

Parenting a Child with Chronic Illness: A Metasynthesis

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Increasing numbers of children are diagnosed with chronic illnesses each year. Some parents are finding themselves providing all the care to these children. The experience of parents caring for a child with a chronic illness is examined in this metasynthesis.

The United States Maternal and Child Health Bureau (MCHB) estimates that there are 18 million children diagnosed with chronic illness living in the United States (Maternal Child Health Bureau, 2003). Of these children, many live in a non-institutional setting and are cared for by parents or guardians. Some families receive nursing or personal care attendant hours to assist in the care. However, many families manage the illness and provide all the care for the child with chronic illness.

Chronic illness is defined by Jessup and Stein as an illness that is long term and is either not curable or has residual features that result in limitations in daily living requiring special assistance or adaptation in function (Ludder-Jackson & Vessey, 1996, p. 3); it is expanded further by Ludder-Jackson and Vessey (1996) as an ongoing health condition. In addition, one or more of the following are present at the time of diagnosis or during the trajectory of the illness: (a) limitation of function, (b) disfigurement, (c) dependency on medication, (d) special diet and/or medical technology, (e) special ongoing treatments at home or in school, and (f) need for medical care above the normal need for ongoing health maintenance (Ludder-Jackson & Vessey, 1996, p. 3).

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Parenting is described as a "gift" by the American Academy of Pediatrics (AAP) in the book titled *Caring for Your Baby and Child* (Shelov, 1993, p. x). The authors go on to list the gifts as well as the challenges that the parent and child bring to the relationship. What additional challenges do the parents of a child with a chronic illness face?

A review of the literature revealed many quantitative and topical articles on parenting children with chronic illness; however, the search did not reveal a metasynthesis specifically on parenting children with chronic illness. One metasynthesis on mothering children who are other than normal focuses specifically on the evolution of the role of mother in caring for these children (Nelson, 2002), but not the concept of parenting. The purpose of this metasynthesis is to explore the phenomenon of parenting (by mother and father) a child with chronic illness as reported from a qualitative research perspective. The use of a metasynthesis is an effective way to use the collective information generated from individual qualitative studies. "Qualitative metasynthesis entails a systematic approach to the collection and analysis of qualitative studies..." (Sandelowski, Docherty, & Emden, 2003, p. 154).

Method

The purpose of this study was to create a comprehensive chronicle of the phenomena of parenting a child with a chronic illness. This accumulated body of knowledge is presented from the parents' point of view as they care for a child with a chronic illness.

Procedure. To begin the procedure, a review of the literature was done using the following resources, including online databases such as CINAHL, ERIC, PsycLit, Sociological Abstracts, PubMed, and Dissertation Abstracts. These databases were searched for the time period between 1960 and the present. Studies from all years were reviewed; however, the studies chosen were published between 1989 and 2000. The key words used in the search were chron-

ic illness, pediatrics, parenting, and qualitative study. The key word choice narrowed the search and eliminated studies that did not mention mother and father in the findings. There were several qualitative studies found in the inquiry. In addition, the query produced numerous quantitative studies and topical articles, as well as two triangulated studies that had a descriptive phenomenological component.

Sample. The criteria for inclusion into the studies were (a) the focus of the study was parenting a child with chronic illness; (b) the studies included both mother and father and may have mentioned family life; however, that was not the focus of the criteria; and (c) the research design was qualitative or had a qualitative component.

Articles identified as qualitative research were reviewed. All methods of qualitative research were included in the study. Nine of the 11 designs were exclusively qualitative. Two of the studies were triangulated. The qualitative studies represented several different methods. There were three grounded theory studies, three phenomenological studies, one secondary analysis, two triangulation, and two descriptive qualitative studies.

The literature search yielded 11 studies to be included in the metasynthesis. During the course of the search, it was noted that there is a plethora of quantitative studies and topical articles on parenting and chronic illness. The articles chosen were all from nursing journals, although three studies had second authors from disciplines that included child life, medicine, and human development. Demographic and methodological characteristics of the articles in the sample are shown in Tables 1 and 2.

The 11 studies chosen were conducted in four different countries. Five of the studies were conducted in the United States, one in Japan, one in Germany, and four in Canada. The studies involved 533 participants, with 140 of those clearly identified as fathers. The remainder of the partici-

Table 1. Demographic Characteristics of Participants

Study	Author/Year	Sample Size	Age Range Child	Child's Illness
Mothers' Experience Living Worried When Parenting Children with Spina Bifida	Monsen (1999)	13 mothers	12-18 years	Spina bifida
"They Don't Leave You on Your Own:" A Qualitative Study of the Home Care of the Chronically Ill Child	Kohlen, Beir, & Danzer (2000)	5 families	4 months-9 years	Tracheomalacia, Hydrocephalus, Neurofibromatosis, Congenital Heart Defects, Diabetes
Mothers' Perceptions of Parenting Children With Disabilities	Johnson (2000)	10 mothers	Pre-school thru elementary school	Cerebral Palsy, Spina Bifida, Spinal Cord Injury, Growth Hormone Deficiency, Orthopedic Anomalies, Craniofacial Anomalies, Aperts
Hazardous Secrets and Reluctantly Taking Charge: Parenting a Child with Repeated Hospitalizations	Burke, Kauffmann, Costello, & Dillon (1991)	160 parents (130 w/ disabled children 30 w/o disabilities)	School Age	Cerebral Palsy, Physical Disabilities
Distress and Growth Outcomes in Mothers of Medically Fragile Infants	Miles, Holditch-Davis, Burchinal, & Nelson (1999)	67 mothers	0-16 months	Premature Infants, Bronchopulmonary Dysplasia, Congenital Heart Defects, Neurologic Deficits, Gastrointestinal Illness
Parents' Reports of "Tricks of the Trade" for Managing Childhood Chronic Illness	Gallo & Knafl (1998)	55 mothers 44 fathers	School Age	Diabetes, Asthma, Renal Disease, Juvenile Rheumatoid Arthritis (JRA)
Long Term Follow Up of Cerebral Palsy Children and Coping Behavior of Parents	Hirose & Ueda (1989)	28 mothers 12 fathers	22-29 years: Retrospective	Cerebral Palsy
Parents' Experience of Coming to Know the Care of a Chronically Ill Child	Jerrett (1994)	10 mothers 9 fathers	No age given	JRA
Parents' Perceptions of Caring for an Infant or Toddler with Diabetes	Hatton, Canam, Thorne, & Hughes (1995)	16 mothers 16 fathers	Infants and Toddlers	Diabetes
Caring for Chronically Ill Children at Home: Factors that Influence Parent's Coping	Ray & Ritchie (1993)	29 mothers 29 fathers	3 months-16 years	Apnea, Tracheostomy, Oxygen Dependent, Gastric Feedings, Dialysis, Venous Access
Critical Times for Families with a Chronically Ill Child	Clements, Copeland, & Loftus (1990)	30 mothers 30 fathers	1 year-18 years	Cystic Fibrosis, Diabetes, Cancer

parents were identified as mothers, with the exception of five families from one study with no indication of the parental role of the participants. The age of the children ranged from birth to 22 years of age. One study using older children was retrospective and asked the parents to reflect on parenting when the child was younger.

Data Analysis. The approach used for this metasynthesis on parenting children with chronic illness was based on Noblit and Hare's method (1988) found in their book

Metaethnography: Synthesizing Qualitative Studies. The approach consists of seven phases as listed below.

- *Getting started and deciding on a phenomenon of study.* The researcher chose parenting of a child with chronic illness as the area of interest.
- *Deciding what qualitative studies are relevant to the initial interest.* The researcher reviewed over 30 studies to narrow the selection based on inclusion criteria stated earlier.
- *Reading the qualitative studies.*

Each study was read and reread to identify key metaphors, themes, or concepts. Detailed notes were kept on these themes, concepts, and metaphors.

- *Determining how the studies are related to each other.* In this phase, the synthesizer made a list of the key metaphors in each study and their relations to each other. The term "metaphor" referred to themes, concepts, or phrases. Three different assumptions can be made about the relationships

Table 2. Methodological Characteristics of the Qualitative Studies Included in the Metasynthesis

Author	Discipline	Year	Country	Data Analysis	Qualitative Research Design
Monsen	Nursing	1999	USA	Heidegger	Hermeneutics
Kohlen, Beir, & Danzer	Nursing/Medicine	2000	Germany	Descriptive Qualitative	
Johnson	Nursing	2000	USA	Strauss & Corbin	Grounded Theory
Burke, Kauffmann, Costello, & Dillon	Nursing	1991	Canada	Morse, Glaser, & Strauss	Grounded Theory
Miles, Holditch-Davis, Burchinal, & Nelson	Nursing	1999	USA		Methodological Triangulation
Gallo & Knafel	Nursing	1998	USA	Thorne	Secondary Analysis
Hirose & Ueda	Nursing/Human Development	1989	Japan		Descriptive Qualitative
Jerrett	Nursing	1994	Canada	Benner	Phenomenology
Hatton, Canam, Thorne, & Hughes	Nursing	1995	Canada	Benner	Phenomenology
Ray & Ritchie	Nursing	1993	Canada		Triangulation
Clements, Copeland, & Loftus	Nursing/Child Life	1990	USA	Glaser & Strauss	Grounded Theory

between the studies to be synthesized. These key assumptions are “(1) the accounts are directly comparable as reciprocal translations; (2) the accounts stand in relative opposition to each other and are essentially refutational; or (3) the studies taken together present a line of argument rather than a reciprocal or refutational translation” (Noblit & Hare, 1988, p. 27). In this metasynthesis, the synthesis took the form of reciprocal translations because the studies were about similar themes. With reciprocal translations, each study is translated into the metaphors of the others and vice versa.

- *Translating the studies into one another.* As Noblit and Hare (1988) explained, “Translations are especially unique syntheses, because they protect the particular, respect holism, and enable comparison. An adequate translation maintains the central metaphors and/or concepts of each account in their relation to other key metaphors or con-

cepts in that account” (p. 28).

- *Synthesizing translations.* This involves creating a whole as something more than the individual parts imply. The translations as a group are one level of a metasynthesis. Next, the translations can be compared to decide if the same metaphors/themes or concepts can be encompassed into those of others. This is a second level of synthesis. At this point, the study was reviewed by an expert in qualitative research as a check in the analytic process.
- *Expressing the synthesis through the written word, plays, art, videos, or music.* The preface to the book written by Noblit and Hare includes the following poignant quotation. “When we synthesize, we give meaning to the set of studies under consideration. We interpret them in a fashion similar to an ethnographer interpreting a culture” (1988, p. 7).

The qualitative researcher must enter this endeavor well aware of the

responsibility to clearly synthesize the information and present it for the reader to make sense of the phenomena. In the metasynthesis, each parent’s words coalesce to provide the practitioner insight into the life of parenting a child with chronic illness.

Results

The 11 studies yielded a rich supply of metaphors. The first step was to construct a table of metaphors from each of the studies. During the construction of the table, seven themes evolved from the studies. The themes are listed in Table 3. Each of the themes is then illuminated through the rich quotations of the parents caring for their child with chronic illness.

Living worried. The term “living worried” is quoted in the title of one of the studies of parenting a child with spina bifida (Monsen, 1999); however, this theme appeared in five of the 11 articles as worry or anxiety by the parents. The parenting role includes some worry when parenting normally developing children. The parents of children with chronic illness have worry as a bona fide part of everyday life.

Often, worry began at birth. In Monsen's (1999) study, one mother of a child with spina bifida recalled events in the delivery room: "I remember Kenny being born, and I remember they wouldn't show him to me or anything.... I did not hear any crying.... I said is he ok? Is my baby ok?" (p. 160).

Worry while parenting a child with chronic illness is ever in the present as well as being projected into the future. The mother of a child with spina bifida shared this story:

"I can remember at least two birthdays if not three...the night before... she would ask me the night before the birthday 'When I wake up tomorrow and I am (four, five, six) can I walk?' ...she finally realized this was permanent. And I think for me that was the very hardest of any (birthday) that we have done" (Monsen, 1999, p. 161).

In four studies parents expressed concerns about the child's care when they were no longer able to care for their child. One mother talked about the child who was currently living with her. She said "...But when you get old and something happens to you what's going to happen to them?" (Monsen, 1999, p. 161). Overall worry about the child's future was clearly articulated in several articles. In the study by Hirose and Ueda (1990) parents of children with cerebral palsy stated the aging of the child brought on more anxiety about care. In this study the mothers expressed this concern about the future; however, it was not shared by the fathers in the study.

The phenomenon of worry had a broad spectrum that was described in several of the articles. Worry was not only a passive state that was expressed in words and actions. It also drove parents to action. Parents spoke of vigilance in their caregiver role. Parents were on guard, observing for changes in health status, problems at school, and concern about siblings.

The worry of the parents around health status change was articulated by one mother of a child with cystic fibrosis who recalled it as hard times. This mother expressed her worry in the form of questions. Clements, Copeland, and Loftus (1990) shared this quotation:

"...when to call the doctor, when to start the antibiotic? Do you start it if she sneezes once or do you wait till she sneezes twice? This is the hardest part of it all. I'm the one who makes that decision?" (p. 160).

Parents of children with chronic ill-

ness worried about the sibling from several aspects of concern. First of all, parents wondered about the impact of the chronic illness on their relationship with their well children. Second, they had concerns about how to maintain a normal family life, discussed under the topic of "survival as a family." Finally, parents worried if the siblings would care for the child with the chronic illness. Could the siblings manage the care of their loved one in the future when the parents were no longer able to care for their brother or sister (Hirose & Ueda, 1990)?

Worry about school was diffuse and present during the developmental milestones ranging from entering kindergarten to graduating from high school. "Anticipation of the child entering play school...caused considerable anxiety and worry for parents [of children with chronic illness]" (Hatton, Canam, Thorne, & Hughes, 1995, p. 574).

The parents of children with a variety of chronic illness spoke of the uncertainty associated with the worry. "It is always something" (Johnson, 2000, p. 131). Parents shared the constant uncertainty and the daily challenges in managing the illness.

In one study, a parent of a child with a variety of physical disabilities made the comment "...you expect the worst...something's going to happen" (Burke, Kauffmann, Costello, & Dillon, 1991, p. 43). These comments were specifically related to children receiving care that included invasive procedures including intravenous medications and chemotherapy. In relation to this worry, parents spoke of the experience of the learning professional providing care to their child. These learning professionals included nursing students or new medical residents. This situation enhanced worry around the procedures. "The first time we were there the person who was to start the IV tried five times.... He [the child] was suffering; he had tears come to his eyes. I insisted that they get someone else" (Burke et al., 1991, p. 43).

Staying in the struggle. Parents in several out of the 11 articles (Burke et al., 1991; Hatton et al., 1995; Hirose & Ueda, 1989; Johnson, 2000; Kohlen, Beier, & Danzer, 2000; Monsen, 1999) shared the strife of caring for a child with a chronic illness. Parents felt helpless when their child was discharged from the hospital. They were often overwhelmed by the care the child requires everyday. They expressed the immense responsibility

for the complex care for the child's very existence. Overwhelmed by guilt, parents vacillated between hope and defeat. Staying in the struggle for these families meant not giving up (Monsen, 1999).

"We wanted to get home to relax, to sleep in our own beds...but the impact of the total responsibility for our child suddenly hit us. We couldn't sleep...we were so anxious.... It was a total nightmare..." (Hatton et al., 1995, p. 573). These are the feelings relayed by parents of a toddler with diabetes.

"Being there, just in case" is expressed by parents in this way: "I do feel that kids get better care when a parent is there. You know what I mean? If someone is there, then you know what is happening" (Burke et al., 1991, p. 43).

The experience of parenting children with chronic illness evoked strong emotions in the parents to protect their child mixed with the desire to withdraw from the situation. Parents shared examples of feeling these emotions in all of the 11 articles. The following are examples of the range of emotions they were feeling.

Sadness was mentioned in several articles. One mom of a child with cerebral palsy said initially "I could not do anything initially but weep for a week" (Hirose & Ueda, 1990, p. 765). Some parents talked of emotional detachment "...I almost had to detach myself emotionally in order to deal with it. I am not proud of it" (Johnson, 2000, p. 130).

Anger emerged as an emotion expressed by some of the parents. The parents often focused their anger and frustration on the health care professionals caring for their child. One mom shared her frustrations as the lab tech made repeated attempts to draw blood. She said: "I literally screamed and then rushed from the room..." (Burke et al., 1991, p. 44).

One mother of a child with Juvenile Rheumatoid Arthritis (JRA) explained: "You go through feelings of anger or sometimes sadness; you go through the whole thing. The first year was just dreadful, it was a tempest..." (Jerrett, 1994, p. 1053).

Some parents described staying in the struggle by devising the "tricks of the trade." These tricks were developed as strategies for improving their ability to assess their child's condition accurately or implement prescribed treatments. "I follow medications to the T. We want him to be well and don't want to take any chances. We don't listen to others or read

Table 3. Themes

Study	Living Worried	Staying in the Struggle	Carrying the Burden	Survival as a Family	Bridge to the Outside World	Critical Times	Taking Charge
<i>Mothers' Experience Living Worried When Parenting Children with Spina Bifida</i>	Worry about birth, future always present	Exhaustion, hopelessness, overwhelmed hope, defeat, not giving up, deep disappointment		Worried how siblings will shoulder responsibility of the ill child			
<i>"They Don't Leave You on Your Own:" A Qualitative Study of the Home Care of Chronically Ill Children</i>		Helpless at discharge	Extremely burdened by care, carrying all responsibility	Home nurses give family time and integrate care into daily life	Mom unable to leave home and nurse is the bridge	Discharge from the hospital	Refusal of care from a new home care nurse
<i>Mothers Perceptions of Parenting Children With Disabilities</i>	Worry about the future, missing work	Self pity, emotional detachment		Close bond of the disabled child with the family; we are a family first	Only other parents can grasp the heartache, find a support group	Meeting or not meeting milestones	Advocate, rise to the occasion, fight for services
<i>Hazardous Secrets and Reluctantly Taking Charge: Parenting a Child with Repeated Hospitalizations</i>	Worry about procedures, learning professionals	Recycling grief Exhaustion, planned breaks	Exhaustion for designated parent usually the mother		In the provider parent relationship information not always shared		Vigilance, gaps in information
<i>Distress and Growth Outcomes in Mothers of Medically Fragile Infants</i>			Mother as primary caregiver must be flexible	Adapting treatment to make it fit with family life			Develop tricks of the trade to manage illness
<i>Parents' Reports of "Tricks of the Trade" for Managing Childhood Chronic Illness</i>		Tricks of the trade, adherence	Mothers have the tricks of the trade in their head every day				
<i>Long-Term Follow Up of Cerebral Palsy Children and Coping Behavior of Parents</i>	Anxiety of what happens at parents death	Weep for a week, could not think	Major burden carried by mother	Organize care and fit into family schedules	Initial isolation improves with clinic visits, support groups helpful	Diagnosis, infancy, turning age 5,18, going to school or not, parents too old to give care	
<i>Parents' Experience of Coming to Know the Care of a Chronically Ill Child</i>		Confusion, anger, turmoil, feel unprepared, overwhelmed		Multiple losses for the family, concern about sharing energy with all family members, pervasive influence in each member of the family	Isolation, being at odds with health care providers		Control time and be organized, increase confidence, parents accept managing illness is a daily job

Table 3. Themes (continued)

Study	Living Worried	Staying in the Struggle	Carrying the Burden	Survival as a Family	Bridge to the Outside World	Critical Times	Taking Charge
<i>Parents' Perceptions of Caring for an Infant or Toddler with Diabetes</i>	Anticipatory worry, future worry, stress	Immense responsibility, complex care, anger, fear, grief, guilt, overwhelmed	Mothers give up work, loss of ideal mom-child relationship, fathers rearrange schedules	Restriction of family activities, difficult to find time for siblings	Social isolation, accepting the lack of support from the family and friends, loss of support at discharge, trapped, vulnerable and afraid	Hospitalizations, diagnosis, Learning care, toddler, entering school, milestones	Taking charge of the situation, being assertive and advocating for the child
<i>Caring for Chronically Ill Children at Home: Factors that Influence Parent's Coping</i>	On guard constantly, perpetual demanding care		Mothers not able to work and carry the burden of caregiving				Parents walk a fine line between assertion and insulting the health care professional
<i>Critical Times for Families with a Chronically Ill Child</i>			Mothers are primary care givers, mother centered patterns		Religion and spirituality a support	Diagnosis, first year after diagnosis, learning symptoms, calling MD, rehospitalization or relocation	

books" (Gallo & Knafl, 1998, p. 98). These parents followed what the authors called strict adherence to the plan of care. Other families fell on a spectrum of adherence from strict to flexible. Gallo and Knafl (1998) suggest that mothers have to develop "tricks of the trade" to manage their child's chronic illness day to day and maintain family routines. Their "tricks of the trade" are in the parents' thoughts daily as part of the routine.

Carrying the burden. The focus of this metasynthesis was parenting a child with a chronic illness. During the literature search, the focus was on the key word parenting, not mother/father roles; however, seven of the 11 articles reported that the mother was the primary caregiver and "carried the burden" as stated by the mothers themselves (Hirose & Ueda, 1990). One mother shared: "My husband was alone with her once. And that was it. He's never stayed alone with her again" (Ray & Ritchie, 1993, p. 221). This places the burden of all the care on the mother and does not allow her to have a break from the routine and the responsibility.

The mother as primary caregiver often experienced exhaustion. One group of mothers shared their frustrations with the loss of an ideal mother-

child relationship due to the need to provide complex care to the child (Hatton et al., 1995). All articles used the phrase "carrying the burden" when describing the role of the mother as the primary caregiver of the child with a chronic illness.

One group of fathers described a closer bond with their child with diabetes due to the illness; however, they still identified the mother as the primary caregiver (Hatton et al., 1995). The author went on to speak of fathers who rearranged work schedules so they could come home to help with needles or blood tests.

Clements and colleagues (1990) reported that 30% of the 30 families in their study reported what they called mother-centered patterns. In this pattern, the mother assumed responsibility for the care of the household as well as for the chronically ill child. "The men don't have that inner strength that women do.... I think a woman is a lot stronger than a man. It's been proven over and over again. They [men] are strong physically, but mentally, they have no backbone" (p. 159).

The mothers in the Clements et al. (1990) study went on to share how they were resigned to the fact that their husbands would not help with care. "...he probably wouldn't be

able to do a good job of it anyway..." (p. 159).

Mothers often had to give up their jobs to care for the child with chronic illness. The mothers often had great difficulty finding babysitters. Once the sitter was found, the question arose, "Can I trust this person with my child?" The loss of a job was often socially isolating for mothers. It also had the potential to place a financial strain on the family.

Survival as a family. The impact of chronic illness was not only felt by the parents. The chronic illness has an impact on the whole family including extended family relationships. Siblings were often affected by the burden of the parents caring for a child with a chronic illness. Many of the articles talked about adapting as a family, and three specifically spoke about finding time for siblings and worry for their well being. Parents felt the lack of time spent with the siblings was having a negative impact on the children. The illness takes on a greater part of the parent's energy and time. Often the siblings begin to assume some of the responsibilities of the parents. One four-year-old child took on the role of alerting his parents when his sister was cyanotic and needed oxygen (Ray & Ritchie, 1993).

One pregnant mother of a child with diabetes explained, *"I am terrified about having another baby. Taking care of (the child with diabetes) is already like caring for two children.... I wonder how I can share my love and energy"* (Hatton et al., 1995, p. 574).

Repeatedly parents shared the challenge of managing the care and fitting it in to a normal family routine. Parents reported that increased organization around the therapy and a schedule allowed them to carry out family responsibilities (Jerrett, 1994).

Home care nurses helped many families ease the burden of care on family dynamics. One mother said the nurse *"gives the family a piece of normal life back"* (Kohlen et al., 2000, p. 370). Parents shared regrets about how they attempted to survive as a family. *"I wish I had not taken things so seriously.... I need to lighten up. We are a family first"* (Johnson, 2000, p. 133).

Bridge to the outside world. Parents described a loss of freedom. *"Being trapped...you can never get away. Never be free again. Like a prisoner, only the prison is the diabetes and the chains are the insulin and blood tests."* *"We never get out"* (Hatton et al., 1995, p. 573). Parents experienced loss of support systems because family and friends are reluctant and/or afraid to offer support or care for the child. Former support systems including babysitters are no longer available for the family. In some cases, it was by the family's choice to decline help as they did not feel comfortable leaving the child. In some instances, the support system was unwilling or unable to be there for the family.

Mothers who were not able to leave the home due to the overwhelming obligation of providing care found home care nurses to be the "bridge to the outside world" (Kohlen et al., 2000, p. 370). In another study, Johnson stated:

"Parents of children with a variety of chronic illness discussed the value of peer support groups. They stated that only a parent of a disabled child could grasp the feeling of heartache, resentment, guilt, failure, and fear that they experienced" (2000, p. 131).

Hirose and Ueda's (1990) study revealed that mothers of infants were supported by a few people such as spouses and relatives. This group of mothers received increased support when they began to regularly attend clinics at the hospital. They began to meet parents of children with similar

disabilities. Despite the support at the clinic, at times parents reported that all the information they need is not always shared with them by health care professionals. The omission of information given to parents would lead to gaps and frustration for the caregivers.

Some parents gained support from their religious beliefs and prayer. Clements et al. (1990) reported that 33% of the 30 families they interviewed stated that they received support from those beliefs. In the same study, 40% of the parents reported that the child with the chronic illness was a source of support for the family. The child's support and strength was what helped the family carry on with the daily duties. *"...I've just held him and said to him I'm so sorry you have to have this, sorry for what's going on. He's a great kid. He'll say, 'It's ok Mom' ...I get a lot of support from him"* (Clements et al., 1990, p. 159).

Critical times. Parents in six of the studies shared critical times during the parenting of a child with chronic illness. The first major grouping of critical times was around diagnoses and initial discharge home from the hospital. *"Parents feel helpless after the child's release from the hospital. They do not feel confident with their assessments of their child's condition"* (Kohlen et al., 2000, p. 369).

The initial impact of diagnosis was targeted as a critical time by 70% of the 30 families interviewed by Clements and colleagues (1990). *"I remember feeling everything was sort of superficial, like I was walking around in a dream..."* (p. 159). Adjustment at home was described as a time with "intangible losses" such as the loss of joy and the spark of life (Hatton et al., 1995).

The shock of the diagnosis was discussed in several studies. Isolation and fear were words seen repeatedly in the accounts of the time around diagnosis. In addition, several parents were severely depressed and expressed suicidal ideations. One mother of a child diagnosed with cerebral palsy said, *"I could not think at the time, I wanted to commit suicide with the child"* (Hirose & Ueda, 1990, p. 765). A father of a child newly diagnosed with diabetes spoke of creating a bonfire to clear away brush and having a strong desire to just walk in to the fire. *"...to disappear and end it all"* (Hatton et al., 1995). The early weeks were a time when parents contemplated suicide. *"I was driving across the bridge...and I sud-*

denly thought I can't go on with all this, I had the desire to drive into the oncoming traffic" (Hatton et al., 1995, p. 573). *"We get depressed too, like she does. We just try to go on and live every day"* (Johnson, 2000, p. 130).

The whole first year was the hardest to accept the problem, the care and the diagnosis for the future (Clements et al., 1990). In addition, changes in the child's condition were considered critical. Exacerbation of physical symptoms placed an increased burden on parents, especially at night. Clements et al. (1990) shared this mother's concern:

"When to call the doctor...? But during the night, when you're alone with the machines and the coffee and things then it gets scary, and do I get dressed and get ready to go or do I hang in there until daylight? Once daylight comes I feel safer, I do not know why, but I do" (p. 160).

The second grouping of events that are critical times occur during moments of major milestones for the child and their peers. Milestones not met are sources of frustration and a reminder of the child's chronic illness. The times are loosely defined as toddlerhood, entering school, and turning 18 years old. Each transition was unique in its success and challenges.

Increased physical strength, which on the surface would be a time for celebration, became a source of escalating struggles and conflicts for the parents of a toddler with diabetes. The invasive procedures and food challenges were exacerbated during the terrible twos and threes. One mom of a child with diabetes shared how she was reported for child abuse. *"A neighbor heard my 2-year-old screaming 'Don't do it Mommy... please don't hurt me anymore.' At 13 months when she was diagnosed she only cried"* (Hatton et al., 1995, p. 374).

Another critical time parents identified was the milestone of entering an organized school setting from preschool to kindergarten. Seventy-one percent of the 30 families in the study by Clements and colleagues (1990) shared their emotional distress at this critical time. The stress is often from the combination of the challenge by the parent to let go and the child's ability to care for him or herself on some level. The parent of an adolescent shared, *"I guess right now when she is trying to grow up and be on her own...and you find she did not take her pills...thinking she can stay up all night and then being sick the next day..."* (Clements et al., 1990, p. 161).

Changes in development often meant disequilibrium in the family, especially for those who are providing direct care for the child. Major milestones cause stress in the developmental progression of all children; however, parents of children with chronic illness face additional challenges.

Taking charge. As the role of the parent evolves, many discussed moving into the advocate role for their child's care. Burke et al. (1991) spoke of parents reluctantly taking charge. Within this concept were three layers of response: Vigilance and taking over, negotiating and calling a halt, and tenacious information seeking.

Kohlen and colleagues (2000) shared accounts of parents voicing strong opinions about the direction of care from home care nurses. If the nurse is not a regular, they requested that he or she not work with the child.

The concept of taking charge emerged in many of the studies. These phenomena included fighting for services for a child. Parents stated they must "rise to the occasion.... You are not a saint, just a parent.... Balancing the need to view the children as normal and the need to secure services for their special needs was an ongoing struggle for parents. Parents took charge in this situation but the situation was called 'parental straddling'" (Johnson, 2000, p. 4).

The move to reluctantly taking charge was evident in several of the articles. The parents share stories about times when medical professionals are unwilling or unable to meet the child's needs. As they reluctantly take charge, they "call a halt" (Burke et al., 1991, p. 44) to care when the child has had enough. Calling a halt, however, does not come without much angst from the parents. They worry about how they are perceived by the care providers. They "...didn't want to be one of those crazy screaming parents" (Burke et al., 1991, p. 44).

Another component of taking charge is seeking information. The parents balance the need to know with the worry they will offend or become estranged from the health care team. They valued the health care professionals' expertise; however, they wanted their experience and knowledge of their child's care recognized. "Parents bring something special to the decision – the personal element versus the scientific part" (Jerrett, 1994, p. 1054). "Parents viewed the health care system as both a resource and a constraint" (Ray & Ritchie, 1993, p.

221). They described the fine line between being assertive to assure care without alienating the professionals:

...sometimes they have you in an awkward situation. I highly respect their training, and we have met some wonderful people. But sometimes they are a little insulting to you. But you are afraid because... I can't be insulting. I can't be rude. I can't be assertive. I can't ruffle their feathers, because they might withhold care from my daughter (Ray & Ritchie, 1993, p. 222).

Discussion

The role of parenting a child with chronic illness has been examined in many studies using both quantitative and qualitative methods. The 11 qualitative studies included in this meta-synthesis provided insight into the role from the parents' point of view. The studies represented a compilation of experiences of parents who daily care for children requiring medications, treatments, and technology support every day of their lives.

"Qualitative metasynthesis is not a trivial pursuit, but rather a complex exercise in interpretation: carefully peeling away the surface layers of studies to find their hearts and souls in a way that does the least damage to them. Synthesists must analyze studies in sufficient detail to preserve the integrity of each study and yet not become so immersed in detail that no usable synthesis is produced" (Sandelowski et al., 1996, p. 370).

Conclusion

This analysis of the 11 studies allows the clinician to get a glimpse into the life of parents of children with chronic illness. Nurses interact with these parents on a daily basis, whether in the acute care setting, primary care office, or school setting. The parents shared common feelings around the diagnosis and management of the child's illness. The need for support during the early days was clear in the narratives of parents struck with grief and fear. The nurse can plan care for the child and family that includes built-in support systems and recognition of the stress felt by the parent. Exhaustion, constant worry, and carrying a burden are themes that show up repeatedly in all the studies. Deep depression with suicidal ideations also appeared as part of the phenomena parenting of a child with chronic illness.

The process of completing the metasynthesis revealed seven rich themes. In addition it brought to light

some findings that would perhaps become clearer with further research. The deep depression expressed by several parents may be one area where further research could be done. In addition, it is important for the nurse to remember the role of the mother in these 11 studies.

Based on these findings, the clinical nurse can be proactive to provide support systems for families, respect their full range of emotions, and prepare to work with them as team members in the management of their child's care. Special emphasis must be placed on the mother because she is identified as the one who "carries the burden of care for the child with chronic illness." Support and caring can go a long way to ease the burden of parents who "live worried" caring for children with chronic illness.

Future research may look at understanding the role of the nurse in support of this group of parents. Often isolated and overwhelmed, these parents may look to the nurse for help with technical care as well as coping strategies. The nurse may find him or herself in the unique role of care provider, teacher, and support person for these families. Sensitivity to the complex needs of the child and the parents is a key component of nursing care for children with chronic illness.

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