



The Lived Experience of Foster Parents of Children With Special Needs Living in Rural Areas

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The experience of 10 foster families living in rural communities in the Northeastern United States was explored through phenomenological inquiry. Through an unstructured interview approach, parents were asked to describe what it was like to parent foster children with specialized health care needs. Recorded interviews were transcribed verbatim and analyzed using van Manen's method. Data analysis revealed that parents fostering children in rural communities have concerns related to accessing medical care and decision making. They expressed feelings of being overwhelmed and unprepared, isolated, and stigmatized. © 2010 Elsevier Inc. All rights reserved.

CURRENT ESTIMATES SHOW that there are more than 520,000 children in the United States foster care system (Department of Health and Human Services [DHHS], 2006). Most children entering foster care have experienced physical, emotional, or sexual abuse (Stahmer et al., 2005) or have been neglected in having their physical, emotional, or medical needs met (O'Hara, Church, & Blatt, 1998). Many of these children exhibit behavioral, emotional, developmental, and medical or physical problems (Carlson, 1996; O'Hara et al., 1998) and have a higher than normal incidence of acute and chronic health care needs (Gorski et al., 2002; Simms, Dubowitz, & Szilagyi, 2000).

Children With Special Health Care Needs

Advances in medical technology and nursing care have improved survival rates for children with chronic illness and complex health care needs. The 1994–1995 National Health Interview Survey (NHIS) on Disability data estimated that approximately 15% to 18% of children in

the United States are affected by chronic illness (Newacheck et al., 1998). It is likely that rates of chronic illness and disability in children are higher, but childhood chronic conditions are now defined differently, and more recent trend data are not comparable with the 1994–1995 NHIS data (Perrin, Bloom, & Gortmaker, 2007). The new data, defined as child special health care needs data and obtained from the Child and Adolescent Health Measurement Initiative as part of the National Survey of Children with Special Health Care Needs (NS-CSHCN, 2007), show similar statistics; approximately 10.2 million or 13.9% of U. S. children have an existing special health care need. This means that 1 in 5 or more than 8.8 million households in the United States have at least one child with a special health care need (NS-CSHCN, 2007).

The care of children with complex special health care needs has shifted from the hospital to the home setting. Parents now are the primary care givers and are reporting significant stressors and challenges affecting the family. The impact of stressors on some families or more specifically the complexity of the child's needs can be overwhelming and often creates a situation in which the natural parent is unable or unwilling to provide a child's care (Schneiderman, 2003). Consequently, children needing specialized care may require placement with foster parents who have training in caring for children with complex health care needs.

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Foster Parenting

Becoming a foster parent to a child with special health care needs requires knowledge, skill, and expertise that differ from those who parent healthy children. In addition to providing day-to-day care and responding to the child's emotional and behavioral needs, foster parents also arrange transportation of the child to medical and counseling appointments and court hearings as well as advocate on behalf of the child and arrange visits with birth parents (Chipungu & Bent-Goodley, 2004). Some complex issues faced by foster parents are a lack of training and support, inadequate respite care, and the need to constantly adapt to the increasing complexity of children's problems (Lauer, 2005). Other issues confronting foster parents are lack of understanding by nurses and other health care professionals about their role (Barton, 1999) and misconceptions about the knowledge and skills needed to be successful in parenting children with special health care needs. Furthermore, foster parents face challenges related to their legal rights in caring for children with special health care needs. Laws surrounding the ability of foster parents to provide consent to medical treatment for foster children vary among each state's DHHS. For example, in the Commonwealth of Pennsylvania, there is no regulation that allows foster parents to consent to medical treatment whether routine or nonroutine (Rosado, Chernoff, Field, & Shah, 2006), whereas the Oklahoma Department of Human Services (OKHHS) recognizes foster parents as the child's legal custodian and permits the foster parent to give consent for ordinary medical care as well as treatment in a medical emergency when the biological parent or OKHHS case worker is unavailable (OKHHS, 2007).

More than a decade ago, Carlson (1996) suggested that foster parents may not have the necessary knowledge and skill to care for children with special health care needs, and Beeken (1996) reported that nurses often make erroneous assumptions about foster parents' knowledge of the health care needs of foster children. Yet, today's literature does not reflect that nurses have a better understanding of the problems faced by foster parents or that foster parents of children with special health care needs have the requisite knowledge and skill to do so.

What is well documented in the literature is a steady decline in the numbers of foster parents willing to provide care to children with special health care needs and urgency on the part of child welfare agencies to locate families for these children. At one time, keeping the child in the biological family's community and enlisting extended family members as kinship caregivers was a useful strategy to facilitate child placement. Now, to find enough homes for these children, agencies have extended outreach to faith-based communities, some of which are located in rural areas (Wulczyn & Hislop, 2002). Although rural communities have proved to be valuable resources for child welfare agencies in that recruitment of foster parents by other foster parents in the same faith community facilitates child

placement (North American Council on Adoptable Children, 2001; Riggs, 2005), it is not known if children placed with foster families residing in rural communities have access to adequate health care resources or if foster parents living in rural areas receive adequate training to safely care for children with special health care needs. Data from the Rural Healthy 2010 report show access to health care to be a priority concern for those living in rural America, and the health and the well-being of mothers, infants, and children is ranked ninth among the 15 priority concerns of rural communities (Gamm, Hutchison, Dabney, & Dorsey, 2003). Knowing the challenges faced by rural Americans invites one to seek a better understanding of the experience of parenting children with special health care needs for those foster parents who live in a rural area.

Context of the Study

This study explored the experience of foster parents with children with special health care needs who live in rural communities and remote areas. There is limited published research examining the phenomenon of parenting foster children with specialized needs and, in particular, about the experience of foster parents who live in rural areas. Further, the barriers to health care experienced by this population of parents have not been explicated in the literature.

The study was chosen because of the researcher's deep interest in pediatric nursing, family-centered care, and the barriers to health care that are faced by those living in rural communities, particularly foster parents of children with special health care needs. The researcher is an experienced parent-child nurse who has provided care to foster families with children with special needs in acute care settings for many years. The purpose of the study was to compose a vivid description of the experience so that nurses will have a better understanding of the problems faced by foster parents of children with special health care needs who live in rural areas. The research question for this study was: What is the lived experience of foster parenting a child with special needs in a rural community? What is the essence of the experience?

Philosophical Framework

The aim of this inquiry was to describe the lived experience of foster parents of children with special health care needs who live in rural communities from a phenomenological perspective. Phenomenology is a qualitative research methodology associated with philosophers such as Husserl, Heidegger, and Gadamer. Husserlian phenomenology is transcendental-epistemological, emphasizing the questions of knowing (Koch, 1995). Bracketing perceptions and holding them in abeyance is a technique

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