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THE LIVED EXPERIENCES OF PARENTS WITH CHRONIC SORROW WHO ARE CARING FOR CHILDREN WITH A CHRONIC MEDICAL CONDITION

by

LORI BATCHELOR

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of the requirements for the degree of
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Abstract

THE LIVED EXPERIENCES OF PARENTS WITH CHRONIC SORROW WHO ARE CARING FOR CHILDREN WITH A CHRONIC MEDICAL CONDITION

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Caring for the millions of children living with a chronic medical condition creates multiple parental burdens. Parents whose children have a diagnosis of a chronic medical condition may experience an ongoing, unresolved grief or sadness phenomenon known as chronic sorrow. This may impact parental ability to manage their child's health care needs and may lead to negative health outcomes for the parent caregiver, affected child, and the family.

The aim of this interpretive phenomenological study was to understand the nature and meaning of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition**.** A cohort of parent participants whose children have various chronic medical diagnoses was included to determine similarities as well as unique and diverse experiences of chronic sorrow. Data were collected through semi-structured interviews and analyzed for common themes. Demographic data, field notes and a reflexivity journal were important components of data analysis. Demographic data was analyzed using SPSS version 19 software. Six themes captured the nature and meaning of chronic sorrow for twelve participants and overarching truth of *life goes on* represented the six themes. Implications included early recognition of persons at risk and those who have chronic sorrow, development and testing of assessment tools, inclusion of fathers and children in future research, and inclusion of chronic sorrow content in curricula across the disciplines of healthcare.

Chapter 1

Overview of the Research

The prevalence of individuals living with or caring for someone with a chronic condition continues to rise. This is also true for parents caring for their own children with a chronic condition. In 2012, the United States (US) Census Bureau estimated 56.7 million people, or 19% of the population, had a disability associated with a chronic condition. According to the National Survey for Children with Special Health Care Needs, almost one in every four families has at least one child diagnosed with a chronic medical condition (U.S. Department of Health and Human Services, 2013). Lowry (2010) estimated the prevalence of chronic health conditions in children in the US rose from 12.8% in 1994 to 26.6% in 2006. The author speculated that this upward trend may be attributed to improved access to healthcare and better quality diagnostic tools for health providers. Although the incidence of chronic sorrow (CS) is unknown, the prevalence of chronic medical conditions in children creates the inevitability that many parent caregivers may experience CS. Much of the research to date has been disease-specific, exploring CS in parent caregivers whose children have a specific diagnosis.

The experiences of grief and mourning are well-established phenomena in the literature, but the term chronic sorrow (CS) is relatively new and speaks to the unique experience of what has been defined as a *living loss* (Roos, 2002). Distinctions between CS and that of grief or mourning have been carefully described (Eakes, Burkes, & Hainsworth, 1998; Roos, 2002; Teel, 1991). Chronic sorrow is an ongoing phenomenon while acute grief or mourning may resolve over time. The term chronic sorrow was first defined and described by Olshansky (1962) in his work with parents of mentally disabled children and their lifelong experiences of sadness and grief. He described the emotional response to caring for a chronically ill child a normal or appropriate emotional response. Since this initial work, researchers have learned that CS can occur in both the individuals affected with a chronic condition as well as the caregiver. (Burke, Hainsworth, Eakes, & Lindgren, 1992; Isaksson, Gunnarsson, & Ahlstrom, 2007). Understanding that the experience of CS is an appropriate and typical emotional response to an unanticipated and unfamiliar situation is an important distinction for healthcare professionals (Eakes, Burkes, & Hainsworth, 1998; Olshansky, 1962; Roos, 2002).

This phenomenological study took place within a major metropolitan children's hospital. This environment provides for parents who are caring for children with diverse chronic health conditions. Although the literature describes CS in various populations, healthcare providers lack appropriate knowledge of CS and lack access to the needed tools to assess its presence. Furthermore, healthcare professionals should be proactive in assessments and provision of relevant interventions for parents of children with a chronic condition. The presence of CS in the parent caregiver could have consequences including depression (Bumin, Gunal, & Tukel, 2009; Churchill, Villarreal, Monaghan, Sharp, & Kieckhefer, 2010; Hobdell, 2004) that can compromise care of children with chronic medical conditions and adversely affect the caregiver and family.

Purpose of the Study

The intent of this study is to delve deeply into the holistic lived experiences of parents with chronic sorrow who are caring for a child who has a chronic medical condition. Discerning the meaning of what it is like to live with CS while caring for a child with a chronic medical condition sheds light on the timelines and chronicity of such a diagnosis.

Introduction of Articles

The first manuscript, “State of the Science: Chronic Sorrow in Parents Caring for Chronically Ill Children,” is an extensive review of the literature about parental experiences of CS for parent caregivers who care for children with a chronic disease. Medline, CINAHL, and PubMed electronic databases were used along with a Google search. A review of references in foundational articles identified additional literature sources. Multiple keywords were used to make the search as broad as possible so that the researcher could review each article for relevance. Keywords included “chronic sorrow,” “parent caregiver,” “chronic condition,” and “chronic conditions in children.” A review of existing models and frameworks regarding CS assisted the researcher to assess existing knowledge about chronic sorrow in parent caregivers and identified the gap of knowledge that exists in this phenomenon. This systematic review of the state of the science concerning CS described several models that illustrate the complexity of this emotion and described the weight of caring for a chronically ill child. Some tools have been developed to determine family management style, which facilitates adaptation to the new norm. Due to the lack of proper preparation and an appropriate CS assessment tool when a chronic diagnosis is received, many parents experiencing CS are already in crisis when nursing interventions begin.

This exhaustive literature review served as the foundation for the second manuscript, “The Lived Experiences of Parents with Chronic Sorrow Who Are Caring for Children with a Chronic Medical Condition,” which is a report of an interpretive phenomenological study. The study represents 12 parents, all mothers, who have a child (birth to 18 years of age) with a chronic condition. Six themes represent the nature and meaning of CS while caring for a child with a chronic medical condition as experienced by the participants: surreality of diagnosis, unrealistic expectations, the battle, keeping it together, doing whatever it takes, and serendipities. These six themes are embodied in an overarching truth that resonated across all participants’ stories. Results of this study have significant implications for practice, research, and education that can facilitate healthier coping and adaptation for parents and families affected by CS.

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Chapter 2

Literature Review

Abstract

Parents who have a child with a diagnosis of a chronic disease or condition may experience an ongoing unresolved grief or sadness phenomenon known as chronic sorrow (CS), known to have adverse effects on a family. In order to gain a more thorough perspective on the state of the science regarding CS and to identify scientific gaps, an in-depth literature review was conducted. This literature review ranged from 1962-2015, and included (a) qualitative or quantitative research, (b) conceptual articles regarding chronic sorrow, and (c) articles related to parent caregivers of children with specific or any type of chronic illness. The search terms used were “chronic sorrow,” “chronically ill children,” “children with a chronic condition,” “parents and chronic sorrow,” “parental grief,” “caregivers of the chronically ill,” and “chronic disease.” Databases included MEDLINE, CINAHL, PubMed, and Google search. Reference lists of foundational articles were also reviewed to locate additional articles. Results yielded 80 total references, and upon further screening, a total of 34 articles were reviewed. Conclusions were that the concept of chronic sorrow is well established, described, and is an accepted phenomenon. However, research regarding parental CS was limited to target populations of specific diseases, and none discussed CS in target populations that had a variety of chronically ill conditions. Implications of this review yielded the question of whether or not CS is manifested similarly or differently when the child has a specific as opposed to any type of chronic condition.

Introduction

Survival of children with serious congenital conditions or acquired diseases in the United States (U.S.) and other developed countries has increased during the last three decades. This survival rate is a result of improved diagnostic testing, new treatments, and the skill of healthcare professionals to care for children with serious pediatric conditions, (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Almost one in four U.S. families have a child diagnosed with a chronic medical condition (U.S Department of Health and Human Services, 2013). The top categories of chronic disease in children include asthma, cystic fibrosis, diabetes, cerebral palsy, premature birth and its consequences, mental illness, and obesity (Torpy, Lymn, & Glass, 2007).

Caring for a child with a chronic medical condition creates both physical and emotional burdens for parent caregivers (Bettle & Latimer, 2009; Bumin, Gunal, & Tukel, 2008; Gravelle, 1997; Hobdell, 2004; James, 2011). Gravelle (1997) described the parent experience of caring for their chronically ill child as an ongoing process of facing, defining, and managing adversity. When parents comprehend that their child has a chronic medical condition, the new reality for their child is different than expected or dreamed (Eakes, Burkes, & Hainsworth, 1998; Roos, 2002; Teel, 1991). These parents may experience intense sadness and grief, also known as chronic sorrow. The loss of the normal or idealized child is a phenomenon similar to grieving a death. This loss may have a traumatic onset, and parents may perceive an unforeseeable future if their child has significant unanticipated birth defects or a diagnosis of a chronic disease (Roos, 2002).

The term chronic sorrow (CS) was first described by a clinical psychologist over 50 years ago to explain the lifelong experience of episodic sadness and grief parents may have toward their children with mental disability (Olshansky, 1962). Since then, researchers have learned that chronic sorrow (CS) can occur in both the caregiver of the chronically ill as well as the affected individual (Burke, Hainsworth, Eakes, & Lindgren, 1992). Health care professional must understand that the emotional reaction of parents and their experience of CS is an expected and *normal* response to an unfamiliar and unanticipated situation is important for health professionals (Bettle & Latimer, 2009; Eakes, Burkes, & Hainsworth, 1998; Olshansky, 1962; Roos, 2002). Nursing professionals' understanding of the phenomenon of CS continues to develop. This review of the literature was undertaken to identify trends in definitions and conceptions of CS, understand theoretical philosophies through models and frameworks, and determine how that information is used in research

Methods

Sample

The purposes of this systematic review of literature were to learn the state of the science and knowledge regarding the concept of chronic sorrow with a specific focus on the parent caregiver experience, and to determine scientific gaps. This literature search on the topic of CS spanned more than 50 years, and focused on literature which explored the parent caregiver of a child with a chronic illness and chronic sorrow. This literature review ranged from 1962-2015 with a focus on foundational articles, and literature from the last fifteen years (2000-2015). Inclusion criteria for articles were the following: (a) qualitative or quantitative research, (b) conceptual articles regarding chronic sorrow, and (c) parent caregivers of children with specific or any type of chronic illness. Exclusion criteria were articles that included (a) a focus on adults living with chronic illness and their adult caregivers, (b) children's experiences living with a chronic condition, (c) parent experiences with adult children with chronic conditions, (d) adult children caring for their chronically ill parents, and (e) simple literature reviews on the topic of CS.

Results yielded 81 total references. With a focus on the parent caregiver experience and parent management of children with a chronic condition, 35 published works were identified to match the inclusion criteria. The following articles were rejected: (a) ten articles were about adults and adult caregivers with CS, (b) three articles were about the child's experience, (c) two articles were parent experiences with adult children, (d) one article was about an adult child caring for a chronically ill parent, (e) twelve articles were literature reviews and proposed interventions, (f) seventeen articles were quality of life studies, and others included a study on the impact of chronic illness caregivers, CS impact on employment, and one foreign language journal article that had no translation.

Procedures

The electronic search was conducted using MEDLINE, CINAHL, PubMed, and Google search. A manual search of references in selected articles provided a list of foundational articles not found in the electronic search. Search terms that were used included "chronic sorrow," "chronically ill children," 'parents and chronic sorrow," ‘children with a chronic condition,” “parental grief,” “caregivers of the chronically ill,” and “chronic disease.”

After the literature search was completed, the material was reviewed and analyzed to determine its relevance to the research question. All studies on the topic of CS were included in the review without regard to research method or strength of evidence. Each article was first evaluated by its title and then by the abstract content to determine if inclusion criteria were met. Forty-six articles were rejected after review of the abstract, and in some instances, further review of the entire publication and findings. The 34 articles which matched inclusion criteria included eleven literature analyses, twelve qualitative studies, eight quantitative studies, and three conceptual studies, which provided foundational concepts and frameworks. See Table 1 for a listing and description of all articles.

Findings

Conceptual and Operational Definitions

Conceptual. Olshansky (1962) described a prolonged unresolved sadness in parents caring for their children with mental disabilities, and coined the term chronic sorrow (CS). Descriptive characteristics of CS have continued to evolve since his initial definition. Roos (2002) defined CS as “a set of pervasive, profound, continuing, and recurring grief responses” (p. 26) as a result of a significant loss or absence of oneself (self-loss) or to another living person (other-loss) where a deep connection exists. Bettle and Latimer (2009) include CS characteristics of periodic emotional reaction due to additional losses and report that emotions are expressed through anger, frustration, sadness, grief, guilt, fear, and hopelessness. The Nursing Consortium for Research on Chronic Sorrow (NCRCS) developed the middle range theory of chronic sorrow and characterize the attributes of chronic sorrow as “pervasive, permanent, periodic, and potentially progressive” (Eakes et al., 1998, p. 180). Antecedents to chronic sorrow include adversity, loss, sadness, disparity, and recurring or repeated loss experiences (Eakes, Burkes, & Hainsworth, 1998; Roos, 2002; Teel, 1991). Lindgren (1996) explained that CS is a grief process without an end that occurs in a pattern of cycles. These cycles are based on trigger events that cause feelings of sorrow to resurge, and these feelings are intermingled with times of quiet, calmer emotions and positive experiences of satisfaction and happiness (Kearney and Griffin, 2001; Lindgren et al., 1992; Teel, 1991).

Chronic sorrow is a distinctly different experience in contrast to grief or mourning (Eakes, Burkes, & Hainsworth, 1998; Roos, 2002; Teel, 1991). Common emotional reactions occur in an individual who experiences the death of a loved one. Kubler-Ross (1969), asserts that bereavement or mourning come to resolution over time, and through progressive stages, which may or may not occur in a linear fashion. Conversely, CS is cyclical and remains as long as the disparity created by the loss is present. The loss is continually redefined as the chronic illness continues to evolve, repeated losses are perceived, and new problems occur that require continual adaptation (Eakes et al., 1998; Lindgren, Hainsworth, Burke, & Eakes, 1992; Lowes & Lyne, 2000; Northington, 2000; Roos, 2002; Teel, 1991).

Operational. The NCRCS developed the first tools, the Burke/NCRCS Chronic Sorrow Questionnaire (Caregiver Version) (Burke et al., 1992) to assess CS. This tool was developed based on an extensive search of the literature and was used in the spina bifida population with the intent to examine chronic sorrow through telephone and face-to-face interviews. Interrater reliability of this qualitative instrument was scored with a measure of 1.00. This questionnaire is composed of 16 semi-structured questions and additional demographic items regarding participants and family (Burke et al., 1992, Appendix A).

As research develops and researchers gain experience with the phenomenon of CS, tools to assess and measure CS continue to evolve. The Adapted Burke Questionnaire (ABQ) (Appendix B) is an instrument that was adapted from Burke's Chronic Sorrow Questionnaire. Two sections of this tool are used: one (ABQA) that retrospectively measures the mood state at the time of diagnosis and the other (ABQB) that is a descriptive concurrent measure of chronic sorrow (Hobdell, 2004). The ABQA is a grid of the eight most frequently reported mood states (grief, shock, anger, disbelief, sadness, hopelessness, fear, and guilt) that parents experience when they learn of their child's diagnosis. Parents are asked to indicate the intensity of their mood state on a 4-point Likert scale (3 = very intense to 0 = absent). The tool is summed and has a range score of 0-24 with a higher score indicating increased sorrow. ABQB assesses concurrent experience of chronic sorrow in parents—a measure to indicate parent's current mood state through a set of five open-ended response questions that address the cyclical nature and intensity dimension(s) of chronic sorrow, (Hobdell, 2004; Hobdell, 2007). The reliability of the instrument was determined in a pilot study of 26 parents of children with cancer, pulmonary disease, or neurologic disease (Hobdell, 2004). Content validity and reliability has demonstrated a Cronbach's alpha of 0.90 for parents, 0.89 for fathers, and 0.91 for mothers (Hobdell, 2004).

The Kendall Chronic Sorrow Instrument (KCSI) was developed to measure dimensions of CS that Kendall describes as triggers, disparity, sadness, lack of voice, isolation, feelings of unfairness, and renormalization (Kendall, 2005). The initial tool demonstrated reliability with a Cronbach’s alpha of 0.80. The author completed extensive reliability testing and reduced this 57 item, 18 part tool; to an instrument of 18 items, with a Cronbach’s alpha of .91 (Appendix C). The range score for this tool was 0-124: 0-38 no CS present, 39-82 likely CS present, and scores greater than 83 CS present. In Kendall’s (2005) study, the mean score was 62.08 with a standard deviation of 20.03. Kendall compared the KCSI to two other instruments in an effort to demonstrate construct validity: Center for Epidemiologic Studies-Depression Scale (CESD) and the General Well Being Scale (GWBS). The CESD was used to assess convergent validity of the KCSI instrument, while GWBS was used to measure discriminate validity. While the KCSI may develop into a very significant tool, the effort to produce convergent and discriminate validity with other tools not consistent with the phenomenon of CS creates question of validity. The KCSI uses a Likert scale (0=Almost Never, 6=Almost Always), similar to the ABQ, and is sum scored with lower scores representing the absence of CS at the time of assessment. The range sum scores for the ABQ are 0-24, with greater intensity of CS related to higher scores. This research focuses on the ABQ instrument for the purposes of this study due to the foundational research, which determines the mood states expressed by parents and the simplicity of the tool when interacting with parent caregivers.

Theoretical and Conceptual Frameworks

Olshansky (1962) believed that a variety of factors influence the intensity of chronic sorrow including ethnicity, social class, religion, and the personalities of the parents. His exploration of this phenomenon had two purposes: (1) to reveal that parents whose child had global developmental delays suffer from a reaction he called chronic sorrow and (2) to suggest implications for counseling interventions for parents. He argued that healthcare professionals treated chronic sorrow like an irrational manifestation rather than a natural response to a “tragic” reality (Olshansky, 1962, p. 191). He also laid the groundwork for future research by Kearney and Griffin (2001) by asserting that parent caregivers with chronically ill children also experience satisfaction and joy. A number of other researchers (Ahlstrom, 2007; Bettle & Latimer, 2009; Fraley, 1986; Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007; Gordon, 2009; Isaksson, Gunnarsson, & Ahlstrom, 2007; Lee, Strauss, Wittman, Jackson, & Carstens, 2001; Lowes & Lyne, 2000; Melvin & Heater, 2004; and Northington, 2000) in various disciplines have further explored the phenomenon of chronic sorrow in case study reports and research conducted in various settings and in different disease-specific populations. Roles and emotions of caregivers, the experience of loss in persons with severe chronic illness, and the meaning of chronic sorrow in parents caring for children with various disease specific diagnoses were among the influential factors discussed.

Many researchers use tools developed by the NCRCS, including the chronic sorrow questionnaire adapted by Burke (ABQ).

Nursing theorists Burke, Eakes, and Hainsworth (1998), expanded on the concept of chronic sorrow through their proposed model, the middle range theory of chronic sorrow (MRTCS). The MRTCS model illustrates the experience of people who suffer CS in ongoing and perhaps single loss events. The MRTCS model is cyclical and begins with the awareness of the onset or initial loss event. This experience is defined as either a single (catastrophic) event or a series of ongoing losses. This loss experience creates disparity, which the authors define as the gap between what was expected or idealized and the situational reality. Disparity then moves to the advanced emotional state of chronic sorrow (Burke et al., 1998). In the MRTCS model, chronic sorrow is addressed through methods of managing the experience. Management methods refer to both personal coping strategies (internal), interventions provided by healthcare professionals, and support of family and friends (external) to manage chronic sorrow. These coping strategies are part of caregiver adaptation and may be internal or external; they may be ineffective or effective; and they may create increased comfort or discomfort. This cycle begins again with another loss event which could be the progression of disease, loss of previously gained milestones, or new complications which can serve as the trigger to start the cycle of CS again (Burke et al., 1998).

Northington (2000) generated a theory of chronic sorrow in African-American caregivers of school age children with sickle cell disease (SCD). This model illustrates how families have established patterns of behavior and must incorporate the diagnosis of

SCD into family life, creating new patterns of behavior around management of the individual with SCD. With sequelae of SCD, these patterns are disrupted and again the family strive to adapt and establish a new normal for the family. Northington's model appears to be a disease specific adaptation of the MRTCS. Gravelle's (1997) conceptual model, Northington's (2000) disease specific model, and the MRTCS (Eakes et al., 1998) share the common theme that parents adapt and seek to establish a new normal for life, which incorporates the complexities of their child into the family system.

Family Management of CS

Chronic Sorrow is an emotional response that is appropriate to the loss event or chronic condition and may occur in both the individual with the chronic condition and in their family caregiver (Bettle & Latimer, 2009; Burke et al., 1992; Eakes et al., 1998; Olshansky, 1962; Teel, 1991). In this way, the loss as perceived defines the reality of chronic sorrow (Roos, 2002). Typically, this loss is sudden, unanticipated, or has a traumatic onset such as discovering a significant, unanticipated birth defect or a diagnosis such as cancer, diabetes, or asthma. In these situations, parents have a sense they can no longer see the future for their child and family. Parents experience a periodic recurrence of intense feelings as they did at the time they first learned of the chronic condition. These intense feelings may be predictable or unpredictable and may be triggered by stress associated with care of the child, continually redefined in new situations that present to the parent caregiver, and serve as a constant reminder of the ongoing loss of their idealized child (Lindgren et al., 1992; Roos, 2002). Recurrence, or the waxing and waning of the emotions associated with CS in mothers was triggered by healthcare crises while in fathers it was triggered by conflicts in social norms (Sallfors & Hallberg, 2003). These authors identified qualitatively different roles for parents and categories of coping: parental vigilance (anxiety, parental protection, and watchfulness), emotional challenges (uncertainties, communication with others, the unknown), and continual adjustment (living here and now, looking for information, striving for relief and strength) (Sallfors & Hallberg, 2003).

Gravelle (1997) alludes to adaptation to CS by way of addressing adaptation to chronic illness in the illness trajectory model. Gravelle describes the features of this model as facing, defining, and managing adversity. The energy used to define and manage this adversity may lead to successful adaptation. Gravelle’s (1997) model initiates at the beginning of disease diagnosis and continues across the lifespan to death. Throughout the spectrum, she further divides the trajectory into sections described as a period free from symptoms, progression to minor physical manifestations, advancement to complex chronic condition, and, lastly, palliation. Gravelle (1997) further explores the section defined as complex chronic condition into loops that she identifies as define adversity, manage adversity, define new adversity, and manage new adversity. This is intended to demonstrate the parents’ efforts to adapt and establish a new norm and to cope with new or recurrent aspects of the chronic illness (Gravelle, 1997).

Patrick-Ott and Ladd (2010) identified the need for parents to reframe their child’s missed milestones and adapt to the new normal for their child and family. The authors revealed two levels of sadness: sadness for self as a parent with loss of social independence due to the ongoing demands of caring for a child with a chronic condition and sadness for ongoing lifelong losses for their child both in the sense of what could have been (what was dreamed for the child) and progression of the chronic medical condition. Their case report suggested that there is a unique perspective in regards to how mothers cope versus the coping of fathers. They also refer to the duality that can exist for healthy siblings who may serve both the roles of youngest child and first born when the chronically ill sibling also has developmental delay or mental disabilities.

Knafl, Deatrick, Gallo, Dixon, and Grey (2013) define family management for parents caring for a chronically ill child as a combination of family functioning and integration of the child’s treatment and care into the norms of the family. The family may alter their world view while adapting to the new normal which may include reorienting their perspective of the family, redefining the roles of each family member, and deepening their understanding of the disease or condition. The family may employ a “day to day” coping strategy (Gravelle, 1997). Some families that have a child with a chronic condition seem to have better coping and management mechanisms than other families. Some families experience depression while other families experience chronic sorrow and do not have the same symptoms of depression (Bumin, Gunal, & Tukel, 2009; Churchill, Villarreal, Monaghan, Sharp, & Kieckhefer, 2010; Hobdell, 2004).

Though not specific to CS, tools for assessing family management have been developed for use in children with chronic illness and are included in this review. Over the last 25 years, a group of qualitative researchers have developed the family management style model and its refined family management style framework (FMSF)

(Deatrick & Knafl, 1990; Deatrick, Thibodeaux, Mooney, Schmus, Pollack, & Davey, 2006; Knafl, Deatrick & Havill, 2012).

This framework describes a family response to health-related challenges, and its purpose is specifically for increasing nursing knowledge regarding family response to chronically ill children (Knafl, Deatrick, & Havill, 2012). The FMSF describes interacting dimensions that are common to all families, including how they define and manage the circumstance and the burden of caring for a child with a chronic disease or condition as well as the perceived consequences to the family (Deatrick et al., 2006; Knafl et al., 2012). The eight dimensions used in this framework are child identity, illness view, management mindset, parental mutuality, parenting philosophy, management approach, family focus, and future expectations (Deatrick et al., 2006; Knafl et al., 2012).

Measurement of the degree to which a family is managing the care of a child with a chronic illness was developed from the FMSF (Deatrick et al., 2006; Knafl et al., 2012) and is called the Family Management Measure (FaMM) (Knafl, Deatrick, Gallo, Dixon, & Grey, 2013). The current version of this tool is a quantitative tool measuring parents' management methods with a goal of understanding factors that support or hinder ideal child and family functioning and wellness. The final testing of this tool was conducted by telephone interview with a sample of over 400 families of children with a variety of chronic conditions (Knafl et al., 2013). Internal consistency and reliability for the scales, adjusted for inter-parental correlation, ranged from .72 to .90 for mothers and .73 to .91 for fathers (Knafl et al., 2013). A sixth scale was only used for two parent families. This final scale measures the dimension of parental mutuality, and assesses how the couple works together to manage their child. It measures the degree of support they receive from each other and their shared view of management of their child's condition (Knafl, Deatrick, Gallo, Dixon, & Grey, 2013). This tool has also been evaluated in a quantitative study in Portugal, with methodology intended for the translation and cross-cultural adaption of instruments. (Ichikawa, Bousso, Misko, Mendes-Castillo, Bianchi, & Damião, 2014). This study confirmed properties of the FaMM that certify its quality, conceptual application, quality by-item, and semantic, idiomatic, and operational equality, as well as content validation to assess management in families with children with a chronic condition, within the cultural of Portugal.

This tool reports greater ease or greater difficulty in managing the child's condition and family life. Higher scores in the first category of three scales [child's daily life, condition management ability, parental mutuality] indicate greater ease managing the child's condition, higher scores in the second category [condition management effort, family life difficulty, view of conditions impact] indicate greater difficulty in managing the child's condition (Knafl et al., 2013).

Interpretations

Relative consensus on definitions of CS were present in the literature as well as antecedents and management. Distinctions were made between sorrow associated with bereavement and mourning and chronic sorrow associated with ongoing and recurrent losses. Bereavement and mourning are typically time-bound grief (Lowes & Lyne, 2000), while chronic sorrow, as outlined by the literature, may be ongoing and recurrent throughout a lifespan. Chronic sorrow exists in parents when there is a gap or disparity between the idealized healthy normal child and the reality of a child with a chronic disease or condition (Bettle & Latimer, 2009; Eakes, Burkes, & Hainsworth, 1998; Roos, 2002; Waite-Jones & Madill, 2008). Frameworks exist for studying CS (Eakes et al., 1998), for determining a family's response to health challenges (Deatrick et al., 2006; Knafl et al., 2012), and for assessing resources for adaptation to having a child with a chronic illness (Knafl et al., 2013). We know that loss on multiple levels is experienced as part of CS. Measurement of CS was limited to two valid and reliable tools: the Adapted Burke Questionnaire, and the Kendall Chronic Sorrow instrument (Hobdell, 2004; Kendall, 2005). The literature discusses the need for healthcare professionals to assist parents in the development of healthy coping skills and guide them to locate resources such as support groups. The experience of CS varies from person to person and depends upon individual coping strategies, which can be dramatically different between mothers and fathers (Fraley, 1986; Stroebe & Schut, 1999; Landridge, 2002; Scornaienchi, 2003). Therefore, strategies like this should be considered when developing interventions to assist with adaptation to the new norm. While related to CS, much of the literature deals more with the child who is chronically ill and their related issues but does not specifically address the child and family with CS. The literature reflected primarily Western culture and limited sources could be located that studied cultural variations in the West, despite the growing cultural diversity in the U.S.

Implications

This literature review yields significant scientific gaps that carry strong implications for further research. Although the literature reflects knowledge in both breadth and depth regarding CS, nothing could be located regarding assessment for the presence of CS in parents with a newly diagnosed child with a chronic condition. It is unknown how to determine parent caregivers at risk for CS. No known tool exists to aid in prediction of CS in parents with their child's newly diagnosed chronic condition. While models illustrate the concept of chronic sorrow, its progression and recurring patterns and management, the current literature focuses primarily on CS in specific diagnoses. Are the experiences of parents caring for children with various chronic conditions or diagnoses similar? Is chronic sorrow different for parents with children who have developmental and cognitive delays as compared to those with a normal cognitive development? Gordon (2009) recommends further research to determine if suffering from chronic sorrow is present in parents caring for children with chronic illness without disability. She suggests a need to determine the relationship of depression or the risk of depression to chronic sorrow.

Further study is still needed to determine how parents define and manage adversity within the illness trajectory model (Gravelle, 1997). Lee et al., (2001) questioned if the change in role or loss of the expected role for the caregiver contributes to feelings of chronic sorrow. Are these experiences different for mothers versus fathers? Further research is needed to address these important recommendations and observations of CS and cultural influences. Northington (2000) believes that an instrument is needed to assess or quantify the depth and characteristics of chronic sorrow, especially in varying cultures and to determine triggers that contribute to ongoing sorrow or disparity. Strobe and Schut (1999) state, "although grief is essentially a universal human reaction to loss of a significant other, cultural prescriptions impact on the way that grief is manifested" (p. 9). Can the prevalence of chronic sorrow be determined in parents caring for children with chronic conditions and diseases? Will all families whose child has a chronic condition experience CS? Is it disease specific, or is it disease chronicity that serves as the key determinant of CS?

Boiling (2005), suggests that external support from health care professionals is needed to aid in a family's functional and emotional needs when they have a child who is chronically ill. Further education on parent experience of CS and management of chronic illness is needed for health care professionals. This additional knowledge will improve nursing professionals' competency to provide families with resources for social and volunteer support services along with current and relevant information about their child's disease or condition and treatment options (Boiling, 2005). Melynk, Feinstein, Moldenhouer, and Small (2001) also recommend interventions to enhance coping in parents of chronically ill children.

The models discussed may be combined to make one model that illustrates the parent caregiver experience with their chronically ill child, similar to the model described for sickle cell disease (Northington, 2000). This single model would incorporate the cyclical nature of chronic sorrow and the competing experiences of joy and sorrow described by Kearney and Griffin (2001). The illness trajectory model in particular is an appropriate source to begin the understanding of chronic illness and may serve as the starting place in building a single, comprehensive model which links the phases of disease with the elements of sorrow and onset of chronic sorrow (Gravelle, 1997).

Conclusions

This review of 34 articles reflected information regarding basic definitions and characteristics of CS but yielded significant scientific gaps that, if addressed, could positively impact child and family outcomes. CS tools and frameworks have been developed, but they need further testing and refinement through research. With the increased prevalence of survival of children (and adults) with chronic medical conditions, there is an inevitability that CS may be experienced by many parent caregivers. Much of the research to date has been disease specific with studies that explore CS in parent caregivers whose children have a specific diagnosis. This disease-specific research trend may have created a gap in what is known regarding the prevalence of CS as well as common experiences of parent caregivers with CS regardless of the diagnosed chronic medical condition. Parents can be immediately plunged into the experience of sorrow at the diagnosis of a chronic disease or condition for their child. In the cases of mothers, these parents are frequently facing this diagnosis with a newborn while still recovering from the physiological and emotional experiences of childbirth. Parents may continue this experience of chronic sorrow throughout the lifespan of their child which could be years into their child’s adulthood. It appears that the combined parent caregiver role is unique.

Substantial and additional knowledge is essential for nursing professionals to adequately prepare and provide interventions for parent caregivers. Nurses and other healthcare professionals must agree upon the definition of what constitutes a chronic disease or condition. Nursing must also move beyond a particular disease to consider the broader aspects of caring for an individual with a chronic medical condition. In defining chronic disease or condition, researchers and healthcare professionals must determine if disability has an impact on CS and if it influences the determination of a chronic condition. Researchers and clinicians who take the opportunity to answer these questions will open doors to better care for chronically ill children and their parents. Answering these questions may also open doors to an understanding of how healthcare professionals assess for CS and develop interventions to assist with family management and adaptation.

Table 1. Literature Review

Author	***Purpose***	***Design***	***Participants***	***Findings***
Ahlstrom (2007)	To describe loss and in individuals with a chronic illness.	Qualitative, with inductive analysis.	51 individuals between 18-64 years, with a physical disease or injury.	8 categories of experiences of recurring loss.
Bettle & Latimer (2009)	Case study of CS in care of adolescent with neurodegenerative disease.	Descriptive case study.	Parent caregiver (mother).	Maternal adaptation and coping and new and existing resources.
Broger & Zeni (2009)	Fathers' coping related to parenting.	Descriptive correlational survey.	54 biologic fathers with chronically ill children	Coping mechanisms and correlation between relationship of perceived severity of child's chronic condition and fathers' coping.
Bumin, Gunal, & Tukel (2008)	To investigate the relationship of anxiety and depression in mothers of disabled children.	Correlational study.	107 mothers	Mothers with disabled children have anxiety and depression, these negatively affected the mothers' quality of life.
Burke, Hainsworth, Eakes, & Lindgren (1992)	Foundational article on current knowledge of CS.	Qualitative study.	Nursing Consortium Researchers of Chronic Sorrow (NCRCS), familiar with the	When CS occurs and what characteristics it displays and in what populations.

			research and topic of CS.	
Deatrick & Knafl (1990)	To understand how families who have children with a chronic condition make daily adjustments to accommodate the children's special needs.	Descriptive literature analysis.	6 selected articles that identify family management behaviors.	Identified need for further development, define, and complete concept analysis of management behaviors. Identify characteristics of management behavior. Foci: the ill child, the family system, and the social system.
Deatrick, Thibodeaux, Mooney, Schmus, Pollack, & Davey (2006)	To introduce the Family Management Style Framework, to assess families who have children with cancer.	Descriptive literature analysis.	11 articles related to the tool and 44 articles pertaining to children with chronic illness.	Supports use of the Family Management Measure (FaMM), tool in pediatric oncology affected families.
Eakes, Burke, & Hainsworth (1998)	Introduction of the middle-range theory of CS.	Descriptive literature analysis.	10 qualitative studies conducted by the NCRCS.	Description of model and lifespan concept of CS with antecedents, trigger events, and management methods.
Fraley(1986)	To describe the experience of parents of premature children.	Descriptive survey.	47 parent caregivers (39 mothers and 8 fathers).	Parents of premature children do not resolve their fear and grief and experience CS.
Gordon (2009)	Assist nurses to recognize, assess, and support parent caregivers with CS.	Descriptive literature analysis.		Research on internal coping strategies, and relationship between CS and depression.
Gravelle (1997)	Exploration of day to day experience of parent caregivers for their child with a	Qualitative phenomenological study.	11 parent caregivers (5 mothers and 3 couples).	Illness trajectory described with primary themes of facing

	progressive life-threatening illness.			adversity, managing adversity, and subthemes of normalization and loss.
Hobdell (2004)	To describe parental CS following birth of a child with a neural tube defect and to explore the relationship between CS and depression.	Descriptive survey.	132 initial subjects enrolled and 69 total completed the study. 91% of mother father pairs completed, the remaining were single parent participants.	Evidence of statistically significant relationship between CS and depression on ABQB tool.
Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana (2007)	To compare parental coping and CS in parents of children with epilepsy.	Correlational study.	97 parent caregivers, with 67 completing the study.	Statistical analysis did not reveal any significance in coping between parents of children with or without refractory epilepsy. Although refractory was anticipated to be higher.
Ichikawa, Bousso, Misko, Mendes-Castillo, Bianchi, Damião, (2014)	To determine if the Family Management Measure (FaMM) is a valid instrument in a cultural that is different, form the cultural it was established.	Quantitative study with methodology for the translation and cross-cultural adaption of instruments,	72 Families participated.	The FaMM's Portuguese version, named Instrumento de Medida de Manejo Familiar, demonstrated properties that certify its quality, conceptually, by-item, semantic, idiomatic, and operational equality, in addition to content validation.
Isaksson, Gunnarsson,	To explore the presence and	Descriptive cross-sectional survey.	61 participants with 61% (38	Seven themes described the

& Ahlstrom (2007)	meaning of CS and depression in person with multiple sclerosis.		participants) meeting criteria for CS.	losses that caused sorrow: loss of hope, loss of body control, loss of integrity and dignity, loss of a healthy identity, loss of faith that life is just, loss of social relationship, and loss of freedom.
Kearney & Griffin (2001)	To explore the experienced of parents who have children with significant developmental disability.	Qualitative interpretive study.	6 parent caregivers, 2 couples and 2 single mothers.	Major themes of joy and sorrow. A model was developed in order to visualize these themes and their dynamic complex interplay.
Kendall (2005)	To study the usefulness of the Kendall Chronic Sorrow Instrument a quantitative tool for CS.	Descriptive/correlational survey.	96 females.	Further refinement of the tool, from 57 question instrument to an 18 question tool. Correlation of instrument with two additional instruments to explore convergence and discriminant validity.
Knafl, Deatrick, & Havill (2012)	Continued development and refinement of Family Management Style Framework (FMSF).	Systematic review of literature associated with sociocultural influences on family management of childhood chronic condition.	64 studies.	Evident to support the 8 dimension of the FMSF. Changes to contextual influences (social network, access to resources, and interchanges with healthcare and school systems). Refined broader relevance by

				changing term to person with the condition, and individual family members.
Knafl, Deatrick, Gallo, Dixon, & Grey, (2013)	To measure how families manage caring for a child with a chronic condition/illness and incorporation of condition management into everyday family life.	Family Management Framework including purpose, development, scales, validity, and scoring of tool.	16 articles referenced by collaborative who developed the Family Management Style Framework and then the FaMM.	Data from the FaMM expected to contribute to clinicians' and researchers' ability to understand family functioning in the context of childhood chronic conditions. By measuring key aspects of family management.
Landridge (2002)	To describe the role of the community health nurses in assisting families experiencing CS, with specific interventions to assist with family life.	Descriptive literature analysis.		Reducing the impact of CS is a realistic preventive health role for community health nurses and other professionals; who receive appropriate training.
Lee, Strauss, Wittman, Jackson, & Carstens (2001)	To examine the intensity of CS in caregivers of adults with mental illness, geriatric and pediatric individuals with chronic illness.	Correlational study.	3 sample caregiver groups with specific experience; adults with mental illness, children with chronic disabilities, and geriatric individuals with chronic illness.	Parent caregiver experienced the greatest level of sorrow at three months after diagnosis. The parent caregiver role was highly correlated with CS at diagnosis and at the time of study.
Lindgren, Burke, Hainsworth, & Eakes (1992)	Effects of chronic illness on caregivers, CS lifespan concept.	Concept analysis and CS review summary.		Beginning step to develop nursing theory that provide direction for

				care of this population.
Lindgren (1996)	To determine the presence and nature of CS in persons with Parkinson's and their spouses.	Qualitative explorative study.	10 total individuals: 6 participants with Parkinson's disease, 3 spouses, one other.	Findings similar to individuals with Multiple Sclerosis and their caregiver. Despite differences in presentation, onset, pathology; both disrupt the life course of the afflicted individual and spouse caregiver with losses and continual adjustments.
Lowes & Lyne (2000)	Review of the literature and implications for practice of newly diagnosed diabetes.	Descriptive literature analysis.		Majority of parents were able to adapt to the diagnosis and management of their child's diagnosis; however, it is also noted that parent caregivers may never recover from the impact of the diagnosis and may experience CS.
Melvin & Heater (2004)	To differentiate suffering and chronic sorrow through review of the literature.	Descriptive literature analysis.		Paradigm for nursing practice, central concern for all people facing life altering diagnosis; fear of abandonment. The nurse establishes a forum for healing.
Mokkink (2008)	Defining what constitutes chronic disease.	Systematic Literature search and theoretical	27 Clinical Research experts.	Standardize mechanism to determine

		framework of determinants.		presence of chronic disease that must meet 4 criteria.
Northington (2000)	To examine the process of CS in caregivers of school age children with Sickle Cell disease (SCD).	Qualitative grounded theory.	12 African American caregivers.	Diagnosis of SCD was the initial trigger for CS. Each subsequent trigger changed the caregiver situation and created the need to reestablish equilibrium.
Olshansky (1962)	To describe parents who have a mentally retarded child suffer from a psychological reaction, to suggest implications for CS.	Case study description of psychological reaction.		Chronic sorrow as the term to describe the reaction and that this is a *normal* response.
Patrick-Ott & Ladd (2010)	To examine the life trajectory of a mother of child with several disabilities and concepts of CS and ambiguous loss.	Case study.	Single parent caregiver.	CS and ambiguous loss lasts a lifetime for parents of children with significant disability.
Roos (2002)	In-depth exploration of the concept of CS.	Publication with details of from conception of CS to implications and directions for research.		Chronic sorrow, interpreting the loss, living with CS, families, loss, and CS, existential issues, complicating factors, professional support and treatment, implications and directions for research.
Sallfors & Hallberg (2003)	To explore parent caregiver experiences of living with a child with juvenile chronic arthritis.	Qualitative study grounded theory design.	22 parents (6 of these were fathers).	Three core categories: parental vigilance, emotional challenges, and continual adjustment. Recurrent of CS

				in mothers was triggered by healthcare crises while in fathers it was triggered by conflicts in social norms.
Scornaienchi (2003)	To understand the experience of one mother with two children with Lissencephaly.	Case study.	Family unit: parents-mother, father, with 3 children, 2 with lissencephaly.	Mothers and fathers may interpret their child's disability differently and use different coping strategies. Nursing can use results to help assess parents' coping styles and promote healthy coping.
Stroebe & Schut (1999)	Authors propose a revised model of coping with bereavement, the dual process model.	Literature review.		Model identifies two stressors, loss oriented and restoration-oriented. Grieving individual at times confronts, other times avoids tasks of grieving. Model proposes the natural adaptive coping process is composed of confrontation--avoidance of loss and restoration stressors.
Teel (1991)	Chronic Sorrow: concept analysis.	Literature review, concept analysis.		Review identified elements of periodicity, variability and permanence of psychological pain and sadness. Specifics of antecedents,

				attributes, and consequences.
Waite-Jones (2008)	To describe what it is like to be a father of a child with Juvenile Idiopathic Arthritis (JIA).	Qualitative grounded theory study.	32 family members (8 adolescents with JIA).	Five themes were identified specific to fathers: comparison, loss, constraints, concealment, and social and emotional adjustment.

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Chapter 3

The Lived Experiences of Parents with Chronic Sorrow Who are Caring for Children with a Chronic Medical Condition

Abstract

Caring for a chronically ill child can result in tremendous burdens for parent caregivers, resulting in long term debilitating effects, including chronic sorrow (CS). The aim of this interpretive phenomenological study was to explore the lived experiences of parents with chronic sorrow caring for their child with a chronic medical condition without regard to the child's diagnosis. In-depth recorded interviews of 12 parents with chronically ill children were conducted. Hermeneutical analysis resulted in six themes. Understanding shared, common experiences may shift the focus from managing the specific type of disease to caring for these families by helping them to manage the chronic nature of disease. With this knowledge, a set of standard nursing assessment and appropriate proactive interventions can be developed based upon the common issues and concerns present for parent caregivers. Interventions may assist the parent to make adaptations to their added caregiver role and support exploration of effective management methods to improve parental coping and outcomes for their chronically ill children.

Problem and Significance

Advances in healthcare technology have led to increasing numbers of individuals living with the challenges of a chronic medical condition or caring for someone with a chronic medical condition. About 25% of families in the U.S. have a child diagnosed with a chronic medical condition (U.S. Department of Health and Human Services, 2013). Survival of children with serious congenital or acquired diseases in the United States and other developed countries has increased during the last several decades. This is a consequence of improved diagnostic tests, treatments, and the ability of healthcare professionals to care for children with life-threatening pediatric conditions (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Asthma, cystic fibrosis, diabetes, cerebral palsy, premature birth and its consequences, mental illness, and obesity which may lead to diabetes; are the top categories of chronic disease in children (Torpy, Lymn, & Glass, 2007). The most common chronic condition occurring in children is asthma, impacting millions of children (National Center for Health Statistics, 2014).

Caring for a child with a chronic medical condition creates physical and emotional burdens for the parents caring for these children. Gravelle (1997) described the parent experience of caring for a chronically ill child as an ongoing process of facing adversity, while Kearney and Griffin (2001) discussed the dynamic interplay of joy and sorrow for these parent caregivers. Several research groups have investigated the presence of themes in different populations with various results. A literature review regarding parent caregivers caring for their medically complex children described the consistent themes of (a) role conflict for caregivers and family, (b) financial burden for parents, (c) parent caregiver physical care burden, and (d) independence and often isolation that comes from being a parent caregiver (Ratliffe, Harrigan, Haley, Tse, & Olson, 2002). Research in fathers of children with juvenile idiopathic arthritis (JIA) revealed themes of comparison, loss, constraints, concealment, and social and emotional adjustment (Hovey, 2005) as well as parental vigilance (Sallfors & Hallberg, 2003). Caregiver roles, caregiver emotions toward the chronically ill, and chronic sorrow intensity were compared in a mixed cohort study of adult caregivers for geriatric adults, children, and persons with mental illness. Different roles were explored that included caregiver, friend, family member, and spouse or significant other. The highest intensity of sorrow was experienced by the caregiver role. The caregivers of the pediatric group were noted to have the greatest level of sorrow at diagnosis, the mental health group experienced the greatest level of sorrow at three months after diagnosis, and the geriatric group caregiver experienced the greatest level of sorrow at the present moment in time (Lee, Strauss, Wittman, Jackson, & Carstens, 2001). Parents who have a child with a chronic medical condition experience a new reality when they recognize that their child is different than what they expected or dreamed (Eakes, Burkes, & Hainsworth, 1998; Roos, 2002; Teel, 1991). These parents may experience intense sadness and grief, which may advance to the more complex feeling of chronic sorrow. Similar to grieving a death, parents experience loss of the normal or idealized child. The loss of the idealized child may have traumatic onset, such as with significant unanticipated birth defects or a later diagnosis of chronic disease such as cancer and parents may perceive an unforeseeable future (Eakes et al., 1998; Roos, 2002).

The term chronic sorrow was first coined by Olshansky (1962) to explain the lifelong experience of episodic sadness and grief of parents toward their children with mental disability. Since then, researchers have learned that chronic sorrow (CS) can occur in both the caregiver of the chronically ill as well as the affected individual (Burke, Hainsworth, Eakes, & Lindgren, 1992; Isaksson, Gunnarsson, & Ahlstrom, 2007; Lindgren, 1996). It is important to understand that the experience of CS is an appropriate emotional response and typical for parents experiencing an unfamiliar and unanticipated situation (Bettle & Latimer, 2009; Eakes, Burkes, & Hainsworth, 1998; Olshansky, 1962; Roos, 2002). The experience of CS waxes and wanes in intensity with the progress and set-backs associated with caring for the chronically ill. There is a dissimilarity in the phenomena of chronic sorrow from acute grief or mourning, and researchers have clarified that these are distinctly different (Eakes, Burkes, & Hainsworth, 1998; Melvin & Heater, 2004; Roos, 2002; Teel, 1991). Unlike grief and mourning, chronic sorrow is an unresolved phenomenon while time may allow completion of the acute grief or mourning period to resolve (Kubler-Ross, 1969).

With the increased presence of chronic medical conditions, it is inevitable that CS may be experienced by many caregivers and individuals affected by chronic disease. Much of the research to date has been disease specific with studies that explore CS in parent caregivers whose children have a specific diagnosis such as spina-bifida (Burke, Hainsworth, Eakes, & Lindgren, 1992), asthma (Kurnat & Moore, 1999), diabetes (Lowes & Lyne, 2000; Monaghan, Hilliard, Cogen, & Streisand, 2001), sickle cell disease (Northington, 2000), lissencephaly (Scornaienchi, 2003), neural tube defects (Hobdell, 2004), epilepsy (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007), juvenile idiopathic arthritis (Sallfors & Hallberg, 2003; Waite-Jones & Madill, 2008), neurodegenerative disease (Bettle & Latimer, 2009), or cancer (Fletcher, 2010). This disease specific research trend has resulted in a gap regarding the prevalence of CS, as well as common experiences of parent caregivers with CS regardless of the diagnosed chronic medical condition.

The intent of this study was to gain an in-depth and comprehensive understanding of the lived experiences of parents with chronic sorrow who are caring for a child who has a chronic medical condition. Anticipated findings of this research include the following: (a) by studying the experiences of parent caregivers of children with various chronic conditions, awareness of the meaning of what it is like to live with CS may reveal similar CS experiences, (b) CS may not be associated with a specific chronic medical condition diagnosis but rather the chronicity of that diagnosis, and (c) if the latter was demonstrated to be true then an assessment tool for identifying parents who may be at risk for chronic sorrow can be developed for use in parents when they discover their child is diagnosed with a chronic illness.

Review of the Literature

The literature on the topic of chronic sorrow spans more than 50 years. As a rehabilitation therapist, Olshansky (1962) described CS as a pervasive psychological reaction that is not always recognized by healthcare providers. Chronic sorrow is an appropriate typical emotional response to a loss event, and in the case of parental CS, the loss is of the normal or idealized child (Bettle & Latimer, 2009; Eakes et al., 1998; Roos, 2002). Nursing diagnosis taxonomy has previously referred to this phenomenon as complicated or dysfunctional grief. Attributes of dysfunctional grief include anger, denial, and idealization of loss; these losses are often associated with a chronic illness. Healthcare professionals have begun to recognize that the individual may instead be experiencing chronic sorrow (Doenges, Moorhouse, & Murr, 2010). Olshansky's (1962) work has led to further study of CS including descriptions and attributes of CS that include loss and disparity, adversity, and coping. This literature review describes the CS characteristics and caring for a child with a chronic medical condition.

Chronic Sorrow: Antecedents and Predisposing Factors

A significant loss may serve as the trigger event for chronic sorrow. This loss could be a self-loss or other loss (Burke et al., 1992; Eakes et al., 1998; Roos, 2002; Teel, 1991). Antecedents to CS include a relationship of deep attachment that is impacted by a loss other than death, a disparity between the past or idealized present, and the reality of the actual relationship (Teel, 1991). Self-loss is the loss of one's idealized life following the diagnosis of a loved one's chronic or disabling medical condition (Ahlstrom, 2006; Burke et al., 1992; Eakes et al., 1998; Isaksson, Gunnarsson, & Ahlstrom, 2007). Parents expecting a newborn typically establish a deep attachment to the unborn child and anticipate the birth of a healthy normal child. Chronic sorrow exists in parents when there is a gap or disparity between the idealized healthy normal child and the reality of a child with a chronic disease or condition (Eakes et al., 1998; Fraley, 1986).

Chronic Sorrow: Attributes and Characteristics

Chronic sorrow is a different experience in contrast to grief or mourning (Eakes et al., 1998; Roos, 2002; Teel, 1991). The experience of acute grief or mourning typically comes to resolution over time, and through progressive stages (Kubler-Ross, 1969). The grief or mourning stages are common emotional reactions to experiencing the death of a loved one and are not necessarily linear. However, CS is an ongoing phenomenon, a living loss that cannot be removed and which requires continual adaptation (Burke et al., 1992; Eakes et al., 1998; Isaksson et al., 2007; Lee, Strauss, Wittman, Jackson, & Carstens, 2001; Lindgren et al., 1992; Roos, 2002). Attributes of CS include (a) sadness or sorrow that has variable intensity for a person and can be different from one person to the next, (b) permanent continuance throughout the lifetime of the chronically ill or disabled person, and (c) cyclical experiences based upon internal or external triggers that bring the loss back into focus. Loss is continually redefined as the chronic medical condition evolves; repeated losses occur; and new problems associated with care happen. These challenges serve as the recurrent catalysts for sadness and sorrow and begins the cycle again. (Eakes et al., 1998; Lindgren, 1992). Typically, loss is sudden, unanticipated, or has a traumatic onset, and parents perceive an unforeseeable end. This is experienced in regards to relationships where there is deep attachment and the reality of that relationship is forever changed, such as the loss of the idealized child, or the loss of the healthy spouse or parent to unrelenting chronic medical condition or disability (Hobdell, 2004; Roos, 2002). Loss is also characterized by loss of hope, loss of body control, loss of integrity, and loss of identity as it applies to the experience of living with chronic sorrow due to one’s own disease state (Isaksson et al., 2007). This sadness or sorrow is progressive and can intensify even long after the initial loss, and there are intermingling experiences of satisfaction and happiness (Burke et al., 1992; Eakes et al., 1998; Kearney & Griffin, 2001; Lindgren et al., 1992; Northington, 2000; Teel, 1991). Lindgren (1996) described CS as continuous grief that occurs in a pattern of resurging feelings of sorrow interspersed with periods of calmer emotions. This is congruent with the middle range theory of chronic sorrow that characterizes the attributes of CS as “pervasive, permanent, periodic, and potentially progressive” (Eakes et al., 1998, p. 180). This loss experience is recurrent and remains as long as the disparity created by the loss is present (Eakes et al., 1998; Lowes & Lyne, 2000; Northington, 2000; Teel, 1991).

A periodic recurrence of intense feelings occurs, which may be predictable or unpredictable and may be triggered by stress associated with care of the child and serves as a constant reminder of the ongoing loss of the idealized child (Roos, 2002). The existence of CS is determined by the way in which the loss is perceived (Roos, 2002). Because the loss continues to be present, it is considered a living loss (Eakes et al., 1998; Roos, 2002).

Chronic Sorrow: Impact and Consequences

Loss. The concepts of loss and disparity are very closely linked, and differences can be difficult to discern. Disparity occurs when there is a difference between the idealized child and the reality of the child with a chronic medical condition (Eakes, Burkes, & Hainsworth, 1998). Within the phenomenon of CS, disparity may follow loss after a period of time or may be immediately realized (Burke et al., 1992; Eakes et al., 1998; Lindgren et al., 1992). A case study by Scornaienchi (2003) noted that the mother’s trigger event for CS was learning of the diagnoses of lissencephaly and its prognosis for her sons. The disparity occurred when the mother came to realization of the loss of her idealized sons. As long as the disparity remains, the experience of CS will continue to be cyclical (Eakes et al., 1998).

Parents perceive the progression of chronic disease as additional losses for the child and parent due to declines in their social and personal lives (Gravelle, 1997). This could be true of any caregiver of an individual with a chronic condition. Various issues of the child's condition contribute to this loss including: (a) how extensively the child is affected; (b) speed, change, or progression of condition, disease, or disability; (c) number of children within the family with a given diagnosis or diagnoses; and (d) the age and developmental level of the affected child (Deatrick & Knafl, 1990; Gravelle, 1997; Kearney & Griffin, 2001). According to Lowes and Lyne (2000) some parent caregivers may never recover from the impact of their child's diagnosis and continue to experience CS.

Patrick-Ott and Ladd (2010) discovered the concept of ambiguous loss in their case study about CS in a mother caring for her premature child who had cerebral palsy (CP). Ambiguous loss is defined as a loss that is incomplete and uncertain. During an evaluation with her child's physician, the mother realized that her child's limitations were more than physical when she inadvertently learned her child also had mental impairment with the expectation of lifelong health issues. This realization subsequently led to her experiences of recurrent pain. Similar to Kearney and Griffin's (2001) discussion of no hope and despair, when learning about the change in her child's potential, the mother recalled the day she learned of the full implication of her child's diagnosis that "the hopes and dreams for the life of my first son were dying a slow death" (Patrick-Ott & Ladd, 2010, p. 78).

Parent caregiver emotions. A case study of a mother describes her emotions of uncertainty, sadness, grief, fear, and anger at her son's diagnosis of progressive neurodegenerative disease. These emotions recurred when there were developmental changes, ongoing and complex healthcare needs, and during periods of new or worsening symptoms of disease progression (Bettle & Latimer, 2009). Other researchers have identified that when parents learn of their child's chronic diagnosis, they experience these same emotional responses as well as denial, frustration, guilt, grief, mourning, anxiety, and depression (Hobdell, 2004; Hobdell et al., 2007; Lee et al., 2001; Northington, 2000; Sallfors & Hallberg, 2003). Kearney and Griffin (2001) explored the two themes of parental sorrow and parental joy in parents who had chronically ill children. They proposed a model that included tensions that reflected confusion, doubt, ambiguity, joy, sorrow, hope and hopelessness, defiance, and despair. They observed that the presence of a disabled child was viewed by society as a tragedy but suggested that this feeling could be muted by a supportive response from healthcare professionals, friends, and family toward the child and family. Oddly, parents reported feelings of sorrow and despair as a results of responses to parental CS by healthcare professionals, friends, and family.

The father's role was explored in two studies that reflected similar findings of loss from different and unique perspectives. Fathers of children with a chronic condition perceived that (a) their family was different when compared to a normal child in other families, (b) communications were difficult between father and child, (c) they experienced failed masculinity for fathering an ill child, and (d) they attempted to hide distress and emotion through denial and distraction. (Hovey, 2005; Waite-Jones & Madill, 2008). Distress for these fathers was associated with losses of provider status and a protectorate role over the family and child, anticipated family future, difficult playmate and family group activities due to the complexity of the child's illness, and their paternal role in making their families happy and comfortable (Waite-Jones & Madill, 2008).

Adapting to adversities. Gravelle (1997) conceptualized the experiences of parents caring for a child with a chronic medical condition through a model she calls the illness trajectory. She speaks to the sequential experiences of hardship and the challenges faced by parents due to the progression of the disease state and labeled these hardships as adversity. The trajectory model depicts adversity in a cyclical and continuous manner with loops of defining adversity, managing adversity, re-defining adversity. This process illustrates the parent's effort to normalize the hardship or adversity into the daily activities of caring for a child with a chronic medical condition. Each time a new hardship or adversity presented itself, the parent began the cycle of defining or re-defining and managing the adversity. Parents often expressed feelings of being overwhelmed by the progression of the complex chronic condition. This progression required specialized care for which parents may have no training or experience and care that is time intensive and occurs around the clock (Gravelle, 1997). The medically complex child requires a great deal of high quality care, which, in turn, requires planning, organization, and coordination and, therefore, places additional demands on parents (Gravelle, 1997).

Decreases in social support and increasing demands of their child's care may cause parents to struggle to define and manage adversity and lose balance between effective and ineffective coping (Gravelle, 1997). Internal and external coping may include maintaining personal life activities, searching for respite opportunities, seeking information that helps them to cope with the loss experience, normalizing the new reality, listening with empathy, offering and providing support, and acknowledging feelings (Eakes et al., 1998). Redefining and adapting to the new norm of caring for a child with a chronic condition is a coping strategy in itself (Bettle & Latimer, 2009; Gordon, 2009; Gravelle, 1997). Families incorporate disease exacerbations into family life in order to form a new normality for the parent and family. The new normality can be compared with complexity theory that states chaos is created through system disruptions but the system will seek to find new patterns to adjust to the new norm (Northington, 2000).

Hovey (2005) found that fathers who had a child with a chronic disease and who could accept the situation and treat their chronically ill child no differently than their healthy children experienced positive adaptation. Thirteen percent (n=48) of these fathers reported using negative coping strategies such as smoking tobacco, drinking alcohol, or using drugs. In families where there was poor coping or adaptation, the families experienced conflicts, felt guilty about having a child that was not normal, and had difficulty caring for their child. Their attitude toward their chronically ill child was markedly different from their attitude toward their healthy children. However, the majority of these fathers used positive coping strategies to help them with their child’s chronic medical condition such as (a) finding information, (b) reading about the problem, (c) looking at options, (d) weighing their choices, and (e) trying to determine and agree with their spouse on what to do next (Hovey, 2005). Parent caregivers strive through the emotional work to cope with the reality of their child’s condition, and they struggle with acceptance and adaptation to a new norm (Bettle & Latimer, 2009; Gravelle, 1997; Scornaienchi, 2003).

The between joy and sorrow model (Kearney & Griffin, 2001) speaks to joy as the determination of the parents to maintain hope and to advocate for their child with a focus on survival and development. The authors label these characteristics as defiance and hope: defiance that their child did not die and celebration for the small accomplishments of their child and hope through new perspectives gained about their child and their child’s care. Although these parents are aware of their children’s limitations, their expressions of defiance and their dependence on hope for their children allowed them to cope with the reality of life. In spite of these conflicting experiences of joy and sorrow, these parents describe the positive impact of being better people who have been strengthened by their experiences.

Parents caring for their chronically ill child also experience career and work adversity. Primary parent caregivers often have to quit their job or risk losing their job or their career due to the care demands for their child, difficulty obtaining appropriate and affordable childcare, and difficulty maintaining a regular schedule due to their child’s chronic medical condition (George, Vickers, Wilkes, & Barton, 2008; Chung, Garfield, Elliott, Vestal, Klein, & Schuster, 2013). Most parents felt that their employer neither acknowledged their family situation nor had an understanding about the constant persistent stress that was involved in the parent caregiver role (George et al., 2008).

Summary

The literature reflects evidence concerning experiences of parent caregivers of children with specific diagnoses and parental chronic sorrow. Antecedents, attributes, and consequences of chronic sorrow, as well as adaptation have been studied, but there was no information available regarding parental chronic sorrow in children who have different types of chronic medical condition. This interpretive phenomenological study delved deeply into the lived experiences of parent caregivers with CS of children with a variety of chronic medical conditions so that similarities among them could be identified. Proactively identifying and supporting parent caregivers at risk for chronic sorrow can help mediate the adversities experienced with development of chronic sorrow.

Research Question

What is the nature and meaning of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition?

Study Design

Philosophical Basis

The philosophical roots of phenomenology were derived from Edmund Husserl, a German philosopher. He believed that the perception of the human experience by individuals had value and could be used to understand the motivations and behaviors of those individuals (Lopez & Willis, 2004). According to Higginbottom (2004), phenomenology strives to discover an individuals' experience and what meaning they make of those experiences. Husserl's work was focused on descriptive phenomenology—describing the experience. He believed that the researcher would have to approach the descriptive experience with naïve eyes. This was so important to his philosophy of phenomenology that he recommended no literature review should be completed and researchers should bracket their experiences, excluding any foreknowledge or supposition of the group or phenomenon to be studied (McConnell, Chapman, & Francis, 2009).

Heidegger, a student of Husserl, moved this notion from simple description of the lived experience to one of a hermeneutical understanding of the lived experience. The word hermeneutics is derived from the Greek *hermeneuein*. Hermeneutics attempts to interpret that which is not easily comprehensible (Streck, 2010) and reveal the hidden meaning of the experience (Lopez & Willis, 2004). Hermeneutics is about being in the participant’s world within the milieu of relationships, customs, cultural expectations, language, and personal symbols which impact and inform their lived experience (Miles, Francis, Chapman, & Taylor, 2013). Heidegger was more interested in the relationship of the participant to the “lifeworld” than a simple description of the experience. The term lifeworld was used to describe the concept that each individual’s personal reality of being in the world is influenced by their perception of the world in which they live (Lopez & Willis, 2004). The lifeworld is considered to be the framework or accumulation of all of an individual’s experiences and their perception of those experiences. Heidegger believed that there was more in the lived experience than could be seen. The human experience is laden with meaning, and hermeneutics is the recognition and exploration of that meaning (Guignon, 2012). Hermeneutics also holds that human creation is only accessible because everyone is a part of this human experience in the shared lifeworld. Heidegger notes that humans have a sense of time and can be aware of the future and what is possible.

According to Heidegger (1962) a “relationship of being” recognizes that the day to day issues of life and experiences of a person has an impact on the person as a whole.

Heidegger proposed that the researcher is an instrument who brings value to the research being conducted into these lived experiences. He believed that to understand the experience being explored, the researcher must be involved in understanding and interpretation of the experience through language, not separated from the experience as Husserl recommended (Wilson, 2014). Context shapes understanding, and prior structure and knowledge of a phenomenon to be studied augments the interpretation of lived experiences. Heidegger called this “fore-structure or fore-conception” (McConnell et al., 2009, p. 9). Because the researcher is an instrument of the research, the interpretation of data is dependent on fore knowledge or conception of the phenomenon being studied.

This particular methodology works well for the proposed research and researcher who has foreknowledge and personal experience with chronic sorrow. Heidegger believed that understanding is always preceded by supposition. One cannot understand any phenomenon from a purely objective position; instead, one achieves understanding within the context of their own disposition and involvement in the world (Johnson, 2000). The term phenomenon is derived from the Greek verb *phainein* which means “to show itself”, that which show itself or is made visible in the light (Heidegger, 1962, p.51). This researcher has her own perception about the phenomenon of chronic sorrow based on her own lifeworld experience and *a priori*, intimate knowledge of the community and its members from both personal and professional perspectives. The intent of this study was to explore the phenomenon of CS in order to uncover the deep meaning of the lived experiences of parents caring for a child with a chronic medical condition.

Interpretive, hermeneutical phenomenology guided the methodology for answering the research question: What is the nature and meaning of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition? This method strives to achieve an in-depth understanding of the experiential meaning of chronic sorrow in parents who care for a child with a chronic medical condition. Participants offer their story, and by evaluating and re-evaluating the words used to describe their experience the researcher searches for what is not immediately evident to find the ontological perspective, or the nature of being within the phenomenon being studied. This method allows the researcher to extract those experiences and uncover the deep meaning or nature of the phenomenon to be studied which may otherwise be unknown (McConnell et al., 2009). In the study of this phenomenon, the intent was to endeavor to understand what it is like to be a parental caregiver with CS caring for a child with a chronic medical condition.

Methods

Sample and Setting

Parent participants were recruited from the outpatient specialty clinic setting at Arkansas Children's Hospital and from the Arkansas State Parent Advisory Board (PAB). The PAB is a parent lead group for families whose children have special healthcare needs. Flyers (Appendix D) were placed in the specialty clinics, including but not limited to hematology oncology, neuroscience, rheumatology, diabetes endocrinology, pulmonology asthma, and gastroenterology, and made available electronically to the leader of the PAB for distribution to parents. Clinic nurses also gave the flyers to parents and referred parents who were interested in participation. Participant recruitment was initially through convenience sampling (Etikan, Musa, & Alkassim, 2016). Snowball sampling was also used as parents who participated in the study notified other potentially eligible parents to participate.

Once contact was made with the parent, the researcher discussed the purpose of the study, the screening process and data collection procedures. If the parent expressed interest in participating, an invitation to complete the screening tool was offered. Screening eligibility occurred in person or by telephone. For participants that met diagnosis and screening eligibility criteria, discussion followed about the study to determine the interest of the parent in participation. If the candidate expressed continued interest, then arrangements were made to complete the formal consent discussion, and schedule an interview. For candidates who did not meet eligibility criteria, the researcher encouraged the parent to continue follow up care and referred them to a social worker or other support service if they requested additional resources.

Protection of Human Subjects

This research study underwent review and approval by both the Institutional Review Boards of Arkansas Children's Hospital and University of Arkansas for Medical Sciences, as well as The University of Texas at Tyler. The researcher obtained consent from each eligible parent through a careful explanation of each element of the consent document; risks and benefits were outlined. The requirements of study participation, and the voluntary nature of participation were described. The participants were informed that they could withdraw from the study at any point. Questions from participants regarding participation were answered prior to obtaining consent. Privacy was maintained by meeting with participants in a private space or location based on the specific participant needs. Participant confidentiality was facilitated through the assignment of a unique identifying code for each participant. This code links the participant to the transcripts and results of the screening tool.

In order to be eligible to participate, participants must: (a) be a parent or parent caregiver of a child who has a chronic illness as defined by the Dutch National Consensus Committee (DNCC) on Chronic Diseases and Health Conditions in Childhood, (b) be 18 years of age or older, and (c) show presence of chronic sorrow as indicated by the Adapted Burke Questionnaire (ABQ). The DNCC (Mokkink, van der Lee, Grootenhuis, Offringa, & Heymans, 2008) mandates that all four of the following criteria must be met in order for the child to have a chronic illness: (a) occurs in children birth to 18 years, (b) is based on medical knowledge and can be established based on acceptable instruments, tests, and professional standards, (c) is not yet curable and, (d) has been present for more than 3 months, or has occurred three times or more during the previous year.

Exclusion criteria included foster parents and adoptive parents. Foster parents change often and have the children for an undetermined length of time. Additionally, foster parents are monitored by the state in regards to care decisions. One of the elements of the middle range theory of chronic sorrow is that a disparity exists between the anticipated normal child and the reality of a child with a chronic condition (Eakes et al., 1998). Adoptive parents may elect to adopt a child with a known chronic condition, so the element of an anticipated normal child has been removed and a disparity does not exist as defined by middle range theory. Though these parents may experience grief, they are excluded due to the disparity event that is the onset trigger for chronic sorrow.

The ABQ instrument is a two-part tool, form A and form B, that measures parental chronic sorrow and the intensity of the most commonly reported CS mood states (Hobdell, 2004). The ABQA (Appendix B) is a grid of the eight most frequently reported mood states (grief, shock, anger, disbelief, sadness, hopelessness, fear, and guilt) that parents experience at the time when they learn of the child's diagnosis. Parents are asked to indicate the intensity of their past mood state on a 4-point Likert scale (3 = very intense, 2 = somewhat intense, 1 = not intense to 0 = absent). The tool is summed and has a range score of 0-24 with a higher score indicating increased sorrow. Only this portion of the tool was used in eligibility screening as an objective measure to demonstrate the presence of CS for this population. The Adapted Burke Questionnaire, form B (ABQB) (Appendix B) assesses chronic sorrow in parents through a set of five open-ended response questions that address the cyclical nature and intensity dimension(s) of chronic sorrow (Hobdell, 2004; Hobdell et al., 2007). The ABQB portion of the tool was not used for screening but was used for subjects who consented to participate in this study as an adjunct to the interview guide. Content validity of this tool reflected 100% agreement (Hobdell, 2004). The reliability of the instrument was determined in a pilot study of 26 parents of children with cancer, pulmonary disease, or neurologic disease with a

Cronbach's alpha of 0.72 for ABQA and 0.80 for ABQB, and in the full study, a Cronbach’s alpha of 0.90 for parents (Hobdell, 2004). Study participants for this research were eligible if they scored 16 or greater on the ABQA.

A total of 17 individuals were screened for study inclusion. Two males and three females did not meet eligibility by failing to achieve a score of 16 or greater on the ABQA Chronic Sorrow Screening tool. Of note, one of the males summarized to the researcher that he did not meet eligibility because he felt that others were in worse situations, and he knew how to cope to “move forward.” Twelve participants met eligibility criteria; all were female and biological mothers of a child or children with a chronic health condition.

Sample size was dictated by the presence of data saturation. Data saturation occurs when the researcher stops collecting data because there are no new themes revealed (Charmaz, 2006). Although there is some debate about sample size to achieve data saturation in qualitative design, smaller samples may generate rich data sets (Starks & Trinidad, 2007). A sample of 12 parents of children with a chronic medical condition participated in this study and data saturation was achieved.

Data Collection

Once a participant was deemed eligible, an interview was scheduled at a mutually-agreed upon time and location that best served the participant given the complexity and time constraints of caring for their chronically ill child. Participants chose to meet in in one of two locations, their home, or at the hospital when they were there for healthcare-associated visits. Interviews at the hospital occurred either on the unit where the child was receiving care or in a private office environment. Once consent was obtained, a demographic form was completed. Demographic data (Appendix F) included gender, age, occupation and education of participant, makeup of nuclear family, grandparent(s) or other extended family living in the home, household income, and family ethnicity and race. The interview began after demographic data collection was completed and started with an open-ended question: Tell me what your life has been like since your child was diagnosed with X? The intent of this open-ended question was to allow the parent to give a free-flowing narrative of their experiences which prompted further probing by the researcher.

The researcher is considered a key instrument in phenomenological studies (Johnson, 2000). Knowledge of the literature and the personal experiences of the researcher contribute to the research by determining areas of needed study and make the research a meaningful endeavor (LaVasseur, 2003; Lopez & Willis, 2004). Field notes were maintained for purposes of data contextualization (Polit & Beck, 2017). For this study, the researcher used a reflexive journal in addition to field notes. The journal assisted the researcher in applying the principle of reflexivity to the proposed study by considering feelings and attitudes regarding the interview and the participants interviewed (Lopez & Willis, 2004). According to Heidegger (1962), the dimension of what is closely experienced may become a reflection and, therefore, a theme for reflection of the experience itself as well as a task for the calculation and measurement of the experience. The reflexive journal facilitated the researcher’s ability to take into account personal perceptions and awareness about the experience being studied (Van den

Hoonaard, 2002). The journal was an inward and outward reflection about the research, the participant, and the researcher. This tool allowed the researcher to express a growing understanding of the phenomenon being studied and guided the researcher in the interview process and validation of a subjects' perspective, data analysis, and researcher interpretation (Ortlipp, 2008). Journaling was particularly important given this researcher's *a priori* knowledge of the phenomenon of CS, through her own experience as a parent of a chronically ill child.

Data Management and Analysis

The goal of data analysis was to determine commonalities among the participants based on their unique individual experiences. The audio recordings of the interviews were transcribed by a professional transcriptionist who acknowledged the critical importance of confidentiality. The first transcriptionist was identified as a possible candidate but chose not to participate. After choosing not to participate, she transcribed the first five transcripts but was unable to complete additional transcripts due to the emotional pain caused by the transcription process and the deep empathy she felt for the interviewed parents. The remaining seven transcripts were completed by a second transcriptionist. The transcribed interviews were analyzed in conjunction with investigator field notes and the reflexive journal. The researcher began the analysis of data through reading, reflective writing, and interpretation (Kafle, 2011). The hermeneutical circle illustrates the researcher's understanding and interpretation by regarding interpretation as the movement from the data (part) integration to the understanding of the phenomenon of study (whole) contextualization (Ajjawi & Higgs, 2007). Aijawi and Higgs (2007) identified six stages of data analysis in hermeneutical research: (a) immersion-organize data into text, iterative reading, preliminary interpretation to facilitate coding; (b) understanding-identifying first order constructs (participant); (c) abstraction-identifying second order constructs (researcher), grouping these constructs into sub-themes; (d) synthesis and theme development; (e) illumination and illustration of phenomena-linking themes to literature and reconstructing interpretations into stories, and (f) integration and critique. Upon review of the complete transcript, the researcher made notes on the hard copy document defining the experience and perception of the experience by the researcher, highlighting the document for common participant experiences and common threads of information. This process was completed for each transcript. Once this was completed, the researcher organized the data into a spreadsheet of categories for each participant transcript. During each iteration of this process, the researcher reconsidered the data organization to ensure data had been assigned to the correct category to ensure data consistency. Finally, after this extensive and exhaustive review, the researcher sought to create brevity by crafting summary statements for each category.

Demographic data was analyzed using descriptive statistics, including mean age, education, income, and other quantitative data. The ABQA screening tool was sum scored with a data range score of 0-24. Higher scores indicate greater intensity of sorrow. For study inclusion, a score of 16 or greater, was necessary. The ABQA results of intensity of CS results were also examined.

Results

Methodical and thorough review and analysis of the participant transcripts for this study revealed six themes that included surreality of diagnosis, unrealistic expectations, the battle, keeping it together, and doing whatever it takes. There was also a change in life perspective that occurred as a result of the overall experience of caring for a chronically ill child. These changes in perspective could be described as serendipities for the participants; finding positive consequence in trying circumstances. An overarching truth shared by all participants was the realization that life goes on, regardless of what is happening for the child, parent caregiver, or family.

Of the 12 participants, all were female, one was Asian-American, one described herself as bi-racial (White and Native American), and the others were White, non-Hispanic. All were married with the exception of one divorced, single parent, and their ABQA scores ranged from 16 to 24 (Demographic Table, Appendix G). There was a mix of diagnoses for their children including juvenile rheumatoid arthritis, epilepsy and microcephaly secondary to chromosomal deletion, a rare liver disease known as Budd-Chiari, acute lymphocytic leukemia, prematurity of birth, hypoplastic left heart, Turner syndrome, pervasive developmental disorder, IgM nephropathy resulting in end stage renal disease, and 3 children with autistic spectrum disorder.

Surreality of Diagnosis

Participants described how surreal it was to learn of their child’s diagnosis. Some parents were aware that something was wrong but were not given a diagnosis for months or even years. Whether they learned their child’s diagnosis either immediately or after many years of struggling to understand their child’s healthcare challenges, parents described various feelings. Being unprepared, being at a loss, feeling the diagnosis to be unreal, feeling shocked and stunned, and sensing a loss of hope for their child were among the feelings described. The sudden knowledge of their child’s diagnosis created a gap in the parent’s understanding of their own reality. Individuals have the ability to sense time in their reality, can see themselves in the context of a future reality, and can plan for that future life (Heidegger, 1962). However, when the future is unseen due to an unimagined or surreal event, that anticipated or planned future becomes unknown and unknowable. One parent described that having learned of her son’s diagnosis, “I felt kinda like the big bucket of cold water poured over your head.” Another mother said, “We were in shock....over finding all of this out. You know, I kept saying, we just went in for a stomach problem.” Even parents that were relieved to have a diagnosis after months or years of searching for answers were shocked: “the wave didn’t hit me until I started getting online and researching and you know, you can just find out some terrible, horrible things.” With this surreal experience, parents were faced with a new reality then and for the future.

Unrealistic Expectations

Parent caregivers seemed to function in daily life in accordance to how life was pre-diagnosis rather than from a new perspective informed by the knowledge of their child’s diagnosis. It takes time for the parent caregiver and family to find balance in a new reality, and sometimes balance is not achieved due continued disturbance of the family system by new challenges. Parent caregivers were trapped with the full burden of care and knowledge of their child’s needs and their personal struggles to adapt. Because their lives were functioning under the pre-diagnosis reality, they struggled with accepting others’ offers of help with their new responsibilities. Participants described the experience of guilt about their child’s chronic condition while also feeling resentment about their child’s needs and the difficulty of managing their new reality alone. Parents were asking big life questions about this new reality, “why me?” and “why my child?” Many parents attempted to find purpose in their new reality. One mom described it this way:

> Why should any kid have to put up with this? On a lot of levels, I knew we were extremely fortunate because I have friends whose kids have systemic [disease] and that’s truly an evil disease. We got off light in some ways, but you know everyone has their own row to hoe. This is ours.

Parent caregivers who had other children talked about the demands on themselves and the family to give equal attention to all of their children and their needs. A chronically ill child has increased needs that demand more time, more engagement, and more energy by the parent caregiver. One mother described her other child “being tossed” from family member to family member, so that she could be with her chronically ill child in the hospital and during weekly treatments. In some families, the healthcare demands of the chronically ill child served as the catalyst for sibling rivalry. This was manifested by the “well” child desiring the same level of attention and wishing for a chronic condition, like their sibling. Another parent reported that her child with a chronic condition described himself as the “bad guy” while he described the other sibling as the “good guy.” In another family, there was blatant jealousy and anger. Most of the chronically ill children had some occasional behavioral challenges, like any child. Mothers were challenged to learn how to discriminate between behaviors that were associated with the chronic condition versus attention-seeking behaviors that were inappropriate in both their “well” and chronically ill child. Attention seeking and jealous behavior in both the child with a chronic condition and siblings became an area of conflict. One mother said about her relationships with her other children, “It’s hard to say without feeling guilty. Because sometimes I feel like [chronic care] takes from them. I end up not resenting him, but resenting the issues with him, because I feel like it’s taken from the other children’s time.”

Hopelessness was described by participants. Loss of hope occurs when one cannot see the future or even the path to the future because of the multiple and overwhelming burdens they carry. The multiple challenges experienced in caring for a chronically ill child resulted in expanded roles for the mothers. They experienced physical and mental exhaustion due to around-the-clock care demands and the struggles of dealing with the disease and its sequalae. One mother discussed the division between her and her husband and his unwillingness to engage in the care of their child. The mother was working a full-time job and then returned home to prepare a meal, and care for her child throughout the night with no support from her spouse. This care and schedule demand became such an overwhelming challenge that the marriage did not survive. This mother is now parenting alone and terminated the rights of the father. Another parent described their experience as having “no light at the end of the tunnel.” This analogy of being in the dark is the loss of hope and a future that is obscured from view. This burden and responsibility is so great that another mother said “I can’t lie down and die, who else will do this?”

Their experiences impacted not only their family life but their life outside of family within their social framework of friends, relatives, and personal interactions. All of these women had career aspirations of some sort, but most of them had to give up jobs and career goals due to the demands of caring for their chronically ill child. Several of the mothers were highly educated individuals who gave up their professional careers to be a full-time parent caregiver. Only a few of these women continued in their careers and those who did talked about the importance of their employer’s understanding and flexibility regarding the needs of their child and the demands on them as an employee.

The mothers discussed their social isolation. Losing a social connection with work and career created the first piece of social isolation. This detachment is followed by the loss of income that comes with loss of job, limiting the family’s financial resources. A limitation of resources cuts out most of the social play that is a part of rearing children and typical family socialization. Additionally, those involved in churches or other spiritual, emotional, or social support are lost typically because the child is too complex to be cared for by someone other than the parent, adding even more social isolation. Mothers reported that while friends and family attempted to engage them in events, these groups lacked the understanding of the child’s condition and often judged the parent on how they cared for, managed, and disciplined their child. This predicament served to further isolate parent caregivers. Sometimes this isolation is driven by societal structure and sometimes by the parent who is too exhausted to tolerate judgment or explain decisions to individuals that cannot begin to understand their reality. Other times, the care of their child is so demanding that they are unable to continue with normal social interactions, "… It felt like every time I made a plan, it would not happen… I would think … we're going to do this really great thing (but)…We'd end up in the hospital getting care."

The mothers discussed the loss of a "normal" life. Loss of normality created anger and envy in many of these parents for what life could have been. "When she was little it would upset me. My niece…was doing all this stuff that she couldn't do. …she is already crawling and my daughter can't do that." Observing other parents with their normal child brought into clear perspective that their children were not "normal."

The Battle

Controversies regarding family roles, whose career gets priority, and who takes responsibility for the child with the chronic condition reflect participant experiences of battling daily life. Participants compared their life with others in that "normal" families experience episodic crises, whereas these mothers reported daily occurrences: "It just seems like there is something crazy happening on a daily basis, if not several times a week … [it] is just that constant anxiety level that I stay at to be ready for stuff that happens."

Battling a healthcare system that lacks understanding of parental expertise, parental desires for their child's well-being, and the parent's endless pursuit for knowledge was discussed by all participants. Parents needed to know more about their child's diagnosis as well as what care should be and could be done for their child.

Cultural expectations and the differences in those expectations within culturally homogenous and heterogeneous families resulted in family conflicts. These cultural expectations informed the roles for the mothers and how they managed their chronically ill children and any other children. In addition, the complexity that comes with a blended family and the issues associated with step-parenting (see demographic table on makeup of families, Appendix G) contributed to family strife.

Some of this strife is likely due to the burden of care, the heaviness of that care, and physical exhaustion experienced by being the 24-hour caregiver and decision maker for the child's healthcare. It comes from the expected role of the mother caregiver. The fathers in these families were the primary or only wage earner. With the opportunity to leave the home, they had colleagues and friends to engage about their struggles. They were not as closely connected to their chronically ill child since the mother was the chief manager of the healthcare visits, healthcare plans, implementation of care at home, and overall nurturing for the entire family system. This balance deserves additional research specifically to examine the differences in roles and coping based on the given or assumed parent role.

Sometimes mother caregivers battled with spouse, family, and God regarding decision making for what is best for their child's health care, considering what is the best plan, what is the best treatment, what is the best therapy, and what is best for the family as a whole. This battle also circled back to those larger life questions—why me, why my child? This painful new reality caused them to question God, and in some, blame God for allowing this to happen to their child, to themselves, and to their families. One mother described the vastly different perspective she and her husband had on how to manage their child's chronic health condition. This was a culturally homogenous family, both parents highly educated professionals, yet the gap between mother's desires and father's desires was enormous. This mother was prepared to do anything in hopes that it would help her child

> …from the start… I've just been so desperate to try and fix my son…and anyone who is out there with their snake oil and story promising a cure, we have been out there throwing down money at it. My feelings are, if it might help and it won't hurt…

Her husband had a firmer grasp on what was possible and what treatment was available. He understood her desperation to heal their child, but he had clear perspective and knew what actual care was and what might not be genuine. This dichotomy of purpose created a battle within this family with the mother willing to spend their last dime on desperate hope and the father pushing back to ensure the family's economic stability.

During some of the most intense experiences for themselves and their child these mothers experienced the "presence of God in the storm." One mother tells a story of when her child's physician had proposed a specific treatment, and she told him she needed to pray about the decision for the proposed treatment plan. "…God, show me a sign. If summer is the right time to do this [procedure], give me a sign...that night we were under a tornado watch...we had no power and were hearing the wind and sirens." When this parent emerged from her home there was devastation all around but they were unharmed by the storm. Mother was convinced that this was a sign that God would be present in the storm of care as He was in the actual storm. She contacted the doctor and shared her confidence in the “sign” and scheduled the procedure which she believes “quite [possibly] saved her child’s life.”

Keeping It Together

Building unity within the family and the parent’s life reflected the theme of keeping it together. **“**It wasn’t the head piece, it was the heart piece. It was a sort of the dissociating from my emotions …staying, focused on the information. I’m not ready to feel it… that’s not going to help… I need to keep it together”, a mother said reflecting on learning the diagnosis and struggling to keep it together. In spite of this ongoing battle, couples were able to come together and agree on priorities: sleep versus physical intimacy, how to manage money, quiet time with family versus attending an organized church worship. While the majority of these families professed a religious belief system, they often used the typical worship day as a time for family. This time was used as an opportunity for recovery from the demands of the week. All of the mothers expressed some type of mechanism that assisted them in day to day coping, including faith in a higher power that is in command of the situation, as well as the value of prayer and meditation. Many of these mothers journaled in some manner. Some journaled in a physical book that they referenced during their interview, while others used their Facebook page as a daily journal. Many of these families participated in an organized parent support group, or found similar diagnosis resources through online parent blogs and support. They used these groups to help them to cope with the unexpected and also to give encouragement and suggestions to help them overcome a particular challenge.

All discussed the help they needed and how hard it was to accept help. One mother tells a story of their friends and family raising several thousand dollars to help them with the expenses of their chronically ill child. Rather than accepting the gift, they gave this money to a research foundation associated with their child's condition. This mom says several months later when the financial burden was truly realized she wished she could get that money back. Overtime, she along with the other mothers learned to accept help gracefully. These parents reported help from a variety of groups: help from work companions who supported the parent emotionally or through fundraising efforts to defray financial hardship, family members coming in and doing laundry and household chores, and churches and support groups that provided prayer, encouragement, and as one mom described a "food train" during a very difficult and demanding time.

Couples who survived the stress of a chronically ill child sought marital counseling, and even some step-parents sought counseling with their wives to come to common ground on expectations for the family and for the child with chronic healthcare needs. This assisted with building trust between the parents, which laid the foundation for keeping it together as a family.

Doing Whatever It Takes

Participants were willing to do whatever was required to meet the needs of their chronically ill child. They often put their parenting role aside and gave priority to the role of advocate for their child. Regardless of the stress these families were facing, that reality came crashing in and they realized that life continues on. One mother shared her experience with this when she had to leave the side of her chronically ill child, "I had to drive home… And I had to leave my son. I had to walk away from what was important to go do stupid stuff like bills. Although they are important, at that time they weren't. It was just an aggravation, I wanted everyone to stop, let us catch up." Another mother said about the daily grind of caring for herself, her family, and her child, "I don't want to do this, and I have to, and just do it, just do it. It felt like that over and over."

Participants advocated for treatment needed, for a clear and transparent plan of care; they demanded answers; and they pushed for what they believed was best for their child. These parents advocated for specific needs for their children outside of the typical care plan. They pushed for needed therapy services, and put schools on notice about denial of needed services. One mother involved the local paper and media by identifying a school district that was not willing to work on the needs of her child or set individualized education goals. She described this experience as a fight; "it is absolutely against the law to treat people with disabilities differently. We called the TV station…, and there was somebody there, and they changed [the school's] mind." When asked about winning the battle, the mother said, "I made a difference, and almost…saved him from a train-wreck; that is kind of my word." These parents were advocates for their child based on their knowledge of their child's diagnosis, educating teachers, healthcare providers, friends, and buffering these children from fathers and extended family that did not understand the diagnosis and associated challenges. All participants talked about being in the survival or fight mode. One mother shared that when she saw her father shortly after her son's chronic diagnosis; that he examined her state of mind and questioned her about why she wasn’t grieving, to which she responded, “Dad, I did all my crying last night, now it’s fight mode.”

These parents had to shift from their parental role to caregiver/advocate role. Many of them spoke of insensitive healthcare providers and the lack of understanding of what these parents were going through. Of many stories shared, one in particular is very powerful. A mother recalled a dramatic plane trip to another state for emergency care of her child. This mother had been up with her very sick child for over 20 hours without rest or food. Upon arrival to the airport out of state, the child and mother was move to an ambulance for transport to the hospital. “I’m in the back of an ambulance, and I’ve been awake this whole time… it’s probably one or two in the afternoon, and I haven’t eaten since 4:30 or 5:00 the evening before. I haven’t slept; I feel completely out of it. I look at one of the paramedics back there with me and I said, I might throw up. And the paramedic said, “she is not going to live, let’s see you live that down if you’re back here and you throw up.” This mother is a true expression of *doing whatever it takes*. She sacrificed her personal well-being to ensure she was with her daughter during a time of crisis.

One mother described that her husband and she totally disengage in the reality of their child’s condition by planning an escape every 4-8 weeks. Sometimes the escape is only a weekend respite in a hotel in town while their child receives care at home. This allowed them to recover, rest, and prepare for the next battle. This is a luxury few parents have available to them. Additionally, respite care is very difficult to find, and few of these families had someone that could provide the same level of care as the primary mother caregiver.

These mothers are also battling with their own needs. One mother described that doing things to rest or restore herself was, “a waste of time.” She described that very little is gained, and whatever may be gained is quickly lost due to mounting demands that are not completed during that period of restoration. This is worrisome from a health promotion standpoint given the burden of care, and the known risks of depression for these caregivers. The reality is that if a mother (parent caregiver) becomes ill, not only will the family struggle even more, but the child with the chronic condition could have serious exacerbations when others in the family do not understand or know how to provide care and treatment in the home.

Healthcare providers should recognize the importance of the parent/advocate role as the absolute resource expert on their child. Parents were willing to do whatever they believed was right regardless of real or perceived barriers. They were able to stand toe to toe with physicians, nurses, and family in respectful disagreement and debate. They were ready for the battle and willing to push back to whomever might interfere with what they believed was best for their child. All this advocacy and determination was the shift from grief acceptance to the fight. To accomplish this shift to fight mode, parents had to reframe their experience and consider the perspective of their actual reality. They all came to the awareness of the new normal, but each parent had to approach this adaptation in their own time, and in their own way. Participants then strove to assist the family adaptation to the new normal, and this cycle continued with each complicating event.

While they worked to adapt to their new reality and assist the family to adapt; they exerted control wherever possible. Their need to control helped them to organize their life so that managing the adaptation necessary for this new reality could be achieved.

Serendipities

Parent caregivers spoke of unanticipated serendipities, finding something valuable that they were not expecting by way of these experiences. They all spoke of empathy for others and the importance of being kind and patient with others because no one really knows what they may be going through in their life. Even though all had children with a chronic condition, these parents compared their circumstance to others and how terrible it could have been. These parents referred to having a child with a diagnosis different than their own. One mom with a totally dependent teenage child said, "I have learned a lot about people…parents who deal with mental and behavioral issues and to me that is a lot harder. Those [parents] are rock stars. That is their world, and to them that is normal, and to me my child is my normal, and someone else has a normal. I'm lucky, and I'm happy I have my kid." Another mother whose child had cancer said, "My child will be cured of his disease, but a child with autism… that would be terrible." These are parent adaptations working to reframe their perspective and cope with the diagnosis of their own child.

Although there were typical sibling rivalries, many parents spoke of siblings who not only helped the parent to care for the chronically ill child, but also created a unique bond with their chronically ill sibling. One mother shared that her son has major socialization issues and struggles to express himself, but when his older sister is around, he is an entirely different child. Although they have tried to interact with him similarly, her presence creates a unique interplay within the family. Another mother described her adult children who chose careers in healthcare because of their experiences with their chronically ill brother. She said, “[The siblings] were old enough to understand and be a little more tolerant than if they were younger…they are different people than they would have been. Absolutely.” Another mother described, in depth, the burden she placed on her oldest daughter who assisted her with care of the chronically ill child or supported other children in the home, while she too was also just a child. The participant spoke of her respect and dependence on her daughter, and how although it may not be an ideal situation, her daughter knows no difference. “As a child, she is learning so much about life.” Another parent described the oldest college age child who provided interim care and support for the youngest child while mom had to travel out of state for specialized care with the chronically ill middle child. She observed that this has created a unique relationship between these two siblings, forged by their shared experiences with the chronically ill sister.

The stress of caring for a chronically ill child was often overwhelming for these parents, and they expressed their need to be close to their support group, their church, and their family. However, one mother describes how she found peace in an unexpected place. Due to the complexity of her child’s disease, this family had to leave their community to receive care for their child. This parent caregiver was balancing her job, her family, and her extended family; as well as the needs of her chronically ill child. With so much to manage, she realized that when they had to travel for care that she received a respite from all burdens except the care of her sick child. It gave her time for bonding with her chronically ill child during an intense treatment regimen. This mother described coloring together, reading books, talking, playing games, and the value of this uninterrupted time with her child—in spite of the fact that all of her support resources were in her home community. This mother saw this as a chance to escape the stress of family, job, and social expectations. She took what could be perceived as a negative experience during this time and turned it into a positive by using the time with her child to connect.

All of the participants expressed some spiritual component during these interviews. They spoke of their faith, their certainty that God was in control, and the purpose in their experiences. While all these parent caregivers expressed that there was no measurable change in their faith, no increase or decrease in intensity, they shared that there was a maturing in their spiritual life. One mother described "it's a more grown up tangible faith now."

Truth: Life goes on

The overarching truth for all of the participants was that life goes on. Regardless of the round the clock care, and the demands of having a chronically ill child; time did not stop. These mothers had to meet the typical demands of life, managing their household budget, caring for the entire family, managing relationships, and in some cases jobs. The cycle of chronic sorrow continued, but so too did the cycle of life and its daily grind. There is no way to stop the ebb and flow of life, as one poet said "Time and tide waits for no man." (Chaucer, 1395).

Discussion

The phenomenon of chronic sorrow is about the living loss (Roos, 2002). This loss experience is based upon the state of mind of the individual and how that experience is interpreted. Each individual has their own unique experience of loss and chronic sorrow based upon their own worldview. The description these mothers provided about the loss of the dream of having a normal child is consistent with the work of Eakes et al. (1998) regarding the presence of disparity. These parent caregivers shared how they came to an understanding of their child's unique needs and how they, as parents and members of families, incorporated this new norm into the family. According to hermeneutical phenomenology, when considering the point of view of real existence, it can be described as the understanding of something, being able to manage it, or being competent to do something about it (Heidegger, 1962). Northington (2000), in her work to understand chronic sorrow in parents of children with sickle cell disease, refers to complexity theory in the work of adapting to the new norm. She refers to systems (such as the family system) that function in a steady state until a clash occurs and chaos or disorganization ensues. Although the system in chaos appears to be without organization, it will seek to find new patterns based on past lessons learned. These patterns serve to bring the system back into balance, creating the new norm. Gravelle (1997) discussed this adaptation in her work of describing the illness trajectory and the aspects of defining and managing adversity. As in Gravelle's work, each time a new challenge occurred they had that defining and managing re-normalization process to experience before moving forward into the new norm.

Similar to findings in this study that mothers wanted to be more knowledgeable and participate in treatment option decision making, other studies have found that parents recognize the expertise of their child's healthcare professionals and they want to be acknowledged for their own expertise in management of their child's needs and contribute to the conversation about care decisions (Boling, 2005; Miller & Nelson, 2012; Scornaienchi, 2003). According to Førde and Linja (2015), parents' inclusion in discussions about their child's care increased the parent's confidence in healthcare. Parents reported that providers were too pessimistic, and providers' descriptions of their child was biased and incomplete. Other research determined that parents of pediatric patients with chronic conditions believed their child's doctor developed strategies for avoiding parent questions regarding the child's disease and care. This perception can be compounded by providers' use of medical jargon with parents, and demands on providers' time to adequately participate in conversations with parents about their chronically ill child (Konstantynowicz, Marcinowicz, Abramowicz, & Abramowicz, 2016).

All mothers interviewed experienced some form of guilt: guilt about feelings of resentment about their child's condition, guilt regarding time lost with their other children in care of their chronically ill child, and guilt that they somehow contributed to the reality of not having a "normal" child. According to Heidegger (1962), reality or call of conscience may produce feelings of guilt which is a unique, individual experience. Guilt as an existential structure is not to be assumed as a psychological feeling that one gets when one breaks some moral or ethical code. According to Heidegger, it must be *a* *priori* for there to be a moral code. While this emotional experience is ongoing, the parent caregiver is attempting to proceed with life for themselves, their family, and their child. They described a sense of drowning and hopelessness, the social isolation of sole caregiving and decision making, dealing with sibling jealousy, and managing the economics of their situation. The parents had unreal, maybe unachievable expectations for themselves as a parent and caregiver as well as the other myriad roles to which they are responsible. They lacked the resources needed to help them manage their children and all the demands and decision-making required to care for their child with a chronic condition.

In a study on quality of life (QOL) in families and children with chronic conditions, Sikorova and Buzgova (2016) determined QOL for parents and children are closely related. The individual, distinct perceptions of parent caregivers and chronically ill children inform the way in which they cope together and individually with the burden of the chronic disease (Sikorova & Buzgova, 2016). The authors propose that interventions should be based on family-centered care and focused on psychosocial health promotion for child and family.

Because of their muddled perspective of reality (previous reality and new reality), participants described experiencing challenges regarding family and social expectations and how they should or should not conduct themselves. In Western cultures, the assumption is that mothers have primary responsibility for the care and rearing of children. Women manage multiple roles including parent, spouse, caregiver, and employee; however, these mothers fail to acknowledge the importance of their own physical and emotional well-being and its impact on family health and well-being (Wyn & Ojeda, 2003). The responsibility of motherhood is magnified with the addition of a child with a chronic condition. Often fathers are engaged in outside work and their career, and the mothers realize the typical role of primary decision-maker and caregiver in the healthcare of their chronically ill child.

Implications for Practice, Research, and Education

Implications for Practice

Children with chronic conditions are regularly seen by their health practitioner for follow-up care and management of their condition. This practice allows nurses who are coordinating their care the opportunity to engage in family-centered care while guiding families through the healthcare experience, treatment, and care management and assisting with adaptation and coping. Since many of these families become single wage earning families0, they may need access to social services resources. Assistance is needed in managing the demands of care, such as special transportation, access to therapy services, school accommodations, and access to financial healthcare resources such as state agencies that support children with special healthcare needs.

Healthcare professionals of all disciplines must include the expertise of the family and primary parent caregiver in the management of a child with a chronic condition. While healthcare professionals have the technical knowledge and expertise, the parent is the expert on the unique character of the family unit and understands the subtle nuances of their child better than anyone else. These professionals must be challenged to truly listen to the intent that is being communicated by the family, not just the words. They must learn skilled communication with difficult issues and assist the family as a guide while they make the decisions that are correct for their child’s care.

When a child is diagnosed with a chronic condition, nurses do not conduct an assessment to determine if the parent has chronic sorrow or if the parent is at risk for chronic sorrow. It is incumbent upon the nurse to perform an assessment and follow through with appropriate family-centered interventions before parent crises occur. The Family Management Measure tool (Knafl, Deatrick, Gallo, Dixon, & Grey, 2013) can be used to assess the family’s ability to adapt and achieve a new norm. In this small group of participants studied, life for these families is different after diagnosis of a chronic condition. Participants work to reframe their perspective of reality which is now filled with uncertainty for the future due to their child’s condition and changes in social roles and expectations. This FaMM tool allows nurses to assess families and determine those parents whose management style would interfere with their successful adaptation and intervene with “supportive psychosocial care that matches their psychosocial profile” (Deatrick, Thibodeaux, Mooney, Schmus, Pollack, & Davey, 2006, p. 26).

Implications for Research

Further research is needed to determine cultural factors that may influence coping in these families. The U.S. continues to expand in breadth of social cultural variation. Understanding these cultures and their beliefs and expectations around chronic disease may enhance healthcare delivery for these populations. With the continued growth of Spanish-speaking populations, it is important to include Spanish-speaking families in future research efforts (Krogstad & Lopez, 2015).

Much of the research in chronic sorrow in parents has been with mothers due to the typical role of primary parent rearing children. Though this study did not intentionally recruit just mothers, no fathers were eligible to participate. Questions regarding whether or not coping is different between fathers and mothers, the father's perceptions regarding roles in families who have a chronically ill child, the impact of chronic sorrow on a child with the chronic condition, how children with a chronic illness adapt and cope, how coping relates to parent/family coping and adaptation, and the impact the family experience has on siblings without chronic illnesses are still to be answered. Qualitative research should be expanded to include a larger group with mixed diagnoses, to further explore how the issue for these families is the chronic nature of a disease, rather than the specific disease or condition.

The profession of nursing should develop a comprehensive assessment tool to determine those who may be at risk for chronic sorrow. When a diagnosis of chronic condition is made, this assessment can be completed to determine risk and develop family-centered interventions to help families adapt to the new norm and manage daily life with the added responsibility of a caring for a chronically ill child.

Implications for Education

Although a nursing diagnosis of chronic sorrow exists, few nurses either know or understand this concept. With the continued rapid growth of healthcare technology, healthcare professionals can anticipate more individuals who are at risk for chronic sorrow. Chronic conditions today are more prevalent with technology and advances in healthcare. Students of nursing and other health care professions must be educated about this phenomenon as a fundamental concept in navigating the experiences of a chronic condition throughout a lifespan. This education should be included in curricula for all health professionals. Discussion of chronic sorrow and how it typically occurs must be included along with approaches to assist with adaptation and coping strategies that help manage the stressors and demands of caring. Additionally, hospitals should provide orientation to nurses in critical and long term care units on this phenomenon and how to begin conversations of hope and encouragement upon diagnosis and development of family centered interventions.

Strengths and Limitations

Strengths

Qualitative rigor is expressed in the elements of trustworthiness, a) credibility or truth value, b) applicability or transferability, c) consistency or dependability, and d) neutrality or confirmability (Thomas & Magilvy, 2011). Qualitative research creditability is focused more on the procedural pathway rather than the outcomes. Understanding this pathway may allow the researcher to develop tools to influence the outcome of individuals on the path being studied. Credibility allows others to understand the participant experience, and can be immediately recognized by those who share the experience. Although this study may not have direct transferability, thick descriptions were used in the population studied and this same method could be used in other populations of different language or cultural experience, establishing transferability. Dependability is found through the clearly stated purpose and population studied and how the data were collected, reduced through multiple step-wise iterations, and analyzed for findings. While the qualitative researcher may have a distinct perspective, the degree to which the research outcomes can be validated by other people is confirmability. To achieve confirmability the data analyzed were checked and rechecked under each iteration of its review and synthesis. Credibility is established when transferability, dependability, and confirmability are achieved (Thomas & Magilvy, 2011). Because qualitative research is more interested in the pathway this method permits for objectivity by allowing the subjects to drive the conversation through semi-structured interview that are conversational in style, flexible and guided by the participant being interviewed. The participants were interviewed in the environment of their choice, often their own home. The use of open-ended interviewing, audio recording and verbatim transcription increased data accuracy (MacLean, Meyer, & Estable, 2009; Starks & Brown-Trinidad, 2007). A subject file was maintained to include information such as location of the interview, individuals present with the subject, time of day, and unsolicited details the subject may have shared before the interview began.

The intent of this research was to understand the experiences and perceptions of chronic sorrow in these subjects. The researcher worked intently to produce credible results through a rigorous research process maintaining consistency with the Heideggerian phenomenological method, immersion within the population, creation of robust data through authentic conversational relationships with the participants, and systematic data collection and analysis (Lincoln & Guba, 2000). According to Armour, Rivaux, and Bell (2009), *a priori* knowledge may be used to enhance awareness of the researcher in the participant’s life world and could enhance rigor by understanding the phenomenon being studied and how to probe further into the lived experience. While the lifeworld is not the same for everyone, awareness can help to better understand the meaning of what participants are saying and therefore nature of their experience. Armour, Rivaux, and Bell (2009) recommend that the researcher assess the methodology to determine if it will facilitate answering the research questions, attempt to reduce power inequities, assess researcher for potential bias, provide a setting and personal interaction that is conducive to authentic conversations, and consider contextualization of the findings. In an effort to delve deeply into the lived experiences of these parents, the researcher used multiple resources to create thick descriptions of these experiences. The researcher immersed herself in multiple data sources audio recordings, verbatim transcripts, field notes regarding body language and non-verbal cues, as well as reflexive journal. Reflexive journals attempt to maintain research objectivity and confirmable findings (Barusch, Gringeri, & George, 2011; Nakkeeran & Zodpey, 2012).

The researcher becomes the primary instrument of data collection and analysis through an immersion experience. The words used by these subjects were carefully considered in an effort to understand what the nature of their experiences meant to the participants, and what was being said beyond just the words. Familiarity of the phenomenon of CS, is an experience shared by the researcher through her own experiences with one of her children and her husband. This researcher followed a rigorous methodological process and an audit trail was conducted by a Ph.D. prepared qualitative researcher. Consensus was reached regarding data analysis and conclusions.

Limitations

The size of this cohort was small creating limitations on the transferability of the results. The interview was limited to 60-90 minutes in an effort to respect the time of the subjects and to not invade further upon their personal life. The interview could have easily continued beyond that time frame. The study may have benefitted from a two-part interview to allow the participants to reflect on the first part of the interview. This reflection may have revealed additional important aspects of the parent experience. The researcher could have opened the research to individuals that scored 14 on the Adapted Burke Questionnaire, which would have included several more subjects in this study. Although the researcher endeavored to remain objective, due to her own personal experiences with chronic sorrow, she may have created unintentional bias based on her *a priori* knowledge.

The experience of chronic sorrow may also be influenced by a number of other variables, number of children within the family with a chronic medical condition, economic or financial resources of the family, health insurance, access to community resources, makeup of the nuclear family, religious or spiritual belief systems, cultural norms and expectations, and difference in perceived and socially-accepted gender specific roles. Individual coping styles and personalities may also influence one's ability to cope with the challenges of caring for a chronically ill child. What may be managed well by one parent may be overwhelming and unachievable to another. More study is needed to understand the impact these variables may have on the possible presence of chronic sorrow and its intensity.

Summary

The study was an interpretive phenomenological study that focused on the nature and meaning of chronic sorrow in parents who had a chronically ill child. Twelve mothers were interviewed using in-depth, probing, and exploratory techniques. Six themes emerged that represented chronic sorrow for the participants. The umbrella category that unifies these six themes together is that *life goes on*. Despite multiple challenges and overwhelming burdens, the mothers were able to move beyond the struggles of caring for their chronically ill children and progress into adaptation to the new norm and even gain optimism about their future.

The study met major criteria for credibility and rigor. The major implications for practice include screening for chronic sorrow at the time of diagnosis of a chronic condition and implementation of patient/family-centered interventions that will assist in adaption. Research implications include inclusion of fathers and children in chronic sorrow related studies, and development of an assessment tool to screen for parents at risk of CS. Implications for education include chronic sorrow-related content in courses for all healthcare professionals.

The difficulties parents face with the life journey of caring for a chronically ill child extends well beyond the disease itself. The impact on their personal, spiritual, and social health could have lifelong impact on the caregiver, child, and family. The majority of healthcare professionals are oblivious to the lifelong burden of chronic sorrow; however, nurses have the opportunity to implement adaptation and coping strategies through early assessment and implementation of holistic family-centered care.

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Chapter 4

Summary and Conclusions

A systematic review of the literature revealed scientific gaps that carry implications for practice, research, and education. Further knowledge is essential for nursing professionals to adequately prepare and provide interventions for parent caregivers of chronically ill children. Much of the literature addresses the stresses and demands of parenting and caregiving for a child with a chronic condition, but does not attend specifically to the child, parent caregiver, and family with chronic sorrow (CS). This qualitative study focused on the nature and meaning of parent-lived experiences with the emotion of CS, who care for a child with a chronic condition.

Using an interpretive phenomenological approach allowed the researcher to explore the lived experience of CS with individual parent caregivers who had children with a chronic condition. The researcher had knowledge of this phenomenon allowing for in-depth interview and probing questions. Participants were 12 biologic mothers of children with 11 distinctly different chronic conditions who shared their experiences and challenges of chronic sorrow and caring for their child. After comprehensive analysis of data from individual participant interviews, six themes emerged: surreality of diagnosis, unrealistic expectations, the battle, keeping it together, doing whatever it takes, and a positive reflection of serendipity. These themes were connected by an overarching truth that life goes on.

The researcher recruited participants by posting a recruitment flyer (see Appendix D) at Arkansas Children’s Hospital outpatient pediatric specialty clinics, by providing an electronic copy of the flyer for distribution to membership of the Arkansas State Parent Advisory Board, and through snowball-sampling techniques once a few participants were identified. Those who expressed an interest in participation received eligibility screening for inclusion, and 12 participants met the inclusion criteria.

The use of open-ended interview questioning and audio recording allowed participants to explore their experiences with the researcher. The researcher also kept a reflexive journal and field notes for each participant interview. Audio recording and verbatim transcription increase data accuracy and allowed the researcher to provide thick descriptions of the participant’s experiences. This method could be used for populations with different languages or cultural experiences, establishing transferability. Data demonstrated dependability by providing a clearly stated purpose and study population; a careful description of how the data were collected; and evidence of data immersion through organization into text, iterative reading, preliminary interpretation and coding, synthesis, and theme development.

Findings

Each participant described their own unique experience of loss, disparity, and chronic sorrow based upon their own worldview. The description provided by these mothers about the loss of the dreamed child is consistent with the current literature on CS. These parent caregivers shared their efforts to understand their child’s unique needs and how they, as parents and members of families, adapted those into a new family norm. In addition to the experience of CS, and the six revealed themes and overarching truth, these mothers experienced guilt: guilt about feelings of resentment about their child’s condition, guilt regarding time lost with their other children in care of their chronically ill child, and guilt that they attributed to the reality of not having a “normal” child.

Of particular interest, the participants expressed a positive theme, which the researcher categorized as serendipities—finding positive consequence in trying circumstances. All participants spoke of their individual growth of empathy toward others, unique bonds that developed in their families between siblings, their ability to find peace in unexpected places, and their spiritual maturing as a consequence of their experiences with CS and caring for their child. Education level, access to care, and financial resources were not mentioned as having a significant impact on the experience of CS in this small cohort. The degree to which these descriptors may have significance deserves specific and further exploration.

Limitations

This project included a small cohort with only women participating which limits the transferability of the results. The study would have benefitted from a two part interview, allowing reflection on the first part of the interview before participants begin second part of interviewing. The researcher would likely have had additional participants if the eligibility score for the Adapted Burke Questionnaire was changed to 14. Although the researcher endeavored to remain objective, due to her intimate experiences with chronic sorrow, unintentional bias may have occurred.

The experience of chronic sorrow is likely subject to a number of other variables, including number of children within a family with a chronic medical condition, healthcare insurance, financial resources of the family, access to community resources, makeup of the nuclear family, religious or spiritual belief, cultural norms and expectations, and difference in gender-specific roles. The coping style of each individual may also influence one's ability to adapt to the new norm and challenges associated with caring for a chronically ill child.

Implications and Future Research

Healthcare professionals of all disciplines must agree upon the definition of what constitutes a chronic disease or condition. When defining chronic disease or condition, researchers must investigate if disability has an impact on CS and if it influences the determination of a chronic condition. When receiving care in a healthcare setting, professionals of all disciplines must recognize and include the expertise of the family and primary parent caregiver in the interdisciplinary management of their child. Further research is needed to understand the influence of cultural factors on CS, and future research should include fathers of children with CS and a chronic condition to determine if coping and adaptation practices and strategies in these parents is different from mothers.

Nursing should develop an assessment tool to be used when a diagnosis of a chronic condition is made to determine if parents are at risk for CS. Finally, education is needed in all healthcare disciplines on chronic sorrow and its implications to the outcomes of patients and families. Treating the patient's condition is not adequate to address the needs of the family who cares for someone with a chronic illness. There must be comprehensive understanding of CS so that all disciplines can support patients and families and improve healthcare outcomes for both.

Summary and Conclusions

This interpretive phenomenological study focused on the nature and meaning of chronic sorrow in parents caring for a chronically ill child. Twelve mothers were interviewed, and six themes emerged that represented chronic sorrow for the participants. These six themes came together under the overarching truth that *life goes on*. Regardless of multiple challenges and overwhelming burdens mothers faced, they moved beyond the struggles of caring for their chronically ill child and led their families into adaptation of a new norm. With all of the adversity they faced, they still achieved optimism about their future and the future of their family.

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Appendix A: Burke/NCRCS Chronic Sorrow Questionnaire

(Caregiver Version)

I would like to ask you some questions about some of the thoughts and feelings you have experienced since ___________________________________ (name) was diagnosed with ___________________________________ (condition). I am interested in learning your point of view so that nurses can become more sensitive and helpful to people like yourself.

1. How did you first learn that ________________________________ (name) had ____ (condition)?
2. Can you recall your feelings when you first learned about it? (May add: What went through you mind?)
3. What was most helpful to you in adjusting to the news about ______________________'s condition?
4. Was there anything in particular that happened that was not helpful? (If yes: Please give an example.)
5. Thinking back to how you reacted at first to the news of __________________________'s condition, has there been a time since then when something happened and you had those same feeling of ____(use individual's words in his/her response to #2) all over again? (If yes ask questions 7-30; if no ask question 6).

6. What feelings do you have right now when you think about ______________________'s condition? (If feelings consistent with chronic sorrow are described ask questions 7, if not, go to question 14).
7. Can you tell me about one (if using question 6, insert "other" here) time when you felt this way? (May add: What were the circumstances Can you describe your feelings?).
8. Some caregivers say that certain events tend to bring up these feelings again. Were there other times when you had these feelings? (If yes: Can you tell me about some of these times).
9. How would you compare these later experiences to your feelings when you first learned of ___________________'s condition?
    a. Usually more intense
    b. Usually just as intense
    c. Usually less intense
10. Were other people aware that you were having these feelings? (If yes: How did they know?).
11. When you were experiencing those feelings were any people particularly helpful? (If yes: Who were they? Can you recall what they did that helped you?).
12. What people were least helpful? In what way?
13. When a caregiver gets to feeling really down about his/her ___________________'s condition, what could he/she do to feel better?

14. I hope that my study will help us give really practical advice to people who are roving care for individuals with ______________________ (condition). What would you tell them they can expect? What will they need to know?
15. Is there anything that you would tell nurses or other professionals about helping people like yourself?
16. Let me just check one point with you before I move on to the next section. Some caregivers have said that they felt really sad when they learned about their ______________'s condition and that every so often something happens and they feel the sadness all over again. Other caregivers haven't felt that way. What is true for you?

Appendix B: Adapted Burke Questionnaire

Adapted Burke Questionnaire Form A (ABQA)

Mood State **Rank for each reported mood state 0-3**

Grief	0 Absent	1 Not Intense	2 Somewhat Intense	3 Very Intense
Shock	0 Absent	1 Not Intense	2 Somewhat Intense	3 Very Intense
Anger	0 Absent	1 Not Intense	2 Somewhat Intense	3 Very Intense
Disbelief	0 Absent	1 Not Intense	2 Somewhat Intense	3 Very Intense
Sadness	0 Absent	1 Not Intense	2 Somewhat Intense	3 Very Intense
Hopelessness	0 Absent	1 Not Intense	2 Somewhat Intense	3 Very Intense
Fear	0 Absent	1 Not Intense	2 Somewhat Intense	3 Very Intense

Appendix C: Kendall Chronic Sorrow Instrument

		Almost Always	**Frequently**	**Sometimes**	**Not Sure**	**Usually Not**	**Infrequently**	**Almost Never**
1	I think about the loss as if it had just happened	**6**	**5**	**4**	**3**	**2**	**1**	**0**
2	I feel saddened when I think of the loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
3	I feel just as sad when I think of the loss as I did when the loss first happened.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
4	I feel like crying when something reminds me of the loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
5	I feel full of sorrow.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
6	I feel sadness when I am reminded of the loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
7	I feel saddened by things that other people see as unimportant or minor.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
8	I feel full of sorrow when I think about what might or could have been if the loss had not happened.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
9	I feel that the sadness related to the loss comes and goes.	**6**	**5**	**4**	**3**	**2**	**1**	**0**

10	I feel that I have to give up things in my life because of the loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
11	I feel that I have control over my life situation.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
12	I feel my life is not the same as I had hoped or dreamed it would be because of the loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
13	I think about what my life might have or could have been when I am reminded of the loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
14	I feel alone during times that I feel sadness related to the loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
15	I feel that I have enough energy to deal with my life.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
16	The changes in my life because of loss are unfair.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
17	I believe that life is unfair.	**6**	**5**	**4**	**3**	**2**	**1**	**0**
18	I feel older than my age because of my loss.	**6**	**5**	**4**	**3**	**2**	**1**	**0**

Appendix D: Recruitment Flyer

Does your child have a chronic medical condition like:

- Arthritis?
- Asthma?
- Cancer?
- Epilepsy or Neuro-degenerative disease?
- Diabetes?
- Premature birth?
- Sickle cell disease?
- Spina-bifida?

Parents who have a child with a chronic medical condition may experience a sadness or grief that goes on for a long time and doesn't seem to get better. We would like to learn more about this sadness or grief so that we can find new ways to help families care for their child and themselves during this time.

If you would like to learn more about this research study please contact: **Lori Batchelor**-Pediatric Nurse
Arkansas Children's Hospital
501-364-1903
817-692-4720

Appendix E: Interview Guide

Interview Guide

The items below are broad questions that will be followed by thoughtful probing into the concepts of loss and disparity, adversity, and coping to elicit thick descriptions of the phenomenon of chronic sorrow in parents of children with chronic medical condition.

1. Please tell me what your life has been like since your child was diagnosed with X?
2. When did you learn your child had a chronic medical condition?
    a. Tell me what it was like for you when you learned of the diagnosis.
    b. How old was your child when you learned the diagnosis?
    c. How was the diagnosis and information shared with you and your family?
3. How does this affect your life?
    a. If married, your marriage.
    b. If siblings, sibling relationship, your relationship with healthy children.
    c. If employed, your job or career.
    d. Your physical health
    e. Your psychological health
    f. Your spiritual health
4. Please tell me about any other times when you had similar feelings like when you first learned of the diagnosis.
    a. How do those feelings compare to the first time.
    b. Are there other events or occasions when those feelings come up again?
5. What other information related to this can you share with me?

Appendix F: Demographic Data

Demographic Data

1. Diagnosis of child
    a. time from symptoms until diagnosis;
    b. time since diagnosis
    c. number of hospitalizations total and in the last 12 months
2. Gender of participant
3. Makeup of nuclear family
    a. single parent home
    b. two parent home
    c. number of other children
    d. grandparent/s or other extended family in the home
4. Marital status
    a. Married
    b. Separated
    c. Divorced
    d. Widowed
5. Highest level of education
    a. Elementary school
    b. Middle school
    c. High school graduate or GED
    d. Some college
    e. Bachelor’s degree
    f. Master’s degree

    g. Doctoral degree

6. Household income
    a. Less than $25,000 per year
    b. $25,000-$50,000 per year
    c. $50,000-$75,000 per year
    d. $75,000-$100,000 per year
    e. Greater than $100,000 year
7. Parents employment status
    a. one working parent
    b. two parents working
    c. one parent unemployed
    d. both parents unemployed
8. Family ethnicity and race
    a. White
    b. Black or African American
    c. American Indian or Alaska Native
    d. Asian
    e. Native Hawaiian or other Pacific Islander
    f. Hispanic/Latino

Appendix G: Participant Demographic Data

Demographic Table of Participants

Participant	Sex	Age	CS Score	Number parents in the home	Marital Status	Highest Education	Income	Number working parents	Race	Step Parent
1	F	38	18	2 Parent	Married	Bachelor	>100K	2	White	No
2	F	43	19	Single Parent	Divorce	Bachelor	25-50K	1	White	No
3	F	36	23	2 Parent	Married	Doctoral	75-100K	1	Asian	No
4	F	40	18	2 Parent, plus grdparent	Married	Some College	50-75K	1	Bi-racial	Yes
5	F	54	17	2 parent	Married	Bachelor	>100K	1	White	No
6	F	40	18	2 Parent	Married	Bachelor	75-100K	2	White	Yes
7	F	31	20	2 Parent	Married	Bachelor	50-75K	1	White	No
8	F	27	16	2 Parent	Married	High School	<25K	1	White	No
9	F	36	20	2 Parent	Married	Some College	<25K	1	White	No
10	F	29	23	2 Parent	Married	Master	>100K	1	White	No
11	F	42	18	2 Parent	Married	Some College	75-100K	2	White	Yes
12	F	34	18	2 Parent	Married	Some College	25-50K	1	White	No

Appendix H: Informed Consent

INFORMED CONSENT FORM AND AUTHORIZATION TO SHARE PERSONAL HEALTH INFORMATION IN RESEARCH

Protocol Title:	The Lived Experiences of Parents with Chronic Sorrow Who are Caring for Children with a Chronic Medical Condition: Exploring the Phenomenon.
Study Location:	Arkansas Children's Hospital Outpatient Specialty Clinics.
Principal Investigator:	Lori Batchelor BSN, MHA, RN, CPN, NEA-BC 1 Children's Way, Slot #667 Little Rock, Arkansas 72202 501-364-1903

What you should know about a research study

- We give you this consent form so that you can read about the purpose, risks and possible benefits of taking part in this research study. Please review it carefully.
- The main goal of a research study is to learn things to help future patients.
- We cannot promise that this research study will help you.
- Someone will explain this research study to you. Feel free to ask all the questions you want before you make a decision.
- A research study is something you volunteer for. Whether or not you take part in this research study is up to you.
- You have the right to choose not to take part in the research study. Also if you agree to take part now, you can change your mind later on.
- Whatever you decide it will involve no penalty or loss of benefits that you would get anyway.

Why are you being asked to volunteer?
Parents whose children have a diagnosis of a chronic disease may experience a sadness

and grief that is ongoing and unresolved. This type of grief is called chronic sorrow. Parents who have a child with complex chronic medical condition, such as cancer, epilepsy, diabetes, asthma, etc. may experience this unresolved sadness.
We would like to learn more about this sadness or grief so that we can develop interventions to assist families to care for their child and themselves during this time.

What is the purpose of this research study?

The purpose of the research study is to understand the nature and meaning of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition.

How long will you be in the study? How many other people will be in the study?

The study will be a one-time interview with the principal investigator lasting one-two hours. The interview may be divided into two sessions at the request of the participant. The study will be completed within 15-30 days of your enrollment. Approximately 10-15 adult parents 18 years of age or older, with children with a diagnosis of a chronic medical condition will be enrolled in the study.

What are you being asked to do?

You are being asked to meet with the principal investigator, who will conduct an interview in a private setting to learn more about what your life has been like since you were told your child has a chronic medical condition. This interview will be tape recorded.

The principal investigator will screen the study participant for inclusion and if the inclusion criteria are met then a time will be scheduled to meet with you for an interview:

- The Adapted Burke Questionnaire Form A will be used as the screening tool for study inclusion.
- An interview guide with questions about your experience will be discussed
- The Adapted Burke Questionnaire Form B will be used in addition to the interview guide.
- Some information will be collected about you: including but not limited to your child’s diagnosis, your age, race, and ethnicity; your marital status, religious preference, and highest level of education.

What are the possible risks or discomforts?

- The interview will take one to two hours and you may become tired answering questions. A break will be provided if needed, a second interview session can be scheduled or you may withdraw from the study.
- Talking about your feelings and about your child’s diagnosis and caring for your child may make you sad.

- The research may have unforeseeable risks. One of those risks could be the possible loss of subject’s confidentiality.

What if new information becomes available about the study?

During the course of this study, we may find more information that could be important to you. This includes information that, once learned, might cause you to change your mind about being in the study. We will notify you as soon as possible if such information becomes available.

What are the possible benefits of the study?

There will be no direct benefit to the study participants in this pilot study; however, knowledge gained from the study could potentially provide future benefits to parents experiencing chronic sorrow and caring for their child with a chronic medical condition.

What other choices do you have if you do not participate?

You may choose not to participate in this study. Some resources available to help you with your experiences of caring for your child include your physician and care team, a social worker in the hospital, your personnel clergy or religious leader, local or national support group organizations that focus on your child’s diagnosis.

Will you be paid for being in this study?

There is no compensation for participation in this study.

Will you have to pay for anything?

You will not have to pay for anything in this study.

When is the Study over? Can you leave the Study before it ends?

The study is planned as a single interview and will be over when that interview is complete. Participants may requests the interview be divided into two sessions.

This study is expected to end after all participants have completed all visits, and all information has been collected.

If you decide to participate, you are free to leave the study at any time. Withdrawal will not interfere with your future care. By signing this consent form, you are not waiving any legal right to which you are entitled.

Who can see or use your information? How will your personal information be protected?

If you answer yes to participate in this study the data collected during this study will be stored in a password protected file. The tape recording of the interview will be stored in a locked cabinet in the investigator's office. The tape recording will be copied onto a paper record and stored with your research record. Written notes will be in a locked cabinet, and study participant information will be stored separately from the interview notes. We will do our best to make sure that the personal information in your research record will be kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. If this study is being overseen by the University of Arkansas for Medical Sciences (UAMS) Institutional Review Board (IRB), the Office for Human Research Protections, other institutional oversight offices may review your research records. By law, the study team must release certain information to the appropriate authorities if at any time during the study there is concern that child abuse has possibly occurred or you disclose a desire to harm yourself or others.

Who can you call with questions, complaints or if you are concerned about your rights as a research subject?

If you have questions during the study about the research, you should contact Lori Batchelor at 501-364-1903. You may call the Institutional Review Board (IRB) at 501-686-5667 regarding a research-related injury, with questions about your rights as a research participant or to discuss any problems or concerns about the research. Also, you may call this number if you are unable to reach the Investigator or you wish to speak to someone not directly related to this study.

Authorization to Share Personal Health Information in Research

We are asking you to take part in the research described in this form. To do this research, we need to collect health information that identifies you. We may collect information from your Arkansas Children's Hospital medical record, information concerning your child's diagnosis. This information will be used for the purpose of confirming your child’s diagnosis, and to verify your contact information. We will only collect information that is needed for the research. Participating in this research study will not create new health information: the focus of this study is on the parents’ experience and the record of those discussions will not be stored in the child’s medical record. For you to be in this research, we need your permission to collect, create and share this information.

We will, or may, share your health information with people at Arkansas Children’s Hospital who help with the research or things related to the research process, such as the study staff, the University of Arkansas For Medical Sciences (UAMS) Institutional Review Board and the research compliance office at Arkansas Children's Hospital Research Institute and the University of Arkansas for Medical Sciences. Also we may need to share your health information with people outside of Arkansas Children’s Hospital who make sure we do the research properly such as, the Office for Human Research Protections. Some of these people may share your health information with someone else. If they do, the same laws that Arkansas Children’s Hospital must obey may not apply; therefore, information may be re-disclosed by the recipient and is no longer protected under the Health Insurance Portability and Accountability Act (HIPAA). If you sign this form, we will create, collect, use, and share your health information until December 31, 2016. We may collect some information from your medical records even after your direct participation in the research project ends.

If you sign this form, you are giving us permission to create, collect, use and share your health information as described in this form. You do not have to sign this form. However, if you decide not to sign this form, you cannot be in the research study. You need to sign this form and the research consent form if you want to be in the research study. We cannot do the research if we cannot collect, use and share your health information.

If you sign this form but decide later that you no longer want us to collect or share your health information, you must send a letter to the person and the address listed by “Principal Investigator” on the first page of this form. The letter needs to be signed by you, should list the “Study Title” listed on this form, and should state that you have changed your mind and that you are revoking your “HIPAA Research Authorization”. If the HIPAA authorization is revoked, you will no longer be a part of the research study and we cannot collect or share any more health information from the revocation date forward. However, in order to maintain the reliability of the research, we may still use and share your information that was collected before the Principal Investigator received your letter withdrawing the permissions granted under this authorization.

During the course of the study, you may be denied access temporarily to certain study related information about you that is obtained/collected as a part of the study. However,

the Principal Investigator and staff will not automatically deny a request, but will consider whether it is appropriate under the circumstances to allow access. If access is denied during the study, once the study is completed, you will be able to request access to the information again.
If you decide not to sign this form or change your mind later, this will not affect your current or future medical care at Arkansas Children's Hospital.

The researcher will give you a copy of the consent form and you should ask any questions you may have before signing the consent.
The subject will be asked to sign this form if consent is given to participate.

Signature

The purpose and voluntary nature of this study, as well as the potential benefits and risks that are involved have been explained to me. I have been able to ask questions and express concerns, which have been satisfactorily responded to by the study team. I have been told that I will be given a copy of this consent form.

The health information about ____
(Printed Name of the Participant)
can be collected and used by the researchers and staff for the research study described in

this form.

____________________________________ ________
(Signature) **(Date)**

Signature of person obtaining consent

Any study-related questions expressed by the people whose signature is above have been answered

____________________________________ ________
(Signature of Person Obtaining Consent) **(Date)**

Appendix I: University of Texas at Tyler IRB Documents

THE UNIVERSITY OF TEXAS AT TYLER
INSTITUTIONAL REVIEW BOARD

EXPEDITED RESEARCH APPLICATION

IRB: Sp2015-78

Approved by: Leonard Brown

Date: *May 7, 2015*

To qualify for expedited review research must present no more than minimal risk to human subjects and cannot explore sensitive topics. In addition the research must fit the categories of expedited research, per OHRP regulations.

Attach (electronically) with this application:

- Written consent form using the UT Tyler Consent Template unless a waiver of written informed consent is requested
- Signature page of Thesis or Dissertation Committee members showing proposal approval
- Brief research proposal that outlines background and significance, research design, research questions/hypotheses, data collection instruments and related information, data collection procedures, data analysis procedures. **Most of this can be copied and pasted to relevant parts of the application but please keep B & S brief for the application.**
- Human Subject Education Certification for PI, co-investigators, and research assistants participating in recruitment, data collection, data analysis, or, if they have any exposure to identifiable data (if training has not been completed at UT Tyler within a 3 year period of time)
- Tool/instrument/survey; if copyright or other issues prohibit electronic form, submit one hard copy

COMPLETE ALL ITEMS TO AVOID DELAY IN IRB APPROVAL

DATE: *4/10/15*

Principal Investigator	*Batchelor* *Lori L.* (Last) (First) (MI)

PI Title and Credentials	☐Assistant Professor ☐Associate Professor ☐Professor ☒ Student PhD candidate ☐Other Lori Batchelor, BSN, MHA, RN, CPN, NEA-BC
Faculty Sponsor Name and Email if PI is Student	*Gloria Duke PhD, RN; gduke@uttyler.edu*
PI Phone PI Email	*817-692-4720* *LBatchelor2@patriots.uttyler.edu*
Co-Investigator(s)	*None*
Co-Investigator(s) Email and Telephone	*N/A*
Secondary Contact Person in Absence of PI	**Gloria Duke**
Secondary Contact Person's Telephone and Email	Phone: *Click here to enter text.* Email: *gduke.uttyler.edu*
Title of Proposed Research	*The Lived Experiences of Parents with Chronic Sorrow Who are Caring for Children with a Chronic Medical Condition*
Source of Funding	☐NIH ☐Local ☐ Industry ☐ Other Federal (Specify) ☒Other (Specify) *minimal expense student funded*

1. **Designate the category that qualifies this proposal for expedited review** (see UT Tyler Expedited Categories at the end of this application) and justify this designation by responding to the statements below each category

Category # *7* Information Required for Justification (See specific information under each category) *"Research on individual or group characteristics or behavior or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies".* *This is a qualitative study with data collection chiefly obtained through semi-structured interview and audio-tape recording as well as PI notes and reflexive journal.*

2. For proposals involving Personal Health Information (PHI) data: If this is a retrospective chart review (Category 5) (health records research), or, data involves

review of PHI, refer to the IRB's HIPAA policies and procedures in the IRB Handbook and complete any appropriate forms. All can be located on the UT Tyler IRB site: http://www.uttyler.edu/research/compliance/irb/

2a. Does this protocol include the use of PHI? ☒ Yes ☐ No

NOTE: *If the protocol includes the use of PHI, refer to the IRB Handbook on HIPAA policies and relevant forms that must be completed before IRB approval can be obtained.*

3. **Purpose of Study:** *The aim of this study is to understand the nature and meaning of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition.*

4. **Research Questions:** *What is the nature and meaning of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition?*

5. **Brief Background and Significance of Study:** *Parents whose children have a diagnosis of a chronic medical condition such as but not limited to diagnosis of spina-bifida (Burke, Hainsworth, Eakes, & Lindgren, 1992), asthma (Kurnat & Moore, 1999), diabetes (Lowes & Lyne, 2000; Monaghan, Hilliard, Cogen, & Streisand, 2001), sickle cell disease (Northington, 2000), lissencephaly (Scornaienchi, 2003), neural tube defects (Hobdell, 2004), epilepsy (Hobdell, Grant, Valencia, Mare, Kothare, Legido, & Khurana, 2007), juvenile idiopathic arthritis (Waite-Jones & Madill, 2008), neurodegenerative disease (Bettle & Latimer, 2009), or cancer (Fletcher, 2010) are at risk for an ongoing unresolved grief phenomenon known as chronic sorrow. The Dutch National Consensus Committee (DNCC) on Chronic Diseases and Health Conditions in Childhood defined what constitutes a chronic condition or disease in children (Mokkink, van der Lee, Grootenhuis, Offringa, & Heymans, 2008). The ABQ instrument is a two part tool; form A and form B, that measures parental chronic sorrow and the intensity of the most commonly reported CS mood states (Hobdell, 2004). The ABQA is a grid of the eight most frequently reported mood states (grief, shock, anger, disbelief, sadness, hopelessness, fear, and guilt) that parents experience. Parents are asked to indicate the intensity of their average mood state on a 4-point Likert scale (3 = very intense, 2 = somewhat intense, 1 = not intense to 0 = absent). The tool is summed and has a range score of 0-24 with a higher score indicating increased sorrow. This portion of the tool will be used as an objective* *measure to demonstrate the presence of CS for this population. The Adapted Burke Questionnaire form B (ABQB) assesses chronic sorrow in parents through a set of five open-ended response questions that address the cyclical nature and intensity dimension(s) of chronic sorrow (Hobdell, 2004; Hobdell et al, 2007). There have been a number of research studies to examine the presence of chronic sorrow in various specific diagnoses however to date the research has been disease specific and has not explored the broader range of chronic sorrow in other conditions or diseases. There have been no studies to determine if the parental phenomenon of chronic sorrow is similar regardless of the chronic medical condition for the child. The goal of this study is to determine if chronic sorrow is a similar phenomenon in parents whose children have various chronic medical conditions.*

6. Population to Be Studied:

a. **Ages:** *18 years or older*

b. Gender: *Male and Female*

Explain below if either gender is to be excluded.

N/A

c. Are all racial and ethnic groups included? ☒ Yes ☐ No

Explain below if a racial or ethnic group is to be excluded.

.

d. Number of Anticipated Subjects: *10-15, when data saturation is achieved.*

e. Inclusion Criteria for Sample Eligibility: *Parent age 18 years or older. Parent/s of children with chronic medical condition. Chronic medical condition diagnosis must have been at least 3 months ago* *and meet the requirements of the DNCC to constitute a chronic condition. Adapted Burke Questionnaire Form A screen with a score of 16 or greater. Parents must be English speaking and able to read English.*

Note: *Any study involving* ***prisoners*** *requires a full board review, and may not be approved under expedited review.*

7. Explain the locations or settings for sample recruitment and data collection:

Outpatient clinics at Arkansas Children's Hospital; possibly through the Arkansas Parent Advisory Board for recruitment if needed.

8. Explain from whom permission has or will be obtained from the settings in which sample recruitment and/or data collection will take place:

Parent or parents of a child with a diagnosis of chronic medical condition as outlined above.

9. Explain in detail who will be recruiting participants and the sample will be recruited:

The principle investigator will be recruiting subjects. Flyers will be placed in specialty clinic waiting areas, and the researcher will meet with physician and nurse leaders to provide education regarding this study. Providers and clinicians may wish to refer patients for study inclusion as appropriate. Additionally the flyer will be sent to the Leader of the Arkansas Parent Advisory Board, a state funded program to support parents of special needs children. He will then distribute the flyer to the group and they may contact the principal investigator in the event of their interest to participate in this study.

10. Copy and paste text below from any flyers, ads, letters etc. that are used for recruitment of participants. In addition, attach any recruitment materials if there are *graphics* or other figures used other than text.

Does your child have a chronic medical condition like:

- Arthritis?
- Asthma?
- Cancer?
- Epilepsy or Neuro-degenerative disease?
- Diabetes?
- Premature birth?
- Sickle cell disease?
- Spina-bifida?

Parents who have a child with a chronic medical condition may experience a sadness or grief that goes on for a long time and doesn't seem to get better. We would like to learn more about this sadness or grief by interviewing parents so that we can find new ways to help families care for their child and themselves during this time.

If you would like to learn more about this research study please contact: **Lori Batchelor RN**-Pediatric Nurse
Arkansas Children's Hospital
501-364-1903
817-692-4720

Informed Consent

. **Prospective research ordinarily requires written informed consent. If any special classes are eligible to participate, discuss how the consent process will differ. Inclusion of children (under 18 years) requires permission of at least one parent AND the assent of the child (refer to UT Tyler's Policy on Informed Consent of Children)**.

If written consent is to be used, terminology must be about the 8th grade level, or as appropriate for the accurate understanding of the participant or guardian.

If there are questions about the literacy or cognitive level of potential participants, there must be evidence that the participant is able to verbalize basic information about the research, their role, time commitment, risks, and the voluntary nature of participating and/or ceasing participation with no adverse consequences.

Please use the template posted under the IRB forms as a guide, and attach as a separate document with the application submission.

11. This section only for those requesting a waiver or alteration of written informed consent:

Justify the waiver or alteration in accordance with the following four criteria established under 45CFR46.116(d)(1-4).

All four criteria must be met in order to have signed written informed consents. In other words, you must answer "yes" to all four of the criteria below in order to NOT have written and signed informed consents.

If you are requesting a waiver of written and signed informed consent, Indicate "yes" if the statement is true about your proposed research:

1. The research involves no more than minimal risk to the subjects ☐ Yes ☐ No

2. The waiver or alteration will not adversely affect the rights and welfare of the subjects
☐ Yes ☐ No

3. The research could not practicably be carried out without the waiver or alteration,
☐ Yes ☐ No **AND**

4. Whenever appropriate, the subjects will be provided with additional pertinent information after participation ☐ Yes ☐ No.

12. When prospective informed consent is waived, explain how you will obtain permission to use participant's data. If no permission is planned, please explain your rationale.

Please find attached informed consent required by the UAMS Institutional Review Board and Arkansas Children's Hospital.

13. Detailed Data Collection Procedures

Once a participant has been verified to meet inclusion criteria and proper informed consent is completed the interview will be scheduled at a mutually-agreed upon location that will best serve the participant given the complexity and time constraints of caring for their chronically ill child. The location will be conducive to digital audio-recording, and in a space that will minimize interruptions and maximize privacy for the participant, such as a small conference space in a hospital inpatient or outpatient setting, or in a setting that gives the participant the most comfort, such as a park, spiritual setting, or in their home. When meeting the participant to conduct the interview, the study will be explained in detail to the participant, and they will then be asked to verbally repeat the essential elements of informed consent. These include the general purpose of the study, their expectations, any known risks of their participation, benefits of the study, the voluntary nature of participating or cessation of participation with no adverse outcomes, and ways to contact the respective IRB representatives and the researcher. The consent form will then be signed and a unique identifier code for that participant will be assigned. The only documents with participant names will be an electronic Word document with their unique code, name and contact information, and the consent form.

Following consent signing, the demographic form will be completed. The participant will be asked if they prefer to use a pseudo name or their real name during the interview. They will be told there are no right, or wrong answers, to be as transparent as possible, and to notify the researcher if they need a break or want to cease participation temporarily or permanently. During the interview process the researcher will assess participant for fatigue, distress or other adverse emotions and offer a break, schedule a return, or discontinue participation in the study. The researcher will also use skilled listening techniques and be open to any statements needing further probing, and observe for non-verbal communication. The intention is to gain perspective from the participant's world which means understanding the individual's view of their experience, in this case the parent perspective. Field notes will be written as soon as the interview session concludes, and will include information about body language, the setting, perceived emotions, and other important contextual information. The length of the initial interview session is expected to be about 60-90 minutes.

For this study the researcher will be using a reflexive journal in addition to field notes. This journal will allow the researcher to express a growing understanding of the phenomenon being studied and guide the researcher in the interview process and validation with participants' perspective, data analysis and interpretation (Ortlipp, 2008). This tool will be especially important given this researcher's a priori knowledge of the phenomenon to be studied. Demographic data will include: gender, age, occupation and education of participant makeup of *nuclear family, grandparent(s) or other extended family living in the home, household income, type of health insurance, and family ethnicity and race. The interview will begin with an open ended question: "Tell me what your life has been like since your child was diagnosed with X?" This will allow the parent to give a free flowing narrative of their experiences that will likely prompt further probing by the researcher. At the conclusion of the interview, the researcher will express her gratitude for participation, and notify them to contact her if additional information is recalled. In addition, participants will be informed that they may be contacted following the interview to address additional topics that may arise in other interviews, clarify interview content, and verify findings following data analysis.*

14. Data Analysis Procedures:

The interview recording of the qualitative data from the study participant will be transcribed by a transcriptionist who acknowledges the critical importance of confidentiality. There will be no identifiable information on this audio recording to protect the participant's confidentiality. Participants will be asked to verify accuracy of the transcript. If the participant provides additional information it will be integrated into the transcript and included in the final analysis. The transcribed interviews will be analyzed in conjunction with investigator field notes and reflexivity journal. The researcher will begin the analysis of data through reading, reflective writing and interpretation. NVivo qualitative software will be used to assist with thematic coding. The researcher will incorporate basic tenets of the hermeneutical circle which illustrates the researcher's understanding and interpretation by regarding interpretation as the movement from the data (part) integration to the understanding of the phenomenon of study (whole) contextualization. This will be accomplished through immersion and organization of data into text, iterative reading, preliminary interpretation to facilitate coding; understanding-identifying first order constructs (participant), coding data using NVivo; abstraction-identifying second order constructs (researcher), grouping these constructs into sub-themes; synthesis and theme development; illumination and illustration of phenomena-linking themes to literature and reconstructing interpretations into stories, integration and critique (Ajjawi & Higgs, 2007). Demographic data will be analyzed using descriptive statistics, such as mean age, education, and income. The ABQA screening tool is sum scored with a data range score of 0-24. Higher scores indicate greater intensity of sorrow. The ABQA results of intensity of CS results will also be analyzed with SPSS software.

15. Risks and benefits of this research to the subjects and/or society

Risks: *The risks associated with this research study are minimal. The participants may experience distressing emotions when discussing their experience or they may become fatigued during the interview. A break will be offered and the researcher will provide resources to study participants to assist in navigating their emotions associated with caring for their chronically ill child and themselves to include but not limited to, social workers, chaplain or spiritual leader, local and national health organizations and community support groups. There is the potential risk associated with loss of confidentiality. Measures to protect the confidentiality of study participants will be implemented as described in the Confidentiality of Data section below.*

Benefits: *There will be no direct benefit to the study participants in this study; however, knowledge gained from the study could potentially benefit parents experiencing chronic sorrow and caring for their chronically ill child in the future. Talking about their experiences may also have some unknown therapeutic value to the parent.*

16. **Confidentiality of Data:** Specify how confidentiality will be secured and maintained for research data and/or specimens.

The Principal Investigator will carefully monitor study procedures to protect the safety of research subjects, the quality of the data and the integrity of the study. All study subject material will be assigned a unique identifying code or number. The key to the code will be kept separately from data collection in a locked file in the principal investigator's office. Only the principal investigator will have access to the code and information that identifies the subject in this study. Measures to protect confidentiality: 1. Interviews will be conducted in a private setting; 2. Study participant data-audio-recordings will be destroyed after publication or within 2 years of completion of data analysis; 3. Study participant demographics will be stored in a locked cabinet in the principal investigator's office and participant data will be kept in a separate locked cabinet. 4. Informed stored on computer will be password protected and neither computer nor laptop will be left unattended at any time.

17. **Identifiability of data or specimens**: Will the specimens or data be identifiable?

(NOTE: Any time code numbers are used, or signed consent forms are used, there is ALWAYS potential identifiability of data).

☒ Yes ☐ No If yes, complete item 17a

17a. State the type of identification, direct or indirect, on any specimens or data when they are made available to your study team: *Indirect identifiers*

Direct Identifiers include subject name, address, social security, etc.

Indirect Identifiers include any number that could be used by the investigator or the source providing the data/specimens to identify a subject, e.g., pathology tracking number, medical record number, sequential or random code number)

18. **Access to Data**: Specify faculty and staff (members of the study team) permitted to have access to the study data.

Transcriptionist will have access to audio-taped recordings but no other data. Dr. Gloria Duke will have access to all data collected and analyzed materials. Audio-taped recordings will be linked by identifier key code and not subject name.

19. **Have all individuals who have access to data been educated about human subject ethics and confidentiality measures?** (NOTE: This is responsibility of PI)

☒ Yes ☐ No

20. **Protection of Data: State** how data will be protected, e.g., located filing cabinet in investigator's office, on password protected computer, location(s) of computer, etc.

21. **If data is on a laptop, acknowledge that the laptop will never be in an insecure location where theft is possible (e.g., in a locked car)**

This study will be conducted in accordance with all applicable government regulations and University of Texas at Tyler (UT Tyler) research policies and procedures as well as the University of Arkansas for Medical Sciences (UAMS) research policies and procedures and the policies of Arkansas Children's Hospital (ACH). Data will be stored in locked cabinets in the researcher's office at Arkansas Children's Hospital as outlined above in section on data confidentiality. Some data may be stored on a password-protected laptop and that laptop will not be left unsecured *and will be in the office or home of the researcher and never stored in a locked vehicle. This protocol and any amendments will be submitted and approved by the UAMS Institutional Review Board (IRB) as well as the UT Tyler IRB to conduct the study. The formal consent of each subject, using the IRB-approved consent for required by UAMS and ACH, will be obtained before the subject participates in any study procedure. All subjects for this study will be provided a consent form describing this study and providing sufficient information in language suitable for subjects to make an informed decision about their participation in this study. The researcher obtaining consent will thoroughly explain each element of the document and outline the risks and benefits, alternate treatment(s), and requirements of the study. The consent process will take place in a quiet private room, and subjects may take as much time as needed to make a decision about their participation. Participation privacy will be maintained and questions regarding participation will be answered. No coercion or undue influence will be used in the consent process. This consent form must be signed by the subject, and the researcher obtaining the consent. A copy of the signed consent will be given to the participant, and the informed consent process will be documented in each subject's research record. Signed consent forms and unique identifiers and codes will be kept in separate locked file than data.*

SIGNATURE OF PRINCIPAL INVESTIGATOR: Signature indicates agreement by the PI to abide by UT Tyler IRB policies and procedures in the UT Tyler Handbook and the Federal Wide Assurance, to the obligations as stated in the "Responsibilities of the Principal Investigator" and to use universal precautions with potential exposure to specimens.

Lori L. Batchelor BSN, MHA, RN, CPN, NEA-BC, PhD(c)
April 12, 2015

Principal Investigator Signature Date
Please print name or affix electronic signature.
Electronic submission of this
form by PI indicates signature

Appendix J: Arkansas Children's /University of Arkansas for Medical Science IRB

Closure Letter

February 3, 2016.

Institutional Review Board
University of Arkansas for Medical Sciences
4301 West Markham, #636
Little Rock, AR 72205-7199

IRB Administration,

Please note that I am closing study **Protocol Number:** 204084; **Protocol Title:** The Lived Experiences of Parents with Chronic Sorrow Who are Caring for Children with a Chronic Medical Condition. This study received the Institutional Review Board approval for 07/20/2015 modification on 07/28/2015, using expedited review procedures.

I have enrolled twelve (12) study participants. I am closing the study for a couple of reasons. I have completed a target number for study participants, and moving to another state. I continue in my PhD program at the University of Texas at Tyler and will complete participant interview transcription and data analysis. My hope is to complete my analysis and defend my dissertation before May of 2016.

The study data and documents has been secured on an encrypted device for confidentiality reasons and hard copy records have been secured in a locked cabinet.

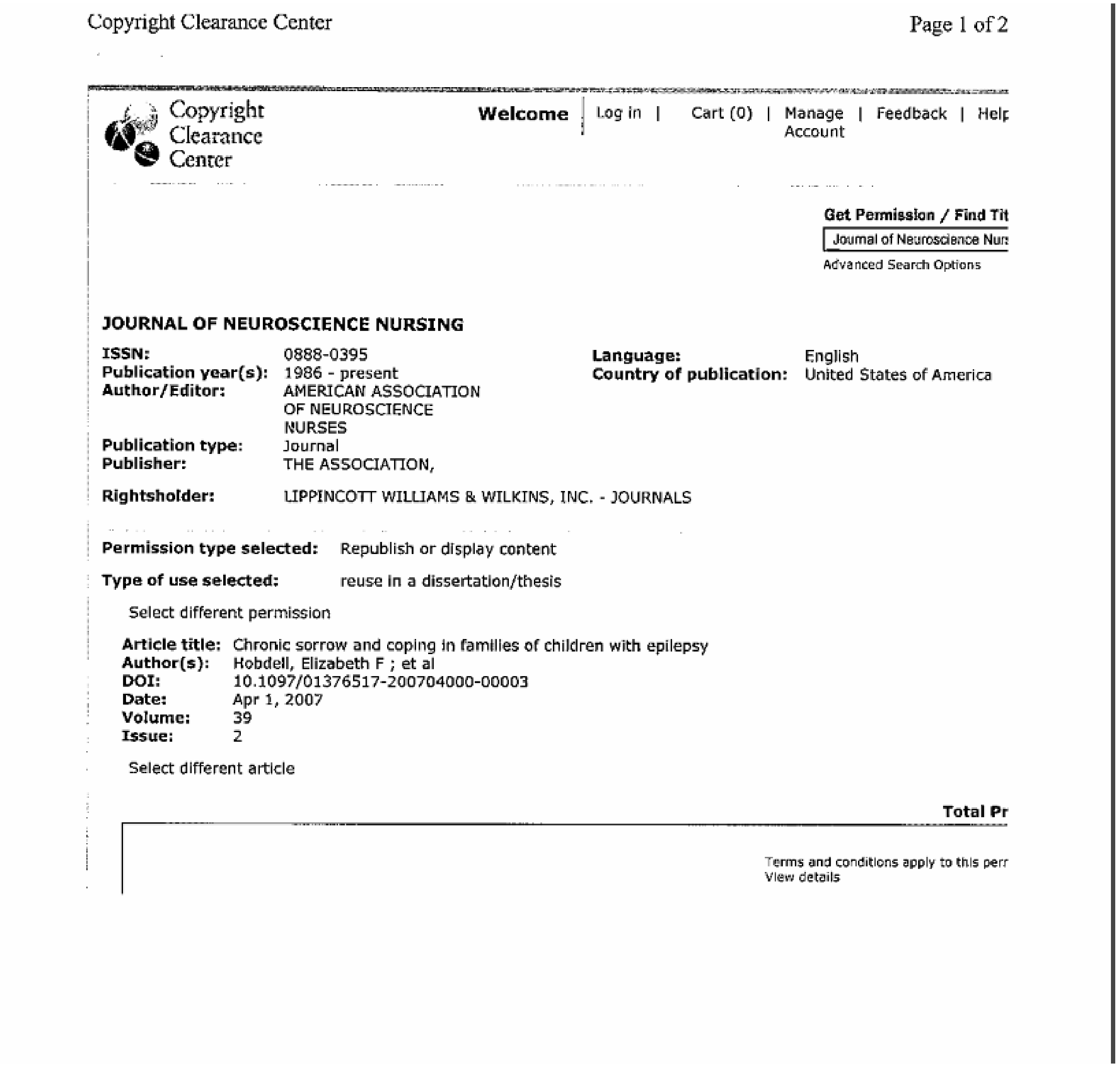
Thank you for your kind assistance on this very interesting research project.

I look forward to sharing results in the future.

Kind regards

Lori Batchelor BSN, MHA, PhD(c), RN, CPN, NEA-BC
Principal Investigator
817-692-4720
LBatchelor2@patriots.uttyler.edu
Cc: Gloria Duke PhD, RN Dissertation Chair
University of Texas at Tyler

Appendix K: Permission to Use ABQ Instrument, Wolters Luwere Lippincot Williams



JOURNAL OF NEUROSCIENCE NURSING

ISSN: 0888-0395
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Author/Editor: AMERICAN ASSOCIATION OF NEUROSCIENCE NURSES
Publication type: Journal
Publisher: THE ASSOCIATION,
Language: English
Country of publication: United States of America

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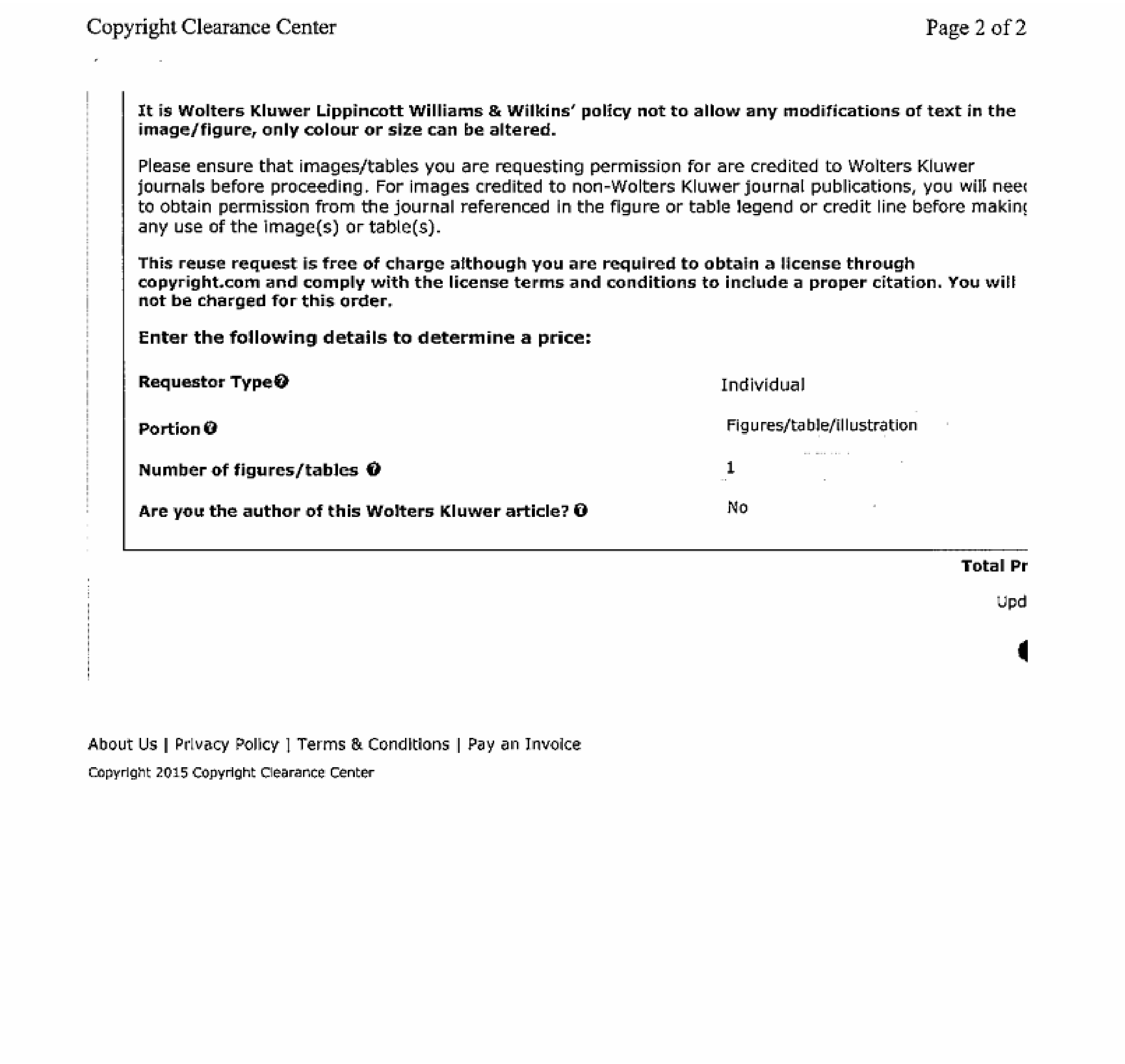
Author(s): Hobdell, Elizabeth F ; et al
DOI: 10.1097/01376517-200704000-00003
Date: Apr 1, 2007
Volume: 39
Issue: 2



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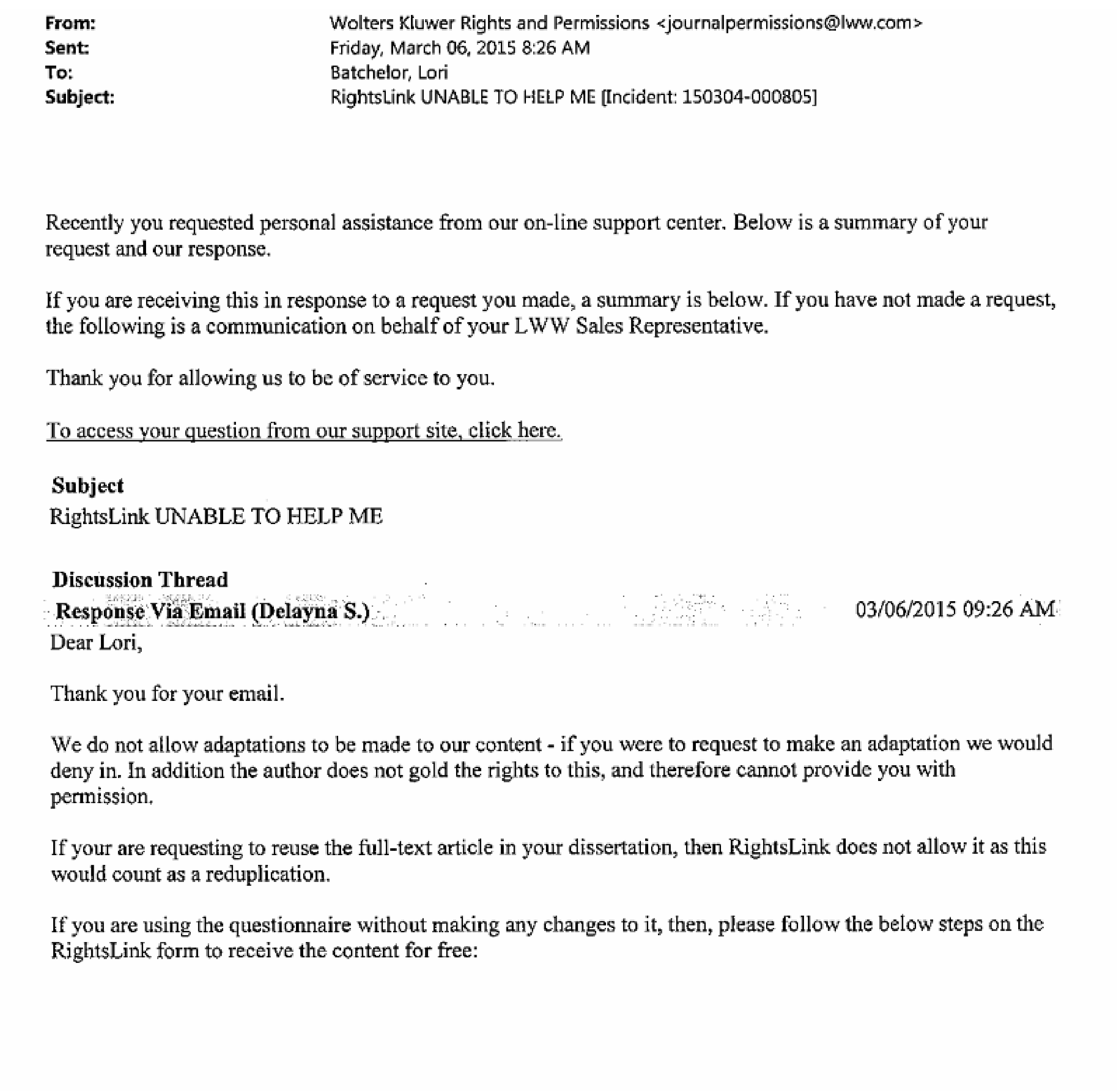

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To: Batchelor, Lori
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Subject
RightsLink UNABLE TO HELP ME

Discussion Thread
Response Via Email (Delayna S.) 03/06/2015 09:26 AM
Dear Lori,

Thank you for your email.

We do not allow adaptations to be made to our content - if you were to request to make an adaptation we would deny in. In addition the author does not gold the rights to this, and therefore cannot provide you with permission.

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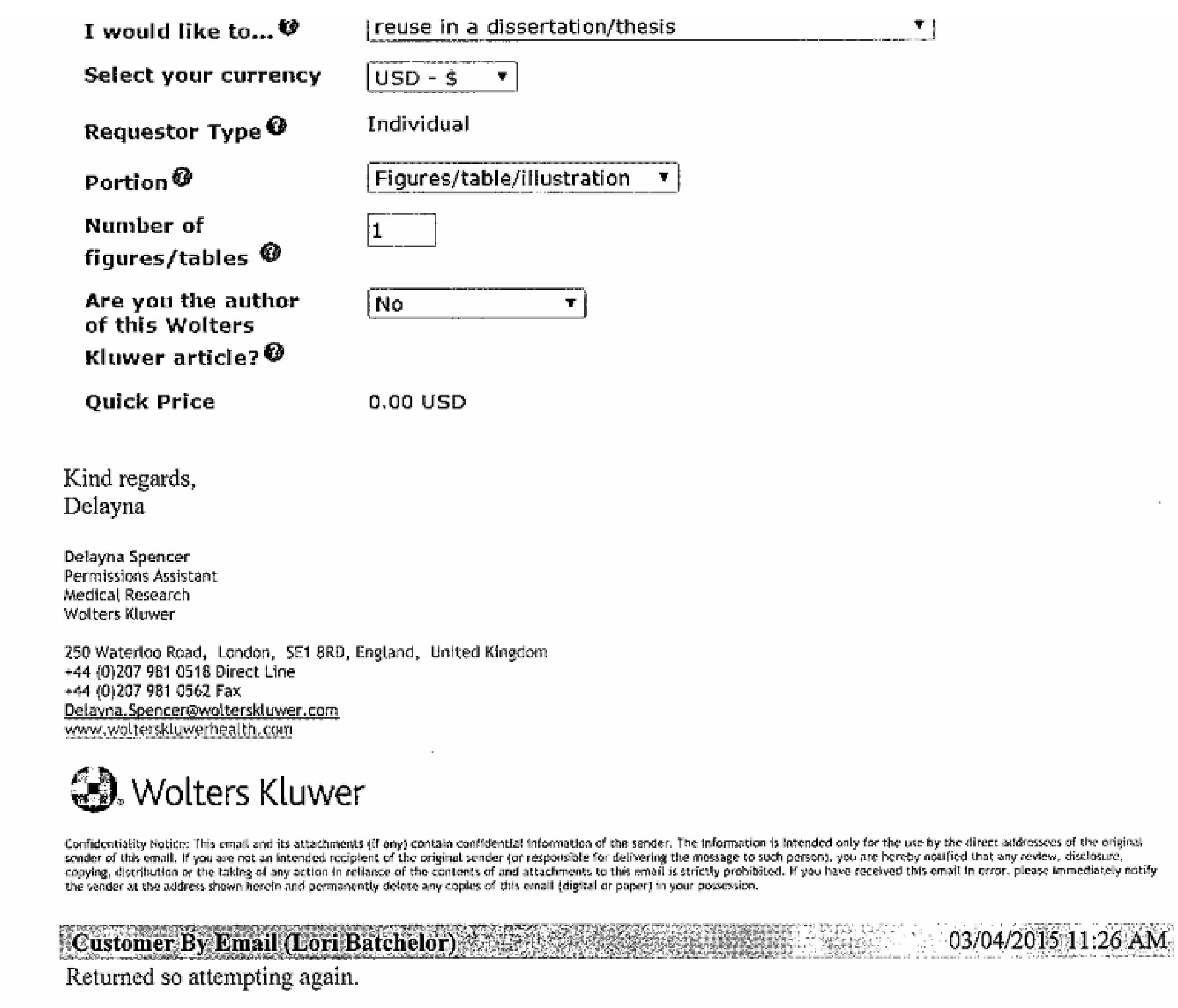

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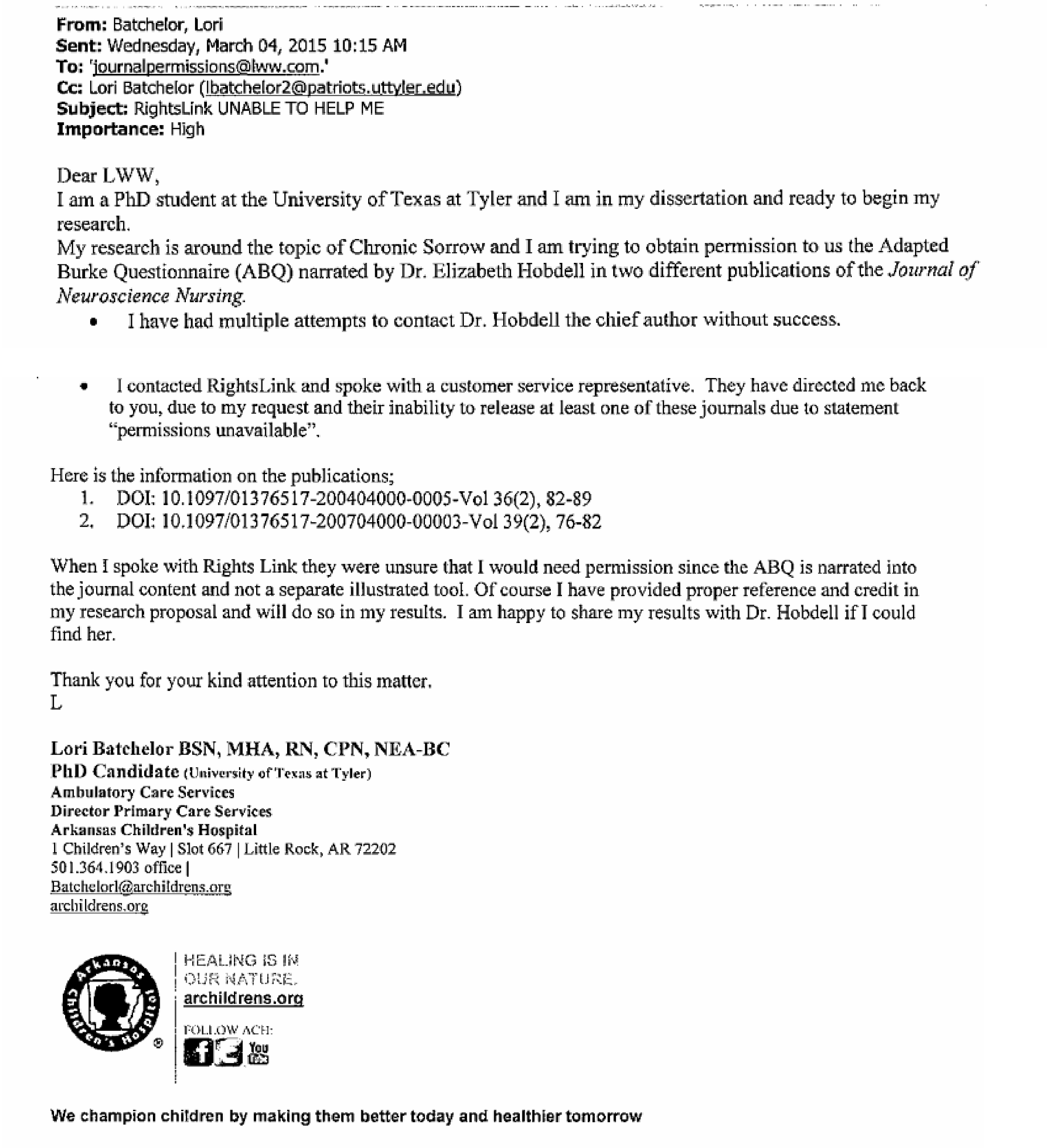
Customer By Email (Lori Batchelor) 03/04/2015 11:26 AM

Returned so attempting again.



From: Batchelor, Lori
Sent: Wednesday, March 04, 2015 10:15 AM
To: 'journalpermissions@lww.com.'
Cc: Lori Batchelor (lbatchelor2@patriots.uttyler.edu)
Subject: RightsLink UNABLE TO HELP ME
Importance: High

Dear LWW,
I am a PhD student at the University of Texas at Tyler and I am in my dissertation and ready to begin my research.
My research is around the topic of Chronic Sorrow and I am trying to obtain permission to us the Adapted Burke Questionnaire (ABQ) narrated by Dr. Elizabeth Hobdell in two different publications of the *Journal of Neuroscience Nursing.*

- I have had multiple attempts to contact Dr. Hobdell the chief author without success.

- I contacted RightsLink and spoke with a customer service representative. They have directed me back to you, due to my request and their inability to release at least one of these journals due to statement "permissions unavailable".

Here is the information on the publications;

1. DOI: 10.1097/01376517-200404000-0005-Vol 36(2), 82-89
2. DOI: 10.1097/01376517-200704000-00003-Vol 39(2), 76-82

When I spoke with Rights Link they were unsure that I would need permission since the ABQ is narrated into the journal content and not a separate illustrated tool. Of course I have provided proper reference and credit in my research proposal and will do so in my results. I am happy to share my results with Dr. Hobdell if I could find her.

Thank you for your kind attention to this matter.
L

Lori Batchelor BSN, MHA, RN, CPN, NEA-BC
PhD Candidate (University of Texas at Tyler)
Ambulatory Care Services
Director Primary Care Services
Arkansas Children's Hospital
1 Children's Way | Slot 667 | Little Rock, AR 72202
501.364.1903 office |
Batchelorl@archildrens.org
archildrens.org

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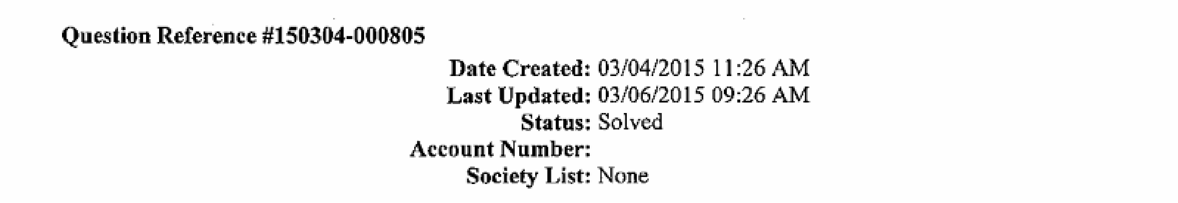

Question Reference #150304-000805

Date Created: 03/04/2015 11:26 AM
Last Updated: 03/06/2015 09:26 AM
Status: Solved
Account Number:
Society List: None

BIOGRAPHICAL SKETCH

NAME: Batchelor, Lori L. BSN, MHA, RN, CPN, NEA-BC
POSITION TITLE: Executive Director Pediatric Outpatient Services, University Children’s Health

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
TEXAS CHRISTIAN UNIVERSITY, HARRIS COLLEGE OF NURSING, Fort Worth, TX	B.S.N.	05/1995	Nursing
UNIVERSITY OF MARY HARDIN-BAYLOR, Belton, TX	M.H.A.	12/2001	Healthcare Administration
UNIVERSITY OF TEXAS at TYLER, Tyler TX PhD Candidacy August 2014	Ph.D.	12/2017	Nursing Philosophy and Research

A. <u>Personal Statement:</u>

First and foremost I am a parent of a chronically ill son. I wanted to be a nurse as a child and lost my way and then I was gifted with medically complex and fragile child. The experiences of having a child with a chronic medical condition created in me a passion for not only pediatric patients, but also their families and how I can change their experiences for the better.

I am a passionate board certified pediatric nurse with broad experiences in pediatric critical care, pediatric specialty, and pediatric primary care nursing from both bedside and administrative perspectives. My goals are to keep the focus on the patient and family and improve healthcare outcomes for both by advancing care at the bedside. As healthcare continues to advance, management of patients and families must keep pace, ensuring that we as professionals are working to improve care.

As a pediatric nurse I have experience in both nursing and medical research. As a nurse researcher I endeavor to advance our understanding of the role of nursing and its impact on pediatric outcomes with focus on social determinants of health.

B. Positions and Honors:

a) Medical Legal Partnership Advisory Board, Arkansas Children's 2011-2016
b) Professional Advisory Board, Greater N. Texas Epilepsy Foundation, 2000-05
c) Recipient of Great 100 Nurses Award Dallas/Fort Worth 2003
d) Teen Court Advisory Board, City of Hurst, TX 2002-2004
e) Professional Advisory Board, Tuberous Sclerosis/Treasure Street Board, 1997-2005
f) TCU Harris College of Nursing-Spirit of Nursing Award 1995-1st TCU recipient
g) TCU Harris College of Nursing Dean's List 1995
h) Proclamation: awarded by Honorable Mayor Bob Bolen, Fort Worth, TX 1989, for "pioneering work with children/families with special needs"

C. Contributions to Science:

Presentations

a) A Nurse's influence on Social Determinants of Health: Focus to impact one Domain. 4th Annual Cultural Inclusion Conference; Linking Social Determinants of Health to Health Disparities and Cultural Inclusion, San Antonio, TX April 2017. Panel Presentation.
b) The Nursing Role in MLP: Raising Awareness and Involvement of the Nursing Discipline. 2013 Medical Legal Partnership Summit, Bethesda, MD, April 2013. Platform Presentation
c) Reduction of Hospital-Acquired Pressure Ulcers through a Focused Education Program: New Frontiers in Quality Care 3rd Annual Data Use Conference National Database of Nursing Quality Indicators, Dallas, TX. January 2009.
d) Seizure Control: The Ketogenic Diet, Panel Presentation, National Family Conference on Tuberous Sclerosis, Washington, D. C., July 1999.
e) An Interdisciplinary Approach to a Ketogenic Diet: A Treatment for Seizures, Poster Presentation, United for Children Pediatric Nursing Conference, Fort Worth, Texas, Oct. 1997.

Publications

Batchelor, L., Nance, J., Short, B., (1997). An interdisciplinary team approach to Implementing the Ketogenic Diet for the treatment of seizures, *Pediatric Nursing*, 23(5), 465-471.

Chudnow, R.S., Wolfe, G.I., Sparagana, S.P., Delgado, M.R., Batchelor, L., Roach, E.S., (2000). Abnormal sudomotor function in the hypomelanotic macules of Tuberous Sclerosis Complex. *Journal of Child Neurology*, 15(8), 529-532.

Tucker, A.J., Northrup, H., Ohl, C.J., Roach, E.S., Sparagana, S.P., Delgado, M.R., Batchelor, L.L., Au, K.S., (2001). Patients definitively diagnosed with TSC yield a higher mutation detection rate. *American Journal of Human Genetics*, 69(4), A2733.

Sparagana, S.P., Delgado, M.R., Batchelor, L., Roach, E.S. (2003) Seizure remission and antiepileptic drug discontinuation in children with tuberous sclerosis. *Archives of Neurology*, 60, 1286-1289.

Ewalt, D.H., Diamond, M.D., Rees, C., Sparagana, S.P., Delgado, M.D., Batchelor, L., Roach, E.S. (2005). Long-Term Outcome of Transcatheter Embolization of Renal Angiomyolipoma Due to Tuberous Sclerosis Complex. *Journal of Urology*, 174, 1764-1766.

Au, K.S., Williams, A.T., Roach, E.S., Batchelor, L**.**, Sparagana, S., Wheless, J.W., Baumgartner, J.E., Roa, B.B., Wilson, C., Smith, T.K., Cheung, M.Y., Whittemore, V.H., King, T.M., Northrup, H. (2007). Genotype/Phenotype Correlation in 325 Individuals Referred for a Diagnosis of Tuberous Sclerosis Complex in United States. *Genetics in Medicine*, 9(2), 88-100.

Lockwood, S.**,** Batchelor, L & Bittenholder, E. (2010). ICE-CREAM for research: increasing staff understanding about research. *Journal of Nursing Staff Development* 26(3), 129-33.

Canon S, Shera A, Phan NMH, Lapicz L, Scheidweiler T, Batchelor L, Swearingen C, (2014), Autonomic dysreflexia during urodynamics in children and adolescents with spinal cord injury or severe neurologic disease, *Journal of Pediatric Urology* doi: 10.1016/j.jpurol.2014.08.011.

Educational Videos

a) *Lighting the Way,* Treasure Street/Tuberous Sclerosis Clinic at Texas Scottish Rite Hospital for Children, Educational Video, Lori Batchelor Co-Producer Health Science Communications Association-Bronze Award, 2001 Media Festivals.

b) *A Total Commitment: The Ketogenic Diet*, Texas Scottish Rite Hospital for Children
Educational Video, Lori Batchelor Production participant, 5th International Audio-Video Epilepsy Festival-Gold Lamp Award, 1997.

c) *Care of the Child with an Ostomy: A Guide for Parents*, Information Utilization Institute
Educational Video, Lori Batchelor Co-writer/Production Participation.

D. Additional Information: Research Support and/or Scholastic Performance

I have not received any research grants to date, due to my commitment to direct patient care, nursing leadership, and furthering my education; however I do anticipate efforts to apply for grants in the future to advance knowledge about chronic sorrow.

Scholastic Performance

Phi Kappa Phi Induction University of Texas at Tyler 2012

Nurse Executive Advanced Board Certified-American Nurse Credentialing Center 2010

Certified Pediatric Nurse- Pediatric Nursing Certification Board 2007 (10 years)

Sigma Theta Tau International Honor Society of Nursing Induction 2003

Texas Christian University Dean’s List (BSN) 1995