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**Exploring Components for a Family-Focused Intervention for Families with a
Child Diagnosed with Cancer and Other Chronic Illnesses**

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DISSERTATION

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**Exploring Components for a Family-Focused Intervention for Families with a
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Abstract

Chronic illnesses are often life-long and affect academic performance, social development, psychological well-being, and family functioning. The broad effects of childhood chronic illnesses are often assessed using measures of child health-related quality of life (HRQL). Parent factors (parental distress, perceptions of child vulnerability, overprotection) and family factors (maintaining rituals, open communication, positive coping) have been associated with changes in child HRQL. This study sought to discover how parent and family factors were associated with child HRQL, and how such factors were perceived by families for inclusion in future interventions. Results demonstrated that parental perceptions of child vulnerability were associated with both family factors and child HRQL. Open communication and parental positive coping were also significant predictors of child HRQL. Open ended questions were consistent with quantitative results. Taken together, this specific targets for an intervention should include parental perceptions of child vulnerability, positive coping, and open family communication.

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Chapter 1

Introduction

Chronic illnesses have been given many definitions by different authors; however, they are generally those that disrupt school attendance and schoolwork; disrupt participation in normal childhood activities; and require either frequent medical attention, regular visits to a hospital, or consistent medication use (Compas et al., 2012). Not to mention, chronic illnesses generally have long durations, they do not spontaneously resolve, and they are never completely cured (Compas et al., 2012). Given advances in medical care, diagnoses that previously were classified as acute are now considered chronic. For example, the increase in survival rates among childhood cancer patients has shifted the focus of research to long-term outcomes for childhood cancer survivors. This has led to a reclassification of pediatric cancer as a childhood chronic illness.

Chronic illnesses among children pose a large public health and financial burden to both the health care system in general, and to families of children with a chronic illness. Likewise, many children with a chronic illness may have a hard time adjusting to their illness and chronic illness may disrupt a child's ability to adjust to life stressors (Wallander & Varni, 1998). This has placed an increased research emphasis on overall quality of life for children with chronic illness. Current understanding of child adjustment and wellbeing focus on morbidity, emotional dysfunction, and behavioral problems faced by long-term survivors and children with chronic illnesses (Harding, 2001; Spieth and Harris, 1996). Collectively, these domains are considered child health-related quality of life (HRQL), recognized by the World Health Organization as the multidimensional way to describe child adjustment and wellbeing related to social, physical, cognitive, and psychological functioning.

Study Aims

The goal of the proposed study is to analyze potential factors that can be targeted for a primary prevention intervention focused on improving the functioning of the family as a whole in order to improve the health-related quality of life (HRQL) for the child diagnosed with cancer specifically and chronic illnesses more generally. Much of the literature regarding child HRQL has been looked at in a variety of chronic illness diagnoses. Although this study seeks to discover factors that would improve the functioning of the family as a whole for children with cancer, those same factors are likely similar across illness groups. Thus, a broad sample of children with multiple chronic illnesses was collected. Individual components of family functioning, such as family cohesion (Santos et al., 2015), family coping (Kupst et al., 1995), family communication (Varni et al., 1996), maintaining family rituals and activities (Markson & Fiese, 2000), and maintaining a supportive family environment (Corey et al., 2008) have been shown to influence a child's health-related quality of life. Thus, it can be concluded that improving multiple facets of family functioning, rather than just a component or just parental distress, would also improve a child's HRQL. To this end, HRQL will be briefly examined in the context of pediatric chronic illness, parental factors that may negatively impact child HRQL will be discussed in detail, potential family factors that may positively impact child HRQL will be discussed, and then previous interventions will be evaluated from the lens of a family systems approach. Because children are embedded within their family context, it is important to look at multiple aspects of family functioning when discussing prevention techniques. Since parents (or primary caregivers) generally maintain the family dynamic (i.e., the way families interact with one another), particularly when children are very young, many of the proposed factors will target parental functioning (i.e., helping parents improve their conversation style with

their children). It is important to note that standards for psychosocial care for pediatric cancer patients and their families were developed by a special committee in 2015 (Wiener et al., 2015); however, the standards developed by this committee (i.e., child access to interventions, parental access to interventions, sibling access to interventions) take an individualistic focus and do not account for the importance of the family dynamic. Since pediatric cancer patients, and all children with chronic illnesses, are dependent on their families for care and support, improving the health of the family system will likely improve the health of the individual constituents. This does not deny the importance of the standards of care outlined by the committee; however, the current study differs from the proposed standards of care in that its focus is primary prevention, and its method of action is aimed at the family system as a whole.

Family-Based Interventions

Family systems theory posits that the relationships between members, maintained by patterns of behavior and communication, create a whole unit that cannot be reduced further (Bavelas & Segal, 1982). Another component of family systems theory suggests that the behavior of one member of a family impacts the other members of the family (Newton-John, 2022). Thus, attempting to focus on a specific attitude, behavior, or skill of an individual member of a family unit for an outcome would, by definition, not qualify as a family intervention according to the family system's theory. It is important to note the definition of a family system prior to proposing a family-based intervention because the literature currently fails to adequately define the family system when self-designating an intervention "family-based."

When considering family functioning within a family systems framework, family functioning includes the patterns of relationships between members of the family, rather than key factors of an individual member (Patterson & Garwick, 1994). Within this definition, family functioning includes several components that define how members of the family relate to one another: communication styles, expression of affection, flexibility, problem-solving style, and behavioral control (Patterson & Garwick, 1994). Therefore, an intervention would be considered family-based if it accounted for patterns of communication, expression of affection, flexibility, problem-solving, and/or behavioral control between members of the family. A family-based intervention would also consider which factors shift the overall patterns within the family unit in positive or negative directions. Unfortunately, much of the literature on family-based interventions focuses on specific parental outcomes, such as parental distress, rather than family outcomes. Although a focus on parental distress itself does not necessarily disqualify a study as family-based, since it has the potential to shift the patterns of relationships within the family, parental distress as an outcome would indicate an individual focus rather than a family systems focus. Thus, the current “family-based” intervention literature will be further explored within this study, with an aim at critically examining the measured outcomes from a family systems lens.

Health-Related Quality of Life

The World Health Organization takes a multidimensional approach to health-related quality of life, including domains of disease state and physical symptoms, functional status, psychological functioning, and social functioning (Harding, 2001; Spieth and Harris, 1996). Thus, discussing the impact of childhood chronic illness on HRQL requires an integration of

research looking at the impact on physical health, functional status, psychological health, and social functioning.

Overall, it appears that the experience of childhood chronic illness can have broad impacts across many domains of HRQL. Pain, fatigue, and physical changes due to treatment have been shown to impact the physical domain of health-related quality of life (Hedström et al., 2003; Whitsett et al., 2008). In addition, children currently undergoing treatment for chronic illnesses experience high levels of fear, distress, and anxiety related to medical procedures and uncertainty about their future (Hedström et al., 2003; Nunes et al., 2017; Robiero et al., 2009; Wright et al., 2009). After treatment has ended, childhood cancer survivors, and children with other chronic illnesses, often face increased levels of depression, anxiety, and PTSD symptoms (Pless & Stein, 1996; Rourke et al., 2015). Part of the psychological distress faced by children being treated for cancer and childhood cancer survivors is directly related to the physical effects and impairments from cancer treatments (Rourke et al., 2015). Children with other chronic illnesses have also reported reductions psychological health related to physical effects related to their diagnosis (Sawyer et al., 2004). Physical changes from cancer treatments also influence social functioning among childhood cancer patients, as well as children with diabetes, asthma, and cystic fibrosis (Abrams et al., 2007; Sawyer et al., 2004). Further social problems in children with chronic illnesses are due to increases in sensitivity, social isolation, decreases in self-confidence, and prolonged isolation from their peers (Nunes et al., 2017; Pan et al., 2017). Finally, a combination of functional impairments in cognitive abilities and problems with social functioning often influence a child's ability to reintegrate into school (Abrams et al., 2007; Nunes et al., 2017; Pan et al., 2017; Sawyer et al., 2004; Vannatta et al., 2009). Thus, there is

evidence to suggest that the domains of health-related quality of life are often interrelated in children with chronic illnesses.

Children's Psychological Functioning

Of particular interest to psychological-based work is that although many children adjust well after the initial distress of a chronic illness diagnosis, there is considerable evidence to suggest that pediatric patients have an increased risk of psychological distress both during and after treatment. This contrasts with early speculation, which suggested that children were resilient and would habituate to the stressors of treatment. However, it is now known that not all children are able to become accustomed to the stressors of hospitalization and medical procedures (Patenaude & Kupst, 2005). Children also do not spontaneously learn to cope with treatment (Patenaude & Kupst, 2005). In addition, the age of the child at diagnosis often influences the level of distress the child experiences. For example, during treatment, young children (0-3 years of age) often feel distress and boredom at being expected to remain confined to a hospital bed or a room for the duration of the treatment (Hedström et al., 2003).

During treatment, pediatric patients may have elevated levels of worry regarding medical procedures (Nunes et al., 2017). For example, researchers found that children who had received a Port-a-Cath experienced intense worry and fear of pain before the procedure (Robiero et al., 2009). Many of the children in the study described being worried and afraid of the unknown when they received new treatments or diagnostic procedures (Robiero et al., 2009). Particularly in young children, behavioral signs of distress are often exhibited during medical procedures (Dahlquist et al., 1994). These children also show significant anxiety

when anticipating another procedure (Dahlquist et al., 1994). This indicates that even very young children experience intense worry and fear of medical procedures.

Other stressors for children during chronic illness treatment include uncertainty and worry about death (Hildenbrand et al., 2011; Nunes et al., 2017; Wright et al., 2009). In fact, one study found that for children between 8 and 12 years, fear of death may be the most emotionally distressing part of the cancer experience (Hedström et al., 2003). Among other chronic illness populations, fear of pain, fear of missing out on important life events, and fear about long-term physical consequences, were also reported to be highly distressing (Wright et al., 2009). Other children experience worry and distress over their appearance during medical treatment. Fear of hair falling out, scars, fluctuations in weight, or other physical changes due to medications or surgeries were reported by many adolescents (Hildenbrand et al., 2011; Nunes et al., 2017; Wright et al., 2009). In fact, changes in their physical appearance were particularly distressing for adolescent cancer patients (Hedström et al., 2003; Nunes et al., 2017). These physical changes are associated with decreases in self-esteem and self-confidence (Nunes et al., 2017). Among adolescents, self-esteem is more intimately tied with physical sense of self than at any prior point in development (Abrams et al., 2007). Adolescents, therefore, are uniquely positioned to be distressed by the physical changes that occur during medical treatments. Other studies of adolescents have reported that the reaction of other to an adolescent's appearance (i.e., staring) may further negatively impact an adolescent's self-perception (Abrams et al., 2007).

Among pediatric cancer survivors, there is mixed evidence about the psychological long-term effects of the cancer experience. One study that compared pediatric cancer survivors to sibling controls found that pediatric cancer survivors had an increased risk of

developing depressive symptoms (Zebrack et al., 2002). In fact, pediatric cancer survivors were 1.6 to 1.7 times more likely to experience levels of depressive symptoms high enough to be clinically diagnosed (Zebrack et al., 2002). A similar study found that adolescent pediatric cancer survivors had slight increases in depressive and anxiety symptoms compared to matched sibling controls (Schultz et al., 2007). So, although most childhood cancer survivors have mental health rates comparable to healthy controls, a subset of children continue to experience psychological distress (Rourke et al., 2015). For example, pediatric cancer survivors were twice as likely as their siblings to report clinical levels of emotional distress (Zeltzer et al., 2009). In addition, roughly 25% of adolescents and young adults who are in the survivorship period of pediatric cancer report higher levels of global psychological distress than the average adolescent or young adult (Rourke et al., 2015). A study of Swedish children both on and off treatment found that psychological risk was higher for children during the post-treatment period (Von Essen et al., 2000). Post-treatment Swedish pediatric cancer survivors had higher rates of depression and anxiety and lower levels of psychological well-being and self-esteem than their healthy peers (Von Essen et al., 2000).

In addition, most adolescent survivors of pediatric cancer have rates of Post-Traumatic Stress Disorder (PTSD) comparable with non-ill adolescents (Rourke et al., 2015). However, a large proportion of adolescent survivors of pediatric cancer report some symptoms of PTSD but not enough to meet the full diagnostic criteria (Rourke et al., 2015). In fact, between 10% and 20% of adolescent survivors of pediatric cancer meet at least 75% of the needed diagnostic criteria (Brown et al., 2003; Erickson & Steiner, 2001; Kazak et al., 2010). Another study found that half of all study participants had reexperiencing symptoms of PTSD after being reminded of their cancer treatment (Kazak et al., 2001). A pilot study of

children who had received a bone marrow transplant found that a subset of children experienced PTSD symptoms similar to children who had experienced a violent and life-threatening experience (Stuber et al., 1991). These symptoms were found to persist even a year after the transplant procedure (Stuber et al., 1991). Although most adolescents and young adult survivors of pediatric cancer have only subclinical levels of PTSD symptoms, these may still significantly impact the individual's ability to manage the long-term diagnostic procedures that are involved in cancer survivorship (Rourke et al., 2015).

Other studies have found that pediatric cancer survivors may have increased externalizing behaviors (Allen et. al., 2004; Holmbeck et. al., 2002). Evidence from research on other pediatric chronic illnesses have also suggested increases in behavioral problems compared to healthy controls (Colleti et. al., 2008; Mullins et. al., 2007). However, other studies have indicated that pediatric cancer survivors may have lower levels of behavioral problems compared to other children with chronic illnesses (Patenaude & Kupst, 2005).

Research suggests that these deficits in psychological functioning are not exclusive to pediatric cancer patients. In general, children with chronic illnesses are more likely than their healthy peers to have difficulties with psychological adjustment (Swanston et al., 2000). Similar to the above discussion of children with pediatric cancer, children with a chronic illness diagnosis are at higher risk for developing emotional problems (Pless & Stein, 1996) and are twice as likely to be diagnosed with a psychiatric disorder (Cadman et al., 1987). Thus, it can be concluded that psychological functioning is impacted by chronic illness diagnoses generally and pediatric cancer diagnoses more specifically.

Parental Factors that May Negatively Impact HRQL

The parent-child relationship is an important source of comfort and support for a child undergoing a stressful experience (Mullins et al., 2004). During painful and invasive cancer-related procedures, parents who are able to remain calm can help children remain calm as well (Blount et al., 1991). In fact, research suggests that children, regardless of health status or diagnosis, prefer to have their parents present during all painful medical procedures (Young, 2005). However, parents who are unable to regulate their own emotions or react to their distress may reduce the health-related quality of life for children with chronic illnesses. This indicates that although some of the reductions in health-related quality of life may result directly from the experience of pediatric chronic illness and its treatments, these reductions may also be related to or mediated by parental behaviors. In the literature, three parental behaviors have been named as likely influencers of pediatric health-related quality of life: parental distress, parental perceptions of vulnerability, and parental overprotection. Each of these variables has been found to impact both the parent-child relationship and child adjustment.

Parental Distress

Children who are securely attached to their parents will reference their parents during stressful circumstances to ensure that they are behaving appropriately. Thus, it is not surprising that there is an association between parental distress and child distress at a child's illness (Robinson et al., 2006). In fact, although children generally prefer to have their parents present during procedures, parental anxiety over a medical procedure has been shown to increase a child's distress during the procedure (Jay et al., 1983). Parental distress when faced with an ill child may be a universal principle. Studies suggest that high levels of parental distress are common in families caring for a chronically ill child (Peirce et al., 2016

Pai et. al, 2007; Roddenberry & Renk, 2008; Tsai et. al., 2013), suggesting that parental distress is an important factor across different chronic illness diagnoses. A study of pediatric cancer patients and their families found that mothers of children with cancer had high levels of distress (Pai et. al., 2007). Levels of maternal distress may remain high throughout the child's treatment. Overall, meta-analytic data show that high levels of distress in parents of children diagnosed with chronic illnesses may vary by type and time since diagnosis (Roddenberry & Renk, 2008). Thus, parents often respond with high levels of distress to child chronic illness, but the level of distress varies.

Although most parents experience distress at their child's chronic illness diagnosis, parental coping strategies and ability to remain a secure base for their child vary. Parents who are able to remain calm and help distract and comfort their children are able to help their children cope with the stressors inherent with illness treatment and hospitalization (Jay et al., 1983). Consequently, responsive parenting during medical procedures has been shown to be important (Jacobsen et al., 1990). Parents who accurately interpret indicators of child distress and gave appropriate explanations or distractions had children who were less distressed during needle insertions (Jacobsen et al., 1990). However, parents who were unable to cope with their own levels of distress generally have children who cope poorly and are unable to adjust to the stressors of the cancer experience (Jay et al., 1983). Similarly, longitudinal studies have suggested that families who cope poorly at the time of a leukemia diagnosis generally continue to cope poorly at 10-year follow-up (Kupst et al., 1995). Another study of children with children with sickle cell disease found that higher parental distress at baseline was associated with increased number of hospital visits and poorer disease management at one year follow-up (Barakat et al., 2007). This indicates that parental distress not only

influences child quality of life during chronic illness treatment, but that parental distress and coping may continue to influence child quality of life into the survivorship/ long-term management period.

Parental distress is also associated with overall decrease in family functioning, which is an important variable in the health-related quality of life and overall adjustment for chronically ill children and their siblings (Streisand et al., 2003). Overall family functioning has been found to be a buffer against paternal distress for young boys with cancer (Robinson et al., 2006). It is speculated that if one parent is distressed, other family members are able to display positive coping mechanisms and remain a secure base for the child if the overall family system is positive. However, poor family functioning and poor family coping during the cancer experience is associated with reductions in health-related quality of life in pediatric cancer patients (Robinson et al., 2006). Finally, parental distress is associated with decreased physical health per child self-report among pediatric cancer patients (Pierce et al., 2016), reduced lung function in children with cystic fibrosis (Patterson et al., 1993), and more asthma attacks and hospitalizations among children with asthma (Weinstein et al., 1992). Other studies have suggested that parents who are able to overcome distress and maintain a supportive parenting style have children who are more adherent to cancer treatment regimens (Manne et al., 1993). Parents with a more supportive parenting style are more responsive to child distress and had better family functioning (Manne et al., 1993).

Considering socio-ecological principles and attachment theories, a child's level of adjustment is dependent on their family system (Broffebrenner, 1979; Bowlby, 1958). Understanding the importance of the family system makes the relationship between parental distress and child adjustment clearer. Beyond evidence from families coping with child

chronic illness, children of mothers who struggle with depression display increased levels of internalizing and externalizing behaviors (Robinson et al., 2006). Additionally, several studies have indicated that parental distress is associated with increased behavioral problems in children with chronic illnesses (Colleti et. al., 2008; Mullins et. al., 2007). One study found that pediatric cancer patients displayed increased acting out behaviors and lower positive social behaviors when their parents had higher levels of parental distress (Colleti et al., 2008). A longitudinal study found that the association between parental distress and child externalizing symptoms was still operative during the one-year follow-up (Fedele et al., 2011). Children of mothers who experience anxiety are also more likely to display anxiety symptoms (Robinson et al., 2006). And parental distress has been linked to increases in child illness uncertainty (Mullins et. al., 2007).

Thus, children may be more vulnerable to internalizing symptoms when their parents experience increased levels of internalizing symptoms after a child's chronic illness diagnosis (Robinson et al., 2006; Szulczewski et al., 2017). In fact, a study of adolescents with cancer indicated that parenting distress was associated with increased child distress and poor child adjustment (Trask et. al., 2003). Evidence suggests that parents of children with cancer who display higher levels of distress have children who display lower levels of emotional, behavioral, and social adjustment (Colleti et al., 2008). Other studies also suggest a direct link between parental distress and child distress (Robinson et al., 2006). The link between maternal distress and child distress has been well researched and has been shown to be robust. In fact, one study sought to find any mediational or moderation variables that may influence the association between maternal distress and child distress during cancer treatment (Robinson et al., 2006). However, they found that the main effect of maternal

distress on child distress was pervasive and was not influenced by any of the factors examined in the study (Robinson et al., 2006). The same study also looked at the effect of father distress on child distress during cancer treatment. They found that younger children and male children were more influenced by paternal distress (Robinson et al., 2006).

It is clear that parental distress is related to child adjustment and wellbeing. This may be due to changes in behavior due to parental distress. This is exemplified by the research suggesting that parental distress decreases child treatment compliance and medication adherence (Spinetta et al., 2002). In turn, decreased adherence is associated with increased physical discomfort among pediatric oncology patients (Spinetta et al., 2002). It may also be due to the child's own perceptions being influenced by his parent's distress. Parental distress and perceived child vulnerability have been found to be associated with poor emotional functioning among chronically ill children (Colleti et. al., 2008). However, relations between parental distress and child emotional functioning have been found to be mediated by parental perceptions of child vulnerability in children with diabetes, asthma, and cystic fibrosis (Carpentier et al., 2008; Mullins et. al., 2004). Other studies have shown significant associations between parental distress and parental perceptions of child vulnerability in parents of preterm infants (De Ocampo et al., 2003). Thus, increased levels of parental distress in the face of a child's chronic illness may influence the development of parental perceptions of child vulnerability.

Parental Perceptions of Vulnerability

One important part of the parent-child bond is the parent's perception of the child. Parental perception of child vulnerability is the perception from one or more parent that their child is particularly vulnerable and sensitive (Thomasgard and Metz, 1996). This generally

involves parental attitudes and beliefs, which may influence parent-child interactions (Mullins et. al., 2004; Carpentier et al., 2008). Having a child with a chronic illness increases the likelihood that a parent will perceive their child as vulnerable (Thomasgard, 1998). This perception of child vulnerability may increase the likelihood that the parent-child bond will be strained or disrupted (Allen et. al., 2004). Research indicates that parental perceptions of vulnerability have profound effects on all domains of child HRQL in a variety of chronic illness diagnoses (Allen et. al., 2004; Carpentier et al., 2008; Colleti et. al., 2008; Hullmann, et al., 2010; Mullins et. al., 2004; Mullins et. al., 2007).

First, parental perceptions of child vulnerability influence a child's perception of their own physical health. For example, research has shown that when parents perceive their child as more vulnerable, their child is more likely to act sick (Walker and Zeman, 1992). This can form a cycle where the parent views their increasingly "sick" child as becoming worse and thus seeks more care for their child. This is seen in research when parental perceptions of child vulnerability increase the likelihood that mothers will seek increased pain management options for their child (Vrijmoet-Wiersma et. al., 2010). Moreover, parental perceptions of child vulnerability increase the likelihood that parents will complain about the care offered to their child by medical personnel (Connelly et al., 2012). Increased medical procedures and emergency room visits have been shown to reduce child perceptions of health-related quality of life (Barbarin, 1990). Additionally, statistical models have indicated that the relationship between parental distress and health care utilization is mediated through parental perceptions of vulnerability (Connelly et al., 2012). Thus, parents who view their child as more vulnerable have children who behave as if they are more vulnerable, which in turn further influences the parent to behave as if their child is vulnerable.

This ties into research that has indicated that parental perceptions of child vulnerability increase child illness uncertainty, especially among adolescents (Mullins et. al., 2007). Illness uncertainty is the perception of some illness related doom constantly hanging over you (Cohen, 1999). Models of illness uncertainty suggest that it is comprised of the following four components: “perceived ambiguity concerning the state of the illness, complexity regarding treatment, lack of information regarding the seriousness of the illness and prognosis, and perceived unpredictability of the illness course” (Mishel, 1984). Children may feel that they are not in control of their illness and that it may swoop down and harm them at any minute. It is speculated that when parents hold fearful and uncertain beliefs about their child’s illness, children may internalize these beliefs and become fearful and uncertain about their own illness (Mullins et. al., 2007). Thus, parental perceptions that the child is vulnerable are communicated to the child through parental fear and uncertainty and the child comes to believe that he or she is vulnerable, which increases illness uncertainty (Steele et al., 1997). Finally, illness uncertainty has been linked to several negative outcomes and poor health related quality of life. Research suggests that child illness uncertainty increases psychological distress in children with chronic illnesses (Mullins et al., 1997). Evidence also shows that child illness uncertainty increases depressive symptoms (Hoff et al., 2002; White et al., 2005) and child anxiety symptoms (Hommel et. al., 2003). Given that psychological functioning is part of HRQL, illness uncertainty would decrease child HRQL.

Parental perceptions of child vulnerability have also been associated with increased child emotional dysregulation, anxiety symptoms, depressive symptoms, and poor adjustment to chronic illness (Carpentier et al., 2008; Colleti et. al., 2008; Mullins et. al., 2004; Mullins et. al., 2007). A study of pediatric cancer patients found that children had poorer emotional

adjustment when their parents reported higher levels of perceptions of vulnerability (Colletti et al., 2008). This implies that when parents communicate, either directly or implicitly, that the child is more vulnerable, the child is more prone to experience anxiety and depression symptoms (Colletti et al., 2008). Another study found that perceptions that a child is vulnerable may mediate the association between parental distress and anxiety among chronically ill children (Lopez et al., 2008). This suggests that distressed parents may communicate their fears over child vulnerability, such as described by Colletti and colleagues (2008), or it may change parental behaviors which indirectly communicate to children that they are vulnerable (Lopez et al., 2008). A longitudinal study sought to look at long-term outcomes for children with cancer and parental perceptions of vulnerability. The researchers found that parental perceptions of vulnerability at time 1 were associated with child internalizing symptoms at follow-up (follow-up ranged from 12-29 months) (Fedele et al., 2011). Of particular interest in this study was that parental perceptions of vulnerability declined in most parents between time 1 and follow-up; however, the presence of parental perceptions of vulnerability at time 1 were strong enough to influence child emotional adjustment over a year later (Fedele et al., 2011). This suggests that parental initial reaction may have more influence over their children than later parental actions.

Although not all studies of parental perceptions of vulnerability are in children with cancer, since cancer is considered a pediatric chronic illness, it is justifiable that parental perceptions of vulnerability should result in similar outcomes across chronic illnesses. For example, one study showed that children with pulmonary illnesses, whose parents perceived them as more vulnerable, showed higher levels of distress in social situations (Anthony et al., 2003). These children displayed higher levels of distress in general social situations and to

novel social situations (Anthony et al., 2003). An additional study of parental perceptions of vulnerability in parents of children with type 1 diabetes found that increased levels of parental perceptions of vulnerability were associated with increased depressive symptoms in children (Mullins et al., 2004). Another study of parents of children with juvenile arthritis found that parental perceptions of child vulnerability increased child depression and anxiety symptoms (Anthony et al., 2011). This further supports studies that parental perceptions of vulnerability reduce emotional adjustment in children with cancer.

Parental perceptions of child vulnerability also increase behavior problems in chronically ill children (Allen et al., 2004). In fact, parents of preterm infants who perceived their child as vulnerable at the time of discharge from the neonatal intensive care unit were more likely to have a child with externalizing problems two years later (De Ocampo et al., 2003). Another study done in children diagnosed with cancer found that parental perceptions of child vulnerability were associated with increased child behavioral problems over a year later (Fedele et al., 2011).

Parental Overprotective Behaviors

Some authors suggest that parental perceptions of child vulnerability induce a particular parental behavior termed parental overprotective behavior (Levy, 1980; Vrijmoet-Wiersma et al., 2010). However, others have suggested that parental overprotective behaviors may stem from an attempt to exert control in a situation rife with uncertainty (Mullins et al., 2007). Parental overprotective behavior was first defined by Levy (1931) to categorize parental behaviors that included excessive physical or social contact, prolonged infantilization, active discouragement of independent behavior and social maturity, and either a dominating excess or an overindulgent absence of parental control. Parents of children with

a chronic illness have shown increased levels of overprotective behavior in relation to parents of healthy children (Holmbeck et. al., 2002). There is mixed evidence regarding the link between parental overprotective behaviors and child health related quality of life. Some studies have found parental overprotection is linked to poorer child adjustment (Levy, 1980; Vrijmoet-Wiersma et. al., 2010). However, Mullins and colleagues did not find a relationship between parental overprotective behaviors and illness uncertainty in children with type 1 diabetes mellitus (2007).

There has been some speculation that during periods of acute illness, parental overprotective behaviors may be adaptive and helpful because the children are actually more vulnerable and need more care during this time (Colleti et al., 2008). For example, a study of children currently receiving treatment for pediatric cancer found no association between parental overprotective behaviors and child emotional, social, or behavioral adjustment (Colleti et al., 2008). However, when that same sample was tracked overtime, parental overprotective behaviors at time 1 were associated with increased internalizing symptoms and behavioral problems at follow-up over a year later (Fedele et al., 2011). This suggests that although these parental behaviors were not harmful during treatment, they have long-term consequences for child behavior and emotional adjustment (Fedele et al., 2011).

Other studies done in children with chronic illnesses have also found that parental overprotective behaviors influence child emotional adjustment. A study of children with spina bifida found an association between parental overprotective behaviors and child internalizing symptoms (Holmbeck et al., 2002). Another study done in children with cystic fibrosis found that parental overprotective behaviors were associated with reduced psychosocial functioning (Cappelli et al., 1989). A study done on children undergoing cancer

treatment found that parental overprotective behaviors were associated with an increase in child emotional problems (Williams et al., 2014).

Further studies found that parental overprotective behaviors influence child behavioral responses. For example, Holmbeck and colleagues found that children with spina bifida whose parents displayed higher levels of overprotective behaviors displayed higher levels of externalizing behaviors, particularly defiant and non-compliant behaviors (2002). In fact, parental overprotective behaviors were associated with reduced child behavioral autonomy and decision-making skills in chronically ill children (Holmbeck et al., 2002). A study of pediatric cancer patients looked at the overindulgent type of parental overprotective behaviors. The study cited that parents who did set limits on child behavior often did not want to punish their ill child, particularly if the child was upset. They found that lax parenting, an inability to set rules and consequences, and overprotection was associated with child behavioral difficulties (Williams et al., 2014).

Conclusion and Integration

Evidence suggests that although children prefer to have their parents present during stressful events, such as chronic illness diagnosis and treatment, this is sometimes beneficial and sometimes leads to poor outcomes. Parents who are able to be supportive and responsive have children who are more resilient and who cope better in response to stressors. In contrast, parents who are unable to cope effectively or provide responsive care have children who experience greater adjustment problems. First, a wealth of evidence indicates that increasing levels of parental distress in the face of a child's chronic illness may influence the development of parental perceptions of child vulnerability. Research suggests that parental perceptions of child vulnerability are associated with child health related quality of life. It is

speculated that parental perceptions of vulnerability influence both child perceptions and parent behaviors. The first pathway was confirmed with an abundance of evidence that parental perceptions influence child perceptions, such as increasing child illness uncertainty. Social referencing, which occurs in the context of the parent-child attachment relationship, may explain how children internalize parental perceptions. These child perceptions then influence child behaviors and child health related quality of life. Other research suggests that parental perceptions of child vulnerability increase parental overprotective behaviors. Thus, the emotional, behavioral, and social adjustment of children are influenced by a complex network of parental emotions, attitudes, and behaviors.

In addition, there are several demographic variables that influence a parent's ability to cope with the distress that is inherent in learning of and managing a child's chronic or life-threatening illness. First, evidence suggests that parental education influences the ability of a child to respond to their chronic illness in a way that promotes child well-being and adjustment. One study even found that parental education significantly predicted parental overprotective behaviors (Thomasgard & Metz, 1997). The same study also found that parental education and family socio-economic status significantly predicted parental perceptions of vulnerability (Thomasgard & Metz, 1997). There are also differences in child responses to parental distress. Children who are younger and who identify as male are more influenced by paternal distress than female and older children (Robinson et al., 2006). Additionally, maternal distress influenced all children regardless of demographic variables (Robinson et al., 2006).

Family Factors that May Positively Impact HRQL

Evidence suggests that parental distress, attitudes, and parental behaviors can reduce the ability of children with chronic illnesses to adjust and thrive during and after diagnosis. However, evidence also suggests that family and parental factors may also promote resilience and adjustment among children with chronic illnesses. Improving the following family factors during treatment may help prevent negative child outcomes.

Family Structure and Characteristics

Family Rituals. Family routines and rituals are generally an important part of daily life for children. Family rituals can include religious events, such as attending church services and related events, or they can be dinnertime routines (Markson & Fiese, 2000). Understanding the influence of family rituals requires two considerations: the way in which these rituals are an important part of family routine and the way in which these rituals have meaning for the family (Markson & Fiese, 2000). The routine dimension involves how often this ritual is undertaken, who participates and plans the ritual, and who has particular roles in the ritual (Markson & Fiese, 2000). The meaning dimension involves expectations about attendance at the ritual, any forms of expression involved in the ritual, any symbolism the ritual holds, and plans to continue the ritual (Markson & Fiese, 2000). Studies have found that when families maintain family rituals, it may help family members cope with stressors involved in chronic illness (Boyce et al., 1997; Markson & Fiese, 2000; Quittner et al., 1992).

Family rituals are able to help children adjust and cope with chronic illness. A study of children with cystic fibrosis found that the ability of families to maintain family rituals was a better predictor of child adjustment than global family stress (Quittner et al., 1992). Another study of children with asthma found that by building intentional and meaningful family rituals into the family routine, children were able to be more resilient (Markson &

Fiese, 2000). Meaningful family rituals were, in fact, associated with less anxiety in children with asthma (Markson & Fiese, 2000). Not only did family rituals influence children, they also reduced parental distress (Markson & Fiese, 2000). Mothers who found meaning in family rituals and fathers who had family routines endorsed less parental stress when raising a chronically ill child (Markson & Fiese, 2000). Overall, research indicates that chronically ill children whose parents maintain normal family rituals, routines, activities, and traditions have higher ratings of health-related quality of life (Santos et al., 2015).

Family Support. Children who are undergoing medical treatments for chronic illnesses face many stressors. As mentioned above, nausea, fatigue, and pain can be particularly distressing for children undergoing medical treatment (Hedström et al., 2003; Whitsett et al., 2008). However, family support can help to alleviate some of the stress associated with the side-effects of medical treatment for chronic illnesses. One study of adolescents undergoing cancer treatment reported reductions in insomnia during treatment for adolescents who had more family support, but the results only approached statistical significance (Corey et al., 2008). Another study found that parents who had supportive parenting styles that were responsive to child distress had better family functioning during a child's cancer treatment, as well as better child adherence to cancer treatment regimens (Manne et al., 1993). More generally, family support was reported to be essential for children during hospitalizations related to chronic illnesses (Nabor et al., 2019). Research generally indicates that parents who use positive coping mechanisms and distraction strategies with their children during painful procedures can help to reduce child distress (Suzuki & Katz, 2003). In fact, adolescent cancer patients have indicated that even a parental behavior as simple as calmly holding the child's hand during a painful procedure can help ease treatment-

related pain (Weekes et al., 1993). Children hospitalized with other chronic illnesses have also reported that parents and siblings serve as distractions, which improve their ability to cope with the hardships of hospitalization (Nabors et al., 2018).

Family support, one component of positive parenting, is also able to help improve mood among chronically ill children. A study of adolescents found that perceived family support was associated with better mental health among adolescents hospitalized for cancer treatments or other chronic illnesses (Corey et al., 2008; Nabors et al., 2018). More specifically, increases in perceived family support were associated with decreases in adolescent depressed mood during cancer treatment (Corey et al., 2008). Additionally, parental support has been associated with later teacher reports of more socially acceptable behaviors by children who are reintegrated into a classroom after cancer treatment (Noll et al., 1999). Considering the evidence that children are likely to be more sensitive, more bullied, and have fewer social skills after reintegrating into a classroom after cancer treatment, this is a significant finding. Overall, support is associated with better coping among childhood cancer survivors and children living with chronic illnesses (Kupst & Schulman, 1988; Sanger et al., 1991; Swanston et al., 2000).

Family Openness, Positivity, and Communication. Families who are able to speak openly with one another and provide support to each other cope better in the face of stressors. For example, families that “are flexible, cohesive, find new meaning in life, and communicate and problem-solve effectively” often have better adjustment and psychological health (Haase, 2004). Research indicates that better parental coping is associated with better child adjustment (Suzuki & Kato, 2003). A longitudinal study of the families where at least one child has a cancer diagnosis found that families who had better coping styles had

healthier family coping and adjustment up to ten years after the child was diagnosed with cancer (Kupst et al., 1995).

Additional research discovered that open family communication and family decisions to try to live more in the present moment were associated with better family coping at two years post child cancer diagnosis (Kupst et al., 1984). In fact, open family communication was also associated with better family coping six years post-child cancer diagnosis (Kupst & Schulman, 1988). Another study of young adults with type 1 diabetes found that childhood family connection (operationalized by family warmth and open communication) was associated with better outcomes in young adulthood (Whitaker et al., 2020). Openness was also found to be a resilience factor among families who have a child with a developmental disability (Muir & Strnadová, 2014).

Comparatively, an additional study of children with cancer found that an open and expressive family environment was able to help buffer child distress during the cancer experience (Hammen et al., 2004). In like manner, another study found that directly after a child cancer diagnosis, families that are more cohesive and expressive had children who displayed fewer internalizing symptoms (Varni et al., 1996). An aforementioned study found that a more cohesive and positive family environment can buffer the association between paternal distress and child distress during cancer treatment (Robinson et al., 2006). Family cohesion helps to increase hope among pediatric cancer patients (Santos et al., 2015). Increased levels of hope help to increase health related quality of life and is related to decreased depressive and anxiety symptoms (Germann et al., 2015). Family cohesion and adaptability have also been associated with better adjustment in childhood cancer survivors, children with asthma, and children with diabetes (Hamlett et al., 1992; Rait et al., 1992).

An equally important aspect of family communication involves parental communication with the child about their chronic illness experience. Evidence suggests that even young children who are given direct information about their diagnosis have better outcomes and adjustment to the cancer experience (Last & Van Veldhuizen, 1996; Slavin et al., 1982). Other research suggests that parents who are able to responsively adapt to their child's level of distress and provide appropriate explanations of specific medical procedures have children who are less distressed during needle insertion in cancer treatments (Manne et al., 1993). In fact, oncologists and pediatric physicians have recommended honest and open communication with children regarding their cancer diagnosis and treatment options since the 1980s (Katz & Jay, 1984). Research also indicates that parental communication of general information regarding cancer is associated with lower levels of depressive symptoms and improved self-image among pediatric cancer patients (Jamison et al., 1986; Kvist et al., 1991). Similar findings have been found indicating that parental communication of general cancer information lowers child anxiety about diagnostic and treatment-related procedures (Hockenberry-Eaton & Minick, 1994). Overall, families who have better communication about the cancer experience have lower levels of distress and the child with cancer has greater social functioning and better self-confidence (Spinetta & Maloney, 1978; Varni et al., 1996).

Family Roles and Adaptability. A common theme among families who have a child diagnosed with a chronic illness is the need to adapt and reorganize the family structure. Evidence suggests that the ability of a family to adapt has been shown to be associated with better outcomes among childhood cancer survivors (Rait et al., 1992). Additionally, the ability to reorganize roles has been shown to be important in families with a child diagnosed

with type 1 diabetes (Benoliel, 1975). In fact, the ability of parents to assume the responsibility of a child's treatment and medication schedules has been shown to increase treatment compliance and adherence among pediatric cancer patients (Breitmayer et al., 1991; Breitmayer et al., 1992). Parental assumption of responsibility for a child's cancer care also increases child adjustment (Breitmayer et al., 1991; Breitmayer et al., 1992).

Attachment

Attachment, conceptualized by Bowlby (1969, 1973, 1980), includes the bonds between mothers and their children based on the basic needs for security and affection. He proposed that these bonds, or attachments, were the basis for a child's social and emotional development. Bowlby's initial theories were expounded on by a study that suggest there are specific patterns of attachment between mothers and children: secure, avoidant, and anxious-ambivalent (Ainsworth et al., 1978). Assessment of attachment styles are generally assessed through the Strange Situation, which is a structured observation of how a mother and child interact during a series of separations and reunions between the parent, child, and friendly stranger (Ainsworth et al., 1978). A fourth attachment style, disorganized, largely associated with maltreatment, was added later (Belsky, 2002).

Individuals with secure attachments are thought to perceive stressful events as less threatening and cope better with stressors (Belsky, 2002). Securely attached individuals are generally more open and more willing to seek support from others when needed (Belsky, 2002). Individuals with more insecure attachment styles have been found to be more anxious and more likely to ruminate on negative thoughts and emotions (Belsky, 2002; Feeney, 1999).

Considering socio-ecological principles and attachment theories, children's adjustment is largely dependent on their family system (Broffebrenner, 1979; Bowlby, 1958). Understanding the importance of the family system makes the relationship between parental distress and child adjustment clearer. A meta-analytic review has demonstrated that children with chronic medical conditions often display more insecure attachment behaviors than healthy children (van Ijzendoorn et al., 1992). It was speculated that this increase might reflect the higher risk of abuse among children with disabilities (van Ijzendoorn et al., 1992). Another speculated reason was that child differences might induce more disorganized parental responses, leading to a higher rate of disorganized attachments among children with medical conditions (van Ijzendoorn et al., 1992). Children with insecure attachments are also more likely to report more pain and somatic symptoms than their securely attached peers (Feeney, 1999). Children's illness behaviors and anxiety have also been found to be associated with insecure attachment styles (Feeney, 1999).

Waters and colleagues (2001) found that mothers who reported at least one stressful life event were 66% more likely to have a child who switched to a more insecure attachment style. Other research indicated that the association between attachment and child disability may be more related to parental attitudes than the child's disability (Howe, 2006). For example, the quality of parenting has been shown to partially mediate the relationship between a child's medical condition and attachment (Clements & Barnett, 2002).

Secure attachment is particularly important among children with chronic illnesses. Children with chronic illnesses have been shown to be more vulnerable to difficulties with adjustment (Swanston et al., 2000), the development of emotional problems (Pless & Stein, 1996), and to be diagnosed with a psychiatric disorder (Cadman et al., 1987). In addition,

insecure attachment styles are also associated with higher reports of pain, somatic symptoms, anxiety, and maladjustment (Feeney, 1999). However, research suggests that when parents can provide a secure base for their child (developmentally appropriate level of support and perceived safety to experience difficult procedures), children have improved mental health outcomes and better coping during treatment for chronic illnesses (Corey et al., 2008; Kupst & Schulman, 1988; Nabors et al., 2018; Sanger et al., 1991; Swanston et al., 2000). A “secure base” is a term coined by Bowlby (1988) to describe the use of a parent as a touch stone or “secure base” from which a securely attached child could explore the world. Access to a secure base has been shown to allow children to express and process negative emotions more effectively, allowing for better adjustment (Ehrlich et al., 2019). A recent study of children with asthma found that children who perceived their mothers as a secure base had improved asthma-related immune function and increased family asthma management (Ehrlich et al., 2019). This suggests that parents who provide a secure base for their child during the chronic illness journey may improve child HRQL. This is particularly important when considering an intervention that would target improving child HRQL. Parents who can be taught to provide a secure base, would be better able to provide appropriate support for their child during medical procedures related to their chronic illness.

Conclusion

Taken together, this research indicates that although treatment-related procedures can be stressful and increase distress for both parents and children, there are several strategies that parents can use to improve child HRQL and related outcomes. Improving family functioning (e.g., maintaining family routines, providing family support, maintaining positive communication, etc.), improving family open communication, and coaching parents to use

developmentally appropriate coping strategies with their children has the potential to increase the quality of life of children diagnosed with chronic illnesses.

Prior Interventions for Children Undergoing Cancer Treatment

Family Interventions

Family interventions generally target the functioning of the entire family rather than a single member. However, each single member would expect to benefit from improved functioning of the family as a whole. A family systems framework has been suggested as necessary for ensuring improvements to family functioning for children with chronic illnesses (Patterson & Garwick, 1994). A family systems approach examines the pattern of relationships between individual members of a group, or in this case, a family. Since chronic illness alters the social, emotional, and behavioral functioning of the family as a whole, some researchers have noted the importance of ensuring that the family is identified as a target for intervention. In fact, Patterson and Garwick (1994) explained that a preventative, family-focused intervention should be designed to help improve the negative outcomes faced by families who have a child with a chronic illness. Unfortunately, such a preventative, family-focused intervention has not been successfully created. The majority of the research into family-focused interventions for families with a child with a chronic illness has occurred in the context of pediatric cancer. Although a broader goal would be to target all families of children with chronic illnesses, a thorough review of the current literature targeting pediatric cancer patients was conducted in order to gain a better understanding of the current standing of a family focused intervention.

Reducing Child Distress During Procedures. Many of the interventions that were conducted in the 1990s involved teaching parents to help their children cope with painful

medical procedures used in cancer treatment. One such study taught parents to instruct their children to use “attentional distraction (children puff on party blowers), paced breathing (parents count child breaths on the blower), and positive reinforcement (children receive stickers for cooperating during the procedures)” during procedures involving needle insertion (Manne et al., 1990). Overall, the study found that this parent training reduced child distress and parent distress during medical procedures (Manne et al., 1990). It did not, however, reduce child ratings of pain after the procedure (Manne et al., 1990). Another study compared pediatric leukemia patients who were randomly assigned to a medication only condition or a medication and parent coaching condition (Kazak et al., 1996). The only difference between the two conditions was that mothers in the coaching condition perceived that their child was in less pain during the procedure (Kazak et al., 1996). An additional study found that when parents were trained on positive coping techniques, they were able to teach these coping skills to their pre-school aged children undergoing treatment for leukemia (Powers et al., 1993). Children who utilized the positive coping strategies showed less behavioral distress during painful procedures (Powers et al., 1993). Overall, evidence suggests that parents are able to be trained to help children cope during painful procedures that are part of pediatric cancer treatment.

Family Function Interventions. Another area of pediatric cancer intervention is to target the parenting and family contexts in an effort to help overall child HRQL. However, many studies that claim to target family functioning actually target parental distress. Although they are included here as family-functioning interventions, because that is how they refer to themselves, they do not technically meet the criteria of a family-focused intervention from a family systems framework. These interventions do focus on individual

family members of children with cancer, which may highlight a semantic and conceptual problem faced by researchers and health care professionals who are attempting to understand the benefit of a family-focused intervention.

Early studies that attempted to improve overall parental and family functioning did not yield promising results. One study used a randomized controlled trial to compare a manualized psychoeducation and cognitive behavioral treatment to standard oncology care (Hoekstra-Weebers et al., 1988). The purpose of the manualized treatment was to reduce parental distress, which would also reduce child distress and promote adjustment among pediatric cancer patients (Hoekstra-Weebers et al., 1988). Hoekstra-Weebers and colleagues, in an intervention they referred to as “family functioning intervention,” found that there were some reductions in parental negative mood at follow-up, not during the treatment period, but no increase in positive mood was observed (1988). Another study attempted to improve overall family functioning using a multicomponent intervention program; however, there were no significant differences in post-treatment family functioning between treatment and control groups (Kupst et al., 1982).

Compared with older studies, more recent studies have demonstrated more positive results. A study that used mindfulness-based stress reduction to help reduce parental distress among caregivers of chronically ill children found significant reductions in parental distress after eight sessions (Minor et al., 2008). There is ongoing research to find an evidence-based treatment for families with children diagnosed with cancer. A recent pilot study found that a combined cognitive behavioral therapy and family therapy was acceptable and appeared to reduce distress among pediatric cancer survivors and their families (Kazak et al., 2005). This included three sessions, two of which allowed parents to process their experience during their

child's diagnosis. Another study of pediatric cancer survivors and their families used a brief, one day, combined cognitive behavioral therapy and family therapy approach to help reduce post-traumatic stress symptoms (PTSS) in the childhood cancer survivors and their parents (Kazak et al., 2004). The authors found that the treatment reduced intrusive thoughts in fathers and arousal in cancer survivors (Kazak et al., 2004). A study done in Iran examined the effects of group Hope Therapy on both hope and depression among mothers of children who have been diagnosed with cancer (Shekarabi-Ahari et al., 2012). Shekarabi-Ahari and colleagues found that 8 weeks of group Hope Therapy significantly increased hope and decreased depression among mothers of children who had been diagnosed with cancer (2012). Another form of therapy called Problem-Solving Skills therapy was studied with mothers of children recently diagnosed with cancer (Sahler et al., 2013). In a randomized controlled trial, Problem-Solving Skills Therapy was able to improve mood and reduce anxiety and posttraumatic stress symptoms in mothers of children diagnosed with cancer (Sahler et al., 2013). However, another randomized controlled trial of PTSS with mothers of children who had recently been diagnosed with cancer found no significant differences between the treatment and control groups (Stehl et al., 2008).

In a meta-analysis of psychological interventions for families with a child diagnosed with cancer, findings suggest that there was a small but significant effect size for interventions to reduce parental distress; nevertheless, there was no significant reduction in child distress or increase in child adjustment or well-being (Pai et al., 2006). However, it was striking that there were only 12 studies that met the criteria to be included in this meta-analysis (Pai et al., 2006). Taken together, there is promising evidence for several studies to reduce parental distress. However, many of these studies refer to themselves as “family-

focused” because they focus on families; but they do not actually target the functioning of the family system. Therefore, there are currently no evidence-based interventions that can be used with families to improve overall family functioning in order to improve child health-related quality of life.

Another meta-analysis of interventions for families of a child with a chronic disease was conducted in 2014 (Law et al., 2014). The study found that many interventions used a behavioral family systems model, which examines the behaviors and maladaptive thoughts of individual members of the family. Both Cognitive-Behavioral Therapy (CBT) and Problem Solving Therapy (PST) fall within this model. Although both forms of therapy have strong empirical support for helping individuals, neither of these treatments account for the functioning of the family as a whole but rather attempt to improve the functioning of individual members. This theoretically would improve the family system, but it does not target the relationships between members of the family, nor does it target key components of family functioning (communication, cohesion, support, organization, etc.). The other model that the study found was a Systemic Therapy (ST) approach, which attempts to understand how broader family and social factors influence the functioning of an individual. The authors found that out of all the studies collected for the meta-analysis (37 total), only a small portion used a ST approach (10), while the others used CBT (18) or PST (9) (Law et al., 2014). Outcomes evaluated for this study included parent mental health, parent behavior, family functioning, child mental health, child behaviors/disability, and child medical symptoms.

Law et al. pooled data across all 37 studies to examine outcomes (2014). They found that there were no significant effects in a pooled analysis of interventions for parent mental health, family functioning, child mental health, child behaviors/disability, or child medical

symptoms (Law et al., 2014). Of note, only three studies included in the meta-analysis examined family functioning as an outcome at follow-up. These studies included adolescents with asthma and diabetes and focused on using STs to change adolescent behavior. The authors did find a significant effect in a pooled analysis for positive changes in parent behaviors (Law et al., 2014) but not family functioning. When the effects of interventions were examined by therapy type, there were no significant effects across all outcomes for CBT-based interventions, PST-based interventions had small but significant effects for improving parental mental health and parental behaviors (specific behaviors not specified within the article), and ST therapies either had too few studies to report effects or found non-significant effects (Law et al., 2014).

Overall, the meta-analytic review found modest support for using PST to improve parent behaviors and mental health (Law et al., 2014); however, given the lack of quality data on family functioning, it can be surmised that further studies are needed to determine effective intervention strategies for improving overall family functioning. Additionally, a theme among the studies examined was a focus on individual well-being rather than overall family cohesion, family openness, family communication, and functioning. Despite the support for PST to improve parent behaviors and parent mental health, there are additional factors that influence family functioning (i.e., communication, family coping, a supportive family environment, maintaining family routines, etc.) that were not addressed in these studies. Given the dearth of quality interventions on improving family functioning for children diagnosed with chronic illnesses, a more thorough examination of potential family factors for inclusion in an intervention is warranted.

Family Functioning and Prevention

Overall, there is currently no family-focused treatment with strong empirical support that will improve family functioning in order to prevent reductions in child HRQL. A family-focused intervention would attempt to improve many family functioning domains rather than a single individual. According to family systems theory, by improving the functioning of the family, the functioning of each individual family member would be improved. Although a wealth of research exists on childhood chronic illnesses, the majority of these studies do not include interventions, they are descriptive or correlational (Kazak, 2002). There are some studies that have found cognitive behavioral approaches with families, or with an indicated child, have produced reductions in child distress during painful procedures (Kazak, 2005). Thus, there are “well-established treatments” to help parents coach their children through procedural pain that occurs during cancer treatment (Kazak, 2005). However, there is currently no family-focused intervention aimed at preventing negative psychological and health-related quality of life outcomes among children with chronic illnesses.

Currently, evidence appears to indicate a need for parents to provide a secure base, or a source of support and comfort, for their child during the stressors of the chronic illness diagnosis and treatment experience. In addition, family coping skills, communication strategies, and problem-solving skills appear to be essential for emotional, behavioral, physical, and social adjustment among children with chronic illnesses. To date, only feasibility studies have been done in this realm of pediatric psychology. Evidence indicates that the Surviving Cancer Competently Intervention Program—Newly Diagnosed (SCCIP-ND) program may address some of the family factors mentioned above (Kazak et al., 2005). This program involves separate group sessions for cancer patients, siblings, and parents. The groups meet three times, once to discuss how cancer has affected them, once to discuss CBT

coping skills, and once to discuss moving forward (Kazak et al., 1999). However, this still lacks an integrated family model, where the family learns skills that can improve the functioning of the entire family.

In fact, during a recent group meeting of pediatric oncology psychosocial specialists, standards of care were developed for children with cancer and their families (Wiener et al., 2015). Despite their intensive literature review, they did not comment on family-focused factors, such as improving family coping, family communication, or family functioning, for prevention of psychological sequelae of cancer treatment. Relevant aims, however, were developed. First, the committee found strong evidence that children with cancer and their families should have access to psychological and psychiatric support (Wiener et al., 2015). A family focused intervention aimed at providing information and support to families early on in the cancer process both meets the terms of this aim and could potentially prevent some children from requiring psychological and psychiatric care. By bolstering family functioning, child quality of life will likely improve. Second, the committee found moderate evidence that parents and caregivers of children with cancer should have access to assessment and interventions targeted at their mental health needs (Wiener et al., 2015). A family focused intervention would facilitate coping and positive communication among parents and children, thus improving mental health or allowing family members to seek appropriate care with the support of their family.

Third, the committee suggested that children with cancer and their families should be given “psychoeducation, information, and guidance... tailored to their developmental and specific needs” (Weiner et al., 2015). Information regarding prevention of behavioral and psychological problems through parental behavior management targeted in a family-focused

intervention would meet part of this requirement. In addition, improving family coping and communication would allow information given by therapists, health care workers, and social workers to be properly processed and communicated to the entire family. Fourth, the committee recommended that children should be given “developmentally appropriate preparatory information about invasive medical procedures” (Wiener et al., 2015). Although the importance of preparing children for medical procedures cannot be understated, parents are uniquely placed to both understand their child’s developmental level and to spend the appropriate amount of time explaining and coaching their child prior to medical procedures. A family-focused intervention could improve open communication between parents and their children. Open communication is essential for parents to properly explain medical procedures.

Additionally, attachment-aimed treatment goals would improve parental understanding of providing a secure base during painful or scary procedures, as well as providing support throughout the treatment process. And finally, the committee suggested that other children in families who have a child with cancer would benefit from sibling supportive services (Wiener et al., 2015). By improving family coping and communication, sibling outcomes could also be improved. Thus, a family-focused intervention aimed at prevention would meet several aims of the committee, as well as potentially alleviate the need for some of the committees’ recommended services.

Finally, many parents view themselves as advocates for their children during and after cancer treatment. Research indicates the importance of family-centered care that allows parents to gain knowledge and emotional strength to advocate for their children (Holm et al., &2003). Despite their distress, parents want to be able to do the best thing for their child

during cancer treatment. Thus, there is an important role for pediatric psychologists to step in and assist families after a child has been diagnosed with cancer. In fact, pediatric oncologists have indicated one of the main roles of psychologists in pediatric oncology departments is to help understand the importance of working within the family system when treating children (Kazak and Noll, 2015).

Chapter 2

The Current Study

This study sought to evaluate potential factors that may be essential in developing and implementing a family-focused intervention for families of pediatric cancer patients currently undergoing treatment specifically, and for children newly diagnosed with a chronic illness more generally. A thorough review of the literature suggests that parental distress, parental perceptions of child vulnerability, parental overprotective behaviors, parental coping skills, family communication, parenting style, and family secure base knowledge may be important for child adjustment and well-being after diagnosis with a chronic illness. Overall, the results of this study will provide information regarding the necessity and acceptability of the previously stated family factors in improving child health related quality of life. Factors that are found to be directly connected to children's health-related quality of life and are found to be deficient in a clinically relevant portion of the population will be considered for a future intervention. Additionally, participants will complete open-ended questionnaires regarding their thoughts on the helpfulness of targeting the aforementioned factors, as well as any barriers to complying, with a potential intervention.

There is currently limited empirically-supported for family-focused interventions aimed at improving multiple domains of family functioning, coping, and HRQL during the childhood chronic illness. Prior studies have suggested that family communication and coping may influence child health-related quality of life even years after treatment. Improving coping skills of families, and thus children, may improve adjustment and quality of life among children with chronic illnesses. By using a qualitative method, this study will also derive family perceptions of a family-focused intervention. It will also allow for an

understanding of barriers to delivering an intervention of this magnitude. Examining these factors may lead to developing a brief intervention which will allow for future pediatric psychologists and social workers to provide essential assistance to the majority of families, which will potentially prevent a portion of poor outcomes requiring more intensive psychosocial services. In addition, since our current understanding of how families adjust to life with a chronic illness is conducted in a variety of chronic illnesses and not just within the context of a cancer diagnosis, it will be important to compare the results of children diagnosed with cancer compared to those of children with other chronic illnesses to ensure generalizability.

The primary goal of this study was to examine the relationship between parental attitudes (perception of vulnerability), behaviors (parental overprotection), and parental distress with parental coping, family communication style, parenting style, and child HRQL. The secondary aims were 1) examine the relationship between parental coping skills, family communication style, parenting style, and child HRQL and 2) assess qualitative information regarding helpfulness and potential barriers to a family-focused intervention during treatment, as well as specific family stressors and coping strategies.

Aim 1: Examine the relationship between parental attitudes (parental perceptions of vulnerability), behaviors (parental overprotection), and parent distress with parental coping, family conversation orientation, family openness to discuss diagnosis information, negative parenting style, and child health-related quality of life.

Although medical interventions increase survival and physical health of children with chronic and life-threatening illnesses, research suggests that time in the hospital, intrusive and painful procedures, and uncertainty about survival may have negative impacts on child

development and adjustment (Barbarin, 1990). Parental attitudes, behaviors, coping skills, and communication styles are important factors that may exacerbate or alleviate the impact of illness and hospital related stressors on a child's adjustment and wellbeing. Prior research has indicated that specific parental attitudes and behaviors play an important role in child adjustment; these include parental stress, parental perceptions of child vulnerability, and parental overprotective behaviors. Current understandings of child adjustment and wellbeing focus on morbidity, emotional dysfunction, and behavioral problems faced by long-term survivors and children with chronic illnesses (Spieth & Harris, 1996; Harding, 2001). Collectively, these domains are considered child health-related quality of life, which was recognized by the World Health Organization as the multidimensional way to describe child adjustment and wellbeing relating to social, physical, cognitive, and psychological functioning. Child health-related quality of life is often measured by parent proxy, which has been shown to be correlated with child reports among pediatric cancer patients (Russell et al., 2006).

Hypothesis 1: Parents endorsing high levels of perceptions of child vulnerability, parental overprotective behaviors, and parental distress will report lower levels of parental coping, less open conversation orientation style, less openness, more negative parenting styles, and poorer child health-related quality of life.

Aim 2: To examine the relationship between parental coping skills, family conversation and conformity orientation, parental style, and child health-related quality of life.

It is clear that parents can influence the health-related quality of life of children with cancer. It has long been documented that parent distress increases child distress during the cancer experience (Jay et al., 1983). However, parents who are able to provide sensitive

support (positive parenting style) are able to improve the adjustment of children with chronic illnesses. Prior studies using evidence-based interventions to train parents to coach children through painful procedures have shown promising results (Kazak et al., 1996; Manne et al., 1990; Powers et al., 1993). Given this past success, teaching parents healthy coping skills may provide two results: it will reduce overall parental distress as parents use the coping skills and it will help parents to coach their children on the use of healthy coping skills.

In addition, research suggests that family cohesion and communication strategies influence adjustment among children with chronic illnesses. Increasing family communication by coaching parents to have sensitive and developmentally appropriate conversations with their children about diagnosis, procedures, emotions, and physical sensations may reduce child anxiety and improve adjustment (Hockenberry-Eaton & Minick, 1994). Training parents to have sensitive conversations with their children may reduce parental distress and improve child health-related quality of life.

Hypothesis 2: Families with parents with greater coping skill utilization, more open communication, higher family conversation orientation, lower family conformity orientation, more positive and less negative parenting, will report greater levels of child health-related quality of life.

Aim 3: To assess the qualitative information regarding perceived helpfulness and potential barriers to a family-focused intervention during treatment, as well as specific family stressors and coping strategies.

Although research examining empirically based importance of potential intervention components is important, an intervention is only useful if it is utilized by those it is designed to help. Therefore, gathering information directly from families is important when designing

a family-based intervention. Previous literature has looked at changes that families undergo, challenges they face, and potential sources of growth and resilience. Parents have long reported that their families undergo many changes, most of them negative, when their child is diagnosed with cancer (Van Dongen-Melman et al., 1998). This is also true for families who have a child with any chronic illnesses (Patterson & Garwick, 1994). However, until 2012, there was not enough literature using qualitative methods to conduct a thorough review or meta-analysis of the themes parents described. A 2012 systematic review identified important themes based on parent responses to interviews (Gibbins et al., 2012). Specific themes that were identified included parents wanting more information, parents describing their own internal journey when confronted with their child's diagnosis, having to continuously adjust or learn new and better coping strategies throughout the process, the negative impact cancer had on the family, experiences of personal growth or positive changes, sources of support, gender differences between parental approaches, and cultural differences in parent perspectives (Gibbins et al., 2012).

At this time, there has only been one other study that looked at family perspectives regarding an intervention during a child's cancer treatment. The study used focus groups to determine the psychosocial needs of families after a diagnosis, how an intervention might be helpful, the best timing for an intervention, and barriers to participating in an intervention (Hocking et al., 2014). An important finding from the qualitative study was that parents preferred not to engage in an intervention that specifically focused on their distress because their focus was on their child (Hocking et al., 2014). This is particularly important because many of the current interventions focused on parental distress in order to improve child distress. This parental preference could help explain the lack of efficacy found in reducing

child distress through interventions based on improving parent distress or focusing on parental maladaptive thoughts. Another important finding highlighted parent preference for focusing on helping their child rather than participating in parent focused interventions, particularly in the months immediately following diagnosis (Hocking et al., 2014). This highlights the need to frame interventions as improving child quality of life when providing them to parents.

This study will help to clarify what would entice families to participate in an intervention, what they would find helpful, and what barriers they believe would hinder their participation. It will also determine what parents currently do that they believe is helpful. Capitalizing on current strengths will help to improve the outcomes of an intervention. This will provide valuable information to researchers and practitioners who seek to aid families undergoing the diagnosis and treatment phase of the childhood chronic illness journey. Previous qualitative studies have provided essential information for improving potential interventions, highlighting the need for parent input when creating interventions.

Chapter 3

Methods

Participants

Participants were initially recruited from University of New Mexico Hospital Pediatric Oncology Department. Flyers with the study information were given to families by a nurse, physician's assistant, or doctor either during an inpatient treatment stay or during an outpatient treatment appointment. The flyer contained information regarding the study, as well as contact information for the study coordinator. Interested families were able to contact the study coordinator or discuss the study with oncology staff to schedule a virtual meeting with the study coordinator. Given the nature of this study, inclusion was designed to be broadly inclusive to recruit as many families as possible. Families were eligible to participate in the study if they have a child diagnosed with cancer, they are able to speak and understand English, and at least one parent or guardian is able to attend all study meetings.

Due to the ongoing restrictions closures, restrictions, and precautions needed for study participants and researchers to stay safe and healthy during the covid-19 pandemic, multiple changes were made to the protocol to ensure that the sample could be recruited without additional risks related to the pandemic. In addition, due to the nature of their treatments (i.e., immunosuppression related to chemotherapy or bone marrow transplant), cancer patients are uniquely at risk during the pandemic. Due to the increased stressors on this patient population, recruitment efforts were made more difficult. Thus, the sample population was expanded to include children with other chronic illnesses. Chronic illness participants were recruited from online community forums (Craigslist) and social media ads. Interested participants were given a link to an electronic consent form through REDCap and

the link to the electronic survey through Opinio. They were also provided with available dates and times to sign up for the virtual interview portion of the study. Families were eligible to participate in the study if they could speak English fluently and had a child who had been diagnosed with a chronic illness.

A total of 51 participants consented to participate in the study. The data from 10 participants was excluded from the analysis because they had failed to answer any study question other than the demographic questions of the study questions. Thus, 41 participants were used in the main analyses. Of the 41 participants, 4 of them had some missing data and were included in all analyses for which they had complete data. Overall, 14 of the participating families had a child with a cancer diagnosis and the remaining 28 families had a child diagnosed with another chronic illness. Other chronic illnesses included lung and breathing disorders (n = 6), congenital heart defects, (n = 1) GI disorders (n = 2), diabetes (n = 1), neurodevelopmental disorders (n = 4), skin conditions (n = 1), congenital cataracts (n = 1), and chronic mental illnesses (n = 4). Unfortunately, despite all families answering a screening question about their child's chronic illness prior to being enrolled in the study, several families (n = 8) declined to put their child's diagnosis into the survey. Since screening information could not be linked to survey responses, there is no accurate way to identify which chronic illness diagnosis match those families who declined to write it into the survey. In addition, one parent or caregiver was asked to complete the study measures. However, when asked to write in their relationship to the child, the majority of participants wrote if their child was their son or daughter, rather than stating if they were mother, father, or caregiver to the child. Therefore, this study was unable to differentiate responses by mother versus father.

Measures

Demographics

A demographic questionnaire was given to parents. Questions assessed parental age, marital status, mean household income, parental education, parental race/ethnicity, and family structure. Parents also answered questions about child age, sex, child race/ethnicity, child diagnosis/illness status, and type of treatment.

Parental Perceptions of Vulnerability

Parental perceptions of vulnerability were assessed using the Child Vulnerability Scale (CVS) (Forsyth et al., 1996). This scale was designed to assess parents' beliefs about their child's overall vulnerability to health problems. Thus, the scale includes items regarding a child's general health, fear that the child might die, and difficulty with setting limits of behavior. Sample items include "I sometimes get concerned that my child doesn't look as healthy as s/he should," and "I often check on my child at night to make sure s/he is okay." The CVS is a parent report measure with 8 items. Parents rate each item on a 4-point Likert scale from 0 (definitely false) to 3 (definitely true). Higher scores on the CVS represent greater levels of perceived child vulnerability. The normative sample for the development of this measure consisted of mothers of children who were attending pediatricians' offices. Prior studies of the CVS have demonstrated adequate internal reliability (Cronbach's $\alpha = .74$) (Forsyth et al., 1996). This measure is widely used within the literature as a measure of parental perceptions that their child is vulnerable, having been used extensively within the pediatric chronic illness literature. Within this study, the CVS was found to have high internal reliability (Cronbach's $\alpha = 0.82$).

Parental Overprotection

Parental overprotective behaviors were assessed using the Parent Protection Scale (PPS) (Thomasgard et al., 1995). The PPS allows parents to self-report on several areas of protectiveness. It is a 25-question scale where parents rate each item on a 4-point Likert scale from 0 (never) to 3 (always). Higher scores on the PPS represent greater parental overprotective behaviors. The PPS has been found to have moderate/high internal reliability (Cronbach's $\alpha = .73$) and a high test-retest reliability score ($r = .86, p = .001$) in norming samples (Thomasgard et al., 1995). Within this study, the PPS had a moderate/high internal reliability (Chronbach's $\alpha = 0.79$).

Parental Distress

Levels of distress experienced by parents was measured with the Perceived Stress Scale-10 Item version (PSS-10) (Cohen et al., 1994). This scale is ideal for looking at parental distress given that it measures how upsetting or distressing an event is perceived to be. The PSS-10 is a 10-item self-report questionnaire answered on a 5-point Likert scale from 0 (Never) to 4 (Very Often). The PSS-10 was designed to measure an individual's perception of their stress. A meta-analytic review of reliability and validity of the PSS-10 found that internal consistency reliability was acceptable among all reported studies (Chronbach's $\alpha > 0.70$) and the test-retest reliability was acceptable across all studies (>0.70) (Lee, 2012). Although this measure has been reliable across other studies, in this study, internal reliability was found to not be adequate (Chronbach's $\alpha = 0.38$).

Parental Coping Strategies

Parental coping was measured using the COPE Inventory- Version II (Carver et al., 2013). The COPE-II is a 60-item self-report questionnaire answered on a 4-point Likert scale from 1 (I usually don't do this at all) to 4 (I usually do this a lot). The COPE-II items load

into 15 subscales. A previous study found that active coping, planning, suppression of competing activities, restraint coping, seeking of instrumental social support loaded onto a factor that was named problem-focused coping (Carver et al., 1989). Seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion were found to load onto emotion-focused coping (Carver et al., 1989). For the purpose of this study, problem-focused coping and emotion-focused coping were viewed as positive coping strategies. Another factor, negative coping, was reported to include denial, mental disengagement, and alcohol-drug disengagement (Carver et al., 1989). These subtests were not included in the analysis in order to focus only on potentially helpful coping strategies. The Chronbach's alpha coefficients were .70 (positive coping) and .65 (negative coping) (Carver et al., 1989). Within this study, the items included in the positive coping strategies had a high internal reliability (Chronbach's alpha = 0.87).

Family Communication

Family communication patterns were assessed using two scales. Family communication patterns were assessed using the Revised Family Communication Pattern (RCFP) instrument (Ritchie & Fitzpatrick, 1990). The RCFP is a 26-item scale assessed on a 7-point Likert scale from 1(always) to 7 (never). Previous studies have found acceptable reliability for this tool across multiple settings (Schrodt et al., 2008). The test-retest reliability was found to be acceptable for both conversation orientation (r close to 1) and conformity orientation ($r = 0.93$) (Fitzpatrick & Ritchie, 1994). Another study found the Cronbach's alpha coefficient between to be 0.84 and 0.92 (Rubin et al., 2009). This scale measures two domains: conversation orientation and conformity orientation. The conversation orientation domain examines family willingness to express their opinions openly, express feelings,

discuss private issues together, and express ideas (Shojaee et al., 2018). Conversation orientation was chosen as a measure of open communication styles, which the literature suggests as a protective factor for children with chronic illnesses (Spinetta & Maloney, 1978; Varni et al., 1996). The conformity orientation domain assesses the family tendency to avoid conflict, seek approval, and limit discussions to common interests (Shojaee et al., 2018). Avoiding conflict, limiting discussions, and seeking approval creates a family environment where difficult topics are avoided and therefore not processed or coped with as a family unit. Given the importance of family openness to child HRQL, conformity orientation was included in the analysis as a potential contributor to poor child HRQL. Internal reliability for conversation orientation (Chronbach's $\alpha = 0.94$) and conformity orientation (Chronbach's $\alpha = 0.90$) were both found to be high within this sample.

An additional measure of family openness was used (Spinetta & Maloney, 1978). This family openness questionnaire has been used previously to assess open communication in families with a child diagnosed with cancer (Spinetta & Maloney, 1978), it has 5 questions scored on a 4-point Likert scale. Within this study, the internal reliability of this measure was poor (Chronbach's $\alpha = 0.19$).

Parenting Styles

Parenting style were assessed using the Multidimensional Assessment of Parenting Scale (MAPS) (Parent & Forehand, 2017). The MAPS is a 34-item scale assessed on a 5-point Likert scale from 1 (Never) to 5 (Always). The scale measures aspects of both positive and negative parenting. The subscales for proactive parenting, positive reinforcement, warmth, and supportiveness load onto positive parenting. This measure was chosen because the literature suggests that parental warmth and supportiveness (i.e., supportive parenting) are

protective factors for children with chronic illnesses (Corey et al., 2008; Nabors et al., 2018), while failure to provide rules and boundaries (i.e., lax parenting) are contributors to poor child HRQL. The subscales for hostility, lax control, and physical control load onto negative parenting. A psychometric study conducted on 1790 parents of children 3-17 found strong internal consistency and test-retest reliability ($r = 0.91-0.81$) (Parent & Forehand, 2017). This sample was found to have good internal reliability for positive parenting (Chronbach's $\alpha = 0.86$) and negative parenting (Chronbach's $\alpha = 0.96$).

Child Health-Related Quality of Life

Child HRQL were assessed using a measure of child health-related quality of life. The PedsQL 4.0 is a modular parental and self-report measure to assess health-related quality of life in children with a chronic illness (Varni et al., 2001). The main core of questions consists of 23 items, which assess physical, emotional, school, and social functioning. The child (8-18) and parent-proxy scales are rated on a 5-point Likert scale from 0 (never a problem) to 4 (always a problem). The young child self-report measure (5-7) has a 3-point Likert scale (0 = not at all a problem; 2 = sometimes a problem; 4 = a lot of a problem). The Chronbach alpha statistics of the measure was found to be acceptable in a normative sample of 2–18-year-old children and their parents ($\alpha = .88$ for child self-report and $\alpha = .90$ for parent report) (Varni et al., 2001). This measure produces a total HRQL score, where scores indicate higher levels of quality of life. Within this study, the internal consistency for the PedsQL was high (Chronbach's $\alpha = 0.92$).

Attachment Script Assessment

The Attachment Script Assessment (ASA) is an interview designed to measure secure base script knowledge among adults (Waters & Rodrigues-Doolabh, 2001; Waters &

Rodrigues-Doolabh, 2004). Secure base script knowledge is the current method within the literature for measuring a parent's ability to provide a secure base for their child (Waters et al., 2015). Participants were given a list of words and asked to create a story using as many words and details as possible. The 6-word lists framed 4 attachment-relevant stories and 2 neutral stories. Participant narratives would be audio-recorded and transcribed. ASA coding would be on a scale of 1-7 (7 being the most script knowledge). The ASA would be administered by trained interviewers. The ASA would be coded by a trained coder who underwent rigorous training and reliability testing.

Qualitative Questions

Parents were asked to provide answers to open ended questions regarding perceived helpfulness of an intervention targeting domains of family functioning, perceived barriers to participating in an intervention during their child's treatment, the most stressful part of having a child with a chronic illness for their family, and what their family does to manage stress. The questions included a) Would you find an intervention to help families improve the quality of life for children diagnosed with a chronic illness helpful?, b) What components would you want included in a family-based intervention to help families improve the quality of life for children diagnosed with chronic illness?, c) What barriers do you think might get in the way of families participating in an intervention to help improve the quality of life for children diagnosed with chronic illnesses?, d) What has been the most stressful part of the chronic illness diagnosis and treatment process for your family?, and e) What does your family do to help cope with the stressors of having a medically complex child?

Based on the literature and previous qualitative studies (Gibbins et al., 2012; Hocking et al., 2014), specific themes were hypothesized as possible for each question. For question 1,

it was hypothesized that parents would be eager to improve their child's quality of life but would be skeptical regarding parental supports instead of child supports. For question 2, it was hypothesized that parents would request psychoeducation and basic skills regarding how to parent a child with a chronic illness, how to talk to their child about their illness, and how to comfort their child when he or she experienced pain or distress. For question 3, it was hypothesized that families would report that time and money would be barriers to participating in an intervention. For question 4, it was hypothesized that parents would report illness uncertainty and seeing their child in pain as the most stressful part of the illness journey. Finally, for question 5, it was hypothesized that families would report maintaining family rituals, maintaining family organization, and social supports as helpful for them currently.

Initial Procedures

Interested families contacted the study coordinator or discussed the study with the health care provider who initially provided them with the flyer. A meeting between the family and the study coordinator was arranged according to one of the following scenarios:

- 1) Families who wish to have a face-to-face meeting will be given a link to a zoom meeting
- 2) Families without reliable internet access can conduct a meeting via the telephone. The meeting went through the informed consent documents verbally and described the procedures for the study. Families who consented to participate were originally mailed the following documents to complete and send back: informed consent document, demographics, qualitative questions, Child Vulnerability Scale, Parental Protection Scale, Perceived Stress Scale-10, PedsQL, COPE-Inventory-II, Revised Family Communication Pattern Instrument,

and Family Openness Questionnaire. Families received a gift certificate for participation in the first part of the study upon return of the documents.

Families then scheduled a time to meet with a trained interviewer via a zoom meeting or via the telephone. A 30-minute interview using the Attachment Script Assessment was administered by a trained interviewer. Families who completed the second part of the study were able to receive an additional gift certificate. However, no participants were willing to return for a zoom interview, so the Attachment Script Assessment was excluded from the study.

Protocol Changes Related to Covid-19

Participants were recruited from a variety of sites, including flyers given to patients at University of New Mexico Children's Hospital, as well as online community forums (Craigslist) and social media ads. Interested participants who met inclusion criteria were given a link to an electronic consent form through REDCap and the link to the electronic survey and open-ended questions through Opinio. They were also provided with available dates and times to sign up for the virtual interview portion of the study to complete the attachment script interview.

Chapter 4

Statistical Analyses

Data Analysis

All data were analyzed using SPSS version 25. Initial data analysis included bivariate correlations of continuous demographic variables with each dependent and independent variable and Chi-Squared analyses for categorical demographic variables. Demographic variables that were found to be both statistically and empirically significant were used to adjust later statistical models. Additional analyses were performed to assess differences between families with a child diagnosed with cancer versus children with other chronic illnesses.

Sample Size

Power analyses using GPower software suggest that to identify a moderate effect size of 0.3 using a multiple regression model, a sample of 45 families would be required.

Methodology and Analysis for Aim 1

Hypothesis 1: Parents endorsing high levels of perceptions of child vulnerability, parental overprotective behaviors, and parental distress will report lower levels of parental positive coping, less open conversation orientation style, less openness, more negative parenting styles, and poorer child health-related quality of life.

To investigate the relationship between parental attitudes, behaviors, and distress with parental coping, family communication, and child adjustment, data were collected on parental perceptions of child vulnerability, parental overprotective behaviors parental distress, parental coping styles, family conversation orientation style, and child health-related quality of life. Bivariate correlations between all variables were assessed. Multiple regression

analysis was used to predict parenting style, parental coping styles, family conversation and conformation orientation style, family openness to discussing diagnostic information, and child health-related quality of life from a model including parental overprotective behaviors, parental perceptions of child vulnerability, and parental distress, as well as any relevant demographic variables.

Methodology and Analysis for Aim 2

Hypothesis 2: Families with parents with greater coping skill utilization, more open communication, higher family conversation orientation, lower family conformity orientation, and more positive and less negative parenting will report greater levels of child health-related quality of life.

To investigate the relationship between parental coping, family communication, parenting style, and child health related quality of life, data were collected on parental coping styles, family communication styles, positive and negative parenting style, and child health-related quality of life. Bivariate correlations between each variable were assessed. Multiple regression analysis was used to predict child health-related quality of life from a model including parental coping styles, family communication styles, positive and negative parenting style, and relevant demographic variables.

Methodology and Analysis for Aim 3

Families provided answers to open-ended questions about perceived helpfulness of a family focused intervention during treatment, perceived barriers to participating in an intervention, current stressors for their family, and how their family coped with the stress of having a child with a chronic illness.

Themes were derived from the parental responses based on the methodology suggested in a meta-analysis by Braun and Clarke (2006). The initial analysis sought themes from within the data by locating repeated, meaningful, patterns of responses. These patterns were identified as “themes.” Following the guidelines suggested by Braun and Clarke (2006), patterns were then reviewed by the coders to provide clarified names and definitions of each theme. During this phase, the coders searched for as many codes as possible using a data-drive approach, the smaller codes were then analyzed using tables that grouped them into larger themes (Braun & Clarke, 2006). An example of grouping the codes into larger themes was grouping “coping skills,” “communication skills,” and “mindfulness skills” into one larger “skills” theme. Initial themes were derived by two graduate students on their pre-doctoral internship who specialized in pediatric psychology, including clinical work and research with children who have chronic illnesses. Next, a graduate student read and coded the parental responses in accordance with the review phase suggested by Braun and Clarke (2006). In order to ensure reliable coding, each statement was coded to reflect a single theme (Burla et al., 2008). The two pre-doctoral interns who created the categories then met with the blind coder and discussed the results of the coder’s categorizations. They came to a consensus regarding categories and the descriptions of each category were amended for increased clarity. A second graduate student was then asked to code the data based on category descriptions given by the researcher. Kappa scores between the second independent blind coder and the consensus codes were calculated to analyze agreement.

Analytic Changes Related to Covid-19

During data collection, participants refused to return for an additional zoom interview. Therefore, data for the attachment script interview was not able to be collected. Thus, a measure of attachment was removed from all aims, hypotheses, and analyses.

Chapter 5

Results

Descriptive Statistics

Descriptive statistics for sociodemographic and family variables were reported in Table 1. Children included in the study ranged from 2 years to 16 years in age, with a mean age of 7.2 years. The race and ethnicity of the children was 43.9% non-Hispanic white, 34.1% Hispanic, 9.8% Black, 4.9% Asian, and 7.3% Native American. Children were roughly split between males and females (56.1% male). Mean maternal age was 32.2 (range 24-51) years and mean paternal age was 35.2 (range 25 to 57) years. The majority of parents reported that they were married or partnered (97.6%) and college educated. Roughly half (51.2%) of the reporting parents reported that they had a bachelor's degree, 36.6% had a master's degree or higher, 7.3% had an associate's degree or some college, 4.9% had a GED/High School Diploma or had not completed high school. Family income in the sample included 7.3% under \$30,000 per year, 29.3% between \$30,000 and \$50,000 per year, 41.5% were between \$50,000 and \$80,000 per year, 12.2% were between \$80,000 and \$100,000, and 9.8% made over \$100,00 per year.

Associations with Demographic Variables

Overall, in this sample, child race and ethnicity were not associated with family or HRQL variables. The age of the child was significantly associated with family communication styles, with older age of child associated with higher levels of conversation orientation ($r = 0.580$, $p < 0.001$) and lower levels of conformity orientation ($r = -0.358$, $p = 0.030$) (Table 2). Child age was also negatively associated with negative parenting methods ($r = -0.545$, $p < 0.001$) (Table 2). The sex of the child was significantly associated with child

HRQL, parental distress, and level of conversation orientation (Table 2). Female children (mean = 29.8) were reported to have significantly lower HRQL than male children (mean = 45.0) and to engage in lower levels of conversation orientation-based family communication. Parents of female children reported higher levels of parental distress (mean = 22.7) than parents of male children (mean = 19.6). Parents of children with a cancer diagnosis reported significantly higher levels of parental distress than the parents of children with other chronic illnesses (cancer mean = 23.7, other chronic illness mean = 19.1, $p = 0.003$). Parents of children with a cancer diagnosis also reported significantly lower levels of conformity orientation-based family communication (Table 2). Additionally, family income was found to be significantly associated with family openness, with higher levels of family openness reported at higher levels of family income. Parental education was found to be significantly associated with child HRQL and parental over protection (Table 2).

Aim 1: Examine the relationship between parental attitudes (parental perceptions of vulnerability), behaviors (parental overprotection), and parent distress with parental coping, family conversation and conformity orientation, family openness to discuss diagnosis information, negative parenting style, and child health-related quality of life.

Hypothesis 1: Parents endorsing high levels of perceptions of child vulnerability, parental overprotective behaviors, and parental distress will report lower levels of parental coping, less open conversation orientation style, higher family conformity, less openness, more negative parenting styles, and poorer child health-related quality of life.

Predicting Coping Skill Utilization

Coping skill utilization was significantly associated with parental perceptions of child vulnerability ($r = 0.732$, $p < 0.001$) but was not associated with other parent variables (Table

3). Parental perceptions of vulnerability, parental overprotection, and parental distress were then used to predict coping skill utilization with hierarchical linear regression. No demographic variables were significantly associated with coping skill utilization and parent variables so no demographic variables were included in the model. Table 4 presents the results from hierarchical linear regression modeling of predictors of coping skill utilization. Since parental perceptions of child vulnerability was significantly associated with coping skill utilization, it was included at step one of the model. The addition of parental perception of child vulnerability did contribute significantly to the model ($R^2=0.535$, $F=39.151$, $p<0.001$). The second step included hypothesized parenting variables that were not significantly correlated with coping skill utilization. The addition of parent distress and parental overprotection did not contribute significantly to the model. In the final model, only parental perceptions of child vulnerability was found to be a significant and unique predictor of coping skill utilization ($\beta = 0.732$, $p<0.001$). Thus, the final model predicted that for every one unit increase in parental perception of child vulnerability, coping skill utilization increased by 1.824 points.

Predicting Family Conversation Orientation

Family conversation orientation was significantly associated with negative parenting styles ($r = -0.690$, $p < 0.001$). Family conversation orientation was not significantly associated with parent distress, parental perceptions of child vulnerability, or parental overprotection (Table 3). Table 5 presents the results from hierarchical linear regression modeling of predictors of family conversation orientation. Since the sex of the child was significantly associated with both family conversation orientation and parent distress, it was included in the model as step 1. The addition of the sex of the child did contribute significantly to the

model ($R^2=0.143$, $F=5.665$, $p= 0.023$). The second step included hypothesized parenting variables that were not significantly correlated with conversation orientation. The addition of parent distress, parental perceptions of child vulnerability, and parental overprotection did not contribute significantly to the model. In the final model, only the sex of the child was found to be a significant and unique predictor of family conversation orientation (beta = -0.378, $p = 0.023$).

Predicting Family Conformity Orientation

Family conformity orientation was significantly associated with parental perceptions of child vulnerability ($r = -0.371$, $p = 0.024$). Family conformity orientation was not significantly associated with parent distress or parental overprotection (Table 3). Table 6 presents the results from hierarchical linear regression modeling of predictors of family conformity orientation. Since the child cancer diagnosis was significantly associated with both family conformity orientation and parent distress, it was included in the model as step 1. The model indicates that child cancer diagnosis did contribute significantly to the model ($R^2=0.179$, $F=7.435$, $p= 0.010$). The addition of parental perceptions of child vulnerability was also significant ($R^2=0.321$, $F=7.818$, $p= 0.002$). Parent overprotection and parent distress did not contribute significantly to the model. In the final model, child cancer diagnosis (beta = -0.440, $p = 0.016$) and parental perceptions of child vulnerability (beta = -0.416, $p = 0.019$) were significant and unique predictors of family conformity orientation. Thus, in the final model predicted that for every one unit increase in parental perceptions of child vulnerability there is a 0.089 point decrease in family conformity orientation.

Predicting Family Openness

Family openness was significantly associated with parental overprotection ($r = 0.431$, $p < 0.001$) but was not associated with other family or parent variables. Parental perceptions of vulnerability, parental overprotection, and parental distress were then used to predict child HRQL with hierarchical linear regression. No demographic variables were significantly associated with both family openness and parent variables so no demographic variables were included in the model. Table 7 presents the results from hierarchical linear regression modeling of predictors of family openness. Since parental overprotection was significantly associated with family openness, it was included at step one of the model. The addition of parental overprotection did contribute significantly to the model ($R^2 = 0.170$, $F = 8.163$, $p = 0.007$). The second step included hypothesized parenting variables that were not significantly correlated with conversation orientation. The addition of parent distress and parental perceptions of child vulnerability did not contribute significantly to the model. In the final model, only parental overprotection was found to be a significant and unique predictor of family openness ($\beta = 0.421$, $p = 0.019$). Thus, the final model predicted that for every one unit increase in parental overprotection, family openness increased by 0.091 points.

Predicting Negative Parenting Style

Negative parenting style was significantly associated with parental perceptions of child vulnerability ($r = 0.451$, $p = 0.006$) but was not associated with other parent variables (Table 3). Parental perceptions of vulnerability, parental overprotection, and parental distress were then used to predict negative parenting style with hierarchical linear regression. No demographic variables were significantly associated with both negative parenting style and parent variables so no demographic variables were included in the model. Table 8 presents the results from hierarchical linear regression modeling of predictors of negative parenting

style. Since parental perceptions of child vulnerability was significantly associated with negative parenting style, it was included at step one of the model. The addition of parental perception of child vulnerability did contribute significantly to the model ($R^2=0.203$, $F=8.671$, $p= 0.006$). The second step included hypothesized parenting variables that were not significantly correlated with conformity orientation. The addition of parent distress and parental overprotection did not contribute significantly to the model. In the final model, only parental perceptions of child vulnerability was found to be a significant and unique predictor of negative parenting style ($\beta = 0.418$, $p = 0.024$). Thus, the final model predicted that for every one unit increase in parental perception of child vulnerability, negative parenting style increased by 0.070 points.

Predicting Child HRQL

Bivariate correlations were run between parent, family, and child HRQL variables (Table 3) as a first step in determining variables for the subsequent regression model. Child HRQL was significantly associated with parental perceptions of child vulnerability ($r = -0.594$, $p < 0.001$). Child HRQL was not significantly associated with family openness or parental overprotection.

Parental perceptions of vulnerability, parental overprotection, and parental distress were then used to predict child HRQL with hierarchical linear regression. Since parental education was associated with both parental report of child HRQL and parental overprotection, and sex of the child was associated with both child HRQL and parental distress, they were included in the analysis as the first step. Table 9 presents the results from hierarchical linear regression modeling of predictors of child HRQL. The model indicates that parent education and the sex of the child did contribute significantly to the model

($R^2=0.313$, $F=7.505$, $p=0.002$). The addition of parental perceptions of child vulnerability was also significant ($R^2=0.518$, $F=11.441$, $p<0.001$). Parent overprotection and parental distress did not contribute significantly to the model. In the final model, both parent education (beta = -0.401, $p=0.012$) and parent perceptions of child vulnerability (beta = -0.442, $p=0.005$) were significant and unique predictors of child HRQL. Thus, the model predicted that for each category increase in parent education, child HRQL decreases by 9.968 points. In addition, the model predicts that for each unit increase in parental perception of child vulnerability, child HRQL decreases by 1.203 points.

Aim 2: To examine the relationship between parental positive coping skills, family conversation and conformity orientation, parental style, and child health-related quality of life.

Hypothesis 2: Families with parents with greater positive coping skill utilization, more open communication, higher family conversation orientation, lower family conformity orientation, more positive and less negative parenting will report greater levels of child health-related quality of life.

Bivariate correlations were run between family and child HRQL variables (Table 3). Child HRQL was significantly associated with family conversation orientation ($r=0.629$, $p<0.001$), positive coping skill utilization ($r=-0.438$, $p=0.007$), positive parenting styles ($r=-0.338$, $p=0.044$), and negative parenting styles ($r=-0.578$, $p<0.001$). Bivariate correlations were also run between coping skill utilization and family communication and parenting styles (Table 3). Coping skill use was significantly correlated with positive parenting ($r=0.676$, $p<0.001$). Coping skill use was not significantly correlated with family openness, family conversation orientation, negative parenting style, or family conformity orientation. The

relationship between positive parenting and child HRQL was further examined through bivariate correlations of the subgroups that comprised the positive parenting domain. Child HRQL was significantly associated with proactive parenting ($r = -0.434, p = 0.008$). Child HRQL was not significantly associated with positive reinforcement, warmth, or support.

Coping skill utilization, communication style, and parenting style were then used to predict child HRQL with hierarchical linear regression. Since child age was associated with both parental report of child HRQL and family variables, it was included in the analysis as the first step. Table 10 presents the results from hierarchical linear regression modeling of predictors of child HRQL. The model indicates that child age did contribute significantly to the model ($R^2 = 0.098, F = 4.824, p = 0.035$). The addition of family communication variables (family conversation orientation and family conformity orientation) ($R^2 = 0.480, F = 9.052, p < 0.001$) and positive coping skill utilization ($R^2 = 0.564, F = 12.329, p < 0.001$) also contributed significantly to the model. The addition of parenting style (positive and negative) did not contribute significantly to the model. Thus, the best and final model included child age, family conversation orientation, family conformity orientation, and coping skill utilization. In the final model, family conversation orientation ($\beta = 0.611, p < 0.001$) and coping skill use ($\beta = -0.417, p = 0.001$) were unique and significant predictors of child HRQL. The model predicted that child HRQL would increase 8.799 points for every one unit increase in family conversation orientation. The model also predicted that for every one unit increase in coping skill use, child HRQL would decrease 0.454 points.

Aim 3: To assess the qualitative information regarding perceived helpfulness and potential barriers to a family-focused intervention during treatment, as well as specific family stressors and coping strategies.

Open-ended questions were given codes and kappa scores were calculated to check for agreement between the agreement codes and a blind consistency coder. The first question, which asked about if families would find a family-based intervention helpful, had the lowest kappa score (0.855) (Table 11); however, it was still in the substantial agreement range (0.81 to 1.0). Themes found in respondent answers can be found in Table 12 and included: “yes,” “support,” “resources,” “awareness/education,” “psychological,” and “no.” Among the responses gathered, only 2 participants (6.9%) reported that they would not want a family-based intervention. About 41.4% of responses stated that they would want a family-based intervention and the remaining 51.7% of responses named a component that they would wish to include in a family-based intervention. Specifically, the most frequently reported component that families required was support (20.7%), followed by psychological help (13.8%), increased awareness and education (10.3%), and resources (6.9%) (Table 12).

The second question, which asked what components a family would want included within a family-based intervention had a high level of agreement between coders (kappa = 0.956) (Table 11). Themes found in respondent answers included: “community,” “skills-based learning,” “resources,” “online formats,” “psychological,” and “none/don’t know.” Overall, the most commonly requested component by families was psychological help (34.8%), such as psychoeducational components and therapeutic counseling. The second most common response was resources, specifically financial aid or support in obtaining financial help (21.7%). Other responses included skills-based components (17.4%), community (13%), and online options (4.3%). In addition, 2 responses noted that they did not know what to include in a family-based intervention.

The third question asked families what barriers they perceived would get in the way of them participating in a family-based intervention and had a high level of agreement amongst coders ($\kappa = 0.944$) (Table 11). Themes found in respondent answers included: “financial,” “location,” “time,” “lack of support,” “taboo,” “psychological distress,” “lack of knowledge,” “physical health,” and “none/don’t know” (Table 12). The most commonly reported barrier to participating in a family-based intervention was reported to be financial (23.8%), or any costs associated with the intervention. Other barriers reported by families included lack of support from insurance or medical providers (14.3%), negative emotions associated with talking about the diagnosis (14.3%), not having additional time to engage in any other therapies (9.5%), worry about logistics like the location (9.5%), lack of knowledge about interventions (9.5%), poor physical health (9.5%), or taboo regarding the diagnosis (4.3%). Only two participants reported not knowing what barriers would prevent them from participating in a family-based intervention.

The fourth question, which asked what the most stressful part of the diagnosis and treatment process for their family had been, had a high level of agreement between coders ($\kappa = 0.939$) (Table 11). Themes found in respondent answers included: “financial,” “lack of support,” “timely appointments,” “psychological/physical distress,” “treatment,” and “none/don’t know” (Table 12). The most common response from families regarding the most stressful part of the diagnosis and treatment process was the negative mental and physical toll of the disease (36.7%). Other stressors included unexpected costs (10%), lack of support from others with the same diagnosis (6.7%), the treatment itself (6.7%), and the unavailability of timely appointments (3.3%). Three participants reported that they did not know what their stressors were.

The fifth question, which asked what families currently did to handle the stress of having a medically complex child had a high level of agreement between coders ($\kappa = 1.00$) (Table 11). Themes found in respondent answers included: “spoil/indulge child,” “parent self-care,” “withholding information,” “quality family time,” “psychological support,” “religion,” “knowledge,” “social support,” and “none/don’t know” (Table 12). The most common method that families reported using to cope was psychological tools (16.7%) such as deep breathing or mindfulness (Table 12). Other coping methods included religion (13.3%), seeking social support (10%), spoiling the child or giving them special things (10%), researching or gathering knowledge (6.7%), spending quality time as a family (6.7%), withholding information from the child (6.7%), and taking time as a parent to care for themselves (3.3%). Four of the participants reported that they did not know what they did to cope with stress.

Chapter 6

Discussion

Summary of Findings

The purpose of this study was to evaluate potential factors that may be essential in developing and implementing a family-focused intervention for families of children with a chronic illness. The primary goal was to examine the relationship between parental perceptions of child vulnerability, parental overprotective behaviors, and parental distress with parental coping, family communication style, parenting style, and child HRQL. The secondary goals included examining the relationship between parenting coping skills, communication style, parenting style, and child HRQL. The third aim was to assess qualitative information provided by the families. By using a qualitative method in addition to quantitative methods, this study hoped to derive family perceptions of a family-focused intervention and build an understanding of barriers to delivering an intervention of this magnitude.

Aim 1: Examine the relationship between parental attitudes (parental perceptions of vulnerability), behaviors (parental overprotection), and parent distress with parental coping, family conversation orientation, family openness to discuss diagnosis information, negative parenting style, and child health-related quality of life.

The goal of this aim was to examine the relationship between parent variables, family variables, and child HRQL. This would provide insight into which variables should be included in a future intervention aimed at improving family functioning in order to improve child HRQL. There have been several studies that aimed to enhance child functioning by improving parental functioning. In fact, multiple studies have shown reduction in parental

distress both at time of intervention and at follow-up (Hoekstra-Weebers et al., 1988; Minor et al., 2008). However, neither CBT-based interventions nor mindfulness-based interventions that improved parental distress found significant changes in child distress (Hoekstra-Weebers et al., 1988; Minor et al., 2008). This suggests that although parental distress likely plays a role in overall child well-being, there are additional variables that were not included within these past studies.

It was hypothesized that families endorsing high levels of perceptions of child vulnerability, parental overprotective behaviors, and parental distress would report lower levels of family coping, less open communication styles, more negative parenting styles, and poorer child health-related quality of life. Preliminary and exploratory bivariate correlations found a significant relationship between parental perceptions of child vulnerability and child HRQL, coping skill utilization, negative parenting style, positive parenting style, and family conformity orientation. The direction of the relationships supported the hypothesis that higher levels of parental perception of child vulnerability were associated with lower levels of child HRQL and higher levels of negative parenting style. Further analysis using parent attitudes, behaviors, and distress were used to predict child HRQL. Both higher parent education and parental perceptions of child vulnerability were found to predict lower parent ratings of child health-related quality of life.

The literature regarding parent education and its impact on parent reports of child HRQL is mixed. In several studies done with parents of children with sickle cell disease, parent education was found to both significantly impact child HRQL (Panepinto et al., 2005) and not to significantly impact child HRQL (Palermo et al., 2002). Some studies have mentioned that parents higher in sensitivity, who have a higher understanding of their child's

illness and symptoms, might be better reporters of child HRQL (Upton et al. 2008). Parent education may be linked to parent understanding of their child's illness and symptoms. However, other studies have suggested that parent education is linked to socioeconomic status, which increased child HRQL through access to materials and supports (Panepinto et al., 2005).

The finding that greater parental perceptions of child vulnerability were significantly associated with decreased child HRQL is well supported within the literature. Parental perceptions of child vulnerability have been associated with increased child emotional dysregulation, anxiety symptoms, depressive symptoms, and poor adjustment to chronic illness (Carpentier et al., 2008; Colleti et. al., 2008; Mullins et. al., 2004; Mullins et. al., 2007); higher levels of distress in social situations (Anthony et al., 2003); and increased behavior problems in chronically ill children (Allen et. al., 2004; De Ocampo et al., 2003; Fedele et al., 2011). More importantly, parental perceptions of child vulnerability were also associated with increased parent reported distress and overprotective behaviors. Previous research has suggested that increasing levels of parent distress in the face of a child's chronic illness may be directly related to the development of parental perceptions of child vulnerability. Specifically, parental distress and perceived child vulnerability have been found to be associated with poor emotional functioning among chronically ill children (Colleti et. al., 2008; De Ocampo et al., 2003).

When further analyzed, the relations between parent distress and child emotional functioning have been found to be mediated by parental perceptions of child vulnerability (Carpentier et al., 2008; Mullins et. al., 2004). In the current study, higher levels of parent distress were related to higher levels of parental perceptions of child vulnerability. Other

research suggests that parental perceptions of child vulnerability increase parental overprotective behaviors (Levy, 1980; Vrijmoet-Wiersma et. al., 2010). In the current study, higher levels of parent perceptions of child vulnerability were associated with higher levels of parent overprotection. It has been speculated that parental perceptions of child vulnerability may mediate the association between parent distress and child HRQL by influencing child perceptions and behaviors, as well as parent behaviors. However, contrary to the initial hypothesis, parent distress and overprotective behaviors were not associated with child health-related quality of life in this study. Thus, the relationship between these variables may be more complex than originally believed. It may be that when parents, despite their distress, are able to manage their own emotions and maintain a supportive presence for their child, reductions in HRQL are not observed. However, given the significance of parental perceptions of child vulnerability to HRQL within this study, parental distress may impact child HRQL by altering parental beliefs about their children, which may in turn alters how they interact with their children.

Within the chronic illness literature, parent overprotection has an equivocal relationship with child HRQL. Some studies have found that parental overprotection during the initial diagnosis and treatment period is a protective factor (Coletti et al., 2008). However, other studies have suggested that overprotective parenting reduces child independence and may increase child behavior problems (Holmbeck et al., 2002). In a pending publication by the current author, child independence was found to be an important factor related to continued elevations of stress reactivity among pediatric cancer survivors (Erickson et al., 2022), demonstrating the importance and potential negative consequence of independence reductions seen in relation to parental overprotection. The current study did not

find a significant association between parent overprotection and child HRQL. This suggests that the pathway by which parental overprotection influence a child's overall wellbeing may be more complicated than the simplified model suggested by previous literature.

The relationship between parent distress and child HRQL has been clearly documented in the literature and it was surprising that in the current study, child HRQL and parent distress were not significantly associated. However, other studies suggest that despite overall high levels of parent distress when their children are diagnosed with a chronic illness, parents who are successfully able to cope with their distress and provide support for their children have children who are better able to adjust to their diagnoses (Corey et al., 2008; Nabors et al., 2018). For example, factors such as maintaining overall family functioning has been found to be a buffer against paternal distress for young boys with cancer (Robinson et al., 2006). Thus, family factors may have influenced the relationship between parent distress and child HRQL in this study, as subsequently discussed.

Contrary to the initial hypothesis, parental perceptions of child vulnerability were associated with increased positive coping skill utilization. The initial hypothesis was that parents with higher perceptions of child vulnerability would have lower coping skill utilization. Little research was available regarding the relationship between parental perceptions and parent coping. It was speculated that parents who utilized fewer coping skills would have greater distress and therefore greater perceptions that their child is vulnerable. In the current study, the opposite relationship emerged. This may be a sign that these parents need to use more positive coping skills due to having higher levels of distress. For example, a study of parents of children with sickle cell disease and thalassemias found that parents had to utilize coping skills, even when children were relatively healthy, due to fear and

uncertainty related to future health concerns for their child (Atkin and Ahmed, 2000). Thus, this finding may represent further evidence that parent uncertainty and distress related to their child's diagnosis may influence the development of parental perceptions of child vulnerability.

Also contrary to the initial hypothesis, parent distress and parent overprotective behaviors were not significantly associated with negative parenting style, parental coping skill use, or family conversation orientation. Positive parenting traits, such as warmth, have been associated with active coping skill use amongst adolescents as one indicator of positive adolescent adjustment (Wolfradt et al., 2003). In the same study, negative parenting styles such as control and pressure were associated with higher rates of anxiety amongst adolescents (Wlfradt et al., 2003). Additionally, parent stress has long been associated with negative parenting styles. Distressed parents are more likely to utilize harsher discipline and control methods, particularly when their external stressors overwhelm their coping capabilities (Warren et al., 2019). Thus, it was expected that higher levels of parental distress would overwhelm parental coping skills use and would disrupt parental behaviors, such as overprotectiveness and parenting styles, as well as reduce positive parenting styles such as maintaining an open conversational environment and be associated with increased negative parenting behaviors. However, our analysis did not support this hypothesis. In fact, parental perceptions were better predictors of coping skill use and parenting style, pointing to the importance of how parents perceive their children relative to their level of distress or their parenting behaviors.

It is also important to note that female sex was significantly related to higher levels of parental distress, lower child HRQL, and lower conversation orientation. Most of the

literature exploring these topics looks at the child's sex as a moderating factor or incidental variable. Little information relates directly to the effect of the child's sex on how parents experience distress, report HRQL, or create patterns of family communication. Regarding parental distress, in contrast to our findings, a meta-analysis examining parental distress among parents of children with neurodevelopmental disorders found that parents reported *less* distress when their child was female (Theule et al., 2013). However, Theule and colleagues (2013) noted that their findings contrasted with previous studies that found either no gender differences and opposite gender differences. Additionally, although female sex was initially significantly related to child HRQL, it did not significantly predict child HRQL once parental education was added to the model. Some studies have found lower parental reports of child HRQL with female children compared with male children (Michel et al., 2009), while others have found no gender differences in reports of child HRQL (Haraldstad et al., 2011). Overall, there does not appear to be clarity within the literature regarding differences in parent report of distress or child HRQL based on child gender. Future research is needed to explore this topic further. In the regression model predicting family conversation orientation, only the sex of the child predicted family conversation orientation. There is little evidence that one gender elicits specific types of communication; however, there is some evidence that the type of communication might vary by parent-child gender congruence, with mothers and daughters having more open conversation styles (Schrodt et al., 2009). Future studies may be warranted to explore female gender as a potential risk factor for reductions in child HRQL and parental distress when communication styles are altered due to chronic illness.

Aim 2: To examine the relationship between parental coping skills, family conversation and conformity orientation, parental style, and child health-related quality of life.

The goal of this aim was to examine which family variables were related to child HRQL and thus, should be included in a family-focused intervention. Previous studies that attempted to improve parental and family functioning did not show significant changes in child HRQL. However, many of these studies focused primarily on parental distress to improve child functioning. In addition, when the entire family was involved in the intervention, family members were often separated into different groups rather than receiving an intervention focused on the family unit as a whole. For example, one program involved separate group sessions for cancer patients, siblings, and parents. The groups meet three times, once to discuss how cancer has affected them, once to discuss CBT coping skills, and once to discuss moving forward (Kazak et al., 1999). However, many of the previous studies, such as the Kazak and colleagues study (1999), did not include specific modules or skills aimed at family factors, and instead, attempted to improve individual factors for each family member in order to improve the system as a whole.

We hypothesized that families with greater coping skill utilization, more open communication styles, higher family conversation orientation, lower family conformity orientation, and more positive and less negative parenting styles would report greater levels of child health-related quality of life. We also hypothesized that families with more open communication styles would utilize more coping skills. Preliminary and exploratory bivariate correlations found a significant relationship between child health-related quality of life and family conversation orientation, coping skill utilization, positive parenting styles, and negative parenting styles. Child HRQL was not significantly associated with family openness

to discussing diagnosis and health-related information or family conformity orientation. This suggests that an overall atmosphere of openness where individual family members feel comfortable bringing up emotional or difficult topics is more important than simply discussing diagnosis-related information. A recent study of family communication among children diagnosed with epilepsy found that families with higher family communication were associated with higher child health-related quality of life, as well as more positive illness attitudes and self-perceptions (O'Toole et al., 2021). The same study found that when families communicate openly about their child's diagnosis, but those conversations are filled with negative emotions, children have more negative opinions about their diagnosis (O'Toole et al., 2021). This finding highlights that open communication about a diagnosis is not enough to improve child functioning: a family environment where negative topics can be discussed in an open and honest way, without negative family emotions about the conversation (i.e., getting upset that a difficult topic was brought up), is a key factor for improving child adjustment to a diagnosis and future well-being.

In addition, the directionality of these relationships suggests that higher parent ratings of child HRQL were related to lower levels of both positive and negative parenting, higher levels of family conversation, and lower levels of coping skill utilization. Initial bivariate correlations confirmed the original hypothesis that higher child HRQL would be associated with more open family conversation styles and lower levels of negative parenting. In the initial bivariate correlations, child age was also associated with child HRQL, conversation orientation, conformity orientation, and negative parenting. The directions of these associations suggests that older child age is associated with higher HRQL, higher conversation orientation, lower conformity orientation, and lower negative parenting.

Previous literature suggests that the age of the child may be associated with varying risks among domains of child HRQL. For example, cognitive late effects of pediatric cancer are more likely the younger the child was at diagnosis (Vannatta et al., 2009), while adolescents are at the highest risk for psychological and social impairments (Vannatta et al., 2009). In addition, as children age and become more emotionally mature, it is expected that parents will increase their openness about difficult topics while children may attempt to assert their own opinions, leading to greater conflict between parent and child ideas (Koerner & Fitzpatrick, 2006). Thus, child age was included in the model that predicted child HRQL but was not significant after the addition of family factors (family conversation orientation, family conformity orientation, positive parental coping, positive parenting style, and negative parenting style). This suggests that the relationship between child age and child HRQL may be mediated by family conversation orientation.

Further models found that when child age, family conversation, coping skills, and parenting style were added to the model, only increased family open conversations and lower positive parental coping skill utilization predicted higher levels of child HRQL. Many forms of positive parenting are associated with improved family conversation orientation. For example, a study of children with epilepsy found that authoritative parents who promoted open communication had children with higher levels of health-related quality of life (O'Toole et al., 2021). Thus, when both family conversation styles and parenting styles were added to the model, conversation orientation more strongly predicted child HRQL. Additionally, the lower levels of positive parental coping skill utilization may represent a higher need for coping skills when children have poorer health-related quality of life.

However, the finding that higher levels of child HRQL were associated with less positive coping skill use and lower levels of positive parenting did not support the initial hypothesis. Further examination of the positive parenting subgroups (warmth, supportiveness, positive reinforcement, and proactive parenting) found that higher levels of child HRQL were associated with lower reports of proactive parenting only; other subgroups were not found to be significantly related to child HRQL. Proactive parenting involves responding to potential difficulties before the child faces them (Parent & Forehand, 2017). Proactive parenting is similar to overprotective parenting, which the literature suggests is associated with reductions in child HRQL.

Aim 3: To assess the qualitative information regarding perceived helpfulness and potential barriers to a family-focused intervention during treatment, as well as specific family stressors and coping strategies.

Qualitative data was organized into themes using a systematic, data-driven thematic review process (Braun & Clarke, 2006). Overall, families reported that they would like an intervention that targeted family functioning in order to improve their child's health related quality of life. Many families responded very positively to the idea, saying, "I would do literally ANYTHING to improve my son's quality of life, so totally yes." Previous qualitative data suggested that families were more focused on their children and would prioritize their child's mental health over their own functioning. Qualitative interviews of families whose children were undergoing treatment for cancer found that parents were ambivalent about treating their own distress, preferring to help their children (Hocking et al., 2014). This suggests that although parents were less willing to receive services for themselves, if an intervention is framed as improving the functioning of the entire family and advertised as

seeking to improve health-related quality of life for the child diagnosed with a chronic illness, parents are more likely to express a desire to participate.

In addition, several themes arose throughout the responses to the open-ended questions. Parents reported in multiple places that they desired social support and a sense of community with other families who understood their experience. There are many support groups for parents, siblings, and children diagnosed with chronic illnesses. However, the participants in the study continually brought up including components of social support within an intervention. This points to the difficulty families have in locating quality community-based support groups on their own. Even when families attempt to find online support on their own, continued participation in groups is variable. One study that examined data from large internet-based support groups for chronic illnesses found that about 60% of individuals who register with online groups did not continue interacting with the group after registering (Wang et al., 2012). The same study found that participation increased when strong emotional bonds and support were offered within the online community (Wang et al., 2012) as compared to knowledge-based support. This suggests the importance of care teams in connecting families with quality support groups, either online or in their communities. Another theme that parents frequently reported included wanting information and skills-based help that would improve their child's quality of life. Some families specifically mentioned wanting help with "more communication skills" and others mentioned psychological or psychoeducational components that would improve their family functioning. This is particularly important given the previous literature's agreement that family communication styles impact child quality of life.

When asked about barriers that would impact their ability to participate in a family-based intervention, the most common answers included financial and logistical barriers. Many families mentioned needing financial support, improved access to resources, and help addressing unexpected costs as difficulties that they faced during the diagnosis and treatment stages of their child's chronic illness. Several studies have found that financial strain affects a large portion of families who have a child with a chronic illness. Childhood chronic illnesses are associated with a variety of costs, including medical care, medication, transportation, and time away from work. Additionally, in a study of cancer patients, financial hardships and lost income were found across all income levels but the burden of these financial difficulties disproportionately affected families in lower income brackets (Bona et al., 2014). This financial strain has also been associated with decreased family-functioning (Pelletier & Bona, 2015) and increased levels of caregiver distress and maladjustment (Galtieri et al., 2022). These findings highlight the need for continued involvement of social workers and case managers in aiding families who are navigating a pediatric chronic illness diagnosis.

In addition, other barriers mentioned included time, location, and lack of support from medical and insurance institutions. A randomized controlled trial examining the feasibility and effectiveness of a three-session parental intervention given within the first month of a child's cancer diagnosis found that although parents who participated found the intervention helpful, the feasibility of the intervention was questionable based on the low participation rate (23%) (Stehl et al., 2008). Families in the study mentioned that they required more flexibility during the time of their child's hospitalization and initial treatment due to the sheer number of appointments, as well as high levels of parent and child distress (Stehl et al., 2008). In this current study, many participants commented about "not having

enough time to do what they have to do already, much less adding in something else.” Other comments included: “location, I am not sure if this is something that needs to happen where you are in close proximity to something or someone, but location could potentially be a problem.” Taken together this suggests that families require flexible and accessible interventions that work around their medical appointments and are given in convenient locations in order to increase participation.

Finally, when asked about what they currently do to manage distress, families described a mixture of both beneficial and potentially harmful coping skills. Some families noted that they continue to spend quality time as a family, such as attending family get togethers and taking family vacations. Prior research has demonstrated the importance of continuing with family routines, such as family gatherings for holidays or important dates. Other families reported that they sought support from friends, family, and religion. However, other families stated that they withheld information from their child. One caregiver stated that they, “try not to show this problem to the child, letting him have a normal life, as much as possible.” Unfortunately, research suggests that children adjust better to their diagnosis when parents have open and honest conversations with them about their diagnosis and treatment (Last & Van Veldhuizen, 1996; Slavin et al., 1982). In addition, other families reported that they attempted to spoil or indulge their child to cope with the distress of their diagnosis and treatment. The research on overindulgence and overprotection during the treatment process is mixed. Some research suggests that during acutely vulnerable periods, such as during chemotherapy, parental overprotection helps children adjust to the hardships of treatment (Fedele et al., 2011). However, when parental overprotection continues past the acute phase of a chronic illness diagnosis, it has been associated with poorer long-term

outcomes (Fedele et al., 2011). Thus, it will be important for providers who implement interventions with chronic illness communities to carefully validate positive coping strategies while also providing information on more effective long-term strategies.

Clinical Implications

Overall, the findings of this study suggest that within this sample, lower child health-related quality of life was associated with higher levels of parental beliefs that their child is vulnerable, lower levels of open communication in the family, higher parent coping skill use, higher levels of proactive parenting (i.e., responding to difficulties before they occur), and higher negative parenting styles (harsh and coercive parenting). In adjusted models, parent beliefs that their children were vulnerable, open communication, and parent coping were all significant predictors of child health-related quality of life. Thus, when considering which factors would be important to include within an intervention that focused on family-functioning in order to improve the health-related quality of life of a child diagnosed with a chronic illness, targeting parent perceptions and beliefs about their child's diagnosis and health, helping parents foster an environment of openness, and improving the coping of families should be included.

In many of the models run for this study, parent perceptions of child vulnerability were one of the most important predictors of child health-related quality of life. This is consistent with a wealth of literature that has made the connection between parent perceptions of child vulnerability and child outcomes. However, this study was unique in examining other parent variables in conjunction with parent perceptions, pointing to the overwhelming importance of targeting parent beliefs about their child in order to improve child outcomes. Specifically, parents who believed that their children were more vulnerable

also were more likely to engage in proactive parenting and be more overprotective, potentially acting as one pathway through which parental perceptions of child vulnerability influence child HRQL. This may be due to beliefs that children are more vulnerable and therefore require more help or protection. Thus, helping parents to understand their child's health status and realistic levels of vulnerability could help parents to promote independence and autonomy in their children, which previous studies have linked to improved outcomes in child cancer survivors (Erickson et al., 2022). Parents who believe that their children are more vulnerable also endorsed higher levels of parent distress, which have both frequently been cited as important (negative) correlates of child health related quality of life in the literature. Previous studies have speculated that parent beliefs that their child is more vulnerable may be caused by higher levels of parental distress and therefore be a pathway through which parent distress influences child HRQL. In this study, parental perception of vulnerability was a better predictor of poor child HRQL than parent distress, adding to the evidence of this claim. Therefore, even if targeting parent distress is not feasible, targeting the way that parent distress influences their beliefs about their children may be the more appropriate intervention target. Additionally, parents who endorsed higher beliefs that their children were more vulnerable also endorsed higher positive coping skill use, which may be indicative of parental attempts to reduce higher levels of distress.

Parents who believed that their children were more vulnerable also reported less family conformity and higher levels of negative parenting. Other studies have linked reduced warmth and autonomy support combined with higher levels of harsh and controlling parenting with reductions in child HRQL in children with cerebral palsy (Aran et al., 2007). Perceptions that their child is more vulnerable may cause parents to tighten control in an

attempt to protect their child. Thus, intervening with both parental beliefs and behavior is likely important in a future intervention. This also suggests the importance of interdisciplinary work in addressing these factors, where a physician or patient educator may be more uniquely placed to improve parental beliefs about their child's vulnerability. In open-ended questions, many parents mentioned seeking further education or awareness about their child's diagnosis and treatment as important components, others suggested psychoeducational pieces. These requests for information or psychoeducation about their child's health align with the finding about parent perceptions of child vulnerability, adding further evidence of the importance of this component. Therefore, an interdisciplinary approach utilizing psychoeducation about their child's diagnosis, actual vulnerability, and health would be important to combine with other family factors in a family focused intervention.

Another important component of a future intervention would be improving the family communication environment. It was originally hypothesized that families who had more open communication about their child's diagnosis would have better outcomes. However, the data suggests that it is more important for the family to have an overall communication style that promotes open conversations, even about difficult topics. Family members should be comfortable bringing up potentially controversial or hard topics in order to receive support or validation from their family. Importantly, in open ended questions, families asked for specific skills, such as communication skills, to be included within an intervention. Therefore, a future intervention should work towards improving the communication patterns within families.

Positive parent coping skill utilization was also found to be an important predictor of child HRQL, as well as connected to perceptions of child vulnerability. Families who endorsed lower levels of child HRQL endorsed higher positive coping skill use, suggesting a higher level of unmitigated distress among these families. Additionally, families had noted that specific psychological skills should be included in an intervention, indicating the importance of positive coping strategies as part of a family focused intervention. The emphasis should be on positive strategies, since several families reported methods of coping that have traditionally been associated with poorer outcomes, such as withholding information from their child or spoiling their child.

Furthermore, a wealth of literature discusses the link between parental distress at children's chronic illness diagnosis and parent perceptions of child vulnerability and parent overprotection. Further research suggests a link between the overall functioning of the family and the functioning of a child with a chronic illness. However, little research has examined the connection between these parent variables and family factors. For example, parental perceptions of child vulnerability were found to be associated with positive parenting style, parental coping, and family conformity. This suggests that parental beliefs influence the overall functioning of the family such that parents utilize harsher and more controlling parenting methods and family conflict is increased when a parent endorses high vulnerability. Another parent factor, parental overprotection, was found to be positively associated with family openness to discussing diagnosis information and positive parenting. In previous literature, parental overprotection within the diagnosis and acute treatment phase of a child's cancer diagnosis was associated with better outcomes, indicating a place for protectiveness. The final parent variable, parental distress, was not associated with any of the family

variables. This is important because it suggests that despite their distress, parents can still provide a supportive and open environment for their child. Thus, reductions in parent distress, which have been the previous targets of interventions, may not be as important as the overall functioning of the family.

Additionally, a previous study that asked parents to articulate their perceptions regarding an intervention targeting parent distress after a child's cancer diagnosis in order to improve child distress found that parents preferred to ignore their own concerns and focus on their child's distress (Hocking et al., 2014). Upon learning that their child was diagnosed with cancer, parents noted that their whole focus became supporting that child's well-being. Another study that attempted to identify feasibility of a three-session manualized intervention for parents of recently diagnosed pediatric cancer patients found very low participation rates for their intervention (Kazak et al., 2005). This suggests that overall, parents would prefer not to participate in an intervention aimed at parent distress reduction during the diagnosis and treatment phase of pediatric cancer. In addition, when parent distress was successfully targeted in previous interventions, those reductions did not translate into reductions in child distress. However, the parents in the current study reported that they would want to participate in an intervention that aimed at improving family functioning in order to improve child health-related quality of life, counter to the aforementioned study. The response among participants was overwhelmingly positive and many even reported specific components that they hoped would be included. Since previous studies of feasibility have generally been aimed at parent factors, and have been poorly received, the different response among families in this study suggests that focusing on family is key for improving participation. Although parents may be reticent to take time away from their child to focus on themselves, they

appear to be more willing to focus on their family as a whole. Given the lack of success that previous interventions have had these findings point to the importance of a family-focused intervention rather than a parent- or child-focused intervention.

Taken together, it is clear that parental perceptions of child vulnerability are highly related to both family factors and child HRQL, making it a clear target of intervention. In addition, the components that parents asked for in an intervention largely lined up with those that were found to be important in the quantitative portion of the study. Families asked for education or awareness about their child's condition, which would help improve parent perceptions of their child's vulnerability. Families also asked for direct skills, such as communication skills, or psychological skills. These components align with the importance of family open communication and effective coping skill use. Thus, a successful intervention would likely involve interdisciplinary work, with flexible appointments, offer online options, make supportive connections for families, contain a psychoeducational component, and improve the overall family environment by promoting openness and reducing controlling or overprotective parenting techniques.

Limitations and Directions for Future Research

First, given the recruitment strategies, it is possible that selection bias may have affected the representativeness of the cancer patients and other children with chronic illnesses. The low recruitment of cancer patients speaks to the possibility that cancer patients who agreed to participate differed systematically from those who were approached but declined participation. In addition, the online nature of the study may have pulled for families who are currently experiencing higher levels of distress and therefore are searching for answers online. Or alternatively, families with lower levels of distress may have had more

time and interest in participating in research. Also, since families who reported that their child had a cancer diagnosis provided broad diagnostic and treatment information (i.e., the child had chemotherapy, or the child had cancer) instead of specifics, the study was not able to include information about treatment severity or types of cancer among participants.

Additionally, since the hospital and university had specific rules about hospital visitors during Covid-19, a study coordinator was relied upon to give information about the study to pediatric cancer patients. Due to hospital and university policies related to visitors and social distancing, data were not able to be collected on who was invited to participate, who demonstrated interest, and who declined. Thus, overall participation rates were not able to be calculated.

Families also refused to return for a second part of the study, which included a zoom meeting to conduct an attachment script interview. This highlights the importance of streamlining research procedures. This is particularly important among families experiencing high levels of distress or with busy schedules. Also, zoom fatigue due to online school and work meetings may have also prevented participants from being willing to participate in an additional zoom-based study sessions.

An additional limitation of this study was the use of parent reported child health-related quality of life rather than a direct child measure of HRQL. A meta-analysis of literature looking at agreement between parent and child reports of HRQL using the PedsQL found that there was good agreement across all domains of the PedsQL (Upton et al., 2008). However, the authors also reported that several papers suggested that concordance between parent and child reports of HRQL is higher on easier to observe scales, such as physical health, and lower on psychosocial subscales (Upton et al., 2008). Additional research has

suggested that older child age (Uzark et al., 2003) and female gender (Waters et al., 2003) both reduce agreement between children and their parents on measures of child HRQL. However, it is important to note that parent-proxy report is the current best method of determining child HRQL in young children, particularly those who are unable to read or comprehend survey materials. The mean age of children reported in the current study was 7 years of age, with the youngest reported at 2 years of age. Thus, the best method for determining child HRQL for the children within a study using a broad age range would likely be parental report.

Another limitation of this study was the inclusion of multiple chronic illnesses rather than just pediatric oncology patients. Much of the literature of childhood chronic stress focuses on a single illness and extrapolates across other chronic illness populations. However, an article that looked at HRQL across obesity, eosinophilic gastrointestinal disorder, inflammatory bowel disease, epilepsy, type 1 diabetes, sickle cell disease, post-renal transplantation, and cystic fibrosis found differences based on type of disorder (Ingerski et al., 2010). In this study, children diagnosed with cancer did not have significantly different ratings of child HRQL compared to children diagnosed with other chronic illness diagnoses; but parents of children with cancer had a higher level of parent distress compared to parents of children with other chronic illnesses. Future research using larger sample sizes of both children with cancer diagnoses and children with other chronic illnesses would be important to determine the generalizability of the findings across all illness groups or to detect true group differences.

An additional limitation is that this study was conducted during the Covid-19 pandemic. The pandemic, particularly in the early months, added additional stress to families

already struggling with vulnerable children. New research on the pandemic indicates that, in general, both parents and children are living with elevated levels of stress (Cluver et al., 2020; Imram et al., 2020; Serlachius et al., 2020). Further research has shown increases in overall family stress and disruptions in family routines that have increased anxiety in both parents and children (Serlachius et al., 2020). Additionally, Covid-19 has disrupted many services that families of children with chronic illnesses rely on to improve their children's HRQL, such as occupational therapy, physical therapy, speech therapy, psychological services, social support groups, and academic services. Research suggests that the lack of these supports may have impacts including increased behavioral problems, social withdrawal, and internalizing problems (Imram et al., 2020). Given the heightened stress levels and changes in the pandemic across the past 18 months, parent distress and other parent and family variables may have been inflated or altered across the board based on their reaction to the pandemic. The current study did not include questions regarding specific family reactions to the pandemic. Future research on the impacts of the Covid-19 pandemic on families of children with chronic illnesses will be important, as chronic stress has long-term mental health implications.

Additionally, although the majority of the measures used within this study demonstrated a high level of internal reliability both within the normative samples and in the sample collected for this study, two measures had lower than expected internal reliability. The Perceived Stress Scale had been used extensively in the literature and has previously demonstrated an acceptable internal reliability. Within the current sample, the reliability was only moderate, which may have impacted the ability of the analyses to pick up meaningful associations between this measure and other covariates. It was unclear why the internal

reliability of this measure was lower within this study compared to previous literature. Changes in overall stress responses and perceived stress due to the pandemic may have affected participant responses to this questionnaire. The second measure, the Family Openness Questionnaire, was a set of 5 questions used to assess family openness to discuss a child's chronic illness. These questions had been used in a previous study, but the psychometrics had not been reported. Within this sample, the internal reliability of the questions was low, which may have been reflected in the lack of associations between this measure and other covariates.

A final limitation of this study was that family-based intervention was not defined for participants prior to having them complete the open-ended questions. Given the confusing nature of "family-based" within the literature, it is unclear if participants had an adequate understanding of a family system prior to answering the open-ended questions. Future research should include a brief discussion about family systems theory or gather information from interviews where a trained researcher can guide the discussion to ensure that all participants understand the nature of a family-based intervention.

Chapter 7

Conclusion

In sum, this study represents a unique investigation of the connections between parental distress, parent attitudes, parent behaviors, family factors, and child health-related quality of life. The findings offer insight into how parental factors, such as beliefs about their child's vulnerability, overprotective behaviors, and parent distress are associated with one another. Parent education and parent perceptions of child vulnerability both predicted child HRQL. In addition, parent perceptions of child vulnerability were associated with many of the family variables, including family conformity orientation, negative parenting style, and coping skill utilization. This suggests that parents' perceptions that their child is particularly vulnerable is an important target for improving both family functioning and overall child well-being.

This study also looked at the connections between family factors and child HRQL. In an adjusted model, the ability of a family to have open and honest conversations, as well as parent coping skill use, were significantly associated with child HRQL. Thus, targeting family factors and improving both how families communicate with one another and how they cope with their child's diagnosis would be important to include within an intervention.

Finally, families suggested that they would like to participate in a family-based intervention. A family intervention was viewed as more acceptable in this study than an intervention focusing only on parental distress, as targeted in previous studies (Gibbins et al., 2012; Hocking et al., 2014). Families noted that they desired access to a community of other families who understood their experience. Thus, connecting families in person or online could be an important component of an intervention. Families also reported wanting to learn

specific skills, such as better communication or how to cope with stress. They also stated that they wanted psychoeducation components and therapeutic skills for their child. Thus, the inclusion of educational components regarding how to cultivate an environment of openness within their family, how to utilize positive coping skills, and how to provide appropriate support to their children will also be important components. This information is particularly important considering previous interventions focused on reducing parent distress as a means to reduce child distress. Those studies found little evidence that such interventions were helpful in improving child wellbeing. This study suggests that changing the target of a family-focused intervention to parent perceptions of child vulnerability and improving the functioning of the family as a whole would be more beneficial.

Tables

Table 1. Means and frequencies for all dependent and independent variables.

Variable (range)	<u>mean (SD) or frequency (%)</u>
Child Age (2-16)	7.2 (4.2)
Child Sex	
Male	56.1%
Female	43.9%
Child Race/Ethnicity	
Hispanic	34.1%
Non-Hispanic White	43.9%
Black	9.8%
Asian/Pacific Islander	4.9%
Native American/Alaskan	7.3%
Native	
Cancer Diagnosis	
Cancer	34.1%
Other Chronic Illness	65.9%
Parent Race/Ethnicity	
Hispanic	34.1%
Non-Hispanic White	43.9%
Black	7.3%
Asian/Pacific Islander	4.9%
Native American/Alaskan	7.3%
Native	
Maternal Age (24-51)	32.2 (6.2)
Paternal Age (25-57)	35.2 (7.6)
Parent Education	
Some High School, High School Diploma, or GED	4.9%
Some College or Associate's Degree	7.3%
Bachelor's Degree	51.2%
Master's Degree, Professional Degree/Ph.D.	36.6%
Family Income	
Under \$30,000	7.3%
\$30,000 - \$50,000	29.3%
\$50,000 - \$80,000	41.5%
\$80,000-\$100,000	12.2%
Over \$100,000	9.8%
Family Openness (0-15)	11.4 (2.0)
Child HRQL (0-100)	38.6 (18.3)
Parent Distress (0-40)	20.8 (4.8)
Child Vulnerability (0-36)	23.4 (6.7)
Family Conversation (1-7)	4.2(1.2)

Table 1: *Descriptive Statistics* (Continued)

Family Conformity (1-7)	3.5 (1.2)
Coping (36-144)	101.6 (16.5)
Positive Parenting (1-5)	3.7 (0.7)
Negative Parenting (1-5)	3.0 (1.1)
Parental Overprotection (0-75)	52.4 (9.1)

Table 2: *Correlations and ANOVA of sociodemographic variables by family, parent, and child measures.*

	<u>Correlation[^]</u>		<u>ANOVA^{^^}</u>			
	Child Age	Child Race/ Ethnicity	Child Sex	Cancer Diagnosis	Family Income	Parent Education
Family Openness	-0.304	1.034	1.77	2.927	5.043**	1.002
Child HRQL	0.327*	1.335	7.384*	0.283	2.268	5.819**
Parent Distress	-0.031	2.191	3.987*	10.212**	0.801	1.465
Child Vulnerability	-0.133	1.344	1.273	0.002	2.315	1.207
Family Conversation	0.580***	0.970	5.951*	1.674	2.428	1.627
Family Conformity	-0.358*	1.484	2.456	7.841**	1.097	0.547
Coping Positive	-0.018	1.911	0.600	1.311	0.766	1.486
Parenting Negative	0.158	1.741	0.431	0.375	1.268	0.251
Parenting Parental Over Protection	-0.545***	0.662	1.876	1.998	1.562	1.861
	-0.247	1.370	2.802	2.103	2.238	3.231*

*p < .05, ** p < .01, ***p < .001
[^] Pearson r value
^{^^} F value

Table 3. *Correlations between family variables, child HRQL, and parent variables.*

	Child Vulnerability	Parental Over- protection	Parental Distress	Positive Coping	Family Conversation	Family Conformity	Family Openness	Positive Parenting	Negative Parenting
Child HRQL	-0.594***	-0.308	-0.263	-0.438**	0.629***	0.298	-0.277	-0.338*	-0.578***
Child Vulnerability	1.00	0.351*	0.354*	0.732***	-0.211	-0.371*	0.165	0.623***	0.451**
Parental Over- protection		1.00	-0.046	0.243	<0.001	0.027	0.440**	0.348*	0.255
Parental Distress			1.00	0.201	-0.148	0.281	-0.081	0.219	0.099
Positive Coping				1.00	0.018	-0.254	0.108	0.676***	0.239
Family Conversation					1.00	0.112	-0.132	0.084	-0.690***
Family Conformity						1.00	0.114	-0.374*	-0.130
Family Openness							1.00	0.213	0.037
Positive Parenting								1.00	0.051
Negative Parenting									1.00

*p < .05, ** p < .01, ***p < .001

Table 4. *Coping skill utilization predicted by parental perceptions of child vulnerability, parental overprotection, and parental stress.*

	<u>Unstandardized Coefficients</u>		<u>Standardized Coefficients</u>			F	R ²	F Change Significance
	B	Standard Error	Beta	t	Significant			
Analysis 1: Addition of Child Vulnerability						39.151***	0.535	<0.001
Child Vulnerability	1.824	0.292	0.732	6.257	<0.001			
Analysis 2: Addition of other Parent Variables						12.302***	0.536	0.986
Child Vulnerability	1.851	0.339	0.742	5.453	<0.001			
Parental overprotection	-0.032	0.237	-0.018	-0.137	0.892			
Parent Distress	-0.054	0.477	-0.015	-0.114	0.910			

*p < .05, ** p < .01, ***p < .001

Table 5. *Family conversation orientation predicted by child sex, parental perceptions of child vulnerability, parental overprotection, and parental stress.*

	<u>Unstandardized Coefficients</u>		<u>Standardized Coefficients</u>			F	R ²	F Change Significance
	B	Standard Error	Beta	t	Significant			
Analysis 1: Addition of Child Sex						5.665*	0.143	0.023
Child Sex	0.943	0.396	0.378	2.380	0.023			
Analysis 2: Addition of Parent Variables						1.853	0.193	0.594
Child Sex	1.027	0.442	0.412	2.324	0.027			
Child Vulnerability	-0.042	0.034	-0.221	-1.213	0.2334			
Parental Overprotection	0.027	0.025	0.193	1.057	0.299			
Parent Distress	0.015	0.051	0.055	0.303	0.764			

*p < .05, ** p < .01, ***p < .001

Table 6. *Family conformity orientation predicted by child cancer diagnosis, parental perceptions of child vulnerability, parental overprotection, and parental stress.*

	<u>Unstandardized</u>		<u>Standardized</u>		t	Significant	F	R ²	F Change
	<u>Coefficients</u>	<u>Coefficients</u>	B	Standard Error					
Analysis 1: Addition of Child Cancer Diagnosis							7.435*	0.179	0.010
Cancer Diagnosis	-1.097	0.402	-0.423	-2.727	0.010				
Analysis 2: Addition of Parent Perception of Child Vulnerability							7.818**	0.321	0.013
Cancer Diagnosis	-1.121	0.372	-0.433	-3.016	0.005				
Child Vulnerability	-0.073	0.028	-0.377	-2.682	0.013				
Analysis 3: Addition of Parenting Distress							5.089**	0.323	0.792
Cancer Diagnosis	-1.178	0.434	-0.455	-2.714	0.011				
Child Vulnerability	-0.076	0.030	-0.391	-2.527	0.017				
Parenting Distress	0.013	0.051	0.046	0.266	0.792				
Analysis 4: Addition of Parent Overprotection							3.763**	0.327	0.675
Cancer Diagnosis	-1.141	0.448	-0.440	-2.545	0.016				
Child Vulnerability	-0.081	0.032	-0.416	-2.484	0.019				
Parenting Distress	0.015	0.052	0.050	0.283	0.779				
Parental Overprotection	0.010	0.023	0.069	0.423	0.675				

*p < .05, ** p < .01, ***p < .001

Table 7. *Family openness predicted by parental perceptions of child vulnerability, parental overprotection, and parental stress.*

	<u>Unstandardized Coefficients</u>		<u>Standardized Coefficients</u>			F	R ²	F Change Significance
	B	Standard Error	Beta	t	Significant			
Analysis 1: Addition of Parental Overprotection						8.163	0.170	0.007
Parental Overprotection	0.095	0.033	0.440	2.857	0.007			
Analysis 2: Addition of other Parent Variables						2.698	0.127	0.848
Parental Overprotection	0.091	0.037	0.421	2.460	0.019			
Child Vulnerability	0.013	0.053	0.043	0.241	0.811			
Parent Distress	-0.042	0.074	-0.096	-0.572	0.571			

*p < .05, ** p < .01, ***p < .001

Table 8. *Negative parenting style predicted by parental perceptions of child vulnerability, parental overprotection, and parental stress.*

	<u>Unstandardized</u> <u>Coefficients</u>		<u>Standardized Coefficients</u>			F	R ²	F Change Significance
	B	Standard Error	Beta	t	Significant			
Analysis 1: Addition of Child Vulnerability						8.671**	0.203	0.006
Child Vulnerability	0.076	0.026	0.451	2.945	0.006			
Analysis 2: Addition of other Parent Variables						2.907*	0.214	0.802
Child Vulnerability	0.070	0.030	0.418	2.362	0.024			
Parental overprotection	0.013	0.021	0.107	0.633	0.531			
Parent Distress	-0.004	0.042	-0.017	-0.105	0.917			

*p < .05, ** p < .01, ***p < .001

Table 9. *Child HRQL predicted by parental education, parental perceptions of child vulnerability, parental overprotection, and parental stress.*

	<u>Unstandardized</u>		<u>Standardized</u>	t	Significant	F	R ²	F Change
	<u>Coefficients</u>	<u>Coefficients</u>	<u>Beta</u>					
	B	Standard Error	Beta					Significance
Analysis 1: Addition of Demographic Variables						7.505**	0.313	17.722**
Parent Education	-11.270	3.866	-0.453	-2.915	0.006			
Child Sex	7.215	5.578	0.201	1.2915	0.205			
Analysis 2: Addition of Parent Perception of Child Vulnerability						11.441***	0.518	15.627***
Parent Education	-8.969	3.348	-0.360	-2.679	0.012			
Child Sex	5.748	4.763	0.160	1.207	0.236			
Child Vulnerability	-1.269	0.344	-0.467	-3.686	<0.001			
Analysis 3: Addition of Parental Overprotection						8.351***	0.519	0.737
Parent Education	-9.204	3.506	-0.370	-2.625	0.013			
Child Sex	5.942	4.886	0.165	1.216	0.233			
Child Vulnerability	-1.297	0.365	-0.477	-3.559	0.001			
Parental Overprotection	0.076	0.280	0.038	0.271	0.788			
Analysis 4: Addition of Parent Distress						6.647***	0.526	0.640
Parent Education	-9.968	3.723	-0.401	-2.678	0.012			
Child Sex	4.555	5.360	0.127	0.850	0.402			
Child Vulnerability	-1.203	0.395	-0.442	-3.048	0.005			
Parental Overprotection	0.044	0.287	0.022	0.153	0.880			
Parent Distress	-0.397	0.600	-0.097	-0.661	0.514			

*p < .05, ** p < .01, ***p < .001

Table 10. *Child HRQL predicted by child age, family communication, coping skill utilization, and parenting style.*

	<u>Unstandardized</u> Coefficients		<u>Standardized</u> Coefficients		t	Significant	F	R ²	F Change Significance
	B	Standard Error	Beta						
Analysis 1: Addition of Child Age							4.824*	0.124	0.035
Child Age	1.532	0.698	0.352	2.196	0.035				
Analysis 2: Addition of Family Communication Variables							9.052***	0.459	<0.001
Child Age	0.636	0.829	0.146	0.768	0.448				
Conversation Orientation	7.381	2.584	0.513	2.856	0.007				
Conformity Orientation	4.026	2.153	0.287	1.870	0.071				
Analysis 3: Addition of Coping Skill Utilization							12.329***	0.614	0.001
Child Age	0.102	0.727	0.024	0.141	0.889				
Conversation Orientation	8.799	2.254	0.611	3.904	<0.001				
Conformity Orientation	1.786	1.954	0.127	-0.914	0.368				
Coping	-0.454	0.129	-0.417	-3.528	0.001				
Analysis 4: Addition of Parenting Style							8.061***	0.625	0.654
Child Age	0.050	0.769	0.011	0.065	0.949				
Conversation Orientation	8.298	2.639	0.576	3.144	0.004				
Conformity Orientation	1.275	2.066	0.091	0.617	0.543				
Coping	-0.340	0.180	-0.312	-1.890	0.069				
Negative Parenting Style	-3.526	4.146	-0.139	-0.850	0.402				
Positive Parenting Style	-1.306	2.828	-0.081	-0.462	0.648				

*p < .05, ** p < .01, ***p < .001

Table 11. *Kappa scores between consensus codes and blind coder for themes on each open-ended question.*

Question	Kappa Score
1	0.855
2	0.956
3	0.944
4	0.939
5	1.00

Table 12. *Responses to open-ended questions.*

Theme	Example(s)	N	%
Question 1: Would you find an intervention to help families improve the quality of life for children diagnosed with a chronic illness helpful?			
Yes	“I would do literally ANYTHING to improve my son's quality of life, so totally yes.”	12	40%
Support	“I would love a community of other families going through similar things to what my family is going through so that we can discuss, support and help each other”	6	20%
Resources	“any resources”	2	6.7%
Awareness/Education	“bring more awareness to the diseases”	3	10%
Psychological	“support their self esteem and spending time caring them and giving them positive thoughts”	4	13.3%
No		2	6.7%
Question 2: What components would you want included in a family-based intervention to help families improve the quality of life for children diagnosed with chronic illness?			
Community	“I would want a community of other families that are going through similar situations that we can post stories and have others comment and give support through their words. It would also be great if there was a way to find other children close by that are going through something similar as my son that he could meet and finally have someone that truly understands him, what he's going through, and how he feels, because no matter how hard I try, I will never fully understand what he goes through.”	3	10%
Skills-based learning	“More communication skills”	4	13.3%
Resources	“financial help that doesn't require paperwork, forms, etc.”	5	16.7%
Online	“A lot of interactions and online availabilities.”	1	3.3%
Psychological	“psychologists and courses”	4	13.3%
Psychoeducation		2	6.7%
Therapist/counseling	“timely counseling”	6	20%
None/Don't Know		2	6.7%
Question 3: What barriers do you think might get in the way of families participating in an intervention to help improve the quality of life for children diagnosed with chronic illnesses?			
Financial	“Financial costs getting in the way.”	5	16.7%

Location	“location, I am not sure if this is something that needs to happen where you are in close proximity to something or someone, but location could potentially be a problem”	2	6.7%
Time	“Not having enough time to do what they have to do already, much less adding in something else”	2	6.7%
Lack of Support	“inadequate support from medical insurance firm”	3	10%
Taboo	“Taboo and any diseases that are private”	1	3.3%
Psychological Distress	“they feel very sad to others talking”	3	10%
Lack of Knowledge	“Lack awareness,” “Ignorance”	2	6.7%
None/Don’t Know		1	3.3%
Physical Health	“Sometimes they feel low”	2	6.7%
	“family's dealing with intense medical treatments”		
Question 4: What has been the most stressful part of the chronic illness diagnosis and treatment process for your family?			
Financial	“Having to deal with all the unexpected expenses!”	3	10%
Lack of Support	“The uncertainty and feeling like we have a lack of support. I would love to join a group in my area with other parents of a child with cancer or a serious illness, we could be friends and support each other because besides my husband, we don't have much outside support or help.”	2	6.7%
Timely Appointments	“Able to forward to medical appointments with a faster time.”	1	3.3%
Late Effects	“The end results and the permanent damage it costs”	1	3.3%
Psychological/Physical Distress	“emotions and manage the emotional effects of cancer, including anger, fear, stress, and depression”	11	36.7%
Treatment	“Chemotherapy, very disheartening time”	2	6.7%
None/Don’t Know		3	10%
Question 5: What does your family do to help cope with the stressors of having a medically complex child?			
Spoil/Indulge Child	“One night of every other week we have an evening filled with whatever my son wants to do, whether it be dinner and a movie in the theater, or the day spent at an arcade, whatever he wants, we do for that day, once every other week.”	3	10%
Parent Self-Care	“My husband and I also make sure to take some time for ourselves every week, sometimes I go shopping or to the spa to pamper myself, and my husband will go golfing or out with his male friends.”	1	3.3%
Withholding Information	“Try not to show this problem to the child, letting him have a normal life, as much as possible.”	2	6.7%

Quality Family Time	“Always make sure we take time to spend together as a family like get togethers and vacations.”	2	6.7%
Psychological Support	“Know your own stress cues. Practice deep breathing or mindfulness.”	5	16.7%
Religion	“we put lot of hope in God and we used to pray during stressful situation which made us to handle those anxiety depression”	4	13.3%
Knowledge	“take it easy and research about”	2	6.7%
Social Support	“We bring other family into our home, we enjoy much love from other people”	3	10%
None/Don't Know		4	13.3%

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