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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 illnesses 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).

FINDINGS
Five innumerable, 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 a pretty normal child... I think they really pulled the wool over our eyes because I wasn’t long after we got her she ended up getting a stroke. It was one of those things right after another after another.

Theme 2: Coming to know the needs of the child

Categorizing:
Learning as student
Caring as service
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, 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
Antidotes of professionals

“It’s hard with getting good meals and keeping hygienic. There’s a lot of turn over. One nurse, I said, you don’t need to come back. I still was one nurse and as soon as she know what to do she got a job at a hospital...”

Theme 4: Sleasing the loss of a foster child

Reframing experience
Feeling
Preparing for reframing
Remembrance
Near death/trauma experience
Remembrance

“The first one was a terrible experience for me. I couldn’t prepare my mind for her passing away... I hope thinking this can’t be happening. I remember shaking for her then I held her in my arms and cried...”

Theme 5: Becoming

Self
Identity
Future
Vesting

“It’s taught us about people who are more needy. We can’t count a fraction or two. It taught us to be less self-oriented. It’s yielding our characters that way.”

CONCLUSIONS
Parenting foster children with complex medical 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.