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Struggling in the Dark to Help My Child: Parents' Experience in Caring for a Young Child with Juvenile Idiopathic Arthritis

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ABSTRACT

Purpose: The purpose of this study is to describe parents' experiences in caring for 2–5-year-old children with juvenile idiopathic arthritis (JIA).
Design and methods: A qualitative study using single-occasion in-depth interviews was conducted. Nine parents (eight mothers and one father) were interviewed in-person or via telephone. Data were analyzed using inductive content analysis. Methods used to protect the trustworthiness of study results included maintenance of an audit trail, peer debriefing, and member checks.
Results: The core construct Struggling in the Dark to Help My Child explained parents' experience in six domains: not knowing, trying to reach out in the dark, feeling my child's pain, working out the kinks to stay on top to manage, feeling drained by the whole process, and being hard on the entire household. Parents struggled with the unknown, searched for resources, witnessed their child's suffering without knowing how to help, and tried every possible way to stay on top of the child's illness and treatment, even when they felt drained physically and emotionally. JIA not only consumed their lives, but also affected the entire family, including the siblings and spouse, and the relationships among family members.
Conclusion and implications: Findings highlight the day-to-day lived challenges parents face when caring for a young child with JIA. Healthcare providers including nurses need to assess the particular needs of an ill child and parents as well as the impact of the illness on the physical and psychosocial health of the entire family so that proper resources can be provided.

Introduction

Juvenile idiopathic arthritis (JIA) is a common pediatric autoimmune condition that currently has no cure. An estimated 350,000 children in the United States are diagnosed with JIA (Espinosa & Gottlieb, 2012). Children experience unpredictable episodes of active disease that are characterized by joint inflammation, pain, tenderness, and limited mobility (Prakken, Albani, & Martini, 2011). The management of JIA can be time-consuming and complex, and includes pharmacological interventions, physical therapy, routine laboratory and imaging tests, and regular appointments with specialists such as ophthalmologists and dentists (Prakken et al., 2011). Medical care and management of JIA requires parental involvement, particularly for young children. However, few studies have examined the illness-related demands and challenges parents encounter when caring for a young child with JIA.

Several qualitative studies have described parents' experience in caring for children and adolescents with JIA. Common parents' experiences have included confusion and emotional turmoil; feelings of guilt, anxiety, anger, frustration, and fear; caregiving demands and burden interfering with varies aspects of family life; and a lack of social support (Barlow, Harrison, & Shaw, 1998; C. Britton & A. Moore, 2002a; C. Britton & A. Moore, 2002b; Gomez-Ramirez et al., 2016; Jerrett, 1994; Jones, Rodger, Broderick, & De Monte, 2009; Knafl, Leeman, Havill, Crandell, & Sandelowski, 2015; McNeill, 2004; Stinson et al., 2012; Waite-Jones & Madill, 2008). The majority of these studies involve parents of 6-to-18-year-old children diagnosed 1–16 years prior to the time of interview, or are limited to specific experiences (e.g., parents' emotional experience). To our knowledge, studies have not focused specifically on young children 2–5 years, which is the peak age for disease onset for two common JIA categories (Espinosa & Gottlieb, 2012). Furthermore, studies that examined parent functioning in children with other chronic conditions such as cancer, diabetes, and epilepsy report age differences, with having younger children associated with poorer parental functioning (Goldbeck, 2006; Melnyk, Feinstein,

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Moldenhouer, & Small, 2001). The purpose of this study is to understand parents' perceived stress, illness-related challenges, coping behaviors, and adaptation to the stress and challenges of caring for their 2–5-year-old child with JIA.

Conceptual Framework

An integration of Family Systems Theory and the Resiliency Model of Family Stress, Adjustment, and Adaptation – hereafter called the Resiliency Model – formed the conceptual framework that guided the formulation of the interview questions (Broderick & Smith, 1979; M. A. McCubbin & McCubbin, 1993; Olson, Russell, & Sprenkle, 1983). Family Systems Theory views the family as an emotional unit with interconnected and interdependent individuals. Illness in a family member can impose different levels of burden and strain on parents, siblings, caregivers, and other members of the family (Broderick & Smith, 1979; Kerr & Bowen, 1988). However, the Family Systems Theory does not address family stress. The Resiliency Model complements the Family Systems Theory by adding the processes of stress, coping, and adaptation. Coping refers to the family members' behaviors designed to maintain or strengthen the family as a whole, maintain the emotional stability and well-being of its members, use resources to manage the situation, and initiate efforts to resolve family challenges created by the stressor, in this case, JIA. Family adaptation describes the outcome of family efforts to bring a new level of balance, coherence, and functioning to family stress. A family could fall within a continuum of adaptation, ranging from bonadapation (positive changes within the family to achieve new balance between demands and the family' capabilities and resources to meet the demands) to maladaptation (continued imbalance between demands and resources) (M. A. McCubbin & McCubbin, 1993; Olson et al., 1983). This framework, however, was purposefully not used to guide the data analysis, but rather to cast a broad conceptual net that included family challenges, relationships, and coping responses to the illness experience.

Methods

Participants

Fourteen primary caregiving parents (either mother or father) of a 2- to 5-year-old child with JIA were recruited from a prior observational study of sleep and health outcomes in young children with JIA and their parents. Study sample size was limited to families who participated in the prior study and gave consent to be contacted for future studies. Parents were eligible for the prior study if they were at least 18 years of age, able to speak and read English, and were the primary caregiver of a 2- to 5-year-old child diagnosed with JIA. Of the fourteen eligible families, eight mothers and one father ($n = 9$) from eight families were enrolled and completed the current study (57% response rate). In one family, both parents identified themselves as the primary caregivers. Six families did not respond to the recruitment letter or follow-up phone calls.

Parents ranged from 31 to 39 years (median age 34 years). Among the nine parents, 11% ($n = 1$) were divorced at the time of JIA diagnosis, and 44% ($n = 4$) were separated or divorced at the time of the interview; 67% ($n = 6$) were employed full time; 67% ($n = 6$) identified themselves as White. The median time since their child's JIA diagnosis was 18 months (range from 10 to 33 months). The median age of the child with JIA was 3.5 years.

Procedure

Human Subjects approval was obtained from the study center's Institutional Review Board prior to study initiation. Parents were mailed a recruitment letter informing them about the study and were instructed to contact the Principle Investigator (PI) within two weeks if they did not want to hear about the study. None of the parents opted out within the two-week period. After two weeks, the PI contacted the parents and asked if they were willing to participate. If the parents agreed to participate, the PI mailed the consent form, and explained the study purpose and procedure over the phone. Interested parents signed and returned the consent form to the PI, after which the PI scheduled an in-person or phone interview. One parent chose to be interviewed in-person at the study center and eight parents chose to be interviewed by phone. Participants chose to be interviewed by phone most likely because of the distance of their homes to the research center. Because the current study has specific aims and the researchers' immersing in the environment is not necessary, telephone interview is a comparable data collection method compared to face-to-face interview (Sturgers & Hanrahan, 2004).

The semi-structured interview consisted of open-ended questions (Table 1). Interviews were audio-recorded with permission. Interviews lasted 22 to 74 min (median 45 min). The recordings were transcribed by a professional transcriptionist and verified for accuracy by the PI. Each participant received a gift card for participation.

Data Analysis

Transcribed interview data were imported into qualitative analysis software Atlas.ti Mac Version 1.0. Using a multi-phased process, data were analyzed using inductive content analysis by the first author. Inductive content analysis was developed by Glaser and Strauss (1967), Krippendorff (1980) and Strauss and Corbin (1990), and extended by Lewis and Deal (1995). This method was derived from grounded theory methodology. By coding the data inductively, the researchers remained receptive to new concepts and processes parents were experiencing. Data analysis occurred in five phases, details of which are described in Table 2. The names of the core construct and domains were from the participants' own words.

The trustworthiness of study results was protected by maintaining an audit trail, peer debriefing by the second author, and member checks (Cho & Trent, 2015; Corbin & Strauss, 2008). Both the first (WY), second (FML), and third authors (AJW) have conducted inductive content analysis before and have prior research experience with families in which members had chronic conditions (Walker, Lewis, Al-Mulla, Alzawad, & Chi, 2017; Yuwen & Chen, 2013; Yuwen et al., 2016). Audit trails involved chronological records of analysis that provided documentary evidence of the sequence of activities, beginning with the first step of the analysis and continuing throughout all phases. Peer debriefing occurred in five areas that examined: (a) the accuracy of the unitized data; (b) the initial open codes from the units; (c) the categories, their labels, and definitions; (d) the organization of the categories within the domains; and (e) the identification of the core construct. Throughout analysis, the second author used constant comparative analysis to protect the fit of the unit with the category, the uniqueness and distinctness of each category and domain, and worked with the senior author to constantly review and refine the categories and domains and their definitions. Disagreement about any aspect of the analysis was discussed and resulted in a refinement in the definition of a category or a domain, a reassignment of a unit or category, or the development of a new category or a domain. Coding decisions were based on 100% agreement

Table 1
Interview questions.

1. During the first year after your child was diagnosed with JIA, what were some challenging situations you and your family experienced?
2. How did the situation (or these situations) affect you/your partner/your child with JIA/your other child(ren)/the relationships between family members?
3. What are the things that you have been doing to manage this challenging situation (or these challenging situations)?
4. How is it working for you and your family?
5. What resources have you used to manage this situation (or these challenging situations)?

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