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Parenting Foster Children With Chronic Illness and Complex Medical Needs

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The experience of parenting foster children with chronic illness and complex medical needs was explored in a phenomenological inquiry with 10 foster families. Thirteen participants currently fostering chronically ill children with complex medical needs were interviewed. Recorded interviews were transcribed and analyzed using van Manen's method. Data analysis yielded five essential themes: Foster parents described being committed to the child in their care, coming to know the needs of a medically complex foster child, and identifying effective and ineffective interventions encountered through day-to-day living with a medically complex child. Furthermore, they shared what it was like to experience loss of a child through relinquishment and death. Last, for these parents, fostering children with complex health care needs was a life-changing experience. The findings show that parenting a chronically ill foster child with complex medical needs is a multifaceted experience having implications for multiple disciplines.

Keywords: *chronic illness; foster parenting; phenomenology; van Manen*

Most children who enter the U.S. foster care system have suffered physical, emotional, or sexual abuse (Stahmer et al., 2005) or have been neglected in having their physical, emotional, or medical needs met (O'Hara, Church, & Blatt, 1998). Many of these children exhibit behavioral, emotional, developmental, and medical/physical problems (Carlson, 1996; O'Hara et al., 1998) and have a higher-than-normal incidence of acute and chronic health care needs (Gorski et al., 2002; Simms, Dubowitz, & Szilagyi, 2000). Consequently, few families today are willing to provide care to foster children.

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Two major issues that contribute to the small number of foster care homes and capable foster parents include recruitment of foster parents and attrition of foster parents from the system (Chipungu & Bent-Goodley, 2004; Pasztor & Wynne, 1995). Difficulty with recruitment of foster families has been found to be associated with the low value placed on child care, as well as the trend of the dual-income family and, more recently, the extensive demands placed on the foster parent. Foster parents are expected to not only provide for the day-to-day needs of the child but respond to the child's emotional and behavioral needs, arrange and transport the child to medical and counseling appointments and court hearings, and advocate on behalf of the child and arrange visits with birth parents (Chipungu & Bent-Goodley, 2004). Furthermore, low reimbursement rates, the lack of training and support, inadequate respite care, the increasing complexity of children's problems, and foster parents' retirement from the system (aging out) are causes of attrition.

Nurses in all settings work with families. One important aspect of nursing is the emphasis placed on caring for the family as a unit. Thus, it has become common for nursing to ascribe a family-centered model of care for families with children. Although most nurses typically apply this model of care to traditional families who have a child with or without a chronic illness, they have been inconsistent in applying this approach to families with foster children. Moreover, many nurses have misconceptions about the nature of foster care and the experience of being a foster parent (Barton, 1999).

Parenting Chronically Ill Children

Advances in medical technology and nursing care have improved survival rates for children with chronic illness and complex health care needs. The 1994–1995 National Health Interview Survey on disability data estimates that approximately 15% to 18% of children in the United States are affected by chronic illness (Newacheck et al., 1998). It is likely that rates of chronic illness in children are higher, but childhood chronic conditions are now defined differently, and recent trend data are not comparable with 1994–1995 survey data (Perrin, Bloom, & Gortmaker, 2007). However, specialized health care needs data are now being captured, and van Dyck, Kogan, McPherson, Weissman, and Newacheck (2004) report that the National Survey of Children With Special Health Care Needs shows that 13% to 18% of U.S. children have existing special health care needs.

Because the care of children with chronic illness and special health care needs has shifted from the hospital to the home setting, parents (now the

primary caregivers) are reporting the stressors and challenges affecting the family. Financial, physical, and emotional stressors, including feeling anxious and uncertain about the child's condition as well as seeking normalization, are hallmarks of this experience (Deatrick, Knafl, & Murphy-Moore, 1999; Ratliffe, Harrigan, Haley, Tse, & Olson, 2002). Moreover, parents describe their experience as a developmental and continual process of adaptation (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003).

Foster Parenting

Current estimates show that there are more than 520,000 children in the U.S. foster care system (Administration for Children and Families, 2006). Most children who enter foster care have behavioral, developmental, medical, or physical problems, many of which are chronic. In some instances, it is a lack of resources and support (Sobel & Healy, 2001) or the child's unique health problem, such as a genetic defect or chronic medical condition, that creates a situation in which biological parents are unwilling or unable to provide care for these children (Carlson, 1996; Simms, Freundlich, Battistelli, & Kaufman, 1999). As a consequence, a child who needs specialized care may require foster home placement with parents who have specific training and skills to provide hands-on care.

Many foster parents are similar to biological parents in their reluctance to accept the responsibility associated with parenting medically fragile children, and most do not have the necessary skills. Ward (1998) reported that almost 35% of the families licensed to provide foster care in the United States do not have foster child placements because they lack the desire or skill to care for children with special needs. Consequently, the decrease in the willingness and ability of foster parents to provide care to medically complex or fragile children presents an already-overburdened foster care system with even more difficult and pressing concerns.

An additional problem is that there is no gold standard to ensure that training is appropriate to the special needs of the individual child. Furthermore, although foster parent pretraining programs have been identified as an important aspect in the recruitment and retention of foster parents (Baum, Crase, & Crase, 2001; Orme, Buehler, McSurdy, & Rhodes, 2003), research fails to capture the knowledge that foster parents need in order to be successful in parenting chronically ill children with complex medical needs. In addition, nurses' misconceptions about foster parenting continue to hinder the application of a family-centered care approach to these families.

Promoting the health and well-being of foster children requires that the nurse have knowledge of the foster-parenting experience, make an effort to connect with the foster parent, and develop a trusting professional relationship (Sobel & Healy, 2001). Nurses have yet to view the experience from the perspective of the foster parent. To view the experience through the lens of the foster parent is a beginning step to gain understanding of his or her world.

Method

Phenomenological inquiry using van Manen's methodology (1990, 1998) was employed for this study. This method is particularly suited to the study of lived experience research because of its focus on description, interpretation, and meaning.

Participants

Appropriate institutional review boards were consulted, and all participants signed an informed consent.

Purposive sampling using criterion and snowball techniques served as the mechanism to obtain participants for this study. The participants met the essential criterion of parenting foster children with chronic illness and complex medical needs for at least 6 months. Participants were obtained through networking with those who knew others in the same situation. Friends, colleagues, and health professionals who knew foster parents who met the study criterion, as well as foster parents who knew other foster parents who were parenting chronically ill foster children with complex medical needs, aided the identification of participants.

The participants consisted of 13 foster parents who described the day-to-day experience of parenting chronically ill foster children with complex medical needs. Seven foster mothers were interviewed individually; three interviews included both the foster mother and the foster father. All participants were married and White, and all lived in a central region of one state in the northeastern United States. Because of the caregiving responsibilities associated in parenting and caring for the foster children, two mothers described themselves as actively practicing nurses, and one foster mother described herself as an actively practicing physical therapist. Additional foster parent participant demographic information is depicted in Table 1. The years of experience parenting a foster child with chronic illness and complex medical needs ranged from 8 months to 20 years. All foster children had multiple health problems (see Table 2). Six families had adopted children

Table 1
Foster Parent Participant Demographics

Participants	Age	Education	Reported Employment Status
10 foster mothers	24 to 66 years	GED to bachelor's degree	Homemakers, foster parents
3 foster fathers	29 to 66 years	High school graduate to master's degree	Employed outside of home, one retired

Table 2
Foster Children Demographics

Age	3 months to 16 years		
Race	Primarily African American Caucasian (<i>n</i> = 3) Native American (<i>n</i> = 1)		
Medical diagnoses	Apnea Asthma Cerebral palsy Cognitive developmental delay Colitis Fetal alcohol syndrome Gastroesophageal reflux disease		Hirschprung disease Hydrocephalus with ventricular-peritoneal shunt Physical developmental delay Respiratory insufficiency Seizure disorder Spina bifida Stroke
Complex health care needs	Central line care Colostomy care Gastric tube Gastric tube feedings Intravenous medication administration Intravenous therapy		Oral Physiological assessment Physical therapy Tracheal suctioning Tracheostomy care Urinary catheterization Ventilator management

Table 3
Number and Relationship of Children to Parents of Each Foster Family Household

Foster Family	1	2	3	4	5	6	7	8	9	10
Biological children	0	2	3	3	2	3	4	0	2	4
Adopted FC	0	1	1	1	1	0	0	1	3	0
FC without CN	0	0	0	0	1	0	0	0	1	0
FC with CN	5	1	1	1	2	1	2	1	1	2

Note: FC = foster child; CN = chronic health care needs.

with complex health care needs whom they had previously fostered. All but two families had biological children in the household. The number and relationship of children to parents of each foster family household are shown in Table 3.

Data Collection and Analysis

Data were collected in participants' homes and at a children's hospital by use of an unstructured interview strategy that was guided by one broad interview question, probes, and open-ended clarifying questions. Each participant was interviewed once. The length of time for the interviews varied from 45 min to 3 hr. The interviews were audiotaped and later transcribed verbatim by the investigator. Each written transcript was compared with the audiotape for accuracy, and any errors in transcription were corrected. Although no particular approach was used to transcribe the data, words spoken in emphasis were typed in uppercase letters. Specific medical interventions performed on the child, gestures, emotions, laughing, and so on, were noted in parentheses. Elongated words or expressions were written out using several dashes (e.g., *um—m*).

This study used van Manen's process of data analysis (1990, 1998). According to van Manen (1998), data analysis is an activity that involves "reflecting on essential themes which characterize the phenomenon" (p. 30). Data analysis was a circuitous process in which reflection was initiated with the first interview and then continued concurrently with data collection and included listening to audiotapes and reading of transcripts multiple times. Initially, each transcript was read to obtain a sense of the whole, after which each transcript was broken down line by line into parts. Significant statements were highlighted on the original transcript, with keywords recorded in the margins. Using a four-column-table approach, significant statements that were abstracted from the whole were placed into the first column. The words contained within the significant statements were then varied and placed into the second column, after which the varied words were raised to a higher level of abstraction through the development of a formulated meaning, which then was placed into a third column. Key elements then were abstracted from the statements, clustered, and recorded in the fourth column. This extraction process is shown in Table 4.

From the key elements and through recognition of similarities, meaning units were identified, then grouped to construct theme clusters. Theme clusters were then sorted according to relationships and raised to a higher level of abstraction to construct essential themes. This identification process is

Table 4
Extraction Process

Original data	<p>She was born premature with a prenatal drug history and they didn't think she'd be able to develop normally. I didn't see why she shouldn't be given a chance.</p> <p>I knew from the moment he opened his eyes in the hospital and looked at us with those big beautiful eyes that I wanted him. He opened up those eyes and he had me right there.</p>
Significant statements	<p>They didn't think she'd develop normally. I didn't see why she shouldn't be given a chance.</p> <p>I knew that I wanted him when he looked at us with his big beautiful eyes.</p>
Formulated meanings	<p>Foster parents believe every child deserves a chance to develop. For foster parents there is a defining moment of awareness when they experience a connection with a child.</p>
Key elements	<p>Hearing the story</p> <p>Seeing the child</p>

represented in Table 5. Data analysis was enhanced through exploration of the professional literature and artistic resources such as poetry, music, and works of art.

Four operational techniques were employed to support methodological rigor and ensure trustworthiness, as identified by Speziale and Carpenter (2006). Trustworthiness was enhanced through intersubjective communication with peers and other qualitative researchers. A qualitative research expert validated the appropriateness and usefulness of the unstructured interview guide and potential probes. Each interview was audiotaped and transcribed. Credibility was enhanced through prolonged engagement with the subject matter and participants' recognition of their personal experiences. Three foster parents validated the essential themes, theme clusters, and meaning units. Confirmability was established by leaving a clearly written decision trail. This seven-phase abstraction process involved the transcription of raw data; the identification of significant statements; the formulation of meanings; and the identification of key elements, meaning units, theme clusters, and essential themes. Last, coded data were developed indicating the location of supportive data for each theme. The ability of findings to fit into contexts beyond the study and have significance to others in similar circumstances was enhanced through discussion with a retired foster parent, external to the study. This retired foster parent stated that many similarities exist between her experiences and the experiences and feelings described by the participants.

Table 5
Identification Process of Elements, Units, and Themes

Key elements	Personal goals	Awaiting
	Balancing needs of children	Hearing the story
	Encouragement from others	Seeing the child
	Determining ability	Child's response
	Accuracy of information	Developing confidence
	Family sacrifice	Intervening
Meaning units	Influencing factors	
	Accepting medical complexities	
	Connecting with a child	
	Advocating for the child	
Theme cluster	Choosing to foster parent	
Essential theme	Committing to parenting a foster child with chronic illness and complex health care needs	

The findings of this study represent one group of foster parents who lived within rural settings in a northeastern state in the United States. Limitations include the composition and representativeness of the study population because there may be other foster parents in the United States and other countries with different intentions, motivations, and experiences. An additional limitation is that seven of the interviews were conducted with primary caregivers, whereas three interviews were conducted with couples. The perceptions of nonprimary caregivers may provide differing insights.

Findings

Five interwoven themes emerged from the data. Each major theme contains one or two theme clusters and several meaning units that compose the broader theme (see Table 6). The essential themes that form the structure of the phenomenon are as follows: committing to parenting a foster child with complex needs, coming to know the needs of a medically complex foster child, intervening, sensing the loss of a foster child, and becoming. Foster parents' verbatim accounts are included as examples of the meaning units that support each main theme.

Theme 1: Committing to Parenting a Foster Child With Complex Medical Needs

Theme 1—committing to parenting a foster child with complex medical needs—shows that parenting foster children with chronic illness and complex

Table 6
Theme Cluster and Meaning Units of Each Essential Theme

Theme 1: Committing to parenting a foster child with complex medical needs	
Choosing to foster parent Influencing factors Accepting medical complexities Connecting with a child Advocating for a child	
Theme 2: Coming to know the needs of a medically complex foster child	
Caregiving Learning as student Caring as novice Experiencing the child Adapting to change	
Theme 3: Intervening	
Effective interventions Physical support Emotional support Spiritual support	Ineffective interventions Health care coordination Continuity of care Attitudes of professionals
Theme 4: Sensing the loss of a foster child	
Relinquishment experience Feelings Preparing for relinquishment Remembrance	Near-death/death experience Feelings Remembrance
Theme 5: Becoming	
Self Identity Future Valuing	

medical needs requires a high level of commitment that is influenced by many factors. Foster parents described the factors that influenced their decision to parent foster children with complex medical needs. First, they revealed that they chose foster parenting as a means to meet personal goals, which also caused them to question whether taking on such responsibility was in the best interest of the family, specifically, their biological children. Parents also questioned their ability to balance the needs of their biological children with those of the foster children, and they expressed grave concern that the experience could negatively affect their biological children. One

foster mother stated, "I worried about slighting our own kids. Ya know? Whatever we decided to do. That was the hardest thing to deal with." Foster parents also revealed that the encouragement and support provided by friends and acquaintances influenced their decision to become foster parents. By pointing out parenting strengths and acknowledging positive parenting attributes, friends and acquaintances gave parents the confidence and courage to take on foster parenting.

Determination of ability, accuracy of information, and family sacrifice were the elements that influenced the foster parent to accept a child's medical complexities. Before assuming the care of the children, most foster parents were unaware that the majority of children in the foster care system had unmet physical and psychological health care needs, and they had no previous experience in parenting a child with a chronic illness. Then, after accepting a child placement and welcoming a child into the home, many foster parents perceived that they had been provided inadequate, inaccurate, and deceptive information about the child's health. Although they believed that when taking on the child, they had gone in with eyes wide open, they had not anticipated that the child's health care needs would be more extensive than what they were told. Moreover, parents were unprepared for the degree of sacrifice and depth and the breadth of change that were required in parenting such children. This knowledge came to light in hindsight. One foster mother expressed,

When she first came to us, they said she was going to be a pretty normal child . . . which I think they really pulled the wool over our eyes because it wasn't long after we got her, she ended up getting her G-tube, and it was one thing right after another, after another.

Feeling connected to a child occurred rapidly, involved the senses, and was strengthened by the way in which the child responded to the parents. Parents were acutely aware of the moment in which they felt a bond with the foster child. Awaiting, hearing the story, seeing the child, and witnessing the child's response were keys to the bonding experiences, as expressed by one foster mother:

I just knew . . . I mean . . . I knew from the moment he opened his eyes in the hospital and looked at us with those big beautiful eyes that I wanted him. He opened up those eyes and he had me right there.

Taking on the responsibility of parenting a chronically ill foster child required parents to advocate on behalf of the child. Child advocacy required parents to be confident of their knowledge about the individual child's

physical and psychological needs. Developing confidence was an evolutionary process that occurred as foster parents became accustomed to providing the child's care and as they observed the child's response to that care. One foster mother stated,

Sometimes it was hard for me to ask questions because I didn't want them to think I didn't know. I didn't want to sound stupid to the doctors. That's not the case any more. Now if I have something to say, well . . . let's just say, I say it.

As a result of knowing what did or did not work well in the care of the child and feeling confident in their knowledge, parents began to first question, then direct, the care of the child provided by others. Parents who were once reluctant to speak out on behalf of the child were no longer silent, and they frequently intervened to ensure that health professionals provided appropriate, timely medical and nursing care. Diligence and persistence were the hallmarks of intervening experiences.

Theme 2: Coming to Know the Needs of a Medically Complex Foster Child

Theme 2—coming to know the needs of a medically complex foster child—describes the foster parents' process of learning to care for a medically complex child. Before receiving a child into care, foster parents took on a student role. They attended trainings (formal training programs) held by the foster care agency, or they received instructions from nurses at the time of a child's discharge from the hospital. Trainings were designed to teach prospective parents how to manage specific medical equipment, such as tracheostomies, catheters, gastric tubes, and nasogastric tubes. Because most did not have experience in providing care to ill children and had never performed medical procedures, feelings of fear, anxiety, and uncertainty emerged. These fears were allayed through perseverance and repetition and eventually yielded skill mastery. Competently performing basic skills formed a foundation for learning more advanced skills, after which parents developed confidence.

The ever-changing, increasingly complex health care needs of the foster child required parents to learn new psychomotor skills, and it caused a reemergence of uncomfortable feelings. Required to continually adapt to change, parents felt overwhelmed. One foster mother described her experience:

The apnea monitor . . . I could handle that, but she broke us in because, first, it was the apnea monitor, then it was the G-tube, and you know, I cried before

each new thing. "I can't do this," I said, "I can't handle a G-tube," and I carried on with each new thing.

Foster parents as novice caregivers felt uncertain when providing care to the child in the home for the first time. Although they had received supervised instruction, it was providing the hands-on care in the home that was most important in adapting to the child's care. Learning the most effective, developmentally appropriate caregiving strategy was a process of discovery for parents. A foster mother stated, "I learned what I needed to do, but it wasn't 'til I was doin' it, actually doin' it with her, that I learned the best way to do it for her."

Providing care for a medically fragile child was viewed as more than a set of caregiving tasks to be performed at set intervals. Caring for the child required listening to one's intuition, gaining an understanding of the child's personality and behavioral characteristics, and placing the child's symptoms within previous situational context. Through experience with the child, parents spoke of simply knowing when something was "just not right," when they needed to be diligent in caring for the child, and when to go with their gut feelings in seeking medical care. Over time, parents came to understand the child's personality and unique behaviors and the significance of those unique behaviors. Noting subtle changes in the child's behavior allowed foster parents to be proactive in responding to new and evolving health care needs and in seeking appropriate medical care. When drawing on knowledge from previous illness experiences, parents placed reemerging symptoms within that situational context and aggressively sought out medical care. One foster father stated,

The child, he lives in danger all the time. You really need to get to know the child. They give you cues, but if you don't know the language, didn't learn the language, you can't respond in the right way, and that can be detrimental.

Intuiting, knowing behavioral cues, and making contextual judgments were thus inherent in caregiving.

Parenting these foster children required adaptation to a child's growth and development and ever-changing health care needs. Moreover, parents expressed an array of feelings associated with the changes in a child's health status, and they described how they coped and accepted the changes. One foster mother described her experience like a "roller coaster, an emotional roller coaster," because she was never sure what was "gonna happen next."

Theme 3: Intervening

Theme 3—intervening—demonstrates the significance of professional and family interventions, and it differentiates between those that were effective and ineffective. The participants identified supports and interventions that were helpful and unhelpful in caring for their foster children. They discussed their inability to access much-needed services, as well as their rationale for not tapping into services that some viewed as potential supports. Although most primary caregivers were foster mothers, participants viewed parenting a foster child with complex medical needs as a two-parent responsibility in which the spouse provided the most consistent and significant support. Furthermore, some parents viewed respite services and in-home nursing as being essential to maintaining physical and emotional health. A brief time away from the responsibilities of providing care to the child offered foster parents an opportunity to rest and restore themselves.

Although home nursing care provided relief from the continuous demands of complex caregiving and most parents viewed it positively, some foster parents held conflicting feelings regarding respite care. Parents believed it to be valuable service in theory, but philosophical beliefs about parenting were a deterrent. Furthermore, locating qualified, knowledgeable respite caregivers was difficult, and most parents did not know where to begin to look for this kind of help. One foster mother stated,

We can respite as much as we want. I mean, if you can find a family that was willing to do that . . . You're the one who has to find the family. . . . It entails finding a family, someone to agree upon it, and making sure they're trained. It's as easy as that . . . and as hard as that 'cuz even though you only have to do those three things, sometimes you can't find a family to agree on it and then, of course, if they do, you might not feel comfortable . . . or they might not feel comfortable dealing with all the medical things anyway.

Discussions surrounding home nursing care were volatile. Parents were affected by the nursing shortage, the rapid turnover of nurses, and the need to train nurse in the care of the child. One foster mother stated her frustration related to home care nursing:

Things are really hard with getting and keeping nurses. . . . I just switched agencies because the first agency I was working with had a lot of turnover. One nurse, I said, "You don't need to come back," and I did train one nurse, and as soon as she knew what to do, she accepted a full-time job at one of the hospitals, and I had to start training a new one all over again.

Parents viewed the emotional support provided by others as being essential in helping them cope with the uncertainty of parenting a medically fragile child in the home and throughout a child's hospitalization. Parents highly valued the nurse who gave a hug or was present throughout moments of stress and uncertainty. More important, parents wanted to have their opinions about the child's care respected. Parents felt valued and supported when physicians and nurses asked for their input about the child's care.

Foster parents sought spiritual support through prayer and a religious community when managing day-to-day living and caregiving responsibilities. Prayer, a daily activity for most parents, provided the comfort needed to manage the many stressors of complex caregiving. One foster mother shared, "God gives me the strength to go on with taking care of my family and keeping me on track." Through prayer, parents felt peace and gained an inner strength to manage the uncertainty of a child's medical condition.

Theme 4: Sensing the Loss of a Foster Child

Theme 4—sensing the loss of a foster child—provides insight into what it is like for a foster parent to lose a child through relinquishment or death. Foster parents described their experiences and feelings associated with relinquishing a child to adoption, another foster care home, or reunification with birth parents. For these parents, a deep sense of loss and feelings of depression were linked to planned and unplanned relinquishment experiences. The parents' descriptions highlight that feelings of anger, powerlessness, uncertainty, grief, and guilt were predominant. Foster parents also felt powerless and angry when the judicial system, without consideration of their perspective on the child's readiness, ordered a foster child to be reunited with biological parents or a family member. Moreover, parents described feeling uncertain whether the care provided by others would equal their care. One foster mother said,

I've had the experience where you're goin' along takin' care of the child, and before you have time to get yourself ready, well, the whole family ready, you're told the child's goin' home whether you think the child's ready or not, or you're ready or not, and that makes me angry 'cuz there's just nothing you can do. . . . When they go, you wonder, are they getting what you were giving them?

The participants grieved the loss of each relinquished foster child. The grief experience was described as one similar to the grief experienced with the death of a loved one, a feeling of intense sadness because the child was

no longer physically present. One foster mother stated, "We actually went through a grieving period like you would with any death in the family . . . not to have him there, ya know was VERY DIFFICULT, and we did, the whole family went through a grieving period."

These feelings led some foster parents to take a break from foster parenting to heal emotional wounds or choose to parent those children who were less likely to be adopted or reunited with biological parents or family members. The foster children chosen were those who had been abandoned or had exceedingly complex health care needs.

Although parents reported feeling angry, powerless, and grief in all relinquishment situations, feelings of guilt were particularly strong when requesting a different caregiving arrangement. Even though they did not feel personally competent in providing the child's care, they worried that the decision to relinquish the foster child may not be in the child's best interest.

The foster parents in this study described the psychological and physical preparation that they underwent to ready themselves and their family to relinquish a child to another caregiving arrangement. Relinquishing a child to another's care was an intense, highly charged experience, described as "an emotional roller coaster." Many participants prepared themselves psychologically when making the decision to be foster parents by reminding themselves that fostering children was a temporary arrangement and that relinquishment was part of the job.

Focusing on tasks was the way in which most foster parents emotionally dealt with preparing to relinquish a child to another's care. They gathered the child's belongings and taught new caregivers about the care of the child. Focusing on concrete tasks helped parents to manage feelings of grief and loss when waiting for the day of relinquishment.

The participants in this study also described the importance of remembering what each child meant to them. Parents chronicled the growth and development of the foster children and their families in photographs and reported being constantly aware of all children parented after relinquishment. The memories of each child were stored within photo albums as well as their minds. Moreover, these parents experienced delight in reminiscing with the researcher about each special foster child. Remembrance and memorabilia were ways to express feelings of sadness and facilitate resolution of grief. One foster mother recalled,

I know the first one was . . . we had this incredible bond. . . . I loved him so much. . . . I'll just never forget putting the outfit on him that last time. I'll never forget putting him in the car seat and getting him to where I was to meet the caseworker, and ya know, I just thought I couldn't let him go.

These families described personal experiences and feelings associated with the foster child's death or near death. The recovery of a child from each medical crisis was characterized as being uncertain at best, and foster parents had a difficult time coming to terms with the possibility that a child may not recover. Moreover, the death of a foster child was described by the foster parents as an excruciatingly painful experience, one in which they were unprepared physically and emotionally. These foster parents experienced shock and feeling overwhelmed, denied that a child may die in their care, and felt guilty and grieved with a child's death.

The unexpected death of a foster child emotionally devastated the participants. Three foster parents in this study described the experience of finding a lifeless child in their care. Reaching out to hold a dead child and gently cradling the child in their arms shows the intense connection between foster parent and child. Moreover, finding the words to express feelings of anguish, grief, and despair with the death of a child was difficult. One foster parent described the experience, with hesitation:

The first one was an awful experience for me because she had been our first severely involved child . . . and for some reason . . . I hadn't prepared in my mind for her passing away. . . . I think I knew she would, but I really didn't prepare myself in any manner . . . and I got up and found her and she had passed away during the night and that . . . that was just a, a, . . . awful experience. It was a shock. I kept thinking, "This CAN'T be happening." . . . It was like my brain wasn't lettin' it sink in, and at the same time, I remember reaching for her, and then I just . . . I just held her in my arms and cried.

The participants in this study described the importance of remembering what each child meant to them throughout the fostering experience, and they shared photographs of each child. Foster parents also reported being constantly aware of the child after his or her death, and they chronicled the illness experiences of each child for this research. Reflecting on the downward spiraling of the child's medical condition, foster parents reported feeling guilty and blaming themselves for the child's death. One foster mother questioned, "Did I do enough? Was there one more thing I could have done?" Moreover, it was the health care professionals who offered support and solace and told these parents that they did everything possible for the child and should not feel responsible for a child's death, which helped foster parents deal with the loss.

Theme 5: Becoming

Theme 5—becoming—shows that fostering children with complex health care needs is a life-changing experience. Changes that occurred in identity as a result of committing to parenting foster children with chronic illness and complex medical needs and a sense of becoming the people whom they were meant to become were hallmarks of these fostering experiences. Parents described lifestyle changes, as well as changes in personal characteristics, their role, and a reformulation of identity, as a result of the fostering experience—and they expressed no regret. For example, those who were once shy and acquiescent became assertive, confident child advocates and consequently expanded the definition of the parenting role of teaching, guiding, nurturing, and protecting to include responsible caregiving.

This change in role was inevitable because expertise developed in the care of the foster child. Furthermore, the changes in relational roles and parenting philosophy that occurred were brought to light. The identity of these parents changed from that of parent to that of attentive parent and from foster parent to expert practitioner in the care of medically fragile children. One foster mother stated,

I just wanted to love her, help her progress, and get over her obstacles, but it turned into a challenge, not one we were necessarily up to, because when we became foster parents, I wasn't expecting anything so medical. . . . Who'd a thought we'd be doing what we're doing for her today? . . . Takin' care of the Broviac [catheter], TPN [total parenteral nutrition], G-tube, teachin' home nurses how we do things.

The foster parents in this study also valued children and children's rights. They believed that every child deserved to be part of a family with loving parents, and they believed in making sacrifices for others. In making these sacrifices and sharing their hearts and homes and their love and care with medically fragile children, their biological children came to internalize these values. One foster mother expressed how the fostering experience affected her family:

It's taught us an awful lot about people who are . . . more needy than we are. . . . We've learned to be content to miss a function or whatever to give the children the care they need. So it's taught us to be less self-oriented. So it's building our characters in that way.

Finally, the foster parents in this study held a clear vision for the future of their foster children, biological children, and themselves. In anticipation of the future, the participants disclosed personal dreams and aspirations that

were intricately interwoven with past and present parenting experiences. Their future was tied to their biological and foster children and the image that all children would succeed in reaching their potential.

Discussion

It is evident that the foster parents in this study were committed to meeting the daily challenge of parenting and caregiving, as well as the needs of the family. Insight into this highly personal, multifaceted experience showed that the reasons for taking on the foster parent role were similar to those discussed by Cole (2005) in a study relating the context of caregiver motivation and infant attachment. Committing to a child begins when people decide to become foster parents and give careful consideration to the potential impact on their biological children. Weighing pros and cons, accepting medical complexities, connecting with the child, and practicing advocacy are hallmarks in committing to a foster child with complex health care needs. Of interest are reports that information from child welfare agencies about a child's medical condition was inaccurate and that foster parents believed that agencies were deliberately deceptive in placement practices. This finding is not unique to this study, given that in Stromberg's study (1994), 25 of 30 medically specialized foster families reported agreeing to parent medically complex children strictly by accident.

For foster parents, coming to know the child's needs was a learning process. Initially finding themselves in a student role, then as an inexperienced novice, parents were fearful of having taken on the responsibility. It was through day-to-day living and continual adaptation to change that these parents became the experts in the child's care. Parenting these children was a highly charged emotional experience in which feelings of uncertainty, frustration, eager anticipation, and anxiety emerged and needed to be managed. Similarly, biological parents of chronically ill children struggle with managing these types of feelings (Jerrett, 1994; Johnson, 2000).

Through a variety of caregiving experiences, foster parents developed organizational skills and provided individualized care based on the needs of the child. Over time, they became dedicated child advocates and demanded appropriate, timely medical and nursing care from health care professionals (Lauver, 2005). Likewise, reports by biological parents have shown that established routine and advocacy are important aspects of parenting chronically ill children. Gallo and Knafl (1998) described tricks of the trade to manage the child's illness on a day-to-day basis, and Jarrett (1994) reported a process of coming to know the needs of children with juvenile rheumatoid

arthritis. Moreover, Burke, Kauffmann, Costello, and Dillon (1991) described how parents moved into the advocate role when a child experienced multiple hospitalizations.

Helpful and unhelpful interventions were also identified by participants. The interventions most helpful to foster parents were those of physical and emotional support provided by the spouse and nurses, spiritual support, and respite care. Florian and Findler (2001) reported similar findings in their discussion of helpful interventions during critical times for families with chronically ill children, and Gavin and Wysocki (2006) reported the significance of paternal involvement.

Although respite and home nursing care were viewed as being necessary by some participants and potentially helpful by others, these types of services were not readily available to all. Participants did not know if they qualified for in-home nursing care, and others had been denied the service. Foster parents also spoke about the effort required on their part to locate qualified respite caregivers, whereas others did not consider it an option, for a variety of reasons. The lack of respite caregivers, a common concern expressed by families caring for individuals with complex health care needs, is a common dilemma for foster families and biological families caring for children with complex health care needs in the home (Heaton, Noyes, Sloper, & Shah, 2005; Kendle & Campanale, 2001; Neufeld, Query, & Drummond, 2001; Olsen & Maslin-Prothero, 2001). Furthermore, locating qualified, competent, and sensitive health care providers was difficult.

The nursing shortage and the need to facilitate the development of competency in nurses who care for chronically ill children continue to plague biological and foster parents. The findings in a study by Kohlen, Beiler, and Danzer (2000) show that parents have strong opinions about the care provided by home care nurses and that vigilant parents often refuse to allow nonregular nurses to provide care for their children.

In giving of themselves to these children, these parents exposed themselves to feelings of loss and helplessness through relinquishment or death of a child. Foster parents went through a grieving process with both types of loss. This process did not differ from the grieving process experienced by other families in similar situations.

Foster parents and their families also experienced growth and a change in personal identity as a result of the caregiving experience. They believed the experience to be unique and one in which they received more than they gave. Likewise, many families who effectively incorporate illness into everyday life experience positive growth in spite of the pitfalls associated with parenting a child with continuous and complex health care needs (Deatrick et al., 1999).

Implications and Recommendations

Practice

Implications for nursing practice include the need for pediatric nurses to evaluate their beliefs about children in the foster care system. Pediatric nurses should develop knowledge about the health care needs of medically fragile foster children. Moreover, nurses must show greater sensitivity and be responsive to the knowledge that the primary caregivers of these children hold. Recognizing that foster parents view themselves to be the parents of these children just as biological and adoptive parents view themselves to be their children's natural parents and incorporating the caregiver's knowledge into the nursing care of the child could decrease stressors for both the child and the foster parent. Furthermore, the deteriorating medical condition of a foster child and the near-death/death experience must be viewed as an emotionally devastating experience for foster parents, who experience the same grief reactions as do parents of biological children. Pediatric nurses must be available to provide the much-needed emotional support.

The safe performance of a technical skill is only one aspect in the foster parent's development of expertise in the care of the child. Careful consideration should be given to in-home follow-up after discharge to help facilitate the foster parent's transition from supervised to unsupervised caregiving. Furthermore, pediatric nurses should recognize the importance of honoring the knowledge and skills of the foster parent, and they should inquire about the way in which the child's care is provided. Inquiring how the foster parent performs a procedure and how the child typically responds to the treatment can be helpful in decreasing stressors for the child and the foster parent.

Nurse managers of pediatric nursing units in hospital settings should evaluate staffing patterns and ensure the availability of competent nurses to provide care for these families. Continuity of care could be enhanced by assigning a select group of nurses to care for a particular group of children for a set period. Furthermore, home health care agencies should recruit seasoned pediatric nurses with knowledge about the needs of foster families, as well as the needs of medically fragile children.

The results of this study also have important implications for individuals beyond the boundaries of nursing practice. The findings have applicability to physicians who provide primary care to foster children with chronic illness and complex medical needs and to emergency physicians who interact with foster parents when a child requires emergency health care. Opening lines of communication between physician and foster parent

by listening to and respecting the knowledge that foster parents hold about a child can facilitate timely and appropriate medical care and ensure better health care outcomes for the child.

Research

Replicating this study with foster parent participants located in urban areas may be helpful to validate and expand findings. Consideration should also be given to using a grounded theory approach to explore the processes of committing to caring for a child with chronic illness and complex medical needs, coming to know the needs of the child, and individual becoming. The grounded theory approach would facilitate the development of explanations and theories about these processes.

The perceptions held by physicians and nurses about foster parents who parent medically fragile children should be explored. Identifying misconceptions about parenting medically fragile foster children is a beginning step in improving relationships between health care professionals and foster parents.

The process that foster parents undergo to develop knowledge and confidence in their ability to advocate for the medically fragile foster child has not been described in the literature. Because one of the most important roles of the foster parent is that of child advocate, research is warranted to determine the way in which foster parents learn the advocacy role. Nurses could use this information to teach parents how to best advocate for the child.

The participants in this study expressed concern for the well-being of their biological children. Thus, research is warranted to determine the psychological and physiological impact on the family, in particular biological children, in those families that parent chronically ill and technologically dependent foster children. A longitudinal study could be useful to examine the perspectives of the biological children over time, especially when foster children with complex problems remain in the family long term or are adopted.

The experience of grieving the death of a foster child also deserves consideration. The grief experience of the foster parents and the impact of the foster child's death on other children in the family (foster children and biological children) should be examined.

Finally, another lens from which to view the experience is needed. The experience should be investigated from the perspective of the nonprimary caregiver.

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