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Maternal Caregiving and Strategies Used by Inexperienced Mothers of Young Infants with Complex Health Conditions

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ABSTRACT

Objective: To describe maternal caregiving and related strategies used by first-time mothers of young infants with complex health conditions (CHC) in the first 6 months after discharge.

Design: Grounded theory.

Setting: Data were collected in participants' homes in the Northeast United States.

Participants: Eight first-time mothers of infants age 6 months or younger with CHC.

Methods: Purposive and theoretical sampling were used. Semistructured interviews were completed at 2-month intervals, beginning 2 weeks after their infants' discharge. Analysis of 28 interviews was done with the constant comparative method.

Results: A grounded theory of maternal caregiving was conceptualized from the data. This time-and-experience-mediated process involved three phases of increasing confidence and expertise, developing in the context of decision-making responsibility. Related maternal strategies included appraising, normalizing, organizing, assessing, practicing, validating, experimenting, nurturing, and negotiating. Mothering became predictable and integrated in everyday life by about 6 months after the infant's discharge home.

Conclusion: Findings can help clinicians and researchers better understand what happens over time as new mothers care for infants with CHC. Exploration of these patterns in a more diverse group of mothers of children with CHC can support the development of targeted interventions for this specialized population.

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Approximately 11.2 million children in the United States have special health care needs (SHCN), that is, chronic health conditions that result in significantly greater need for health care than typical children (U.S. Department of Health and Human Services [USDHHS], 2013). Almost 10% of these children are younger than age 5 years, and this group includes young infants with complex health conditions (CHC), also known as medically fragile infants. Serious, complicated, and long-term health problems are typically related to complications of premature birth, congenital anomalies, or neonatal illness (Federal Interagency Forum on Child and Family Statistics, 2013; Harrigan, Ratliffe, Patrinos, & Tse, 2002; USDHHS, 2013). Infants with CHC require continuous skilled care and vigilant monitoring and often require medical devices or technology for survival. They are at high risk for serious health and developmental problems (Harrigan et al., 2002; Hudson, 2013; Rehm, 2013). Factors such as the unstable nature of the health conditions, their dependence on medical technology and complicated assessment, medication, and treatment regimens (i.e., medicalized care), along with risks for developmental and other serious disabilities, differentiate these infants from the larger group of infants with SHCN. Importantly, these factors and related infant characteristics can influence their mothers' adjustment to parenting during the postpartum period and beyond (Miles, Holditch-Davis, Burchinal, & Brunssen, 2011). To effectively help this group of new mothers, more information about their experiences caring for their infants over time is needed.

The early infancy period is crucial in the transition to motherhood, as well as for consolidation of the mother/infant relationship.

Background

Although few in number compared to the overall population of chronically ill children, infants with CHC need a greater number of and more expensive health care resources (Mentro, 2003; Rehm, 2013; USDHHS, 2013). Their care is usually provided by their mothers, who are often still recovering from pregnancy and childbirth; this care is infrequently supplemented by care from fathers and/or other family members or health care workers (Rehm, 2013). Researchers also suggest that female caregivers of infants and children have less unpaid assistance, higher time and cost burdens, and more unmet information needs than caregivers of adults (Crowe, Van Leit, & Bergmans, 2000; Martin, 2003; Meleis & Lindgren 2001; National Alliance for Caregiving, 2009; USDHHS, 2013; Wuest, 2001).

In previous studies, investigators demonstrated that mothers of medically fragile older children felt overwhelmed by the care required, had difficulty integrating children into family patterns and differentiating between their maternal and their caregiving roles, and struggled to assume new roles related to their ill children (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Kirk, Glendinning, & Callery, 2005). Less is known about the experiences of new mothers giving home-based care to medically complex young infants, such as how their mothering patterns develop, the strategies they use in maternal caregiving, how closely their mothering and caregiving strategies parallel those of other populations of mothers, or how effectively they are prepared for such caregiving experiences.

The early infancy period is crucial in the transition to motherhood and for consolidation of the mother/infant relationship (Crockenberg & Leerkes, 2000; Mercer, 1985, 2004; Rubin, 1984). Mothers of infants with CHC have early mothering experiences that are very different from those of mothers of well infants, including extended periods of separation from their infants during the early weeks of life; performing highly complex health care/caregiving tasks that could cause distress, pain, or medical complications in their infants; evaluating the health status of their infants and providing required care; and negotiating infant care, health care, and nurturance responsibilities with health care workers (Brunssen & Miles, 1996; Kirk, 2001; Miles & Frauman, 1993; Nelson, 2002). As Mercer (2004) noted, "the transition to motherhood is a major developmental life event. Becoming a mother involves moving from a known, current reality to an unknown, new reality" (p. 226). Examination of the unique intersection between mothering and caregiving can support understanding of maternal patterns, critical experiences, and needs in the transition to maternal caregiving roles. This intersection is important because effective parenting and caregiving can promote improved health outcomes in these high-risk, vulnerable infants. Thus, the aims of this study were to describe maternal and caregiving processes and practices in inexperienced mothers of young infants with CHC and to describe the strategies they used in mediating mothering and medicalized caregiving over the first 6 months after an infant's discharge to home.

Methods

The study was guided by grounded theory methods congruent with questions about processes used by individuals as they experience transitions, take on different roles, and make decisions in the context of the meanings that they assign to all of these (Charmaz, 2006; Strauss & Corbin, 1998). The method is oriented to derivation of a substantive, or grounded, theory describing processes, context, actions, consequences, and relationships among these (Dey, 1999; Strauss & Corbin, 1998). The processes of interest in this study were mothering and caregiving. *Mothering* was defined as the role, processes, and set of behaviors that evolve over time in response to maternal experiences and are associated with nurturing and caretaking behaviors in the context of the mother-infant/child relationship (Grace, 1993; Mercer, 1985; Nelms, 2000; Pridham & Chang, 1992; Zabielski, 1994). *Caregiving* was defined as the role, process, and set of behaviors associated with the care of another that involves response to the need or obligation to care for another and the provision of personal and health care (Schumacher, 1995; Swanson et al., 1997). Caregiving behaviors include tasks and skills that in certain settings would more traditionally fall within the domain of nursing practice (Office of Technology Assessment [OTA], 1987).

Setting and Sample

In-depth interviews were conducted with study participants in their respective homes in the