

# Chronic Sorrow in Parents With Chronically Ill Children

Lori L. Batchelor and Gloria Duke

Survival of children with serious congenital or acquired diseases in the United States and other developed countries has increased during the last several decades. Asthma, cystic fibrosis, diabetes, cerebral palsy, the consequences of premature birth, mental illness, obesity, and diabetes mellitus are the top categories of chronic disease in children (Torpy, Lymn, & Glass, 2007). About 25% of families in the United States have a child diagnosed with a chronic medical condition (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2013). Caring for a child with a chronic medical condition creates physical and emotional burdens for parent caregivers, which reflects an ongoing process of facing adversity (Gravelle, 1997) with a dynamic interplay of joy and sorrow (Kearney & Griffin, 2001). Parents caring for their medically complex children described role conflict for caregivers and family, financial burden for parents, parent caregiver physical care burden, and independent caregiver, as well as social isolation associated with constant demands of being a parent caregiver (Ratliffe, Harrigan, Haley, Tse, & Olson, 2002). Parents who have a child with a chronic medical condition experience a new reality when they recognize their child is different than what they expected or dreamed

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**Purpose:** 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.

**Designs and Methods:** An interpretive phenomenological design was used. Participants were parent caregivers with chronic sorrow and had a chronically ill child. In-depth recorded interviews of 12 parents were conducted. Transcriptions were analyzed using hermeneutical techniques.

**Results:** Six themes emerged from the data: surreality of diagnosis, unrealistic expectations, the battle, keeping it together, and doing whatever it takes. Life goes on, regardless of what is happening with the child, reflected an overarching truth for parents.

**Conclusions:** Parent caregivers experience multiple challenges and overwhelming burdens in their lives. However, they were able to move beyond the struggles of caring for their chronically ill children, adapt to the new norm, and even gain optimism about their future.

**Practice Implications:** Health care providers should be more familiar with chronic sorrow and its impact on the daily lives of families. Health care professionals of all disciplines must include the expertise of the family and primary parent caregiver in the management of the child's care. Although health care professionals have 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 understands.

**Key Words:** Parent caregivers, chronic sorrow, adaptation, children, chronic illness.

(Eakes, Burkes, & Hainsworth, 1998; Roos, 2002), and may experience intense sadness and grief, which may advance to the more complex emotion of chronic sorrow (Eakes et al., 1998).

Chronic sorrow was first coined by Olshansky (1962) to explain the life-long experience of episodic sadness and grief of parents toward their children with mental disability. Since then, researchers have learned chronic sorrow can occur in both the caregiver of the chronically ill as well as the affected individual (Isaksson, Gunnarsson, & Ahlström, 2007). 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).

Much research to date has been disease-specific, with studies that explore chronic sorrow in parent caregivers of children with specific diagnoses, including but not limited to diabetes mellitus (Lowes & Lyne, 2000; Monaghan, Hilliard, Cogen, & Streisand, 2001), sickle cell disease (Northington, 2000), epilepsy (Hobdell et al., 2007), neurodegenerative disease (Bettle & Latimer, 2009), or cancer (Fletcher, 2010). This disease-specific research trend has resulted in a gap regarding the prevalence of chronic

sorrow and common experiences of parent caregivers with chronic sorrow regardless of the diagnosed chronic medical condition. This study intended to gain an in-depth and comprehensive understanding of the lived experiences of parents with chronic sorrow who are caring for a child with a chronic medical condition.

## Background

Chronic sorrow is an appropriate typical emotional response to a loss event, and in the case of parental chronic sorrow, the loss is of the normal or idealized child (Bettle & Latimer, 2009). 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. Health care professionals have begun to recognize that the individual may instead be experiencing chronic sorrow (Doenges, Moorhouse, & Murr, 2010).

### Chronic Sorrow: Antecedents And Predisposing Factors

A significant loss may serve as the trigger event for chronic sorrow, which could be a loss that happens for one's self or other loss (Eakes et al., 1998; Roos, 2002; Teel, 1991). Antecedents to chronic sorrow include a relationship of deep attachment impacted by a loss other than death; there is a gap or disparity between past relationship and the idealized future relationship; and the actual relationship changed by the loss (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 (Ahlström, 2007; Eakes et al., 1998; Isaksson et al., 2007). Chronic sorrow exists in parents when a gap or disparity exists between the idealized healthy normal child and the reality of a child with a chronic disease or condition (Eakes et al., 1998).

### Chronic Sorrow: Attributes And Characteristics

Chronic sorrow is an ongoing phenomenon, a living loss that cannot be removed and that requires continual adaptation (Eakes et al., 1998; Isaksson et al., 2007; Lee, Strauss, Wittman, Jackson, & Carstens, 2001; Roos, 2002). Attributes of chronic sorrow

include sadness or sorrow that has variable intensity for a person and can be different from one person to the next, permanent continuance throughout the lifetime of the chronically ill or disabled person, and 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).

Typically, loss is sudden, unanticipated, or has a traumatic onset, and parents perceive an unforeseeable end. This is experienced in relationships of deep attachment. The reality of that relationship is forever changed, such as in the loss of the idealized child, or the loss of the healthy spouse or parent to 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). Chronic sorrow is progressive and can intensify even long after the initial loss, with intermingling experiences of satisfaction and happiness (Eakes et al., 1998; Kearney & Griffin, 2001; Northington, 2000; Teel, 1991). Chronic sorrow is a continuous cyclical grief process that occurs in a pattern of resurging feelings of sorrow interspersed with periods of calmer emotions (Eakes et al., 1998). Attributes of chronic sorrow are "pervasive, permanent, periodic, and potentially progressive" (Eakes et al., 1998, p. 180). The existence of chronic sorrow is determined by the way in which the loss is perceived (Roos, 2002), and can be impacted by additional new losses or progression in disease and/or milestones not achieved. Because the loss continues to be present, it is considered a living loss (Eakes et al., 1998; Roos, 2002).

### Chronic Sorrow: Impact and Consequences

The concepts of loss and disparity are very closely linked, and differences can be difficult to discern. According to the Oxford Dictionary (2019), loss is the state or feeling of grief when deprived of someone or something of value. Disparity occurs when a differ-

ence or gap that exists between the idealized (dreamed for) child and the reality of the child with a chronic medical condition (Eakes et al., 1998). For one mother, the trigger event for chronic sorrow was learning of the diagnosis of lissencephaly and its prognosis for her sons (Scornaienchi, 2003). The disparity occurred when the mother realized the loss of her idealized sons. As long as the disparity remains, the experience of chronic sorrow 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). According to Lowes and Lyne (2000), some parent caregivers may never recover from the impact of their child's diagnosis and continue to experience chronic sorrow.

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). Coping strategies may include external activities, such as maintaining personal life happenings, searching for respite opportunities, and seeking information that helps parent caregivers to cope with the loss experience. Internal coping strategies could include learning how the new reality can be adapted as the new normal; seeking family, friends, or professionals that can listen with empathy; offering and providing support; and acknowledging parent caregiver 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 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).

The between joy and sorrow model (Kearney & Griffin, 2001) speaks to joy as the parents' determination to maintain hope and 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 accom-

plishments 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. Despite these conflicting experiences of joy and sorrow, these parents described 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 (Chung et al., 2013; George, Vickers, Wilkes, & Barton, 2008). George and colleagues (2008) reported that most parents felt their employer neither acknowledged their family situation nor had an understanding about the constant persistent stress involved in the parent caregiver role.

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 and adaptation have been studied, but no information was available regarding parental chronic sorrow in children who have different types of chronic medical conditions. This interpretive phenomenological study delved deeply into the lived experiences of parent caregivers with chronic sorrow of children with a variety of chronic medical conditions to identify similarities among them. Proactively identifying and supporting parent caregivers at risk for chronic sorrow can help mediate the adversities of chronic sorrow.

## Design and Methods

### Design and Participants

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 caring for a child with a chronic medical condition? Hermeneutics is about being in the participant's world within the milieu of relationships, customs,

cultural expectations, language, and personal symbols that impact and inform their lived experience (Miles, Francis, Chapman, & Taylor, 2013). The human experience is laden with meaning, and hermeneutics is the recognition and exploration of that meaning (Guignon, 2012). To understand the experience being explored, the researcher must be involved in understanding and interpretation of the experience and not separated from the experience (Wilson, 2014).

### Sample and Setting

Parent participants were recruited from the outpatient specialty clinic setting at a large metropolitan children's hospital and a support group (PSG) for special needs children and their parents. Snowball sampling was also used as parents who participated in the study notified other potentially eligible parents to participate. If candidates were verified as having chronic sorrow expressed continued interest, arrangements were made for the consent process and interview. The researcher encouraged parents who did not meet eligibility criteria to continue follow-up care, and referred them to a social worker or other support service if they requested additional resources.

Eligibility criteria included the following: a) be a parent or parent caregiver of a child with 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 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 3 times or more during the previous year. Exclusion criteria included foster parents and adoptive parents.

Presence of chronic sorrow was determined using the ABQ instrument. This instrument is a two-part tool, form A and form B, that measures parental chronic sorrow and is a grid of the 8 most frequently reported

mood states (grief, shock, anger, disbelief, sadness, hopelessness, fear, and guilt) that parents experience at the time they learn of the child's diagnosis. Only this portion of the tool was used in eligibility screening as an objective measure to demonstrate the presence of chronic sorrow for this population. The ABQ form B (ABQB) assesses chronic sorrow in parents through a set of 5 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 (see Figure 1). 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. The sample size of 12 participants was dictated by the presence of data saturation (Charmaz, 2006).

### Data Collection

Participants chose to meet in their home or at the hospital during a scheduled appointment. 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. Field notes were maintained for purposes of data contextualization (Polit & Beck, 2017). The researcher used a reflexive journal to facilitate the researcher's ability to consider personal perceptions and awareness about experiences being studied (Ortlipp, 2008; Van den Hoonaard, 2002). Journaling was particularly important given the researcher's (first author) *a priori* knowledge of the phenomenon of chronic sorrow through her own experience as a parent of a chronically ill child.

**Figure 1.**  
**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 a 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 of 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?

This study was approved by both the academic and clinical facility Institutional Review Boards. The informed consent process was assured with participant verbalization of purposes, risks, benefits, and voluntary nature of the study, and was instituted as an ongoing process. The researcher was particularly sensitive to participant distress, and offered breaks or opportunities to withdraw from the study with no adverse consequences. Privacy was maintained by meeting with participants in a private space or location based on specific participant needs.

### Data Management And Analysis

Audio recordings of interviews were transcribed by a professional transcriptionist who acknowledged the critical importance of confidentiality. Transcribed interviews were analyzed, and investigator field notes and reflexive journal were reviewed alongside transcribed interview. Upon review of the complete transcript, the researcher made notes on the hard copy document defining the experience and the researcher's perception of the experience, highlighting the document for common participant experiences and common threads of information. Once this was completed, the researcher organized 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 maintain consistent data. Finally, after this extensive and exhaustive review, the researcher sought to create brevity by crafting summary statements for each category. Demographic data were analyzed using descriptive statistics, including mean age, education, income, and other quantitative data.

### Results

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; their ABQA scores ranged from 16 to 24. The average age of participants was 37 years, with the youngest being 27 and the oldest being 54 years of age. There was a mix of diagnoses for their children (see Table 1). An in-depth analysis of transcripts revealed six themes that included surreality of diagnosis, unrealistic expectations, the battle, keeping it together, and doing whatever it takes. A change in life perspective also occurred as a result of the overall experience of caring for a chronically ill child. 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.

### Surreality of Diagnosis

Some parents were aware that something was wrong but were not given a diagnosis for months or even years. 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 parent understanding of their own reality. 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. 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." 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 following knowledge of their child's diagnosis. 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. Many parents attempted to find purpose in their new reality. One mother 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.

**Table 1.**  
**Participant Demographics**

Subject	Sex	Age (Years)	Chronic Sorrow Score	Diagnosis	Number of Parents in the Home	Marital Status	Highest Education	Income in \$1,000s	Number of Working Parents	Race	Step-Parent
1	F	38	18	Juvenile arthritis	2	Married	Bachelor	>\$100	2	White	No
2	F	43	19	Epilepsy with chromo 2q deletion	1	Divorced	Bachelor	\$25-\$50	1	White	No
3	F	36	23	Autism	2	Married	Doctoral	\$75-\$100	1	Asian	No
4	F	40	18	Autism	2, + grandparent	Married	Some college	\$50-\$75	1	Bi-racial	Yes
5	F	54	17	Autism	2	Married	Bachelor	>\$100	1	White	No
6	F	40	18	Budd-Chiari disease	2	Married	Bachelor	\$75-\$100	2	White	Yes
7	F	31	20	Acute lymphocytic leukemia	2	Married	Bachelor	\$50-\$75	1	White	No
8	F	27	16	Premature birth: Dysphagia, retinopathy of prematurity	2	Married	High school	<\$25	1	White	No
9	F	36	20	Hypo-plastic left heart	2	Married	Some college	<\$25	1	White	No
10	F	29	23	Turner syndrome pulmonary atresia	2	Married	Master	>\$100	1	White	No
11	F	42	18	Asperger's syndrome	2	Married	Some college	\$75-\$100	2	White	Yes
12	F	34	18	IgM nephropathy	2	Married	Some college	\$25-\$50	1	White	No

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. One mother described her other child “being tossed” from family member to family member so she could be with her chronically ill child in the hospital and during weekly treatments. In some families, health care 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. 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.

Participants described hopelessness because of the multiple and overwhelming burdens they carry. They experienced physical and mental exhaustion due to around-the-clock care demands and the struggles of dealing with the disease and its sequelae. One mother discussed the division between her and her husband and his unwillingness to engage in the care of their child, and their marriage ultimately ended. Another parent described her 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. The burden and responsibility are so great that another mother said: “I can’t lie down and die; who else will do this?”

Social isolation was discussed as first losing a social connection with work and career. This detachment was accompanied by limited financial resources due to loss of their jobs. 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 who 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. One parent stated: “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 reflected 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.”

All participants discussed battling a health care system that lacks understanding of parental expertise, parental desires for their child’s well-being, and parents’ endless pursuit for knowledge. Parents needed to know more about their child’s diagnosis, as well as what care should be and could have been 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

issues associated with step-parenting (see Table 1) contributed to family strife.

Some of this strife was 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 health care. This comes from the socially expected role of the mother caregiver. The fathers in these families were the primary or only wage earner. These fathers had the opportunity to leave the home, and had colleagues and friends to engage about their struggles. They were not as closely connected to their chronically ill child because the mother was the chief manager of health care visits, health care plans, implementation of care at home, and overall nurturing for the entire family system. This balance or lack of 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? For some families, their painful new reality caused them to question God, and in some, to 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, and both parents were highly educated professionals; however, the gap between the mother’s and father’s desires was enormous. This mother was prepared to do anything in the hope 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 firm grasp on what was possible and what treatment was available. He understood her des-

peration 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 told 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. The mother was convinced 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 that 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. A mother reflected on learning the diagnosis and struggling to keep 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."

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. Although 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 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 mothers journaled in some manner. Some journaled in a book that they referenced during their interview, while others used their social media page as a daily journal. Many 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 cope with the unexpected, and 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 told a story of their friends and family raising several thousand dollars to help 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 mother said several months later, when the financial burden was truly realized, she wished she could get that money back. Over time, she along with the other mothers learned to accept help gracefully. These parents reported help from a variety of groups, from work companions who supported the parent emotionally or through fundraising efforts to defray financial hardship, from family members coming in and doing laundry and household chores, and from churches and support groups that provided prayer, encouragement, and as one mother described, a "food train," during a very difficult and demanding time.

Only one subject experienced divorce; while step-parents were in this cohort, the blended families occurred before the child with chronic condition was part of the new blended family or was not yet diagnosed. Most couples sought marital counseling, and even some step-parents sought counseling with their spouses to agree on common ground and 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. 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." These parents were advocates for their child based on their knowledge of their child's diagnosis; educating teachers, health care providers, and friends; and buffering the children from fathers and extended family who 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, 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 health care 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 were moved to an ambulance for transport to the hospital. The mother told the paramedic she “might throw up.” The paramedic responded: “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 how she and her husband totally disengaged in the reality of their child’s condition by planning an escape every 4 to 8 weeks. Sometimes the escape was only a weekend respite in a hotel in town while their child received 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 who could provide the same level of care as the primary mother caregiver.

These mothers were 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 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 also have serious exacerbations when others in the family do not understand or know how to provide care and treatment in the home.

### Serendipities

Parent caregivers spoke of unanticipated serendipities, finding something valuable they were not expect-

ing 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. Although these participants had a child with a chronic condition, these parents compared their circumstance to others who also had children with chronic conditions and how much worse it could have been. Parents referred to having a child with a diagnosis different from their own. One mom with a very dependent teenage child said: “Parents who deal with mental and behavioral issues...it is harder. Those [parents] are rock stars. That is their world, and to them, that is normal, and to me, my child is my normal, I’m lucky 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 health care 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 the 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, church, and family. However, one mother described 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, family, and 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, 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 – despite 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 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 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.”

### Overarching Truth: Life Goes On

The overarching truth for all 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, working at their jobs. The cycle of chronic

sorrow continued, but so 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 his/her own unique experience of loss and chronic sorrow based upon his/her own worldview. The description these mothers provided about the loss of the dream of a normal child is consistent with the work of Eakes and colleagues (1998) regarding the presence of disparity. These parents 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. To understand chronic sorrow in parents of children with a particular disease, Northington (2000) mentioned complexity theory in the work of adapting to the new norm. Northington (2000) 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.

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 to care of their chronically ill child, and guilt they somehow contributed to the reality of not having a "normal" child. Although this emotional experience is ongoing, the parent caregiver is attempting to proceed with life for him/herself, the family, and the child. Parent caregivers 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. Parents had unreal, maybe unachievable expectations for themselves as a parent and caregiver, as well as the other myriad roles for which they are responsible. They lacked the resources needed to help them manage their children, and all

demands and decision-making required to care for their child with a chronic condition.

Because of subjects' 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. Fathers are often engaged in outside work and their career, and mothers take on the role of primary decision-maker and caregiver in the health care of their chronically ill 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. Although 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 managing the adaptation necessary for this new reality could be achieved.

## 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 health care experience, treatment, care management, and assisting with adaptation and coping. Many of these families become single wage-earning families; thus, they may need access to social services resources. Assistance is needed in managing demands of care, such as special transportation, access to therapy services, school accommodations, and access to financial health care resources, including state agencies that support children with special health care needs.

Health care 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. Although health care 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 his/her child. These professionals must be challenged to truly listen to the intent being communicated by the family, not just the words.

### Implications for Research

Further research is needed to determine cultural factors that may influence coping in these families. The United States continues to expand in breadth of social cultural variation. Understanding these cultures and their beliefs and expectations around chronic disease may enhance health care 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. Further research is needed to determine experiences in fathers, 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 ill-

## Instructions For Continuing Nursing Education Contact Hours

### Chronic Sorrow in Parents with Chronically Ill Children

Deadline for Submission: August 31, 2021

PED 1904

#### To Obtain CNE Contact Hours

1. To obtain CNE contact hours, you must read the article and complete the evaluation through the **Pediatric Nursing website** at [www.pediatricnursing.net/ce](http://www.pediatricnursing.net/ce)
2. Evaluations must be completed **online** by August 31, 2021. Upon completion of the evaluation, your CNE certificate for **1.3** contact hour(s) will be mailed to you.

#### Learning Outcome

After completing this educational activity, the learner will be able to recognize attributes of chronic sorrow, and proactively identify and support parent caregivers of chronically ill children at risk for chronic sorrow.

#### Learner Engagement Activity

To learn more about the prevalence of families with children with special needs, visit:

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2013). *The National Survey of Children with Special Health Care Needs chartbook 2009-2010*. Retrieved from <http://mchb.hrsa.gov/cshcn0910/population/pages/pc/pcih.html>

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nesses still need to be answered. Qualitative research should be expanded to include a larger group with mixed diagnoses to further explore if the issue for these families is the chronic nature of a disease rather than the specific disease or condition.

#### Implications for Education

Although a nursing diagnosis of chronic sorrow exists, few nurses either know or understand this concept. With the continued rapid growth and advances in health care technology, health care professionals can anticipate more individuals who are at risk for chronic sorrow. Students of all health care professions must be educated about the phenomenon as a fundamental concept in navigating the experiences of a chronic condition throughout the lifespan. Hospitals should provide orientation to nurses in critical, rehabilitation, and long-term care units. Staff should be trained about this phenomenon and how to begin conversations of hope and encouragement upon diagnosis, with a focus on developing family centered interventions.

#### Strengths and Limitations

##### Strengths

The researcher worked intently to produce credible results through a rigorous research process maintaining consistency with the Heideggerian phenomenological method (Lincoln & Guba, 2000). 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 use of open-ended interviewing, audio recording, and verbatim transcription should increase data accuracy (MacLean, Meyer, & Estable, 2009; Starks & Trinidad, 2007). The researcher was immersed in multiple data sources, audio recordings, verbatim transcripts, field notes regarding body language and non-verbal cues, as well as reflexive journal. Although this study may not have direct transferability, these thick descriptions used in the population studied and use of the same method could be used in other populations of different language or cultural experience, establishing transferability. To achieve confirmability, data analyzed were checked and

rechecked under each iteration of its review and synthesis.

The researcher becomes the primary instrument of data collection and analysis through an immersion experience. The words used by these subjects were carefully considered to understand what the nature of their experiences meant to participants, and what was being said beyond just the words. Familiarity of the phenomenon of chronic sorrow is an experience shared by the researcher through her own experiences with one of her children. *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 (Armour, Rivaux, & Bell, 2009). This researcher followed a rigorous methodological process, and an audit trail was conducted by a PhD-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 results. The interview was limited to 60 to 90 minutes to respect the time of the subjects. The interview could have been allowed to finish when subjects completed sharing what they wanted. The study may have benefitted from a two-part interview to allow participants to reflect on the first part of the interview. This reflection may have revealed additional important aspects of the parent experience that could be shared in the second interview. The researcher could have opened the research to individuals who scored 14 on the ABQ, 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.

The experience of chronic sorrow may also be influenced by several other variables, including the 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 research is needed to understand the impact these variables may have on the possible presence of chronic sorrow and its intensity.

## Conclusion

Difficulties parents face with the life journey of caring for a chronically ill child extends well beyond the disease itself. These parent caregivers are experiencing chronic sorrow as defined by previous researchers, and they are struggling to find the new normal in their lives and the lives of their families. Even with very different diagnoses and very diverse families, they are having similar experiences while coping with chronic sorrow. Chronic sorrow has an impact on the parent caregiver's personal, spiritual, and social health, and could have a lifelong impact on the parent caregiver, the child, and the family as a

whole. Perhaps the chronic nature of the disease is the catalyst for chronic sorrow and not the specific disease diagnosis. The majority of health care professionals are unaware of these challenges and the experience of chronic sorrow endured by parent caregivers. However, nurses and other health care professionals have the opportunity to implement interventions, adaptations, and coping strategies through early assessment and application of holistic, family-centered care. ■

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