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# Parenting Foster Children with Chronic Illness and Complex Medical Needs

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## BACKGROUND

Current estimates show there are more than 520,000 children in the U. S. foster care system. Most children entering foster care have behavior, developmental, medical, or physical problems, many of which are chronic. In some instances, a lack of resources and support or the child's unique health problem, such as a genetic defect or chronic medical condition create a situation in which biological parents are unwilling or unable to provide care for these children. 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 possess the necessary skills. The unwillingness and inability 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. As a result, child welfare agencies advocate enrolling foster parents in training programs to facilitate technical skill development, and the placement of these children into "medical homes". However, research fails to capture the knowledge that foster parents need in order to be successful in parenting these children. Further, nurses' misconceptions about foster parenting continue to hinder the application of a family-centered care approach to these families.

## PURPOSE

The aim of this study was to explore the lived experience of parenting chronically ill foster children with complex medical needs.

## METHODOLOGY

Phenomenological inquiry using van Manen's method, which focuses on description, interpretation, and meaning, was employed. The guiding theme of phenomenology is to go "back to the things themselves" (Husserl). It is the study of essences; and, the description of experiential meanings we live as we live them (van Manen).

## PARTICIPANTS AND SETTING

Purposive sampling using criterion and snowball techniques served as the mechanism to obtain participants. The number of participants in the study was based on repetition of discovered information. Thirteen foster parents met the essential criterion of parenting foster children with chronic illness and complex medical needs for at least six months and described the day-to-day experience of parenting chronically ill foster children with complex medical needs. All were married and White, and lived rural areas of one state in the northeastern U. S.

Foster Parent Demographics			
PARTICIPANTS	AGE	EDUCATION	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 Grad. to Master's Degree	Employed Outside of Home, One Retired

Foster Children Demographics			
Age Range	Medical Diagnoses	Complex Health Needs	
3 months to 16 years	Apnea	RAD	Tracheostomy / Trach Care
	BPD	DD	Ventilator / Resp Treatments
	Epilepsy	FAS	Central Line Care / IV Therapy
	GERD	VP Shunt	G-Tube / Tube Feeds
	Hirschprung	CP	Colostomy Care / Urinary Cath
	Spina Bifida	Stroke	PT / OT / Specialized Equipment

## DESIGN & ANALYSIS

Data were collected via an unstructured interview strategy that was guided by one broad interview question, probes, and open-ended clarifying questions. Interviews were audio recorded, then transcribed verbatim. A seven-phase abstraction process was used to identify significant statements, formulated meanings and key elements as well as meaning units, theme clusters, and essential themes.

Extraction Process	
Original data	She was born premature with a prenatal drug history and <i>they didn't think she'd be able to develop normally. I didn't see why she shouldn't be given a chance. 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 open up those eyes and he had me right there.</i>
Significant statements	They didn't think she'd develop normally. I didn't see why she shouldn't be given a chance. I knew that I wanted him when he looked at us with his big beautiful eyes.
Formulated meanings	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.
Key elements	Hearing the story Seeing the Child

## FINDINGS

Five interwoven, interconnected, essential themes emerged from the data. Each major theme contained one or two theme clusters and several meaning units that compose the broad theme.

### Theme 1: Committing to parenting a child with complex needs

Influencing factors	Exemplars
Choosing to foster parent Accepting medical complexities Connecting with a child Advocating for a child	"When she first came to us, they said she was gonna be a pretty normal child...I think they really pulled the wool over our eyes because it wasn't long after we got her she ended up getting a G-tube. It was one thing right after another after another..."

### Theme 2: Coming to know the needs of the child

Caregiving	Exemplars
Learning as student Caring as novice Experiencing the child Adapting to change	"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. That can be detrimental."

### Theme 3: Intervening

Effective interventions	Ineffective interventions	Exemplars
Physical support Emotional support Spiritual support	Health care coordination Continuity of care Attitudes of professionals	"It's hard with getting good nurses and keeping nurses. There's a lot of turn over. One nurse, I said, you don't need to come back. I did train one nurse and as soon as she knew what to do she got a job at a hospital..."

### Theme 4: Sensing the loss of a foster child

Relinquishment experience	Near death/death experience	Exemplars
Feelings Preparing for relinquishment Remembrance	Feelings Remembrance	"The first one was a terrible experience for me cuz I hadn't prepared in my mind for her passing away...I kept thinking this can't be happening. I remember reaching for her then I held her in my arms and cried..."

### Theme 5: Becoming

Self	Exemplars
Identity Future Valuing	"It's taught us about people who are more needy. We're content to miss a function or two. It's taught us to be less self-oriented. It's building our characters that way."

## CONCLUSIONS

Parenting foster children with complex health care needs is a life changing experience for the foster families as well as foster children. A multifaceted experience, it has implications not only for nursing but multiple disciplines.

### Road Not Taken

*Two roads diverged in a yellow wood  
And sorry I could not travel both  
And be one traveler, long I stood  
And looked down one as far as I could  
To where it bent in the undergrowth*

*Then took the other as just as fair  
And having perhaps the better claim  
Because it was grassy and wanted wear  
Though as for that, the passing there  
Had worn them really about the same*

*And both that morning equally lay  
In leaves no step had trodden black,  
Oh, I kept the first for another day!  
Yet, knowing how way leads onto way  
I doubted if I should ever come back*

*I shall be telling this with a sigh  
Somewhere ages and ages hence  
Two roads diverged in a wood  
And I took the one less traveled by  
And that has made all the difference*

Robert Frost

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