2007

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Recommended Citation
https://jdc.jefferson.edu/nursfp/25

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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.

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

Choosing to foster parent

Influencing factors

Accepting medical complexities

Conciliating with a child advocating for a child

Exemplars

“When she first came to us, they said she was going to be this normal girl. I thought they really picked the worst of our kids because she was 13 years old and we were new. She ended up getting a G-tube. It was one of those things right after another another.”

Theme 2: Caring to know the needs of the child

Categorizing

Learning as student

Caring as novice

Experiencing the child

Adapting to change

“Hey, lives in danger all the time. You really need to get to know the child. They give you care, but if you don’t know the language, you can’t teach them the right way. That can be detrimental.”

Theme 3: Intervening

Effective interventions

Physical support

Emotional support

Ineffective interventions

Health care coordination

Continuity of care

Antiquities 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 didn’t mean her name and as soon as know what to do get a job at a hospital...”

Theme 4: Sustaining the loss of a foster child

Reframing as experience

Preparation for reframing

Remembering

Near death experience

Remembrance

“The first one was a terrible experience for me because I had prepared my mind for her passing away... I thought this can’t be happening. I remembered looking for her then I held her in my arms and cried...”

Theme 5: Becoming

Self

Identity

Future

Vesting

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

REFERENCES


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.