Parenting Foster Children with Chronic Illness and Complex Medical Needs

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2011

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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.

The aim of this study was to explore the lived experience of parenting chronically ill foster children with complex medical needs.

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.

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Parenting Foster Children with Chronic Illness and Complex Medical Needs

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Participant and Setting

Purposive sampling using criteria and snowball techniques served as the mechanism to obtain participants. The number of participants in the study was based on a replication 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 intertwined, 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

Choosing to foster parent

Influencing factors

Accepting medical complexities

Counseling with a child Advocating for a child

“When she first came to us, they said she was going to be a normal child... I think they really pulled the wool over our eyes because I hardly ever asked questions about her. She ended up getting a UTI. It was one thing right after another after another.”

Theme 2: Knowing 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, 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

Anticipate of professionals

“It’s hard with getting good nurses and keeping nurses. There’s a bit of a turn over. One nurse, I said, you don’t need to come back. But I took one more and as soon as you know when to do a job at a hospital...”

Theme 4: Senses the loss of a foster child

Reframing experience

Feeling

Preparing for reframing

Remembrance

“The first time was a terrible experience for me. I wasn’t prepared at all for her passing away... I hope thinking this can’t be happening. I’m remembering thinking of her there in bed, I realized that she’s in my arms and cradling.”

Theme 5: Becoming a foster carer

Self

Identity

Future

Vesting

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

REFERENCES