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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).

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, formulate meanings and key elements as well as meaning units, theme clusters, and essential themes.

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

AGE RANGE | MEDICAL DIAGNOSES | COMPLEX HEALTH NEEDS
--- | --- | ---
3 months to 16 years | ADHD, RAD, BPD, Epilepsy, CP | Thrombocytopenia, Traumatic Birth, Ambulatory Care, Stroke
13 Foster Parents | Tracheostomy, VENT, Oxygen, PICC Line, G Tube, TPN, Tube Feedings | Palliative Care, Palliative Care, Palliative Care

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 pretty normal child... I think they really pulled the wool over our eyes because she’s not long after we got her she ended up getting a tube. It was one thing right after another after another.”

Theme 2: Caring for the Needs of 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, you can’t respond in the right way. That can be detrimental.”

Theme 3: Intervening
- “It’s hard with getting good nursing and keeping nursing. There’s a lot of turn over. One nurse, I said, you don’t need to come back. I told one nurse and as soon as she knew what to do she got a job at a hospital...”

Theme 4: Struggling to Be a Foster Child
- “The first one was a terrible experience for me because I hadn’t prepared my mind for her passing away... I kept thinking this can’t be happening. I remember standing for her then I held her in my arms and cried...”

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 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