severe; however, it is a progressive disease without a known cure, so Neurofibromatosis is a lifelong condition for all who receive the diagnosis.

In order to shrink his tumors, Thomas receives a third round of chemotherapy treatments during regular outpatient hospital visits. Thomas also receives regular magnetic resonance imaging (MRI) scans in order to monitor the tumor growth. Currently, a tumor is located on Thomas' brain that is affecting his vision to the point that he has no sight in his left eye. Thomas' mother provides a majority of his maintenance healthcare needs at home, such as his tube feedings and medications. George identified several sources of support that he has utilized throughout Thomas' illness. He has participated in various organizations and camps for families of children with CMC. He has benefited from the opportunity to share his feelings and experiences with other parents going through similar situations. In addition, George relies on his faith in God and on his faith community for support and prayer. He prays daily with a friend and attends Bible studies in order to find hope and encouragement to get through each day.

Jeff

Jeff is a 46-year-old Caucasian male who is passionate about supporting his family and dedicated to providing a normal life for his daughter. For his initial interview, Jeff met this researcher at a restaurant during off-peak hours; consequently, there were only two or three other tables with customers at the time of Jeff's interview. Jeff was already at the restaurant sipping on a drink when the researcher arrived. Music was playing on overhead speakers, but it did not appear to distract Jeff from the interview questions. Jeff was talkative from the very beginning. He used his hands to gesture, especially during explanations surrounding his daughter's illness. He frequently made eye contact with the researcher and smiled frequently throughout conversation. Despite the limited amount of time Jeff was available to meet with the researcher the afternoon of initial interview, Jeff did not appear rushed and was able to answer questions

thoroughly. Jeff participated in a second interview over the phone several months later to fill in details of his story and confirm themes from his initial interview.

Jeff has been married to his 42-year-old wife for 16 years. Together, they have an 11-year -old daughter, Megan. Jeff is currently in-between jobs and is enrolled in part-time classes that he needs in order to complete his bachelor's degree. Jeff encountered his own health problems over the past year, which have limited his ability to work and caused him to leave his former position. Jeff expressed that his former employer has often been a source of frustration, offering little flexibility or understanding regarding Megan's medical needs. Jeff recalled a time when his former boss announced that he and his fellow co-workers would not be allowed to miss any days of work. Jeff inquired about whether he could receive an exception if Megan became ill. Jeff asked his boss, "*What if I have to take Megan to the ER?*" and his boss' shocking response was, "*Well she better be dying.*" Jeff was unable to find flexibility and understanding regarding his daughter's or his own health needs at his former place of employment. His family remains strained financially while he currently pursues other career options through higher education. Jeff's wife formerly worked in the music industry; however, since being in Georgia, she has committed to staying home full-time in order to provide for Megan's medical needs and to facilitate Megan's home-school education.

Jeff gave a detailed account of how he and his wife discovered Megan's illness. Her story began in the year 2000 when Megan developed severe headaches and unexplained bruising. After seeing physicians in Tennessee, the family's home state, Megan was sent to Atlanta, Georgia to be examined by a pediatrician who diagnosed her with Cystic Fibrosis (CF). Cystic Fibrosis is a genetically inherited disease that affects the lungs and digestive system. People with CF have an altered gene that causes the body to produce thick, sticky mucus that causes

multiple threats to a person's health. One problem is that the mucus clogs the lungs leading to life-threatening lung infections. A second problem that mucus creates is that it obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food (Cystic Fibrosis Foundation, 2008).

Megan's experiences with CF have primarily affected her digestive system; she has had very few respiratory or lung issues. Even though Megan was not diagnosed until she was several years old, physicians explained to Jeff and his wife that CF is a congenital disease. Without a diagnosis, Megan lived her first few years of life without treatment. As a result of the untreated CF, Megan's liver went into failure. She received a liver transplant in November 2000. Over the next several years, Megan experienced many complications related to her transplant and underwent various procedures to continue to improve her liver functioning. In 2002, Jeff and his family moved to Georgia in order to be closer to the physicians who had been caring for Megan. Currently, Megan is showing signs of liver failure once again. Physicians prepared the family that Megan will need a second transplant; however, they are unsure when a transplant will be necessary. While the first transplant was covered by insurance, this time Megan will need a living-related split liver transplant, which insurance will not approve. Consequently, Megan's parents will have to pay for the entire cost of a living donor transplant. Until the transplant is necessary though, Megan has regularly scheduled outpatient clinic visits and regular lab work done. Daily, Megan receives maintenance care from her mother such as continuous tube feedings at night and a variety of medications.

Jeff shared his frustrations and feelings of helplessness regarding many of Megan's chronic health issues. He understands the seriousness of her illness and feels limited in the ways he can protect her. He described his main sources of support as his wife and his faith in God.

He has a very open relationship with his wife that involves talking through each of their concerns and sorting through all of their options regarding Megan's healthcare. In addition, he firmly believes that God has been present throughout his daughter's experience with CF. The relationships he has built with members of his faith community have also been supportive through friendship and even fundraising.

Brian

Brian is a 41-year-old Caucasian male who has been in the unique position of choosing to raise a child with a chronic illness. Unlike the other participants, he adopted his child into his home and made the purposeful choice to live with a chronic illness. At the time that Brian agreed to participate in the interview, Brian's family was going through another period of transition because his wife had just given birth to a son three weeks earlier. Brian admitted that he had been sleep deprived over the previous three weeks and had a particularly difficult night with the newborn the night before the interview. Brian suggested meeting at a coffee shop for his initial interview. The coffee shop had a steady flow of customers throughout the interview. Quiet music was playing over the loud speakers. After purchasing coffee, Brian and the researcher sat down at a small table. At the beginning of the conversation, the surrounding noise was very low. Towards the middle of the interview, however, a loud conversation started at the table adjacent to Brian that appeared to distract him for a while. The other pair of individuals eventually quieted down, and the conversation between Brian and the researcher continued to flow naturally. Brian gradually used more eye contact with the researcher as the interview progressed. He often hesitated before answering and apologized to the researcher when he felt he was unable to produce adequate responses to the interview questions. The researcher reassured him that it was natural to take time to think and she made sure that he understood there

was no rush. Brian admitted that he would be better prepared for an interview with more rest and assured the researcher that he would be available for a follow-up interview. The follow-up interview took place over the phone a few months later. Brian was able to share more examples of support at this time, as well as to reflect on how the introduction of his second son has affected his needs and experience with support.

Brian shared that he has been married to his 39-year-old wife for 12 years. Together, Brian and his wife adopted their 7-year-old son David and have a second son who is now about 1-year-old. Brian has completed a master's degree and currently works full-time as a charter financial analyst for a banking company. His wife works part-time with a non-profit organization. Both employers have been supportive when Brian and his wife needed to take time off when David has required hospitalization or has medical appointments.

Brian explained that David spent the majority of the first three years of his life in and out of the hospital with complex liver issues. David's biological mother brought him to the hospital when he was 8-months-old where it was discovered he was in acute fulminant hepatic failure. This type of liver failure results from severe damage to the liver cells and has a sudden onset of unknown cause (Children's Healthcare of Atlanta, 2008). This failure occurs without the presence of a pre-existing liver disease. Because of the acute nature of this disease, David's liver was unable to be repaired or medically managed. His only chance of survival was to receive a liver transplant, which he underwent very shortly after being diagnosed.

After some time, David's transplanted liver went into failure. Fortunately he received a second transplant when he was 2-years-old. David's biological mother, a native of Central America, faced many challenges to caring for a child with such complex medical needs including limited financial resources, frequent follow-up visits, and the ever-present language barrier.

Brian and his wife discovered that David's biological family was unable to provide for a child with such complicated medical needs and made the decision to take responsibility for David and his healthcare by becoming his foster parents. After several years of being foster parents, Brian and his wife officially completed the adoption process when David was 5-years-old.

Since David's second transplant, his major medical needs have included frequent lab draws at outpatient clinics and the administration of his daily medications. David's outpatient visits gradually became less frequent as he continued to experience good health. David required an occasional, short hospitalization for issues such as fevers over the last year. Since David has required less medical interventions recently, Brian explained that his current stress is related to learning how to balance David's needs with the needs of their newborn son. Brian worries about keeping each child healthy and about how they will manage future hospitalizations with their second child. Brian identified his parents and his faith community as sources of support as he and his wife transition into a larger family.

In regards to David's biological family, Brian and his wife decided that it is best for David to continue to have a relationship with his birth mother. David visits his biological mother and his biological brother every 6-8 weeks. Occasionally, David will also talk to his biological mother or brother on the phone. Although David is comfortable in both homes, lately David has made fewer requests to visit his biological family and stays for shorter amounts of time when he does visit them.

Bruce

Bruce is a 48-year-old Caucasian male. Bruce is the only participant who was unable to meet for a face-to-face initial interview. The researcher called Bruce from a speakerphone in order to tape-record the interview verbatim. Bruce was at home for the conversation and the

researcher was located in a private office at the hospital where she is employed. The researcher received a verbal consent and verified that Bruce was able to hear her clearly before continuing with the interview questions. Despite the researcher's inability to see the participant and read his body language, the conversation flowed very smoothly. There were no interruptions during the interview. Bruce appeared comfortable with the subject matter of the questions and articulated himself with hardly any prompting. A brief, second interview was also conducted over the phone in order to fill in missing details regarding his son's medical history and to verify themes from the first interview.

Bruce shared about his family and his career. He has been married to his 51-year-old wife for 16 years. They have two biological sons who are 11- and 14-years-old. Bruce has completed a college degree and works fulltime outside of the home as a supervisor at a computer software company. Fortunately, his employer has been flexible over the years and has allowed Bruce to work irregular hours when necessary, especially during periods when his son has been hospitalized.

Bruce's 11-year-old son, Micah, was diagnosed 10 days after birth with a single ventricle heart, meaning that his heart had only one effective pumping chamber. Micah's heart disease is congenital, which means that his condition was present at birth, even though it was not discovered until several days after birth. His diagnosis is more specifically known as Double Inlet Left Ventricle (DILV). Unlike the typical heart that has two separate right and left lower chambers (or ventricles) that receive oxygen-poor and oxygen-rich blood respectively, individuals with DILV have only developed their left lower heart chamber. As a result, the oxygen-rich blood mixes with oxygen-poor blood, which is then carried into the body and the lungs (MedlinePlus, 2009). Surgical procedures are required in order to balance the blood flow

in individuals with this diagnosis. Other complications include feeding and weight gain (Cove Point Foundation: Congenital Heart Disease, 2009).

At 10-days-old, Micah's diagnosis was confirmed and he was admitted to the cardiac intensive care unit, where he stayed for two months and underwent two open-heart surgeries. His complex condition required a series of two additional surgeries that attempted to improve his heart function over the next several years. Unfortunately, Micah's problems persisted, requiring multiple, lengthy hospitalizations and eventually a heart transplant at the age of 3-years-old. One of the major responsibilities of Micah's medical care is his complex medication regiment. Micah has only had a few hospitalizations since his transplant including revisions to his previous heart surgeries.

Despite Micah's current good health, Micah's heart condition has seriously affected Bruce and his family's way of life over the last 11 years. While Bruce was able to take family leave from work for the first three months of Micah's life, he has worked full-time since then. Bruce described the challenge of dividing responsibilities for Micah and his old brother between himself and his wife. Bruce explained that a major source of support for him was extended family that traveled from out of town to stay with their oldest son when Micah was hospitalized. Friends also opened their homes to Bruce's oldest son for periods of time when Bruce and his wife were living at the hospital with Micah. In addition, Bruce identified hospital staff, such as nurses, as being supportive with building confidence in his ability to care for a child with a CMC. Over the years, Bruce has developed coping mechanisms including taking advantage of every opportunity to spend with his family and developing a system of mutual support and understanding with his wife. He described this mutual support, *"My wife and I divided things up and managed to keep things going....We had a system where, if one of us could go nuts and the*

other one would like hold things together.” Neither individual expects the other to remain strong at all times, so there is an ability to be understanding when one person needs to take a break and will require more support from the other.

Scott

Scott is a 44-year-old Caucasian male. For his convenience, the researcher met him at his office during his lunch break for his interview. Since his employer was flexible, the meeting was not rushed. Scott suggested that they walk to a restaurant down the street from his office building so they could eat while they talked. Scott asked the researcher several questions regarding her background and the study as they walked to the restaurant. The restaurant was very noisy with the hustle of the lunch crowd. In order to establish an atmosphere most comfortable for Scott to answer interview questions, the interview took place at an outdoor table where they could talk with the most privacy and the least number of distractions. There was minimal noise from the parking lot and a few interruptions from Scott’s coworkers who were eating at the same restaurant. Scott acknowledged his coworkers and then quickly returned to thoughts he was sharing before interruptions began. Scott shared openly about his experiences and was able to express emotions despite this public setting. Several months later, Scott participated in a second interview over the phone that included an update on his daughter’s health and additional suggestions for male support.

Scott has been married to his wife for 10 years. They have three biological daughters who are ages 5-, 7-, and 9-years-old. Scott has a college degree and works fulltime for a commercial real estate company. His wife works fulltime at home as a mother to their three daughters.

Scott's oldest daughter, Emma, was diagnosed with Acute Lymphocytic Leukemia (ALL) when she was 8-years-old. The term "acute" refers to the seriousness of the disease and how quickly it can progress. "Lymphocytic" refers to the origin of the cancer within cells called lymphocytes. Lymphocytes are a type of white blood cells found in the bone marrow (the soft center of the bones where new blood cells are created). In most cases, the leukemia invades the blood quickly and then has the possibility of spreading to other parts of the body. Treatment consists of three phases of chemotherapy that typically last two to three years. ALL is the most common type of leukemia found in children (American Cancer Society, 2008).

Pediatric physicians confirmed Emma's diagnosis of ALL and immediately admitted her to the hospital. Within 24 hours, she began her chemotherapy treatments. This hospital admission lasted about two weeks and consisted of numerous areas of education and future planning for Emma's medical treatment. After being discharged from the hospital, Emma returned for regular outpatient visits to the oncology clinic. Emma attends some clinic appointments solely for chemotherapy. Other visits are more time consuming and include additional procedures such as spinal taps or bone marrow biopsies. These procedure days are more stressful for Emma and her parents, so it is important to Emma that both parents are there at those appointments. Gradually, Emma's outpatient visits have become less frequent. In fact, she was scheduled to complete her last phase of chemotherapy treatment in December 2008. Emma has had a few hospital admissions over the last year. One admission was necessary because of the complications of an outpatient procedure and the other was due to persistent chemotherapy side-effects.

Throughout Emma's battle with cancer, Scott has identified and utilized various support resources. The support that he acknowledged as most effective was the friendship from a college

friend. This friend was present at the hospital to help Scott sort through overwhelming amounts of medical information and is committed to meeting twice a week to listen to Scott as they exercise together at the gym. Scott also explained how supportive it has been when friends coordinated meals and childcare for his well children during periods of hospitalization. In addition, Scott talked about the reassurance he has in the healthcare team that treats Emma. He has experienced support though having immediate access to physicians when he has questions or concerns about Emma's health.

CHAPTER 5

RESULTS

This chapter includes a description of the major themes that the researcher found throughout each of the participant interviews. Quotes from the fathers are included to illustrate fathers' experiences in their own words.

The major themes found throughout the interviews include (a) stress related to the inability to be the fathers they envisioned themselves being, (b) support that assists fathers in managing stress, and (c) barriers to receiving and requesting support.

Stress Related to the Inability to be the Fathers They Envisioned Themselves Being

Since support is conceptualized as a way of managing and coping with stress, it was essential to begin this investigation by examining fathers' sources of stress. Fathers expressed many different areas of stress including personal, relational, emotional, and illness specific stress. One overarching theme that was expressed by all the fathers was stress resulting from their inability to be the fathers that they envisioned themselves being to their children now that a chronic illness has interrupted their lives. Fathers focused on several specific aspects of stress that relate to disappointment including: (a) father-child dynamics, (b) accepting the child's differences from typical children, (c) feelings of helplessness, and (d) limitations illness imposes on family.

Father-Child Dynamics

Parents have expectations about the types of interactions they can look forward to having with their children. Men gather these expectations from a variety of sources such as their own families, friends, religious groups and communities. Those various sources have influenced

men's roles and attitudes about parenting. Participants in this study agreed that there is a certain level of comfort with meeting those parenting expectations.

One of the fathers, Bruce, clearly described his own expectations by saying, "...*men just naturally interact with kids, especially with boys, [through] play...*" Bruce compared the play dynamics that fathers share with their children to the more nurturing role taken by mothers:

...In a normal family, when the kids have got a cold or something, it's Mom who is doing all the stuff and tucking them in, putting a pillow behind there, making them feel better. And Dad's like, 'Hurry up and feel better so we can go do something.' It's just not quite the way we are wired.

As a father, Bruce has found it more natural to participate in activities with his sons rather than to offer them comfort. The word "wired," suggests that, in addition to the multiple influences on father-child dynamics mentioned above, there might also be an innate aspect of the interactions fathers have with their children.

In addition to an innate aspect of father-child dynamics, previous parenting experience also plays a role in how fathers form their expectations about how they will interact with their children with CMC. Four out of five fathers participating in this study had previous experience raising healthy children or spent several years with their children before they developed chronic illnesses. During these periods of good health, fathers interacted with their children according to their expectations. Once their children's health issues were diagnosed, however, fathers were forced to re-examine the way that they interacted with their children. Fathers experienced stress related to learning how to be a parent to a child with a CMC.

Bruce described his lack confidence in knowing how to interact with Micah as a newborn because of his heart condition. He compared this to how easily and naturally he interacted with his older son as a newborn:

Our oldest son is healthy as an ox. I mean, you could pick him up, I mean, literally from the day he was born his head wasn't flopping around; he was just strong and everything. Here is this tiny, little, half-starved looking, blue, miserable-looking kid. And, to tell you the truth, for a long time I was really kind of scared holding him. I mean, he was just so fragile...

Likewise, George compared his interactions with Thomas and those interactions he had with his older son.

I try to play games [with Thomas] like normal kids. I try to have more patience than I would with a normal kid. With my older child, we used to do normal things. It was almost easy. With Thomas, it's like a test every day...To go out and play with Thomas, it takes a lot of patience. [I have to] give so much direction...

Sometimes fathers described a more generalized sense of frustration about not knowing how to be a parent after receiving a chronic diagnosis. Scott made a plea for help after he learned of his daughter Emma's diagnosis of ALL. Even though he felt like a competent father a few days before, he was in a much different position when he said, *"Someone needs to help us figure out what we need so that we can do our jobs as parents because now being a parent is completely changed, and I don't know what to do..."*

Accepting Differences from Typical Children

A child's diagnosis of a CMC influences nearly every area of a father's life. Fathers must learn to accept their children's differences from typically developing, healthy children.

Fathers in this study described the overwhelming disappointment that they experienced as they learned to accept their children's limitations. Fathers have to balance the severity of the diagnoses with their own desires to provide normal childhoods for their children. Jeff described how isolated he felt when he considered all the special precautions he had to take with Megan because of her diagnosis of CF:

Normal, everyday people have no idea the stress levels of how to deal with a terminal child. Because, as they told us right from the get-go, 'You cannot treat Megan as a normal child anymore.' If she spikes a fever, she has to be in an ER or the hospital within four hours. If she goes beyond four to eight hours she could start becoming septic, and within eight to twelve hours she could be dead.

Jeff detailed the seriousness of Megan's condition. He recognized that because there is no cure for CF, he has to do everything he can to protect her from complications that would worsen her chances of survival. Unlike most parents with whom he interacts, he has to be extremely cautious and conscientious with even the smallest of his child's symptoms.

Most of the participants revealed how their children's medical conditions have affected their children's academic progress and their ability to keep up with their peers. In some cases, this was because of cognitive delays. In other cases, the child's challenges resulted from frequent school absenteeism. Fathers comments centered around the challenge of seeing their children struggle more than most children to be successful academically, and in some cases just to participate in school at all. Scott expressed how Emma's cancer has affected her academically:

She's back in school, and we're trying to keep her there. She's in a Special Education program now. She was a bright child before all this started... she got pushed down into

Special Ed. Chemo has affected her sight and vision...we're dealing with all the ancillary stuff now...

On a similar note, Brian described how David's chronic hospitalizations and health issues have created academic and cognitive challenges:

The first 3 years of his life, he spent the majority of that in the hospital. He's still, even after all this time, a little bit behind developmentally or educationally. I mean, we notice things. We've held him back a year in school, or waited to start him.

In addition to the cognitive challenges, fathers revealed social implications of their children's chronic conditions. Bruce described how Micah has been challenged to keep up with his peers during scouting activities because of his cardiac issues:

That's one thing that kind of hurts every once and a while with doing the scouting stuff is that Micah just doesn't have a lot of physical endurance. You know, he'll do okay for about the first hundred yards and then...

Bruce found it impossible to deny his son's differences when he was engaged in social situations. It was difficult to watch his son struggle to do the same things that his peers appeared to accomplish nearly effortlessly.

Other physical activities that are challenging for many CCMC are athletics. Although Thomas has vision and balance issues, George and his wife have encouraged Thomas to participate in activities that he enjoys such as sports. Thomas is a member of little league baseball team that understands his limitations and adapts Thomas' role on the team according to his abilities. Despite these efforts, George talked about how hard it is to see Thomas trying to fit in with his teammates at the ballpark:

... It really hurts that most of the kids, I'm not saying that they are 100% healthy, but they

can play ball. And then you see your child out there, that he can, you know, can barely move. It hurts. It really hurts. But you have to let it go...let them do what they feel comfortable doing. And, I'm not going to worry...

Despite George's resolution to support Thomas in his adapted sporting endeavors, George honestly admitted that he grows weary of watching Thomas struggle:

And then sometimes you lose your patience because you want them to be a normal kid, but he can't be... like baseball, we know he can't see the ball, and we try to be ok with it. But honestly, it gets old. It seems like you are going backwards.

George described the frustration of knowing that Thomas' physical abilities will not improve with practice like they would for most typically developing children. In fact, the gap between Thomas and his peers continues to widen as Thomas' tumors affect areas of his brain that control his coordination and sight.

These scenarios exemplify how chronic medical conditions invade every area of these families' lives. Fathers participating in this study outline the many different ways in which their children's CMC have set their children apart from their peers. It is stressful for fathers to recognize that there is no way to protect their children from these painful experiences. In the next section, fathers' lack of control leading to feelings of helplessness will be explored.

Feelings of Helplessness

Traditionally, there are certain expectations about the way that fathers will interact with their children. Fathers participating in this study expressed that when they have been unable to fix their children's problems or take away their children's pain, they have faced feelings of helplessness. When fathers discover their inability to solve problems actively, they find themselves in a much more passive role. Fathers explained that part of the reason that a passive

role is so disconcerting is because it is inconsistent with the parenting roles that they have imagined for themselves.

Jeff told about the initial helplessness a father experiences when he first learns his child has a terminal illness:

...It's a very sensitive time. They are going through this news about their child being sick and they want to fix it, but they can't because we don't know what is going on. [They are] feeling rushed and unable to help, unfatherly like.

George expanded on this thought by explaining that he not only experiences pain when he is forced to admit that he cannot fix his child's problems, but also how difficult it has been interacting with others who do not understand the magnitude of his challenges:

Every dad goes through the same thing, seeing your child like this, but there's nothing you can do. I try to fix broken things, hard not being able to do anything. Only God can handle this. People at work get frustrated about small things, but I think, 'Come see my world.' Some people understand. It clicks. For others, it doesn't. Compared to our problems that we can't fix... it's hard.

George continued to explain how his feelings of helplessness are related to the specific expectations he has for himself regarding being able to provide for his children:

I guess most of men like me have the same problem, is that you kind of feel like handicapped. That you can't, you can't fix the problem. You can't fix somebody else's problem, but you can't do anything to fix your own problem, especially when it comes to your kids.

Jeff told of similar pain regarding Megan's chronic illness, "And when you see your child laying in that bed hurting, and not be able to fix it... that was probably, and still is, the hardest thing to

deal with.” Scott experienced similar feelings of helplessness regarding his inability to fix Emma’s chronic pain. He explained how his helplessness often results in feelings of depression, “What makes me depressed? Yeah, it’s when Emma, when she is sick, or sick through the leukemia or unable to, when she’s in pain...” Emma’s leukemia is not only physically painful for her, but it is also emotionally taxing on her entire family. Scott revealed how hard it is to cope with the realization that his inability to help Emma could result in him outliving his daughter, “You know, it’s like, it’s not that you just want to give up, but God forbid something happen to my daughter, I kind of think, can I go on?”

Bruce described feeling out of his element trying to be a caregiver to his son with cardiac issues and being so aware of his son’s fragility:

Dads are much better at dealing with healthy kids that they can do stuff with. I mean, dads are there to throw the kid up in the air and do piggyback rides and stuff like that. Sitting there watching him in the bed, you feel absolutely powerless. It’s like, okay, I’ve just got to sit here and watch him, or, you know, hope and pray nothing happens.

Loss of control is an element of helplessness that multiple fathers focused on during their interviews. Scott told about how his vision of what he should be able to provide his daughters had been shattered:

I think as a male traditionally we are growing up that the male is the, you know, is the provider of the family....he’s the police man, he’s the security guard, he’s the banker, he’s the lawn service, he’s the everything guy. And now, all the sudden, you can’t control. So that is, I think that affects us.

George described how helpless he feels regarding making a difference for his son:

Feels like no matter what you do, it doesn't make any difference. Maybe best to leave him be. He'll be on chemo forever, but taking risks is hard. Talking to others helps, but what works for one child may not work for mine. Like winning the lottery, hoping for hope. You pray every day, seems like you take one step forward, three steps back. It's hard to stay focused... maybe God knows.

While each of these fathers has different circumstances that have rendered them helpless, there was a common theme around the loss of control and frustration surrounding the inability to fix their children's problems. These quotes exemplify how stressful and disappointing it can be for fathers to have such limited roles in their children's lives and to experience roles that are so contrary to the roles they envisioned for themselves.

Limitations Illness Imposes on Family

In addition to their feelings of helpless and loss of control, fathers also focused on the ways in which a chronic illness places limitations on their families. Limitations included lack of time, energy, and opportunities.

Four of the five fathers have other children besides the target child with the CMC. These fathers discussed how the demands of a CMC often leave little time for other responsibilities. In fact, they frequently mentioned the guilt surrounding disappointing their well children. Fathers felt responsible for maintaining normalcy for the well children, but they also expressed how challenging this task becomes with the demands of the illness.

Bruce described the difficulty he has had trying to celebrate holidays with this family. In this situation, he recalled a Halloween when Micah was hospitalized and he tried to sneak away

for a while to enjoy trick-or-treating with his well son:

It really killed me, because I actually came up from the hospital to take [our older son] trick-or-treating. And, you know, its like, 'Ok, we've done this little section of the neighborhood, now I have to go back down to the hospital'. And it's like 'Dad, why do you have to go?'

Bruce described the extreme guilt that results from questions such as these from well children. He knows that there is only so much time he has to offer and does the best he can, but it never feels like enough.

Scott told about a similar frustration of not being able to give his other children the time and attention they deserve. While he acknowledged that what he actually needed was help from other people, he described how pride often stops him from asking others for assistance:

I'm not going to go ask anybody, what I need is a babysitter. What I need is someone to go hang out with Emma's siblings to make them happy so that we can spend some time with Emma, so we can take her to the emergency room. Otherwise, you just kind of just say, 'You know, we'll take care of ourselves' because it's human nature. But the reality is that you can't take care of it yourself.

Scott explained that the needs of his well children are extremely significant, but he is not capable of meeting those needs while juggling Emma's medical needs. He admitted that most fathers have difficulty acknowledging that they need this assistance, but there comes a point when a father must recognize that his family's needs are more important than retaining a sense of pride and independence.

Even when fathers are ready to receive help, finding help that is specifically geared towards the well siblings is not always easy. Scott described the challenge of not being able to

give his well children the attention he desires and the frustration with getting help for his well children:

Your siblings need somebody to talk to. Somebody needs to make sure that the siblings aren't being neglected, so there's all those follow-ups, but people don't want to pay for those things. Organizations don't want to pay for those things because, you know, you always want to help the child that needs...I'll help Emma...somebody just help me with the other kids.

In this case, Scott has encountered organizations and groups who are willing to provide resources to assist the child with the CMC, but help for well children is harder to locate. Scott identified this gap in resources available to families and suggested that sibling support is an area that could use improvement. Scott and several other fathers emphasized their determination to make sure that their well children do not suffer because of their own limited time and the limited number of resources that include the siblings of CCMC. Examples of support that families use in the absence of organizations and groups that support siblings include family, friends, faith communities, and teenage babysitters.

Fathers also described the challenge of making choices about how to spend the time that they do have with their well children. Ideally, there are experiences and opportunities that fathers would want to give their children. Scott talked about how he wants to teach his children about Jewish traditions, but the demands of Emma's medical needs limit their involvement in religious activities:

I typically would go to synagogue because I wanted my kids to know how important it was. I mean, I'm too far gone already and that's why I kind of laugh, but I wanted my kids to know. But now, we just got busy.

Scott described how his patience is strained more than usual when Emma feels badly from the chemotherapy side effects:

When Emma does not do well, it just kind of creates, it makes [my wife] and I anxious and then it creates all sort of, or a whole new set of issues between [my wife] and I and the kids. Now I'm very upset, and that means her siblings do something and my temper is very short.

Bruce described the way he and his wife would divide responsibilities in an effort to dedicate equal attention to each of their children and to provide some semblance of a normal life:

It kind of ends up evolving into almost a single parent household. You've got the normal half where the siblings are still doing their things: going to school, going to daycare. They've got whatever social outlets they might have. You know, like peewee baseball or whatever. And you're trying to keep things as normal as you can for them. And yet, you're running around, literally some days we were driving between two hospital visits for me, and going to work and everything else, a hundred and some odd miles a day...so you try and keep things as normal as possible, and yet, that's almost an impossibility.

In addition to being limited in what time they can offer their well children, several of the participating fathers also mentioned guilt surrounding being absent from their CCMC. Brian talked about how torn he has felt when David has been hospitalized:

I guess for me it was just trying to balance, you know, kind of supporting [my wife] and David while they're in the hospital and being there, but then also having work responsibilities and kind of feeling guilty no matter where I was. If I was at the hospital, I felt like I needed to be getting some work done, which wasn't happening. Then, if I was

at work, you know, kind of wondering what was going on and feeling bad that I was there.

When asked if anything about the experience of raising a child with a CMC has made him angry, Bruce described how he remained unsatisfied with the amount of time he was able to spend with different members of his family during periods of hospitalization:

Just how frustrating it was to try to juggle everything and how guilty you felt when, you know, I'd really like to spend another 10, 20 minutes. I'd like to spend as much time as possible here, but I've got to spend as much time possible there too.

Support That Assists Fathers in Managing Stress

Considering the significant stress that fathers described regarding developing a new set of expectations about parenting, it becomes necessary to explore the ways in which fathers have learned to manage this stress. The following section includes some of the strategies that fathers used to cope with disappointment and the stress of parenting a child with a CMC.

Support that Relieves Guilt and Makes up for Limitations

While there are a variety of sources of support that fathers mentioned, one specific area of support that fathers emphasized is the support that helps them cope with their limitations and accruing guilt that was outlined in the previous section. Many examples of this kind of support include support from other individuals such as friends, family or co-workers. Scott talked about how limited his time has been since Emma has started treatment for ALL and how supportive it has been when others relieve some of his personal burdens so he is free to spend time with his daughters:

I mean, I would laugh, people call me and ask what can I do for you? And I'm like, do my

yard. I'm so busy trying to take care of my kids. I can either go spend an hour with them or I can go spend an hour doing this. Or somebody just come over and clean my house.

Fathers described how difficult it was not having time to complete those daily tasks they had pictured themselves being able to do for their own families. Pride was a major concern for these men who find it difficult to ask others for help. Some of the fathers found themselves needing financial assistance because of the major costs of medical care. Jeff talked about the support he found in a network of friends who were determined to assist with the financial aspect of Megan's medical needs:

Now we have a support system, not only from our church, but we have friends... who are incredible. I mean, they have done fundraisers. We didn't ask them, they just did it. And I mean, it's just incredible the people who have come around us to help us. We put on a benefit concert...And they are helping us raise money to give the transplant that Megan needs and we need for her health. We need to do a living-related split-liver transplant which is an out-of-pocket, voluntary type of thing.

Brian described the way that David's school has been supportive of his academic and social challenges through a mentoring program. David had a very different start to his life than many of his peers. His first few years were spent in and out of the hospital and his biological family spoke limited English. David has also transitioned into a new home, unlike most of his classmates. Brian explained how the mentoring program has provided relief for his own anxiety surrounding how David will cope with his differences from his peers:

... [The school] tried to pick kids who need extra help either academically or whatever...he's chosen probably because he's shy. It's a unique public school in that that it's really good. It has over-the-top parental involvement, but it makes the school

good. The mentor program is different than a lot of other schools. I'm interested to see where it goes. I hope it helps him. We try to set goals with the mentor. See what they can do to help him be expressive because he's normal around us or around his good buddies. But in the bigger environment he clams up.

Some fathers explained the importance of being intentional about the types of people that they seek out for support. Brian suggested seeking supportive individuals who would be willing and able to help deal with your guilt, *"Try to find folks that you know give you support, whether it be just kind of reinforcing, helping you not have that guilt about being at work or things like that."*

In many situations, the support that fathers described as most effective was support from other families of CCMC - those individuals who have been through similar experiences. George talked about the benefits of talking to other families of CCMC:

And then you get to meet a lot of people who go through the same, the same channels.

And this is when you start sharing a lot of information that, you know, kind of helps you go through the struggle of the, this disease.

George went on to mention the relief of being with other parents, who feel uncertain about the future and how to be a parent to a chronically ill child:

That is why sometimes we rely on group peoples and stuff like that. So when you talk to them they understand exactly where you are coming from. Waking up in the middle of the night just thinking 'What am I going to do?'

Bruce described how talking to other parents who have been through similar situations with their children has allowed him to gain perspective on his situation:

That's probably the one thing that helps the most, when some other parent can say, 'Yeah, my kid had the same thing yours did and look at him now.' And for a while, the family support people [at the hospital] would sit there and say 'You probably ought to talk to this family because their situation was very similar to what Micah's originally was.' Or 'You know these people? Their kid just had a wound infection, a post-surgical wound infection.' 'Oh, we did that! You know, isn't it gross?' 'Yeah, it sure is!'

Not only can sharing with other families of CCMC give hope to families about their children's futures, but it also helps families feel less isolated. They can take comfort in knowing that other people have gone through similar situations and survived.

Another form of support that helps make up for limitations involves activities facilitated by various organizations and groups. Bruce explained how activities at the hospital that create opportunities for fathers to be in a more traditional role are most comfortable and supportive, *"That would be good...the dads would have a chance to see other dads and the kids would be playing. It would be like the day at the park..."* He also recalled a time when the hospital provided such an opportunity:

They had lunch in the garden and they had a Putt-Putt course set up...and yeah, thinking back on it, there were a butt load of dads there. And you know, dad is sitting there, you know, holding the kid's arms when he's using the little putter. That's the kind of stuff that dads are much better at than trying to provide cuddle and comfort when the kid's sick.

Bruce talked about the support that he has received from hospital staff regarding opportunities to celebrate normal events even when medical issues put limitations on the family:

That's really something that is supportive...is the ability to do things, like you know, like birthdays and things like that. Even though you're stuck, one of you is stuck in the hospital. Just a little something. I mean, this gal brought in I think it was like a tray of brownies with a couple of candles stuck in it for my older son. She picked up something. We ordered pizza in and had a little party on the floor of the room. That's, like I said, that's probably one thing where people could help. Kids are sick whenever they are sick. You will spend every holiday, every family event, and every anniversary, there's something where you're going to be in the hospital.

Because of so many medical expenses, fathers expressed great appreciation to organizations such as Starlight Starbright Children's Foundation, which provided opportunities for their families to enjoy events together:

So it's probably one of the best things we've been involved in because you know what, they make available things we'd not normally be able, well we'd never be able to afford or be able to do, and they've allowed us to do that...They give you something, and with limited finances that families have, or that we have, we're not able to spend money on tickets or different things like that. (Jeff)

Creating a New Kind of Normal/Developing a New Set of Expectations for Themselves

Another area of support involves resources that help fathers reframe what is normal for them as parents now that their children have been diagnosed with chronic medical conditions. Fathers describe the people, organizations and methods that have been helpful to them as they strive to establish new, realistic attitudes surrounding their roles as fathers. Fathers explain how

these resources have assisted them in dealing with emotions such as disappointment, grief and guilt surrounding raising a child with a CMC. Once these emotions have been acknowledged and validated, fathers also describe how these resources have supported them in moving towards acceptance of their situations and appreciation for their unique families.

One of the stressors fathers described in previous sections was the limited types of activities in which CCMC can participate with their peers. Even though some CCMC may attempt to join their peers in typical settings, their limitations often set them apart. It can be painful for fathers to watch as their children struggle to find acceptance. Fortunately, organizations exist that provide opportunities for children with CMC to participate in activities with other children with the same diagnoses through experiences such as camps for children with unique health needs. “Normal” is completely redefined in the context of chronic illness. Reflecting on his experiences with camps for children with cardiac illnesses, Bruce described how witnessing his son Micah interact with other children who have similar limitations creates a much needed sense of normalcy:

I was a counselor one year, a cabin counselor, at [the] camp [that the hospital] puts on for the cardiac kids. To tell you the truth, I had probably one of the best weeks of my life there...it's a joy to see these kids being almost normal kids. Or being as normal as physically possible. It works wonders for me.

In the midst of so many other children who have unique physical needs, Bruce feels more comfortable and finds assurance. Outside of the camp setting, Bruce and his family seek out opportunities to surround their son Micah with other children who will understand his limitations. Bruce described the benefits of seeing Micah with other kids who have physical

limitations during outings sponsored by a support organization for families of CCMC:

...it's nice to be sometimes in a group where if your kid really is sick but he's able to go out, it's nice to know, well we're not always tail-end-Charlie because Micah can't keep up or we have to stop and do this, that, or the other because you're not the only one in that boat....being in a group where, you know, there isn't a lot of people saying 'come on, come on, come on...you're holding everything up'...usually some adult smacks them on the back of the head and says 'Stop! Your brother's not moving any faster than that either'. That sort of thing has been really cool.

Seeing other families who are dealing with the similar challenges provides relief and a sense of belonging for parents and children alike.

In some situations, fathers feel that their own attitude is what can make the most difference in managing their stress. It may involve surrounding themselves with people who can understand and who can resist taking setbacks too seriously. Fathers often learned how to cope with the seriousness and complexity of a CMC through interactions with other families of CCMC. Jeff talked about how his family has learned to use humor in ways that others, who are outside of the healthcare world, may not understand:

When we were going through [the] diagnosis, even though it was heavy information, [we] tried to keep it fun, tried to find things to laugh at. A lot of people who don't have hospital visits, they hear stories and think it's horrid. At the time, it wasn't funny, but looking back, it's quite humorous. We try to laugh as a family.

What had previously seemed absurd to Jeff and his family is now an effective way of coping with the stress of the illness and the reality that life will never be what it was before the illness.

Beyond relationships with other families of CCMC and involvement with diagnosis specific organizations, fathers also rely on religious groups as a way of establishing routine and acceptance. Bruce described how his faith community has provided a much needed sense of normalcy for his family:

[Micah] kind of grew up there, and people were aware of what was going on, and that was a big help. I think for me it was like, yeah, we're not quite normal, but we can at least kind of spend some time, you know, doing normal things like going to services and stuff like that.

Like Bruce, Brian focused on the ways in which the relationships he has with other parents within his faith community have allowed him and his wife to feel supported. In fact, his church is a place where their differences are diminished and their similarities are emphasized. While the friends that Brian has through his faith community are concerned about David's health and are available to help when David has medical needs, David's medical issues are not the focus of attention in this setting. Brian explained why his involvement with his church has been so positive:

...because they got to know David and [they] ask about the kids. It's a good environment for our family. There are so many other people in our stage of family, so they understand....they can help us out when we need it. We have an outlet. We can relate and share experiences. [It is a] good crowd, we share the same values and want the same things for our families. It's a supportive environment.... the kind of folks you could call no matter what when you need help or prayers, and we would do the same for them.

While most of the fathers focused on the daily management of stress and the routine needs of their families, there was also emphasis on how support can help during unique times

such as hospitalizations, especially those that coincide with the holidays. Bruce described how supportive it is when others can help provide normalcy that he cannot create for his own family during periods of hospitalization:

That's probably one thing where people could help. Kids are sick whenever they are sick. You will spend every holiday, every family event, every anniversary, there's something where you're going to be in the hospital...I remember when some group did Thanksgiving dinner. And it was just really, really nice just to have some touch of the normal cycle of events through a year even though there's no way on earth you can run home and like cook a 14 lbs turkey and bake a pumpkin pie.

Rather than becoming devastated about their inability to celebrate the holidays as planned or desired, fathers learn how to find comfort in the gestures offered by others. Bruce acknowledged that life will continue to proceed despite a CMC and his family continues to learn how to reframe what is normal and cherish the experiences they share as a family.

Several of the fathers focused on the necessity of dividing responsibilities between themselves and their wives as another way of managing the complex needs of a child with a CMC. While most fathers described a desire to be more involved in the daily management and care of their CCMC, they also have financial responsibilities that require them to work outside of the home. Out of necessity, the responsibilities must be shared between parents. Brian suggests that fathers focus on the positive aspects of dividing responsibilities between parents. "...it's something that's good for the kids to see, that dad or mom [are working to support the family]...that's an important element of family life and it's even demonstrating that work ethic." Brian has decided that he will not downplay his important contribution to his family or the important example that he is setting for his sons about responsibility through his dedication to his

job. A simple reframing of this work obligation may also help other fathers grapple with guilt due to absence from their families and help them to value the financial contributions they are making.

As fathers learn to reframe what is normal and develop new expectations for themselves as parents, it is necessary to develop a sense of openness about what it is that their families need. Participants explained that this could be extremely challenging for many men because their pride often stands in the way of admitting that they need assistance at all. For example, George has had to learn to be more honest in expressing the needs of his family. He explains that it is impossible to get the support that will be effective without being open with those people who are offering to assist. He claims that, “ *...there are a lot of people that are willing to help, but it is like I was saying, you’ve got to be open to letting people in otherwise they don’t know how to help you.* ” George admitted that this is a new way of interacting for him as a male. Despite how unnatural it seemed at first, he described how sharing became easier over time. In fact, he is now at a point where he feels comfortable encouraging other fathers who are still having trouble with openness to embrace a new sense of normal that involves admitting the need for support.

Barriers to Receiving and Requesting Support

During conversations about support that helps fathers relieve their stress, fathers verbalized many of the obstacles they have encountered to accepting support. While some obstacles, such as personality and pride, are internal, there are other issues revolving around the practicality of the support itself. Does the support meet the fathers’ current needs? Is the support convenient? Moreover, are these resources natural for men to use? The following examples are meant to share the unique male perspective on accepting and requesting support.

While many of the fathers described the ease with which mothers interacted with each other during lengthy hospital stays, fathers explained that this was not true for them. Bruce described the unique dynamics between fathers on the hospital unit. His impression was that unlike mothers, fathers feel far less natural building relationships with each other than mothers do. He shared how hard it is for him to imagine fathers interacting similarly to the way he sees mothers interacting, *“I really couldn’t see the dads just kind of looking down the hall, going, ‘Hi. How long have you been here?’ It’s not quite the way they work.”* One practical reason that fathers are less likely to form relationships with other parents is that they are less present in the hospital setting. Bruce continued sharing the challenges that result from being the breadwinner and the parent who has to leave the hospital more frequently, *“The dads have to do in and out, in and out, between the real world and the hospital world that they don’t quite build as much of a network as the moms do.”*

One type of support that is commonplace within chronic health populations is support groups. All of the fathers participating in this study have had the opportunity to participate in such groups, yet many have been reluctant to engage in these groups. Bruce theorized that men do not have the same natural inclinations to share feelings as their wives might have:

...I don’t know that most men would just get together and, you know, talk about this and that of being with a sick kid except if it’s in the family setting and two moms are just chatting away and it’s sort of like, well we’re all sitting at the same table and you just kind of get drawn in to it. Just because I think that if you presented it like an Oprah moment ‘Let’s all go open up and talk about how we feel,’ then it’s, yeah right, not happening.

Perhaps men benefit from support group sessions that are couple oriented, but Bruce doubts that a group made up exclusively of men trying to share experiences would be successful.

One of the alternatives to a purely conversational support session is more activity-based sessions for fathers to form friendships in a setting that is less directly dependent on fathers being willing to share their feelings. Despite the appeal of gathering fathers of CCMC in a casual setting in order to promote therapeutic friendships, the guilt that fathers described about being away from their families during these group meetings is a barrier to their participation in these events. Jeff explained, *“Men could do activities like golf or fishing, but depending on child’s circumstances, they may not feel that they can go. Hard to talk them into it. Don’t want to induce guilt on the fathers.”*

Another major theme was the pride that keeps fathers from requesting or accepting support. Scott described the need for people and organizations to be persistent in order to break through the barrier of pride:

They were so aggressive about ‘What can we do to help you?’ And that’s what I think people need. Otherwise, you just kind of just say, ‘You know, we’ll take care of ourselves’ because it’s human nature. But the reality is that you can’t take care of it yourself, and people are too proud to say, ‘You know, I need some help.’

George also described how his pride has become an obstacle towards accepting help from others, *“It just don’t feel right to me that someone just comes and gives it to you.”* Not only does he feel awkward allowing others to provide for him and his family, he also acknowledged that admitting a need has to precede accepting help. George understands that men often feel uncomfortable admitting that they have problems:

I know that women share a lot more than we do, but most guys just don’t. We know, just

go to a place, and if they don't ask you, nobody's going to know what's, what's inside you. So I think that it helps if you start kind of just let it go, just open it up. It's nothing wrong that people know you have a problem. There's nothing wrong with that. The problem's not going to go away until you start saying things. And it's like I said, maybe this is when people are willing to help you out. Because there's a lot of people out there who are willing to help you out, but the problem is, is that they don't know how to help you out until you start, you know, talking.

CHAPTER 6

DISCUSSION

In the following section, interview findings are applied to the research questions that the researcher used to guide this study. The themes and findings are used to answer the researcher's questions regarding how fathers define and use support related to their children's chronic medical conditions. In addition, the relationship between the interview findings and the current literature is explored.

How Do Fathers of CCMC Define Support?

The first research question "How do fathers of CCMC define support?" needs to be answered in context of the type of stress that fathers of CCMC experience. Since the fathers participating in this study focused on the stress surrounding not being the fathers they envisioned themselves being, the way that fathers define support is related to the disappointment of not meeting those expectations about fatherhood. According to the participants, one aspect of support involves resources that assist fathers in managing various emotions such as disappointment, guilt, confusion and loss of control regarding parenting a child with a CMC. George recalled how talking with other parents of CCMC has validated his concerns and has created a sense of relief, "*...they went through the same thing, so they know exactly what you're talking about.*" Fathers admitted that even though sharing can be beneficial, men need encouragement to be open about their feelings. Bruce suggested that support should include, "*something to convince [fathers] that it's okay to talk about it with other people who are in the same situation.*" Support that offers a comfortable atmosphere for men to share with other parents of CCMC was a major theme throughout the interviews.

Fathers also defined support as a way of coping with their limitations as parents and learning how to accept assistance from others. In American culture where people take pride in independence, fathers often feel shame and embarrassment when they are forced to rely on others for assistance. Fathers described support as a means of normalizing receiving assistance from others. Surrounding themselves with other fathers of CCMC who have managed hesitations with accepting help is an example of this type of support. Other examples include friendships, faith communities, and organizations for families of CCMC.

In addition to coping with emotions and learning how to accept assistance from others, fathers desire support that establishes new expectations for their families. Fathers explained that support helps to create a new sense of normalcy and a new set of expectations for themselves as fathers. Becoming involved with other families of CCMC can help to create a new environment where limitations are accepted and expected. Fathers also described how talking to other parents of CCMC helps them to obtain a clearer picture of what they can realistically expect for their children with CMC, as well as help to reevaluate their priorities.

What Types of Support Are Helpful to Fathers of CCMC and Under What Circumstances?

The second research question was “What types of support are helpful to fathers of CCMC and under what circumstances?” According to the main themes that surfaced during participant interviews, fathers need support in managing the stress that comes from having to learn how to parent a child with a CMC. Support that relieves guilt and makes up for limitations is most useful to fathers, as well as resources that aid fathers in creating new kind of normal and/or establishing new expectations for themselves. Fathers expressed that parenting is completely transformed and unfamiliar once a child is diagnosed with a CMC. Fathers identified a need for community of individuals who are able to guide newly diagnosed families in learning an adapted style of

parenting and who remind parents that they are not entirely isolated. Brian explained how group activities with other families of CCMC have been supportive, *“There’s other families there that we know. They’re in similar situations. Sometimes it’s nice just to kind of share stories. At least you know somebody else is kind of going through the same thing.”*

Since participants agreed that the sense of community and support from other families of CCMC has been essential to their coping, it was important to look more closely at the characteristics of these opportunities that create the most effective context of support for fathers. Fathers identified specific qualities of the groups they found most beneficial. For one, fathers have had positive experiences with groups that invite couples to attend sessions together. Scott explained the benefits of couple sessions:

...When you go to these things there’s a spouse that’s always quiet. So if you’ve got two of them, somebody’s going to talk, and it’s such a charged topic that the other spouse will say, ‘Don’t forget about such and such and such.’

Scott described the way that personality plays into support group dynamics and conversational flow.

In addition, Scott’s experiences have taught him that groups that include families with a large range of experiences are helpful to parents who are attempting to gain perspective on their lives. He described the benefits of attending group sessions with other families at various stages of cancer treatment :

There’s people at all different levels of where their child is sick. Some people are brand new and some people are two years into it. I liked the range. One, I liked that there were people who were brand new because it made me feel, ‘Thank God, we’re so much farther ahead.’ And I’m sure it made them feel that there is a light at the end of the tunnel.

On the other hand, Scott recalled how group sessions included families whose children were doing much more poorly. While he empathized with these families who are dealing with very difficult health issues, these were also opportunities to be thankful for all that had been going well with Emma.

Another facet of support that fathers described as helpful is offering support centered around activities. Men often feel more comfortable when the primary focus on the event is an activity rather than conversation. Fathers explained that through casual activities, conversation often follows. Brian proposed that fathers are more likely to spend their spare time attending support group activities if they involve, not only an activity, but the entire family. He suggested sporting events or picnics with other families of CCMC as a way of connecting fathers and starting support networks. As mentioned before, these activities are also a reminder for fathers that other families are adapting to life with a CMC as well. Whereas so many other activities within their normal communities highlight their children's differences, these types of events create a sense of acceptance and reassurance.

In addition to a sense of belonging and encouragement from other families going through similar experiences, some fathers also described a need for friendships rooted in religion and faith. Brian shared how he has relied on other families from his church when he has been in need, *"[They're] always really good about helping out. The kind of folks you could call no matter what... [when we] need help or prayers. We would do the same for them."* George described the relief that came from knowing individuals who have been committed to praying for him, *"...Somebody committed to praying for you means a lot to me. [It's], hard to pray for yourself. [You have to] rely on those others to do that."* Fathers recognized the benefits of

surrounding themselves with people of faith who can help provide strength and faith that fathers cannot find within themselves.

Fathers have also found strength and support from the healthcare team, especially with techniques and requirements of parenting CCMC. Fathers recalled how members of the healthcare team have been successful in supporting families when they felt uncertain about what actions to take regarding their children's health and how best to support their children. For example, George shared how meaningful it is when the healthcare team took time to ensure that his son Thomas was comfortable with the various treatments and procedures necessary to his care:

[The] doctors are all nice, trying to comfort Thomas, make him feel like a person, not just a patient. Help play things down for kids, even if hard for adults. Sometimes people want to get things done and get you out, but these people have patience. Thomas is paranoid of needles, [so they] play games and stuff. Even if it takes 20 minutes to get a shot, they are willing to do that. Many times, they spend a lot of time with him to convince him and it works most of the time. It helps knowing that people really care for the child.

George felt supported when the healthcare team recognized the stress that children undergo during hospital admissions and clinic visits and when they took time to treat his child with dignity.

In addition, the medical team has supported fathers by providing much needed information in an efficient manner. Scott explained how comforting it is that he has immediate access to physicians when he has concerns or questions about Emma's health. Despite the overwhelming amount of information Scott and his wife received after Emma's diagnosis and the multitude of questions that remained, Scott was reassured that physicians made themselves

available by phone all hours of the day to answer questions. Likewise, Jeff explained that even though he often missed important conversations with physicians during the daytime while he was working, physicians would repeat their reports upon his return to the hospital. Jeff recalled how these efforts from the physicians took the burden off his wife of having to recount every detail of medical conversations, and it also allowed him to feel like an equal partner in his daughter's care.

Members of the healthcare team have also been instrumental in connecting families with resources that will be available to families during periods of nonhospitalization. Bruce mentioned how difficult it can be for parents to take the time to research organizations and additional supportive resources beyond hospital staff. He remembered how helpful it was for the healthcare team to connect him with outside agencies and also with other families going through similar situations. Bruce explained how the hospital staff attempted to connect families who could be supportive to each other, *"The family support people there would sit there and say you probably ought to talk to this family because their situation was very similar to what Micah's originally was."* Even though some families are more open and will seek out other families managing similar CMC, many families need assistance making those initial connections. Fathers recognized how instrumental the hospital staff was in facilitating meetings between parents who could offer encouragement and advice about the future.

In addition to professional support services, fathers emphasized the support that they have found within their own marriages. Each of the participants are in committed marriages and each discussed how their relationships with their wives have been supportive. Bruce clearly stated, *"...our marriage has been the best support group of all."* Jeff and Brian shared similar statements about the strength that they have found in their marital relationships. While George

shared that he often desires to go to his wife for support, he admits he struggles with knowing how much to share with his wife because he feels it is unfair to burden her with additional concerns. In response to his struggle, George has developed friendships that have been supplemental to his wife's support. The emphasis on spousal support from each of the participants indicates a constant source of support for these particular fathers. Future research may include fathers who are divorced or widowed to learn more about how these fathers would cope without the consistent support from a spouse.

Having fathers identify desirable sources of support is only the first step toward implementing effective support services. It is also necessary to have fathers describe the circumstances that create the most effective context for support. As participating fathers were asked about the circumstances that are essential to their own use of support, participants shared insights related to the timing of support. Fathers recalled how their need for support was uniquely different at the time of diagnosis than the months and years that followed. Jeff recalled how he felt when his daughter was first diagnosed with CF and made suggestions about how to talk with other fathers who are craving information:

When dealing with a dad that just had a child diagnosed with a terminal disease, be careful about what kind of information you give them. They want to know everything, but it's a very sensitive time....early dads would be overwhelmed by the same conversations.

Times of hospitalization are also unique. Fathers described how the healthcare team provides so much at the hospital that outsider support from friends and family is often not as necessary. Scott recognized the time when he needed support the most was when they returned home after Emma's initial diagnosis and his family faced the daily responsibilities of life for the first time

with a CMC:

You don't really need that first week. You know, we're in the hospital, I don't really need anything. Once we get home, what do we need? I need somebody to talk to. You need somebody for your wife to talk to, and you need somebody for both of y'all to talk to. Your siblings need somebody to talk to. Somebody needs to make sure that the siblings aren't being neglected. So there's all those follow-up [issues]...

Scott identified a time right after diagnosis when he was still utilizing the hospital resources and processing Emma's diagnosis. After separation from the healthcare team and once the reality of the illness sets in, fathers may be more receptive to individuals who follow-up with parents and offer ways to help them cope and adjust to life with a CMC.

What Types of Support Are Unhelpful to Fathers of CCMC and Under What Circumstances?

Throughout the interviews, participants frequently described the barriers they have encountered on their journeys toward accepting support. These barriers serve as a foundation for answering the third and final research question: "What types of support are unhelpful to fathers of CCMC and under what circumstances?" It is necessary to evaluate those circumstances that make accepting support less likely or uncomfortable for fathers of CCMC. One of the most frequently mentioned barriers is pride. If fathers have yet to admit the need for help from others with raising a child with a CMC, they are not going to be ready to utilize offers of support. Being sensitive to where a father is in the process of accepting the child's diagnosis and his own limitations is key in knowing how to approach fathers about support needs.

How a father of a CCMC receives an offer of support is also partially determined by the source. Scott explained that even though other people, even other fathers, may be willing to listen and offer advice, most people are still not in a place to truly support him. He said that,

“unless you can meet a dad who is going exactly through what you’re going through, nobody understands!” Those individuals who have not had a child with a CMC may be willing to help, but their offers to listen may not be as effective as talking with other parents who have been through similar experiences. Scott went on to express that there is nothing quite like having a child who has a life-threatening illness. Even those people who have sick or dying parents try to relate, but there is still a lack of understanding. George described a similar frustration related to receiving advice from people without experience raising a child with a CMC:

...People try to help out, you know, you should try this medicine or something or another, but that’s not the kind of help that you need. You need something more, things that kind of relate to the same problem. There is a lot of people that are willing to help, but sometimes, like I was saying, it’s not really the help that you need. You need more support of what you’re going through. Sometimes it’s not, let me give you money so you can go to eat, take your family to eat. Sometimes it just don’t help, that stuff. Sometimes it helps just to talk about it. What really helps is just, like I was saying, is to talk to people who are going through the same thing,

Despite the various ways people have tried to assist his family over the years by offering solutions and financial assistance, George recognized that those efforts have not been the most effective means of supporting him as he copes with the challenges of raising a child with a CMC. The lack of effectiveness becomes most apparent when George compares these gestures to the sense of acceptance and reassurance that he has received from other parents raising children with CMC.

Another factor that will determine the effectiveness of support offered to fathers of CCMC is how it will impact the time fathers share with their family. For example, fathers who

spend the majority of the week away from their families at work expressed that they are less interested in attending support groups or participating in activities that take them away from their families during their non-working hours. It is important that the opportunity for support does not contribute to the already significant guilt that many fathers experience regarding the amount of time they are obligated to spend away from their families.

While several fathers mentioned prayer and reliance on faith as helpful, others find that faith is less effective source of support. In fact, fathers explained how upsetting it is when outsiders imply that fathers needs more faith or should spend more time in prayer. For example, although Scott was previously very committed to religion, his daughter's illness has shaken his faith. He explained:

We went to synagogue every week. I could probably count on my hands the number of times that I missed. I was the guy that gave to charity. I was the guy who went out of my way to be nice to people, I was the guy who was aware that God is out there and thankful. So now, when people say that they'll pray for me, I'm like "Fuck you!" I was the guy who did everything right. So that's the one that just kind of sends me over the edge. Or when people are like, you know, you need to pray to God to give you some guidance. No! God needs to tell me what was He thinking. What was He trying to tell me? I don't need to pray to God. Just you know, that was probably the one thing that...mind you, I still believe in God...

Scott shared honestly about how his daughter's experience with cancer has caused him to question his trust in God. He has been unable to receive reassurance from those who believe faith is the answer to his problems because he has been let down by faith in the past. It is important

that those people who are offering support through faith take into account how a CMC influences a father's faith and his view of religion.

While these barriers to effective support are subjective, each opinion was expressed by multiple fathers. These ideas are essential to forming effective support groups, attracting fathers to organizations designed to assist families of CCMC, and equipping those people who want to support fathers of CCMC.

Connecting the Findings and the Literature

Having addressed the research questions, it is important to compare this study's findings to the current literature surrounding parents of CCMC and their support systems. Since a majority of the current research has included very few fathers as participants, any findings from this exclusively male study that replicate previous studies are significant. In addition, the results from this study that deviate from previous findings may be useful in developing more comprehensive models of support that are appropriate for both genders. The relation between the findings of this study and the literature enrich the theory and practice of supporting parents of CCMC.

One theme that has been clearly reflected in this research study is the barriers that fathers encounter as they attempt to accept support. Brett (2004) applied the results of her qualitative study with parents of CCMC to explain the process of how parents learn to accept support, including the barriers to acceptance. While Brett primarily interviewed mothers, the current study replicates very similar findings with fathers regarding the various steps parents take towards receiving support. One common theme in both studies was that parents are rarely ready to accept support immediately after a child's diagnosis. Brett's results indicate that in order for parents to accept support, parents need to abandon previous expectations that they should be able

to care for their children independently. Likewise, fathers in this study focused on the necessity of letting go of previous expectations about how they would parent their children with CMC. Other similarities between the findings of Brett's study conducted with mothers and this study include asking for help seen as admission of failure, loss of control and pride. Scott described how he has responded to offers of help towards the beginning of his daughter's illness, "*We'll take care of ourselves, ' because it's human nature. But the reality is that you can't take care of it yourself, and people are too proud to say, 'You know I need some help.' "*" Fathers and mothers both expressed that asking for help requires a change in perspective that involves seeking support as a positive, proactive choice. In both studies mothers and fathers acknowledged that asking for help became easier over time.

One issue that remained unclear through the review of literature is whether males and females have equal access to supportive resources. Fathers participating in this study shared they perceive themselves as having equal access to formal support as their wives; however, fathers were less likely than mothers to form supportive relationships with other parents. Fathers explained in order to cope, especially during periods of hospitalization, families learn to divide responsibilities. This division often required fathers to be in and out of the hospital setting and daily management routines, which allowed fewer opportunities for fathers to form informal support networks with other families of CCMC. Bruce explained the differences between fathers and mothers' hospital routines and how it affects their access to support, "*I do think it's because the dads have to do in and out, in and out, between the real world and the hospital world that they don't quite build as much of a network as the moms do.*"

Regarding formal support resources, the findings from this study indicate fathers have specific goals for participating in support groups and support organizations. While several

fathers shared the need to express their feelings with other parents of CCMC, fathers verbalized that another goal of support group meetings was to gather practical information related to insurance, treatment options, and what to expect for their children's future health. These findings are important in light of previous studies in which researchers reported concerns that parental support is designed from a female perspective and often lacks the ability to address the issues that are most significant to fathers (Chesler & Parry, 2001; Davis & May, 1991).

Implications for involving fathers in support groups include describing and advertising parent groups not only as an opportunity to express feelings, but as a venue for sharing and gathering practical information.

CHAPTER 7

IMPLICATIONS FOR PRACTICE AND FUTURE RESEARCH

Fathers participated in a series of interviews and shared openly about their experiences raising CCMC. It is now necessary to consider how the participants' ideas might be applied in healthcare settings and additional organizations striving to provide appropriate and effective support to families. The following section includes recommendations that participants made throughout their interviews about specific ways to support males who are managing stress related to fathering a child with a CMC. Additionally, the limitations of the study are addressed and recommendations for future research are made. At the conclusion of this section, implications for practice are discussed.

Participant Recommendations for Male Support

Fathers participating in this study described additional ways that professionals and individuals could potentially support fathers raising CCMC. While some fathers have experienced assistance from the supportive resources currently available to their families, many had suggestions for redefining and redesigning support to address the unique needs of men most effectively.

Fathers recognized a need for more attention on support that helps them balance work obligations with their participation in their children's healthcare. Fathers experience tremendous guilt surrounding their absence from their families due to work responsibilities. On top of that guilt, fathers also face challenges when negotiating with employers about time off when their child requires special attention, especially during periods of hospitalization. Brian brainstormed

ways that others might help fathers approach employers:

Some fathers might have some need to have an advocate to their employer to say, you know, help them understand that additional needs of the child who is chronically ill or whatever. Kind of help them work with their employer on being flexible when they need flexible.

If organizations that serve families of CCMC have the resources, it would be beneficial to create a liaison position that could advocate and educate employers about parent needs and rights.

Another major concern for parents is how to retain all the information and teaching that they receive during a hospital admission, especially during the period of initial diagnosis. One father suggested that hospital staff could help parents process the information and keep track of the most important instructions. Information helps build confidence and reassurance during the period of transition from parenting a healthy child to parenting a child with a CMC. Scott elaborated on this type of support:

They could sit in on these meetings [with physicians] and ask the question like, 'Did you hear that Scott? That this is what your responsibility is?' Or write it down... I mean, you give me a sheet. We got like two books of what to expect, but there's probably like 10 things that the doctor said that we'd need to make a decision on. They could go back and say, 'Okay, this is what's going to happen to Emma. Expect this to happen...' So that we wouldn't freak out every time something happens.

The frustration Scott described regarding his inability to absorb all the initial medical information was experienced by multiple other participants. Some parents may need individuals who are less overwhelmed to help them process the information and make informed decisions. Parents who are overcome with emotion have difficulty filtering vital information from

peripheral information. It is important to consider measures the healthcare team can take to assist parents in identifying the information that will be the most immediately applicable, and then follow-up for future education and explanation.

Despite the sundry emotions fathers experience throughout the course of their children's CMC, participants admitted that they have often been uncomfortable seeking outlets for emotional expression such as support groups, despite their known effectiveness. Bruce explained how he learned to view opportunities to interact with other parents in all stages of illness that has been effective for him:

...looking at it as a duty as opposed to a chance to unburden myself. Yeah...and maybe that really is it. Finding somebody who can say they've been in the same position, start the ball rolling to open it up.

Bruce described how fathers who have previously dealt with their fears and learned how to cope with their children's CMC can offer valuable advice and support to those fathers just embarking upon their journeys with chronic illnesses. Bruce recommended reframing the idea of 'sharing for my own benefit' to 'a responsibility to tell others what you have learned.' The benefits of sharing experiences extend to everyone involved, even those who are not admittedly seeking support. In order to encourage fathers to participate in these activities that are often viewed as times to share feelings, he recommended that professionals present support groups as an avenue for fathers to repay the support they once received. With this different frame of reference, support groups may attract more father participation.

When considering the types of supportive resources that are most attractive to men, fathers explain that it is essential to consider the limited amount of time they have to spend with

their families, especially during periods of hospitalization. Bruce explained how much he values the time he is able to spend with Micah:

...probably the biggest thing is, I mean, you know, men just naturally, their interaction with kids is more, especially with boys, is play...you know, when he was well enough, that's the one thing, you know, I would take him, my son, to the playroom a lot...but yeah, that's kind of the way that I would almost think the men's thing would have to be. Like if you're here on the weekend and giving mom a break, if you can make it, bring your son to the play room and we're going to do something.

Rather than pulling fathers away from their children for a support group meeting, Bruce described how much more comfortable he feels when the activity includes his son. Fathers are often separated from their families during periods of hospitalization due to work obligations. Consequently, during times when fathers are present at the hospital, they desire to spend time with their families. Activities that take place on the weekends and evenings, if geared toward male activities, could provide an environment most conducive to support for fathers.

Even if support activities are designed with the characteristics fathers desire, such as the inclusion of couples with a wide range of experiences and being inclusive of children, fathers still face logistical barriers to successful support. Some of the most salient themes surrounding logistics are the timing and location of support. No matter how much fathers desire to participate in activities, location and time of day are essential for recruitment of fathers. Bruce recognized the challenge of participating in support opportunities because of his full schedule. He recommended notifying fathers far in advance about events and establishing fixed days and times fathers can expect events to occur. Brian focused on the timing of events. He explained that certain times of day are absolutely dedicated to his family, *"Coffee and breakfast are easier to*

squeeze in. After work I've got to get home to the family." Even though each father will have unique preferences and logistical barriers, a very simple consideration is whether support activities are offered before or after regular working hours. Possibly offering morning groups for fathers would be more feasible for fathers like Brian. Weekends are another time that fathers are more likely to be off work. It is still necessary, however, to consider whether activities that incorporate the entire family might be more successful since weekends are some of the only times fathers have to spend with their children.

Finally, fathers emphasized how persistence from others is often the only way to confront and eliminate pride barriers in order that fathers can accept assistance. Persistence is also a prerequisite fathers described when they were asked how they might be persuaded to participate in support activities outside of the hospital environment. Scott explained:

It's easy to [contact dads] at the hospital, but you are so overwhelmed [during hospitalizations]. It's once you get home [that you need support]. It's not so much that you call; it's being persistent with multiple calls or offers. One offer to help and I blow them off. The second time, I think about it. The third and fourth times, I think they really want to help.

George described a similar hesitation with accepting offers of practical support. A friend offered him a car that he was no longer using, but it took multiple weeks of the friend making repeated offers before George was able to accept the gesture. Even though persistence could be misconstrued as pestering, they agreed that it could be extremely effective and necessary for many fathers of CCMC.

Limitations of Study and Implications for Future Research

One of the most obvious limitations of this study was the number of participants. Due to restricted time and resources, this researcher chose to conduct in-depth interviews with a limited number of fathers to produce the richest data. The findings from this study may not be able to be generalized. However, the data includes several new insights that have not been discussed in previous studies that may prove to be a catalyst for future studies.

Another limitation was that all the fathers were recruited from the same geographic area and consequently received care within one healthcare system. Future studies could include participants from multiple hospitals in order to explore the different supportive resources that each institution offers to families. The inclusion of multiple healthcare systems could offer new suggestions for ways to meet the support needs of fathers. In addition, it would be interesting to conduct further studies that include fathers from different areas of the country to explore the possibility of regional differences in the way fathers of CCMC experience support.

An additional limitation was that all participants in this study have been managing their children's illnesses for multiple years and relied on their memories to recall the types of support that were effective during earlier stages of illness. Consideration for future research might include the inclusion of fathers at multiple stages of their children's illnesses. Longitudinal studies could investigate the support needs of fathers throughout different stages of illnesses and possibly provide more accurate recommendations for practice.

Implications for Practice and Conclusion

Considering the themes that surfaced throughout the analysis of data and the recommendations made by participants, there are various implications for professionals who are in the position to support fathers of CCMC. Professionals seeking ways of adapting support to

meet the unique needs of fathers should consider the following recommendations that have developed from the current study.

The disappointment fathers of CCMC expressed about not being the fathers they envisioned themselves being has strong implications for how supportive opportunities for fathers should be designed and approached. The underlying issue appears to be one of identity. Once a CMC is diagnosed, fathers explained that they experience a crisis of identity. Suddenly, fathers are forced to abandon their culturally derived identities as “fixers of problems,” and search for new ways of identifying themselves within their families. Professionals can use a variety of methods to assist fathers with developing a new sense of identity including connecting them with other fathers who learned to manage their disappointed expectations, providing fathers with specific jobs or tasks involving their children’s care, and ensuring fathers have the information they need to make decisions about their children’s treatment.

Regarding the information that fathers receive about their children’s CMC, professionals can consider how to present medical information in a way that is most helpful to fathers. Participants explained they often felt overwhelmed during periods of initial diagnosis or when decisions needed to be made about treatment options. Professionals might consider developing diagnosis-specific handbooks to organize important information for parents. Information participants identified as helpful that might be suitable for handbooks included general timelines for treatments, specific information about medications, lists of daily precautions for children living with CMC, and potential resources within and outside of the healthcare system.

Participants in this study also identified specific considerations for designing effective support groups and events for males. When designing support groups, professionals could include both spouses and also invite families at various stages of treatment. Including both

spouses provides the unique opportunity to receive support as a couple. In addition, combined groups allow each spouse to encourage the other to share their experiences with other in order to help families going through similar situations. Inviting families from various stages in the treatment process assists parents in developing a larger perspective of the illness process. While support groups have been helpful to fathers regarding gather practical information and advice about parenting CCMC, fathers often expressed more interest in activity based events with other families of CCMC. Fathers experience support through interacting with other families of children with similar limitations. Fathers are more likely to attend events that have activities for the entire family. Not only do they get to spend quality time with their families, but they also find support just by being around other fathers who have learned to shift their own expectations about fatherhood.

Fathers explained that the process of learning to accept support from others is often a journey that requires persistence. Professionals must consider how they might be able to present resources and support opportunities to fathers over time so that fathers will still have access to support when they are ready to accept it. Fathers expressed that they sometimes felt overwhelmed at the time of diagnosis and were not ready to accept support immediately. Professionals and organizations striving to connect fathers with supportive resources might poll fathers to learn more about the most appropriate times to repeat offers of support. Mailing information or calling fathers several weeks post-diagnosis or initial treatment may be a starting place to identify needs that fathers may have identified after having time to process information from the healthcare team.

Despite limitations, this study has significant implications for future research and practice. Fathers in this study verified multiple aspects of previous research about support for

parents of CCMC, as well as provided information that helps establish a new framework for approaching support for fathers. Considerations that have developed from this research study include designing support to help fathers manage their disappointment regarding not experiencing the fatherhood they imagined for themselves and establishing support that creates a new sense of normalcy. While a great extent remains to be learned about how fathers experience support, this study proposes further questions to be explored and new ideas to be built upon so that new theories and standards of practice can be established to effectively support fathers of CCMC.

References

- American Cancer Society. (2008). *What is Acute Lymphocytic Leukemia?* Retrieved December 10, 2008, from: http://www.cancer.org/docroot/CRI/content/CRI_2_4_1X_What_Is_Acute_Lymphocytic_Leukemia.asp?sitearea=
- Board, R. (2004). Father stress during a child's critical care hospitalization. *Journal of Pediatric Health Care, 18*(5), 244-249.
- Brett, J. (2004). The journey to accepting support: How parents of profoundly disabled children experience support in their lives. *Paediatric Nursing, 16*, 14-18.
- Cabrera, N. J., Tamis-LeMonda, C. S., Bradley, R. H., Hofferth, S., & Lamb, M. E. (2000). Fatherhood in the twenty-first century. *Child Development, 71*, 127-136.
- Callery, P. (1997). Paying to participate: Financial, social and personal costs to parents of involvement in their children's care in hospital. *Journal of Advanced Nursing, 25*, 746-752.
- Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. *Journal of Advanced Nursing, 18*, 46-53.
- Caplan, G. (1974). *Support systems and community mental health*. New York: Behavioral Publications.
- Carlson, M. J. (2006). Family structure, father involvement, and adolescent behavioral outcomes. *Journal of Marriage and Family, 68*(1), 137-154.
- Cayse, L. N. (1994). Fathers of children with cancer: A descriptive study of their stressors and coping strategies. *Journal of Pediatric Oncology Nursing, 11*, 102-108.
- Charmaz, K. (2003) Qualitative interviewing and grounded theory analysis. In Holstein, J.A., & Gubrium, J.F. (Eds.), *Inside Interviewing: New lenses, new concerns* (pp. 311-329). Thousand Oaks, CA: Sage Publications.

- Chesler, M. A., & Parry, C. (2001). Gender roles and/or styles in crisis: An integrative analysis of the experiences of fathers of children with cancer. *Qualitative Health Research*, 11, 363-384.
- Children's Healthcare of Atlanta. (2008). *Fulminant liver failure*. Retrieved December 10, 2008, from: <http://www.choa.org/default.aspx?id=5455>
- The Children's Tumor Foundation. (2008). *What is NF?* Retrieved December 10, 2008, from: <http://www.ctf.org/Living-with-NF/what-is-nf.html>
- Cohen, M. H. (1995). The triggers of heightened uncertainty in chronic life-threatening childhood illness. *Qualitative Health Research*, 5, 63-77.
- Coleman, W. L., & Garfield, C. (2004). Fathers and pediatricians: Enhancing men's roles in the care and development of their children. *Pediatrics*, 113, 1406-1411.
- Cove Point Foundation: Congenital Heart Disease. (2009). *Double inlet left ventricle*. Retrieved February 26, 2009, from: <http://www.pted.org/?id=doubleinlet1>
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London: Sage Publications.
- Cystic Fibrosis Foundation. (2008). *What is cystic fibrosis?* Retrieved December 10, 2008, from: <http://www.cff.org/AboutCF/>
- Davis, P. B., & May, J. E. (1991). Involving fathers in early intervention and family support programs: Issues and strategies. *Children's Health Care*, 20, 87-92.
- Day, R. D., Lewis, C., O'Brien, M., & Lamb, M. E. (2005). Fatherhood and father involvement: Emerging constructs and theoretical orientations. In V. L. Bengtson, A. C. Acock, K. R. Allen, P. Dilworth-Anderson & D. M. Klein (Eds.), *Sourcebook of family theory and research*. (pp. 341-365). Thousand Oaks, CA: Sage Publications.

- Fisher, H. R. (2001). The needs of parents with chronically sick children: A literature review. *Journal of Advanced Nursing*, 36(4), 600-607.
- Frey, K., Fewell, R., Vadasy, P., & Greenberg, M. (1989). Parental adjustment and changes in child outcome among families of young handicapped children. *Topics in Early Childhood Special Education*, 9, 38-57.
- Garwick, A. W., Patterson, J. M., Bennett, F. C., & Blum, R. W. (1998). Parents' perceptions of helpful vs unhelpful types of support in managing the care of preadolescents with chronic conditions. *Archives of Pediatrics Adolescent Medicine*, 152(7), 665-671.
- Goble, L. A. (2004). The impact of a child's chronic illness on fathers. *Issues in Comprehensive Pediatric Nursing*, 27, 153-162.
- Grootenhuis, M. A., & Last, B. F. (1997). Adjustment and coping by parents of children with cancer: A review of the literature. *Support Care Cancer*, 5, 466-484.
- Hauenstein, E. J. (1990). The experience of distress in parents of chronically ill children: Potential or likely outcome? *Journal of Clinical Child Psychology*, 19, 356.
- Hentinen, M., & Kyngäs, H. (1998). Factors associated with the adaptation of parents with a chronically ill child. *Journal of Clinical Nursing*, 7, 316-324.
- Hobfoll, S. E. (1985). Limitations of social support in the stress process. In I. G. Sarason, & B. R. Sarason (Eds.), *Social support: Theory, research and application* (pp. 391-414). Martinus-Nijhoff: The Hague.
- Horn, J. D., Feldman, H. M., & Ploof, D. L. (1995). Parent and professional perceptions about stress and coping strategies during a child's lengthy hospitalization. *Social Work in Health Care*, 21, 107-127.

Hovey, J. (2005). Fathers parenting chronically ill children: Concerns and coping strategies.

Issues in Comprehensive Pediatric Nursing, 28, 83-95.

Jacobson, D. E. (1986). Types and timing of social support. *Journal of Health and Social*

Behavior, 27(3), 250-264.

Katz, S. (2002). Gender differences in adapting to a child's chronic illness: A causal model.

Journal of Pediatric Nursing, 17(4), 257-269.

Kerr, S. M., & McIntosh, J. B. (2000). Coping when a child has a disability: Exploring the

impact of parent-to-parent support. *Child: Care, Health and Development*, 26, 309-322.

Kids Health. (2008). *Neurofibromatosis*. Retrieved December 10, 2008, from:

<http://kidshealth.org/parent/system/ill/nf.html>

Lamb, M. E. (2000). The history of research on father involvement: An overview. *Marriage and*

Family Review, 29, 23-42.

Lamb, M. E., Pleck, J. H., Charnov, E. L., & Levine, J. A. (1987). A biosocial perspective on

paternal behavior and involvement. In J. B. Lancaster, J. Altman, A. S. Rossi & L. R.

Sherrod (Eds.), *Parenting across the lifespan: Biosocial dimensions* (pp. 111-142).

Hawthorne, NY: Aldine.

Lamb, M. E., Pleck, J. H., Charnov, E. L., & Levine, J. A. (1985). Paternal behavior in humans.

American Zoologist, 25, 883-894.

Lavee, Y., McCubbin, H. I., & Patterson, J. M. (1985). The double ABCX model of family stress

and adaptation: An empirical test by analysis of structural equations with latent variables.

Journal of Marriage and the Family, 47, 142-156.

- Lavee, Y., McCubbin, H. I., & Olson, D. H. (1987). The effect of stressful life events and transitions on family functioning and well-being. *Journal of Marriage and the Family*, 49(4), 857-873.
- Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18, 145-153.
- Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research* (4th ed.). Thousand Oaks, CA: Sage Publications.
- Marsiglio, W., Amato, P., Day, R. D., & Lamb, M. E. (2001). Scholarship on fatherhood in the 1990s and beyond. In R. M. Milardo (Ed.), *Understanding families into the new millennium: A decade in review*. (pp. 392-410). Lawrence, KS: NCFR and Alliance Communication Group.
- May, J. E. (1996). Fathers: The forgotten parent. *Pediatric Nursing*, 22(3), 243-246.
- McBride, B. A., Brown, G. L., Bost, K. K., Shin, N., Vaughn, B., & Korth, B. (2005). Paternal identity, maternal gatekeeping, and father involvement. *Family Relations*, 54(3), 360-372.
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman & J. M. Patterson (Eds.), *Social stress and the family: Advances and developments in family stress theory and research* (pp. 7-37). New York: The Hawthorne Press.
- McCubbin, M., Balling, K., Possin, P., Friedrich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. *Family Relations*, 51, 103-111.
- McGrath, P., & Chesler, M. (2004). Fathers' perspectives on the treatment for pediatric hematology: Extending the findings. *Issues in Comprehensive Pediatric Nursing*, 27(1), 39-61.

- McKeever, P. T. (1981). Fathering the chronically ill child. *Parent-Child Relationships*, 6, 124-128.
- McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Perrin, J. M., et al. (1998). A new definition of children with special healthcare needs. *Pediatrics*, 102(1), 137-139.
- MedlinePlus Medical Encyclopedia. (2009). *Double inlet left ventricle*. Retrieved February 26, 2009, from: <http://www.nlm.nih.gov/medlineplus/ency/article/007327.htm>
- Melnyk, B. M., Feinstein, N. F., Moldenhouer, Z., & Small, L. (2001). Coping in parents of children who are chronically ill: Strategies for assessment and intervention. *Pediatric Nursing*, 27, 548-558.
- Mu, P., Ma, F., Hwang, B., & Chao, Y. (2002). Families of children with cancer: The impact on anxiety experienced by fathers. *Cancer Nursing*, 25, 66-73.
- Nagy, S., & Ungerer, J. A. (1990). The adaptation of mothers and fathers to children with cystic fibrosis: A comparison. *Children's Health Care*, 19, 147-154.
- Neil-Urban, S., & Jones, J. B. (2002). Father-to-father support: Fathers of children with cancer share their experience. *Journal of Pediatric Oncology Nursing*, 19(3), 97-103.
- Newacheck, P. W., & Halfon, N. (1998). Prevalence and impact of disabling chronic conditions in childhood. *American Journal of Public Health*, 88, 610-617.
- Patterson, J. M., Holm, K. E., & Gurney, J. B. (2004). The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology*, 13, 390-407.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. (3rd ed.). Thousand Oaks, CA: Sage.

- Perrin, E. C., Lewkowicz, C., & Young, M. H. (2000). Shared vision: Concordance among fathers, mothers, and pediatricians about unmet needs of children with chronic health conditions. *Pediatrics*, 105, 277.
- Perrin, E. C., Newacheck, P., Pless, I. B., Drotar, D., Gortmaker, S. L., Leventhal, J., et al. (1993). Issues involved in the definition and classification of chronic health conditions. *Pediatrics*, 91(4), 787-793.
- Pinquart, M., & Silbereisen, R.K. (2005). Influences of parents and siblings on the development of children and adolescents. In Acock, A.C., Bengtson, V.L., Klein, D.M., Allen, K.R., Dilworth-Anderson, P. (Eds.), *Sourcebook of family theory and research* (pp. 367-391), Thousand Oaks, CA: Sage Publications.
- Pleck, E. H., & Pleck, J. H. (1997). Fatherhood ideals in the united states: Historical dimensions. In M. E. Lamb (Ed.), *The role of the father in child development*. (3rd ed., pp. 33-48). New York: Wiley.
- Pleck, J. H. (1997). Paternal involvement: Levels, sources, and consequences. In M. E. Lamb (Ed.), *The role of the father in child development* (3rd ed., pp. 66-103). New York: Wiley.
- Pleck, J. H., & Masciadrelli, B. P. (2004). Paternal involvement by U.S. residential fathers: Levels, sources, and consequences. In M. E. Lamb (Ed.), *The role of the father in child development* (4th ed., pp. 222-271). New York: John Wiley and Sons.
- Pless, I. B., & Douglas, J. W. B. (1971). Chronic illness in childhood: Part I. epidemiological and clinical characteristics. *Pediatrics*, 47(2), 405.
- Quinn, P. (1999). Supporting and encouraging father involvement in families of children who have a disability. *Child and Adolescent Social Work Journal*, 16, 439-454.

- Sabbeth, B. (1984). Understanding the impact of chronic childhood illness on families. *Pediatric Clinics of North America*, 31, 47-57.
- Schilling, R. F., Schinke, S. P., & Kirkham, M. A. (1985). Coping with a handicapped child: Differences between mothers and fathers. *Social Science and Medicine*, 21(8), 857-863.
- Stein, R. E. K., Bauman, L. J., Westbrook, L. E., Coupey, S. M., & Ireys, H. T. (1993). Framework for identifying children who have chronic conditions: The case for a new definition. *The Journal of Pediatrics*, 122, 342-347.
- Stein, R. K., & Jessop, D. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. *Social Science and Medicine*, 29(6), 769-778.
- Sterken, D. J. (1996). Uncertainty and coping in fathers of children with cancer. *Journal of Pediatric Oncology Nursing*, 13(2), 81-88.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Tak, Y. R., & McCubbin, M. (2002). Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *Journal of Advanced Nursing*, 39, 190-198.
- Valentine, J. M., Neff, J., Park, A. N., Sharp, V., Maynard, C., Christakis, D., et al. (2000). Pediatric hospitalization patterns for selected chronic health conditions using hospital abstract reporting system data: Methods and findings. *Health Services and Outcomes Research Methodology*, 1, 335-350.
- van der Lee, J. H., Mokkink, L. B., Grootenhuys, M. A., Heymans, H. S., & Offringa, M. (2007). Definitions and measurement of chronic health conditions in childhood: A systematic review. *The Journal of the American Medical Association*, 297(24), 2741-2751.

van Dyck, P. C., Kogan, M. D., McPherson, M. G., Weissman, G. R., & Newacheck, P. W.

(2004). Prevalence and characteristics of children with special health care needs. *Archives of Pediatrics and Adolescent Medicine*, 158, 884-890.

Yeung, W. J., Sandberg, J. F., Davis-Kean, P. E., & Hofferth, S. L. (2001). Children's time with fathers in intact families. *Journal of Marriage and Family*, 63(1), 136-154.

APPENDIX A

Interview Guide

“Hi, I’m Kalli. It’s so nice to meet you in person. Thank you so much for agreeing to meet with me today. There are lots of professionals that want to learn how to best support children and families with chronic medical conditions; however, most of what we know is from the perspective of mothers. It is so exciting to get to hear your unique perspective today.

Your interview, along with those of several other fathers, is going to be used for my Master’s thesis. My goal is to learn more about how professionals can support fathers like yourself.

We can look over this consent form together, answer any questions you might have, and let you sign the form. Then if you could please fill out this brief questionnaire about you and your family, we can get started talking!

You indicated on the consent form that it is okay for me to tape record our conversation. This is just a way for me to keep track of all the things that we talk about today. I am going to turn it on at this point, but hopefully we can just talk and forget that it’s even there. I will be keeping track of time for us...I told you that this interview would last no more than an hour and a half, but do you need to leave by a certain time that I can watch for? I want to respect your time!

1. Tell me about your child’s illness
 - child’s medical history
 - duration of illness
 - primary caregiver of the child
 - how often the child sees her physician and/or receives treatments
2. What are some of the things that have caused you the most stress or anxiety as a father caring for a child with a chronic medical condition?
3. I don’t want to make any assumptions, so let’s start by you telling me about the types of things that have been helpful to you in dealing with your child’s illness.
4. What things have helped you reduce these stressors?
5. What other people have been involved in reducing your stress?
6. What would you say has been the most helpful resource for reducing your stress?
7. Are there any efforts made by others that have been unhelpful or even harmful to you in relieving your daily stress?
 - If so, please describe these situations (who made these efforts? what is their relationship to you?)

8. Can you think of other things that would be helpful for reducing your stress?
 - Can you think of any reasons why these have not been available to you?
9. Thinking specifically about the times when your child was hospitalized, were there any things that were particularly stressful during this time?
 - What were the reason(s) for hospitalization? Were they planned or unexpected?
 - What are some of the ways were you able to reduce these stressors?
 - What other people have been helpful in reducing your stress?
 - What specific stressors were they able to help with?
 - Are there any efforts made by others that have been unhelpful or even harmful to you in relieving your stress during your child's hospitalization?
 - If so, please describe these situations (who made these efforts? what is their relationship to you?)
10. How did you get involved with Starlight? Did someone introduce you to the program or did you find it yourself? Can you share anything about your experiences with this program?
11. Does your family have health insurance?
 - Who does it cover?
 - Are you satisfied with the policy?
12. Since I'm trying to learn as much about how fathers find support during a child's chronic illness, is there anything else that we have not talked about that you would like to share with me today? or any advice you would give fathers going through similar experiences?
13. Have there been any things that have made you angry as a father of a child with a chronic illness?
14. What do you think you have to offer your family? your child? Are there any personal characteristics about you that have helped you in raising your child? Or any family/social dynamics that have helped you?
15. Are there any organizations or groups that you have been involved with that have helped you in coping with your child's chronic illness?
16. Are there any other things that have sustained you? i.e. relationships, beliefs
17. Are there any questions that I didn't ask that you expected me to mention?

Thank you so much for sharing so much about yourself and your family with me today. I really appreciate you giving up your valuable time to talk with me. After I meet with all of the fathers, I will want to do a brief follow-up interview, lasting no more than 30 minutes, in case I have any further questions. Secondly, I would like to take that time to share some of my summaries of what fathers have communicated to see if they truly reflect what you have experienced. I would

prefer to meet in person, but we could arrange a phone-interview if this is more convenient for you. Is it alright if I contact you about this brief follow-up interview?"

"Thank you again!"

APPENDIX B

Demographic Questionnaire

1. How old are you? _____
2. How many people are in your family? _____ What are their ages?

3. How long have you been married? _____ Is this your first marriage?

4. How old is your child enrolled in the Starlight Starbright program? _____
5. Is your child enrolled in the Starlight Starbright program biological or adopted?

6. Your child enrolled in the Starlight Starbright program is enrolled in what type of school program:
____ Public
____ Private
____ Home-school
7. How would you describe your race/ethnicity? _____
8. Do you have any religious/spiritual affiliations? _____ If so, what?

9. Approximately how long have you been involved with Starlight Starbright?

10. What is the highest level of education that you have completed? Choose from the following:
____ some high school
____ high school
____ some college
____ college degree
____ some graduate school
____ Masters degree or beyond
11. What is your family's approximate annual income? Choose from the following ranges:
____ less than \$25,000
____ \$25,001-\$50,000
____ \$50,001-\$75,000
____ \$75,001 or more

APPENDIX C

Consent Form

I, _____, agree to participate in a research study titled "EXPLORING SUPPORT SYSTEMS OF FATHERS OF CHILDREN WITH CHRONIC ILLNESSES" conducted by Kalli Lewis from the Department of Child and Family Development at the University of Georgia (542-4899) under the direction of Dr. Charlotte Wallinga, Department of Child and Family Development, University of Georgia (542-4899). I understand that my participation is voluntary. I can refuse to participate or stop taking part without giving any reason, and without penalty. I can ask to have all of the information about me returned to me, removed from the research records, or destroyed.

The reason for this study is to explore the different ways in which fathers deal with the stress of caring for a child with a chronic illness. If I volunteer to take part in this study, I will be asked to do the following things:

- 1) Participate in a 30-90 minute in-person interview that covers basic information about my family, the stress I've encountered related to my child's medical condition, as well as the people and resources that have been helpful in reducing my stress.
- 2) Participate in a brief follow-up interview either in person or over the phone, lasting no more than 30 minutes. During this follow-up, I may be asked to clarify or expand on some of the same topics from the first interview. Finally, I will have an opportunity to give any feedback about what the researcher has found so far in this study.

I give my permission for the researcher to audio-tape our interview.

Please circle one: YES / NO. Initial _____.

The benefits that I may expect from this study are an opportunity to share my unique perspective as a father of child with a chronic illness as well as the chance to express any of my unmet needs that could help to inform professionals who are in the position of supporting fathers such as myself.

Although no risks are expected, I may experience discomfort or stress when talking about some of the events surrounding my child's chronic illness. I understand that I have the right to skip any question and that I will never be forced to answer a question that makes me uncomfortable.

No information about me, or provided by me during the research, will be shared with others without my written permission, except if it is required by law. I will be assigned an identifying number and this number will be used on all of the notes taken during and after the interview as well as on all audio-tapes. All of the audio-tapes will be destroyed within two months of my interview.

The investigator will answer any further questions about the research, now or during the course of the project (404-583-7338).

My signature below indicates that the researchers have answered all of my questions to my satisfaction and that I consent to volunteer for this study. I have been given a copy of this form.

Kalli Lewis		
Name of Researcher	Signature	Date
Telephone: <u>(404) 583-7338</u>		
Email: <u>kjl@uga.edu</u>		

Name of Participant	Signature	Date

Please sign both copies, keep one and return one to the researcher.

Additional questions or problems regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu