

PARENTAL SPIRITUAL COPING WITH A CHRONICALLY ILL CHILD

by

Chelse D. Cudmore

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Director of Thesis: Dr. Alan Taylor

Major Department: Human Development and Family Science

Upon the diagnosis of a chronic condition for a child, the stressors can be multiple, ongoing, and have the potential to frequently change over the prolongation of the health care journey and affect all members of the family system. The effects of stress on parents are facilitated by their cognitive assessments and coping mechanisms. A large number of people use their spiritual beliefs as a coping mechanism to understand, assign meaning to, and deal with negative life events. The purpose of the current study is to recognize the complexity of stressors for parents with a chronically ill child and to evaluate the presence and effectiveness of spiritual coping on these stressors. An online survey and in-person interviews were conducted for a mixed methods approach. A total of 30 individuals participated in the survey portion and 8 parents were interviewed. Descriptive statistics, a multiple regression, and correlation tests were conducted to analyze the survey portion while the interviews were recorded for a thematic analysis. Although an individual's coping and spirituality do not bilaterally help to decrease the level of parental stress, an individual's spirituality does have significant contributions to the level of parental stress. The thematic analysis revealed the following four themes including: (1) parental spirituality has grown stronger, (2) effectiveness of emotional/instrumental social support, (3) fear of the unknown of child's future abilities, and (4) having a greater appreciation for life in general. An in depth understanding of parental stress in regards to having a chronically ill child,

coping mechanisms, and spirituality are discussed in addition to the implications developed from the results of the current study.

PARENTAL SPIRITUAL COPING WITH A CHRONICALLY ILL CHILD

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by

Chelse D. Cudmore

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by

Chelse D. Cudmore

APPROVED BY:

DIRECTOR OF THESIS: _____
(Alan Taylor, PhD)

COMMITTEE MEMBER: _____
(Ebony Baugh, PhD)

COMMITTEE MEMBER: _____
(Sandra Lookabaugh, PhD)

CHAIR OF THE DEPARTMENT OF HUMAN DEVELOPMENT AND FAMILY SCIENCE

(Sharon Ballard, PhD)

DEAN OF THE GRADUATE SCHOOL

(Paul J. Gemperline, PhD)

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CHAPTER 1: INTRODUCTION

Approximately 20-30% of children under the age of eighteen living in the United States have some type of chronic condition (Brown et al., 2008). Of this group, as many as one to two million children have a severe chronic condition. The life expectancy of chronically ill children and the survival of more severely impaired children has increased due to advances in medical treatment (McCubbin, 1988). The University of Michigan Health System defines a chronic health condition as a “health problem that lasts over three months, affects your child’s normal activities, and requires lots of hospitalizations and/or home health care and/or extensive medical care” (University of Michigan Health System, n.d.). Children who live with a chronic condition can be ill or well at any given time, but the fact remains that they are always living with the condition. Some common examples of chronic conditions in children include: asthma, diabetes, cerebral palsy, sickle cell anemia, cystic fibrosis, cancer, epilepsy, spina bifida, congenital heart problems, etc. Chronic illnesses are more associated with the “care” of the health condition rather than the hope for a “cure”. The presence of a chronic illness has a significant impact on the whole family system (Melnyk et al., 2001). The purpose of this thesis is to recognize the complexity of stressors for parents with a chronically ill child and to evaluate the presence and effectiveness of spiritual coping on these stressors.

With the realization that a chronic health condition affects all members of a family system, a variety of stressors are often experienced by the ill child, their healthy siblings, and with an emphasis on the parents of the child. The stressors can be multiple, ongoing, and can frequently change over the prolongation of the health care journey. A few examples of stressors for these families include: “financial stress, role strains, separations, adjustment to various components of the medical system, interruptions in daily routines and plans for the future, and

the general uncertainty with regard to the child's prognosis" (Brown et al., 2008, p. 409). These stressors can be categorized into four areas of significance, including: at the time of diagnosis, during developmental transitions, ones that are related to the ongoing health care needs of the child, and as the child experiences illness exacerbations and hospitalizations. Recurrent emotions and stressors can be described as chronic sorrow, which allows periodic grieving (Melnik et al., 2001).

CHAPTER 2: REVIEW OF LITERATURE

Stressors among Chronically Ill Children and Parents

Diagnosis. The time of diagnosis can often be seen as one of the most stressful events for parents due to confusion, denial, and shock. Full comprehension and acceptance is not experienced with the initial diagnosis. Prior to the actual diagnosis, parents often experience the initial impact when they realize something is “going on” or “not right” with their child. Parents are frightened, frustrated, vulnerable, and overwhelmed by stress while searching for a diagnosis of their ill child and often allow their imagination to run wild with possibilities (Sallfors & Hallberg, 2003). The principal stressor at the time of diagnosis is “uncertainty of the child’s condition and his/ her potential outcomes” (Cohen, 1993; Melnyk et al., 2001, p. 548). Not being able to care for, protect, and parent the child is extremely stressful along with the potential separation or loss of their child. Common emotions and parental responses to the diagnosis include shock, disbelief, denial, anger, despair, depression, frustration, confusion, guilt, lack of confidence, etc. The array of stressors that follow the initial diagnosis have a tendency to continue for months following. The question of who to tell and how to communicate with health care providers is often another difficulty for parents in this situation (Melnyk et al., 200; Knafl, Ayres, Gallo, Zoeller, & Breitmayer, 1995; Perlman, 1986).

Developmental Transitions. Depending on the nature of the chronic illness, the health condition may have a negative effect on the child’s physical, cognitive, and/or emotional health which can significantly alter developmental transitions and make these tasks more challenging. Parents of these children often experience recurrent negative emotions and responses as they notice their child struggling to attain developmentally appropriate tasks (Melnyk et al., 2001). Winkler (1981) identified ten “crisis points” for parents regarding developmental milestones

which include: (1) 12-15 months when walking is usually accomplished; (2) 24-30 months when delayed speech may become noticeable; (3) age 6 when the child enters school; (4) the beginning of adolescent years; (5) age 21 when the child transitions from pediatric care to adult roles and health care; (6) time of diagnosis; (7) the time at which possible institutionalization occurs; (8) the point in time when younger siblings exceed past the ill child in developmental tasks; (9) occasions when professionals need to intervene in the care; and (10) situations when parents address guardianship issues. The entrance to school is often the first time parents realize the extent in which their child is different than their peers. Children may encounter “teasing, difficulties with establishing friendships, and challenges performing age-appropriate activities” (Melnyk et al., 2001, p.549; Trachtenberg & Batshaw, 1997).

The establishment of parent-infant attachments in families with a chronically ill child are sometimes difficult to form because of parental disappointment, anger, guilt, grief, and/or parental fear that their child may not survive. Challenges of developing autonomy, initiative, and mastery over the environment affect chronically ill children. Parents often experience additional difficulties with parenting and they desire to promote their child’s development, but are torn with “wanting to protect and assist their child with what they perceive he/ she is unable to accomplish” (Melnyk et al., 2001, p. 549). Vulnerable child syndrome is the result of parents often viewing their ill child as fragile, vulnerable, and different and engage in overprotective parenting. This type of parenting can result in unhealthy parent-child relationships, dependent and demanding children, and increased use of medical care services. Another pivotal point in the parent-child relationship occurs during adolescence. Adolescence is a trying period where parents attempt to maintain sufficient supervision but still allowing their children to be independent and gain autonomy. To decrease parental stress and increase adherence,

“professionals can encourage parents and children to collaboratively manage treatment demands” (Cousino & Hazen, 2015, p. 822).

Ongoing Care. Strenuous day-to-day care is often described as the chronic burden of care by parents. Parents of chronically ill children report that “seeing their children in physical or emotional pain and discomfort is heart-wrenching and frequently triggers overwhelming feelings of guilt and inadequacy” (Melnyk et al., 2001, p. 550; Simon & Smith, 1992). These daily regimens are time consuming, rigorous, and unrelenting which eventually takes a toll on parental relationships and family life. Parents are challenged with role and marital strain and often experience high levels of psychological distress. Ongoing care significantly affects the financial burden of families with health care costs, costs related to housing, other lifestyle modifications, special equipment, etc. (Melnyk et al., 2001; Samuelson, Foltz, & Foxall, 1992).

Exacerbations and Hospitalizations. Deteriorating factors associated with a chronic illness usually require hospitalizations, increased services, and changes in lifestyles. Hospitalizations are especially stressful because it interrupts normal daily routines and forces parents to divide their time between their everyday responsibilities and their hospitalized child (Faulkner, 1996; Melnyk et al., 2001). Many families anticipate major procedures or surgeries which bilaterally give hope and doubt. Chances of this fill the family with a new set of uncertainties and constant worry. Uncertainties are the outcome of not being able to assign meaning to the illness and the unpredictability of the outcome (Hovey, 2005).

Parental Role Strain. The diagnosis of a chronic illness within a family is disruptive to the family course of systematic change and development, including role strain on each member of the family. The different parental roles are complementary and necessary for the family. The father’s role is usually defined as protector, communicator, bread-winner, and teacher. Fathers of

children with a chronic illness often feel like the forgotten parent. Frequently fathers obtain more of a passive role with an attitude of wait and see and are labeled as “the waiting father” (Sallfors & Hallberg, 2003). Fathers often report being torn of the “desire to be with the sick child and their need to work to provide the benefits of employment” (Hovey, 2005, p. 85; McGrath & Huff, 2003). There is a tension that exists for fathers between productive work and the emotional pain of their child’s illness. The highest priority of fathers was to protect their children, therefore, they felt the need to constantly be vigilant even through their vulnerable feelings. Father’s attentiveness is the concern of the whole family and usually takes on the responsibility of spending more time with the healthy siblings and having a more optimistic and hopeful view of their child’s prognosis (Sallfors & Hallberg, 2003).

A mother’s role for a chronically ill child is the primary caregiver and to take responsibility for childcare, doctor’s appointments, and other health maintenance issues. Mothers are more closely emotionally and practically involved in their child’s necessities. Mothers were most affected in their “daily lives by the impact of the child’s disability which caused emotional distress, career disruption, and stressful interfaces with the medical system” (Gray, 2003; Hovey, 2005, p. 86). The term “managing mother” is referred to as a strong willed mother who viewed caring for the ill child as her own responsibility, which is naturally desired by both parents. The mothers critical concern was of her own level of fatigue and worrisome of the child’s peer relationships, morale, and practical daily challenges. The psychological well-being of mothers is fundamental for its own right and to strongly correlate with child outcomes (Berntsson, 2000; Cole & Reiss, 1993; Sallfors & Hallberg, 2003).

Mothers are able to realize that they know their child better than anyone and therefore “develop confidence in their knowledge of and abilities to care for the child” (Gibson, 1995, p.

1206). Once mothers are confident in their knowledge of their child, they take charge of the situation. By doing so, this includes: “advocating for the child, learning the ropes to interact with the health care system, learning to persist to get the attention they need for the child, negotiating with health care professionals so that opinions and requests are heard, and establishing a partnership of mutual respect and open communication between the health care professionals and the mothers” (Belenky, Clinchy, Goldberger, & Tarule, 1986; Gibson, 1995, p. 1206). Mothers develop a sense of personal control and are able to have an active role in their child’s treatment plan. Mothers who participated in the process of empowerment were “associates, collaborators, and participants in their child’s care” (Gibson, 1995, p. 1208).

Parental vigilance includes parent’s anxiety, parental protection, and watchfulness and is the result of “the unpredictable chronic condition itself, and emerges from the emotional challenges associated with the new situational demands” (Sallfors & Hallberg, 2003, p. 197). Parents frequently feel anxious, frustrated, and powerless in terms of not having any control over their child’s illness and not being able to guide the course of their child’s life. Parents report the child’s illness always being in the back of their minds which led them to be overly observant and manage any shift in their child’s status. This overprotective way of parenting can lead to social isolation for the parents and prevent the child from being involved in any normal activities. Parenting a chronically ill child is a balancing act of how much protection is necessary and how much risk is acceptable. It is necessary for parents to “integrate treatment demands with everyday work and social activities, stay hopeful, and set limits for the child’s behavior” (Sallfors & Hallberg, 2003, p. 200).

Several themes that families living with a chronically ill child report include living with anxiety, carrying the burden, and survival of the family unit. The negative impact on the marital

relationship is associated with significant role strain and changes in marital satisfaction. The greatest negative effect on the marital relationship due to the child's illness was a significant decline in their sexual relationship (Brown et al., 2008; Lavee & Mey-Dan, 2003). On the other hand, certain aspects of a relationship are positively affected such as communication, conflict resolution, and interpersonal trust. Some families "report greater cohesion and trust and increased communication as a result of the child's illness" (Brown et al., 2008, p. 410; Lavee & Mey-Dan, 2003; Philichi, 1989).

The Impact of Parenting with Other Siblings. An important topic that parents do not instantly contemplate is how to effectively parent the ill child as well as his/her siblings. Parents normally treat the ill child differently after diagnosis than the other healthy siblings. Parents are encouraged to provide as normal of a household as possible. Younger children with a chronic illness may perceive their health condition as something they have caused, while older children are able to understand easier. Children will experience a wide range of emotions including: guilt, anger, sadness, shame, etc. and may react by withdrawing, having poor performance in school, or having aggressive behaviors. Common feelings of the healthy siblings include feeling ignored, guilty, angry, frustrated, resentment toward the ill child and/or jealousy. Recommendations for parenting an ill child and their healthy siblings are as followed in Table 1 (Lewis, 2007):

Table 1

Recommendations for Parenting an Ill Child and Their Healthy Siblings

Parenting an Ill Child	Parenting Healthy Siblings
Explaining the disease to the child	Explaining the disease to the siblings
Keeping life as normal as possible	Being aware of the typical feelings that siblings may experience
Trying to keep a regular routine at home	Encouraging the siblings not to ignore the disease
Not bending the rules or making exceptions in discipline	Encouraging siblings to ask questions
Planning household chores for all children	Asking the siblings how they are feeling
Avoiding false hope for the ill child	Preparing the children to deal with how other peers will react to the illness
Asking the ill child how he/she is feeling	Setting children up with a support group
Allowing the child to be responsible for his/her own care as appropriate	Spending one-on-one time with all children
Encouraging the child to talk about his/her feelings	

Coping

Theoretical models of stress and coping propose that the effects of stress on parents are facilitated by their cognitive assessments and coping mechanisms. Coping can be adaptive or maladaptive which will predict how successful a resolution for the stressor will be. It is important to recognize that a particular way of coping may be effective in one situation but may not be appropriate in another (Lazarus, 1993; Sallsford & Hallberg, 2003). Coping is the process of “attempting to manage the demands created by stressful events that are appraised as taxing or exceeding a person’s resources” (Lazarus & Folkman, 1984; Taylor & Stanton, 2007, p. 378). Coping resources seek to manage, master, tolerate, reduce, or minimize the demands of a stressful environment. Coping plays a mediating role between stressful events and adaptational outcomes, including depression, anxiety, and adjustment (Manne, Bakeman, Jacobson, & Redd, 1993; Sorgen & Manne, 2002; Tyc, Mulhern, Jayawadene, & Fairclough, 1995). Stress can be defined as “a negative experience, accompanied by predictable emotional, biochemical, physiological, cognitive, and behavioral accommodations” (Baum, 1999; Taylor & Stanton, 2007, p. 378). Each individual will choose which coping strategies to engage in response to his/her cognitive evaluation of the stressful situation (Folkman & Lazarus, 1980). Stress-related changes can affect the autonomic and neuroendocrine systems by: “activating the sympathetic nervous system, which leads to increases in anxiety, heart rate, and blood pressure; and activating the hypothalamic-pituitary-adrenal (HPA) axis, which leads to the production of corticosteroids, which are necessary for energy mobilization, but are implicated in both mental and physical health risks” (Dickerson, Kemey, Aziz, Kim, & Fahey, 2004; Taylor & Stanton, 2007, p. 378). Stress-related changes can lead to negative mental health status eventually if not properly assessed. These negative mental health issues can include anxiety, depression, and

possible physical illnesses and in some cases negatively affect development (Taylor & Stanton, 2007).

In order to determine whether the outcome of coping strategies will be effective, an individual must assess how much control of the event is in their hands. Coping behaviors that are used in situations seen as uncontrollable can be significantly different than the coping strategies used in situations that are controllable. It is the individual's responsibility to match the coping strategy to the extent in which they can control the situation. Controllable situations are closely related to problem-focused coping strategies with the intentions to change the stressor. Emotion-focused coping strategies are more specifically used to manage the emotional distress in uncontrollable circumstances (Sorgen & Manne, 2002). Psychological distress is lower when there is a match between appraisals of control and appropriate coping strategies (Lazarus & Folkman, 1987). Implications suggest for professionals to educate individuals on how to recognize and identify controllable and uncontrollable situations and to teach what types of coping are positively correlated with each (Sorgen & Manne, 2002).

Coping Styles. Research has revealed that coping styles, personalities, and stress levels are significant components of quality of life. Coping styles reveal an “individual's cognitive and behavioral efforts to change certain behaviors with the goal of dealing with specific internal and external environmental demands that are appraised as taxing, or exceeding the individual's own resources” with the core aim being change (Ray, Lindop, & Gibson, 1982; Zhang et al., 2014, p. 2). Coping styles are usually organized according to their anticipated functions: “as directed towards resolving the stressful situation (problem-focused coping); palliating event-related distress (emotion-focused coping); or as approaching or avoiding the sources of stress (approach-versus avoidance-oriented coping)” (Lazarus & Folkman, 1984; Taylor & Stanton, 2007, p. 382).

Coping styles can be classified from least mature to most mature. Immature coping styles consist of withdrawal, fantasy, self-reproach, projection, passive aggression, and acting out. Mature coping styles consist of help-seeking, justification, problem solving, suppression, mature humor, and anticipation. Measuring coping styles is bi-dimensional, with one aspect measuring coping resources for stress and the other addressing specific coping styles. The general coping resource factor delivers a reliable target to analyze coping style management. The measurement of coping styles can include both the perception of coping resources and coping styles (Zhang et al., 2014).

Problem-focused coping emphasizes changing or modifying the cause of the stress. Examples of this can include information seeking or developing strategies to avoid the source of stress. Emotion-focused coping allows an individual to take control over their emotions and manage their response to the stressor. Approach-oriented coping refers to behaviors and thoughts focused on managing the stressor and/or feelings it provokes. Examples of this includes problem solving, seeking social support, and creating room for emotional expression. Research has discovered a connection between approach-oriented coping and positive psychological and physical health. Avoidance-oriented coping refers to an individual denying or minimizing the seriousness of a situation and is considered temporary relief by engaging in a non-related activity (DeMaso & Snell, 2013). This type of coping strategy is usually only effective for short term or uncontrollable situations and is generally related to increased distress, chronic disease progression, and mortality (Suls & Fletcher, 1985; Taylor & Stanton, 2007).

Patient coping style is defined as the “pattern of behavior that characterize the individual when confronting new or problematic situations”; and “recurrent patterns of behavior that characterize the individual when confronting new or problematic situations” (Beutler, Harwood, Kimpara, Verdirame, & Blau, 2011, p. 177). This particular coping style recognizes an

individual's vulnerability to change and the tendency to respond to innovation. Coping style behaviors are repetitive and durable across similar events. Externalizers are described as argumentative, independent, gregarious, and outgoing; typically placing blame on others for their problems; and engaging in acting-out behaviors. Internalizers are described as shy, introspective, and withdrawn and tend to ruminate and take blame for their own problems (Beutler, et al., 2011).

Coping Resources. Coping resources improve the aptitude to manage stressful events and are associated with reduced distress and improved health outcomes. A few examples of coping resources include optimism, psychological control or mastery, positive self-esteem, and social support. Optimism refers to anticipation and belief that good things are more likely to happen than bad things. Personal mastery refers to if an individual feels in control of or able to guide the possible outcomes of a situation. A positive sense of self is protective against hostile mental and physical health outcomes (Taylor & Stanton, 2007).

Social support is defined as “the perception or experience that one is loved and cared for by others, esteemed and valued, and part of a social network of mutual assistance and obligations” (Taylor & Stanton, 2007, p. 381; Wills, 1991). Social support can come from many sources including spouse, family, friends, health care professionals, and other families in similar situations. Positive interactions with similar individuals are encouraging, strengthening, and enlightening (Gibson, 1995). Other traditional coping variables include physical exercise, strategic rest, disputation of irrational thinking (cognitive reappraisal), and pacing of activity (alternate planned periods of activity with regular rest periods) (Vowles, McCracken, Sowden, & Ashworth, 2014). The combination of coping resources predicts higher ability to cope effectively and stress-reducing in difficult situations. Secure individual differences in coping resources

stimulate effective coping with stress and have direct effects on mental and physical health. Some coping resources can change across the adult life course and can change with psychosocial intervention (Taylor & Stanton, 2007).

Parental Coping Involving Healthcare. Successful parenting and dealing with the increased responsibilities and emotional demands of caring for a child with special healthcare needs relies on how the parent copes. Regardless of the severity of their child's illness, parental coping was associated with fewer depressive symptoms. Healthcare professionals must emphasize teaching parents specific coping skills as a useful strategy to improve coping abilities and to reduce the presence of depressive symptoms (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010). The assessment of how parents are coping should include the level of emotion that the parents are experiencing, such as anxiety, anger, and depression, as well as how parents are performing in their personal roles and daily life activities. It is essential to evaluate each parent's strengths and positive coping outcomes (Melnyk, Alpert-Gillis, Hensel, Cable-Beiling, & Rubenstein, 1997; Melnyk, Feinstein, Moldenhouer, & Small, 2001). The most often used coping strategies of parents with a chronically ill child are obtaining information, advocating, and receiving support from the healthcare team (Sallfords & Hallberg, 2003). Barlow, Wright, and Shaw (1998) present that too little information and insufficient support delayed the parents' ability to cope with their child's pain and disability. Parental coping has a significant influence on the ability for other family members to cope, including the ill child; having a sense of control over the child's situation is most critical to the family's aptitude to cope. Parental awareness is a necessary condition for parents to gain some control over all the new demands the chronic illness produces (Sallfords & Hallberg, 2003). Folkman (1997) claims that "effectiveness of coping is related to the match between the person's appraisal of

controllability of the situation and the extent to which the outcome is actually controllable” (pg. 1212).

The program Creating Opportunities for Parent Empowerment (COPE) was created to provide parents with strategies for becoming involved in their child’s care, facilitating quality interactions, and enhancing their child’s development. COPE was a four-phase educational-behavioral intervention program over the duration of a week to enhance coping in mothers and children. The program presented behavior information and parental role information to provide parents with strategies for becoming involved in the child’s care. The program included four types of interventions: disease specific educational interventions, stress point interventions, problem solving skills, and educational-behavioral interventions. Other strategies to enrich coping in parents of chronically ill children include: (1) formation of a strong relationship with the interdisciplinary team to enhance bilateral care for the child between the parents and health care providers; (2) educating the child’s teachers at school of his/her condition and any special needs; (3) a list of community resources available; (4) appropriate advocacy; and (5) helping parents in discovering comprehensive health care services for their child. Problem-solving skills training is another intervention that has been developed for parents of children with a new diagnosis. This training helps parents learn the five steps of problem solving which include: identifying problems, determining options, evaluating options and choosing the best one, acting, and seeing if it works (Melnik et al., 2001).

Health care providers are able to provide first-hand information to strengthen the knowledge base for parents. A few implications of coping for parents of a chronically ill child from health care providers include: (1) recognizing and encouraging use of all family members’ social support systems including extended family, church support, close friends, etc.; (2)

modifying any misconceptions including information assembled from the media, the internet, and from well-intentioned friends, coworkers, and family; and (3) providing whatever contributory support is necessary, such as available resources for financial and insurance concerns (Hovey, 2005).

Coping: Gender and Age. The development of adolescent depression is predicted by low levels of approach-oriented coping and high levels in avoidant-oriented coping. Females predominantly cope with stressors by using social support and emotion-focused coping such as relaxation, affective release, and emotional regulation. Females were also more likely to engage in maladaptive behavioral and cognitive strategies for coping with a possible explanation of a perceived lack of empowerment. Females engage in emotionally attentive or ruminative coping strategies that are correlated with the high incidence of depression. Males more often engage in problem-focused coping, instrumental behavior, and a sense of control which results in externalizing behavior. The high prevalence of externalizing behavior in males can be explained by coping strategies anticipated to gain control over the stressful situation (Hampel & Petermann, 2005).

Age has been shown to contribute to the choice of coping behavior. Emotion-focused coping strategies have been found to increase with age which can be explained by the more abstract and sophisticated thought processes that are required. Abstract and sophisticated styles of thinking are results of development of concrete thoughts. Emotion-focused coping consists of sophisticated thinking, an understanding of the stressor, and knowledge of what is vital to cope effectively (Altshuler & Ruble, 1989; Band, 1990; Band & Weisz, 1988; Compas, Worsham, Ey, & Howell, 1996; Sorgen & Manne, 2002).

Children's Coping. Delivering healthcare to children takes particular psychological toughness for the healthcare professionals. Not fully engaging children in medical interactions disables the child to engage, manage, or cope with their own medical condition and care. Healthcare professionals have a responsibility to properly educate children with concerns of their health and how to cope with medical procedures. Without properly preparing the child for their health condition or medical procedures, the child will seek out information in a variety of ways that are inappropriate and misunderstood, which can exacerbate the situation. Accurate information leads to more accurate expectations for medical procedures. When the child is properly educated, the child is more cooperative and the medical procedure is more easily achieved (Clarr, Walker, & Smith, 2002; Mahajen et al., 1998; Randall & Hallowell, 2012). When detailed information about upcoming events is provided, there is an increase in predictability, understanding, and confidence that results in greater coping outcomes.

The child life profession is an example of an education and preparation role for children and families in the hospital to ensure effective coping. Child life specialists are a part of the interdisciplinary team who “are responsible for facilitating coping and stress reduction in children and families facing challenges such as medical treatment, traumatic events, and/or disability by providing developmentally appropriate, family-centered, culturally sensitive interventions” (Corey, Corey, & Callanan, 1998; Sira & McConnell, 2008, p. 33). These specialists are trained to concentrate on the psychosocial, emotional, spiritual, and familial needs of individuals. Specific goals for the child life program are conducted by major objectives, for example, helping the child and family cope with anxiety and stress of the hospital experience, educate and prepare the child and family for upcoming procedures, and to help stimulate the child's normal growth and development while in the healthcare setting (Sira & McConnell,

2008). This preparative information should increase parents' beliefs about their ability to handle the situation, the attached stressors, and result in enhanced emotional and functional outcomes (Melnyk et al., 2001).

Parental distress can restrict the parents' ability to respond to emotional needs of their child and their ability to help their child produce effective coping strategies. Several examples of coping strategies parents can teach their children are active distraction, self-talk, and relaxation training. Active distraction consists of refocusing the child's attention away from anxiety-provoking situations to nonthreatening and engaging or pleasant thoughts. Self-talk is used to encourage a child to use coping statements aloud such as "I am going to get through this" or "I am strong". These statements foster a sense of self-efficacy and results in the child feeling more relaxed. Relaxation training can include diaphragmatic breathing, progressive muscle relaxation, or hypnosis. These techniques are used to calm a child, to release tension in different muscle groups, or to reduce awareness of the child's surroundings. These coping strategies for children encourage an internal locus of control and provide the child with a job (DeMaso & Snell, 2013). Other behaviors including talk about nonmedical topics and using humor have been found to be effective coping strategies for children. Behaviors of empathy and reassurance can often lead to decreased distress (Chorney et al., 2009).

Spirituality

There is research that links religion and spirituality to physical and mental health (George, Ellison, & Larson, 2002; Hill & Pargament, 2003; Koenig, McCullough, & Larson, 2001; Thoresen, 1999; Thoresen, Harris, & Oman, 2001). Spirituality, by definition, has been referred to as the personal, subjective side of religious experience (Hill & Pargament, 2003; Koenig, McCullough, & Larson, 2001). Spirituality is found in all human societies through a

unique connection with the divine, a connection to nature, or through religious practice.

Spirituality is the “core or inner life of the person, sometimes called the soul or spirit” (Lanzetta, 2010, p. 21). Another perspective defines spirituality as “the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship with the sacred or transcendent” (Koenig et al., 2001; Moreira-Almeida & Koenig, 2006, p. 844). Spirituality is a network of theoretical relationships within the field of well-being and provides a basis for adjustment, growth, and reaching one’s human potential (Frey, Daaleman, & Peyton, 2005; Pargament & Mahoney, 2002; Seligman, 2002).

Spirituality can also be defined as “a search for the sacred, a process through which people seek to discover, hold on to, and, when necessary, transform whatever they hold sacred in their lives” (Hill & Pargament, 2003, p. 65; Pargament, 1997, 1999). People commonly treat sacred things in their life with respect and care which can characterize a source of strength, meaning, and coping. The aspects that are viewed as sacred in an individual’s life are usually invested with more time, care, and energy (Hill & Pargament, 2003). The area of the sacred includes God, the Divine, Ultimate Reality, and the transcendent. Denominational affiliation and church attendance may have a comparable link to the spiritual outcomes of health issues (Krucoff et al., 2001; O’Connor, Pronk, & Tan, 2005). Individuals can experience spirituality in many different ways including: “meditating, praying, or singing; while others may be moved by nature, reading scripture or other sacred literature, exercising, listening to music, etc.” (Sira & McConnell, 2008, p. 34). Spirituality is a “complex variable that involves cognitive, emotional, behavioral, interpersonal, and physiological dimensions” (Hill & Pargament, 2003, p. 66). Changes of an individual’s spiritual life have “moments of insight, feel compunction and sorrow, struggle through uncertainty and doubt, suffer loss of prestige or self-identity, and emerge with

deeper integration and self-reliance” (Lanzetta, 2010, p. 21). Spirituality is a developmental process as individuals mature as spiritual beings, comparably to cognitive, physical, and emotional development (Sira & McConnell, 2008). A separate term of nonreligious spiritual propensity explains an individual who “does not use religion as a foundational belief system but believes that all features of spiritual propensity can take on nonreligious forms” (Frey et al., 2005, p. 559).

The connection to God is the ultimate value. This can include systems of religious belief, practice, and relationships designed to become closer to the higher power. God is labeled as an attachment figure by attachment theorists because people look to God as a safe haven to offer care and protection in times of stress. Greater comfort in stressful situations, greater strength, and greater confidence in life are associated with the relationship individuals have with God. The attachment theory predicts that “the perceived sense of closeness to God appears to be particularly valuable to people in stressful situations” (Krause, 1998; Hill & Pargament, 2003, p. 67). Some people understand that spirituality is a structure that positions them to the world and provides motivation and direction for living (Pargament, 2003).

Spirituality can also provide individuals with a sense of their ultimate destinations in life. The empowerment that is resulted from spirituality includes: “people are likely to persevere in the pursuit of transcendent goals; provide stability, support, and direction in critical times; and people can hold on to a sense of ultimate purpose and meaning even in the midst of disturbing life events” (Baumeister, 1991; Hill & Pargament, 2003, p. 68). Higher levels of spirituality are associated with higher self-esteem, greater meaning in life, positive family relations, and a sense of well-being (Hill & Pargament, 2003).

Spiritual Struggle. According to Hill and Pargament (2003), several types of spiritual struggles consist of interpersonal struggle, intraindividual struggle, and struggles with God. Interpersonal struggles are conflicts between an individual and a member of the same social context including spouses, family members, congregation members, clergy, or members of other religious groups. Intraindividual struggles occur internally such as an individual's personal qualities, their feelings, and their behaviors. Struggles with God appear when an individual's struggles are with the divine, questioning God's presence, benevolence, sovereignty, or purpose for the individual. Certain conflicts can cause essential questions about self-worth, self-control, and self-efficacy. Feelings of fear, disillusionment, and distrust may be results of questioning God's nature. Negative spiritual struggles have been accompanied with psychological distress of anxiety, depression, negative mood, poorer quality of life, panic disorder, and suicide. On the other hand, positive spiritual struggles have been accompanied with stress-related growth, spiritual growth, open-mindedness, self-actualization, and lower levels of bias. Spiritual struggles can be envisioned as "a crucial fork in the road for many people, one that can lead in the direction of growth or to significant health problems" (Hill & Pargament, 2003, p. 70).

Spirituality and Health Related Issues. Spirituality have been hearty variables in health-related outcomes. Serious concerns and critics have been the result of discussions of the relationship between spirituality and health. A majority of patients in a hospital would like for their caregiver to ask about the spiritual aspects of their illness. Statistics show, about "95% of Americans recently professed a belief in God or a higher power, a figure that has never dropped below 90% during the past 50 years, and 9 out of 10 people also said they pray" (Gallup & Lindsay, 1999; Miller & Thoresen, 2003, p. 24). Faith is the chief guiding strength in many of American's lives. Spirituality is often reported the main source of strength and comfort for health

care professionals which provides awareness about resiliency in a high stress profession and the aptitude to support patients and families as they cope with the trials of illness and hospitalization (Sira & McConnell, 2008). Health is influenced by many factors including cultural, social, and philosophical in addition to the existence of meaning and purpose in life and the quality of intimate relationships (Ornish, 1999; Ryff & Singer, 1998; Miller & Thoresen, 2003).

Technology advances in medicine have emphasized the importance of a “holistic culture in the health care setting where spirituality, coping, and healing are tied together for facilitating a curative environment” (Sira & McConnell, year, p. 36). Spirituality within the domain of good health status and well-being, can be theorized as “a congruent, meaningful life scheme and high functional self-efficacy beliefs that synergistically promote personal agency” (Bandura, 1997; Frey et al., 2005, p. 561). Even though this is a tough subject to study due to measurability, researchers have found a reliable and valid measure of spirituality connected to subjective well-being in patient populations called the Spirituality Index of Well-Being (SIWB). This measure has a stronger association than other spiritual measures with striking variables of interest. The SIWB is most effective in studies of chronic illness, aging, and end-of-life care (Frey, et al., 2005; Walker & Avant, 1995).

Children and Spirituality. A child’s spiritual beliefs often reveal “a type of simplicity- an acceptance of, and understanding for, the world- a core innocence if you will” (Walters, 2008, p. 278). A child’s spirituality, and spiritual innocence, is particularly different from that of an adult. The presence of a child’s spirituality is especially calming and advantageous to the parent’s ability to cope. A young child is not able to perceive certain aspects or ways of knowing; this can also explain “the presence of degrees of contradiction between levels of cognitive and emotional development and the possession of wisdom and the directedness of

spirit” (Walters, 2008, p. 285). The social and interactive context of a child is the major importance of the “evolution of values and ethics, paving as it does the eventual road to independence of thought, choice, and action” (Walters, 2008, p. 278). Children are able to think about, ask questions about, and integrate spiritual issues into their social and emotional interactions through spiritual experiences. It is imperative to explain spirituality in developmentally appropriate ways while being aware of cultural sensitivity (Sira & McConnell, 2008). Children will unquestionably seek comfort and guidance from adult caregivers, and often God if they are taught of the higher power. Regardless of whether or not the child has a core spiritual understanding, the interpersonal bonding that supplements social structures of church, school, and community will provide indispensable emotional connections. The value of teaching and learning is crucial to spirituality and its eventual hope (Walters, 2008).

Spiritual Coping

A large number of people use their spiritual beliefs as a coping mechanism for many life stressors. Spiritual coping can be defined as “people’s ways of understanding and dealing with negative life events that are related to the sacred” (Pargament & Raiya, 2007; Grossoehme et al., 2011, p. 424). Spiritual coping has the ability to maximize core values that will reduce the tension that is connected to the stressor. Coping works to remove the stressor and leads to the growth of the copier (Pieper & Van Uden, 2012). A few functions of spiritual coping include: emotional comfort and hope, ability to maintain self-esteem, ability to find a sense of meaning and purpose, social support, reframing of stressful events, and ability to provide a sense of control (Hildenbrand & Marsac, 2011; Krok, 2008). When a stressor triggers, individuals turn to actions or thoughts to remove or balance the stressor. This is when some individuals often turn to religious variables such as spirituality, blessing of the body, and religious coping (Grossoehme et

al., 2011). Individuals trust their spiritual resources to be able to deal with stress and control their cognitive and emotional processes. Spiritual coping allows individuals to solve their problems by restructuring the problem and planning possible modifications (Krok, 2008). Spirituality allows individuals to redeem a sense of mastery or efficacy in the middle of chaotic events. Examples of spiritual coping can include: “a partnership with God to solve problems; actively surrendering control to God; passively waiting for God to control an outcome; pleading for God’s direct intervention or seeking control entirely through one’s own initiative without relying on God” (Grossoehme et al., 2011, p. 424).

Spiritual coping is a way to seek comfort or intimacy with God. Examples of the styles of coping to seek comfort or intimacy consist of: searching for comfort or reassurance through God’s care; engaging in religious activities to shift focus away from a stressor; searching for spiritual cleansing through religious actions; or experiencing a sense of connectedness that transcends the individual. Seeking the love and support of congregation members or the clergy is a way to find intimacy with other people (Grossoehme et al., 2011). Spiritual coping practices can also include: scripture reading, prayer, meditation, listening to music, rituals, nature walks, spiritually motivated behaviors, and spiritual thinking (Krok, 2008; Wachholtz & Pearce, 2009). Other effective methods of providing spiritual care include: empathetic listening, praying with children and families, touch, or other ways of silent communication (Feudtner, Haney, & Dimmers, 2003). The extent of spiritual coping increases when a situation presents a more spiritually oriented framework for understanding (Pieper & Van Uden, 2012). Styles of religious coping can be seen as: redefining the stressor through religion as altruistic; redefining the stressor as a punishment from God for one’s sins; redefining the stressor as an act of the Devil; redefining God’s power to influence a stressful situation; looking to religion for help in shifting

from anger, hurt, and fear associated with an insult to peace; or looking to religion for a profound life change (Groossoehme et al., 2011). Faith in a higher God is confirmed to conclude an individual's self-actualization of hope (Kelly, 2004).

Hill and Pargament (2003) give three fundamental reasons why spirituality can motivate individuals. First, individuals may identify many dimensions of life as sacred in significance and character, thus, they will tend to treat those aspects with respect and care. This signifies a source of strength, meaning, and coping for stressful situations. Second, spiritual frameworks can provide individuals with a sense of their goals and meaning in life. These spiritual strivings direct people's lives. Lastly, spiritual directions can give a realistic pathway for reaching these destinations. This allows individuals to have a wide range of spiritual coping methods for stressful situations (Hill & Pargament, 2003).

Positive and Negative Spiritual Coping. Spiritual coping strategies may be categorized as positive or negative. Positive spiritual coping characterizes a sense of spirituality, a secure relationship with an altruistic God, a belief that life has a meaning, a sense of spiritual connection to others, and altruistic reappraisal of an event. This coping style is accompanied with higher self-esteem, better quality of life and psychological adjustment, and spiritual and stress-related growth (Wachholtz & Pearce, 2009; Benore, Pargament, & Pendleton, 2008). To measure positive influence of coping, spiritual aspects of cognitive, affective, behavioral, and social are examined. The cognitive aspect refers to spiritual beliefs that give meaning to an individual's existence and meaning to the individual's problems. Affective aspect realizes that an individual is safe because of the spiritual beliefs that are fostered. Behavioral aspect includes praying and church attendance to provide support. The social aspect refers to fellow believers supporting each other (Pieper & Van Uden, 2012). Support from a belief system and being

connected with a spiritual congregation produces a sense of being loved and nurtured by a higher power (Elkins & Cavendish, 2004). Spiritual support is presented as a foundation for self-esteem, information, companionship, and contributory aid to buffer stress (Cohen & Willis, 1985; Wachholtz & Pearce, 2009).

Negative spiritual coping is characterized by a less secure relationship or discontent with God, a questionable and negative view of the world, a feeling of punishment, a spiritual struggle in the search for meaning, and negative reframing of an event. This coping style is related to depression, emotional distress, insensitivity, poor physical health, reduced quality of life, and difficulty in problem resolution (Benore et al., 2008; Wachholtz & Pearce, 2009). The negative influence of spirituality resulted in anxiety, guilt and shame, lack of autonomy, and lack of spiritual worldview (Pieper & Van Uden, 2012). Pargament et al. (1988) classifies three ways that God plays a role in coping: self-directing, deferring, and collaborative. Self-directing coping refers to the individual being completely responsible for solving the problem with no help from God. Deferring coping refers to the individual placing full responsibility on God for solving the problem. The collaborative style includes the individual and God working together to find a solution to a problem (Pieper & Van Uden, 2012). Collaborative and self-directing styles are perceived to have more positive psychological, physical, and health outcomes (Pargament, Koenig, & Tarakeshwar, 2004; Wachholtz & Pearce, 2009).

Prayer. One major variable of spiritual coping is prayer. According to Groesssoehme (2011), prayer is widely known throughout nearly all cultures. There is no single definition associated with prayer but William James defines prayer as “every kind of inward communion or conversation with the power recognized as divine” (Dein & Littlewood, 2008; Groesssoehme et al., 2011, p. 425). Prayer has the ability to offer comfort, inner strength, and resolution when

dealing with challenging situations (Holt-Ashley, & Lindquist, 2000; Kelly, 2004). Prayer is the primary or secondary most commonly used coping strategy when dealing with physical pain (Koenig, 2001; Rippentrop, 2005; Wachholtz & Pearce, 2009). Parents of chronically ill children may use prayer as a way to work together with God to problem solve when access to other support is not available (Benore et al., 2008; Cole, Benore, & Pargament, 2004).

Cadge and Daglian (2008) reported their findings from a study of examining prayers in an open notebook resulting in prayers that were written primarily for the purpose to thank God, make requests of God for one's self, or for a loved one. Written prayers are usually presented to a God who is accessible and is a source of emotional and psychological support. Prayers can be used as a spiritual connection or for seeking spiritual support. An individual's prayers often shift in the duration of a situation. Prayers often begin by asking to gain control over a situation and eventually change to seeking comfort from God (Groessehme et al., 2011).

Spiritual Coping in Healthcare. Spiritual coping strategies have been associated with a variety of positive mental and physical health outcomes (Harrison, Edwards, & Koenig, 2005; Wachholtz & Pearce, 2009). Chronically ill patients and their parents may discover the clergy, spiritual community, and communion with God to help alleviate the fear, worry, and sadness that is attached to the diagnosis (Benore et al., 2008). Spiritual practices are renovated into tangible forms of coping which holds a strong impact on people's health during times of stress or crisis (Pargament, 2002; Krok, 2008). Spirituality and faith have been found to play a role in medical decision making. In a 2003 study, participants ranked faith in God second, next to physician recommendations, for medical decision making (Knapp, Madden, Wang, Curtis, Sloyer, & Shenkman, 2011; Silvestri, Knitting, Zoller, & Nietert, 2003). Children and parents often utilize inner resources from their belief system as a form of support (Elkins & Cavendish, 2004). A few

examples of the connections between spirituality and better health and well-being includes: “spiritual strivings are empowering; spiritual strivings can provide stability and support in critical times; and spiritual strivings offer a universal philosophy of life” (Emmons, 1999; Krok, 2008, p. 645).

Parents of hospitalized children are constantly faced with medical decision making and may have a greater dependence on faith in God and spirituality as a coping mechanism. Integrating spiritual care into a child’s plan of care is necessary when resolving crises and for optimal health. Spiritual care may be the only source of comfort when a cure is not possible. Spirituality can be seen as a complementary and alternative medicine (CAM) for healing in ways such as: music therapy, touch, humor, guided imagery, storytelling, aromatherapy, and prayer (Cavendish, Russo, & Luise, 2003; Cavendish, Konecny, Luise, & Lanza, 2004; Elkins & Cavendish, 2004; McClosky & Belechek, 2000). Spiritual coping does not inevitably change pain severity but changes pain tolerance (Wachholtz, Pearce, & Koenig, 2007; Wachholtz & Pearce, 2009). The experience of pain can lead individuals into deep spiritual analysis concerning the meaning of suffering (Feudtner et al., 2003). Many parents state that their child’s illness has strengthened their spiritual beliefs (Knapp et al., 2011). Parents reported that their religion, spirituality, or life philosophy (RSLP) is important in providing support, peace, comfort, and moral guidance (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). On the other hand, parents with a chronically ill child can often feel as if they are being punished, tested, or that their child’s illness was divine intervention. Feelings like this can lead parents to behaviors of guilt, anger, fear, anxiety, or blame (Elkins & Cavendish, 2004; Fulton & Moore, 1995; Hart & Schneider, 1997). Common reactions for parents with a chronically ill child include: feeling fearful or anxious; difficulty coping with child’s pain; why my child? Why me?; what is the

meaning of suffering?; feeling guilty; can I be angry at God?; feeling angry, bitter, or hostile; etc. (Feudtner et al., 2003). Some parents reported questioning their faith, experiencing feelings of anger and blame toward God, and rejecting spiritual beliefs and communities. Parents can reject God completely and move away from their faith as a result of a child being seriously ill (Hexem et al., 2011).

Theoretical Perspective

The purpose of this thesis is to recognize the complexity of stressors for parents with a chronically ill child and to evaluate the presence and effectiveness of spiritual coping. Therefore, two theoretical frameworks will be utilized to support this study: Family Systems theory and the Stress and Coping theory.

Family Systems Theory. Hall and Fagan (1956) define a system as a set of individuals and the interactions between these members and the qualities they have to offer. According to Broderick and Smith (1979), a system is separate from its environment but has an effect on the environment. The diagnosis of a chronic illness on a child has an effect on the family system's boundaries, elements, feedback, and equilibrium. Boundaries are referred to as the distinction family members make between the family and the environment. A family can hold either an open or closed boundary system. An open boundary is where there is no barrier to the information shared with the environment. A closed boundary is a tight barrier that exists between the family and the environment and no information goes in or out (Broderick & Smith, 1979; White & Klein, 2008). A critical stressor for parents upon the diagnosis of their child is deciding who to tell about the chronic condition (Knafl, Ayres, Gallo, Zoeller, & Breitmayer, 1995; Perlman, 1986; Melnyk, Moldenhouer, Feinstein, & Small, 2001). An open boundary family may decide

to share the news with all of their friends and families, while a closed boundary family may decide to keep the diagnosis a secret amongst the family system.

An element is referred to as each member of the family and the roles that are expected from each member (Ingoldsby et al., 2004). Although each family member remains in the family system, the diagnosis of a chronic illness often requires a shift in roles for each member of the family. The mother is often the primary caregiver of the ill child which may require a career delay. The father may become the sole provider for the family and usually takes on the responsibility of spending more time with the healthy children (Sallfors & Hallberg, 2003).

Feedback is a circular loop that brings some of the system's output back to the system as input. The main source of feedback with a chronically ill child is the circular loop of information from the healthcare team to the family and vice versa. Equilibrium is a balance of the inputs and outputs and allows the family to remain homeostatic (Broderick & Smith, 1979; White & Klein, 2008). The diagnosis of a chronic illness has the potential to shake the whole family system into an emotional rollercoaster, therefore, the family is constantly striving to regain their balance. When a stressor triggers, individuals turn to actions or thoughts to remove or balance the stressor. This is when some individuals often turn to religious variables such as spirituality, blessing of the body, and religious coping (Grossoehme et al., 2011).

There are a few basic assumptions that are associated with the family system including: system elements are interconnected and systems are not reality. Referring to all parts of the system are interconnected, Burr, Leigh, et al. (1979) report that "the family process group that changes in one part of a system influence all other parts of the system" (p. 98). Correspondingly, the presence of a chronic illness has a significant impact on the whole family system (Melnik et al., 2001). The impact of spiritual coping might not be a reality within all family systems and

even within the system as not all family members may rely on spiritual coping strategies. Those individuals that do choose to rely on their spirituality are able to redeem a sense of mastery or efficacy in the middle of chaotic events. Even so, the family system is greater than the sum of its parts (Ingoldsby et al., 2004; White, 1984). Social support is a great example of how a family system is greater than the sum of its parts when living with a chronically ill child. Social support can come from many sources including spouse, family, friends, health care professionals, and other families in similar situations. Seeking the love and support of congregation members or the clergy is a way to find intimacy with other people (Groesseohme et al., 2011). Other effective methods of providing spiritual care through social support include: empathetic listening, praying with children and families, touch, or other ways of silent communication (Feudtner, Haney, & Dimmers, 2003). Positive interactions with similar individuals are encouraging, strengthening, and enlightening (Gibson, 1995).

Family Stress Theory. Angell (1936) discovered a family's reaction to stress is based off of two things: integration and adaptability. Integration refers to how close a family feels and having a durable sense of family unity. Adaptability refers to how flexible and comfortable families are in talking about problems and making decisions together. Families who are both integrated and easily adaptable are the most capable of dealing with stress. The stressors attached to a chronic illness are multiple, ongoing, and can frequently change over the prolongation of the health care journey (Brown et al., 2008).

According to Hill (1949), families experience four stages when faced with a crisis: crisis, disorganization, recovery, and reorganization. The crisis stage refers to whatever stress-provoking event put the family into crisis. This can include normative and non-normative stressors. The diagnosis of a chronic illness in a child is considered a non-normative stressor.

The time of diagnosis is often seen as one of the most stressful events for parents due to confusion, denial, shock, the uncertainty of the child's condition, and his/ her potential outcomes (Cohen, 1993; Melnyk et al., 2001). A phase of disorganization results from the crisis as the family attempts to cope with the situation. A main source of understanding and coping with negative life events can descend from an individual's spirituality through spiritual coping (Pargament & Raiya, 2007; Grossoehme et al., 2011). Families eventually will enter the phase of recovery when they are able to handle and cope with the situation. Finally, a new level of organization will be reached, sometimes it can be the same as the previous level of organization, or it can be better than it was before. Some families "report greater cohesion and trust and increased communication as a result of the child's illness" (Lavee & Mey-Dan, 2003; Philichi, 1989; Brown et al., 2008, p. 410). Even after parents of a chronically ill child reach a new level of organization, it is common to experience recurrent negative emotions and responses as they notice their child struggling to attain developmentally appropriate tasks (Melnyk et al., 2001).

Reuben Hill (1949) invented the ABC-X model which is the foundation of family stress theory. The ABC-X model is defined as: A being the stressor event; B is the family resources and strengths; C is the family's perception of the event and the meaning they attach to the event; and X is the state of crisis if the family is unable to immediately figure out how to solve or cope with the stressor. Families with a chronically ill child experience all aspects of the ABC-X model. The stressor event (A) can include the time leading up to the diagnosis and/or the time of diagnosis. The availability of resources and the willingness of the family to utilize the resources (B) will determine how beneficial these resources are to handling the stressor. At the time of diagnosis, the family may not have time to acknowledge their perception of the event (C) which can likely result in crisis automatically.

The stressor event is neither positive nor negative since events are neutral prior to our interpretation of them. Both positive and negative events can cause stress. Lipman-Bluman (1975) created eight criteria that affect the degree to which the stressor will impact the family: (1) Whether the stressor is internal or external to the family; (2) Whether the stressor is focused on one member or all members of the family; (3) Suddenness versus gradual onset of the stressor; (4) The severity of the stressor; (5) The amount of time families have to adjust to the stressor; (6) Whether the stressor is expected or not expected; (7) Whether the stressor is natural or handmade; (8) The family's perception of whether or not they are able to solve the crisis situation. All eight of these criteria relate to a family dealing with a chronically ill child. Having a child with a chronic condition is considered an internal stressor that affects all members of the family. The diagnosis can be either gradual or sudden/ expected or not expected depending on if the family has been searching for an answer to a problem for a length of time versus not suspecting anything was wrong at all. The severity of the initial diagnosis will significantly affect the family's reaction. The amount of time the family has to adjust to the diagnosis of the child's chronic condition can be explained by the child requiring immediate medical attention at the time of diagnosis or if the family has time to comprehend the diagnosis before taking action. Chronic conditions are most of the time natural which means there was no way of causing or preventing the illness. Many interlinked variables are involved to determine if the family perceives they are able to handle the crisis or not.

Olson, Lavee, and McCubbin (1988) define a stressor as "discrete life events or transitions that have an impact upon the family unit and produce, or have the potential to produce, change in the family system" (p. 19). Stressors can also be classified as normative or non-normative. A normative event involves three components: it occurs in all families, you can

anticipate its occurrence, and it is short-term (McCubbin & Patterson, 1983). Non-normative stressors are not anticipated and more likely to lead to a crisis. The diagnosis of a chronic illness in a child is considered a non-normative, negative stressor with resources such as features, traits, or abilities of individuals, families, or communities to cope with the event. This can include family members, congregation, optimism, financial support, etc. The spirituality of the parent can be seen as a significant resource when dealing with their child's chronic condition. One's spirituality signifies a source of strength, meaning, and coping for stressful situations (Hill & Pargament, 2003). The combination of coping resources predicts higher ability to cope effectively and reduce stress in difficult situations (Taylor & Stanton, 2007). Crisis is a period of disorganization that rocks the foundation of the family.

Once the stressor has impacted a family, the family must figure out how to deal with the stressor situation. Angell (1936) described the ability to pull together as a family and to be flexible as essential resources. Coping resources improve the aptitude to manage stressful events and are associated with reduced distress and improved health outcomes (Taylor & Stanton, 2007). McKenry and Price (2000) label social support as the most important resource families with a chronically ill child can access. Support from a belief system and being connected with a spiritual congregation produces a sense of being loved and nurtured by a higher power (Elkins & Cavendish, 2004). Lazarus and Launier (1978) insinuate that how the family interprets the situation and what meaning they label it with is as important as taking advantage of resources. Optimism allows individuals to view a stressor as more challenging than threatening which leads to more positive outcomes. Spirituality also allows individuals to assign meaning and purpose to a situation, to reframe stressful events, and to provide a sense of control (Hildenbrand & Marsac, 2011; Krok, 2008). Parents of a chronically ill child who are able to positively reframe the illness

as being something they can handle are better able to manage the stressor. It is beneficial to break down the stressor into manageable tasks so the focus is on one item at a time rather than being overwhelmed with all the parts. Cognitive reappraisal for all family members involved helps to change the emotional energy from negative to positive. Not all stressors will lead to crisis. If the stressful event does lead to crisis, families often function better and are more cohesive after a crisis than they were before (Ingoldsby et al., 2004). Some families “report greater cohesion and trust and increased communication as a result of the child’s illness” (Lavee & Mey-Dan, 2003; Philichi, 1989; Brown et al., 2008, p. 410).

The purpose of this thesis is to recognize the complexity of stressors for parents with a chronically ill child and to evaluate the presence and effectiveness of spiritual coping. The goal is to understand the function of spirituality as a coping mechanism for parents with a chronically ill child. This study had the following specific aims:

- (1) Does spirituality have an impact on parents’ level of stress and coping with a chronically ill child?
- (2) In what ways has spirituality been a positive or negative style of coping for parents of children dealing with a chronic illness?
- (3) Does a parent’s level of coping and spirituality predict the level of stress management while parenting a chronically ill child?

CHAPTER 3: METHODS

Participants. Several online support groups for parents with a chronically ill child were located and contacted to explain the current study. Some examples of the online support groups included Inspire- Together We Are Better and the following groups from Facebook: Heroes for Children, For the Love of Down Syndrome, Parents of Children with a Chronic Illness, The National Children's Cancer Society, Riley's Army, Children with Special Needs, Hope for Children with Cancer, and Parenting Children with Health Issues. The inclusion criteria for participants is being the primary caregiver of a child with a chronic illness and the child must be under the age of 18 years. A total of 30 individuals participated in the survey portion. For a mixed methods approach, voluntary parents were interviewed using a snowball strategy. The participants who were interviewed included eight parents who all reside in North Carolina; 3 married couples and 2 individuals who were married but only one parent was interviewed due to convenience. The range of diagnoses included: down syndrome, cancer, cystic fibrosis, cerebral palsy, epilepsy, legally blind, autism, chronic intestinal pseudo obstruction, neuropathic bladder, traumatic brain injury, double outlet right ventricle, persistent vegetative state, lung disease, chromosome 1 partial deletion, and hypopituitarism. A descriptive summary of all the participants are presented in Table 2 and a descriptive summary of the parents that were interviewed are presented in Table 3.

Table 2

Demographic Summary of All Participants

Characteristic	Category	Percent
Age of Parent	Average: 35.9	Min: 25 Max: 51
Age of Child	Average: 4.8	Min: 1 Max: 17
Race (N=30)	White/ Caucasian	80
	Black/ African American	3.3
	Asian	3.3
	English	6.7
	Bi-Racial	6.7
	Marital Status (N=30)	Single
Education of Parent (N=30)	Married	90.0
	Divorced	6.7
	Some High School	3.3
	High School Diploma/ GED	6.7
	Trade School	6.7
	4-Year College Degree	40.0
	Post Graduate Degree	40.0
State of Residence (N=30)	Other	3.3
	North Carolina	50.0
	Tennessee	6.7
	Minnesota	3.3
	Louisiana	3.3
	Pennsylvania	3.3
	Montana	3.3
	South Dakota	3.3
	California	10.0
	New Hampshire	3.3
Rate of Spirituality (N=30)	Indiana	3.3
	United Kingdom	6.7
	One	13.3
	Two	0.0
	Three	3.3
	Four	6.7
	Five	6.7
	Six	3.3
	Seven	3.3
	Eight	23.3
Nine	13.3	
Ten	26.7	

Table 3

Demographic Summary of Interview Participants

	Age of:			Diagnosis of	Number of
	Mother	Father	Child	Child:	Siblings:
Family 1	34	42	2	Down Syndrome/ Leukemia	1
Family 2	NA	35	2	Chromosome 1 Deletion	1
Family 3	30	36	2	Cystic Fibrosis	0
Family 4	30	30	2	Down Syndrome	0
Family 5	37	NA	1	Down Syndrome	1

Instruments. The following three measures were used: Parental Stress Scale, subscales from the Brief COPE Inventory, and the Spirituality Index of Well-Being. A demographics section was also included in the survey. The demographics section included: age of parent/child; age of child at diagnosis; diagnosis; race/ethnicity; marital status; number of siblings of the ill child; others living in the household; education level; geographic region; and spiritual rating. In addition, a group of parents were interviewed with several open-ended questions.

Parental Stress Scale is an 18 item self-report scale that attempts to measure the levels of stress experienced by parents while taking into account positive and negative aspects of parenting (Berry & Jones, 1995). Participants agree or disagree on a 5-point scale (strongly disagree, disagree, undecided, agree, strongly agree) in terms of their typical relationship with their child. The Parental Stress Scale demonstrated satisfactory levels of internal reliability (.83), and test-retest reliability (.81). The scale demonstrated satisfactory convergent validity with various measures of stress, emotion, and role satisfaction. A few example statements include: Caring for my child sometimes takes more time and energy than I have to give; The major source of stress in my life is my child; It is difficult to balance different responsibilities because of my child; etc. High scores signify a high level of stress while low scores signify a low level of stress.

Brief COPE Inventory is composed of 15 subscales with a total of 60 items (Carver, 1997). The author states that the inventory can be administered using all scales of the Brief COPE, or the researcher has the ability to choose selected scales for use. For the purpose of this study, the following six subscales will be utilized with a total of 24 items: use of instrumental social support, use of emotional social support, active coping, religious coping, acceptance, and denial. Each item states something about a particular way of coping. The original Brief COPE Inventory exhibited excellent internal consistencies displayed by the acceptable values of

Cronbach's alpha for some domains including: instrumental support ($\alpha=0.64$); emotional support ($\alpha=0.71$); active coping ($\alpha=0.68$); religious coping ($\alpha=0.82$); acceptance ($\alpha=0.57$); and denial ($\alpha=0.54$). The participants will answer each item by how frequently they utilize that coping strategy on a 4-point scale (1- I haven't been doing this at all; 2- I've been doing this a little bit; 3- I've been doing this a medium amount; and 4- I've been doing this a lot). A few examples of coping statements include: I talk to someone who could do something concrete about the problem; I've been getting emotional support from others; I pretend it really hasn't happened; I try to find comfort in my religion; I talk to someone about how I feel; I accept the reality of the fact that it happened; etc. The scoring allows the researcher to assess several responses known to be relevant to effective and ineffective coping.

Spirituality Index of Well-Being is a 12-item instrument that measures one's perception of their spiritual quality of life (Daaleman & Frey, 2004). The scale is divided into two subscales: self-efficacy and life-scheme subscale. Participants answer on a 5-point scale ranging from 1 (Strongly Agree) to 5 (Strongly Disagree). This measure demonstrated satisfactory levels of internal reliability (.91) and validity (.75). A few examples statements include: I haven't found my life's purpose yet; There is a great void in my life at this time; I can't begin to understand my problems; etc. The total scores are used to measure the overall perception of spiritual well-being.

Qualitative Data Gathering was conducted in interview style. The interviews were voluntary and led by the researcher through a few sample questions. All of the following questions were asked to every participant: (1) Do you feel like your spirituality has grown stronger or weaker when dealing with your child's chronic condition?; (2) What coping mechanism has been the most beneficial when dealing with the stress of your child's chronic

condition?; (3) Elaborate on what has been the most difficult aspect of your child's chronic condition to cope with?; (4) As you look back over this experience, what have you learned?

Procedures. After approval from the ECU institutional review board (IRB), several online support groups for parents with a chronically ill child were located and contacted. A brief prompt of the current study and the link to the survey were attached for willing participants to each support group. Upon completing the survey, the results were automatically sent to Qualtrics for the researcher's reference. While waiting for completed surveys to be submitted, a set of parents were contacted to participate in the interview portion of the research study. This first couple to be interviewed was arranged and subsequent interviews were arranged through snowball effect. The interviews took place at the participants' home. The interview group allowed the current study to obtain a more in-depth understanding of this population of parents with a chronically ill child in addition to the quantitative survey data. The interview groups were able to support the overall research questions in open dialogue.

Analysis. Once the data collection was complete, a series of statistical analyses were conducted to interpret the results. The dependent variable is the parents' stress level with coping and spirituality being the two independent variables. A standard multiple regression was conducted to determine if the measures of coping and spirituality would predict the amount of stress in parents with a chronically ill child. A correlation analysis was performed on all variables to evaluate the relationship between all three variables. Finally, a thematic analysis was conducted for the qualitative discussion data. Thematic analysis is a process for recognizing, evaluating, and recording patterns within data (Braun & Clark, 2006). Each of the interviews were transcribed word for word in order to interpret and analyze present themes. Common themes were recorded and organized into meaningful groups. This allowed the researcher to

engage in theory building. Theory building is supported by well-documented findings and involves thinking actively and intentionally about a particular phenomenon. Theory building is used to develop systematic, conceptually coherent explanations of the findings (Leedy & Ormrod, 2013).

CHAPTER 4: RESULTS

A *multiple regression* was conducted to determine if the measures of coping and spirituality would predict the amount of stress in parents with a chronically ill child. The regression analysis, predicting the level of parental stress from coping and spirituality scores, was not statistically significant, $F(8,19) = 1.407$, $p = .256$. Although an individual's coping and spirituality do not bilaterally help to decrease the level of parental stress, spirituality does have a significant contribution, $F(2, 25) = 3.990$, $p = .031$. The Self-Efficacy variable makes the strongest unique contribution ($-.606$) to explaining parental stress. Both of the spirituality variables, Self-Efficacy ($p=.030$) and Life Scheme ($p=.014$), make a statistically significant contribution to the prediction of parental stress.

A *Pearson correlation coefficient* was computed to investigate the relationship between parental stress, all coping variables (instrumental social support, active coping, denial, religious coping, emotional social support, and acceptance) and both spirituality variables (self-efficacy and life scheme). There was a strong, positive correlation between two variables, $r = .546$, $n = 28$, $p < .01$, with high levels of life scheme associated with high levels of self-efficacy and vice versa. There was also a strong, positive correlation with high levels of instrumental social support being associated with high levels of active coping strategies, $r = .502$, $n = 28$, $p < .01$. A strong, positive correlation was perceived with high levels of emotional social support related with high levels of instrumental social support as coping strategies for parents, $r = .764$, $n = 28$, $p < .01$. There was a negative correlation between two variables, $r = -.380$, $n = 28$, $p < .05$, with high levels of self-efficacy associated with lower levels of denial coping mechanisms. The full correlation table is presented below in Table 4.

Table 4

Correlation Analysis of Parental Stress, Coping, and Spirituality

		Total Stress	Life Scheme	Self Efficacy	Instrumental Coping	Active Coping	Denial Coping	Religious Coping	Emotional Coping	Acceptance Coping
Total Stress	Pearson Correlation	1	.287	-.178	.131	.202	-.101	.146	-.028	.241
	Sig. (2-tailed)		.139	.364	.506	.302	.608	.457	.886	.218
	N	30	28	28	28	28	28	28	28	28
Life Scheme	Pearson Correlation	.287	1	.546**	.188	.116	-.248	.201	-.003	.221
	Sig. (2-tailed)	.139		.003	.339	.556	.204	.306	.990	.257
	N	28	28	28	28	28	28	28	28	28
Self Efficacy	Pearson Correlation	-.178	.546**	1	.357	.178	-.380*	.170	.157	.114
	Sig. (2-tailed)	.364	.003		.062	.364	.046	.387	.426	.564
	N	28	28	28	28	28	28	28	28	28
Instrumental Coping	Pearson Correlation	.131	.188	.357	1	.502**	-.309	.437*	.764**	.478*
	Sig. (2-tailed)	.506	.339	.062		.006	.109	.020	.000	.010
	N	28	28	28	28	28	28	28	28	28
Active Coping	Pearson Correlation	.202	.116	.178	.502**	1	.136	.389*	.473*	.376*
	Sig. (2-tailed)	.302	.556	.364	.006		.491	.041	.011	.048
	N	28	28	28	28	28	28	28	28	28
Denial Coping	Pearson Correlation	-.101	-.248	-.380*	-.309	.136	1	-.142	-.005	-.067
	Sig. (2-tailed)	.608	.204	.046	.109	.491		.471	.978	.736
	N	28	28	28	28	28	28	28	28	28
Religious Coping	Pearson Correlation	.146	.201	.170	.437*	.389*	-.142	1	.324	.320
	Sig. (2-tailed)	.457	.306	.387	.020	.041	.471		.093	.097
	N	28	28	28	28	28	28	28	28	28
Emotional Coping	Pearson Correlation	-.028	-.003	.157	.764**	.473*	-.005	.324	1	.359
	Sig. (2-tailed)	.886	.990	.426	.000	.011	.978	.093		.061
	N	28	28	28	28	28	28	28	28	28
Acceptance Coping	Pearson Correlation	.241	.221	.114	.478*	.376*	-.067	.320	.359	1
	Sig. (2-tailed)	.218	.257	.564	.010	.048	.736	.097	.061	
	N	28	28	28	28	28	28	28	28	28

During the *thematic analysis*, four main themes were identified in the qualitative portion of the current study. Those four themes include: parental spirituality has grown stronger when dealing with child's chronic condition, effectiveness of emotional/instrumental support, fear of the unknown of child's future abilities, and having a greater appreciation for life in general.

Theme 1: Parental spirituality has grown stronger: When asked "Do you feel like your spirituality has grown stronger or weaker when dealing with your child's chronic condition?", all eight parents responded that their spirituality has grown stronger. Some parents disclosed that their spirituality has always been important in their life, while others stated that the existence of and growth of their spirituality was generated by the onset of their child's chronic condition. Father 2 answered that his spirituality has grown stronger and that "religion is a core thing in my life so it is the place where we (participant and his wife) get relief". Mother 4 said that "even though this has been difficult and we have questioned why, why us, why our daughter, we've been able to see how God is using it in our lives and our daughter's life and it has made us stronger people". Father 1 replied that he was not very spiritual before but "you kind of get spiritual while coping" in comparison to Mother 5 confirming that her spiritual beliefs are a "good coping mechanism". Father 4 believes that since the diagnosis of his daughter, he has been able to "grow dependence on God and depend on God more for help".

Theme 2: Effectiveness of emotional/instrumental social support: Parents perceive spirituality as a healthy coping mechanism when dealing with the stress of their child's chronic condition was the effectiveness of emotional and instrumental social support. Emotional support involves an individual acting as a confidant for someone, while instrumental support is the offering of help or assistance in a tangible or physical way. All of the participants who were interviewed mentioned finding exceptional benefits from the support of their spouse, family,

friends, and other parents in similar situations. “Finding other parents who are where I am; relying on advice from others in the Cystic Fibrosis community; meeting and developing relationships with other moms who have kids around this age with Downs” were some of the responses from parents (mostly mothers). The support from other parents in similar situations provided assistance by being able to “understand where you are without having to explain it to them; and just finding support”. Another huge advantage for these parents is “just having support from family” and that “friends and family are able to help us out when we need it”. Mother 4 shared that “other close friends and family who are not necessarily experiencing that but they do love us and support us in what ways they know how to”. Father 2 and Mother 5 both expressed the gratitude of the support and presence of their spouse while learning how to live with and adjust to their child’s chronic condition.

Theme 3: Fear of the unknown of child’s future abilities: The majority of participants responded that the most difficult aspect of their child’s chronic condition to cope with was the unknown/ uncertainty of their child’s future or their child’s maximum potential and whether he/she will be able to achieve that potential. Across the board, parents expressed their concerns of “not knowing what will happen when she is an adult and how much care she will require; no one can really tell us what the future looks like for her; how well will he be able to do things; will he get married?”. Father 4 thinks about “the things I loved to do as I grew up and going into adulthood- driving a car, living in a dorm room, going to college, just experiencing things- and I don’t know what it’s going to be like for her”. Mother 4 finds it difficult to cope with “the fact that she’s not right where other kids her age are developmentally and already seeing the separation from her and other kids her age”.

Theme 4: Having a greater appreciation for life in general: Every parent expressed a greater appreciation for life when asked “As you look back over this experience, what have you learned?”. Responses of “life is short and it gives us a greater appreciation; a lot of the everyday difficulties are not so difficult; there are certain things that matter in life more than others; and appreciate what you have”. Mother and Father 4 have “become more aware, accepting, loving, and compassionate toward people in general and their differences”. Mother and Father 1 try to “appreciate even the smallest milestones” such as being able to chew food, coordinate things, and learning how to walk; these things are “more interesting and rewarding because she has to work so hard for every little thing she does”. These were just a few that were mentioned even though all parents articulated to have learned a “book’s worth” over their experience.

CHAPTER 5: DISCUSSION

This is one of the first studies to explore the variables of parental stress, coping, and spirituality with regard to a number of chronic conditions in childhood. A multiple regression and correlation analysis between all variables was conducted to address the research questions regarding the level of stress management, spirituality, and coping effectiveness in parents of a child with a chronic illness. Surprisingly, the results from the current study did not reveal a statistically significant prediction of the combination of spirituality and coping to collaboratively decrease the level of parental stress. This finding was a surprise because since each variable is similar and effective in lowering parent's level of stress independently, it was hypothesized to conduct comparable results when analyzed consensually. In contrast, previous research has emphasized the importance of a "holistic culture in the health care setting where spirituality, coping, and healing are tied together for facilitating a curative environment" (Sira & McConnell, 2008, p. 36). Although an individual's coping and spirituality do not bilaterally help to decrease the level of parental stress, an individual's spirituality does have significant contributions to the level of parental stress; specifically, one's self-efficacy and life scheme. This finding reflects literature to prove that spirituality allows individuals to redeem a sense of mastery or efficacy in the middle of chaotic events (Grossoehme et al., 2011). The ability to give meaning to a situation and an individual's capacity to exert control over one's own motivation and behavior result in valuable outcomes. These results correlate perfectly with the definition that spirituality is "the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship with the sacred or transcendent" (Bandura, 1997; Frey et al., 2005, p. 561; Koenig et al., 2001; Moreira-Almeida & Koenig, 2006, p. 844).

The first theme of the thematic analysis revealed that parents level of spirituality grew stronger through the experience of their child's chronic condition. These results reflect previous research that many parents state that their child's illness has strengthened their spiritual beliefs (Knapp et al., 2011). Parents reported that their religion, spirituality, or life philosophy (RSLP) is important in providing support, peace, comfort, and moral guidance (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). While the participants reported the strengthening of their spirituality, they also reported previous circumstances of questioning why this was happening to their child which is supported by previous literature. Feudtner et al. (2003) found that common reactions for parents with a chronically ill child include: difficulty coping with child's pain; why my child? Why me?; what is the meaning of suffering?; feeling guilty; can I be angry at God?; etc. Although none of the parents expressed their spiritual rituals, individuals can experience spirituality in many different ways including: scripture reading, prayer, meditation, listening to music, rituals, nature walks, spiritually motivated behaviors, spiritual thinking, empathetic listening, praying with children and families, touch, or other ways of silent communication (Wachholtz & Pearce, 2009; Krok, 2008; Feudtner, Haney, & Dimmers, 2003). Each participant proclaimed the significant, relevant use of prayer while dealing with their child's chronic condition. Parents of chronically ill children use prayer as a way to work together with God to problem solve when access to other support is not available (Benore et al., 2008; Cole, Benore, & Pargament, 2004). Greater comfort in stressful situations, greater strength, and greater confidence in life are associated with the relationship individuals have with God (Krause, 1998; Hill & Pargament, 2003).

Although the focus of this study was on the use of spiritual coping, emotional and instrumental social support was highlighted in theme two as being a significantly powerful way

of coping for parents of a chronically ill child. Congruent with previous literature, social support can come from many sources including spouse, family, friends, health care professionals, and other families in similar situations (Taylor & Stanton, 2007). Positive interactions with similar individuals are encouraging, strengthening, and enlightening. The use of social support as a coping resource improves the aptitude to manage stressful events and is associated with reduced distress and improved health outcomes (Gibson, 1995). The participants of this study found the support of their spouse, family, friends, and other parents in similar situations to be a beneficial aid in coping with their child's chronic condition through conversation, emotional support, financial support, and tangible support in everyday life. Child life specialists and other members of the healthcare team can encourage these relationships and help to assist in pairing parents in similar situations together as a significant supportive resource.

As illustrated in the third theme, a substantial concern for parents of a child with a chronic condition is the uncertainty of their child's future and maximum potential. Most of the parents interviewed expressed their apprehension of what their child's adult life will be like, what they will be able to experience, and the separation of their child from their peers developmentally. Melnyk et al. (2001) found that parents of these children often experience recurrent negative emotions and responses as they notice their child struggling to attain developmentally appropriate tasks. In addition, children may encounter "teasing, difficulties with establishing friendships, and challenges performing age-appropriate activities" (Melnyk et al., 2001, p.549; Trachtenberg & Batshaw, 1997). Contrasting the current study, several themes that were found in literature of families living with a chronically ill child involve reports of living with anxiety, carrying the burden, and survival of the family unit. (Lavee & Mey-Dan, 2003; Brown et al., 2008). Although responses of anxious feelings were mentioned in the interviews,

none of the parental responses rose concern as a threat to the family unit. The rationale for the differing themes that were found in 2003 and 2008 compared to today is the accessibility of support groups and resources to parents, further awareness of chronic conditions to the general population, and the advancements in the medical field.

The final theme identified in parents of a child with a chronic condition was a greater appreciation of life in general. Although this particular theme was not recognized in previous research, the majority of participants expressed an increase of humility, acceptance, and compassion toward others in everyday life. Previous research identified that some families “report greater cohesion and trust and increased communication as a result of the child’s illness” (Brown et al., 2008, p. 410; Lavee & Mey-Dan, 2003; Philichi, 1989). In addition to these virtues, the parents in the current study have learned to appreciate and celebrate even the smallest milestones of their child’s life because of the extra effort each developmental task requires. The experience of their child’s chronic condition has allowed each parent to cultivate a new perspective and evaluation of life’s adversities.

The mixed method research design was an optimal choice to ensure that the limitations of one type of data are balanced by the strength of another. The mixed methods approach allows the opportunity to answer questions from a number of perspectives and to ensure there are no gaps to the data collected. The qualitative portion of the study was used to understand, interpret, and support the close-ended results for the quantitative data. The quantitative data provides important information such as demographics and user preferences with the ability to perform statistical analyses to derive findings about the data. The current study advances the literature by elucidating potentially advantageous coping mechanisms for parents of a child with a chronic condition and for the skilled professionals that work alongside these families. The results can be

used to provide culturally adapted clinical interventions by leading to better understanding about the experiences, journey, and implications of families with a chronically ill child.

Future Research. Future research may consider locating parents of a chronically ill child who are not seeking any type of support services to gain more insight into the coping differences or lack thereof coping. It would be interesting to compare the results of those who were accessing a support group to those who were not. It is important to recognize that it could be difficult to locate this specific group of parents who are not accessing a support group. Another gap in the research that can be studied is the coping and spirituality differences in the population of parents whose child has just been diagnosed with a chronic condition or the evaluation of parents of children with a more life-threatening chronic condition. The initial diagnosis of any chronic condition and a life-threatening illness will likely portray diverse levels or styles of coping and spirituality in parents. Future research can also explore the engagement of and interplay of other coping variables to investigate the correlation in decreasing parental stress.

Implications. The results from this study demonstrate that an individual's level of self-efficacy and life scheme are predictors of stress level for parents of a chronically ill child. The interdisciplinary team that works with patients in the hospital is composed of a group of individuals including physicians, nurses, social workers, child life specialists, nutritionists, occupational therapists, etc. and all play a vital role in serving patients holistically. Implications suggest for professionals to educate individuals on how to recognize and identify controllable and uncontrollable situations and to teach what types of coping are positively correlated with each (Sorgen & Manne, 2002). An intervention to be able to place meaning to an individual's chronic illness and healthcare situation has been proven through spiritual coping in healthcare settings. Child life specialists in particular can provide parents with effective coping techniques

that have been proven to be advantageous to similar families, including the spirituality piece. A few implications of coping for parents of a chronically ill child from health care providers include: (1) recognizing and encouraging the use of all family members' social support systems including extended family, church support, close friends, etc.; (2) modifying any misconceptions including information assembled from the media, the internet, and from well-intentioned friends, coworkers, and family; and (3) providing whatever contributory support is necessary, such as available resources for financial and insurance concerns (Hovey, 2005). Child life specialists play the role of being an advocate for family centered care and involving each member of the family system. This is especially valuable in regards to the previously listed coping implications and to encourage and emphasize the importance of the spirituality portion in each support system. Resources of these techniques can be given at the time of diagnosis, during hospitalizations or doctor visits, and incorporated into parental support groups. In addition to the resource materials to encourage appropriate emotional and instrumental coping, information on the advantages of the interplay of one's spirituality should be included.

Other professionals that can apply these implications include, but are not limited to, family life educators, chaplains, and family therapists. Each of these professionals have a similar goal to support, provide resources, teach coping, and cultivate individuals into their highest potential. They have the specialized training to apply their expertise and knowledge on an individual basis or to the family unit as a whole. Family life educators bring inclusive family training to provide preventative education. Because it is impossible to predict the onset of a child's chronic condition, family life educators can be accessed during or shortly after diagnoses transpire to educate families on strong communication skills, good decision making skills, parenting approaches, and healthy interpersonal relationships. Chaplains are available inside of

or aside from the hospital to help families redefine and reframe the meaning of their child's chronic condition in order to appropriately cope and learn how to live with the diagnosis. Family therapists come into play when an intervention is required to resolve a problem in order to bring the family unit cohesively back together. The immense options of these professionals can be accessed for patients, parents, and families to receive support and resources outside of the hospital and into their community. The results and coping suggestions of the current study can be advantageous and stimulating for individual readers as well.

Limitations. Despite the numerous strengths of the current study, there are a few limitations worth noting. Although the sample size is fairly diverse, it is considerably small and could be difficult to generalize to a larger population. Acknowledging this, the interviews were implemented to add a qualitative piece which allow this study to remain significant and within adequate sampling range for a mixed methods study. The spiritual coping variable was the only variable evaluated as opposed to other potentially effective coping mechanisms that may be seen as a limitation. As seen in the results section, other coping mechanisms were accredited to be effective by parents but the focus of this study was on the spirituality aspect itself. Finally, the participants are already accessing a support group as a coping mechanism which may set them aside from parents who have not found an effective coping strategy. The results may have been slightly skewed if parents of a chronically ill child who have not sought out a support group were able to be accessed. Future research should aim to address parents who are not coping through a support group to understand the holistic differences. Despite these limitations, this study advances the literature by formulating a theoretical model of parental stress, coping, and spirituality in the family unit of chronically ill children.

Conclusion. A chronic health condition affects all members of a family system with a variety of stressors experienced by the ill child, their healthy siblings, and with an emphasis on the parents of the child. A mixed method approach was conducted to analyze the interaction of how parents of a chronically ill child use their spirituality to cope with and decrease their level of overall stress. Findings present that although an individual's coping and spirituality do not bilaterally help to decrease the level of parental stress, an individual's spirituality does have significant contributions to the level of parental stress; specifically, one's self-efficacy and life scheme. In regards to these results, members of the interdisciplinary team, particularly child life specialists, can educate and encourage parents of chronically ill children of the importance of one's spiritual coping practices to reduce parental stress.

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APPENDIX A: EAST CAROLINA UNIVERSITY IRB APPROVAL

EAST CAROLINA UNIVERSITY

University & Medical Center Institutional Review Board Office

4N-70 Brody Medical Sciences Building· Mail Stop 682

600 Moye Boulevard · Greenville, NC 27834

Office 252-744-2914  · Fax 252-744-2284  · www.ecu.edu/irb

Notification of Initial Approval: Expedited

From: Social/ Behavioral IRB

To: Chelse Cudmore

CC: Alan Taylor

Date: 12/22/2015

Re: UMCRI 15-001966

Parental Spiritual Coping

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 12/21/2015 to 12/20/2016. The research study is eligible for review under expedited category # 6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCRI review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCRI. The investigator must submit a continuing review/closure application to the UMCRI prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workplace).

The approval includes the following items:

Name	Description
Brief Coping Style1.png	Surveys and Questionnaires
Brief Coping Style 2.png	Surveys and Questionnaires
Brief Coping Style3.png	Surveys and Questionnaires
Informed Consent for Interviewed Participants	Consent Forms
Informed Consent for Online Participants	Consent Forms
Interview Questions.docx	Interview/ Focus Group Scripts/ Questions
Parental Spiritual Coping.docx	Study Protocol or Grant Application
Parenting Stress Index Measure.doc	Surveys and Questionnaires
Spirituality Index of Well-Being.png	Surveys and Questionnaires

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

APPENDIX B: INFORMED CONSENT FOR ONLINE PARTICIPANTS

East Carolina University



Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Parental Spiritual Coping with a Chronically Ill Child

Principal Investigator: Chelse Cudmore

Institution, Department or Division: East Carolina University

Address: 1001 E 5th St. Greenville, NC 27858

Telephone #: 901-604-1439

Study Coordinator: Alan Taylor

Telephone #: 252-864-3602

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

Why am I being invited to take part in this research?

The purpose of this research is to recognize the complexity of stressors for parents with a chronically ill child and to evaluate the presence and effectiveness of spiritual coping. You are being invited to take part in this research because you are the parent of a chronically ill child and the researcher wants to evaluate effective coping strategies to help similar families. The decision to take part in this research is yours to make. By doing this research, we hope to learn the effectiveness of spiritual coping when parenting a chronically ill child.

If you volunteer to take part in this research, you will be one of about 500 people to do the online version and there will be 15 interviews to take place.

Are there reasons I should not take part in this research?

I understand I should not volunteer to participate in this research if I am not the primary caregiver of and live with my chronically ill child.

What other choices do I have if I do not take part in this research?

You can choose not to participate.

Where is the research going to take place and how long will it last?

The research will be conducted through your online support group location. You can complete the survey on your own time. The survey should take no longer than 30 minutes to complete.

What will I be asked to do?

You will be asked to do the following:

- Complete a series of 3 short surveys including: Parent Stress Scale, Brief COPE Inventory, and Spiritual Index of Well-Being. The total number of items is 54. The *Parental Stress Scale* is an 18

item self-report scale that attempts to measure the levels of stress experienced by parents while taking into account positive and negative aspects of parenting. The *Brief COPE Inventory* is composed of six subscales of particular ways of coping. The *Spirituality Index of Well-Being* is a 12-item instrument that measures one's perception of their spiritual quality of life.

- After the surveys are completed, you will email the completed survey to the researcher.

What might I experience if I take part in the research?

We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. We don't know if you will benefit from taking part in this study. There may not be any personal benefit to you but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?

We will not be able to pay you for the time you volunteer while being in this study.

Will it cost me to take part in this research?

It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- The study coordinators: Alan Taylor, Eboni Baugh, and Sandy Triebenbacher.
- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

How will you keep the information you collect about me secure? How long will you keep it?

Identifying information will not be included in the research. The data collected from the participants will be stored for three years after completion of the study. Once the researcher has analyzed the data and completed her research, all surveys will be destroyed.

What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 901-604-1439 (Monday-Friday, 8:00 am-5:00 pm).

If you have questions about your rights as someone taking part in research, you may call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you

would like to report a complaint or concern about this research study, you may call the Director of the ORIC, at 252-744-1971

I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By receiving this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

APPENDIX C: INFORMED CONSENT FOR INTERVIEW PARTICIPANTS

East Carolina University



Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: Parental Spiritual Coping with a Chronically Ill Child
Principal Investigator: Chelse Cudmore
Institution, Department or Division: Human Development and Family Science
Address: 1001 East 5th St. Greenville, NC 27858
Telephone #: 901-604-1439
Study Coordinator: Alan Taylor
Telephone #: 252-864-3602

Researchers at East Carolina University (ECU) study issues related to society, health problems, environmental problems, behavior problems and the human condition. To do this, we need the help of volunteers who are willing to take part in research.

Why am I being invited to take part in this research?

The purpose of this research is to recognize the complexity of stressors for parents with a chronically ill child and to evaluate the presence and effectiveness of spiritual coping. You are being invited to take part in this research because you are the parent of a chronically ill child and the researcher wants to evaluate effective coping strategies to help similar families. The decision to take part in this research is yours to make. By doing this research, we hope to learn the effectiveness of spiritual coping when parenting a chronically ill child.

If you volunteer to take part in this research, you will be one of about 15 people to do so.

Are there reasons I should not take part in this research?

I understand I should not volunteer to participate in this research if I am not the primary caregiver of and live with my chronically ill child.

What other choices do I have if I do not take part in this research?

You can choose not to participate.

Where is the research going to take place and how long will it last?

The research will be conducted at either the home of the individual or a public place of the participant's choice. The total amount of time you will be asked to volunteer for this study is one hour.

What will I be asked to do?

You will be asked to do the following:

- Complete a series of 3 short surveys including: Parent Stress Scale, Brief COPE Inventory, and Spiritual Index of Well-Being. The total number of items is 54. The *Parental Stress Scale* is an 18 item self-report scale that attempts to measure the levels of stress experienced by parents while

taking into account positive and negative aspects of parenting. The *Brief COPE Inventory* is composed of six subscales of particular ways of coping. The *Spirituality Index of Well-Being* is a 12-item instrument that measures one's perception of their spiritual quality of life.

- Upon completion of the survey, the researcher will sit down with the participant and ask the following questions in an interview format: (1) Do you feel like your spirituality has grown stronger or weaker when dealing with your child's chronic condition?; (2) What coping mechanism has been the most beneficial when dealing with the stress of your child's chronic condition?; (3) Elaborate on what has been the most difficult aspect of your child's chronic condition to cope with?; (4) As you look back over this experience, what have you learned? The interview's will be audio recorded for transcription purposes.

What might I experience if I take part in the research?

We don't know of any risks (the chance of harm) associated with this research. Any risks that may occur with this research are no more than what you would experience in everyday life. We don't know if you will benefit from taking part in this study. There may not be any personal benefit to you but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?

We will not be able to pay you for the time you volunteer while being in this study. The researcher will offer a gift card as an incentive of completing the interview.

Will it cost me to take part in this research?

It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- The study coordinators: Alan Taylor, Eboni Baugh, and Sandy Triebenbacher
- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.

How will you keep the information you collect about me secure? How long will you keep it?

Identifying information will not be included in the research. The interview will be audio taped for the sole purpose of the researcher to find similar themes in the data. The data collected from the participants will be stored for three years after completion of the study. Once the researcher has analyzed the data and completed her research, all surveys will be destroyed.

What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator at 901-604-1439 (Monday-Friday, 8:00 am-5:00 pm).

If you have questions about your rights as someone taking part in research, you may call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the ORIC, at 252-744-1971.

I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following and if you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

Participant's Name (PRINT)	Signature	Date
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Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person’s questions about the research.

Person Obtaining Consent (PRINT)	Signature	Date
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APPENDIX D: QUESTIONNAIRE

Spiritual Parental Coping with a Chronically Ill Child

Q55 Age of parent:

Q69 Gender of parent:

Q56 Age of child:

Q70 Gender of child:

Q57 Diagnosis of child:

Q58 Age of child at diagnosis:

Q59 Race/Ethnicity:

Q60 Marital Status:

- Single (1)
- Married (2)
- Divorced (3)

Q61 Number of siblings of the ill child:

Q62 Others living in the household (aside from immediate family members):

Q63 Highest level of education earned:

- Some High School (1)
- High School Diploma/ GED (2)
- Post High School Trade School/Vocational Training (3)
- 4-year College Degree (4)
- Post Graduate Degree (5)
- Other (6)

Q64 What state do you reside in?

Q65 Rate how important your spirituality is to you? (1-10, 1 being the least importance, 10 being the most importance)

Q1 I am happy in my role as a parent.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q2 There is little or nothing I wouldn't do for my child(ren) if it was necessary.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q3 Caring for my child(ren) sometimes takes more time and energy than I have to give.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q4 I sometimes worry whether I am doing enough for my child(ren).

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q5 I feel close to my child(ren).

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q6 I enjoy spending time with my child(ren).

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q7 My child(ren) is an important source of affection for me.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q8 Having child(ren) gives me a more certain and optimistic view for the future.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q9 The major source of stress in my life is my child(ren).

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q10 Having child(ren) leaves little time and flexibility in my life.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q11 Having child(ren) has been a financial burden.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q12 It is difficult to balance different responsibilities because of my child(ren).

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q13 The behavior of my child(ren) is often embarrassing or stressful to me.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q14 If I had it to do over again, I might decide not to have child(ren).

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q15 I feel overwhelmed by the responsibility of being a parent.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q16 Having child(ren) has meant having too few choices and too little control over my life.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q17 I am satisfied as a parent.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q18 I find my child(ren) enjoyable.

- Strongly Disagree (1)
- Disagree (2)
- Undecided (3)
- Agree (4)
- Strongly Agree (5)

Q19 I've been using alcohol or other drugs to make myself feel better.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q20 I've been getting emotional support from others.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've being doing this a lot (4)

Q21 I've been giving up trying to deal with it.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q22 I've been taking action to try to make the situation better.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q23 I've been using alcohol or other drugs to help me get through it.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q24 I've been criticizing myself.

- I haven't being doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q25 I've been trying to come up with a strategy about what to do.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q26 I've been making jokes about it.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q27 I've been expressing my negative feelings.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q28 I've been trying to get advice or help from other people about what to do.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q29 I've been thinking hard about what steps to take.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q30 I've been praying or meditating.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q31 I talk to someone who could do something concrete about the problem.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q32 I get sympathy and understanding from someone.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q33 I pretend that it hasn't really happened.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q34 I accept the reality of the fact that it happened.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q35 I ask people who have had similar experiences what they did.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q36 I take direct action to get around the problem.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q37 I try to find comfort in my religion.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q38 I talk to someone about how I feel.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q39 I learn to live with it.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q40 I act as though it hasn't even happened.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q41 I do what has to be done, one step at time.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q42 I pray more than usual.

- I haven't been doing this at all (1)
- I've been doing this a little bit (2)
- I've been doing this a medium amount (3)
- I've been doing this a lot (4)

Q43 There is not much I can do to help myself.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q44 Often, there is no way I can complete what I have started.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q45 I can't begin to understand my problems.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q46 I am overwhelmed when I have personal difficulties and problems.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q47 I don't know how to begin to solve my problems.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q48 There is not much I can do to make a difference in my life.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q49 I haven't found my life's purpose yet.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q50 I don't know who I am, where I came from, or where I am going.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q51 I have a lack of purpose in my life.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q52 In this world, I don't know where I fit in.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q53 I am far from understanding the meaning of life.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Disagree (5)

Q54 There is a great void in my life at this time.

- Strongly Agree (1)
- Agree (2)
- Neither Agree nor Disagree (3)
- Disagree (4)
- Strongly Agree (5)

APPENDIX E: OPEN ENDED INTERVIEW QUESTIONS

1. Do you feel like your spirituality has grown stronger or weaker when dealing with your child's chronic condition?
2. What coping mechanism has been the most beneficial when dealing with the stress of your child's chronic condition?
3. Elaborate on what has been the most difficult aspect of your child's chronic condition to cope with?
4. As you look back over this experience, what have you learned?