FAMILY RESILIENCE FOLLOWING A DIAGNOSIS OF PEDIATRIC CANCER: PARENT EXPERIENCES OF SOCIAL SUPPORT, COPING, AND ADAPTATION

By

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ABSTRACT

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This dissertation explores the family experience of pediatric cancer. The two separate studies comprising this dissertation work in tandem to present a picture of parent and family factors relating to coping and adjustment. The results of these studies contribute to our understanding of the significant resilience-promoting factors, and their relationship to one another, capable of engendering family resilience following the diagnosis of cancer in one's child. Study One focuses on the parental experience of social support and its contribution to effective coping and adaption. Study Two incorporates each of the most relevant family factors of adaptation, and presents them in a model of family resilience.

Study One is a qualitative study describing parents' lived experiences of receiving social support from friends and family following the diagnosis of cancer in one of their children. In this study, I seek to understand the types of social support parents report being unhelpful and helpful to their coping and adaptation following the crisis of a pediatric cancer diagnosis. Seventeen parents, representing nine families were interviewed. In each interview I asked parents about the impact of the crisis of pediatric cancer on the family and how their social supports helped them cope and adjust to the diagnosis. A phenomenological approach was used to guide the data analysis and resulted in rich descriptions of the lived experiences of research participants. One theme of ineffective support and three guiding principles of effective social support emerged from the analysis. The results of Study One have important implications for individuals desiring to aid families coping and adjustment to pediatric cancer. This study brings to light the

importance of intervening in communities to educate family, friends, and community members about effective social support. This study also reveals a need to provide more collaborative, long-term psychosocial care for families to better meet the chronic challenges of cancer treatment and recovery.

Study Two examines factors related to family resilience, and their relationship to one another, following a pediatric cancer diagnosis. I use the grounded theory method to examine resilience processes in families following the diagnosis of pediatric cancer. Data were collected through in-depth interviews from seventeen parents representing nine families. The analysis revealed that family resilience results from the interaction of important pre-cancer experiences, parent factors, family relational dynamics, and extra-familial support. These aspects of resilience are presented in detail in the Natural Family Resilience Model for Pediatric Cancer. This study highlights the importance of recognizing the natural, inherent family strengths capable of helping families cope well with the adverse experience of pediatric cancer. However it also implicates the necessity of improved, routine evidenced-based assessment to better identify families whose natural strengths may not be successfully meeting the psychosocial challenges of cancer.

Taken as a single body of work, these studies suggest the importance for clinical interventions to begin with evidenced-based assessment, consider the long-term needs of the family, to be conducted collaboratively between hospital and community health professionals, and to be family-based. Also, interventions can target community resources as a primary way of improving the effectiveness of social support offered to families. The two studies also help to advance the understanding of how resilience occurs in the family. Family resilience is more than risk and protective factors. Instead, it is a natural, dynamic family process all families are capable of.

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CHAPTER 1: INTRODUCTION

Purpose

There is great potential for adverse parental adjustment and coping to the diagnosis of cancer in their child. Parental adjustment and coping responses have a demonstrated influence on the child patient, his/her well siblings, and the family's ability to successfully adapt to cancer. Thus there is a need to better understand the resources aiding in successful parent adjustment as well as the barriers to successful adjustment. This dissertation distinctively adds to the understanding of parent and family adjustment to pediatric cancer. In Study One, I examine the role of social support in improving family coping and adaptation throughout their experience with their child's cancer. Clear themes of ineffective and effective social support are described in rich detail. In Study Two I explore parents' experiences of the resources, stress pile-up, perceptions of cancer, and family dynamics contributing to family resilience in the face of pediatric cancer. Their collective experiences are organized into a theory of family resilience, which offers a clear picture of the natural, dynamic process of family resilience capable of being easily translated from the world of research to the world of practical application. The results of this dissertation improve our understanding the family experience of a pediatric cancer diagnosis. In addition, the findings contribute guidance for future empirical research on the psychosocial impact of pediatric cancer on the family as well as suggestions for future clinical and community interventions capable of better meeting the myriad needs of these families.

Rationale

In 2014, approximately 15,780 new pediatric cancer diagnoses occurred in children 0-14 years of age (National Cancer Institute [NCI], 2015). For every 10,000 children in the United States, 1-2 children develop cancer. Pediatric cancer is the leading cause of death by disease among U.S. children between infancy and age 15 (American Cancer Society, 2015). The most common types of childhood cancer include leukemia and cancers of the brain and central nervous system, which account for more than half of all new cases, combined, each year (Surveillance, Epidemiology, and End Results [SEER], 2007).

Cancer incidence in children has increased twenty-eight percent since 1975 (SEER, 2007). Additionally, the 5-year survival rates for all pediatric cancers combined has increased from sixty-three percent in the mid-1970s to eighty-three percent in 2012 (NCI, 2012). The struggle against cancer comes at a great financial and emotional cost to families. For example, in 2005 alone the United States lost an estimated total of $130 billion due to decreased productivity due to all cancer illnesses and cancer related deaths (Bradley et al., 2008).

Adverse outcomes of pediatric cancer. As the result of a pediatric cancer diagnosis many adverse psychosocial outcomes may occur in individual patients and in their family members. Psychologically, cancer in childhood is associated with behavioral problems, coping/adjustment difficulties, depression, distress, and posttraumatic stress disorder reactions. Research on behavioral effects of pediatric cancer suggests patients may be at risk for developing social problems, hyperactivity/impulsivity, rule breaking behaviors, and aggressive behaviors (Liang, Chiang, Chien, & Yeh, 2008). Cancer diagnoses not only affect the behavior of the child with cancer, but also their well siblings. Siblings of pediatric cancer patients are vulnerable to increased irritability, mood swings, agitation, increased aggression, yelling, and crying (Williams et al., 2009). If these short-term behavioral changes persist, they have been known to result in social dysfunction and permanent changes to psychological well-being (Verril, Schafer, Vannatta, & Noll, 2000).

Many family members, especially parents, struggle to adapt to the diagnosis of cancer in a young child. Studies show that parents' fear of cancer and their over-protectiveness of the ill child limits the ability of their child to cope (Fletcher, 2010). The emotional and existential crisis associated with the uncertainty of the course of cancer often obstructs the parent's ability to cope (Hutchinson, Willard, Hardy, & Bonner, 2009). When poor adaptation occurs, depression is a common consequence for the child struggling with the disease (Apter, Farbstein, & Yaniv, 2003). Depression may result from predisposing factors such as deteriorating physical conditions, extreme pain, history of previous losses, or from medications used to treat cancer such as chemotherapy, barbiturates, and some antibiotics (Apter et al., 2003). Children with cancer are also at an increased risk of suicide when compared to the general population, especially when the patient's family has a history of depression (DeJong & Fombonne, 2007). Not only is the child patient at risk for depression, but so too are their parents (Greening & Stopplebein, 2007).

Emotional distress is another common adverse psychological outcome in pediatric cancer patients and their family members. Distress in the cancer patient may result from the child's internal feelings of losing control and their feeling of loss associated with the lack of social interactions with peer and siblings (Wilson et al., 2011). Child distress may also occur if parents fail to maintain adequate cancer related communication throughout the course of treatment (Willingham-Piersol, Johnson, Wetsel, Holtzer, & Walker, 2008). If cancer related distress in the child becomes chronic, it may often lead to avoidant behaviors, difficulty readjusting to school, and future worries about their health (Wiener et al., 2006).

Survivors of pediatric cancer are at risk of developing posttraumatic stress symptoms (PTSS) during and after cancer treatment (Gerhardt et al., 2007). For many of these survivors

(10-13 %), PTSS may last beyond the first five years of remission (Erickson & Steiner, 2001). Parents may be even more at-risk for PTSS than their child with cancer. Numerous studies have documented the prevalence of PTSS in parents of pediatric cancer patients ranging from 17- 40% (Dunn et al., 2011; Stoppelbein, Greening, & Elkin, 2006). The prevalence is even higher for parents of children whose cancer has relapsed (Dunn et al., 2011).

Pediatric cancer also causes significant adverse social outcomes in families. Most noticeably, families are at-risk of experiencing direct challenges to family functioning. Family structure and family functioning has a powerful influence on the course and outcome of most pediatric illnesses (Roddenberry & Renk, 2008). Poor family functioning and lack of family support can prove detrimental to the child's health. Conversely, evidence from large epidemiologic studies demonstrates that familial support is health promoting (Berkman, 2000). Family functioning in response to cancer diagnoses in children is often complex and changing over the course of the disease (Snow & Gilbertson, 2011). Cancer causes families to adapt to changes in routine, roles, and finances (Fletcher, 2010). Parents are forced to spend many hours away from home with their sick child, resulting in challenges to family functioning and family well-being (Prchal & Landolt, 2012).

Pediatric cancer's threat to parent quality of life (QoL). Studies have sought to unify the understanding of the concept of QoL as a multidimensional construct comprised of social, physical, and emotional functioning (Bradlyn, 2004). It has been defined as a concept incorporating various aspects of life (e.g. relationships, satisfaction with work, health, recreational activities), integrating them into a whole, and taking into account the changing circumstances of life that may be a threat (DiGallo, Felder-Puig, & Topf, 2007). The issue of QoL for parents of pediatric cancer patients is an important one. It is established in the literature that parents of children undergoing cancer treatment experience lower QoL when compared to parents without a child with cancer (Bolle et al., 2008). Astonishingly, research has shown parents of children with cancer typically even report lower QoL than their child with cancer (Bolle et al., 2008; Jurbergs, Russell, Long, & Phipps, 2008). This suggests parents of children with cancer may be more at-risk for negative psychosocial outcomes than their child.

The uncertainty of the trajectory of cancer, in addition to the caregiving burden, is known to be the largest barrier to successful coping (Hutchinson et al., 2009). Other parent factors related to low QoL are the parents are unable to trust the medical staff and when they perceive their child to be coping inadequately to the cancer (Tremolada et al., 2010). Furthering the adverse affects of parent QoL in response to cancer in their child is that parents whose child's cancer has relapsed experience even greater difficulties adapting to the illness than those who are parents of cancer survivors or of children who have died due to cancer. (Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). Studies examining best practices in providing help to families struggling with adjustment to the cancer diagnosis are needed (Hildenbrand, Clawson, Alderfer, & Marsac, 2011).

Statement of the Problem

A number of studies report a significant association between parental stress and adverse adjustment outcomes in children with cancer (Kazak & Barakat, 1997; Van Dongen-Melman et al., 1995). This concept is known as "reciprocity." Much of the child's ability to adapt to the cancer is dependent upon the parents' level of distress. For example, studies reveal children with cancer are at greater risk for anxiety when their mothers qualify for a diagnosis of depression or anxiety (Barrera et al., 2004; Brown et al, 1993; Manne et al., 1995, 1996; Sawyer et al., 1997, 1998). Higher levels of general distress in parents have also been linked to greater hopelessness in children with cancer (Blotcky, Raczynski, Gurwitch, & Smith, 1985). Additionally, poorer parental adjustment and greater parent anxiety was related to child depression and externalizing behaviors (Frank, Blount, & Brown, 1997). Finally, the father's ability to adapt to the cancer has also been shown to influence the progress, outcome, and secondary physical and emotional complications of the child's illness (Hinds et al., 2004; Tiedje & Darling-Fisher, 1996).

Research also suggests that for parents who perceive their child's illness to be quite severe, the levels of distress in the parent increase markedly (Mereuta & Craciun, 2006). If this parent distress is prolonged, it has been found to be associated with young adult internalizing symptoms (e.g. depression and anxiety) in cancer survivors (Robinson, Gerhardt, Vannatta, & Noll, 2009). Chronic distress in parents also typically leads to poorer family functioning in families battling pediatric cancer (Streisand, Kazak, & Tercyak, 2003). Consistent evidence suggests the child cancer patient's QoL to be closely associated with the adjustment and behaviors of their parents. For example, child cancer patients report lower QoL when their mothers report depressive symptoms, parenting stress, or relationship distress with their partner (Roddenberry & Renk, 2008). Children with cancer also demonstrate lower abilities to cope with their illness when their parents report higher levels of fear and over-protectiveness (Fletcher, 2010).

The pediatric cancer literature is clear in its demonstration of the connection between parent distress and child wellbeing. The success or failure of parents to adapt to the crisis of cancer is one of the most influential factors in predicting positive child and family psychosocial adjustment to pediatric cancer. Improving the understanding of the processes contributing to augmented parent adjustment is perhaps the best way to improve the entire family's wellbeing following a diagnosis of pediatric cancer. Currently, research provides some insight into broad target areas of understanding regarding the processes enabling some parents and families to remain resilient following the cancer diagnosis. For example, it is known that maintaining family functioning significantly aids child adjustment (Fuemmeler, Brown, Williams, & Barredo, 2003). Family functioning remains hardy in the face of pediatric cancer when parents and caregivers successfully alter roles, responsibilities, and day-to-day functioning to accommodate the needs of children with cancer (Long & Marsland, 2011). As parents learn to adapt and cope with their child's cancer, every member of the family experiences a decrease in cancer related distress over the course of the illness and its treatment (Steele, Long, Reddy, Luhr, & Phipps, 2003).

However, what remains less clear in the literature is how these factors interact with one another to aid parents in their ability to maintain high levels of resilience, family functioning, and adjustment after the diagnosis of cancer in their child. Many questions remain unanswered: Why do some parents and families cope well while others struggle? What individual, familial, or community resources enable parents to successfully alter cope with their distress? What specific obstacles provide the biggest obstacles to resilience? Answers to important questions such as these remain unclear in the literature despite their potential to positively impact the parent, child with cancer, and family adaptation to the crisis of pediatric cancer.

Theoretical Underpinnings

The specific aims of this study will be addressed with the use of the biopsychosocial-spiritual and Family Stress Theory frameworks. The combination of these two well established theoretical approaches provides a well organized picture of the multidimensional stress demands of pediatric cancer on the child patients and their family, as well as the typical responses to stress families make that lead to successful and unsuccessful adaptation.

Biopsychosocial-Spiritual framework (BPSS). The biopsychosocial framework was first introduced by Engel (1977), and was extended by subsequent authors to include the spiritual context in addition to the biological, psychological, and social dimensions (Hodgson, Lamson, & Reese, 2007; King, 2000; McKee & Chapel, 1992; Sulmasy, 2002; Wright, Watson, & Bell; 1997). The BPSS framework provides a lens to understand the various components of overall health and well-being. Based on General Systems Theory, developed by Ludwig von Bertalannfy, (1969), Engel's (1981) BPSS model views individuals as part of and a container of multiple systems. Each part of the system affects that system, and each system interacts with other systems (Kelly & Ganong, 2011). Therefore a change in even one part of a system could change all of the systems (Engel, 1981).

The BPSS consists of: the physical systems comprising an individual's biology (e.g. subatomic particles, atoms, molecules, cells, tissues, organs, organ systems, and the nervous system); an individual's mental state (both cognitive and emotional); an individual's relationships with others (e.g. family, friends, community, culture, and society); and an individual's spirituality as defined by their sense of connection with a transcendent and inspiring force capable of bringing meaning to one's life and shaping the way one behaves and operates in the world (Armstrong, 1999; Engel, 1981; Kelly, 2010). The literature mentioned above provides empirical examples demonstrating the interconnectedness of biological, psychological, social, and spiritual systems, as they relate to families experiencing pediatric cancer.

Family stress theory (FST). Family stress research dates back to the Great Depression of the 1930s (Angell, 1936). Researchers began to examine the coping responses of American families as they sought to adapt to the economic and emotional impact of the Great Depression. The early work of researchers during the Great Depression paved the way for sociologist, Reuben Hill (Hill, 1949). Hill expanded on the understanding of how families respond to stress by researching the impact on wives and children of having a father/husband conscripted into the World War II. His work produced the ABCX Formula. The variables in Hill's ABCX model became the basic structure for later family stress research. The variables included in the model are: the crisis-precipitating event/stressor (A); family crisis-meeting resources (B); the family definition of the crisis-precipitating event (C); and the crisis (X).

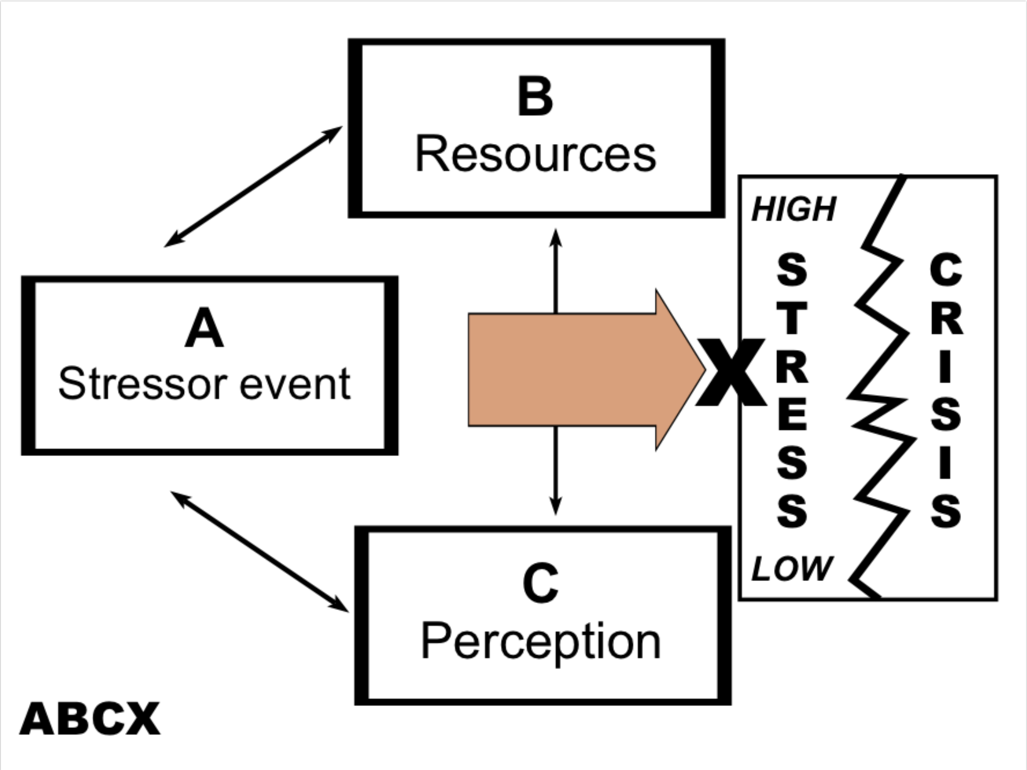

FIGURE 1.1: ABCX Model of Family Stress. From Hill (1949).

Expanding on the early work of Rueben Hill, Hamilton McCubbin and Joan Patterson (1983) formulated the Double ABCX Model of family stress. Their new model kept Hill's original ABC variables but added a second set of ABC variables to describe what occurs to families post-crisis. The post-crisis variables focus on (a) the additional life stressors and changes with potential to impact a family’s ability to adapt, (b) the psychological and social resources families draw upon to help them manage the crisis, (c) the processes families utilize to resolve the crisis, and (d) the outcome of the family’s attempt to withstand the crisis (McCubbin & Patterson, 1983).

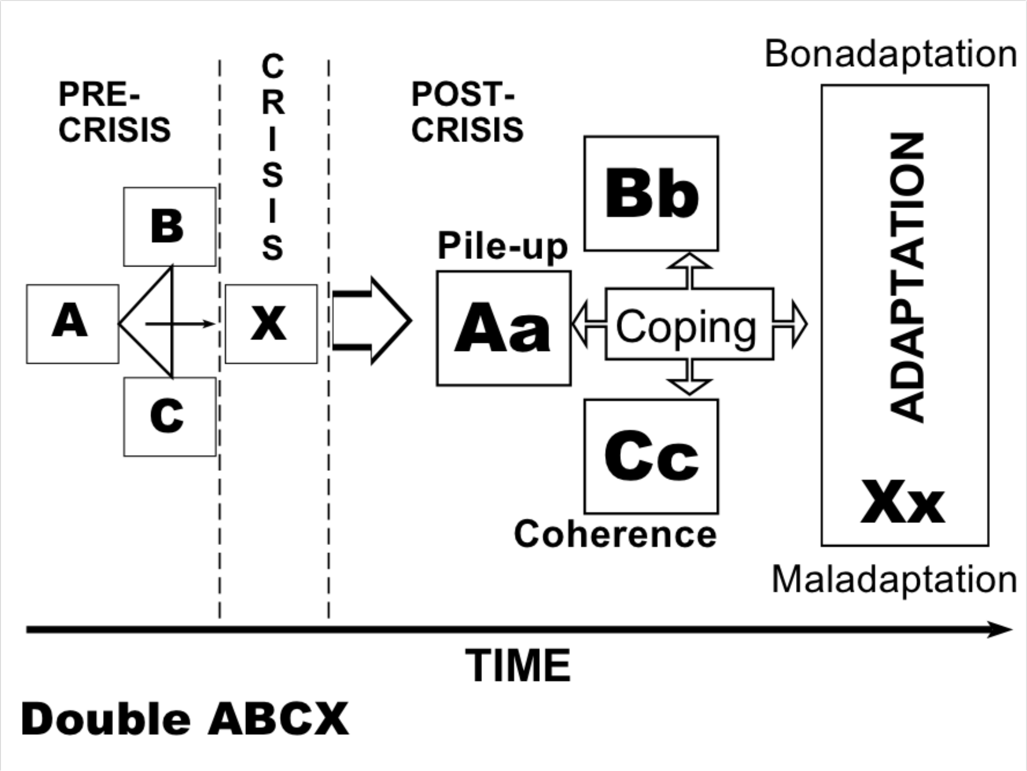

FIGURE 1.2: Double ABCX Model of Family Stress. From McCubbin and Patterson (1983)

The models of family stress response outlined by Hill and McCubbin and Patterson provided a useful framework for developing targets of inquiry designed to increase understanding of how families adapt to the specific stressors of a pediatric cancer diagnosis. The FST model, specifically the Double ABCX Model, focused the work of this dissertation on the possible factors (e.g. stress pile-up, family resources, family perception of the stressor, and coping) contributing to successful family adaptation following a pediatric cancer diagnosis.

While the two aforementioned theoretical frameworks have typically been kept distinct, I developed a composite model to guide my research and analysis. Figure 1.3 demonstrates this framework. Each BPSS system is comprised of pre-crisis stressors (A), resources (B), and perceptions of the stressor (C). These systems become challenged by the crisis of the pediatric cancer diagnosis. Individuals in the family then experience a pile-up of stress demands (Aa), resources (Bb), and new perceptions about the crisis event in each of the BPSS areas. The interaction of these four areas influence coping, which leads an individual's ability to experience health and well-being in spite of the cancer crisis.

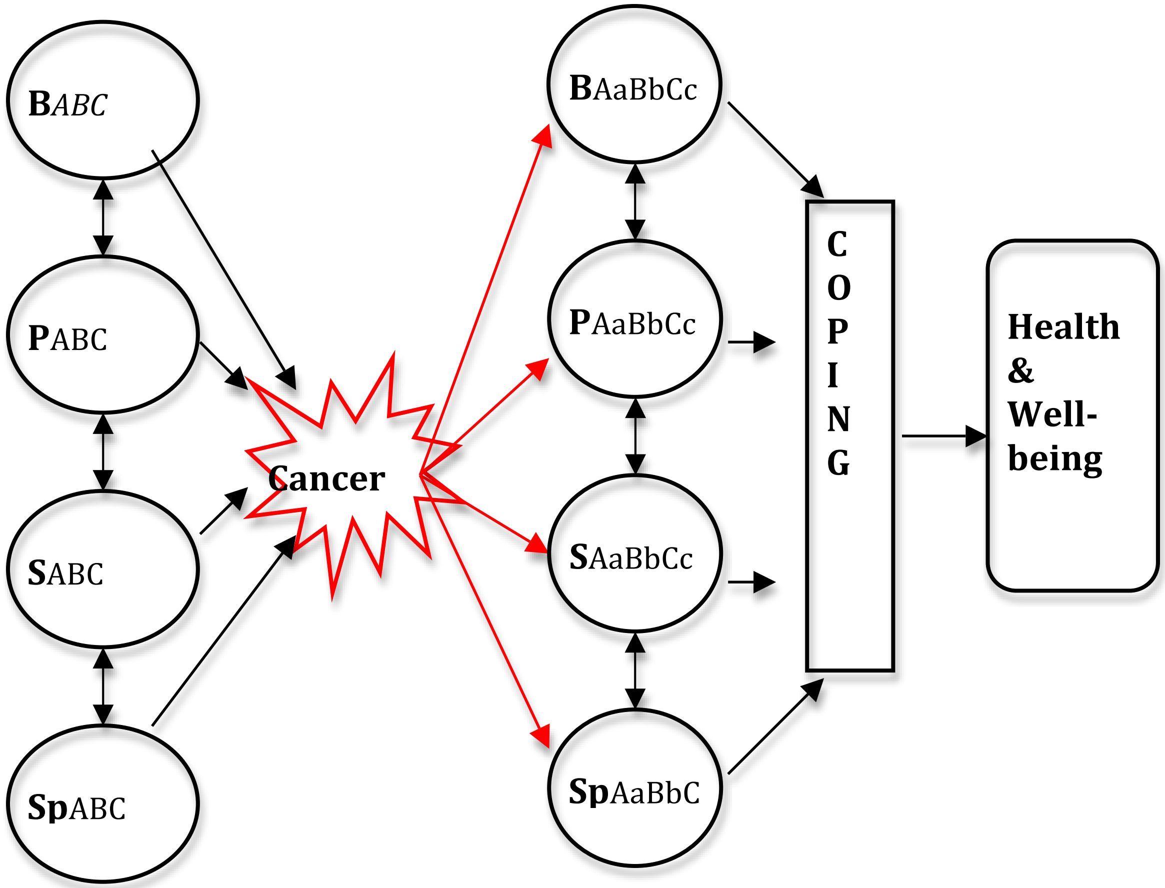

FIGURE 1.3: Composite Theoretical Model

By integrating the BPSS with the FST models, I was able conceptualize the family pediatric cancer experience in terms of a holistic—body, mind, emotions, relationships, and spirituality— view of health and well-being as a system of interacting systems (BPSS Model). Additionally, I was able to translate the specific categories of the family stress experience—crisis, stressors, resources, perceptions, and coping—into various BPSS systems.

In the two studies comprising this dissertation, I use this broad framework to guide my research. In Study One, specific aspects of the families' social experience of pediatric cancer are investigated. The impacts of social support are examined for parent perceptions of the support as a resource or stressor on their emotional well-being, psychology, and adjustment. Study Two seeks to establish a comprehensive view of the multidimensional experience of coping and adjusting to pediatric cancer. A new theory of family resilience is developed. This new theory illustrates specific individual, familial, social, and community factors contributing to the familial pediatric cancer experience. The interactions of these factors with various stressors, as they contribute to family resilience, are also described. The following studies apply the theoretical background of this dissertation in more specific and substantive ways. The studies' contributions to the pediatric cancer research literature are described below.

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CHAPTER 2: STUDY ONE

Help for the Helpers: Parental Experiences of Ineffective and Effective Social Support Following the Diagnosis of Pediatric Cancer

ABSTRACT

The current qualitative study describes parent's lived experiences of receiving social support from friends and family following the diagnosis of cancer in one of their children. The purpose of this study is to understand the types of social support parents report being unhelpful and helpful to their coping and adaptation following the crisis of a pediatric cancer diagnosis. To discover the parents' experiences of social support, sixteen parents, representing nine families were interviewed. Each interview asked parents about the impact of the crisis of pediatric cancer on the family and how their social supports helped them cope and adjust to the diagnosis. A phenomenological approach was used to guide the data analysis and resulted in rich descriptions of the lived experiences of research participants. One theme of ineffective support and three guiding principles of effective social support emerged from the analysis. The results of the current study have important implications for individuals desiring to aid families cope and adjust to pediatric cancer. Implications for health professionals tasked with providing effective psychosocial care are provided as well as suggestions for future clinical pediatric cancer research.

Introduction

Pediatric cancer is the leading cause of death by disease among U.S. children between infancy and age fourteen (American Cancer Society, 2015). The most common types of childhood cancers include leukemia, cancer of the brain, and cancer of the central nervous system. These three diagnoses account for more than half of all new childhood cancer cases each year (Surveillance, Epidemiology, and End Results [SEER], 2007). While the prevalence of invasive cancer in children has increased marginally over the past 30 years, advancement in treatment has improved the 5-year survival rate for all pediatric cancers combined; these rates have improved from 58.1 percent in 1977 to 79.6 percent in 2003 (National Cancer Institute, 2010). Cancer survivorship often creates unique stress on family members due to the ambiguity about the child's future health and the potential need for the parents to provide lengthy and often expensive care (Cardella & Friedlander, 2004). Numerous studies have shown that one of the best ways families cope with the chronic distress of pediatric cancer is through the reception of social support from family, friends, communities, and healthcare professionals (Corey, Hasse, Azzouz, & Monahan, 2008; Fletcher, 2010; Fuemmeler, Brown, Williams, & Barredo, 2003; Lockhard & Berard, 2001).

Social support reduces psychological and physical symptoms in a variety of populations and for a range of distressing life experiences related to psychological and physical well-being (Uchino, 2004; Wills & Ainette, 2011). Cohen and Syme (1985) define social support as the resources provided by others to help cope with a stressful situation. Social support is given in four distinct ways: emotional, instrumental/material, informational, and companionship (Berkman, Glass, Brissette, & Seeman, 2000; Due, Holstein, Lund, Modivig, & Avlund, 1999). Emotional support occurs through the communication that the person is valued and accepted despite the troubles they are experiencing or their personal faults (Berkman, et al., 2000). Instrumental/material support is the provision of tangible aid (e.g. financial, material, and services) that meets specific, concrete needs (Cutrona & Russell, 1990). Informational support comes in the form of helping to define, understand, and cope with the distressing event. It often comes in the form of advice and guidance (Cohen & Syme, 1985). Companionship is spending time with others in leisure and recreational activities such as visiting, dinner, shopping, athletic events, and others (Langford, Bowsher, Maloney, & Lillis, 2008).

As a result of a distressing cancer diagnosis, a variety of negative biopsychosocial consequences can occur for the cancer patient and his/her family (Long & Marsland, 2011; Patenaude & Kupst, 2005). However, the social support a child with cancer and his/her family receive throughout the course of their cancer treatment can significantly reduce the negative impact of the crisis, and assist them in coping and maintaining an optimal quality of life (QoL) in the face of the crisis (Applebaum, Stein, Lord-Bessen, Pessin, & Rosenfeld, 2014; Eom et al., 2013). Social support is helpful for both the child patient and his/her family. Support from family and friends was identified by Trask et al. (2003) as the most important factor in the child's ability to cope with his/her cancer diagnosis and treatment. Social support reduces symptoms of distress in adolescents with cancer (Corey et al., 2008), reduces the feelings of loneliness and isolation that can be common throughout the course of cancer treatment (Yildirim & Kocabiyik, 2010), and is a main source of resilience for child cancer patients (Lockhart et al., 2001).

For parents, support from social networks can help them to better adjust to their child's cancer (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Kupst & Schulman, 1988; Kupst et al., 1995; Smith, Redd, Peyser, & Vogel, 1999). Moreover, social support can improve the family members' ability to remain focused on the positive during their cancer treatment

(Zabaleugui, Cabrera, & Navarro, 2013) and can help combat symptoms of posttraumatic stress over time (Greening & Stoppelbein, 2007). Social support from family and friends can also help families maintain higher levels of healthy functioning which can buffer the risk of poor adjustment to pediatric cancer (Fuemmeler et al., 2003).

However, when social support is perceived to be lacking, child patients and their family members are at increased risk of developing distress as commonly manifested by symptoms of posttraumatic stress, anxiety, hopelessness, and poorer family functioning (Best, Streisand, Catania, & Kazak, 2001; Kazak et al., 1997; Kazak et al., 1998; Manne, Duhamel, & Redd, 2000). Parents especially can be affected by lower amounts of social support. When fathers are dissatisfied with social support they receive, their distress levels increase (Wijnberg-Williams, Kamps, & Hoekstra-Weebers, 2006), and it is the same for mothers. In a study by Altay, Kilicarslan, Sari, and Kisecik (2014) every mother in the study reported the need for social support yet, only 73.9% received support, and many of those who did reported that the support they received was less than they needed. Often the biggest dissatisfaction with social support reported by parents is that it tends to decrease after the initial crisis of diagnosis. After only six months, many families receive markedly less support from family and friends which has a significant negative impact on their QoL as they continue to cope with the ongoing cancer distress (Salonen, Tarkka, Kellokumpu-Lehtinen, Koivisto, & Aalto, 2013). The importance for social networks to provide adequate social support is paramount. The right types of social support have direct effects on reducing negative affect (e.g. depression and anxiety) (Hudek-Knezevic, Kardum, & Pahljina, 2002). The direct impact of social support on reducing negative affect is even more noticeable as the cancer treatment and recovery becomes prolonged. For children with newly diagnosed cancer, the direct and independent effects on reducing negative affectivity was significantly greater at nine months post-diagnosis than at one month (Varni & Katz, 1997). Thus, a primary need for most families with cancer is the presence of social support throughout the entire course of the illness, especially after the initial diagnosis and as the child and the family adjust to the biomedical treatments and subsequent school and social reintegration that needs to occur (Varni & Katz, 1997).

Even when social support is given it is not always beneficial to the patient and the family. Social networks often fall short of meeting the patient's ideal of enduring emotional and practical support (Warwick, Joseph, Cordle, & Ashworth, 2004). Studies have identified various types of actions, meant to be helpful, by social support networks toward cancer patients and their families that actually fail their purpose. For example, when social supporters either avoid their friend or family member and their cancer, or if they are overly focused on how cancer is impacting her or his life, the cancer patient's distress can increase (Gurowka & Lightman, 1995). Lehman and Hemphill (1990) refer to the extremes of avoiding and over-focusing on the cancer as "minimization" (i.e. disputing the serious of the disease) and "maximization" (i.e. catastrophizing and being excessively protective). Often there is even an importance on "who" is providing the social support. Some families going through difficulties report that it is not only the specific action of support but also the source of the support (e.g. family, friend, medical staff). Particular support actions are often perceived to be helpful from some but not other social network members (Dakof & Taylor, 1990). Whether or not supportive actions are defined as helpful or unhelpful is often dependent on the patient. Thus, the type of support provided must fit the individual patient, their family, and their particular situation (Martin et al., 1994).

Purpose of the study

Providing support to a family with a child with cancer can often be a challenging task, even for the most caring friend, family member, or professional. A pediatric cancer diagnosis is an uncommon experience few people must face in their lifetimes. Because of the rarity of this phenomenon, there are not well-established norms to help guide the support actions of social networks. Many family friends are left wondering, “What can I do to help?” The lack of knowledge about how to provide social support that is truly helpful to the child patient and their family is called “social ineptitude” (Dyregrov, 2003). Despite the body of research on the value of social support for families experiencing pediatric cancer, work remains to be done on eradicating the “ineptitude” of support networks attempting to help families experiencing pediatric cancer.

By giving voice to the pediatric cancer families’ experiences of social support, this study seeks to elucidate the supports that were beneficial, in addition to types of support that are unhelpful, and even burdensome. By richly describing the parents’ lived experiences, it is our hope that social support networks (e.g. family, friends, communities) and healthcare providers (e.g. therapists, social workers, nurses, child life specialists, physicians) can learn about what is most helpful to families and can then provide better resources in terms of support. Answering the question of “What can we do to help?” often posed by family and friends is the primary purpose of this study.

Methods

Procedures

This study was conducted in collaboration between a researcher from a large Midwestern university and a children’s hospital located in Grand Rapids, Michigan. Grand Rapids and its surrounding metropolitan area have a population of over 1 million residents. According to the 2010 US Census, the Grand Rapids Metro area is approximately 82.7% non-Hispanic white, 8.4% Hispanic, 6.5% black or African American, and 2.2% Asian (US Census, 2010). The children's hospital is a 212-bed, 14-floor, 464,000 square foot facility housing 55 specialty departments. Among these departments is the Department of Pediatric Hematology/Oncology. As one of the region's few pediatric cancer care facilities, it receives patients from not only the Grand Rapids metropolitan area, but also from surrounding areas of Mid and Northern Michigan, and Indiana.

Following Institutional Review Board approval from both the university and the children's hospital, participants were recruited through advertisements at the hospital and through word-of-mouth among hospital social workers, child life specialists, nurses, and physicians. Participants were recruited for the study using a purposive sampling method, meaning they were selected based on the likelihood they had experiences relating to the phenomena being studied (Kruger, 1988). After parents were notified about the study opportunity, interested participants contacted the researcher regarding their desire to take part in the study. The researcher then described the study to the study prospect in greater detail and, after assessing for participant eligibility, scheduled an in-person interview with the parents. The eligibility criteria included: (a) having at least one child under the age of eighteen who was diagnosed with cancer between six months and five years ago, (b) ability to provide written consent, (c) ability to speak English, and (d) the primary caregiver(s) to the child diagnosed with cancer.

After the parents agreed to participate, the interviews were conducted at a time and location most convenient to the family. Interview locations included either a confidential patient room at the children's hospital or at the participants' home. The author, a licensed marriage and family therapist conducted each interview. Interviews followed a semi-structured format and averaged ninety minutes each and ranged range 56 to 147 minutes. The interviews examined three time points: (a) family life before the cancer diagnosis, (b) the events surrounding the initial diagnosis of the child's cancer, and (c) family life since the diagnosis. Open ended questions were designed to address the parents' experience of the cancer crisis, the stress pile-up since the diagnosis, the resources helpful to their adjustment to cancer, and their perceptions of the family's experience with their child's cancer. Examples of questions include: "How would you describe your family life prior to learning about your child's diagnosis?" "How did you come to know about your child's cancer?" "How did cancer change your family?" "What are the most stressful things about being a parent of a child with cancer?" "How would you describe your social support system since the diagnosis?" "What types of things do you and your family do to help cope with all that you are going through?" "What is your understanding or perception about your child's and your family's battle with cancer?" Each parent participating in the study received a $20 Visa gift card as a thank you for taking part in the study.

Participants

A total of sixteen parents (eight fathers and eight mothers), representing nine families, participated in the study. Seven participating families were represented by both the mother and father in the interview. One family had only the father participate (the mother was unavailable). A single mother represented one family. At the time of the interviews, all child patients were still living. Mean time since diagnosis was 30 months (Range: 10, 50). The mean age of the child's first diagnosis with cancer was 6.4 years old and ranged from birth to 17 years old. Five families had a child diagnosed with Leukemia, three families had a child diagnosed with a malignant brain tumor, and one family had a child diagnosed first with liver cancer and seven years later with a brain tumor. Each family had at least one child (Mean: 2.1; Range: 1, 5) in addition to the child patient. Eight of the families were Caucasian and one family was African American.

Data Analysis

Phenomenological research methods were used to guide the study analysis. The goal of phenomenology is to describe the "lived experiences," or the actuality of specific social and psychological phenomena from the perspectives of the people involved (Greene & Holloway, 1997; Maypole & Davies, 2001; Welman & Kruger, 1999). To achieve this, a simplified version of Hycner's (1999) process of phenomenological data analysis was used (Groenewald, 2004). This process includes five steps: (1) bracketing, (2) delineating units of meaning, (3) clustering units of meaning to form themes, (4) summarizing each interview and validating it, and (5) extracting general and unique themes from all the interview and making a composite summary (Groenewald, 2004).

The first step, bracketing, involves the researcher's attempts to set aside his or her own preconceptions of the phenomena, to refrain from making judgments, and to enter into the experience of each of the participants (Moustakas, 1994). Gearing (2004) explains bracketing as a "scientific process in which a researcher suspends or holds in abeyance his or her presuppositions, biases, assumptions, theories, or previous experiences to see and describe the phenomenon" (p. 1430). Bracketing is an ongoing process throughout the entirety of phenomenological research. Methods used to prevent potential bias included the researcher using rigorous data collection and analysis methods. To achieve this I obtained informed consent from each participant before the interviews were conducted, audio recorded all interviews, wrote memos after each interview to reflect on potential biases, and listened repeatedly to audio recordings to become familiar with the words and meanings of the participants.

Second, the phenomenological researcher must delineate units of meaning from each interview. This involves identifying and isolating participant statements into specific segments of meaning. Each segment of meaning is selected carefully and critically. As the units of meaning are being selected, each is constantly compared to the previously selected units. All non-unique units are eliminated or joined together with previous similar units. Delineation of meaning is a process in which the researcher considers the literal content, the number of times a meaning was mentioned, and how it was stated (Hycner, 1999).

Following the development of the list of units of meaning, the researcher then must cluster the units of meaning to form themes. To accomplish this, units of meaning are grouped together with similar units of meaning by considering their relationship to each other and to the broader context. This process cannot be done without the researcher making judgment calls regarding the relationship of units to one another (Groenewald, 2004). Thus, it is necessary to continue the bracketing process throughout this stage of analysis to minimize researcher bias. Going back and listening to the initial interviews is a key part of the reducing bias as the researcher seeks to remain immersed in the world of the participants and their experiences (Hycner, 1999).

After establishing clusters and themes with the units of meaning, the researcher then must validate these themes by returning to each interview to establish if the essence of the participant's experiences has been encapsulated. For any theme not representing the interviewee's experience, the theme must be modified to better fit the total inner "world" of the participants (Hycner, 1999, pp. 153-154). Finally, the researcher steps back from the individual participant's experiences to look at "the themes common to most or all of the interviews as well as the individual variations" (Hycner, 1999, p. 154). While commonalities between the participants are highlighted, so too should the voices and experiences of the participants who have unique and contrasting experiences. After the general and unique themes are extracted, a composite summary is written that describes the context from which the themes emerged (Hycner, 1999; Moustakas, 1994). This summary also serves to transform the participant's expressions into terminology fitting for academic and scientific discourse (Sadala & Adorno, 2001).

Results

All participants spoke at length about the significance of social support they received from family, friends, and their communities. Social support was a primary resource enabling families to better cope with the crisis of pediatric cancer. However, many parents described how many of those closest to them did not fully understand how to be supportive in the most helpful ways. Thus, the descriptions shared by parents in the study outlined what they would want their friends, family, and community to know about how to be most supportive to them as they coped with pediatric cancer. Four main themes emerged from the study. The first theme describes the families' experiences of ineffective social support. Ineffective support is categorized as: "People just really don't know what to do." The other three themes represent guiding principles of effective social support. The three themes are: "It's a marathon not a sprint;" "You have to just do it;" and "Let us know we're not forgotten." All four themes represent key pieces of knowledge parents of children with cancer desire for their social support systems and individuals to know as they seek to help families experiencing pediatric cancer.

Ineffective Social Support

Every family interviewed for the study shared experiences of social support attempts that were more burdensome than helpful. The primary theme of "People don't know what to do" describes the feeling of the parents as (a) they were repeatedly exposed to social support that was unhelpful, and (b) as important social support people withdrew from them during their time of need. Evidence that many friends, family, and community members did not know what to do is reflected in two primary sub-themes: people getting "Too close to the situation," and parental experiences of how "Some people just disappeared."

People really just don't know what to do. Parents from each of the nine families represented in the study shared experiences of people interacting with them in ways intending to be supportive but were not. As parents tried to understand how family, friends, and community members could be acting in ways actually making their experience with cancer more difficult, the common sentiment was they, "just don't know what to do."

One dad described his experience of the many ineffective support attempts by his support system in the following way:

> A lot of people don't understand that we do actually have a new normal. They don't realize how much you still got to do because of what has happened in the past. How often we go to the doctor, getting labs, doing all that kind of stuff. They see (our son) now and just think everything is normal…even my brother and his family, they just don't know what to do

Another example of parents experiencing the ignorance of some of their social supports comes from a father of a girl with a brain tumor. He said:

> Sometimes people would try to help, but they don't know how to help…People come in, and they don't mean any harm, but some are just like, "I'm glad its not me." Or "When's the funeral?" Or "What's the prognosis?" But that's not the kind of conversation you want to have

The experiences of ineffective social support are often so prevalent to parents that they try to seek solutions for improving the lack of awareness some friends, family, and others can appear to have regarding how their actions and words may negatively impact the family they are trying to help. For example, a mother of son with leukemia said the most important thing for improving the effectiveness of social support for pediatric cancer families is to be, "educating people who are out there, who want to know, who are really wanting to help you." She continued by saying, "I really feel like it's our job as parents of the kids with cancer to help the people who don't know what to say. They don't know how to react…They probably feel uncomfortable…I think that as a parent of a kid with cancer, we need to talk to people about it." Thus in her mind, reducing the negative impact of ineffective social support became another job for the parents who are already burdened with caring for their sick child and helping the rest of their family adapt to the stresses of cancer.

Too close to the situation. Many parents reported frustration when they felt their social supports systems were becoming too involved with their family's attempts at coping with pediatric cancer. This often involved boundary crossing by the support individuals (e.g. coming to the hospital for treatments when they were not invited nor needed). A father of a young boy with leukemia said

> There are a lot of people that want to be so close to the situation that they actually hinder you. Everybody uses the term, 'New Normal." Well these people that are too close, are not helping you establish that. They are actually making it harder

Another mother describes her experience of boundary crossing by her family the night they brought their son to the hospital to be induced for initial treatments. She said:

> It was really frustrating because my family is drama kings and queens. They were very dramatic about it. Everybody was in the hospital. We had like 25 people in the room and people were asking questions and doctors were coming in and out. And all these people were crying and you find yourself trying to comfort everybody else

Her husband followed up by adding, "It was so chaotic those first few days. It was like ‘balls to the wall.’ Everything was 100 miles an hour. It got to the point where I am like, ‘Okay. Everybody is forbidden from being here (at the hospital).”

For other families, their experience of having “people be too close to the situation” became apparent as many people flooded them with pre-made meals the families could cook at home. While families appreciated the gifts, there came a point for families where they had more food than they knew what to do with. Yet friends and family continued to overwhelm the family with unneeded meals. A father of a girl with leukemia said, “We got to the point where we had to turn meals down. There were people bringing us one meal and it would feed us for three nights. That was not going to work.” And a father of a teenage son with a brain tumor said:

> Everybody wants to bring you food. They just wanted to contribute and help in some way, and we appreciated it. But I have very little time. I don’t need six ham dinners…And the food, I keep coming –back to the food, people don’t know what to do. I’m not there to eat it. Everybody is up at the hospital and the food’s rotting in the fridge. Poor plan. We had a lot of that initially, but I said, “Stop”

Whether it was in the form of being physically present with the family during times when it was not welcome, becoming emotionally involved to the point the parents feel they needed to be the ones to provide comfort, or by bringing unneeded meals, there are many ways social support systems can become an unnecessary burden in the family’s adjustment process. This over-involvement can hinder the family’s attempts to cope and adapt to their child’s cancer diagnosis.

Some people just disappeared. In contrast to becoming over-involved and interfering with the family’s coping process, many parents also described experiences of how once trusted friends and family members pulled away from them after their child’s diagnosis. For example, a father of a teenage boy with a brain tumor said:

There were people I had met that I would never had guessed would be as supportive

> emotionally, mentally, financially or otherwise…And then there were the people I thought would have been exceptionally supportive who couldn't deal with it. They just faded off. You could think they are your best friend, but maybe your best friend is not in a position to help you in any way, shape, or form. Or they might be a negative influence. That is what I've learned from this experience: The ones that I would have bet a million bucks that would be at (his son's) funeral, who would be the best emotional, mental support for my wife. I've learned enough now to say you never know where it's going to come from. You just don't know

Many other parents echoed this father's experience. One father said, "The people who we thought were going to be there, they were not there." His wife agreed by saying, "I found that the people who I thought would be most helpful weren't." A father of daughter diagnosed with a brain tumor at birth described how other cancer families he knew also felt this way. He said, "Their motto was, 'the people you think are going to help, leave or bail on you."

It is not just friends and extended family members who are capable of distancing themselves from the family coping with pediatric cancer. Occasionally the distancing comes from within the marital relationship of the child patient's parents. In this study, one mother interviewed divorced her husband within two years after her five-year-old daughter was diagnosed with leukemia. The perceived lack of support from her husband was a significant reason for the divorce. She said:

> He has not gone to any of the appointments. He did come for her getting her port out but only after she (their daughter) begged him, "Daddy, I want you to come so bad." So he came for twenty minutes after her port came out. She wanted him there before, but he didn't come before.

This mother felt very alone and unsupported by her husband's actions. She went on to say, "Having a person there to support you, talking you through everything, and going to appointments with you would be really nice…I was going through this almost completely alone."

Not only do parents feel the pains of loneliness when their expectations of support are met with distance, but so too do the child patients. A mother of a teenager daughter with leukemia reflected the disappointment she felt for her daughter after some of her peers seemed to distance themselves from her while she was being treated for her cancer. She said:

> The hardest thing for me as her parent is knowing the isolating nature of this whole experience for her. It is very hard to deal with…Loneliness is definitely a part of what she has had to deal with on top of everything else. Which is different than the 5 year olds and the 3 year olds who are dealing with leukemia. It's a different thing with the teenage kids. One of the challenges is with her peers. Some of them just disappeared. A lot of it is immaturity. Or they feel uncomfortable with it and they are gone. And then how is she (her daughter) going to deal with that?

Parents reported a keen awareness of knowing when social supports where not present and available to provide emotional or practical support needed to help them better cope with their child's cancer. The unmet expectations of support brought feelings of loneliness and disappointment. Despite attempts of parents trying to be understanding of why friends and family might not be there for them during their time of need, the negative impact of people who "disappeared" was felt deeply by the families in this study.

Guiding Principles of Effective Social Support

Of course not all social support provided to the families failed to adequately support the family. There were many helpful support attempts parents reported receiving. Key themes (principles) emerging from the data related to positive support included: "It's a marathon, not a sprint," "The world keeps pushing on us," and "Let us know we're not forgotten."

It's a marathon, not a sprint. All participants discussed the reality that cancer is a disease that does not go away quickly. The mother of a daughter (thirteen-years-old) with a brain tumor described the indefinite nature of cancer by wondering, "Where is the stop button?" Due to the longevity of cancer and its treatment, parents often find themselves being supported by many at first, but seeing this support dissipate over time. A father of a sixteen-year-old daughter with leukemia said:

> Initially it was just a wave, a tsunami of support. The thing with leukemia is that is it not a sprint. It's a marathon. We are just over half way through the scheduled treatments and she is doing better but (the support) has kind of trickled off. We wanted the material things to trickle off, but the friendships and prayers, we were hoping they would hang on. And some have and some haven't.

The metaphor of "marathon" was a commonly used phrase to describe the family's lengthy struggle with cancer. Parents of a nine-year-old girl with leukemia discussed the work required of social support systems seeking to be helpful to their family throughout the entirely of their daughter's experience with cancer. The mom, said, "The pressure's (to provide ongoing support) on the friends and the other marathon runners." The dad added, "We will need you later (as cancer treatment continues months and years after initial diagnosis).

Families experiencing pediatric cancer need their friends and family to be supportive over the long haul of cancer and its treatment. A mom and dad of a boy diagnosed with leukemia at 17 months of age provide an honest challenge to those wanting to be of help to families experiencing pediatric cancer. They said:

> I ask you to be long-suffering. Don't just be there in the beginning. Be the person that's there at the end. If you are going to decide to be there for somebody, do it towards the end of their treatment. Be like, " Okay, I am going to make a pledge that a year from now I am going to stop in and do something."

The dad also added, "If you want to be a help to somebody expect the fight to be a long fight.…It's crazy but it is going to be a long road."

As described in the previous section, some social supports "disappear" after the diagnosis. Trying to understand why this occurs, the father of a seventeen-year-old boy with a brain tumor described the initial desire for others to be supportive as "sex appeal." Comparing his experience of decreased support to what might occur after having a family member die, he went on to say:

> Everybody wants to cure cancer. Everybody wants to be supportive. It's like walking into a funeral home and saying, 'you have my condolences.' Well, six weeks later when you're still a mess because of the death, the condolences aren't as helpful. Are you going to mow my lawn? Would they even think to call six weeks later? No. It's not in the immediate forefront.

Other parents expressed their views about why it is difficult for friends and family to be there the whole time. One father said:

> The people who you never expect are the ones that are going to show up and do the things that are not glamorous. Sit with the kids in the middle of the night, or do things like that like…you never expect them to do that, a few years down the road…While we had so much help, it does taper off. I don't expect the fireworks of the very beginning to be there at the end. Because they won't, and I don't expect anybody to put their life on hold for mine, and it's understandable.

Many cancers present patients and their families with an indefinite treatment and recovery time. Pediatric cancer is no exception. For many families, treatment and recovery can last years. While for other families, recovery never even occurs. Because of the often lengthy course of cancer battle, social support systems must run the "marathon" with the families if they desire to be optimally helpful.

The world keeps pushing on us. For families with a child with cancer, daily life does not stop when cancer becomes part of their world. As one father of a child with a brain tumor described, "The world keeps pushing on us even though your child has cancer." The many daily errands still needing to get done can easily pile up. Lawns still need to be mowed, groceries bought, kids cared for, meals cooked, and the house cleaned.

Thus, any help parents received from their social supports resulted in relief from the pressures of the world "pushing" on them, and it was greatly appreciated. Parents expressed many examples of gratitude for help with daily life. For example, a mom expressed her relief of getting help cleaning the house by saying, “For a while we had just hired some people to come in and clean once a week. A family member gave us money to use just for that purpose and that took some pressure off us.”

Help with childcare was also an important support for the families. A dad of two kids in addition to their infant daughter with a brain tumor said, “The two of us (he and his wife) don’t get a break (from parenting).” A dad and mom described their appreciation for childcare in the following way:

> Dad: Childcare is so unbelievably hard to come by.
> Mom: Having someone like, “let me watch your kids so that you guys can go on a date,” Oh my god! I will think I would probably fall over we would be so excited.
> Dad: Childcare is such a huge need. Getting time together, just us, is hard to come by.

Another common way parents and their families felt supported occurred when friends and family gifted meals to them that are ready to be made quickly at home. Many parents were grateful to not have to worry about meal planning and spending extra time preparing dinners for their families, especially when they were in the hospital often at the beginning of treatments. The father of a boy who was diagnosed with liver cancer at twenty-one-months-old and then diagnosed with a brain tumor at age nine said, “Meals were always good for me because I still needed to eat!” Although some families could become overwhelmed with too many meals at one time, another father described the helpful plan his friends put in place to better coordinate when the meals were needed. He said:

> What was really helpful was that some of our friends set up meals. They did a care calendar. Then my wife sat down with two of them and said, ‘Ok here’s probably what we are going to need….meals on these nights.” And then you put it on the calendar and people sign up to bring the meal.

The final way commonly described by parents as a means for their support systems to relieve some pressure of the world continuing to "push" on them was through going to the grocery store for them to pick up groceries and prescriptions for them. A father of a son with leukemia describes it this way:

> There are so many simple little things people can do. Like, "Hey! I'm at (the grocery store). Do you need me to grab something for you while I am out?" I am driving by your house anyway." Just little things like that. And it's like, "Gosh that's amazing!" Picking up prescriptions. We need a prescription every three days. So say to us, "Hey I'm at (the grocery store). I will go to pharmacy for you."

All families appreciated support by friends and family when it was thoughtful and creative. The needs of families facing pediatric cancer are so great that anything that could be done for them was be appreciated. A mother of the daughter diagnosed with a brain tumor at birth said, "We were at a point where we needed all the help we could get." This sentiment rang true for all families in the study. Whether it be sewing with their kids or taking them to school or even just sitting at home with the parents while they made phone calls to the insurance company, parents of children with cancer welcomed any practical support given to them. However, on occasion, this became problematic when well-intended supporters would ask the parents for suggestions about the help they needed. Nearly all parents in the study expressed frustration about friends and family putting the onus of coordinating support on the parents of the child with cancer. A common way this occurred is when social support came in the form of "just let me know what you need." The dad of the seventeen-year-old daughter with leukemia expressed his frustration this way:

> People will come up and say, "Hey! If you need anything just let me know…The generic, "Ok. If you need anything just let me know," puts the burden on us and we're not in a position to do [say what we need]…I don't even know what I'm doing tomorrow much less try to coordinate what you can do for me.

Another dad said, “Everybody asks you, ‘What do you need?’ We don’t even know what day of the week it is. We’re so stressed out and trying to make so many other decisions of consequence.”

Parents prefer when their friends and family responded with action (like those listed previously) rather than with a verbal promise of support. A mother of a girl with leukemia (five-years-old) said, ”People are saying, ‘Oh whatever you need we will be there for you’ or, ‘We will help.’ But people aren't going to call you up and say, ‘Hey. You need some help?’ Maybe do things instead of just saying it.”

Other parents described this similar experience in the following way:

> Dad: They (friends) are all, “Well, call me if you need anything.” No cancer family I have ever heard of has ever called anybody when they needed anything.
> Mom: You have to just do it.

The most helpful actions social supporters can take to relieve pediatric cancer families from some of the pressures of life are to take initiative to offer the gifts they know they can give, and by doing it, rather than waiting for the parents of the child with cancer to give them an invitation to help. One mother gives the following advice to social supports. She said, “Be specific. Take time to be creative and think, “What do I have to give that they would need?” And offer when you can do that for us.”

Let us know we’re not forgotten. The third principle of effective social support is a reminder that the parents and families’ need to know they are not forgotten as they continue the lengthy challenge of pediatric cancer. All parents expressed the need to experience the presence and care of friends and families, especially as time passed by after the initial diagnosis.

One way parents were reassured they were not forgotten was by having friends and family available to just to talk to them. A single mom of a five-year-old girl with leukemia said, "Somebody needs to be there to talk. To the people in the hospital especially….Being there for somebody (a family member experiencing pediatric cancer) if they just want to talk to you on the phone and share about their day and listening, just listening to us."

Another way parents felt remembered was through phone calls, emails, and invitations to share a meal together at a friend's home. The mother of the daughter (16 years old) with leukemia said:

> Keep in touch. Just a phone call or an email letting us know we are not forgotten even though we haven't shown our face at basketball for four months. To know they still remember that we are here by dropping by just to say, "Hi." People who just are with us for the relationship, just to invite us into their home because we've been in our home by ourselves or we've been hosting people for a year because of our daughter's immune system (does not allow her to go out often). It was helpful when people invited us to their home for a meal, made phone calls, or sent emails just to remind us we're not forgotten.

One dad described it this way:

> Just to remind parents on a regular basis, and not get tired of it, remind them that they are not alone and not forgotten. I think a faithful friend is hard to come by, and we all need to make an effort to be that for other people.

This same dad went on to say, "For whatever reason people get tired of even just coming around. Not that we are asking them to do something or have pity on us but to just keep sharing life with us."

Parents felt like others were sharing life with them through the ongoing interest and care of others. This interest and care came in various forms, including prayer from churches, social media, and comments to care pages and blog posts. One father describes the persistent support of his church by saying, "It was huge. People remembered us. People were thinking about us. We were in the church bulletin every week for two and a half years."

Social media provided another platform for families to feel remembered throughout the course of cancer treatment. It also provided a medium for parents to connect to other pediatric cancer families to obtain mutual support and learn from the experiences of others in a similar situation. A mom of a daughter with leukemia exemplified this by saying:

> With Facebook, you connect with so many people. I have about a thousand friends on there, but a lot of them are people that I have met since (my daughter) was diagnosed, or that live far away, even in the Netherlands, that have grandchildren or children that have had cancer or are going through cancer too.

Another dad reflected on how the story of his daughter's brain tumor had spread to a large group of supporters around the world. He said:

> It's (his daughter's story) gone around the world. Within hours, maybe within minutes, of the news going out it was around the world…All our technology today. You post something on Facebook and it's all over. We have people come into the hospital that we didn't know. There are so many people that we don't know that know her. How many people has our story touched? We try to think of it in that light.

Besides Facebook, many families found ongoing support as others interacted with their blog posts and "Care Page" about their experiences. Many parents benefited from the ongoing words of support posted by people in response to updates about their child's health. One mother said:

> I write a blog, which has been very helpful. I would suggest to other people, if they are someone who likes writing. The blog has really helped a lot of family members and extended people and friends keep in contact. I update that so they can check and see how everything is going…It's a good way to communicate what's going on.

There are various ways for social supports to help families going through pediatric cancer feel remembered. Whether it be simply listening to how they are doing, sending them an email, calling them on the phone, inviting them over for dinner, or interacting with them on social media, an essential aspect of supporting pediatric cancer families is letting them know they are not forgotten, even if their child's cancer has made it difficult to be as socially involved as they may have been in the past.

Discussion

By describing the lived experiences of parents who received social support from friends, family members, and community supporters following the diagnosis of cancer in one of their children, this study elucidates important aspects of social support that can help or hinder family coping. The result of this study provides guiding principles of both ineffective and effective social support. The guiding principles included: (a) "People don't know what to do, (b) "It's a marathon not a sprint," (c) "The world keeps pushing on us,' and (d) "Let us know we are not forgotten."

The primary theme of "People don't know what to do" consisted of two primary sub-themes: "Too close to the situation," and "Some people just disappeared." These two themes represent opposing ends of the spectrum of involvement in the lives of the pediatric cancer families. The parent's frustration with social supporters who were either too close or too distant during their time of need was not surprising. These experiences are consistent with previous research identifying patterns of social supporters being over-protective or avoiding the cancer patient and their family following their diagnosis (Gurowka & Lightman, 1995; Lehman and Hemphill, 1994). There is a "hidden psychosocial literature" on negative social support for cancer patients and their families (Hamilton, 2000, p. 102). Few articles addressing social support also give attention to negative social support, and of those that do, most do not provide explicit and concrete examples of socially supportive vs. socially unsupported comments and behaviors (Hamilton, 2000). The experiences of parents reported in this study describe specifics of how unwelcomed physical presence, excessive display of emotion, and the gift of unneeded meals can overwhelm the family as they cope with their child's cancer. Additionally, parents disclosed the disappointment and surprise when close family and friends withdraw and do not meet expectations of support, when spouses withdraw from each other, and when teenage peers of the child cancer patient "disappear" are all examples of how negative social supports affects cancer patients and their families. Learning from the experiences of the families in this study may help educate social support networks and develop clearer social norms about how best to communicate support for families experiencing pediatric cancer (Dyregrov, 2004).

Regarding principles of effective social support. This study also helps clarify specific principles to guide the social supporter's attempts to be a coping resource for families experiencing pediatric cancer. The first principle discussed of cancer being a "marathon not a sprint" confirms previous studies highlighting the chronic nature of the illness (Salonen et al., 2013). The cancer treatment period can often last for up to two years for some cancers, like leukemia. In addition, even years after the final treatment has been administered, the fear of relapse is a perpetual concern for most parents (Fletcher, 2010). The fact that the word, "remission" does not mean "cured" is a reality with which all parents of children with cancer must wrestle. Thus, even when treatment has ended and the child appears to be recovering well, there are still realities of cancer capable of perpetuating psychosocial distress in families and maintaining their need for various types of social support many years after the initial diagnosis. However, the parents in this study describe that the support they needed months and years after their child was diagnosed was not necessarily provided by their social support systems. The parents' report in this study that social support typically does not last for the entire marathon is an echo of previous work on this phenomenon (Altay et al., 2014). Parents often indicate they receive the most support around the time of the acute crisis at diagnosis, and then receive less support as time passes (Thoits, 1995). This study aids in the understanding of what families are feeling as they see social support decline months after the initial diagnosis. It also illuminates the family's appreciation for long lasting support over the course of their cancer experience.

The second principle of effective social support, "The world keeps pushing on us" reminds helpers of the specifics of daily life pediatric cancer families often need assistance with as they adjust to cancer and its treatment. This principle provides a new insight for those wanting to offer support to families following a diagnosis of pediatric cancer. The proposal of "let me know what I can do" is one that feels very generous when given by family and friends. It is often a sincere statement meant to imply, "whatever you need, I will do my best to help." However, it is not often known that this sincere offer can actually cause more distress for families as it puts the responsibility of orchestrating the support on the family in need. Parents of children with cancer are often in such immediate distress that they are not able to focus on knowing what they need done for them (e.g. having the house cleaned or picking up groceries). Thus by having caring, supportive friends and family "just do it" helps relieve a burden of thinking about the many day-to-day needs they have that get dwarfed by the cancer crisis.

The concrete practical supports described as most helpful by the parents in this study consisted of: cleaning their house, child care, providing ready-to-make meals, and going to the grocery store to pick up food and prescriptions. These items are similar to the "instrumental" support category of social support (Cutrona & Russell, 1990). They provide specific, concrete help by freeing families up to do other tasks more pertinent to coping with cancer. These specific practices of social support help to buffer families from experiencing a pile-up of stress. Stress pile-up is common when the day-to-day tasks of operating a household combine with the cancer specific stressors to overwhelm the family under duress (McCubbin & Patterson, 1982). Getting help to meet these small stressors before they pile-up results in tremendous relief for the parents and helps improve coping and adaptation.

The principle of "Let us know we are not forgotten" is an integration of the emotional and companionship types of social support (Berkman, et al., 2000; Langford, Bowsher et al., 2008). Parents expressed the common feelings of loneliness and isolation throughout the treatment process and the need for friends and family to simply spend time with them and to be there to talk. The physical presence and emotional engagement of others was a tremendous help for the parents in the study as they sought to feel as though they were still in the hearts and minds of others despite the demands of cancer forcing them to pull back from social events and community. The impact of loneliness and isolation is well documented. For example, Jaremka et al. (2014) found that lonelier cancer patients experienced more pain, depression, and fatigue than less lonely patients from one year to the next. Perceived social isolation also has been shown to negatively impact health behaviors and reactivity to stress while also causing inadequate physiological repair and maintenance due to decreasing one's immune functioning over a period of time (Hawkley & Cacioppo, 2003). However, as social supporters sought out opportunities to talk and listen to the parents and child with cancer, as they made phone calls and sent emails, as they shared they were praying for them, and as they kept in touch through social media, the families felt less alone in their experiences with pediatric cancer. The impact of prayer and technology helping families experiencing cancer feel supported is documented. For example, knowledge of having others praying for oneself is identified beneficial for coping with severe illness (Wacholtz & Sambamoorthi, 2011). Additionally, nearly 70% of cancer survivors report prayer being instrumental in their coping and health improvement (Ross, Hall, Fairley, Taylor, & Howard, 2008). Lastly, social networks expressing support to cancer patients and their family through technology and social media (e.g. Facebook and Care Pages) has been shown to have benefits to coping and adjustment (Suzuki & Kato, 2003).

The lived experience of parents coping with their child's cancer reveal the impact other's support attempts have on their adjustment. The specific and concrete principles and themes described in this study provide guidance to social support networks to improve the help they offer. Pediatric cancer patients welcome emotional and practical support in all their various forms. The life-threatening nature of the disease, in addition to the prolonged treatment and recovery, create a unique need for support (Martin et al., 1994). This need is best met by, first, reducing the "social ineptitude" of supporters providing ineffective support (Dyregrov, 2004). This is especially vital to improved adjustment and coping as negative support often has greater impact on cancer patients and families than does positive social support (Hamilton, 2000). And second, by prioritizing social support to be lasting and long-term, so as to meet the chronic need of social resources throughout the entire length of the family's experience with pediatric cancer (Rook, 1984; Varni & Katz, 1997). Improving the length of availability has challenges. Yet many of these challenges can be met through improving strategies of intervention with pediatric cancer families and their support networks.

Clinical Implications

The need for more sustained support throughout the course of cancer and its treatment is an area in which health professionals can seek to improve. Two primary ways exist in which health professionals can immediately improve services. First, is by improving educational resources for the social networks in which the families are located (e.g. family, friends, neighbors, communities) to help them have an improved knowledge of how to be supportive. A primary way health professionals can collaborate with family social networks is through education. Therapists can work in partnership with churches and hospitals, two institutions with permanence in the community. Together they can educate family and friends through the creation of educational mailings, pamphlets given out at the hospital, informational booths at fundraisers, and establishing an educational website about what can be done to support families experiencing pediatric cancer. Health professionals can also seek to meet with other community and social supports (e.g. schools, churches, business groups, etc.) to hold group educational meetings to inform families on what they can do to help.

An area of intervention research capable of offering a potential model of accomplishing the goal of educating social networks can be found in the community-based intervention research. Community-based intervention research provides a helpful framework for engaging support networks in the community to change behaviors and improve psychosocial outcomes. Two common goals of community-based interventions are: strengthening the health of communities and building community capacity to address health-related issues (Norton, McLeroy, Burdine, Felix, & Dorsey, 2002), both of which reflect the possible result of intervening in a community to improve the social support care provided to families experiencing pediatric cancer. Viewing the community as a resource for change focuses health professionals on the potential for utilizing existing internal resources of a community to promote wellness (McLeroy, Norton, Kegler, Burdine, & Sumaya, 2003). The best resources for families needing support are the friends, family, and community members already in their lives. These are the targets of education that can make the most immediate positive difference in the coping and adjustment of families coping with cancer in their child.

Second, there is a need to improve intervention services for pediatric cancer families and their social networks through tailoring them to better meet the long-term support needs of the family. Social support must be long-term in order to maximize the positive benefits for families. Hospitals and helping professionals must utilize interventions that engage social supports longitudinally, delivering support services for those in need months and years down the road. The long-term support needs of families can best be met through the collaboration of hospital and non-hospital resources (Bender et al., 2012). Collaborative care between hospitals and mental health workers has demonstrated long-term effectiveness for reducing negative affect (e.g. depression symptoms) in cancer patients (Ell et al., 2011). Often, other non-hospital health professionals are better equipped to provide the longer-term support the families in the study described as lacking. Community resources like marriage and family therapists, counselors, and social workers can be available to meet with families on occasion for the months and years after the cancer diagnosis. Hospitals interact with the families most often at the beginning of treatment, especially when the child is induced into intensive treatments immediately following diagnosis. But then their face-to-face contact is more sporadic after the initial treatments. Thus, hospital resources may not be the best long-term solution for families due to their decreasing interaction with the hospital system. Therapists and counselors in the community may be better positioned to maintain contact with the parents and families for psychosocial intervention care (Rodgers et al., 2011). This maintained contact provides opportunity for healthcare professionals, like mental health professionals, to consistently partner with the families they are supporting to continually engage social supports throughout their child's treatment.

Potential ways hospitals and community healthcare professionals can improve the longevity and quality of social support families receive are numerous. Some suggestions include hospitals creating a "long term family care team" that prioritizes its engagement with families six months after the initial diagnosis and beyond. This type of care team can pick up services after the initial hospital care team of social workers and child life specialists subsides. This team can seek to coordinate care for families by engaging their social support networks and by organizing when meals are made, lawn and house care gets done, and families are visited or called. This team can also help collaborate with local mental health workers to provide parents with referrals to therapists who specialize in the type of care in which they are in need.

Another suggestion is to set up a "cancer helpline" that directs families through a tiered model of care service (Hutchinson, Steginga, & Dunn, 2006). Families can call a central line and can be directed through increasing levels of support based on their specific needs, with Level 1 being information-based strategies, Level 2 being psychoeducational care, Level 3 providing brief, peer-based or support group psychological care, Level 4 providing professional psychological intervention, and Level 5 for acute care by a professional psychosocial team designed to meet more complex cases of distress (Hutchinson et al., 2006). Regardless of the specific intervention approach created to better support pediatric cancer families, health professional must increase efforts to assist families in accessing psychosocial and informational resources, because they are often under-utilized by cancer patients and their families (Muzzin, Anderson, Figuerdo, & Gudelis, 1994).

Healthcare professionals can successfully improve these two primary foci of service delivery, however it will not be without challenges. Accomplishing the goals of better intervention services for families with pediatric cancer and increased education of effective social support to their social networks will be difficult if hospitals, community mental health workers, religious institutions, and schools work independently of each other. It is essential for those tasked with providing psychosocial relief to families with cancer to consider the complex set of relationships within the natural and clinical social network of the hospital and the family they are treating (Kane, Hellsten, & Coldsmith, 2004). Treatment teams that approach families from a collaborative approach, and focus on holistic, family-centered care are often the most effective in meeting the needs of families with children diagnosed with cancer. Yet many hospitals and health professionals fail to utilize this approach despite the support for it in the research (Nieto & Day, 2009). Collaborative models of care offer the best approach to engaging social supports and sustaining their effective involvement in family's lives following a diagnosis of pediatric cancer.

Research Implications

Several limitations need to be mentioned regarding this present study. First, the experiences represented here are only that of the parents. No children were interviewed in this study. It is possible the children may have a different perspective about the types of support they found to be most helpful or unhelpful. Interviewing the entire family together would provide a more complete picture of how the family experienced social support. Second, the parents participating in this study may not represent the experiences of all parents of children with cancer. The participants of this study all reside in a similar geographical region, were all recruited from the same hospital, and were not racially or ethnically diverse as a whole. Thus, their experiences may not be able to be generalized to all parents facing pediatric cancer. However, the voices and experiences of the parents in this study draw attention to one of the most important aspects of family coping during a health crisis: social support. Finally, due to the small sample size there are likely many parent voices and experiences not represented in the study. If more parents were able to participate in this study there may be experiences that would contrast with some of the parents' experiences described above, and could provide a more dynamic, and nuanced view of social support.

Future research should focus on gathering the voices of the entire family and considering the totality of the parents, child patient, and sibling voices as both individuals and as an entire family unit. Studying the “whole” while not just examining the “sum of the parts” has long been a challenge for family researchers. However, there is still a need for the application of methods that can help explain the family experiences, and can uncover the best resources and greatest challenges to their coping with pediatric cancer.

Future studies on family coping and resilience to pediatric cancer diagnoses should focus on measures tracking QoL and family functioning as it relates to the specific types of social support offered by family and friends. Quantitative research provides the tools to effectively uncover the direct and indirect impact of each of the social support principles suggested in this study on families facing pediatric cancer. Additionally, understanding how the guiding principles and practices mentioned by parents in this study impact family wellbeing longitudinally would be a great asset to the pediatric cancer field.

Finally, future research must also seek to develop and evaluate the efficacy of family interventions that focus on both developing social support resources for the parents and families experiencing pediatric cancer and helping families deal with people in their life providing unhelpful support (Hamilton, 2000). A variety of family interventions have been developed to meet family needs during the cancer crisis, however it is unknown how well these interventions create better and longer lasting social supports for the family. Social support is an indelible resource for families. Clinical researchers have an opportunity to develop interventions that specifically meet this need (Kazak, 2008).

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CHAPTER THREE: STUDY TWO

A Grounded Theory of Family Resilience Following the Diagnosis of Pediatric Cancer

ABSTRACT

Pediatric cancer is the leading cause of death by disease among children in the United States between infancy and age fourteen. The diagnosis, treatment, and ambiguity of the cancer disease can be very distressing for the child patient and their family members. Yet many families manage to remain resilient despite the myriad biopsychosocial-spiritual challenges of the pediatric cancer diagnosis. To date, questions remain about why some families remain resilient while others do not. A grounded theory study was conducted to examine resilience processes in families following the diagnosis of pediatric cancer. Data were collected through in-depth interviews from 16 parents representing 9 families. The analysis revealed that family resilience results from the interaction of important pre-cancer experiences, parent factors, family relational dynamics, and extra-familial support. These aspects of resilience are presented in detail in the Natural Family Resilience Model for Pediatric Cancer. Implication for clinical practice and research are discussed

Introduction

"The oak fought the wind and was broken, the willow bent when it must and survived."

(Robert Jordan, 2010, p. 437)

Pediatric cancers are the leading cause of death by disease among children in the United States between infancy and age fourteen. In 2014, approximately 15,780 new pediatric cancer diagnoses occurred in children 0-14 years of age (National Cancer Institute (NCI), 2014). While the prevalence of invasive cancer in children has increased marginally over the past 30 years, mortality rates have declined by up to 70% for many childhood cancers (Surveillance, Epidemiology, and End Results [SEER], 2007). While the increased survival rates have benefited families facing the health challenges posed by cancer, the cancer diagnosis, treatment, and recovery all create unique stress on family members due to the ambiguity about the child's future health and the need for the family to provide lengthy care, which has numerous demands (Cardella & Friedlander, 2004).

Due to the challenges of a pediatric cancer diagnosis, a significant portion of families experience emotional distress (Alderfer et al., 2009; Wiener et al., 2006), which may result in various adverse psychosocial outcomes in the individual patient and in their family members. Cancer in childhood is associated with behavior, coping/adjustment, depression, and posttraumatic stress in the child diagnosed (Liang, Chiang, Chien, & Yeh, 2008). However, cancer diagnoses not only affect the behavior of the child with cancer, but also their well siblings. Siblings of pediatric cancer patients are vulnerable to increased irritability, mood swings, agitation, increased aggression, yelling, and crying (Williams et al., 2009). If these short-term behavioral changes persist, they may result in social dysfunction and permanent changes to psychological wellbeing (Verrill, Schafer, Vannatta, & Noll, 2000). Parents of children with cancer may be at the greatest risk of negative psychosocial outcomes. Many parents experience anxiety, post-traumatic stress, depression, and decreased family functioning (Dunn et al., 2011; Mereuta & Craciun, 2006; Streisand, Kazak, & Tercyak, 2003; Williamson, Walters, & Shaffer, 2002).

While some child patients and their families experience a host of psychosocial challenges following the cancer diagnosis, most families reveal a remarkable amount of resilience (Alderfer & Kazak, 2006; Martin et al, 2012). Family resilience can be defined as, “the capacity for adapting successfully in the context of adversity.” (Masten & Monn, 2015, pg. 5). Family resilience grew out of individual resilience frameworks, which focus primarily on internal biological and psychological processes that some individuals have and others do not (Walsh, 1996). Yet family researchers discovered that families could create and maintain interactional processes capable of enabling family members to withstand and rebound from life stressors and crises (Walsh, 1996). Thus moving the locus of resilience from the individual to the family system. Research has identified a variety of important family factors contributing to family resilience. These include, but are not limited to, making meaning of adversity, having a positive outlook, spirituality, flexibility, connectedness, social support, communication, emotional expression, and collaborative problem solving (Walsh, 2006).

Pediatric cancer research has shown evidence of children and their family members demonstrating resilience in various ways. For example, children with cancer have said that the cancer has helped them become a stronger person, make new friends, know how much they are loved, be more patient, and know what is really important in life (Currier, Hermes, & Phipps, 2009). Cancer has also shown to help children gain a new perspective in life, bring their family closer together, and appreciate the experience of returning to well-being (Griffiths, Schweitzer,

& Yates, 2011). Research on siblings of child cancer patients shows that some exhibit positive behavior changes. For example, Heffernan and Zanelli (1997) found that many siblings of children with cancer become more sensitive to the needs of others and are more thoughtful in their play with friends. Additionally, many parents of children diagnosed with cancer do not demonstrate any evidence of posttraumatic stress disorder or posttraumatic stress syndrome (Barakat, et al., 1997; Stuber 1995). Finally, many parents have demonstrated an ability to improve their relationship and marital satisfaction through their experience with their child's cancer (Brody &Simmons, 2007; Hoekstra-Weebers et al., 1998; Wittrock, Larson, & Sandgren). Often these positive changes are maintained for years after the original diagnosis (Kupts et al., 1994). Thus, despite the large body of research on the prevalence of negative psychosocial outcomes for families experiencing pediatric cancer, evidence also directs attention to the capability of many families to successfully adjust and cope with the diagnosis of cancer in a child (Mcubbin, Balling, Possin, Frierdich, & Bryne, 2002).

A balanced picture of the family pediatric cancer experience reveals a reality in which most families cope well with the extreme shock and stress of cancer and its lengthy treatment. Yet some cancer patients and their families do not. Thus a gap in family resilience exists. As Antonovsky (1984) asked, "Why, when people are exposed to the same stress which causes some to become ill, do some remain healthy" (p.117)? Ongoing psychosocial pediatric cancer research continues to attempt to answer this question. Various protective factors have been identified. For example, factors found to be protective in child and family adjustment to cancer are: social support, positive thinking and hope, future orientation, self-care, refocusing on what is important, and remaining close with family (Fletcher, 2010; Griffiths et al., 2011; Prchal & Landolt, 2011; Sung et al., 2009; Yeh, 2001). Additionally, when families successfully alter roles, responsibilities, and day-to-day functioning to accommodate the needs of children with cancer they are often better able to adapt (Martin et al, 2012). Research also suggests that when this successfully occurs, levels of family functioning are similar between families facing cancer and families without cancer or another significant stress (Long & Marsland, 2011). Furthermore, many child patients report their parents are the greatest sources of support, and are able to adapt well to cancer in the context of strong family and social supports (Trask et al., 2003). Family social support and perceived high levels of family functioning by family members buffer the risk of poor adjustment to cancer (Fuemmeler, Brown, Williams, & Barredo, 2003).

The studies listed above all represent various intra-psychic (e.g. positive thinking), familial (e.g. adjusting roles and responsibilities), and social (e.g. social support) aspects of improved coping with pediatric cancer. These studies, while necessary and informative, are largely descriptive in nature and do not integrate findings into a coherent framework for family resilience (VanBreda, 2001). Still missing from our current understanding is a unifying framework capable of explaining how the above factors interact with each other to paint a comprehensive view of family resilience in the face of a childhood cancer experience. Three models of family resilience have been the foci of the majority of research on this topic (Mullins et al., 2015). First, Wallander and colleagues (1979) proposed the risk-resistance adaptation model, which suggests child and parent adjustment to chronic illness are affected by numerous biopsychosocial risk and resistance factors. Second, Thompson and Gustafson's (1996) Transactional Stress and Coping Model, suggested adjustment was impacted primarily by illness-specific variables (e.g. illness severity), demographic variables (e.g. socioeconomic status), and various intrapersonal adjustment processes. Third, Kazak and colleagues' (2006) Social Ecological Model, theorizes child patient and family resilience to be related primarily to the interplay of the many systems (e.g. child, family, school, community, and culture) in which the family resides. These three models of family resilience, in addition to many other models proposed by other researchers, include a number of common features (Mullins et al., 2015). These models are framed within Bronfrenbrenner's (1979) ecological-systems theory, which views family adjustment as the result of numerous intrapersonal (e.g. cognitive appraisals), interpersonal (e.g. social support), and demographic (e.g. age) child and parent variables (Mullins et al., 2015). Yet, due to various limitations, no one theory of family resilience for pediatric cancer has been widely adopted to date. Questions still remain about why some families remain resilient, and others do not.

Family Stress Theory

Family Stress Theory (FST) was one guiding framework informing my inquiry of family coping and resilience to a pediatric cancer diagnosis. During World War II, Ruben Hill (1949) examined how separations and reunions of fathers and husbands impacted families. His work produced the ABCX Formula, which included a hypothesized set of variables present in a stressor situation. These variables include: the crisis-precipitating event/stressor ("A"); the family crisis-meeting resources ("B"); the family definition/perception of the event/stressor ("C"); and the crisis ("X"). While Hill's ABCX formula provided the foundation for the development of family stress theory in the years that followed, most researchers believe his model to be too linear and simplistic to capture adequately the impact of stress on families and their response to crisis (Weber, 2011). Additionally, Hill's ABCX focus primarily attends to pre-crisis variables and does not address family responses post-crisis.

Expanding on Hill's ABCX Formula, Hamilton McCubbin and Joan Patterson (1983a, 1983b) kept Hill's pre-crisis ABC variables and added a second set of ABC variables to describe what occurs in families post-crisis. Their update to Hill's model resulted from their longitudinal study of families who had a husband/father held captive or unaccounted for in the Vietnam War (McCubbin & Patterson 1982, 1983a, 1983b). They called this new model the "Double ABCX Model of Family Adjustment and Adaptation." The post-crisis variables focus on: the additional life stressors and changes post stressful event, and the potential of these to pile-up and impact a family's ability to adapt ("Aa" variable); the psychological and social resources families draw upon to help them manage the crisis ("Bb" variable); the family's perception of their stress pile-up and resources ("Cc" variable); and the family's bonadaptation or maladaptation to the stressor ("Xx" variable) (McCubbin& Patterson, 1983). The Double ABCX Model provided the current study with a broad framework in which the pediatric cancer experience could be explored. The attention to pre and post-crisis stressors, resources, and perceptions supply broad areas of inquiry to investigate connections between the various relevant factors research has identified as being capable to improve individual and family coping. In addition, the broad areas of inquiry are broad enough to allow for an exploration into other areas of the cancer experience not explicitly identified in FST research.

Purpose of the Study

Models of family stress provide a helpful lens to understand how families adjust to crisis. They accomplish this by highlighting the interaction of the precipitating stressor with the family's resources and perceptions of the event. However, these models lack specifics when applied to the pediatric cancer population. They fail to adequately explain the ongoing coping and adaptation processes that dynamically occur throughout the course of cancer and its treatment. Previous pediatric cancer research has successfully identified elements of family resilience, but has yet to adequately integrate these findings into a cogent theoretical model. This study seeks to augment FST's conceptualization of the stress caused by pediatric cancer on families. This study also seeks to explain how cancer related stress interacts with individual, family, and community factors contributing to a family's ability to remain resilient in the face of a cancer crisis. By focusing on the interaction of the various family risk and protective factors, this study aims to propose a theory of family resilience fitting of families experiencing a pediatric cancer diagnosis.

Study Design

Grounded theory was used to develop a rich, comprehensive theory explaining family resilience following a pediatric cancer diagnosis. My experience as a licensed marriage and family therapist served as the starting point for my study design. My clinical training in helping families and individual cope with distressing life events is the primary component of my professional life and knowledge. Included in this knowledge are the foundational principles of FST which has often served as a guide for conceptualizing clinical cases. Therefore, as I approached this study, it was impossible to completely remove this bias from my experience. To reduce bias and influence of FST on my research, it is important to explicitly state the role of FST for this study design (Brown, 2002). Some would argue that grounded theory begins with no theory, and that the researcher should approach the data tabula rasa. However, a growing number of qualitative researchers dispute this idea. For example, Mertz and Anfara (2006) argue, "it is impossible to observe and describe the way things really are, free of any prior conceptual scheme or theory" (pg. 8). All researchers, "come to their fieldwork with some orienting ideas." (Mertz & Anfara, 2006, p. 17). Other researchers describe these "orienting ideas" as "sensitizing concepts" (Bowen, 2006). Sensitizing concepts provide a general sense of reference and guidance in approaching empirical research and suggest directions along which to look (Blumer, 1954). Sensitizing concepts are starting points for any qualitative study (Glaser, 1978; Padgett, 2004). For this study FST served as a sensitizing concept, laying the foundation for study design and data analysis. No hypotheses were brought to the data based on FST or any other theory (Blaikie, 2000). Nor did FST or other theories dictate the focus of my inquiry and interpretation. Rather it served as a guide to orient data collection and analysis (Wolcott, 1995).

Procedures

The current study was done in collaboration between myself, a researcher from a large Midwestern university, and a children's hospital located in a Midwestern metropolitan area with over one million residents. After receiving institutional review board approval from both the university and the children's hospital, participants were recruited using a purposive sampling method based on the likelihood they had experiences related to the phenomena of interest (Kruger, 1988). Using paper advertisements on bulletin boards at the hospital and word-of-mouth advertising from hospital oncology staff, potential participants were made aware of the study. Interested families then contacted the researcher regarding their desire to participate in the study. The researcher screened families for eligibility requirements. Eligibility included: (a) having at least one child under the age of eighteen who was diagnosed with cancer in the previous six months and five years, (b) ability to provide written consent, (c) ability to speak English, and (d) must be the primary caregiver(s) to the child with cancer.

After participants passed eligibility screening, the informed consent process was completed and interviews with parents and caregivers were scheduled. All interviews were conducted either at participants' homes or in a private patient room at the children's hospital. I, a licensed marriage and family therapist, conducted interviews. They followed a semi-structured format and averaged ninety minutes each (range 56 minutes to 147 minutes). Each interview examined three time points in the family's life: (a) family life before the cancer diagnosis, (b) the events surrounding the initial diagnosis of the child's cancer, and (c) family life since the diagnosis. Open-ended questions were used to inquire of the parents' experiences of stress, support, family dynamics, family adaptation, and family coping following the diagnosis of cancer in their child. Example questions included: "How would you describe your family life prior to learning about your child's diagnosis?" "How did you come to know about your child's cancer?" "How did cancer change your family?" "What are the most stressful things about being a parent of a child with cancer?" "How would you describe your social support system since the diagnosis?" "What types of things do you and your family do to help cope with all that you are going through?" "What is your understanding or perception about your child's and your family's battle with cancer?" Each parent participating in the study received a $20 Visa gift card as compensation.

Participants.

Eight fathers and eight mothers, representing nine families participated in the study. Seven families were represented by both parents in the interview; a single mother represented one family, and the other family had only the father participate due to the mother being unavailable for the interview. Eight families were Caucasian and one family was African American. Each family had at least one child in addition to the child patient (Mean: 2.1; Range 1 to 5). The mean age of the child's first diagnosis with cancer was 6.4 years old (Range: 0 to 17). Mean time since diagnosis was 30 months (Range: 10 to 50). Five families in the study had a child diagnosed with Leukemia. Three families had a child diagnosed with a malignant brain tumor, and one family had a child diagnosed with liver cancer at age 2 and a brain tumor seven years later.

Data Analysis.

The data were analyzed using the grounded theory methodology. Grounded theory is a methodology utilized for the purposes of inductively developing theory (Glaser & Strauss, 1967). The grounded theory evolves throughout the data collection and analysis through the constant comparison method. The constant comparison method refers to the continual interplay between data analysis and data collection occurring throughout the entirety of the research process (Glaser & Strauss, 1967). This qualitative methodology aids researchers in producing theory that is conceptually dense—meaning there are many conceptual relationships outlined in the data (Corbin & Strauss, 1994).

The grounded theory data analysis process consists of three primary phases: open coding, axial coding, and selective coding. First, in the open coding process, interviews were read and key themes from the participants' experiences were identified, named, and described (Strauss & Corbin, 1990). The thematic codes were then revised into a coherent representation of the interviewees' responses. The second phase of analysis, axial coding, was accomplished through a process of comparison and contrast. The original themes were organized into broader categories of phenomena and context. Patterns in the themes were examined within and between each of the participant's interviews. Finally, selective coding was used to develop a cohesive theory based on the interrelationships between themes emerging from the data (Creswell, 2007).

Trustworthiness

Trustworthiness in qualitative research addresses the issues of validity and reliability. Techniques for establishing trustworthiness have been outlined in four main areas of qualitative research: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985, p. 296). Credibility refers to taking measures to ensure that the researcher's findings in a qualitative study are congruent with reality (Merrian, 1998). Transferability refers to the extent a qualitative study provides sufficient detail of context of the participants that a reader will be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to the other setting. Dependability refers to documentation of methods and context that could potentially allow a future researcher to repeat the study. Finally, confirmability refers to the steps a researcher must take to demonstrate that findings emerged from the data and not their own predispositions (Shenton, 2004).

Addressing these four aspects of trustworthiness can be accomplished with various qualitative research techniques. For the purpose of the present study, the techniques utilized to address issues of credibility were: (a) adopting an appropriate, well recognized research method such as grounded theory; (b) use of reflective memo writing after each interview and during data analysis; (c) providing thick descriptions of the families' experiences with pediatric cancer; and (d) provision of a comprehensive literature review to frame the findings. To address issues of transferability a detailed description of the study context, its participants, and impact of pediatric cancer on family adaptability was provided. The study's dependability was addressed by providing an in-depth methodological description so that other investigators will be able to replicate the study in another context. Finally openly recognizing the methodological limitations (see Discussion), and by providing an audit trail of research processes both augment the study's confirmability (Shenton, 2004, p. 73).

Results

To best communicate the study findings, the results have been organized into a conceptual framework—a tree and its various parts, which includes each of the significant themes and their relationships emerging from the interviews. Figure 1 depicts the tree framework, entitled The Natural Family Resilience Model for Pediatric Cancer. Figure 2 reports the significant themes in greater detail. The proposed theoretical model ties together pre-cancer variables, individual parent/caregiver factors, family relational factors, and the extra-familial context.

Soil

For trees, the soil is where their life and ability for growth begins. Soil can be healthy or unhealthy. The healthier the soil, the more likely the tree will grow and flourish. The soil in the family resilience framework represents the pre-cancer events, the characteristics, and systemic dynamics of the family shaping the family's "stress narrative." The stress narratives of families reflect their experiences with difficult life events in the past, and their perception about how well they handled previous stressors. Previous success in coping with life challenges presented opportunity for families to develop tools for coping with stress. Families recognizing the various successes they have had combating against stress reported a more positive, confident narrative about their family's ability to adapt to stress. The more positive the stress narrative, the more likely the family was to also report resilience to the pediatric cancer-specific stressors.

The family stress narrative. Developing tools for coping with pre-cancer stress provided the starting point of the family's experience of the cancer diagnosis and had potential to significantly influence their coping trajectory during treatment. These tools were developed through experiencing other life stressors (e.g. finances, marital strain, health concerns, etc.) and figuring out how to adapt. For one family, seeing a counselor during times of stress was an important tool. The father of a girl with leukemia said:

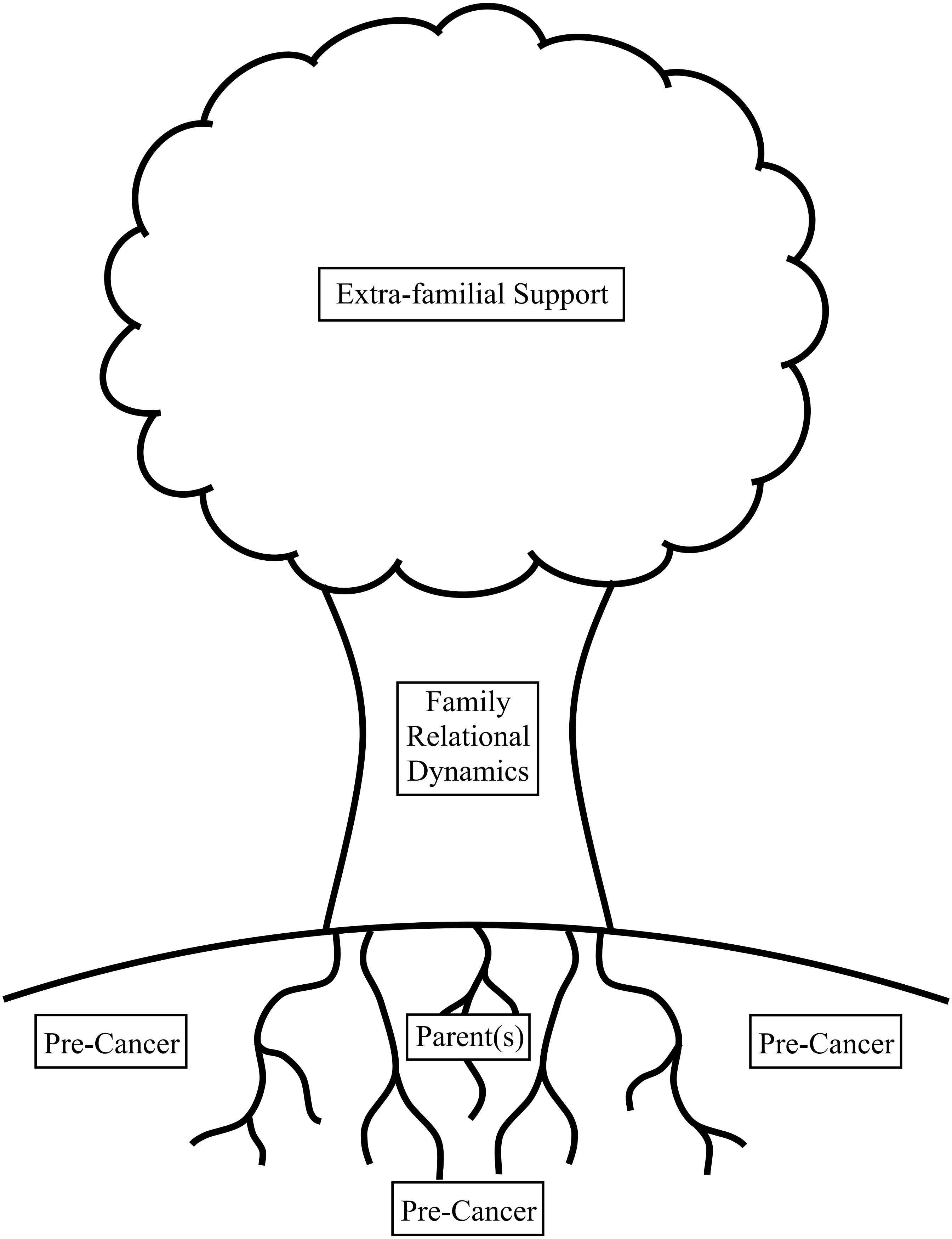

FIGURE 3.1: The Natural Family Resilience Model for Pediatric Cancer

> We had found a Christian counselor recommended by our pastor. We stayed talking with her for many months and toward the end we both felt like we needed to keep going even though there wasn't something urgent going on. We kind of know how we got here, and learned tools to work through this. We've said many times since her diagnosis, "Thank God we stayed on with her and learned a lot about each other and communicating."

Another family shared how using humor was an important tool they developed to help them handle stressors. The dad of a boy diagnosed with leukemia at 17 months old said:

> We always had a good sense of humor. It is not that we are not serious; it is just you learn to not take things so seriously. For us it has always been kind of our thing, being able to laugh at certain situations. It has definitely been therapeutic, even before cancer.

Strong social support was also identified as a helpful pre-cancer tool. The sense of having strong social support came from the belief that the family had friends, neighbors, community members, and institutions that cared about them and were willing to help them during times of distress. Families having a pre-existing support system in place at the time of diagnosis were more likely to receive the needed support from social networks throughout the course of their child's treatment and adjustment. A mom of a girl diagnosed with leukemia at age five described the benefits of their pre-cancer social support in the following way:

> I think we are pretty lucky. We are in a small community so we have a tight knit group of people here. We have quite a few friends…We can rely on them emotionally and socially and somewhat financially if we have to. If we needed them to, they can help us out. We could help them out. Our social support is pretty solid.

A third primary tool for combating stress contributing to a positive pre-cancer stress narrative is spending time together as a family. Ample amounts of intentional family time created family connection and cohesion that insulated families from some potential negative impact of stressors. Families reporting greater levels of quality family time pre-cancer, also described higher levels of support after receiving the cancer diagnosis. A father of a teenage girl diagnosed with leukemia describes his family closeness by saying, “We have always been intentional about spending time together as a family…[such as]...family board game nights. We eat a lot of meals together. We home school our kids. We spend a lot of time together.” Another father said, “We made time to do things together. We made a priority to eat and spend time together as a family.” Purposeful connection prior to the cancer diagnosis developed stronger family relationships and a more positive, confident family stress story.

The pre-cancer stressors in a family’s life become the starting point of their cancer experience. The parent’s reflections on how capably they handled these challenges and whether or not they had successfully resolved these stressors at the time of diagnosis become the family’s stress narrative. This narrative can shape the context of how cancer-related stressors are perceived and can be a boon or a barrier to successful adaptation following the diagnosis.

Roots

Tree roots anchor the tree in the soil, keeping it stable. They also absorb nutrients from the soil that are used throughout the rest of the tree for growth, development, and repair. In this same way, parents and caregivers of children with cancer help to anchor the family, keep it stable, help it grow, and repair it when something goes bad. A good root system is essential to a tree’s health. The parent’s ability to create healthy roots is accomplished in two primary ways. First, parents who are able to maintain a positive perception of the difficulties they face throughout treatment increase their family’s ability to create stability in the midst of challenges and increases a family’s resilience to pediatric cancer. These positive perceptions help parents respond well to past and present stressors. Second, parents guided by proverbs of action are also more likely to remain resilient to the crisis of cancer in their child. These proverbs serve as guiding pieces of advice they tell themselves, which orient them to continual positive coping throughout their family's cancer experience.

Positive perceptions. Disappointment and stress are ubiquitous when one's child is being treated for cancer. There are opportunities each day to be overwhelmed, to lose hope, and to become frustrated. Parents who are able to perceive these myriad challenges more positively are more likely to remain hopeful regardless the stressor. Parents shared a variety of experiences in which stressors occurred but they chose to respond positively. For example, families are constantly interacting with doctors and the medical team throughout the course of the child's cancer experience. They become major characters in the family's life. Due to the nature of the cancer disease, doctors are not always able to respond to the child's health concerns perfectly. Nearly all families in the study had experiences of the treatment not going as it should. For the parents who responded with grace, realizing doctors are doing their best, remained more positive and were able to minimize the negative impact of the medical system on their adjustment. The father of a teenage boy with a brain tumor said:

> Don't allow yourself to become frustrated by the medical profession. And it can be very frustrating. They're doing the best that they can. They just don't have all the answers and the system is what it is. It's not an exact system… I know if you go into the (hospital) lobby and start yelling and screaming and making demands and you're all stressed the hell up, you are not going to get the desired outcome. It's just not going to happen, so don't waste your energy and time on doing that.

Another father echoes this sentiment. His child was diagnosed with cancer on two separate occasions. He said, "Doctors and nurses aren't perfect. We always expect them to be, but they are not going to be. We are not perfect at our jobs, and they are not going to be perfect at theirs. But a lot of people don't think that way. Until you experience it."

Parents who are able to keep their cancer-related stress in perspective with the experiences of other pediatric cancer families were also able to have greater capacity for coping and adjustment. The dad of a young boy with leukemia represents this dynamic. He said:

> We're thankful he's healthy as he is for what he has. And when you walk to the clinic you know that there are so many situations that are so far beyond what we have dealt with. There are people who have never got to leave the hospital, who are still there in isolation…We are trying not to be down in the dumps.

Not only does the family's cancer experience make it easy to be "down in the dumps" but so too does the ongoing non-cancer stressors families face. Things like keeping a house clean, mowing the lawn, running errands, and work stress can pile-up can all overwhelm pediatric cancer families. However, the parents perceiving these non-cancer stressors as no longer very important, were better able to focus on the demands of cancer and to not let other stressors pile-up. One father demonstrates this by saying:

> Leading up to the diagnosis…we had…all this stuff going on,…. A ton of stressors…[but]it wasn't jack shit. That's a poor way of articulating. It meant nothing now. It really did…Ok, now one of our kids is in crisis. We're not doing all that great, but all this other stuff that we thought was really bad turned out to be a non-factor.

Lastly, as parents believed deeper meaning would emerge out of their current suffering with cancer, they were more capable of perceiving their cancer stress as less incapacitating. When parents are able to see a bigger purpose in their child's diagnosis and the challenges they are facing, they were more positive about their ability to cope with cancer. One father said:

> There is a purpose for everything. Anything that happens to you, if you choose to, you can make good out of it by learning from that experience. So we can use all the different aspects of what happened. Even to the point of figuring out how these experiences our son has, how is that going to shape his future? What can he use from learning to deal with this (his cancer)? One thing we found out with him, is that is he really good at working with kids and he is not afraid to see somebody who is sick or that kind of stuff, or somebody who looks different physically.

Often, this perception of a deeper meaning in their suffering originated in the parent's belief system. Faith helped parents through cancer distress by bringing meaning and hope to their experience. One mother said:

> I don't know how people make it through without faith? Our faith has really been a huge part of everything for us and even for our kids. They've had really hard questions, silent questions and verbal ones. Faith is a huge part of the journey. A resource that has been very present for us just to make sense of it, to have hope in it…It's obviously a huge resource for us.

Regardless of the specific stressor the parents faced, whether it was the medical system, comparing circumstances to other cancer families, being overwhelmed with pile-up of stressors, or struggling to see a purpose in their suffering. Those parents who were able to perceive the cancer experience with a lens of hope and positivity were more likely to create a stable, resilient family atmosphere for coping with cancer.

P**roverbs.** Equally important to the parents' ability to remain resilient is their development of proverbs serving to guide their responses to stressors that may arrive along the way. These proverbs are little sayings parents would utilize to advise their actions when they were not sure what else to do. An example of one of these proverbs is "You better be a grown up." To parents, this meant needing to be responsible, reliable, and putting their family's needs above their own, at times. A mother of a daughter with leukemia had this message for parents of children with cancer:

> I think you better be a grown up. There is no room for any sort of selfish behavior whatsoever. From yourself, or from someone else. There is no room for it. There is no room for me to want to be first right now. There is no room for selfishness. You can't have the feeling that my need is more important than anybody else's. That's counterproductive to the team moving forward down this path of wellness.

This proverb helped these parents to be strong even in times they were feeling weak. Another example of this is demonstrated by the proverb of "Keep moving forward." Moving forward entailed not taking time to feel sorry for oneself, getting organized with their child's treatment, and staying on top of hospital visits and the tasks of home life to the best of their abilities. One father describes this approach saying, "You can't go through life in park. It's going to go on, with or without you. Life is going to continue on and you've just got to sort through the mess, and not get slowed down by all of the distractions."

Not all proverbs were centered on providing strength. Some had the purpose of creating a sense of normalcy and connection. For example, multiple parents described the idea of "A new normal." This idea represents parents' efforts to integrate the demands of cancer into their daily lives and seeing it as part of the everyday, rather than by focusing on how the cancer has added difficulties to life they wouldn't otherwise have had. One mother said:

> All through her treatment there is what you call, 'the new normal." This is how life is now. You just adjust to things you never thought you could. Like giving your daughter chemo every day at home and getting her steroids and getting her pills before she goes on the school bus and after it. But it becomes part of your life and everything else is normal. Go to the park. You play. You go out to eat you do whatever normal people do.

Similarly, the proverb of "Celebrate the little things" helped multiple families not let the changes forced upon their lives by cancer overwhelm their ability to live normal lives and to experience joy together. The "little things" parents referred to were the things in life that can often go unnoticed or taken for granted. Things like, having time together as a family, seeing a sunset, or having a good meal. One mother talks about it this way:

> We celebrate the little things intentionally. We don't procrastinate on celebrating whatever there is to celebrate. Not because we don't know if our daughter is going to die tomorrow, but any of us could. Anything can happen. We seem to celebrate more often, more quickly with food or movie night or game night or a hike or just having fun being together.

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TABLE 3.1: Model Themes

Guiding proverbs served as reminders to families about their strength and capacity for normalcy, and these proverbs, combined with positive perceptions about cancer-related stressors, mitigated the negative impact of stress on the family. The reduced stress in turn improved a family's ability for resilience throughout the pediatric cancer experience.

Tree Trunk

The function of the tree trunk is to give the tree its shape and strength. It also connects the roots to the branches and leaves as it carries water, minerals, and nutrients between these two important parts of the tree. Similarly, the relational dynamics within a family system give the family its shape and can improve its strength and resiliency in the face of pediatric cancer stress. The family system dynamics also help to connect the parents (roots) with the other parts of the family and with extra-familial resources. Three primary family relational dynamics improved the family resilience. These dynamics are categorized as: rubber, glue, and fences.

Rubber. Cancer affects almost every aspect of life: from daily activities to social life to physical ability. Thus being capable of adjusting roles, responsibilities, and remaining flexible is essential to family resilience. Families must become like rubber, demonstrating durability, flexibility, and adaptability to maintain wellbeing after a diagnosis of pediatric cancer. When parents, children, and extended family members accept these rubber-like qualities the positive impact is lasting and sustaining. Becoming "rubber" happens in various ways. One example is demonstrated by the parents' ability to successfully balance the numerous new responsibilities piling-up after a cancer diagnosis in their child. This is a challenge many parents often struggle with. However, those who manage to do this well, as a team, tend to cope better to the crisis of pediatric cancer. A father of a teenage son with a brain tumor reflects on how he and his wife sought to balance their responsibilities together. He said:

> We had a division of labor, my wife and I, we've been together since we were sixteen. She has strong points, I have strong points. Between the two of us we're a pretty good team. That became much stronger again because we were at odds about in-laws, finances, job and career selection, child rearing…All that shit got thrown a side. We went back to the old teamwork. She handles the emotional aspect. I handle the practical.

Second, the parent's ability to adjust their parenting approaches to meet the changing life and family circumstance brought on by cancer was also paramount to family resilience. The parents and children both needed to learn to adjust together. Family adaptation occurred best when parents were able to maintain a sense of order and connection at home, with the child patient as well as his/her siblings. The following discussion about parenting changes by a mother and father of a girl with leukemia provides an example of how they made adjustments in their family:

> Mother: We needed to be there for the rest of the family. We have six children. The oldest had just gotten married. There were five still at home. He was doing all of the managing at home that I could not do because I was in the hospital. That is how that arrangement worked out well for us.
>
> Father: It worked. Immediately, family became a lot more practical…When they checked into the hospital, all of a sudden we had to change how we operated. Now, I told the kids, with notes on the counter, here is the schedule and here is what you need to do. As much as I could, I had to be Mr. Mom all of a sudden.

Another important parenting adjustment mentioned by many families in the study was their need to learn how to give adequate time and attention to their non-patient children. Cancer treatment can be very time consuming. It can become easy for parents to direct the majority of their time, energy, and focus to their child with cancer. However, families who remained most resilient to cancer were those who managed to still prioritize making time for their other children who were still needing their mom and dad to be there for them. A mom of a five year old with leukemia said:

> I take them (the two siblings) out on their own without her (the cancer patient) so they get attention from just me without her being an attention hog. That is one thing I would recommend parents to do if they have a child going through this. Even if they are going through it bad, to try to not forget about your other kids.

Overall, parents emphasizing flexibility in balancing the demands of the cancer disease and its treatment were better able to adapt to the many changes. A dad confirms this necessity saying:

> The people around us are flexible. People in our family are flexible. To come over, cover bases if we need to leave or something like that…Does it suck having to be so flexible? Yeah it's really a big bummer to have to cancel plans or to do whatever when not expecting it. But we just tell our kids, "Okay we got to do it."

Flexibility was essential because families reported many occasions in which unexpected events occurred. These events impacted each person in the family system. Families more capable of becoming like rubber—flexing and adapting to the changes— fared better in face of cancer-related stress.

Glue. Another important category of family relationship dynamics is the family's ability to relate to each other in ways capable of reinforcing feelings of connection and closeness. Stress of any kind can push people away from each other, cause frustrations, decrease patience, and create feelings of loneliness. Families in this study reporting intentional positive actions helping their family members move toward each other in emotional closeness reported greater ability to adjust and cope with cancer. These actions became the "glue" keeping the family working as a team and helping individual family members feel supported and safe. Families stayed glued together in various ways. For example, the parents' ability to communicate effectively was central to the family's feeling of closeness. Prioritizing communication kept parents on the same page, built trust, maintained emotional connection, and decreased feelings of loneliness throughout the cancer diagnosis and treatment. A mother demonstrates the importance of communication as she says:

> Because the level of trust was high between us, we'd be able to talk about everything. If I'm wondering about that, or have you thought about this? It'd be easy to get in an argument over some of the many little things, but some of them don't have to even become an issue. Because we had a sense that if we talk about the little things, they won't become big things.

A second important method for engendering family closeness was by recognizing and appreciating other family member's strengths. For parents, expressing recognition and appreciation of their partner's strengths throughout the cancer experience increased and maintained positive feelings between parents. A father of a daughter with a brain tumor shares his feelings about what he has seen his wife do in response to their child's illness. He said, "I look at what she has to do on a daily basis and I'm very proud of her. She's done a great job at either being the 'stay at hospital mom' or she put the chemo into the feeding tube. That was something that not an ordinary mom could do." Equally important is the parents' ability to recognize and acknowledge the strengths in each of their children. Doing this infuses the family with greater positivity during a time when doubt and negativity can penetrate the family system. One father said of his son:

> When you're athletic, when you are strong in studies, when you're a good person, still cancer knows no boundaries. When you get dealt that hand, it's about how you choose to deal with it. That is what we expressed to our son. He's very mature that way. He's never said, 'Why me?' He's never shed a tear over it even though he's been scared to death.

Taking time to express appreciation of strengths in parents and children consistently helped families stick together and feel solidarity in the family's fight with cancer. For many parents in the study, the crisis of cancer did not push them apart despite the myriad difficulties cancer imposed on them. As parents relied on each other more, the impact of cancer distress diminished slightly and they felt more capable of meeting the demands of the disease. For example, a dad of a daughter with leukemia said about his wife:

> This (the cancer experience) has raised my level of respect for her. Watching how she has weathered this and cared for the kids through this. To watch her strength and her commitment has really drawn us closer together. It's meant a lot to me. It's strange in some ways because I go off to work and sometimes that's like an escape where she is here day-in-day-out. It's in her face every day. Through this experience and through the treatment and, especially as we walked through that, I felt a lot closer to her and have more respect, because it's so tough.

Another form of "glue" drawing families closer throughout the cancer experience was the support offered to the family by extended family members. Extended family members were often a significant resource that improved family resiliency. The parents' relationship with their own parents (the child patient's grandparents) was often identified as an integral support. A mother, whose mom helped a daughter through childhood cancer years ago, and a father demonstrate the importance of their parents by saying:

> Mother: My Mom was probably my biggest help. She, obviously having a child having gone through cancer herself, she knew a lot of the things that I would be experiencing. I'm so close with her.
>
> Father: Family is the biggest support for sure. We all live within two miles. We have a close family. My mom is definitely the martyr. She kind of holds everybody together, secures everybody in the loop for better for worse.

Not only were grandparents an important support in improving family resilience, so too were supportive relationships with other extended family members. When parents expressed feeling cared for and supported by cousins, aunts, and uncles they reported less cancer-related distress and greater confidence in the family's ability to adapt to pediatric cancer. For example, a father of a teenage girl with a brain tumor said:

> Because of going through this, it brought my family closer together. Now we've been communicating every day or every other day where before it was like we weren't

> communicating at all. This has even put me in contact with family in Louisiana! I hadn't communicated with them in I don't know how long. Now we got people all over the place, just praying for us now.

Finally, family closeness was commonly created through spending time together. Parents reported spending more time together as an entire family, also reported feeling more positive about the family's coping and ability to adapt. A father of two teenagers, one with leukemia, shared how cancer had forced their family to slow down their busy schedules, thus creating more opportunity to be together as a family rather than running from commitment to commitment. He said:

> For family in general one of the side blessings for us this year is our busyness stopped. We just enjoyed those times sitting around the table playing board games, visiting, watching a movie, doing the simple things of life, the four of us. I really appreciated that.

Families "glued" together by communicating effectively, appreciating each other's strengths, supporting each other, and spending time together were more often resilient to pediatric cancer distress. They less often felt alone, felt more supported, and had maintained emotional connections with the important people in their lives, thus providing strength and safety amidst their distress.

Fences. The final relational dynamic reported to be necessary for improving family resilience was setting boundaries with extended family members. Many families reported the experience of relatives who, in their attempts to help, became over-involved and actually hindered the family's ability to cope. In response to this over-involvement, many parents were able to communicate specific boundaries around how and when extended family members could help. These boundaries provided a helpful "fence" offering space for the family to cope together while limiting interference from others. Extended family members often did not know how to be supportive to the families with cancer. Thus having clear boundaries with extended family members was an important way to combat the potential for added stress. One father said:

> Boundaries were huge. Everyone wants to help, and there are a lot of people that want to be so close to the situation that they actually hinder you. Everybody uses the term “new normal,” but they not helping you establish that. They are actually making it harder.

Rubber, glue, and fences—adaptability/flexibility, family closeness, and healthy boundaries describe the family relationship dynamics contributing to improved family resilience. When these three dynamics were present, parents in this study reported greater levels of competence in meeting the demands cancer was placing on them and their families. In addition, parents reported better coping and well-being compared to parents who did not have one or more of these dynamics in their family life.

The Crown

The tree’s crown consists of its branches, leaves, and fruit. The primary purpose of the crown is to filter dust and other potentially harmful particles from the air. It also helps cool the air by providing shade and mitigates the impact of raindrops on the soil below. The leaves of the tree help the tree make food by using the sun’s energy to convert carbon dioxide from the atmosphere and water from the soil into sugar and oxygen. This food then provides sustenance to the entire tree and helps it remain healthy. Much like the tree’s crown, extra-familial resources help to buffer families from the stress of pediatric cancer, minimizing its negative impact on the health of the family and its individuals, and provide sustenance to the families throughout the cancer experience. The crown of the tree is also where trees produce their seeds. These seeds come in many forms (acorns, fruit, nuts, cones, pods, etc.), but the purpose each seed is to propagate the DNA, or make-up of the particular tree throughout the surrounding area (depending where the seeds fall). Similarly, many resilient families experiencing pediatric cancer have a desire to share their experiences and what they have learned as a way to help and support other families. Support received from friends, church, school, work, not-for-profits, online, the medical system, and other pediatric cancer families, in combination with support the cancer family provides others constitute the "social sustenance" aiding family resilience following a pediatric cancer diagnosis.

Social sustenance. Participants spoke at length about the significance of social support they received from family, friends, communities, and various other sources. Social support was one of the best resources enabling families to cope with the crisis of pediatric cancer, and increase family resilience. Support came in various forms from various sources. Not all families demonstrating resiliency had support from all of these sources. However, each source of social support served as an additional resource increasing a family's ability to cope, adapt, and manage the cancer- related distress. The most helpful sources of social support were friends, church, school, work, not-for profits, online community, the medical system, and other pediatric cancer families.

Parents demonstrated how each of these social supports provided sustaining help. For example, one mother says of her friends:

> We truly had good friends that would do anything. They'd be like, 'I can go to the store for you. What do you need?' It was the little things like that that I loved. Things would be starting to pile up, but they were there to get it taken care of.

Friends were a common source of support. So too was the medical staff. Many parents expressed appreciation for the team of medical professionals tasked with providing healing and comfort to their child. One mother said:

> The vast majority of the caregivers up there (at the hospital) have been phenomenal. They really care about kids. Really did things well.…It wasn't like they were just doing a job.

> They really cared. The oncology team has been phenomenal…we are so grateful for the caring doctors.

Occasionally, the support came from online sources. Technology provided opportunities for families to share their story and to garner social support both from people they knew and those they had never met. One father said:

> Our story has gone around the world. Within hours, maybe within minutes, of the news going out it was around the world. My brother in Washington, he knows people all over. All our technology today, you post something on Facebook and it's all over. We had people come into the hospital that we didn't know. There are so many people that we don't know that know her (their daughter with a brain tumor) and support her.

Another important social resource was other pediatric cancer families. Parents in this study shared how they appreciated meeting other families with a child with cancer because they felt they could better understand their experiences. One mom demonstrated this saying:

> I think all of us that have a child going through any kind of a cancer; we feel a bond and a connection because that other person can understand what I am going through. I can understand what that family is going through. I have been through it and I think people like to hear, and I like to hear, the stuff that people share. The good and also the bad. You can relate to it in ways that other parents don't get to because they haven't gone through it. There is that kind of connection and community you feel with people that have children going through this.

The shared experiences and mutual understanding provided families an outlet to talk about their ups-and-downs. It also helped families to feel less alone as they discovered other people who had gone through similar experiences with cancer.

Social sustenance came not only from specific individuals like friends and neighbors, but also from institutions like churches, schools, jobs, and not-for-profit organizations. Every family in this study shared the significance of receiving support from one or more of these sources. A father shared an example of church support. He said:

> We were between churches. And then it turned out that we went to a church for two Sundays before she was diagnosed, at the invitation of some good friends. So our son kept going to Sunday school, and they just embraced us, the church did. And the church we left embraced us, and the church we were at five years before that embraced us….Initially it was just a wave, a tsunami of support.

Churches helped organize communities to provide support and care for the pediatric cancer families. Similarly, schools were a source of organized support too. One father reflects on the support his family received from his daughter's school. He said, "The biggest support came from her school. They've raised like $3,000 and brought it to us. And the principle is always up here to visit her. It really shows they care." Feelings of care and concern often extended beyond the child's school but also to the parents' workplace. Families reporting experiences of their employers being flexible with them and showing understanding of their unique health crisis were bolstered by this generosity. A father working as an electrician said, "I ended up taking six weeks off in 2010 and I never had any unpaid time! Between my vacation and then there was some donated time that was given to me. That was a blessing."

Lastly, not-for-profits also were a resource of social sustenance for the families in this study. The families talked about experiences with organizations like Make-a-Wish Foundation, Gilda's Club, and Starlite Shores Family Camp (a week-long camp for pediatric cancer families). Each of these organizations helped to ease the burden on the cancer patient and their family. A mother describes it like this:

> Make-a-Wish, which we thought was just for kids who were very near death, but one of the social workers approached us months ago and asked if we would like to do Make-a-Wish and explained that it goes on diagnosis not prognosis. That's been just a real fun blessing to look forward to a trip to Hawaii they are treating her with. It's in February, so it's a good time to go. Fun to look forward to that. The kids are excited.

Social sustenance came in many forms. Sometimes it was big gifts like trips to Hawaii or money. Other times it was in the form of the little things: a phone call, a Facebook message, or a dinner. However it came, it was fundamental to family coping and resilience. An additional form of social sustenance came when the families in the study had opportunity to use their cancer experience to help others. Parents reported having opportunities to use their experience with cancer as an inspiration or as a tool to help others, helped them to feel their experience had meaning and utility to make other's lives better. When families sought opportunities to help others, it reciprocally improved their sense of adaptation and resilience. One father describes how his son's cancer experience through both liver and brain cancer has helped him to seek opportunities to use his experiences to help others. He said:

> Our son…All of his experiences he can use to help others somehow. We work hard at that with him…he wants to work with kids, he wants to work in hospitals. He wants to be a child life specialist because they had an impact on his life. He feels he can help others because he has been there.

Thus the social aspect of cancer coping is an indelible component of family resilience. Whether receiving it or offering it to others, families facing pediatric cancer need it to buffer them from the ongoing stresses of cancer.

Discussion

The primary objective of this study was to understand how families remain resilient to the crisis of pediatric cancer. A diagnosis of cancer in one's child taxes a family's well-being to the limits. While most families are capable of meeting the demands of the cancer experience, some do not. The difference between families remaining resilient in response to the adversity of pediatric cancer results from the synergy of perceptions of pre-cancer experiences, parent factors, family relationship dynamics, and social networks.

The “soil” in which family resilience grows out of is the family’s experience with pre-cancer life stressors and their perceptions about how well they handled these stresses. The narrative families use to describe past experiences with stress can exert a significant amount of influence over perceptions about their present challenges. This dynamic is recognized elsewhere in family research. For example, in marriage research, a pattern of recasting the oral history of a couple’s relationship in negative terms is one of the strongest predictors of negative marital satisfaction and divorce (Buehlman, Gottman, & Katz, 1992; Gottman, 2011). The impact of a positive stress narrative was a significant resource of resilience for the families in this study. Past experiences with stress did not pile-up, rather they served as learning experiences from which confidence and competence to meet the demands of stress were derived.

This study also reveals how parents serve as the “root” system for family resilience—keeping the family grounded and anchored throughout the cancer experience. The first primary aspect of the parent contribution to family resilience is their ability to maintain positive perceptions about the challenges their family was facing. Parents had countless challenges in which negative emotions and cognitive appraisals could occur. For example, when doctors or members of the medical staff made an error. The parents in this study exemplified various methods of positive reframing. One example of this is comparing one’s situation to others who “have it worse.” This concept is known as downward social comparison (Wood, Taylor, and Licthtman, 1985). The process of downward social comparison has been shown to have many positive benefits to the perceptions of cancer survivors (Brakel, Dijkstra, Buunk, & Siero, 2012). Parents also were able to prevent the pile-up of stress by perceiving the non-cancer related stressors as not as important anymore. Kelley and Ganong (2011) referred to this process as parental “focus on the ill child,” and found that unwavering focus on the cancer-related responsibilities was capable of mitigating the negative impact of other family stressors. A final example of parental perceptions as they relate to family resilience is demonstrated by their ability to perceive deeper meaning out of suffering due to the cancer. This is perhaps the single best predictor of a family's ability to cope with the disease (Yanez, et al., 2009). Conversely, when families are unable to make meaning and find peace regarding the diagnosis of cancer in their young child, the chances of adjustment are significantly decreased. Depression, hopelessness, and the desire for death can result when meaning is not found in a cancer diagnosis (Breitbart, et al., 2000; McClain, Rosenfeld, & Breitbart, 2003). Parents' positive cognitive appraisals are a commonly recognized aspect of family resilience to disease and disability in one's child (Hocking & Lochman, 2005; Thompson, Hiebert-Murphy, & Trute, 2013).

A second important component of the parental role in family resilience is the guiding proverbs they use to guide their responses to future cancer-related stressors. Proverbs identified in this study are: "You better be a grown up;" "Keep moving forward;" "The new normal;" and "Celebrate the little things." These guiding self-directed messages improved the parent's understanding of their strength to handle challenges and reminded them to seek continued closeness with their family. This strength and closeness was often then transferred to the rest of the family members who also incorporated these proverbs into their coping experiences. The use of proverbs, mantras, and guiding phrases has not previously been identified in psychosocial pediatric cancer research. Yet their usefulness has been documented in empirical research elsewhere. Family proverbs are shown to be an effective way to transmit family values (McAdoo & McWright, 1994; Page & Washington, 1987). Frequent mantras and proverb repetition can be helpful in reducing stress, anxiety, anger, and improve quality of life and well-being for veterans, healthcare employees, and the chronically ill (Bormann et al., 2007). Proverbs help combat stress by defining one’s experience in terms of the guiding phrase rather than by giving power to the stressor and the possible negative reactions it could impose (Ashley-Farrand, 1999). Parents in this study revealed a connection between guiding proverbs and family resilience through the proverb’s ability to create a more positive definition of self and experience.

Additionally, the contribution of family relational dynamics was also an essential aspect of family resilience in the face of pediatric cancer. The family relationship dynamics provided strength and shape to the family while connecting the family to other resources of support. The relational dynamics of “Rubber, Glue, and Fences” created the “tree trunk” of the proposed Natural Family Resilience Model for Pediatric Cancer (NFRMPC). The “Rubber” consisted of the relational dynamics of balancing roles and responsibilities, parents adapting parenting approaches, and flexibility. Family capacity for flexibility and adjusting roles is a well documented predictor of family resilience. Families able to remain flexible, rather than rigid, throughout their coping experience tend to demonstrate healthier adaptation to cancer distress (Hobfoll & Spielberger, 1992; Reiss & Olivert, 1991). Families successfully altering roles, responsibilities, and day-to-day functioning to accommodate the needs of children with cancer typically experience improved coping (Martin et al, 2012). Since Minuchin (1974), researchers have stated that strong families are characterized by flexibility and adaptability to the changing roles occurring due to a cancer diagnosis (McCubbin & McCubbin, 1992; Trivette, 1990). In addition to flexibility and adaption, family closeness is also an important dynamic to family resilience. Good communication, appreciating each other, supporting one another, and spending time as family are the primary ways families can stay “glued” together during a pediatric cancer crisis. Various family researchers consider effective communication as the cornerstone to strong family (Gantman, 1980; McCubbin & McCubbin, 1992). Additionally, family closeness or cohesiveness is one of the most frequently cited attributes of resilient families (Vanbreda, 2001). When families feel emotionally bonded to one another, they become more capable of responding to stress effectively (Olson, Lavee, & McCubbin, 1988). Families who intentionally interacted with each other often, complimented each other's contributions, and reinforced each other's efforts reported a greater sense of support and closeness. These intentional positive interactions created a greater sense of togetherness and security as the families coped with pediatric cancer. Finally, parents who created healthy boundaries with extended family members also demonstrated greater family resilience. Boundaries help to clarify roles and functions within the family system and help parents to exert their authority as parents of the ill child (Baumrind, 2013; Whitchurch & Constantine, 1993).

Lastly, the "crown" of the tree represents the "social sustenance" experienced by families as they were supported by others, and sought ways to give back. The social support experiences provided families with protection from many stressors created by cancer. It also provided families with a sense of community and belonging, which mitigated feelings of loneliness and disconnect common to a cancer experience. Support from various networks provided families this relief. Social support helped families both emotionally and practically. Social support is helpful for both the child patient and his/her family. Support from family and friends was identified by Trask et al. (2003) as the most important factor in the child's ability to cope with his/her cancer diagnosis and treatment. Social support sustains families through the pediatric cancer crises by reducing symptoms of distress and by reducing feelings of loneliness and isolation (Corey et al., 2008; Lockhart et al., 2001; Yildirim & Kocabiyik, 2010). Social support was a significant addition to a family's ability to remain resilient after a diagnosis of cancer in their child.

Many of the specific concepts identified in this study resonate with previous research on family resilience in response to pediatric illness. Various researchers have offered organization of the variables identified. However, limitations exist in the models proposed to date. For example, the authors of the Risk-resistance Adaptation Model, which emphasizes biopsychosocial risk and resistance factors, argue family resilience results from the presence of more resistance factor than risk factors. However, unlike the NFRMPC, their model does not incorporate larger systems (e.g. schools, community, work) into its framework (Mullins et al., 2015). Additionally, the Transactional Stress and Coping Model states that family resilience is impacted by illness-specific variables, demographic variables, and various interpersonal adjustment processes (Thompson, Gil, Burbach, Keith, & Kinney, 1993). However, this model also does not adequately incorporate the impact of social support for the child on family coping (Mullins et al., 2015). McCubbin and colleagues' (2002) model of family resilience to pediatric cancer includes the importance of appraisals/perceptions, family dynamics, and social support. However, it does not recognize the importance of family perceptions of pre-cancer stress experiences, and the stress narrative's formative power on family resilience that is described in the NFRMPC.

Kazak and colleagues (Kazak, 2006; Kazak et al., 1995) have proposed, perhaps, the most comprehensive model of family resilience. Their Social Ecological Model takes into account child, family, and social contexts and views resilience in a broader, ecological framework (Kazak, 2001). Challenges with their model consist of the difficulty of incorporating all levels of interrelated constructs into clinical research (Mullins et al., 2015). It also may be too broad of a model to measure or utilize with clinical populations. The NFRMPC attempts to expand on the Social Ecological Model by incorporating the individual, family, and extra-familial contexts by providing a less complex framework (the tree) with hopes of increasing the ability to test and understand how the various ecological levels interact to promote resilience.

Similar to Masten's (2001) model of family resilience, the NFRMPC also reflects the centrality of the parent experience in the family resilience process. Studies in childhood illness have consistently indicated that one of the single best predictors of child adjustment is parent adjustment (Chaney et al., 1997; Mullins & Chaney, 2001; Thompson et al., 1994a, 1994b; Thompson et al., 1999; Wagner, et al., 2003). Parents filter the experience of cancer stressors for the rest of the family. When parents are able to perceive and react to stress with resilience, the negative impact of the stress on the more vulnerable children dissipates. Children still have their own unique experience and perceptions of cancer's impact on them and the family. However, they often look to their parents to know how to react. The NFRMPC recognizes this important role of the parent as a key for understanding the whole-family resilience process.

Overall, the NFRMPC shows family resilience is greater than the sum of its parts. Resilience is achieved and maintained via a continuously interactive process of the family's: history, context, individuals, relationship dynamics, and engagement with community. Resilience to pediatric cancer stress is a fluid, dynamic, and living process. It is a process with much more vitality than can be accurately represented in an algebraic formula (see Double ABCX Model). "Resilience does not come from rare and special qualities, but from the everyday magic of ordinary, normative human resources in the minds, brains, bodies of children, in their families and relationships, and in their communities" (Masten, 2001, p. 235). The process of resilience is ordinary and natural to families. The NFRMPC provides an ordinary, recognizable framework to describe an ordinary, recognizable phenomenon.

Clinical Implications

The impact of pediatric cancer on a family is extensive. Certainly, clinical practitioners can serve a valuable role in helping families cope with this emotional experience. Yet, as mentioned previously, most families demonstrate natural resilience to the cancer distress. However, some families require some coping assistance along the way. Thus a primary need for improvement should be directed at creation and testing of evidenced-assessments capable of early identification of the families who may be in need of support (Kazak et al., 2010). The current pediatric hospital model is not always conducive to proactive integrated biopsychosocial care (Kazak et al., 2006). Often care becomes collaborative only after a patient becomes complicated and the limited psychosocial resources can be disproportionately distributed to the most difficult patients. The current pediatric hospital model risks missing the psychosocial concerns of other families who may benefit from intervention support (Kazak et al., 2006). However, by incorporating improved, evidenced-based, routine psychosocial assessment by nurses, physicians, or social workers can proactively identify the families in need and can better direct families to available resources, depending on the level of their need.

Secondly, the development of clinical interventions targeting whole families of children diagnosed with cancer is another priority of future clinical focus. Most treatment centers provide some psychosocial services to families. However, the nature and extent of interventions offered across centers is unknown, as are data regarding outcomes. Many interventions are primarily individually oriented approaches (e.g. pain management) and may include family members but without a specific family therapy or intervention framework (Alderfer & Kazak, 2006). Currently, few intervention programs exist that target the whole family (Alderfer & Kazak, 2006). In many intervention programs, significant parts of the family are excluded from treatment. For example, with the exception of the Surviving Cancer Competently Intervention Program (SCCIP-ND) fathers are typically not included in most intervention studies (Kazak, 2008). Developing interventions targeting family processes (e.g. communication) and involve multiple members of the family may be particularly effective in fostering family level and individual adjustment (Alderfer & Kazak, 2006). However, when it is not possible to include entire families in interventions, the parents should be the primary focus of psychosocial support. The pediatric cancer literature is clear in its demonstration of the connection between parent distress and child wellbeing. The success or failure of parents to adapt to the crisis of cancer is one of the most influential factors in predicting positive child and family psychosocial adjustment to pediatric cancer. The “reciprocity” between the parent adjustment and the child patient adjustment signals the potential impact a clinician may have on the entire family through work with the child’s parent or parents (Apter, Farbstein, & Yaniv, 2003; Greening & Stopplebein, 2007). Incorporating even brief clinical interventions with parents has potential to be effective in improving family resilience. For example, solution-focused family therapy typically last only a few sessions and can help families focus on their strengths, elicit important coping resources and develop a more competent and confident understanding about their abilities to combat challenges (de Shazer, 1994). Effective family interventions capable of being applied to the pediatric cancer population already exist. However, developing improved methods for identifying which families are in need of these clinical resources needs to be an immediate priority.

Thirdly, as family interventions for pediatric cancer are developed an important consideration is the testing and development of both (a) the core components of the intervention and (b) the order of component delivery (Gearing et al., 2011). The NFRMPC provides suggested target components to begin exploration and clinical testing (e.g. pre-cancer factors, parent factors, family relational dynamics, and extra-familial support). However, there may be important components not mentioned in the model that could still be instrumental to family resilience. For example, the importance of parental self-care is a component mentioned by a few families in the study but was not a strong enough overall theme to be included. Yet other research points to the benefits of self-care for caregivers and cancer patients (Dodd & Miaskowski, 2000; Klassen et al., 2007). Lastly, regarding the order of delivery for intervention components, the tree framework suggests a chronology to family resilience. All trees begin their growth in the soil, developing roots, and then growing its trunk, branches, and leaves up from the ground. Just as there is natural order to tree growth, there may also be a natural order to engendering family resilience via psychosocial intervention. If so, the NFRMPC suggests that successful intervention delivery must start with family perceptions of their stress narrative, focusing primarily on the parents. Followed by targeting internal parent factors (i.e. perceptions and proverbs), family relational dynamics, and lastly by intervening with the family's relationship with extra-familial supports. Future clinical research needs to clarify the fit of the components suggested in the NFRMPC, and their order, with the effective augmentation of family resilience.

Limitations

As in McCubbin, Balling, Possin, Frierdich, and Bryne (2002), one could argue that the findings represent parent resilience more than family resilience since it is only the parent's voices recorded in the study. However, this limitation is minimized due to the systemic nature of the interview questions. The parent's descriptions described what the family, as a whole unit, did to manage life after the cancer diagnosis rather than just, parent-specific experiences of adjustment. Despite the researcher's attempt to minimize the impact of this limitation, future research could benefit from adding the child patient's experiences, their siblings, extended family, and important extra-familial supports. Moreover, due to the broad scope of this study important areas of interest could be explored deeper. For example, research participants discussed their dyadic relationship dynamics within the semi-structured interview format, yet these discussions only comprised a portion of the overall interview. There is potential for greater understanding of family resilience processes by limiting the research scope to parent dyads, parent and child dyads, and sibling relationships and how each of these sub-systems impact family resilience. Future research could expand on the findings in this study by exploring specific resilience-related dynamics of these important familial sub-systems.

The small sample size is also a limitation. While saturation of data occurred with the sample size of this study, the sample is not diverse in terms of racial background, economic background, or cancer diagnosis type, thus there are still questions about how a larger and more diverse sample would impact the themes of the NFRMPC. Family strengths are culturally bound and may vary widely between cultures. Family strengths research is often critiqued for it probably reflecting the value system of White, American families (Ponzetti & Long, 1989). The sample in this study is primarily White (only one non-White family participated), thus the experiences shared by parents may reflect a similar cultural understanding and may not reflect the views of a more ethnically and racially diverse sample.

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CHAPTER FOUR: CONCLUSION

Pediatric cancer is extremely stressful for families. Yet many handle the stress well (Martin et al, 2012). Some children with cancer even report their experience with the disease has helped them become a stronger person, make new friends, know how much they are loved, be more patient, and know what is really important in life (Currier, Hermes, & Phipps, 2009). Cancer has also shown to help the child patient gain a new perspective in life and bring their family closer together (Griffiths, Schweitzer, & Yates, 2011). Additionally, many parents of children diagnosed with cancer have demonstrated an ability to improve their relationship and marital satisfaction despite the myriad psychosocial challenges brought on by their child's illness (Brody &Simmons, 2007; Hoekstra-Weebers et al., 1998; Wittrock, Larson, & Sandgren). Often these positive changes are maintained for years after the original diagnosis (Kupst et al., 1995).

However, some families do not maintain well-being after their child's cancer diagnosis (Alderfer et al., 2009; Wiener et al., 2006). Emotional distress from pediatric cancer may cause various adverse psychosocial outcomes in the individual patient and in their family members. Cancer in childhood is associated with patient issues related to behavior, coping/adjustment, depression, and posttraumatic stress (Liang, Chiang, Chien, & Yeh, 2008). Pediatric cancer diagnoses not only affect the behavior of the child with cancer, but also their well siblings. Siblings of pediatric cancer patients are vulnerable to increased irritability, mood swings, agitation, increased aggression, yelling, and crying (Williams et al., 2009). Parents of children with cancer are also risk developing negative psychosocial outcomes. Many parents experience anxiety, post-traumatic stress, depression, and decreased family functioning (Dunn et al., 2011; Mereuta & Craciun, 2006; Streisand, Kazak, & Tercyak, 2003; Williamson, Walters, & Shaffer, 2002).

Understanding why some families respond well and others do not has been a primary focus of pediatric cancer research. To date, various protective factors have been identified. For example, factors found to be protective in child and family adjustment to cancer are: social support, positive thinking and hope, future orientation, self-care, refocusing on what is important, and remaining close with family (Fletcher, 2010; Griffiths et al., 2011; Prchal & Landolt, 2011; Sung et al., 2009; Yeh, 2001). Additionally, when families successfully alter roles, responsibilities, and day-to-day functioning to accommodate the needs of children with cancer they are often better able to adapt (Martin-Moreno et al, 2012). Additionally, family support and perceived high levels of family functioning by family members also buffers the risk of poor adjustment to cancer (Fuemmeler, Brown, Williams, & Barredo, 2003). These studies all represent various intra-psychic (e.g. positive thinking), familial (e.g. adjusting roles and responsibilities), and social (e.g. social support) aspects of improved coping to pediatric cancer, but are largely descriptive in nature and do not integrate findings into a coherent framework for family resilience (VanBreda, 2001). Still missing from our current understanding is a unifying framework capable of explaining how the above factors interact with each other to paint a comprehensive view of family resilience to a childhood cancer experience. Thus there remains a need to have a better understanding of the meaningful differences existing between resilient families and those who struggle to adapt.

Contributions of Studies to Existing Research

The studies comprising this dissertation add to the knowledge base of psychosocial pediatric cancer literature by addressing both “small and big” aspects of the familial pediatric cancer experience. Study One “zooms in” and addresses specific actions of social support and their impact on family coping. With the use of phenomological qualitative inquiry, parents’ experiences of their social support networks were illuminated. Notably, the parents' reports of ineffective social support are an important addition to the literature. Few articles addressing social support give attention to ineffective social support, and of those that do, most do not provide explicit and concrete examples of socially supportive vs. socially unsupported comments and behaviors (Hamilton, 2000). By outlining themes of "people just don't know what to do," "Too close to the situation," and "some people just disappeared" future friends, family, neighbors, and communities can have a better understanding of what not to do as they try to help pediatric cancer families. They will also be more educated about how they can help, and less likely to demonstrate "social ineptitude" (Dyregrov, 2004). Thereby improving the potential for more effective social support for families of children with cancer.

Additionally, Study One also highlights specific effective social support actions capable of mitigating the stress of pediatric cancer on a family. The specific principles of (a) "It's a marathon not a sprint," (b) "The world keeps pushing on us,' and (c) "Let us know we are not forgotten," reflect important realities of social support for families of children diagnosed with cancer. Social support has often been identified as an essential component of improved family adjustment. Social support can improve the family members' ability to remain focused on the positive during their cancer treatment (Zabaleugui, Cabrera, & Navarro, 2013) and can help combat symptoms of posttraumatic stress over time (Greening & Stoppelbein, 2007). Social support from family and friends can also help families maintain higher levels of healthy functioning which can buffer the risk of poor adjustment to pediatric cancer (Fuemmeler et al., 2003). The principles of effective social support identified in this study provides specific examples, based on parents' lived experiences, of support found to be most helpful to their family's cancer adjustment. Parents described the usefulness of instrumental, emotional, and companionship types of social support (Cutrona & Russell, 1990; Berkman, et al., 2000; Langford, Bowsher et al., 2008). The life-threatening nature of the cancer, in addition to the prolonged treatment and recovery, create a unique need for support (Martin et al., 1994). The specific social support principles and themes described in Study One provide guidance to social support networks to improve the help they offer.

Contrary to Study One, Study Two "zooms out" to provide a broader view of family coping with pediatric cancer. This study addresses family coping by presenting the Natural Family Resilience Model for Pediatric Cancer (NFRMPC). This model of family resilience incorporates pre-cancer stress experiences, individual parent variables, family relational dynamics, and extra-familial support into a coherent model of family resilience. This model provides a framework for understanding how families are capable of improving their "capacity for adapting successfully in the context of adversity." (Masten & Monn, 2015, pg. 5).

The framework as a whole is unique because it responds to limitations existing in previous models of family resilience to pediatric cancer. The limitations in previous models typically fail to (a) include a larger systems framework capable of recognizing the role of social supports and family ecology or (b) incorporate larger systems into the model but do so in a way that is complicated and difficult to test empirically or integrate clinically (Mullins et al., 2015). These limitations are outlined in greater detail in Study Two. The NFRMPC adequately represents the role of individual, family, and extra-familial contexts, and does so with a model that is easier to comprehend, integrate clinically, and test. The framework of a tree and its various parts organizes the NFRMPC. In the model, the "soil" in which family resilience grows out of is the family's experience with pre-cancer life stressors and their perceptions about how well they handled these stresses. The narratives families use to describe past experiences with stress can exert a significant amount of influence over perceptions about their present challenges. The "root" system— keeping the family grounded and anchored throughout the cancer experience—is comprised of individual parent factors of the perceptions and proverbs guiding their reactions and approaches to cancer-related stressors. The "tree trunk" is represented by the various family relationship dynamics. These dynamics provided strength and shape to the family while connecting the family to other resources of support. The relational dynamics most pertinent to family resilience are represented by the concepts of "Rubber, Glue, and Fences" which help families remain flexible, emotionally connected, and safe from outsiders crossing family boundaries. Lastly, the "crown" of the tree is represented by the "social sustenance" experienced by families as they were supported by others, and sought ways to give back. The social support experiences provided families with protection from many stressors created by cancer. It also provided families with a sense of community and belonging, which mitigated feelings of loneliness and disconnect common to a cancer experience.

Each aforementioned part of the tree framework offers a target for intervention and empirical testing. Interventions can be developed to address parent and family narratives of pre-cancer stress through application of a family intervention like Brief Solution-Focused family therapy. Solution-focused interventions can help families focus on their strengths, elicit important coping resources and develop a more competent and confident understanding about their abilities to combat challenges (de Shazer, 1994). Interventions at the "root" level with parents can target their perceptions and meanings of their cancer experience and help them create guiding proverbs capable of orienting them toward values and strengths in face of adversity (Ashley-Farrand, 1999). Family relationship dynamics can also be targeted clinically through application of family therapy models that incorporate family structure and relationship dynamics.

For example, structural family therapy is known to effectively address family roles, flexibility, and boundaries (Minuchin, 1974). Lastly, social support can be addressed through intervening with families to strategize how to identify and incorporate support from the non-family resources already present in their life. Also, through community-based interventions, community members and social networks can be better educated to know how to engage pediatric cancer families with effective support (Norton, McLeroy, Burdine, Felix, & Dorsey, 2002).

Each of these areas can also be empirically tested through the recommended methods for studying family resilience suggested by Card and Barnett (2015). Using the NFRMPC to frame quantitative study designs and hypotheses can be accomplished in the following ways. First, Card and colleagues (2015) recommend longitudinal models as the prototypical approach to measurement. The tree model includes a time element (pre-cancer experiences) and the themes included in the various categories (e.g. perceptions, flexibility, boundaries, social support) can be tracked over-time with the use of established measurements with well-established psychometric properties (e.g. the Social Support List Interactions and Discrepancies questionnaire) (Van Sonderen, 1993; Wjinberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). Also, their recommendation for measuring resilience via person-centered conceptualizations vs. variable-centered is fitting to the model. Person-centered approaches identify groups of individuals who share particular attributes or relations among attributes. Person-centered approaches are well suited for addressing questions that concern group differences in patterns over time (Laursen & Hoff, 2006). The NFRMPC's themes and organization of themes suggest specific attributes and relations of attributes of resilient families. These suggested attributes and attribute relations can then be tested empirically to confirm or disconfirm their fit in the model and can elucidate the contributions of the themes to family resilience. Finally, the model's inclusion of multilevel (e.g.

individual parent, family relationships, and community interactions) sets the stage for incorporating a diversity of methods to address the complex relationships between each level (Card et al., 2015).

In addition to providing a unique organization of the various factors contributing to family resilience, Study Two also identified two themes of resilience not previously mentioned in psychosocial pediatric cancer research. First, the "family stress narratives" about pre-cancer stress experiences was shown to exert an important influence on post-cancer coping. This dynamic is recognized elsewhere in family research. For example, in marriage research, a pattern of recasting the oral history of a couple's relationship in negative terms is one of the strongest predictors of marital satisfaction and divorce (Buehlman, Gottman, & Katz, 1992; Gottman, 2011). Second, the parents' use of "proverbs" to guide their coping responses was also shown to be an important aspect of family resilience. Proverbs identified in this study were: "You better be a grown up;" "Keep moving forward;" "The new normal;" and "Celebrate the little things." These guiding self-directed messages improved the parent's understanding of their strength to handle challenges and reminded them to seek continued closeness with their family. This strength and closeness was often then transferred to the rest of the family members who also incorporated these proverbs into their coping experience. Family proverbs are shown to be an effective way to transmit family values (McAdoo & McWright, 1994; Page & Washington, 1987). Frequent mantras and proverb repetition can be helpful in reducing stress, anxiety, anger, and improve quality of life and well-being for veterans, healthcare employees, and the chronically ill (Bormann et al., 2007). Proverbs help combat stress by defining one's experience in terms of the guiding phrase rather than by giving power to the stressor and the possible negative reactions it could impose (Ashley-Farrand, 1999).

In summary, the NFRMPC shows family resilience to be greater than the sum of its parts. Resilience is achieved and maintained via a continuously interactive process of the family's: history, context, individuals, relationship dynamics, and engagement with community. Resilience to pediatric cancer stress is a fluid, dynamic, and living process. It is a process with much more vitality than can be accurately represented in an algebraic formula like those found in the ABCX or Double ABCX models (Hill, 1949; McCubbin & Patterson, 1983). The process of resilience is ordinary and natural to families. The NFRMPC provides an ordinary, recognizable framework to describe an ordinary, recognizable phenomenon. As Masten (2001, pg. 235) says, "Resilience does not come from rare and special qualities, but from the everyday magic of ordinary, normative human resources in the minds, brains, bodies of children, in their families and relationships, and in their communities."

Implications for Clinical Practice of Couple and Family Therapy

The two studies, understood as one body of research, have important implications for clinical practice of couple and family therapy for families experiencing pediatric cancer. First, a greater emphasis should be put on the creation and testing of evidenced-based assessments capable of early identification of the families who may be in need of support (Kazak et al., 2010). Assessment can identify problems and symptoms to appropriately diagnose and clarify the level of family and patient need. It can also identify individual, family, and community strengths and resources (Kazak et al., 2010). By incorporating improved, evidenced-based, routine psychosocial assessment by nurses, physicians, or social workers can proactively identify the families in need and can better direct families to available resources, depending on the level of their need.

Second, there is a need to focus on long-term psychosocial care. With improved, ongoing, proactive assessment, the family's needs will be better recognized throughout the entirety of their cancer experience. Support and resources often decline throughout the lengthy cancer experience. Thus having ongoing assessment and clinical resources available, healthcare professionals will be better able to provide long-term support to families. Potential ways hospitals and community healthcare professionals can improve the longevity and quality of social support families receive are numerous. Some suggestions include hospitals creating a "long term family care team" that prioritizes its engagement with families six months after the initial diagnosis and beyond. This type of care team can pick up services after the initial hospital care team of social workers and child life specialists subsides. This team can seek to coordinate care for families by engaging their social support networks and by organizing when meals are made, lawn and house care gets done, and families are visited or called. This team can also help collaborate with local mental health workers to provide parents with referrals to therapists who specialize in the type of care in which they are in need. Regardless of the specific intervention approach created to better support pediatric cancer families, health professional must increase efforts to assist families in accessing psychosocial and informational resources, because they are often under-utilized by cancer patients and their families (Muzzin et al., 1994).

Third, collaborative psychosocial family care should be the standard for pediatric cancer. The current pediatric hospital model is not always conducive to proactive integrated biopsychosocial care (Kazak et al., 2006). Often care becomes collaborative only after a patient becomes complicated and the limited psychosocial resources can be disproportionately distributed to the most difficult patients. The current pediatric hospital model risks missing the psychosocial concerns of other families who may benefit from intervention support (Kazak et al., 2006). Family support needs can best be met through the collaboration of hospital and non-hospital resources (Bender et al., 2012). Collaborative care between hospitals and mental health workers has demonstrated long-term effectiveness for reducing negative affect (e.g. depression symptoms) in cancer patients (Ell et al., 2011). Often, other non-hospital health professionals are better equipped to provide the longer-term support the families in the study described as lacking. Community resources like marriage and family therapists, counselors, and social workers can be available to meet with families on occasion for the months and years after the cancer diagnosis. Therapists and counselors in the community are well positioned to maintain contact with the parents and families for psychosocial intervention care (Rogers, Gomez, Carpenter, Farley, & Holsen, 2011). This maintained contact provides opportunity for healthcare professionals to consistently partner with the families they are supporting to continually engage social supports throughout their child's treatment.

Fourth, psychosocial interventions should be family-based. Most cancer treatment centers provide some psychosocial services to families. However, the nature and extent of interventions offered across centers is unknown, as are data regarding outcomes. Additionally, most interventions are primarily individually oriented approaches (e.g. pain management) and may include family members but without a specific family therapy or intervention framework (Alderfer & Kazak, 2006). Currently, few intervention programs exist that target the whole family (Alderfer & Kazak, 2006). In many intervention programs, significant parts of the family are excluded from treatment. Developing interventions targeting family processes (e.g. communication) and involve multiple members of the family may be particularly effective in fostering family level and individual adjustment (Alderfer & Kazak, 2006).

Fifth, there is also need to extend interventions to target the community. Community-based interventions can improve the engagement of support networks in the community to change behaviors and improve psychosocial outcomes. Two common goals of community-based interventions are: strengthening the health of communities and building community capacity to address health-related issues (Norton, McLeroy, Burdine, Felix, & Dorsey, 2002), both of which reflect the possible result of intervening in a community to improve the social support care provided to families experiencing pediatric cancer. Viewing the community as a resource for change focuses health professionals on the potential for utilizing existing internal resources of a community to promote wellness (McLeroy, Norton, Kegler, Burdine, & Sumaya, 2003). The best resources for families needing support are the friends, family, and community members already in their lives. Targets these resources can make the most immediate positive difference in the coping and adjustment of families coping with cancer in their child.

Future Considerations

While the two studies presented in this dissertation advance the knowledge base of the psychosocial experience of pediatric cancer, important directions for research should be considered in the future. Primarily, there is a need to include greater racial and ethnic diversity in the study of family resilience. Family strengths are culturally bound and may vary widely between cultures. Family strengths research is often critiqued for it probably reflecting the value system of White, American families (Ponzetti & Long, 1989). The sample in the two studies presented here is primarily White (only one non-White family participated), thus the experiences shared by parents may reflect a homogenous cultural understanding and may not reflect the views of a more ethnically and racially diverse sample.

Not all families cope with cancer the same way. The culture of the patient and their family has been identified as one of the most significant factors in determining how families adapt to the pediatric cancer (Banerjee et al, 2011). Some cultural beliefs lead to variability in how families cope and adjust to cancer (Banerjee et al., 2011). A family's beliefs about health, about communication, and family structure are common influences on how families approach cancer (Thibodeaux & Deatrick, 2007). Language barriers and acculturation stressors also increase risk for higher levels of distress in cultural minorities experiencing pediatric cancer (Johns et al., 2009). Lastly, the meaning of pain and suffering, meaning of death and dying, and the location of end of life care are other primary cultural issues impacting how families respond to cancer (Wiener, Mcconnell, Latella, & Ludi, 2012).

Culture also impacts how families view their interactions with the medical system. Some minority families have greater distrust for physicians or will prefer religious healing over traditional medicine (Banerjee et al., 2011). In some cultures, it may be more appropriate to only include the parents in discussions about the child's health rather than including the child too. For example, in a study on the difference between pediatric oncologists in the United States and pediatric oncologists in Japan, the United States 65% of physicians reported always telling the child about their cancer, while in Japan only 9.5% of physicians reported always telling the child about their cancer (Parsons et al., 2007). Research should be conducted with the purpose of better understanding these cultural differences. If this is successfully accomplished, there will be important implications for improving culturally sensitive patient and family centered care. (Parsons et al., 2007).

It is necessary not only for researchers to consider cultural implications in their work, but also necessary for healthcare professionals as well. A family's values, beliefs, customs, language, and social class must be considered in order to fully understand the depths of a family's response to cancer (Marshall et al., 2011). It is also essential for health professionals working with families in this population to know that culture is more than ethnicity and race. Not only do families bring their unique cultural values and beliefs to the hospital, but the hospital itself, and the various professions involved in pediatric cancer care (e.g. physicians, social workers, chaplains, and nurses), also have unique cultures. In order to provide culturally sensitive care, health professionals must understand the context-related factors impacting how the medical culture interacts with the family's culture in order to improve the support provided to families experiencing a pediatric cancer diagnosis (Sobo, 2004).

Another important future consideration is the connection between family resilience and child survivorship. Answering questions regarding the extent of the family's impact on lifelong child patient adaptation and what factors and processes contribute to improving survivorship outcomes is an important extension of the research presented in this dissertation study. Many current studies on child cancer survivorship are individual focused (Cox et al., 2012). Yet family influence on adjustment and adaptation is well established. Elucidating the connection between processes of family resilience and survivorship through qualitative and quantitative study is an important future research endeavor.

Lastly, an important direction for future research is the testing and development of both the core components of family resilience interventions and the order of component delivery (Gearing et al., 2011). The NFRMPC provides suggested target components to begin exploration and clinical testing (e.g. pre-cancer factors, parent factors, family relational dynamics, and extra-familial support). However, there may be important components not mentioned in the model that could still be instrumental to family resilience. For example, the importance of parental self-care is a component mentioned by a few families in the study but was not a strong enough overall theme to be included. Yet other research points to the benefits of self-care for caregivers and cancer patients (Dodd & Miaskowski, 2000; Klassen et al., 2007). Lastly, regarding the order of delivery for intervention components, the tree framework suggests a chronology to family resilience. All trees begin their growth in the soil, developing roots, and then growing its trunk, branches, and leaves up from the ground. Just as there is natural order to tree growth, so too is there for family resilience. The NFRMPC suggests that successful intervention delivery must start with family perceptions of their stress narrative, focusing primarily on the parents. Then targeting internal parent factors (i.e. perceptions and proverbs), followed by family relational dynamics, and then by targeting the family's interaction with extra-familial supports. Future clinical research needs to clarify the fit of the components suggested in the NFRMPC, and their order, with the effective augmentation of family resilience.

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