

The Quality of Life of Primary Caregivers of Children with Chronic Conditions

BY

EMILY SPORE

BSN, Saint Mary's College, Notre Dame, IN, 2004

THESIS

Submitted as partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Nursing Sciences
in the Graduate College of the
University of Illinois at Chicago, 2012
Chicago, Illinois

Defense Committee:

Agatha M. Gallo, Chair and Advisor
Carol Ferrans
Eileen Hacker
Patricia Hershberger
Chang Park

This thesis is dedicated to:

My mother, who is my biggest fan and has never let me quit.

My grandmother, who showed me what it really takes to be a great nurse and was the reason that
I became one.

ACKNOWLEDGEMENTS

I would never have been able to finish this doctoral thesis without the guidance of my committee members and support from my family.

I would like express my most sincere gratitude to my advisor and committee chair, Dr. Agatha Gallo. Without Dr. Gallo's encouragement, support and never-ending patience, this dissertation would never have become a reality. She never stopped guiding me in this process, even when the road seemed endless. I would like to thank Dr. Chang Park for his direction and diligent follow-through with my data analysis. He didn't let me lose sight of the end of this process, and for that, I am truly grateful. I also would like to thank Dr. Carol Ferrans, Dr. Eileen Hacker and Dr. Patricia Hershberger for their unwavering support and patience. They have generously given their time and expertise to better my work, and I am truly indebted and thankful for their contributions and their helpful support.

Finally, I would like to thank my entire family, who never stopped reminding me that I was capable of finishing this process successfully. Their undying love and support has meant the world to me. Thank you especially to my parents, Jim, Molly, Bridget, Alex, my Uncle Steve and my grandparents.

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Summary

This dissertation is comprised of two papers that address the quality of life (QOL) of caregivers of children with chronic conditions. The first paper is a literature review that critically evaluates study findings pertaining to the quality of life of primary caregivers of children with chronic conditions to determine current findings and gaps. Using a systematic approach, findings were categorized, organized and synthesized using the four domains of the Ferrans Conceptual Model for Quality of Life (QOL). This review showed that the time commitment associated with caring for a child who has a chronic condition affects the reported QOL of the primary caregivers. The QOL of the caregiver as it relates to health, psychological well-being, social networks and support, and the family dynamic can be negatively impacted when a significant amount of time is being committed to the care of the child with a chronic condition. The noted outcomes of QOL among caregivers can vary based on the severity of the child's condition and the caregiver's perceived QOL. It was concluded that more studies on quality of life in childhood chronic illness would add to the body of knowledge and hopefully increase the awareness of these caregivers' needs for clinicians who care for these children.

The second paper is a mixed methods study that assessed the relationship between the caregiver's QOL, the child's functional status and the well-being of the family unit. Results of the Ferrans and Powers Quality of Life Index Generic Version (QLI), the Functional Status Measure II and the Family APGAR were analyzed. The caregivers' overall QOL scores were divided into upper and lower quartiles which facilitated the inspection of the qualitative data collected from the caregiver. This analysis was conducted to better understand the aspects of the caregiver's own life and daily routine that affected their self-reported QOL.

This study shows that the reported functioning of a child with a chronic condition and the well-being of the family unit were directly related to their QOL. The quantitative analysis showed that the measures of QOL, child's functional status and family well-being were strongly

positively correlated. The overall QOL mean scores of the upper and lower quartile were significantly different. QOL was impacted by financial strains within the family as a result of the child's condition, support within the family unit and psychological stressors of the genetic nature of the child's condition. The findings of this study were not driven by the diagnosis of the child; all diagnoses were represented in both the upper and lower quartile of overall QOL scores. This study is unique because of its mixed-methods approach, the use of multiple childhood conditions within the same study and the use of genetic conditions to determine the sample. Based on the results of this study, financial support for these caregivers and their families positively impact their QOL. Caregiver QOL, child's functional status and family well-being were found to be strongly positively correlated. The findings of this study suggest that QOL assessments for caregivers of children with chronic conditions are dependable indicators of caregiver QOL and can assist clinicians in identifying support or resources for these caregivers. The use of QOL measures in a clinical setting can identify aspects of a caregiver's life that may be improved with the use of support services or interventions.

I. Introduction

A. Background

As the current state of pediatric health care continues to progress and further treatments are developed, children who are born with or develop chronic conditions are continuing to live longer lives. Childhood conditions, such as cancers or brain tumors, are beginning to be associated with lower mortality levels and higher morbidity levels, as treatment options continue to be enhanced [1, 2]. The median survival age for individuals diagnosed with cystic fibrosis in infancy has increased to 37.7 [3]. And while the incidence of childhood cancers has increased in the United States since 1975, the five-year survival rate for all childhood cancers combined has increased from 58.1 percent in 1975-77 to 79.6 percent in 1996-2003 [4]. Therapeutic advances in cancer treatment have enabled 80% of pediatric patients with cancer to survive for five years, and most of these patients are cured. Survivors of childhood and adolescent cancer comprise 1 in 570 individuals between 20 and 34 years of age [5]. Living with a chronic condition during childhood not only affects the life of the child but also affects aspects of the life of the caregiver of these children, who often are the child's mother or father, but may also be extended family members. Therefore, a chronic condition not only affects the child but its affect can extend to other members of the child's family [6]. Having a better understanding of the ways in which the child's condition can affect the caregiver's own quality of life can enhance the treatment of the entire family [7]. The devotion and responsibility that is required of families in order to care for children with chronic conditions, especially those who need continuous care, can affect the ability to maintain normalcy and routine in their everyday lives [8]. Information for healthcare providers related to assessing and addressing caregiver QOL can lead to enhanced psychological guidance and further information about disease control, in order to improve the child's health outcomes, therefore increasing the caregiver's self-reported QOL [9].

Quality of life (QOL) has become an important aspect of health care in recent years. QOL is defined by the World Health Organization (WHO) as "an individual's perception of his/her

position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns” [10]. Measures of QOL have been used to determine life-sustaining measures in medical practice, allocation of resources in the public healthcare setting(s), and insight for clinicians regarding a person’s perception of their life’s current state and their ability to fulfill socially useful roles [11]. Traditionally, many QOL studies have focused on the individual who possesses the illness or condition; however, more recent studies have begun to focus on the QOL of the caregiver who provides care to a person who is acutely or chronically ill [12]. In these cases, QOL is measured in the same way, but QOL measurement is used to interpret the caregiver’s self-reported QOL rather than the QOL of the person with the condition.

The ability to measure the QOL of caregivers of children with chronic conditions gives insight to the challenges of the caregivers’ everyday lives as they care for their children. Caregivers are often required to sacrifice aspects of their own personal well-being in order to devote extended amounts of time to care for their children [13]. The quality of care that is provided to a child from a caregiver can often be directly impacted by caregivers’ perceptions of their own QOL [14, 15]. The impact on the caregiver’s QOL may also be determined by the burden of care that the condition possesses: amount of physical stress associated with caring for the child and the amount of time that is required to care for the child’s medical, physical and social needs [16]. Since many childhood chronic conditions are associated with physical disability, the ability to care for these children may become more difficult or physically exhausting as the child ages and grows [17]. Therefore, the QOL of caregivers of children with chronic conditions is influenced by a number of physiological, psychological and social factors associated with the care that each child requires.

B. Significance of the Problem

The QOL of caregivers of children with chronic conditions often is not the main focus of healthcare workers during the process of treating these children, but information on the caregiver's QOL provides understanding about the significance of how attention to these caregivers can be an important part of treatment for any long-term childhood chronic condition [8, 18]. While measures of QOL have become more widely-used in many areas of healthcare practice, caregivers of children with chronic conditions often are not assessed for their QOL [19]. The assessment of primary caregivers' health and well-being could lead to better identification and treatment of physical, psychological and social problems within the family unit [15, 20].

As the advances in treatment for childhood chronic conditions have occurred, findings have allowed for longer lives of these children, who prior to these advances may not have lived into adolescence [21]. The longer lives of these children, in many cases, means that these children require long-term assistance and care from family members and caregivers. The commitment to long-term care for these children can significantly impact the QOL of the caregivers, who often are required to give round-the-clock care in order to meet the child's medical, physical and social needs [22]. While caregiving is a normal part of being a parent, the level of care that children with chronic conditions require increases the level of burden and stress on the parent and can affect the routines of family life and socialization. While all chronic conditions in children may have an effect on the caregiver's QOL, each condition has its own set of challenges for the caregiver, based on the type of treatment that the child requires and/or the concerns associated with the child's condition [23]. Caregivers of children with chronic conditions have a desire for normality, certainty, information-sharing and partnership, with conflicting wishes between wanting optimal health for their child as well as the desire for a normal life for the child [24, 25].

To increase and enhance the body of knowledge surrounding this topic, the importance of funding and the support of local, state and federal agencies is incredibly important. The National Institute of Nursing Research (NINR) made QOL research one of its highlighted and important

areas of research in its strategic plan for 2006-2010. Currently, in the 2011 NINR strategic plan, evaluating caregiver burden, as it relates to the QOL of caregivers who care for individuals with a chronic condition, is a highlighted focus. NINR states that it will support research that will “develop strategies to assist individuals and their caregivers in managing chronic illness, including analyses of caregiver burden and cost-effectiveness”. This emphasis on caregivers and their QOL by research organizations, such as NINR, shows the importance of these studies in adding to the current body of research knowledge in an attempt to make positive changes in clinical practice, therefore assisting caregivers with ways to enhance their QOL.

In addition, federal organizations, such as the Centers for Disease Control (CDC), have made the knowledge about and measurement of QOL a priority in order to understand more about how an individual’s QOL can affect their physical or mental health. As the CDC continues to focus on measuring health-related QOL (HRQOL), the importance of determining relationships between HRQOL and preventable health conditions is information that can be utilized in many disciplines. The CDC has stated, as a result of their current research, that the measure of HRQOL can be considered a valid indicator of service needs and intervention outcomes in all areas of public health [26]. The United States Food and Drug Administration (FDA) has also implemented QOL measurements in the process of approving some drugs used to treat cancer and depression [27].

C. Purpose and Specific Aims

With more children with chronic conditions requiring long-term in-home care from their primary caregivers, it is important to understand the impact of measuring caregivers’ QOL, the factors that influence the caregivers’ QOL, and how the measurement of QOL can provide information for interventions for healthcare professionals [15, 28]. The purpose of this study is to examine the factors associated with the QOL of primary caregivers of children with chronic conditions.

This study will:

- a. Describe the quality of life of primary caregivers ($N = 86$) of children with chronic conditions as measured by the Ferrans and Powers Quality of Life Index Generic Version (Ferrans & Powers, 1985);
- b. Determine the relationship among caregiver QOL, the child's functional status and family well being using the Ferrans and Powers Quality of Life Index Generic Version (Ferrans & Powers, 1985), the Family APGAR (Austin & Huberty, 1989; Smilkstein, 1978) and the Functional Status Measure II (Stein & Jessop, 1991);
- c. Examine qualitative data for the caregivers who scored in the lowest and highest quartiles on the Ferrans and Powers Quality of Life Index, focusing on coding categories in the previously collected qualitative data that may explain trends in the caregivers' quality of life.

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II. THE QUALITY OF LIFE OF PRIMARY CAREGIVERS OF CHILDREN WITH CHRONIC CONDITIONS:

A REVIEW OF LITERATURE

A. Abstract

Purpose/Objectives: To critically evaluate the current literature pertaining to the quality of life (QOL) of primary caregivers of children with chronic conditions to determine current findings and gaps in knowledge.

Data Sources: Published studies included in the review were identified through literature searches of PubMed ©, CINAHL© and EBSCOhost © databases using the index terms “quality of life,” “primary caregivers,” and “children.” All conditions diagnosed among children were included in the review, as there was no restriction set to limit the focus of the child’s condition in the search. In addition the reference lists of identified studies were examined to further obtain additional studies not identified in the online databases.

Methods: A total of 35 studies were used for this literature review. The full-text of each study was reviewed for relevancy to the topic and possession of the inclusion criteria. Inclusion criteria for the review consisted of quantitative or qualitative English-language studies on the QOL of caregivers of children with chronic conditions published between January 2005 and March 2012. The focus of this literature review was on the results of these studies. Using the Ferrans Conceptual Model for QOL as a guide, results of published research that examined the QOL of primary caregivers of children with chronic conditions were categorized into four focused areas. Consistent with this theoretical framework, health and functioning, psychological/spiritual, social and economic, and family, were used to guide this literature review.

Results: The time commitment associated with caring for a child who has a chronic condition affects the QOL of the primary caregivers. The caregiver’s QOL as it relates to health, psychological well-being, social networks and support, and the family dynamic is negatively impacted when a significant amount of time is committed to the care of the child with a chronic

condition. The noted outcomes of QOL among caregivers of children with chronic conditions vary based on the severity of the child's condition and the caregiver's perceived QOL.

Conclusion: Research involving the QOL of caregivers of children with chronic conditions is still evolving, and mixed methods approaches to this type of research have yet to be completed.

Current studies typically focus on a singular childhood condition. Implications for future research include the need for examining caregiver QOL across multiple childhood conditions.

Incorporating qualitative approaches are needed when QOL is measured quantitatively to enhance understanding of caregiver perception of QOL.

Keywords: Quality of life, primary caregivers, children with chronic conditions

THE QUALITY OF LIFE OF PRIMARY CAREGIVERS OF CHILDREN WITH CHRONIC CONDITIONS: A REVIEW OF LITERATURE

As the current state of pediatric health care continues to progress and further treatments are developed, children who are born with or develop chronic conditions are living longer. Childhood conditions, such as cancers or brain tumors, are beginning to be associated with lower mortality levels but higher morbidity levels [1, 2]. The median survival age for individuals diagnosed with cystic fibrosis in infancy has increased to 37.7 years, and long-term survival for cystic fibrosis has now been identified as greater than 25 years of life [3]. While the incidence of childhood cancers has increased in the United States since 1975, the five-year survival rate for all childhood cancers has improved from 58.1 percent in 1975-77 to 79.6 percent in 1996-2003 [4]. Therapeutic advances in cancer treatment have enabled 80% of children with cancer to survive for at least five years, and most of these children are cured [5]. Living with a childhood chronic condition not only affects the life of the child but also affects the lives of the caregivers [6]. Better understanding of the ways in which the child's condition affects the caregiver's quality of life enhances the treatment of the entire family, through greater focused-resource availability for these caregivers and their children [7]. The devotion and responsibility required of families to care for children with chronic conditions, especially those who need continuous care, affects their ability to maintain normalcy and routine in everyday lives [8]. Information for healthcare providers related to assessing and addressing caregiver quality of life (QOL) leads to enhanced psychological guidance and further information about disease control to improve the child's health outcomes, thereby increasing the caregiver's self-reported QOL [9].

B. Background

QOL has become an important aspect of health care in recent years. The World Health Organization (WHO) defines QOL as "an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals,

expectations, standards and concerns” [10]. Measures of QOL have been used to determine life-sustaining measures in medical practice, allocation of resources in the public healthcare setting(s), and insight for clinicians regarding a person’s perceptions of their life’s current state and their ability to fulfill socially useful roles [11, 12]. Traditionally, many QOL investigators have focused on the individual diagnosed with an illness or condition; however, more recent research focuses on the caregiver’s QOL [13].

The ability to measure the QOL of caregivers of children with chronic conditions provides insight into the challenges of the caregivers’ everyday lives while caring for their children [14, 15]. The quality of care that is provided to a child by the caregiver often is directly influenced by the caregivers’ perceptions of their own QOL [16, 17]. The caregiver’s QOL may be determined by the burden of care that is associated with the child’s condition: amount of physical stress associated with caring for the child and the amount of time that is required to care for the child’s medical, physical and social needs [18, 19]. Therefore, the QOL of caregivers of children with chronic conditions is influenced by a number of physiological, psychological and social factors associated with the care that each child requires [20].

C. **Significance of the Problem**

The QOL of caregivers of children with chronic conditions often is not the main focus of healthcare providers during the process of treating these children. However, information on the caregiver’s own QOL provides the healthcare provider with a better understanding how attention to caregiver stresses can be an important enhancement to the treatment for any long-term childhood chronic condition [21, 22]. While measures of QOL have been used in other areas of healthcare practice, caregivers of children with chronic conditions often are not assessed for their QOL [23]. Assessing the primary caregivers’ health and well-being may lead to better identification and treatment of physical, psychological and social problems within the family unit [24, 17].

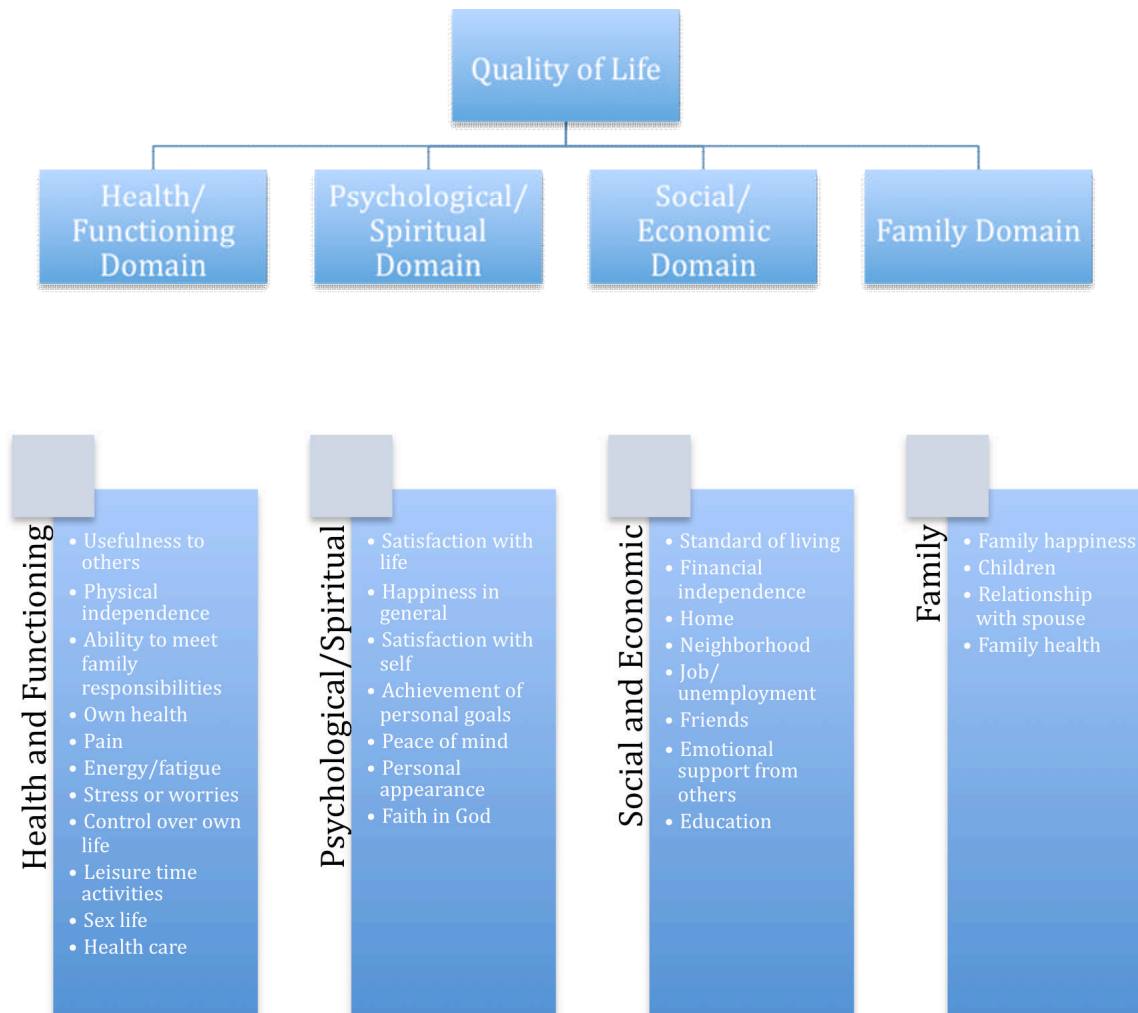
As the advances in treatment for childhood chronic conditions continue and children live longer lives into adolescence, these children require long-term care from caregivers [5]. The commitment to long-term care for these children can significantly impact the QOL of the caregivers, who often are required to give round-the-clock care to meet the child's medical, physical and social needs [25]. While caregiving is a normal part of being a parent, the level of care that children with chronic conditions require increases the level of burden and stress on the caregiver and affects the routines of family life and socialization. While childhood chronic conditions may have an effect on the caregiver's QOL, each condition has its own set of challenges, based on the type of treatment that the child requires and/or the concerns associated with the child's condition [18]. Caregivers of these children have a desire for normality, certainty, information-sharing and partnership with conflicting wishes between wanting optimal health for their child as well as the desire for a normal life for the child [26, 27].

D. **Conceptual Model**

One of the challenges of assessing and measuring a person's QOL is that the definitions and conceptualizations of QOL differ greatly within the literature. QOL measures are typically measured in specific domains. It is important to know what domains associated with a person's QOL are being evaluated when the QOL is measured. The conceptual clarity associated with QOL may affect the outcomes of the research and determine how the research is translated to clinical practice.

The Ferrans Conceptual Model for QOL (see Figure 1) guides the analysis for this literature review [28]. The Ferrans Conceptual Model was developed using qualitative data that focused on what QOL meant to the respondents as well as an examination of the current literature. This conceptual model focuses on the importance that the person reporting QOL is the only proper judge of his/her own personal experience [28].

Figure 1: Ferrans (1996) Conceptual Model for Quality of Life

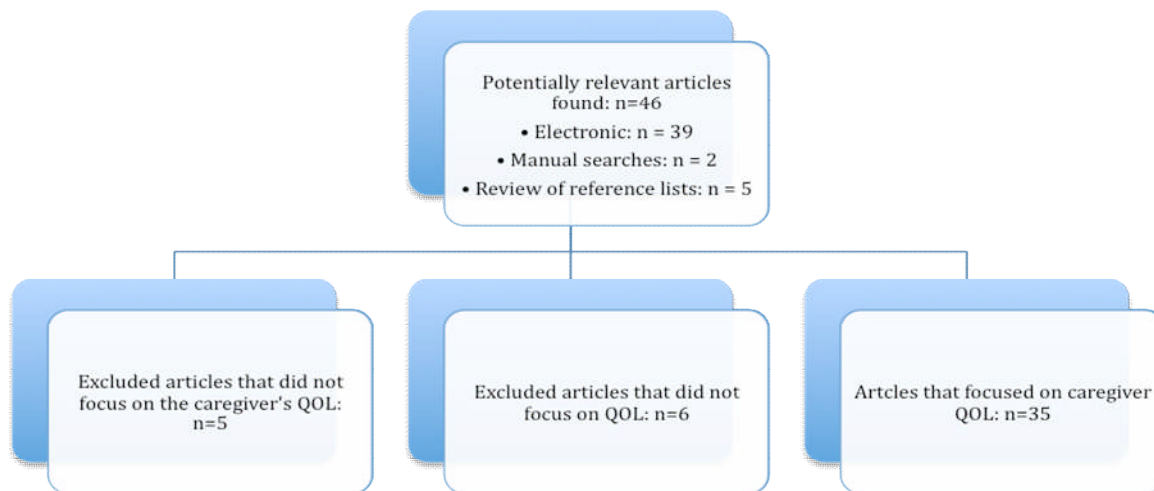


E. Methods

Thirty-five studies were included in this literature review. A total of 46 studies were found, but only 35 studies were used for this review, based on their relevance to the focus of this review: focus on the caregiver's own self-reported QOL and caring for a child with a diagnosed childhood condition (Figure 2). Inclusion criteria for the review consisted of quantitative or qualitative English-language studies on the QOL of caregivers of children with chronic conditions published between January 2005 and March 2012. The full-text of each study was reviewed for

relevancy to the topic and possession of the inclusion criteria. Publications included in the review of literature were identified through literature searches of PubMed®, CINAHL® and EBSCOhost® databases using the index terms “quality of life,” “primary caregivers,” and “children.” Since all conditions diagnosed among children would be included in the review, there was no restriction set to limit the focus of the child’s condition in the search. In addition, the references of the studies obtained through computer indexing were examined to locate any additional articles not indexed in the online databases. Only full-text articles were used for this review. The focus of this literature review was on the results of these studies, not the measurement techniques or the study design. The results from each study included in the review were categorized in a data matrix using the four domains of the Ferrans Conceptual Model for QOL (Health and Functioning, Psychological/Spiritual, Social and Economic, and Family) [28]. Within each of the four domains, the results were synthesized and collectively reviewed for trends, similarities and differences.

Figure 2: Flow Chart of Study Identification



F. Results

Caring for a child with a chronic condition can affect all aspects of a caregiver’s life, including their health and functioning, psychological well-being, social and economic functioning

and their family-life. The need to provide round-the-clock, compassionate, holistic care to these children has been found to impact aspects of the caregiver's QOL.

1. Health and Functioning Domain

A serious negative outcome of impaired caregiver QOL is that the caregiver neglects their own health and well-being to care for the health and well-being of the child with a chronic condition [19]. The implication of caregivers neglecting their own health is the increased incidence of depression, migraines, ulcers and hypertension within this population [30]. Fatigue, lack of sleep, and stress, associated with the long-term, day-to-day care of the child, have been found to contribute to the caregiver's overall impaired physical or mental health [18]. Sleep disturbance was a strong predictor of caregiver QOL, since the amount of caregiver sleep is often determined by the amount of sleep the child receives and the subsequent ability of the caregiver to function during daytime hours [19].

For some chronic conditions, as the child ages and grows, the physical stressors of caring for that child increase and potentially influences the caregiver's physical well-being. Some caregivers who care for children with mobility-limiting disorders, such as cerebral palsy, report physical demands of caring for their child as a factor that negatively influences their QOL [20]. The time commitment for caring for these children prevents caregivers from seeking help from a healthcare professional for their own physical symptoms relating to further impairment of physical health [14].

Some factors that contribute to a caregiver's QOL are inter-related, for example, health-related symptoms and psychological distress of the caregiver. For caregivers of children with cancer, caregiver strain and lack of social support were self-reported as having a negative affect on the caregiver's physical health and functioning. Factors such as emotions, mental health and stress management were seen by caregivers as direct contributors to their physical health and well-being [19]. In one study which focused on health-related QOL differences between mothers and fathers caring for children with chronic pediatric inflammatory bowel disease, fathers

reported that disease activity, such as flare-ups, hospitalizations and changes in medications, had the greatest effect on their own health while mothers reported that the child's adjustment to the condition had the greatest effect on their own physical health [32]. Younger maternal or paternal age, the condition of the child, and the treatment severity negatively affected the physical and psychological health in a longitudinal study following children for two years after a stem cell transplant [33].

2. Psychosocial and Spiritual Domain

Similarly, caregivers of children with chronic conditions have been found to have impairments in their self-reported psychological state. While no study in this literature review focused specifically on the spiritual well-being of the caregiver, some aspects of psychological well-being directly influenced a caregiver's spiritual state or beliefs.

Psychological symptoms among caregivers of children with chronic conditions, such as depression or anxiety, influenced the caregiver's ability to deal with stressful events associated with the child's condition [6]. However, it is not clear whether psychological symptoms, such as depression or anxiety, are associated with the long-term care provided by caregivers as a result of the stress associated with the child's original diagnosis or whether they were pre-disposed to these conditions prior to the child's diagnosis or treatment [34]. In a study examining the caregiver and family unit shortly after a child's diagnosis, the family often became closer as a unit (increased family satisfaction levels), but the caregivers experienced an increased incidence of depression or post-traumatic stress syndrome over time as the child's condition progressed and sometimes worsened [21]. In some cases, the life-limiting condition of the child (such as cystic fibrosis or cancer) may be a factor that contributes significantly to depressive symptoms among caregivers [15]. The consistency of care that is delivered by the caregiver (number of hours per day) has been shown to affect the level of depression or anxiety that the caregiver experiences, which can then lead to further psychiatric health problems [14]. Parental worry and stress affected decisions that caregivers make, specific to their child's condition [30].

The caregivers' psychological stress related to hospitalizations of their child is a risk factor for the caregiver's well-being. A longitudinal study, which looked at the QOL of parents whose child had chronic symptoms following hospitalization for meningococcal septic shock, determined that the presence of emotional stress and altered psychological well-being was seen throughout the sample over time. As many as 17% of the sample sought professional help for anxiety or depression during the two years post-hospitalization [35]. Mothers of hospitalized pediatric oncology patients have also been shown to have a more negatively affected self-reported QOL during the time of the child's hospitalization in contrast to after the child was discharged home to the mother's care [36].

Likewise, the mental and psychological functioning of the child with the chronic condition negatively affects the caregiver's QOL. Caregiver stress increases when faced with their child's mental or psychological issues as a result of their condition, such as the presence of a brain tumor or a diagnosis of autism [37]. Similarly, psychological impairment of the caregiver, such as symptoms associated with clinical depression, can also have a negative effect on the child's condition or functional status. In one study, depressive symptoms in mothers of children with epilepsy negatively affected the child's outcomes including behavioral problems and the child's health-related QOL [38]. Close monitoring of caregivers' mental health and depressive symptoms may lead to the needed support and treatment for caregivers. For mothers of children with leukemia, such monitoring of QOL throughout the child's diagnosis found that the caregivers had a decreased QOL related to their mental health and social functioning, putting them at a greater risk for depression [39].

3. Social and Economic Domain

In some studies focusing on the QOL of caregivers of children with a chronic condition, the social domain was the most significant indicator of poor QOL. Caregivers often have significantly poorer social relationships compared with parents of healthy children [40]. This finding is based on the time commitment that is required to care for their child, a time

commitment which prevents caregivers from spending free time in activities outside of the household. Difficulties in social relationships can stem from lack of free time, significant differences in home life compared with friends (less to talk about), or inability of others to know how to interact with a child with a chronic condition [20]. The higher level of emotional support that a caregiver receives leads to a lower probability of QOL impairment. Caregivers report that they receive emotional support from their spouse, other family member, friends or members of the community [41]. One study showed specifically that the caregiver's age, marital status and level of education were the highest predictors of QOL: caregivers who were older, were not married and had no university-level education had the lowest reported QOL [42].

Some childhood chronic conditions affect the ability of the family to function in social environments. Parents of children with celiac disease, who require specific dietary parameters to avoid a flare-up of the disease, reported impaired in their QOL, specific to their social life as it related to the leisure of their child and the ability of the parent to socialize with others [43]. Similarly for parents of children with severe food allergies, their self-reported QOL in the social relationships domain was significantly lower than parents in a control group [44].

The financial strain of the child's condition and the caregiver's ability to hold a job is a significant factor in determining the caregiver's QOL. The advances in technology that are able to save or prolong the lives of these children do not come without a price. Many of these treatments and advances can be costly and may not be covered by health insurance [1, 27], but caregivers may decide to proceed with the treatments to enhance their child's quality or quantity of life. The financial strain of the child's illness significantly impacted the caregiver's QOL in studies that examined financial stressors [42, 24]. Similarly, for caregivers who that already have financial strain associated with the child's required treatments, the inability to hold a job may add to this stress and negatively impact their QOL [17]. Walker et al. [45] and Tuna et al. [46] found that, when a child misses days of school, then the caregiver most likely misses work days, impacting household income and adding to the financial stressors that already impact QOL. In more cases,

mothers, compared to fathers, reported the need for modifications at their current place of employment or a lack of employment due to the care that was necessary to provide for their child [47]. Similarly, it was noted that even though the mothers were often providing the higher level of traditional caregiver support to children with major congenital anomalies, the fathers reported that the disruption in a “normal” family environment, due to the care that their child required, had a negative effect on their self-reported QOL [17].

The significance of the level of support provided to a caregiver or the entire family considerably impacts the caregiver’s QOL. This level of support for caregivers may be in the form of additional family members who are able to care temporarily for the child or assist with tasks within the home. Support may also be provided within the community in the form of respite programs or social initiatives to assist caregivers who may not be able to complete household tasks or care for themselves due to their caregiving responsibilities. It is estimated that less than 19% of families of children with chronic conditions receive support or assistance from outside of the immediate family (community or neighborhood support) [47]. In addition, parents often feel that they have to be particularly proactive to obtain support or resources for their child’s condition [49, 20]. While the caregivers may be dealing with the stressors already discussed associated with caring for their child, they may be required to spend a great deal of their already scarce free time attempting to obtain support or resources for their child, such as funding or therapies. Raising public awareness about condition prevalence and necessary resources, ensuring access to proper educational services, availability of relevant benefits related to the child’s condition, and provision of necessary social assistance may help relieve caregiver stress and increase their self-reported QOL [49]. In other cases, where the amount of caregiving time was a determining factor in QOL scores, social isolation and lack of socialization leads to significantly decreased QOL [42]. In this case, the caregivers spend most of their time caring for the child, leading to a sense of social isolation and the perception of a lack of social support, therefore impacting their self-reported QOL. For caregivers who perform twenty-four hour care for their

child who is mechanically ventilated, despite knowing that they have become an expert caregiver for their child, a sense of loss and uncertainty is impacted by insufficient support from others and an increased weight of responsibility as the sole provider for their child. Despite being recognized as an expert in their child's care by other family members, healthcare professionals and the community, these caregivers still need enhanced psychological and emotional support in order to maintain their QOL and fulfill the role that they play in their child's life [8].

Some studies reveal that the level of the burden of care associated with caring for their child affects the caregivers' QOL. The physical needs required to care for some of these chronic conditions, such as cerebral palsy or arthritis, affects the amount of time that caregivers have to hold a job, socialize or take care of their own physical needs ultimately impacted their QOL [50, 51, 20]. However, for studies that looked at chronic conditions with a lower burden of care, such as asthma or deafness, the amount of social and family support that the caregiver had directly impacted their QOL [52, 45].

4. Family Domain

Caregivers who self-report their QOL may report a higher level of satisfaction with their family, based on the need for the family to become more cohesive to care for the child [21]. While an individual caregiver may report a significantly lower QOL, the need for family support and cohesiveness in order to care for the child often is reflective in a higher reported level of family satisfaction. Another outcome of impaired QOL is the strain that a child's chronic condition may place on a couple's marriage, which may impact the caregivers' QOL even further. The inability to have time to spend alone together or to socialize with others due to the care that their child requires can put a significant stressor on the couple's marriage [53].

The lack of social programs focusing on support or education of caregivers of children with chronic conditions negatively affects the caregiver's QOL. QOL data, which was collected among caregivers of children with autism and developmental disorders, focused on the need for psycho-education programs for parents to help them handle stress and emotions, identify and

modify false beliefs and solve the daily problems associated with their child's condition [54]. Interventional programs for caregivers and families may enhance the caregiver's QOL as well as provide a means of education about the child's condition and ways simultaneously to take care of themselves [55]. These interventional programs, which may focus on psychosocial support or specialist care for the caregivers, would be fueled by adequate health and social policy measures surrounding the topic of caregiver burden [49].

While there is a growing body of literature that focuses on the QOL of caregivers of children with chronic conditions, other members of the family unit, such as the siblings, are often not targeted in the studies. Sibling adjustment to a child's chronic condition can often be best understood within the context of the family. The affects of the illness on the healthy sibling impacts the QOL and functionality of the family unit [56]. A qualitative study focused on the quality of life of siblings of children with intellectual disabilities found that a sibling's QOL could be self-described but often was not the same as that of the parent's self-reported QOL. Domains such as private time, joint activities and acceptance were found to be specific to a sibling's self-reported QOL [57].

G. Discussion

This literature review was conducted to critically evaluate the current literature pertaining to the quality of life of primary caregivers of children with chronic conditions to determine current findings and gaps in knowledge. The four domains of the Ferrans Conceptual Model for QOL provided the framework for this review [28]. Impairments to the health and functioning of the primary caregiver were reported as being manifested through fatigue, lack of sleep, or stress, associated with the long-term, day-to-day care of the child, which can contribute to the caregiver's overall impaired physical or psychological health [6, 18, 20, 31]. Psychological symptoms among caregivers of children with chronic conditions, such as depression or anxiety, have been found to influence the caregiver's ability to deal with stressful events associated with the child's condition [6, 34]. The social and economic domain was the most impacted among

caregivers of children with chronic conditions due to financial concerns, related to the child's condition, as well as the inability to socialize outside of the home [8, 42, 49]. Within the family domain, caregivers who self-report their QOL may report a higher level of satisfaction with their family, based on the need for the family to become more cohesive in order to care for the child [21].

Many childhood chronic conditions require that a parent or primary caregiver provide round-the-clock, day-and-night care to the child, which can significantly impact the amount of time that is left for the caregivers to attend to their own physical, mental, or social needs [19]. The time commitment associated with caring for a child who has a chronic condition affected the reported QOL of the primary caregivers of these children [30, 18]. The QOL of the caregiver as it relates to health, psychological well-being, social networks and support, and the family dynamic can be negatively impacted when a significant amount of time is being committed to the care of the child with a chronic condition [19]. The noted outcomes of QOL among caregivers of children with chronic conditions can vary based on the severity of the child's condition and the caregiver's perceived QOL. Studies in this domain often hypothesize that the outcome of a lower QOL score would manifest itself in physical, emotional or psychological impairments [21, 18].

H. Implications for Future Study and Practice

Several gaps in the literature were noted and these are important areas for future research. Future research that focuses on this area includes the ability to conduct a mixed-methods review of the primary caregiver's QOL. The ability to choose the appropriate instrument for measuring the caregiver's QOL allows for insightful review of the QOL among these caregivers. However, the addition of qualitative interviews or focus groups would allow the researcher to identify what subjects mean by their responses to a measurement tool and contemplate realistic ways to assist caregivers with increasing their measures of QOL. In this case, through the use of qualitative measures, subjects may also be able to provide insight into what the best means of support are for them given the chronic illness of their child.

One aspect that was not clearly determined in any of these studies but may be addressed through a mixed-methods study is the level of burden associated with caring for specific populations of chronically ill children. Since many childhood chronic conditions largely impact the child's physical abilities, some assume a higher level of burden is associated with caring for children with these chronic conditions. When information regarding care burden is not studied or implicitly stated by the researcher, the caregiver's feelings about the level of burden associated with caring for a chronically ill child remain unknown. Since many QOL measurement tools do not address this specific issue, including a qualitative component in a mixed-methods study that addresses the burden of care associated with particular illnesses may be helpful and insightful.

Studies often have examined the caregivers' report of the child's QOL, but not the caregivers' own QOL, which can have implications for clinical practice. Most pediatric chronic conditions have been studied only once or twice, and there are only one or two studies in the literature focusing on caregivers of children with a specific chronic condition. With regard to caregiver QOL, a large volume of knowledge about the QOL of caregivers of each particular pediatric condition is not provided. The strength of these studies is that they all focus on particular pediatric diagnoses by not putting caregivers of children with any chronic illness into one larger study, which may make the results more transferrable across all childhood chronic conditions. Since there are similarities that have been discovered among caregivers of children with many types of chronic conditions, a non-categorical approach to sampling, based on the child's condition, would be an approach for future research in this area.

One way that QOL studies within this population can enhance clinical practice is the addition of QOL assessments for primary caregivers of children with chronic conditions for clinicians to identify support or resources for these caregivers. Recently, QOL has emerged as an important part of care delivery for these caregivers, and measures of QOL should become part of the standard battery of tests that are used to assess a caregiver's health and well-being. The use of these QOL measures in a clinical setting can identify aspects of a caregiver's life that may be

improved with the use of support services or interventions [24]. Frequent assessments of QOL may be useful within outpatient clinic areas that see the same patients many times over the course of the child's illness. The ability to follow the trends of a QOL assessment over time can provide clues for clinicians to enhance the caregivers' ability to care for their children and to identify ways to assist them. The importance of these types of repeated measures in real-time, clinical practice would be the ability to delineate the difference between statistically significant results and clinically significant results within a caregiver's life. For nurses and physicians who are caring for children with chronic conditions and their caregivers, clinically significant results would be important in influencing the caregiver's QOL. If clinicians understood what the results of a QOL tool translate to in clinical practice, they may be able to complete referrals and assist with areas of support that the caregiver may need and not even know to ask for.

I. Conclusion

In conclusion, this literature review details results from caregivers of children with many different diagnoses, as it related to the caregiver's QOL. For primary caregivers of children with chronic conditions, their QOL may be affected by the demands associated with the care that their child requires and the sacrifices that they make in order to care for their child. More studies in this research area will add to the body of knowledge and increase the awareness of these caregivers' needs for clinicians who care for these children. For those clinicians who aim at providing a well-rounded, family-centered approach to the care that they provide to children with chronic conditions, the data obtained from studies is very important for determining the needs of these caregivers and ways that they can best be supported in the care that they provide. Once these issues are better understood and addressed will these caregivers feel supported by the clinicians who care for their chronically ill children.

The time commitment associated with caring for a child who has a chronic condition impacted the QOL of the primary caregivers of these children. The QOL of the caregiver as it relates to health, psychological well-being, social networks and support, and the family dynamic

is negatively impacted when a significant amount of time is committed to the care of the child with a chronic condition. The noted outcomes of QOL among caregivers of children with chronic conditions varies based on the severity of the child's condition and the caregiver's perceived QOL.

Research involving the quality of life of caregivers of children with chronic conditions is still evolving, and mixed methods approaches to this type of research have yet to be completed. Current studies have focused on a singular childhood condition within one study. Implications for future research include the need for multiple childhood conditions to be included within one study and the incorporation of qualitative data to explain the data discovered through established QOL measurement tools.

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children with obstetrical brachial plexus palsy. *Pediatric International*, 86(5), 234-241.

| TABLE I: LITERATURE REVIEW TABLE | | | |
|---|-------------------------------------|---|---|
| Author & Year of Publication | Child's Condition | Sample Description | Results Related to Caregiver QOL |
| Allik et al. [31] | Asperger Syndrome | Mothers and fathers of 32 children with Asperger syndrome (control group of parents of 32 age-appropriate children) | Mothers of children with Asperger syndrome had lower SF-12 (physical health), compared with the control group. The mothers of children with Asperger syndrome had lower physical health scores compared to the fathers in the same group. |
| Arafa et al. [18] | Heart disease | 400 parents of children with heart disease and a comparison group of 400 parents of children with minor illnesses | Parents of children with heart disease reported significantly poorer QOL, except in pain domains. Factors that impacted QOL were severity of illness, type of heart disease, age of the child, having multiple children, financial situation and presence of comorbid condition. |
| Barrera et al. [33] | Stem cell transplant (SCT) | 84 caregivers of children receiving a SCT | Maternal and paternal physical QOL did not differ. Maternal and paternal psychosocial QOL improved by two years post-transplant. |
| Benjak [49] | Autism | 177 parents of children with autism and 169 parents of non-disabled children | Parents of children with autism self-reported a lower QOL than the comparison group as well as lower general health perception with more physiological symptoms. |
| Bruns et al. [6] | Juvenile idiopathic arthritis (JIA) | 70 parents of children with JIA | Pain and mental health were the items in the SF-36 most affected in this caregiver group. The caregiver burden scale was significantly correlated with the number of limited joints, number of visits, family income, mental health, emotional aspects, vitality and general state of health. |
| Chien et al. [58] | Brain tumors | 30 caregivers of children with brain tumors | The scores in the physical health and psychological domains were lower than normal scores for healthy adults. The child's treatment stage was associated with caregiver scores in the physical health and psychological domains. |
| Davis et al. [20] | Cerebral palsy (CP) | 24 mothers and 13 fathers of children with CP | Caring for a child with CP affects a caregiver's physical well-being, social well-being, independence, family well-being and financial stability. Parents felt unsupported by the services they access in the care of their child. |

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| de Lorenzo et al. [43] | Celiac disease (CD) | 33 parents of children with CD and 63 parents of healthy children | QOL scores were similar between parents of children with CD and the comparison group. However, leisure time was significantly impacted among caregivers of children with CD. |
| Donohue et al. [59] | Low-birthweight infants | 83 caregivers of low-birthweight infants and 84 caregivers of full-term infants | QOL did not differ between the two groups of caregivers. Caregivers of both groups reported mental and physical health problems but had good self-perceived QOL. |
| Driscoll et al. [15] | Cystic fibrosis (CF) | 100 female and 22 male caregivers of children with CF | The rate of depressive and anxious symptoms were elevated in female and male caregivers of children with CF. As depressive and anxious symptoms increased, caregiver QOL decreased. |
| Eiser et al. [1] | Cancer | 87 caregivers of children with cancer | Mothers reported their QOL to be significantly lower than the population norms following the child's diagnosis with cancer. |
| Eker & Tuzun [14] | Cerebral palsy (CP) | 40 mothers of children with CP and 44 mothers of children with minor health problems | The mean scores of the SF-36 subscales were significantly lower in mothers of children with CP than those in the comparison group. The QOL scores of the mother were significantly correlated with the severity of the child's motor disability. |
| Goldbeck [21] | Chronic pediatric conditions | 122 parents of children diagnosed with a chronic pediatric condition | Caregivers of children with cancer reported lower QOL compared with caregivers of children with diabetes or epilepsy. Only the fathers in the study had a well-being score that increased significantly within the first three months after the child was diagnosed with a chronic condition. |
| Hatzmann et al. [41] | Inherited metabolic diseases | 121 parents of children with inherited metabolic diseases | Mainly psychological determinants were predictive of parental QOL. Emotional support was protective for parental QOL while loss of friendship was a risk factor for impaired QOL. |
| Hatzmann et al. [60] | Chronically ill children | 543 parents of chronically ill children | The effect of socio-demographic and medical data on QOL was mediated by days on holiday and emotional support. Also, female gender, being chronically ill as a parent and care dependency of the child were directly related to parental QOL. |
| Juniper et al. [52] | Asthma | 52 primary caregivers of children with asthma | The child's asthma status, as reported by the caregiver, was directly proportional to the caregiver's self-reported QOL. |
| Karande & Kulkarni | Severe learning | 150 parents of children with | Female gender, being currently ill, being in paid work, and having a male child were predictors of |

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| [61] | disability | newly diagnosed specific learning disabilities | lower QOL scores. |
| Klassen et al. [19] | Cancer | 411 parents of children with cancer | Parents of children with cancer reported poorer physical and psychosocial QOL in all psychosocial domains and in most physical health domains, compared to the norm. Characteristics associated with better parental QOL include better eating, exercise and sleep habits, younger age and higher income. |
| Kunz et al. [32] | Inflammatory bowel disease (IBD) | 92 mothers and 43 fathers of children with IBD | Disease activity was associated with all father-reported outcomes and explained twice as much of the variance in father-reported QOL, compared with the mothers. |
| Lawoko & Soares [42] | Congenital heart disease | 1092 parents of children with congenital heart disease (CHD), 112 parents of children with other diseases and 293 parents of healthy children | Mothers reported lower quality of life than fathers, with the lowest levels among the mothers of children with congenital heart disease. Variables such as distress, hopelessness and financial situation were more important in explaining lower levels of QOL than parental gender and the presence and/or severity of the child's heart disease. |
| Lin et al. [24] | Intellectual disabilities | 597 caregivers of children with intellectual disabilities | Mean QOL scores were lower than the general population and slightly higher than the caregivers of adults with intellectual disabilities. Self-perceived health state, household income and stress were significantly correlated to QOL scores. |
| Lv et al. [62] | Epilepsy | 263 parents of a child with epilepsy and 270 parents of healthy children | The parents of children with epilepsy had significantly lower QOL scores in SF-36 for all subscales and higher levels of anxiety and depression. |
| Mah et al. [8] | Neuromuscular disease | 109 caregivers of children with neuromuscular disease | Caregivers of children requiring mechanical ventilation did not report decreased QOL or increased parental stress compared with caregivers of non-ventilated children or in comparison to the norm. |
| Mugno et al. [25] | Pervasive developmental disorders | 212 parents of 135 children with pervasive developmental disorders and 77 parents of 48 healthy children | Compared with parents of healthy children, parents of children with pervasive developmental disorders reported impairment in physical activity and social relationships and worse overall perception of their QOL and health. |

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| Ones et al. [51] | Cerebral palsy (CP) | 46 mothers of children with CP and 46 mothers of healthy children | A significantly worsened QOL was reported in mothers of children with CP. Depression indicator scores were higher for mothers of children with CP, compared with mothers of healthy children. |
| Oskay et al. [65] | Obstetrical brachial plexus palsy (OCP) | 93 mothers of children with OBPP and 88 mothers of healthy children | QOL differed significantly between the two groups. The most noted QOL impairments among the mothers of children with OBPP were in physical activity, energy expenditure and pain. |
| Poley et al. [17] | Congenital abnormalities | 306 parents of children with congenital abnormalities | QOL among these parents was lower than the population norms; this was particularly true for mothers more than fathers. Most parents indicated that their QOL would not change if another individual took on the responsibility of caregiving for their child. |
| Press et al. [63] | Juvenile chronic arthritis (JCA) | Parents of 28 children with JCA and parents of 28 healthy children | Mothers of children with JCA and mothers of healthy children had similar self-reported QOL. The parents of children with pauciarticular-type JCA reported lower QOL and higher levels of anxiety and depression than the parents of children with other types of JCA. |
| Raina et al. [23] | Cerebral palsy (CP) | 486 caregivers of children with CP | The most important predictors of caregivers' QOL were child behavior, caregiving demands and family functioning. A higher level of behavioral problems with the child was associated with lower levels of both psychological and physical health for the caregiver. |
| Shaligram et al. [7] | Thalassemia | 44 caregivers of children with thalassemia | Fifty-seven percent of the caregivers had psychiatric problems, with depressive disorders in 19 of the 444 caregivers. QOL was impacted among half of the caregivers, in comparison to the norm. The greatest concerns were regarding the future, illness and finances. |
| Shu [53] | Autism | 104 mothers of children with autism | Mother's feelings/emotions, history of chronic disease and religion were directly correlated to the self-reported QOL in mothers of children with Autism. |
| Spahn et al. [47] | Cochlear implant | 52 mothers and 42 fathers of 55 children with cochlear implants | Twenty-one percent of parents showed heightened psychological distress. The mean QOL of the parents was reduced compared with normal levels. |
| Tweel et al. [64] | Sickle cell disease (SCD) | 54 caregivers of children with SCD and 28 caregivers of healthy | Caregivers of children with SCD had a lower QOL than the comparison group and the population norm. Caregivers of children with SCD had significantly lower subscale scores for depressive moods, daily activities and vitality. |

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| | | children | |
| Walker et al. [45] | Asthma | 201 parents of children with asthma living in a rural setting | The parents' QOL scores were correlated with parental reports of missed days of work. Parents' QOL was significantly associated with the child's asthma severity. |
| Yamazaki et al. [39] | Leukemia | 97 mother of children with leukemia and 240 mothers of healthy children | Five of the eight subscales for the SF-36 were significantly lower for the mothers of children with leukemia, compared to the control group. The most highly impacted areas of QOL were noted to be mental health and social functioning, putting the mothers of children with leukemia at increased risk for depression. |

**THE QUALITY OF LIFE OF PRIMARY CAREGIVERS OF CHILDREN WITH
CHRONIC CONDITIONS:
A MIXED METHODS STUDY**

A. Abstract

Purpose: Caregivers of children with chronic conditions are particularly at risk for impaired quality of life (QOL) due to the demands of caring for the child. The objective of this study was to assess the relationship between the caregiver's QOL, the child's functional status and the well-being of the family unit. The caregiver's overall QOL scores, generated from the Ferrans & Powers QOL Index Generic Version, were divided into upper and lower quartiles which facilitated the inspection of the qualitative data collected from the caregiver. This analysis was conducted to better understand the aspects of the caregiver's own life and daily routine that affected their self-reported QOL.

Background: In view of the large number of caregivers engaged in the care of children with chronic conditions, this study was designed to describe the quality of life of caregivers, as it is affected by the chronic condition of their child.

Methods: This mixed methods study used qualitative and quantitative data that had been previously collected to examine information management styles in families of children with chronic conditions (N=84). Results of the Ferrans and Powers Quality of Life Index Generic Version, Functional Status Measure and the Family APGAR were analyzed. QOL scores were divided into upper and lower quartiles which facilitated the inspection of the qualitative data.

Results: This study shows that the caregiver's reported functioning of a child with a chronic condition and the well-being of the family unit were directly related to the caregiver's QOL. The quantitative data analysis showed that the measures of QOL, child's functional status and family well-being were strongly positively correlated. The overall QOL mean scores of the upper and lower quartile were significantly different. QOL was impacted by financial strains within the family as a result of the child's condition, support within the family unit and psychological

stressors of the genetic nature of the child's condition. The findings of this study were not driven by the diagnosis of the child; all diagnoses were represented in both the upper and lower quartile of overall QOL scores. This study is unique because of its mixed-methods approach, the use of multiple childhood conditions within the same study and the use of genetic conditions to determine the sample.

Conclusion: Based on the results of this study, financial support for these caregivers and their families positively impact their QOL. Caregiver QOL, child's functional status and family well-being were found to be strongly positively correlated. The findings of this study suggest that QOL assessments for caregivers of children with chronic conditions are dependable indicators of caregiver QOL and can assist clinicians in identifying support or resources for these caregivers. The use of QOL measures in a clinical setting can identify aspects of a caregiver's life that may be improved with the use of support services or interventions.

Keywords: Quality of life, primary caregivers, children with chronic conditions

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Caring for and raising children who have been diagnosed with a chronic condition can be challenging to the health and well-being of the caregiver and the family. The current state of healthcare has allowed for the need for life-long caregiving for children who have been diagnosed with chronic conditions, as these children continue to live longer and much healthier lives [1, 2]. For example, long-term survival for cystic fibrosis has now been identified as greater than 25 years of life, increased from 18 years of life in the early 1990's [3]. Living with a childhood chronic condition not only affects the life of the child but can affect the life of the caregiver of these children, who often are the child's mother or father or an extended family member [4, 5, 6]. Having a better understanding of the ways in which the child's condition can affect the caregiver's quality of life (QOL) can enhance the treatment of the entire family, through greater focused-resource availability for these caregivers and their children [7]. The time-commitment and resources that are required of families to care for these children with chronic conditions, can affect the ability to maintain normalcy and routine in everyday lives of caregivers and families [8]. The ability for healthcare professionals to assess and address caregiver quality of life can lead to enhanced psychological guidance and further information about disease control to improve the child's health outcomes, therefore increasing the caregiver's self-reported QOL [9].

B. Purpose

QOL has become a critical indication of health and well-being in recent years and within a wide variety of populations. The World Health Organization (WHO) defines QOL as "an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns" [10]. Measures of QOL have been used to determine life-sustaining measures in medical practice, allocation of resources in the public healthcare setting(s), and insight for clinicians regarding a

person's perceptions of their life's current state and their ability to fulfill socially useful roles [11, 12]. While many QOL studies focus on the individual with the condition, studies have started to focus on the QOL of the caregiver who provides care to a person who is acutely or chronically ill [13]. In cases where caregiver QOL is being measured, it is often assessed and measured in the same way, but QOL measurement is used to interpret the caregiver's self-reported QOL rather than the QOL of the person with the condition.

The need to measure and assess the QOL of caregivers of children with chronic conditions provides information related to the challenges that caregivers experience as they care for their children. Caregivers are often required to forfeit aspects of their own health or well-being to devote time to care of their children [14, 15]. The ways in which care is provided to a child by a caregiver is often affected by the caregivers' perceptions of their own QOL [16, 17]. The burden of care associated with the child's condition may affect the caregiver's self-reported QOL. The amount of physical stress associated with caring for the child and the amount of time that is required to care for the child's medical, physical and social needs can impact the caregiver's QOL [18, 19]. Since many childhood chronic conditions are associated with physical disability, the ability to care for these children may become more difficult or physically exhausting as the child ages and grows [20].

When healthcare providers are treating children with chronic conditions, the QOL of the caregiver is not a focus of the care. However, understanding the caregiver's QOL can allow for a better perception of how healthcare providers can identify and support the stresses of caring for any long-term childhood chronic condition [21, 22, 23]. A QOL assessment of primary caregivers' health and well-being could allow healthcare providers to identify and treat physical, psychological and social problems within the family unit [24, 17].

As the advances in treatment for childhood chronic conditions continue and children live longer lives into adolescence, these children require long-term care from caregivers [5]. The commitment to long-term care for these children can significantly impact the QOL of the

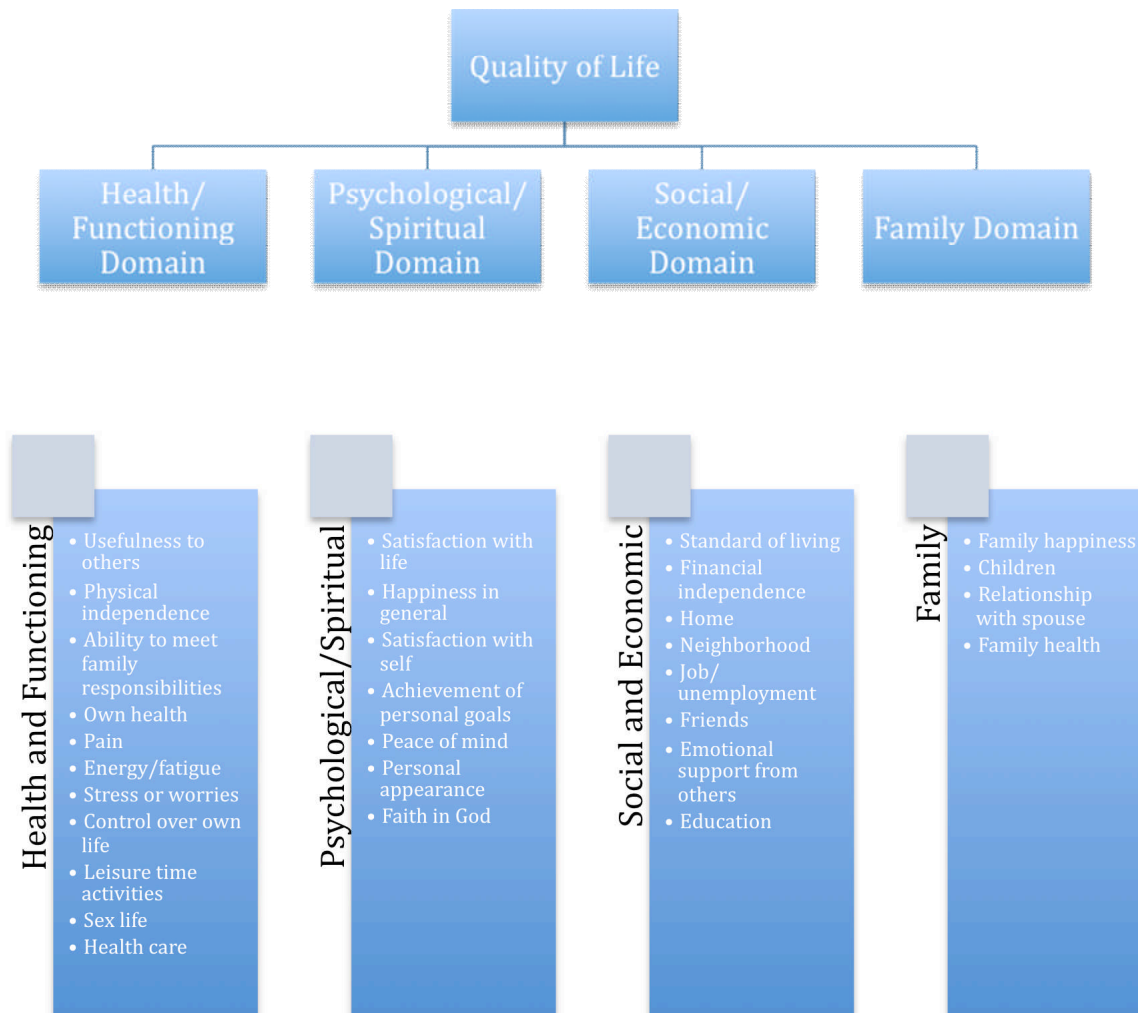
caregivers, who often are required to give round-the-clock care to meet the child's medical, physical and social needs [18, 25]. Caregivers of these children struggle with the desire for a sense of normality in their everyday lives while also desiring a normal life for their chronically ill child [26, 27].

C. Conceptual Model

A challenge of measuring an individual's QOL is that definitions and conceptualizations of QOL often differ greatly within the literature. When assessing and measuring an individual's QOL, it is critical to understand which domains associated with a person's QOL are being evaluated when the QOL is measured [17]. The conceptualization and measurement of QOL has evolved over time to focus on the QOL of individuals and their subjective experience of the current state of their own lives, rather than the overall state of a given population or society [17].

The Ferrans Conceptual Model for QOL (see Figure 1) guides the analysis for this study [28]. The Ferrans Conceptual Model was developed using qualitative data that focused on what QOL meant to the respondents as well as an examination of the current literature. This conceptual model focuses on the importance that the person reporting QOL is the only proper judge of his/her own personal experience [17].

Figure 1: Ferrans (1996) Conceptual Model for Quality of Life



D. Methods

1. Study Design

This study uses a mixed methods approach. Qualitative and quantitative data previously collected as part of a larger study focusing on information management in families of children with chronic genetic conditions were analyzed for this study [29, 30, 31]. The Quality of Life data has never been reported, so this study provides a first-time analysis of these results. Results of the Ferrans and Powers Quality of Life Index Generic Version (QLI) [1, 2], Functional Status

Measure II (FSM II) [3, 4] and the Family APGAR [5, 6] were analyzed. To further understand the high or low QOL scores that caregivers reported using the Ferrans & Powers QOL Index Generic Version, these quartiles were used to define the groups whose qualitative data responses were analyzed.

2. Sample Criteria

In the larger study, the sample inclusion criteria were that the caregiver live in the household with the affected child; the affected child was school-aged (7-12 years of age), the oldest child in the family with a genetic condition (if more than one child was affected), the biological child of at least one of the caregivers, has a chronic condition (phenylketonuria, sickle cell, thalassemia syndromes, cystic fibrosis, hemophilia, von Willebrand, neurofibromatosis, or Marfan's syndrome) and attend school in a regular classroom setting [29, 30, 31, 32]. Caregivers were excluded if the child was experiencing an illness exacerbation such as hospitalization or home-care needs at the point of data collection.

3. Procedures

The caregiver sample was recruited from specialty clinics for children with chronic genetic conditions. Letters of invitation were sent from the medical director of the clinics to families who were eligible to participate. Caregivers who were willing to participate were able to mail in a reply postcard or leave a voicemail message with the research office, noting their interest. The investigator arranged date and time of the data collection with the caregiver at a location of the caregiver's choosing (i.e. home, clinic setting, library or university). Quantitative measures were administered to caregivers at the conclusion of their interview session. Primary caregivers were noted as those who provided full-time care to the child; secondary caregivers provided assistance to the primary caregiver in caring for the child but did not perform full-time care for the child [33, 34, 35].

E. Measures

1. Standardized Measures

The measures administered to the primary caregivers included the Ferrans and Powers Quality of Life Index Generic Version [1, 2, 17], Functional Status Measure II [3.4], and Family APGAR [5, 6].

a. Caregiver Quality of Life

The Ferrans and Powers Quality of Life Index Generic Version (QLI) was used to collect data on self-reported QOL from primary caregivers of children with chronic conditions. The use of the QLI measure allow caregivers to self-report their QOL and measures their degree of satisfaction with (Part I of the measure) and the importance of (Part II of the measure), each part containing 35 items encompassing four domains of their life: health and functioning, socioeconomic status, psychological-spiritual status, and family issues. Caregivers respond using the measure's six-point Likert scale ranging from very satisfied to very dissatisfied for Part I of the measure and very important to very unimportant in Part II of the measure. The QLI produces an overall score and scores for each of the four subscales which can be analyzed and compared. Both overall and subscale scores range from 0-30, with higher scores indicating higher levels of self-reported QOL. Reliability and validity of the QLI have been established and widely reported [1, 2, 17]. In published studies by the authors of this measure, internal consistency of the measure has been supported by alphas from 0.90-0.95 for the entire measure and by alphas of 0.90, 0.84, 0.93, and 0.66 for the health and functioning, socioeconomic, psychological-spiritual, and family subscales, respectively. Test-retest reliability has been reported to be 0.87 and 0.81 for two-week and one-month intervals. Concurrent validity has been supported by correlations of 0.65, 0.75, and 0.80 between the QLI and an overall measure of satisfaction. Support for the QLI has also been provided by the finding that higher QOL scores for subjects with cancer who had less pain and depression and were better coping with stress [2]. The Cronbach's alpha for overall QOL

score for primary caregivers in this study was reported as 0.95. The Cronbach's alpha for the subscale scores within the QLI in this study were 0.89 (Health and Functioning), 0.82 (Social and Economic), 0.91 (Psychological/Spiritual) and 0.78 (Family).

b. Child Functional Status

The affected child's functional status was measured using the Functional Status Measure II (FSM II) [4]. The strength of this measure is its ability to measure the health status of children with chronic physical conditions who are not disabled. This 14-item measure assesses the affected child's ability to perform age-appropriate roles and tasks. The measure considers communication, mood, mobility, energy, sleeping, eating and toileting in addition to behavior in the home, neighborhood and school. Each of the 14 items in the measure contains two parts. Part I asks whether the child performs the specific activity or exhibits a specific behavior "never or rarely", "some of the time", or "almost always." Part II, which is administered after the completion of the entire list of Part I items, looks into those Part I items further which reflect poor functioning, in order to determine whether a given functional impairment was due "fully," "partly," or "not at all" to a health problem. To measure problems only related to the illness, Part I is recorded based on the Part II responses. For example, if a respondent indicated that a child eats well "none or rarely" but on probing also indicated that this is "not at all" related to the illness, the original response to eating is recorded as "almost always." The FSM II has been shown to be sensitive to changes in the affected child's medical condition. Additionally, scores on the FSM II have shown moderate statistically significant correlations with morbidity status. Internal consistency estimates for the 14-item version are all >0.80 [3]. The Cronbach's alpha for the FSM II, as reported by the primary caregivers, in this study, was 0.84.

c. Family Well-Being

The Family APGAR scale focuses on the measure of overall family well-being. The Family AGPAR measure was chosen for further evaluation in this study based on its published reliability and the measure's ability to provide the critical measurement of family strengths, rather

than family dysfunction [5, 6]. The Family APGAR is a 5-item measure designed to measure family members' satisfaction with five basic components of family life: adaptation (family problem solving), partnership (sharing responsibility and decision-making), growth (physical and emotional maturation as well as self-fulfillment), affection (caring or loving relationships within the family), and resolve (commitment to share time, space and material resources with other family members). Item scores range from 0-4 with overall scores from 0-20. Higher scores indicate better satisfaction with family life. Prior studies have reported high internal consistency, showing that the Family APGAR is a unidimensional measure of functioning as it pertains to satisfaction with family life [43]. The Cronbach's alpha for the Family APGAR in this study, as reported by the primary caregivers, was 0.90.

2. Interview Guide

The qualitative data, collected through open-ended one-on-one interviews with caregivers, used a semi-structured interview guide in the larger study. The Family Management Style Framework [44] provided the structure for the development of the questions. The purpose of the questions was to determine how caregivers access, convey and use information, as it relates to their child's chronic condition. Questions focused on the timeline of the child's condition, how the caregiver handled information surrounding the child's diagnosis, seriousness of the condition, and how the handling of information has changed over time. Questions focusing on the sociocultural context looked at the family's interactions with extended family and the healthcare and school systems. The interview guide was tested and then further developed using a small group of families similar to the target sample for this study. Input from genetic counselors in cancer risk centers for adults and children were also asked for their input in revising and enhancing the interview guide prior to its use in this study.

F. Data Analysis

1. Quantitative Analysis

The quantitative results of the Ferrans & Powers QOL Index, Family APGAR Score and Child's Functional Status, as reported by the primary caregivers, were analyzed in this study. SPSS statistical software was used for the quantitative data analysis. Overall and subscale scores were calculated for the QLI and overall scores were calculated for the Family APGAR Scale and FMS II. The a priori statistical significance level was set at the p-value < 0.05 for all statistical tests. Using the overall QOL scores, generated by the QLI, correlation analysis was used to examine the relationship between the caregiver's QOL and the child's functional status and the caregiver's QOL and the family well-being score. The results of overall QOL scores were then divided into quartiles; the upper twenty-one overall scores were compared with the lowest twenty-one overall scores. Since there were 84 total primary caregivers, the number of caregivers for the upper and lower quartiles was chosen based on one-fourth of the sample in each of the quartiles. The upper and lower quartiles were matched with the respondent's corresponding qualitative data and the qualitative data was examined to determine responses that could positively or negatively affect the caregiver's QOL.

2. Qualitative Analysis

Using selected codes from the interview transcripts previously coded in the Atlas-ti software program, the qualitative data were analyzed [45]. When examining the qualitative data of the upper and lower quartiles, based on the results of the QLI, codes specific to the caregiver's QOL were chosen because of their focus on the illness management of the child's condition, which may impact QOL, based on the findings in the current review of literature. The codes that were analyzed were: view of the child, view of the condition, view of the treatment, illness and symptom management, support, impact of condition on family life, and impact of condition on family members. The qualitative data was grouped together using a data matrix and analyzed using the four categories of the QOL Conceptual Model: health and functioning,

psychological/spiritual, social and economic and family [34]. These data matrixes allowed the upper and lower quartile of caregivers to have their qualitative responses grouped together to describe their health and functioning, psychological and spiritual, social and economic, and family functioning for ease of qualitative description.

G. Results

1. Standardized Measures

The sample for this study consisted of 84 primary caregivers (Table II). Overall QOL scores were compared with the caregiver's self-reported functional status of their child and family well-being. Overall QOL scores ranged from 11.84 to 29.60 (SD=5.11) (score of 0-30). A correlation for the data revealed that QOL (QLI) and family well-being (Family APGAR) were significantly related, $r=+.703$, $p<.05$. QOL (QLI) and child's functional status (FSM II) were significantly related, $r=+.399$, $p<.05$. Child's functional status (FSM II) and family well-being (Family APGAR) were significantly related, $r=+.352$, $p<.05$ (Table III).

The subscale scores for QOL were analyzed for the entire sample, upper quartile and lower quartile (Table IV). The upper quartile had overall QOL scores ranging from 23.14 to 29.60 (SD=1.26). The lower quartile had overall QOL scores ranging from 11.84 to 17.84 (SD=4.99). For both the upper and lower quartiles, the psychological/spiritual subscale had the highest scores and the social and economic subscale was the lowest. The overall mean score for the upper quartile was 26.57 (SD = 1.26) and the overall mean score for the lower quartile was 17.25 (SD = 4.99). The differences between the upper and lower quartiles in the overall mean scores and the mean scores for each subscale were statistically significant at 0.05 level of statistical significance level.

2. Interviews

The upper and lower quartile (N=21 for each quartile) of QOL scores were then used to analyze the qualitative data results to draw further conclusions regarding the caregiver's own QOL, as it relates to the care that is provided to the child with the chronic condition. The

pertinent qualitative results from the upper and lower quartiles were placed into a data matrix, facilitated by the four domains of the Ferrans Conceptual Model of QOL: health and functioning, psychological/spiritual, social and economic, and family. The distribution of the childhood conditions was similar for both the upper and lower quartile of the caregiver QOL data (Table II).

a. Health and Functioning

The functioning of the caregiver often was directly influenced by the lack of time that the caregivers had to care for themselves, due to the need to care for their child. The topic of a lack of free time was noted from caregivers in both the upper and lower quartiles, but the caregivers in the lower quartile reported that their lack of free time greatly influenced the routine of the family and the ability of the caregiver to have personal time for themselves. While many of the caregivers in the upper quartile of QOL scores did not express any thoughts related specifically to their own physical health, some of these caregivers still had the desire for more free time to focus on things for themselves outside of the care of their child. For example, one mother of a child with cystic fibrosis said of her free time to care for herself, “Sometimes I don't have as much free time for myself. So it takes, for me it takes, it's, it's very time consuming. And sometimes I don't see where I can, you know, have a little free time.” For some of the conditions of the children whose caregivers were in the upper quartile, caregivers expressed that their child’s condition did not affect their own ability to care for themselves. The care of some of these conditions became minimal or even routine for the caregiver as the child got older and the family unit became more adjusted to the condition “It's become routine. Now it's, it's completely, completely part of the daily routine.” Despite the realization that caregivers had adjusted to the child’s condition, the lack of free time affected some caregivers’ own health or well-being in ways such as lack of a commitment to an exercise routine, due to the inability to devote consistent time to exercise outside of the care of their child.

Caregivers in the lower quartile expressed family disruptions and interference with their personal life more often than caregivers in the upper quartile. There were very few explicit

responses about the caregivers' own physical health in the lower quartile. However, some caregivers specified health and functioning issues that arose as a result of the stress and worry regarding the health of their child: "I think it affects me more than anybody; I'm the one who worries about it." The physical burden of caring for a child with a chronic condition where therapy is required, such as cystic fibrosis (CF), was physically demanding on the caregiver as well as the child: "Well, initially in the very early years, it becomes a both physical and a psychological burden. Taking care of an infant with CF is even more so, because obviously they can't take care of themselves. So, you have to do the physical therapy yourself." These types of medical therapy for a child were noted to be physically and emotionally taxing on the caregivers, leading to a lack of time to focus on their own health and well-being.

b. Psychological/Spiritual

The psychological stressors of caring for a child with a chronic condition were often noted to have been influenced by the genetic nature and severity of the child's condition. Although some caregivers in the upper quartile were psychologically stressed due to caring for their child's chronic condition, the severity of the child's condition, as it was perceived by the caregiver, was noted to be much less than for the lower quartile group. Caregivers in the upper quartile felt that their child's condition was not severe and did not come with many family implications, which led to less psychological stress for these caregivers. Many of the caregivers in the upper quartile indicated that they drew on their spiritual beliefs to get them through the difficult times of their child's condition: "Your religion is a big support and gives you peace and makes you calm and makes you content because there you have no control. You do the best you can and leave the rest to God. It's not in my control." The presence of a spiritual belief system was noted multiple times in the upper quartile group as well as the existence of a support system through many of their churches or religious groups. While some of the caregivers in the upper quartile acknowledged that their child's condition could provide a source of psychological stress, most of these caregivers had ways of coping with that stress, especially as time went on and the

child got older: “I'm sure there's a lot more stress in our family life than other families. There's many stresses in life. I think it's caused stress, but we've learned to manage it. We try not to let it interfere. We still do all of the daily activities we've always done.” Among the caregivers in the upper quartile, ability to cope with the stress of the child's condition was due to the familial or community support systems that they had in place to assist with the care of their child.

Caregivers in the lower quartile conveyed psychological stressors and hindrances in their psychological functioning, based on their child's condition, more frequently compared to the caregivers in the upper quartile group. Some of these caregivers expressed that they had depressive symptoms, often related to the genetic nature of the child's condition: “I used to be depressed. And I used to be like, why did this happen to me? Because I have an older sister and she had kids before me and it skipped her and it came straight to me.” The fact that the child's condition was genetic, and therefore affected by the parent(s) of the child, weighed heavy as a psychological stressor, especially among the lower quartile. Some caregivers thought that the psychological stress of having a child with a chronic condition would not be as severe if the condition had not been genetic. Some of these caregivers also had multiple children with the condition, since it was genetic in nature, which led to the psychological stress and physical workload of caring for more than one child with a chronic condition. Among the lower quartile, there was only one mention of a religious or spiritual affiliation that influenced the way that the caregiver or family dealt with the condition or care of the child. This religious or spiritual affiliation was an additional level of support and strength for the caregivers in the upper quartile that was not seen pervasively among caregivers in the lower quartile.

c. Social and Economic

The social and economic domain was an important one for caregivers in the both the upper and lower quartiles. Of the caregivers in the upper quartile, ten of them expressed little adjustments that were currently being made to the social or economic functioning of the family or the primary caregiver. All ten of these caregivers did acknowledge that at the time of diagnosis,

adjustments needed to be made, but that over time, the family, as well as the primary caregiver, had adjusted to those changes and now they feel as if those changes have become part of their everyday life. A mother of a child with sickle cell disease described that the disease affected the socialization of their family less and less over time: “It doesn't affect us anymore because we still do the, the things that we normally do anyway. So, it really doesn't affect it at all. We still do normal things. And I think that's why we stay so happy, you know.” This realization of normalization of the child's condition within the family over time could be an important one in determining the caregiver's QOL, since the child's condition often became the routine and did not affect day-to-day functioning of the caregiver or family.

Regardless of any normalcy in social functioning of the caregivers, most caregivers in the upper quartile still expressed issues or stressors related to the economic strains of their child's chronic condition. While insurance may cover some of the child's care, it was often a strain to keep up with some of the insurance premiums associated with the care of their child: “More difficult sometimes with the stress which I feel is the financial stress with our insurance premium going up 37% or 40% every year. That is a killer and that's something, you know.” While most of the families in the upper quartile expressed that they had an established insurance plan through a source of employment, even those insurance programs did not cover everything related to the child's care, such as special formulas or equipment for at-home therapy needs. Even the presence of an insurance provider did not eliminate the stress of financial concerns related to the child's condition. In addition, the ability of the primary caregiver to work outside the home, due to the child's condition, also could lead to financial concerns within the family. Among the upper quartile, often the secondary caregiver worked outside the home, providing a source of insurance coverage for the child's condition, but the lack of a second income, as the primary caregiver did not work, was a stressor as insurance premium costs continued to rise.

The ability to interact in social situations, either alone or as a family, was more of a difficulty for the caregivers in the lower QOL quartile. Many of the caregivers in the lower

quartile were single parents, so they felt that there was not an alternate caregiver who was capable of caring for their child so that they could interact in a social setting away from their child. The lack of a secondary caregiver left many of these primary caregivers feeling burdened or overwhelmed with the child's condition because they were unable to get time away to socialize or reduce their stress. Other caregivers in the lower quartile had tried to plan family social outings, such as trips to Disney World or trips to visit out-of-town relatives, only to find out that the accommodations that their child's condition required would make a trip like that impossible: "Like when you go to plan stuff, I mean, anything can happen when you plan." These accommodations led many of the caregivers to feel like they were "trapped" in their own homes, unable to interact with others in social settings or travel long distances due to their child's condition.

Caregivers in the lower quartile expressed more financial strains than those caregivers in the upper quartile. Many of these caregivers were single parents or often the only source of care for their child, so it was difficult for them to hold down a steady job and therefore there was no insurance coverage for the child's care. One mother of a child with sickle cell disease described the strain that it has continued to put on her work situation over the past few years: "It's extremely difficult for me because as a single parent I cannot take a full time job because it has caused a lot of problems in the past when he has needed a lot more hospital care and I've been put in a position to feel like it's a big inconvenience in the office." The inability to have a full-time job caused a great deal of financial strain for many of the caregivers in the lower quartile. Often caregivers felt like they needed to make a choice between the care of their child and the ability to have a steady job: "But, yes, I've gone to work. And, and, yes, I've had to stay home a lot of times when he was sick. So, in order to keep down a job, No, they're not... A lot of jobs aren't understanding about it." In situations where the primary caregiver did have a job outside of the home, it was often difficult to attend work on a consistent basis because of the child's condition. Since they were the only source of care for their child, if the child was sick or had an

exacerbation, the primary caregiver was often forced to miss a scheduled day of work. In two cases, this had led to termination of employment in the past.

d. Family

The caregivers who participated in this study reported that their child's chronic condition had an affect on their family life, although sometimes that affect was not seen to be a negative one. Caregivers in the upper quartile often saw the changes to their family unit as a positive experience, based on the condition of their child. For children with phenylketonuria (PKU), where dietary modifications are necessary to maintain the child's health, caregivers felt that the entire family ate healthier and was more health-conscious as a result: "Well, ever since we had her, we've eaten better. We've had a lot more fruits and vegetables." More of the caregivers in the upper quartile, compared to the caregivers in the lower quartile, were married and therefore had an intact family unit, with a secondary caregiver in place within the home. The notion that this support was present was important to many of the caregivers in the upper quartile. The presence of a secondary caregiver within the home allowed for an additional source of income, the ability for the primary caregiver to socialize outside the home and the existence of another person in the home who could care for the child's medical needs, if necessary.

Many of the caregivers in the lower QOL quartile expressed modifications within the family unit, due to the child's condition. Since many of these caregivers were single parents, the notion that they were caring for the child on their own without familial support was challenging. In addition, the ability to add a significant other to a family of a child with a chronic condition was a stressor that often was avoided. It was difficult for some of these primary caregivers to date, or even socialize outside the home, and the stress of introducing a stranger into the child's need for medical care was not ideal for many of these caregivers. For one caregiver in particular, this stress of being a single parent of a chronically ill child with sickle cell disease was expressed: "As a single parent it hasn't been... Because if I was to go out with anybody I want them to know my family situation to see if they want to be a part of that and so far that has been very limited to

be honest with you.” The acknowledgement of the fact that the child’s condition may also affect the well-being of other children in the family was a concern for some of these caregivers, related to their time and resources, which often have to be focused on the child with the condition: “I think it has affected our family life extremely. So, I think it's affected all of us. I think, as I've gotten older I realize it more too, and as he gets older, and see the affect on the other kids more. So, I think it affects us a lot.” Caregivers noted that there was stress within the family unit when siblings or other children desired more attention that the caregiver was unable to provide due to the need to care for the child with the condition.

One consideration is that because the conditions of the child that were selected for this study focused on genetic conditions, often one of the parents or another child in the family had the same condition as the child, which was an additional concern, and affected the caregiver’s QOL. Having another child or a spouse with the same condition increased the caregiving burden. The stress felt by the caregiver, if they were the carrier of the gene, also affected interactions within the family unit and within marriages, which was mostly seen within the caregivers in the lower quartile.

H. Discussion

The objective of this study was to assess the relationship between the caregiver’s QOL, the child’s functional status and the well-being of the family unit. The quantitative data analysis showed that the measures of QOL, child’s functional status and family well-being were all highly correlated. The strongest correlation was between the Family APGAR and QLI, providing evidence that the caregiver’s with higher QOL also tended to have better family well-being. Significant positive correlations of QOL with family well-being and child functional status indicate that these variables are related and operate synergistically: the caregivers with higher QOL have children with higher functional status and better family well-being. The mean scores of the upper and lower quartile were significantly different. The qualitative data collected from

the caregiver was examined, based on the caregiver's overall QOL score, which was divided into quartiles. This exploratory analysis was conducted to better understand the aspects of the caregiver's own life and daily routine that affected their self-reported QOL.

Overall themes in the qualitative data among the upper quartile of caregivers, who had self-reported a higher overall QOL score, supported by the Conceptual Model of QOL, showed that these caregivers had a more well-adjusted family life, despite their child's chronic condition, when compared with the lower quartile. Very few major changes were required within the family to accommodate the child's condition. While financial concerns remained an issue for both the upper and lower quartiles, the upper quartile of caregivers was able to find better ways of adjusting to the financial strains, as most of them had another caregiver living in the household with them who was able to assist in contributing financially.

The lower quartile of caregivers had more noted psychological distress and higher levels of financial concerns, compared with the upper quartile group, based on the overall qualitative responses. Financial concerns associated with being unable to hold a full-time job, due to the child's condition, and psychological stressors surrounding the genetic nature of the child's condition were seen more frequently in the lower quartile group of caregivers. The need for more social and financial support for members of the caregivers in the lower quartile was noted to be a need and felt to be something that the caregivers believed could enhance their functioning and the functioning of the family as a unit.

All of the conditions contained as part of the sample were represented in both the upper and lower quartile groups (Table II). Therefore, no conclusions could be drawn about the specific type of condition the child had been diagnosed with causing more or less affect on the caregiver's self-reported QOL. This study showed that the reported functioning of the child with a chronic condition and the well-being of the family was directly proportional to the caregiver's reported QOL. This study showed that reported QOL was shown, through qualitative data, to be impacted by financial strains within the family as a result of the child's condition, support within the family

unit (especially the presence of a secondary caregiver in the home), and psychological stressors of the genetic nature of the child's condition. However, it is not clear the extent to which the child's actual condition contributes to deficits in caregiver self-reported QOL, as there were children with multiple conditions in both the upper and lower quartiles of the QOL data (Table II).

This study is unique because the use of multiple childhood conditions within the same study and the use of genetic conditions to determine the sample. Previous studies of caregiver QOL focus on a single childhood condition within one study. By using multiple childhood conditions within the same study, results are able to be generalized to all of the genetic conditions seen in the study, since all conditions were represented in the upper and lower quartiles. The use of genetic conditions for this sample showed the caregiver stressors associated with the care of a child who inherited a condition from one of their parents. Caregivers often noted in the qualitative data that the genetic nature of their child's condition added an extra layer of psychological burden, knowing that they (or their spouse) had passed this condition on to their child.

I. Implications for Practice and Future Study

Based on the results of this study, financial support for these caregivers and their families could positively impact their QOL. The findings of this study suggest that QOL assessments for caregivers of children with chronic conditions are dependable indicators of caregiver QOL and can assist clinicians in identifying support or resources for these caregivers. The use of QOL measures in a clinical setting can identify aspects of a caregiver's life that may be improved with the use of support services or interventions. Frequent assessments of QOL may be useful within outpatient clinic areas that see the same patients many times over the course of their illness. The ability to follow the trends of a QOL assessment over time may provide clues for clinicians to enhance the caregivers' ability to care for their children and to identify ways to assist them. Based on the findings of this study, higher QLI scores among caregivers of children with chronic conditions may indicate higher functional status of the child as well as positively impacted family well-being.

Policy implications related to the findings of this study focus on to the financial and social concerns expressed by these caregivers. The inability to hold a full-time job, due to the demands of the child's chronic condition, was identified as a factor that negatively impacted the caregivers' QOL. The caregivers expressed the need to be able to maintain a job despite the need to miss days of work due to their child's care, which was often seen as a barrier for employers. Enhancement of public policy and support services related to the employment of caregivers of children with chronic conditions could enhance the QOL of these individuals and their families.

The implications for future study within this population focus on the gaps in the current literature. A study focused specifically on the caregiver might better address questions related to the caregiver's QOL. Qualitative questions could be focused more closely on aspects related to the caregiver's QOL, rather than the health of the child or family functioning specifically. Future research needs to continue to explore issues related to QOL of caregivers of children with chronic conditions. As these children condition to live longer, fuller lives, the caregiver's health and well-being should be a primary focus of future research endeavors.

TABLE II. DEMOGRAPHIC CHARACTERISTICS OF PRIMARY CAREGIVERS (N=86)

| Variables | Total Sample N (%) | Upper Quartile n (%) | Lower Quartile n (%) | M (SD) |
|---------------------------------|-----------------------------------|-------------------------------------|-------------------------------------|---|
| Child's Condition | 86 | 21 | 21 | |
| Phenylketonuria | 16 (19%) | 4 (19%) | 1 (6%) | |
| Sickle cell disease | 29 (33%) | 7 (33%) | 10 (47%) | |
| Thalassemia | 4 (5%) | 1 (6%) | 2 (9%) | |
| Hemophilia | 6 (7%) | 2 (9%) | 2 (9%) | |
| Von Willebrand disease | 1 (1%) | 0 (0%) | 1 (6%) | |
| Cystic fibrosis | 16 (19%) | 3 (15%) | 1 (6%) | |
| Neurofibromatosis | 10 (11%) | 2 (9%) | 2 (9%) | |
| Marfan syndrome | 4 (5%) | 2 (9%) | 2 (9%) | |
| Child's Gender | 86 | 21 | 21 | |
| Male | 41 (48%) | 10 (48%) | 13 (62%) | |
| Female | 45 (52%) | 11 (52%) | 8 (38%) | |
| Parent's Gender | 86 | 21 | 21 | |
| Female | 84 (98%) | 21 (100%) | 21 (100%) | |
| Male | 2 (2%) | 0 (0%) | 0 (0%) | |
| Child's Age | | | | 10.1 (3.18) Range: 3.7-15.9 years |
| Parent's Age | | | | 39.24 (7.24) Range 23-57 years |
| Marital Status | 86 | 21 | 21 | |
| Married | 58 (67%) | 16 (76%) | 12 (57%) | |
| Divorced | 11 (13%) | 2 (9%) | 4 (19%) | |
| Remarried | 1 (1%) | 0 (0%) | 0 (0%) | |
| Never Married | 16 (19%) | 3 (14%) | 5 (24%) | |
| Relationship to Child | 86 | 21 | 21 | |
| Mother | 81 (94%) | 21 (100%) | 20 (95%) | |
| Father | 2 (2%) | 0 (0%) | 0 (0%) | |
| Stepmother | 1 (1%) | 0 (0%) | 0 (0%) | |
| Grandmother | 2 (2%) | 0 (0%) | 1 (5%) | |
| Employment Status | 86 | 21 | 21 | |
| Yes, part time | 19 (22%) | 4 (19%) | 2 (9%) | |
| Yes, full time | 34 (40%) | 7 (33%) | 7 (33%) | |
| No, retired | 1 (1%) | 0 (0%) | 0 (0%) | |
| Not employed | 32 (37%) | 10 (48%) | 12 (57%) | |
| Parent Racial/Ethnic Background | 86 | 21 | 21 | |
| Asian | 3 (3%) | 0 (0%) | 0 (0%) | |

| | | | | |
|-----------------------------------|----------|----------|----------|--|
| Black or African American | 32 (37%) | 5 (24%) | 12 (57%) | |
| Hispanic or Latino | 3 (3%) | 1 (5%) | 1 (5%) | |
| Native Hawaiian/ Pacific Islander | 1 (1%) | 0 (0%) | 0 (0%) | |
| White | 45 (52%) | 14 (66%) | 9 (43%) | |
| Mixed Racial Background | 1 (1%) | 1 (5%) | 0 (0%) | |
| Other | 1 (1%) | 0 (0%) | 0 (0%) | |
| Type of Health Insurance | 79 | 21 | 21 | |
| Commercial Insurance | 7 (9%) | 2 (9%) | 1 (5%) | |
| HMO/PPO | 47 (59%) | 15 (71%) | 6 (29%) | |
| Public Assistance | 24 (30%) | 4 (19%) | 13 (62%) | |
| No Insurance | 1 (1%) | 0 (0%) | 1 (5%) | |

TABLE III: PEARSON CORRELATION COEFFICIENTS OF APGAR, CHILD'S FUNCTIONAL STATUS AND CAREGIVER QOL (N = 84 PRIMARY CAREGIVERS)

| | APGAR | Functional | Total QOL |
|------------|--------|------------|-----------|
| APGAR | | .352* | .703** |
| Functional | .352* | | .399* |
| Total QOL | .703** | .399* | |

*. Correlation is significant at the 0.05 level (2-tailed)

**. Correlation is significant at the 0.01 level (2-tailed)

TABLE IV: DISTRIBUTION OF QOL DATA FOR SAMPLE, UPPER QUARTILE AND LOWER QUARTILE

| | Total Sample (N=84) | Upper Quartile (n=21) | Lower Quartile (n=21) |
|----------------------------------|------------------------|--------------------------|-----------------------------|
| Overall QOL | | | |
| Range | 11.84-29.60 | 23.14-29.60 | 11.84-17.84 |
| Mean/SD | 20.72 (5.11) | 26.57 (1.26) | 17.25 (4.99) |
| Health and Functioning * | | | |
| Range | 9.23-30.00 | 25.92-30.00 | 9.23-22.15 |
| Mean (SD) | 23.73 (4.34) | 28.2 (0.97) | 17.17 (3.37) |
| Psychological/Spiritual * | | | |
| Range | 7.50-30.00 | 27.21-30.00 | 7.50-30.00 |
| Mean/SD | 23.92 (5.12) | 29.15 (0.95) | 17.40 (4.96) |
| Social and Economic * | | | |
| Range | 4.50-30.00 | 23.14-30.00 | 4.50-24.64 |
| Mean/SD | 22.26 (5.21) | 27.09 (1.77) | 15.39 (4.92) |
| Family * | | | |
| Range | 8.50-30.00 | 25.20-30.00 | 8.50-25.00 |
| Mean/SD | 24.25 (4.99) | 28.75 (1.39) | 17.03 (4.63) |

* Statistically significant difference between upper and lower quartile at the 0.05 level

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VITA

Emily Spore-Lowder

1740 N. Marshfield Avenue, #11

Chicago, IL 60622

Education

PhD in Nursing Science 2012 University of Illinois at Chicago, Chicago, IL

Doctoral Dissertation: The Quality of Life of Primary Caregivers of Children with
Chronic Conditions

Coursework Concentrations: Nursing Education, Nursing Research and Nursing
Administration

Bachelor's of Science in Nursing 2004 Saint Mary's College, Notre Dame, IN

I. Experience

Manager of Nursing Education, University of Chicago Medical Center, Chicago, IL July 2011 -
present

- Acts as the direct report manager for clinical nurse educators in pediatrics, pediatric critical care, adult critical care, adult medical-surgical, emergency medicine, labor and delivery, newborn nursery and neonatal intensive care unit departments.
- Coordinates educational efforts related to the move to a new adult hospital in February 2013, including safety, building and equipment training for at least 1000 nurses from various adult care clinical settings.
- Coordinates educational in-services, product and equipment education, on-line learning opportunities, and annual nursing competencies for all nurses within the organization (in-patient and out-patient settings, approximately 1800 nurses).
- Assists in performing budget management for three fiscal year budgets related to personnel, orientation and educational training funds.
- Serves as a member of the Nursing Management Council, Regulatory Compliance Group and Central Line Infection Prevention work group. Serves as the co-chair of a hospital-wide taskforce aimed at hospital-acquired pressure ulcer prevention.

Manager of Patient Care Operations, Pediatric and Cardiac Intensive Care Units, Children's Memorial Hospital, Chicago, IL - September 2007-July 2011

- Acted as the direct report manager for up to 35 registered nurses in the pediatric and cardiac intensive care units.
- Coordinated patient care and family services through the charge nurse role and performed administrative responsibilities including staff performance evaluations and evaluation of unit-based quality measures.
- Served as an advisor for unit-based committees, led strategic initiatives related to nursing retention and recognition, and participated in cost-reduction measures and budget formation.
- Beginning in July 2009, performed clinical nurse educator responsibilities by 1.) assisting new graduate and experienced nurses during their orientation process 2.) mentoring preceptors and 3.) providing necessary bedside education for staff.

Staff Nurse, Pediatric Intensive Care Unit, Children's Memorial Hospital, Chicago, IL

A. July 2004-September 2007

- Provided safe, family-centered nursing care to critically ill patients in a 42-bed pediatric intensive care unit.
- Assessed critically ill pediatric patients and provided care through collaboration with PICU medical staff
- Functioned in the role of charge nurse on both day and night shifts and as a preceptor for new graduate and experienced nurses.

Taskforce Advisor, PICU Welcoming, Recruitment and Retention Taskforce, Children's Memorial Hospital, Chicago, IL - November 2009- June 2011

Committee Member, Hospital Pain Committee, Children's Memorial Hospital, Chicago, IL - September 2009-June 2011

Committee Co-Chair, Hospital Recruitment and Retention Committee, Children's Memorial Hospital, Chicago, IL - October 2010-June 2011

Taskforce Advisor, PICU Pain Taskforce, Children's Memorial Hospital, Chicago, IL – September 2010-June 2011

Teaching Assistant, University of Illinois at Chicago, Chicago, IL - Spring Semesters 2007, 2008 and 2009

- Co-taught the undergraduate course Issues in Nursing Practice to at least 100 undergraduate nursing students per semester.

II. Credentials

Advanced Cardiac Life Support (ACLS) Provider, current through June 2014

Pediatric Advanced Life Support, current through June 2014

CPR Provider Certification, current through December 2012

Children's Memorial Leadership Training Courses, Fall 2007/Spring 2008

Leadership and Diversity Training, Children's Memorial Hospital, February 2008

Children's Memorial Hospital Oncology Courses, March 2007

Advanced Registered Nurse, Children's Memorial Hospital, summer 2006

Children's Memorial Preceptor Instruction, May 2005

ECMO Bedside Caregiver Education, March 2005

EKG Interpretation Course, Children's Memorial Hospital, November 2005

Registered Nurse, State of Illinois, current through May 2014

Registered Nurse, State of Pennsylvania, current through May 2014

Professional Organizations

Society of Pediatric Nurses, active member since spring 2006

Poster presentation for SPN Annual Conference, April 2010

"The Quality of Life of Primary Caregivers of Children with Chronic Illnesses"

Society of Pediatric Nurses, Chicagoland Local Chapter, active member since spring 2006

American Nurses Association, member since June 2012

Association of Pediatric Hematology/Oncology Nurses, member, 2006-2008