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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 fragile or complex 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
Purposeful 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.

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
Exemplars
"When she first came to us, they said she was going to be a normal child. She was 18 months old when we got her. She ended up getting a stroke. She was one thing right after another after another.
"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 have the language, don’t learn the language, you can’t respond in the right way. That can be detrimental.

Theme 2: Caring for the needs of the child
Categorizing
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 have the language, don’t learn the language, you can’t respond in the right way. That can be detrimental.

Theme 3: Intervening
Effective interventions
Physical support
Emotional support
Ineffective interventions
Health care coordination
Continuity of care
Anticipating outcomes
"It’s hard with getting good nurses and keeping nurses. There’s a lot of turnover. One nurse, I said, you don’t need to come back. I didn’t name one nurse and as soon as she knows what to do she gets a job at a hospital....

Theme 5: Becoming a foster parent
Self-identity
Identity
Future
Vesting
"It’s taught us about people who are more needy. We can’t just remove a fraction or two. It taught us to be less self-centered. It’s yielding our characters that way.”

REFERENCES

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

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.

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