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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 children presents an already overburdened foster care system with even more 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. A total of 13 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.

**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.

**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 a preemie. I knew she had a lot more in her. I think they actually pulled the wool over our eyes because I can’t imagine that long after they left her she ended up getting a grate. It was one thing right after another for a few years.”

**Theme 2: Caring for the needs of the child**

- Exemplars
  - “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**

- Exemplars
  - “It’s hard to get to and keep doctors. There’s a lot of turnover. One nurse, I said, you don’t need to come back. I did treat 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**

- Exemplars
  - “The first one was a terrible experience for me, so I wasn’t prepared in my mind for her passing away… I felt thinking this can’t be happening. I remember standing for her that I held her in my arms and cried…”

**Theme 5: Becoming**

- Exemplars
  - “It’s taught us about people who are more needy. We can’t relate to a family or two. It taught us to be less self-centered. 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.

**REFERENCES**


Robert Frost

**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
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