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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.

Keywords

chronic illness; family caregivers; juvenile idiopathic arthritis; qualitative research

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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 various aspects of family life; and a lack of social support (Barlow, Harrison, & Shaw, 1998; C. Britton & A. Moore, 2002; C. Britton & A. Moore, 2002; 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, 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 bonadaptation (positive changes within the family to achieve new balance between demands and the family's 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 minutes (median 45 minutes). The recordings were transcribed by a professional transcriptionist and verified for accuracy by the PI. Each participant received a gift card for participation. [Table 1 about here]

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 between the first and second authors. After the initial analysis, a one-page summary was mailed to the participants for purposes of a member check in order to elicit participant feedback on the degree to which the summary reflects their own experiences. All participants agreed to receive the study summary and participate in the member checks at the initial enrollment time. Participants were asked four questions: (a) What is your overall response to the summary? (b) What are the parts that fit your experience? (c) What are the parts that do not fit your experience? (d) What else about the summary do you want to tell me?

Results

The core construct Struggling in the Dark to Help My Child described parents' experiences in caring for their young child with JIA. Parents struggled to understand the disease, the cause, the options for treatment, and the impact of the disease on their child's future. Parents felt alone and in the dark. They tried to find resources from the internet, health care providers, and friends and relatives who may know about arthritis or have children with the same diagnosis, but found few that were available. Parents expressed "feeling their child's pain," and not knowing how to help them. They blamed themselves for their child's pain and felt they were betraying their child when they had to do painful procedures (e.g., injections). Parents tried desperately to manage the illness and help their child, but felt physically and emotionally drained. JIA was consuming and affected the entire family and relationships among family members. The core construct of "Struggling in the Dark" was described in six domains: "Not knowing", "Reaching out in the dark", "Feeling my child's pain", "Working out the kinks", "Feeling drained by the whole process", and "Being hard on the entire household." Given the importance of describing parents' overall experiences in this paper, the results are presented at the domain level. Quotes from parents that illustrate each domain are in Table 3. [Table 3 about here]

Domain 1: Not Knowing

Parents felt blindsided by the huge amount of information they received about the diagnosis and the treatment options. They were expected to make treatment decisions for their child despite their difficulty processing the information and feeling scared and unsettled about the unpredictability of the disease. Parents were told to take a "wait and see" approach because the disease had different trajectories for different children, and their child's prognosis would depend on their response to treatment. They wondered how long their child would be sick, what the long term effects of the disease would be, and how it would affect their future. Parents were frustrated that even the best sources available did not answer their questions.

The initial diagnosis of JIA took several months as healthcare providers ruled out other conditions that could be causing the symptoms before diagnosing JIA. What at first seemed a "minor injury" such as a fracture or bruise ended up being a serious condition. This discernment continued after diagnosis as parents wondered if the cause of their child's pain was from JIA or just "growing pains." Some parents were confused when healthcare providers told them a medication would help their child, only to see their child's symptoms get worse. They didn't know if they should vaccinate their child on the usual schedule or wait since the child was on immunosuppressive medication. They wanted to know if it was safe for their child to go to school when some of the children were not vaccinated. Parents were not sure whether they needed to wear a mask around the child when they were sick, whether they could take their child to the grocery store, or eat out as a family for fear that people were sick.

Domain 2: Trying to Reach Out in the Dark

Parents felt that nobody could understand them and felt totally "alone and in the dark" when their child was diagnosed. Parents had difficulty finding other parents locally with similar

experience. When parents reached out to people who might know about JIA, they tended to hear only scattered stories here and there. As this parent described, “my mom talked to a woman that she knows, whose daughter, has a daughter with JIA. My mom got the girl's phone number and everything... I tried calling this girl a number of times and she never returned my call.” Parents reached out to others even if the others had a totally different diagnosis such as osteoarthritis because this might be the only person they knew with arthritis.

Parents felt they did not really have any resources other than the medical team. For example, some children experienced side effects from JIA treatment, such as extreme fatigue, disturbed sleep, and a compromised immune system. Parents did not know who to ask for help when they had a question about caring for their child with these symptoms. In addition, some parents indicated that they did not have the supportive resources they needed to deal with their own emotions: “I just felt, I, I had no resources to draw on.” Parents described feeling “helpless and powerless.”

Without other resources, parents turned to the internet when they had questions about caring for their child. Unfortunately they found “the worst case scenarios,” which instilled more fear. One parent paid fees to obtain access to online medical journals for information about JIA. One parent described her experience after reading scary stories from the internet:

I'm in my bedroom having a full-on meltdown while my daughter is eating dinner in the kitchen because I read that [scary story]... They [hospital] you know, told you before don't Google. Yes I know that. Um but what are you supposed to do? Who am I supposed to ask? (31-year-old mother).

Domain 3: Working Out the Kinks to Stay on Top to Manage

Parents described the experience of seeing their child “getting sick all the time” from JIA related symptoms or medication side effects. Parents felt that the medication that was supposed to treat JIA was making their child sicker. Parents were told explicitly by the doctors to expect some “subtle” side effects. These side effects, however, did not appear subtle to them. Some side effects were particularly challenging for parents to accept or manage. For example, one parent described her child experiencing severe fatigue from methotrexate, “she would be fatigued for almost the next four days and when I say fatigued...she would take like three two-hour naps, for almost four days. So, when I'm saying fatigued, it was extreme fatigue.” Other symptoms included upset stomach, nausea, and diarrhea. Some medications such as methotrexate suppressed the child's immune system, making them more likely to get sick. Parents were extra vigilant about preventing their child from getting sick and some parents, some even expressing they felt paranoid. They felt “extremely terrified” that an infection might trigger other disease activities.

Parents had to figure out how to best manage their child's care, including attending a variety of medical appointments, paying attention to different types and schedules of medication administration, and finding ways to make their child feel better. Parents tried naturopathic and homeopathic remedies and interventions such as warm baths, heating pads, and blankets to keep the affected joints warm. Parents learned theories about how inflammatory foods,

casein allergy, and gluten sensitivities could affect JIA and tried eliminating different foods. Although parents did not find that alternative diets improved their child's condition, they continued different approaches in their search for relief. Some families lived far away from the hospital with the pediatric rheumatology clinic. Parents found it challenging to travel with their young child, due to issues such as eating and nursing, extended periods sitting in the car, and preparing for frequent, multiple-day trips.

Domain 4: Feeling My Child's Pain

Children frequently had blood draws, received injections into their joints, and experienced pharmacological side effects. Parents felt hurt when their child was hurting, and some even felt they experienced the pain themselves. At times parents had to have a friend or neighbor come to their home to help hold their child down for an injection. Most parents had never given injections before. Even for parents who had professional experience giving injections found injecting their own child while they were screaming and yelling to be a horrifying and traumatizing experience. Some parents also described the painful feeling in situations where their child could not play with others due to JIA: "My heart just breaks watching her have to watch the other kids play and she can't play."

Although parents felt their child's pain, they did not know how to help their child. For some parents, it was even more difficult because they actually knew that they could not do anything to help in situations such as joint pain, disrupted sleep at night, or medication side effects. This helplessness made them feel like a bad parent who had betrayed their child. Parents felt guilty and thought it was their fault that their child had JIA. They also blamed themselves for the medication side effects children experienced. "I was angry at myself for allowing it [medication side effects] to go on."

Domain 5: Feeling Drained by the Whole Process

Challenging situations continued to happen one after another after the JIA diagnosis. Parents described JIA as "consuming [their] life," and felt emotionally, physically, and financially drained. Parents had to take time off work to care for the child, and at the same time had to work extra hours that cut into their leisure time. "I think I was probably a lot more tired than uh, I didn't have as much energy to, to play with him so we would do less energetic activities and more of uh, um sedentary activities." In some families, a child's JIA would remit, but then became active again. The new flare-up impacted the parents even more than the initial diagnosis.

Just last night he [the other parent] actually told me he's probably gonna seek out a therapist for it. Um because we have this new flare up and it's really affecting us again...we're having this emotional stuff happening from the new flare up three weeks ago so it's kinda bringing me back to where we were with the new diagnosis (37-year-old mother).

Although parents had to take lots of time off to care for their ill child, some parents shared the feeling that work was a way for them to "get a little breather." For example, one mother described that the other parent had "to disengage from what was going on at home" while

she “was in the throws of a disorganized home and a child with...a big swollen knee and limping.”

Domain 6: Being Hard on the Entire Household

JIA did not only affect the child, but also impact the parents, siblings, and the relationships between family members. Parents felt that every aspect of their lives was affected by JIA and they had to change daily routines to deal with it. The child’s activities were limited by the symptoms, which in turn restricted activities the family could do together. Some parents decided to hold back and go out less often in order to prevent the sad feelings their child and themselves had watching what other families could do and they could not. Parents felt that their children were judged by other people because of the illness in situations such as the older child sitting in a stroller for longer walks. Parents reported feeling judged by other people for how they cared for their child. Some parents decided not to disclose their child’s JIA diagnosis to avoid such judgments.

Parents reported tension between themselves and their spouses after the JIA diagnosis due to disagreements about treatment or feeling an unequal division of care burden. “I [mother] got to see...pretty much every minute of the day versus he [father] got to kinda escape to work.” Over time, parents felt that their tempers got shorter with each other, and they argued and fought more than usual. These times of elevated tension made the parents feel estranged from each other. The sexual lives of couples were also affected. “Sometimes it would be her sleeping in our bed and [husband] would sleep in our guest room. So it definitely disrupts the fact that we can’t even sleep together... so it affects the sex life, which affects your relationship.”

Nighttime seemed more difficult to manage with JIA. Parents described that their child just could not seem to get comfortable at night especially after having a flare-up or being in pain during the day. The child’s disrupted sleep affected the sleep in the whole family. In families with more than one child, JIA was hard on siblings. Siblings could not understand the illness and struggled seeing their sister or brother in pain. Siblings had hurt feelings because parents paid more attention to or had different standards for their sister or brother with JIA. Some siblings were also frustrated that they had less time together as a family.

Member Checks

Five parents participated in the member checks phone interviews. Interviews lasted 7 to 19 minutes. Parents overall said the summary was very clear and accurate, encompassed many daily things parents thought about, and claimed it was nice to know that other parents had similar experiences. Parents found the summary helpful for other people, including the healthcare team, friends, and family.

I really was pleased with it and I actually had friends read it just because I think I don’t vocalize things that are in my head and my worries enough to people that are around us...I think it helps our family and my mother and his other caregivers really understand where I was coming from when I voiced those worries about what’s going on with him. So it was a nice resource to have for other caregivers to read (34-year-old mother).

Discussion

Despite the advanced medical care for young children with JIA, study results show parents encountered multiple challenges caring for their young child during the initial diagnosis and treatment of the disease. Parents struggled with not knowing, searching for resources, witnessing their child's suffering without knowing how to help, and managing the child's illness and treatment. These struggles impacted the emotional and physical health of the parents and the entire family. Findings from this study expand our understanding of three areas in which parents particularly struggled with when their child was diagnosed with JIA: 1) a lack of information about the illness and how to manage it; 2) the caregiving demands parents encountered with the sick and well care of their child; and 3) the effects of JIA on parents, marital relationships, siblings, and the entire family.

Parents were overwhelmed by the amount of scattered and unclear information they received about JIA and the limited resources. Although parents searched outside the healthcare team, their search was not successful. This finding is consistent with Barlow and colleagues (1998) who also found a lack of information and inadequate support for parents to care for their school-age children or adolescents with JIA (Barlow et al., 1998). After almost 20 years, this lack of support is still occurring in families seeking treatment in a large urban medical center. Other studies have suggested interventions that may be helpful include a structured process to break the news of a JIA diagnosis that reduces uncertainty and doubt (Chausset et al., 2016). Like the current study, connecting with other parents who share the experience locally is difficult, which indicates internet-based support groups and interventions may be more feasible and beneficial for these parents (Glenn, 2015; Stinson et al., 2010; Swallow et al., 2014). In addition, parents' experience of "not knowing" in the current study is similar to the experience of parents of children who were hospitalized in pediatric intensive care units (Hagstrom, 2016). Although JIA is considered a chronic condition, the acute onset of the illness and the uncertainty in disease etiology, treatment, and prognosis affected parents in similar ways. In contrast to our findings, some studies found that parents felt well-informed and reported they continued to develop expertise in managing their child's illness over time (Jerrett, 1994; Thon & Ullrich, 2009). These differences may be attributed to the fact that parents in the prior studies had cared for their child with JIA for years after the initial diagnosis. In contrast, participants in the current study had experienced JIA diagnosis relatively recently. This suggests that parents need different kinds of information at different points along the disease trajectory.

Despite trying everything to manage the illness and its effects, parents in the current study encountered multiple caregiving challenges. Even when the disease-related symptoms were under control, JIA treatments made their child sick in other ways. This finding is consistent with previous studies that also reported children with JIA experienced difficulty and side effects with some medications such as Methotrexate (Bechard et al., 2014; Mulligan et al., 2013; Mulligan, Wedderburn, & Newman, 2015). Parents struggled with administering injectable medications due to the pain and discomfort it caused the child. Some parents blamed themselves for their child's suffering. Specific programs that provide appropriate educational and psychological support need to be developed and evaluated to improve parents' and children's experience to reduce the psychological impacts of certain medication

and alleviate the caregiving burden (Karlsson, Dalheim Englund, Enskar, Nystrom, & Rydstrom, 2016).

The JIA diagnosis had substantial impact on the parents and the entire household. Parents described their feeling of being kicked down like a dog and the first kick was the JIA diagnosis. Many things happened after the diagnosis, and prior strains were exacerbated. The concept of stress pile-up in the Family Stress Process is relevant to our findings (H. I. McCubbin & Patterson, 1983). This framework argues that families rarely are dealing with a single stressor, but rather, experience a pile-up of stressors and strains. The stress pile-up particularly occurs after a major stressor – in this particular case – the diagnosis of a chronic condition in the child. McCubbin and Patterson argued that such strains contribute to the pile-up of demands families must contend within an already stressful situation. These stressors feed into each other and become multiplicative, resulting in a family crisis (H. I. McCubbin & Patterson, 1983). This cumulative stress was also reported among families of children with other health conditions such as cancer (Granek et al., 2014; Klassen et al., 2007). Early assessment and interventions are needed closely after diagnosis of a childhood chronic condition to prevent the accumulation of stress and family crisis.

The application of Family Systems Theory to design interview questions that examined the impact of JIA on the family and its members revealed new findings about the impact of JIA diagnosis on families, which included parents feeling judged by others, and the negative effects of JIA on siblings, marriage, and relationships between family members. Nurses need to understand and assess the impacts of JIA, the ill child, non-ill children, and the parents, so that appropriate resources and support can be provided.

Limitations

There are several limitations in the study. First, the sample size was limited to the prior observational study sample and data were limited to parents' recall. Second, the cross-sectional design limits our ability to understand how parents cope and manage the illness-related challenges over time. Third, the nature of the interview questions may have biased parents' perceptions of challenges and how parents managed and adapted to the challenges.

Implications and Conclusion

Three tentative clinical implications are suggested by study results. First, healthcare providers 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. Second, parents in the current study expressed feelings of isolation and a strong desire to share their experience with other families of children with the same diagnosis at a similar young age. This supports the potential value of connecting the parents with other parents in similar situations. Third, parents encountered multiple challenges after their child's JIA diagnosis, and not all the challenges may be due to the child's illness. Healthcare providers may need to re-evaluate their commitment to family-centered care, and consider the full range of challenges families encounter when a child is diagnosed with a chronic condition, so they can provide necessary resources.

The current study findings are the first to highlight the day-to-day challenges parents encountered when caring for a young child closely after the initial JIA diagnosis. The new knowledge generated from this study may help healthcare providers understand parents' stress and illness-related challenges. Future studies may benefit from studying a larger number of families, both at initial diagnosis and over time, allowing researchers to examine the patterns of stress, coping, and adaptation over time. Findings suggest areas to address in developing and testing new programs or services for parents and young children with JIA. However, the methods and channels for such programs and services await additional future studies. There is no question, given the current study's early results, that parents of children with JIA need and deserve our attention.

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Highlights

- The core construct Struggling in the Dark to Help My Child explained parents' experience in caring for a young child with JIA.
- 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.
- The prolonged struggle substantially impacted the emotional and physical health of the parents and the entire household.

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)?

Table 2**Inductive Content Analysis Steps**

Steps	Details
1. Unitizing data	Data were unitized based on complete ideas, not complete sentences. A complete idea was defined as a verbal expression that included both a verb and noun, and the idea could be explicit or implicit. Thus, a compound sentence with more than one idea was analyzed into its component parts and each part was coded as one data unit.
2. Open coding and identification of initial categories	All unitized data identified in Step 1 were open coded; none was discarded. Open coding required the analyst to put aside preconceived notions about what was expected to be found in the research, be open to all potentials and possibilities contained within the data, and let the data and its interpretation guide the analysis. Open coding involved analyzing, comparing, and categorizing the data units. First, open coding happened within each interview question. Data units were reviewed and organized into categories of units based on one or more common properties. Then, all data units across all interview questions were open coded together to develop the initial set of categories. No unit of data appeared under more than one category.
3. Naming and defining initial categories	Categories were defined with critical attributes according to the shared properties of the units in each category. Category names were chosen from the parents' own words. Constant comparisons were utilized to ensure mutual exclusiveness of the categories. Each unit was compared with each category to maximize the fit of the unit with the category. If the unit did not fit a category, a new category was created. All categories were compared with one another to ensure non-overlapping.
4. Identification of higher order domains, naming and defining domains	Categories were organized into higher order groups called "domains." Categories within a domain represent different dimensions of the domain. Domains were defined according to the shared properties of the categories within each domain. Domain names were chosen to best capture the manifest meaning of the categories, which were labeled with the study participants' own words. Constant comparisons were also utilized to ensure mutual exclusiveness of the domains. Defining and refining categories and domains were performed continuously during the analysis period.
5. Identification of a core construct	Domains and categories were reviewed and a core construct that organized the domains and categories was identified, with the goal that the core construct further organized the domains and described the social processes in which the parents engaged caring for their young child with JIA.

Table 3**Struggling in the Dark to Help My Child: Domains and Categories of Parents' Experiences**

Domains	Illustrating quotes
Domain 1: Not Knowing	<p>"The biggest [challenge] for us really...just emotionally dealing with the fact that we didn't really understand."</p> <p>"We don't know what, how to best treat [JIA] because the treatment that works for one child doesn't necessarily work for the others."</p> <p>"I think we were just so overwhelmed at that time that we couldn't even process all of that information."</p>
Domain 2: Trying to Reach Out in the Dark	<p>"I felt really kind of alone and in the dark when [child] was diagnosed."</p> <p>"I just felt, I, I had no resources to draw on."</p>
Domain 3: Working Out the Kinks to Stay on Top to Manage	<p>"So a lot of crying, especially at night, very uncomfortable, very restless, to the point where I'd wanna pick her up and she wouldn't let me touch her."</p> <p>"Once when he was first on methotrexate, I was really, really paranoid about him being sick all the time...and I'd get kind of frustrated and upset when we had friends that would bring a sick, their sick child, over and then [my child] would get sick"</p> <p>"I think the most challenging thing for us is probably her medication. Just keeping the dosage straight you know, 'cause sometimes it changes."</p>
Domain 4: Feeling My Child's Pain	<p>"Every time you're doing that injection and you're pulling out all the tricks in your hat and you know, your child is not responding to them. You still have to give the injection. So, to hold them down and, and like force it onto them, it's traumatizing."</p> <p>"[You're] empathizing with them and feeling their pain. You almost feel it more than they do."</p> <p>"In his mind, um, I could see that he would feel like that, that I had betrayed him or abandoned him because he always turned to me to comfort him and I couldn't comfort him the way that he was used to."</p> <p>"You feel guilt, too, as a parent, that you're not doing enough or you still wonder if it, if like, did I feed her too much dairy?"</p>
Domain 5: Feeling Drained by the Whole Process	<p>"It kind of started with [child] getting diagnosed with JIA and then a lot of things happened since then that have been hard and difficult and...feeling like, kicking a dog when it's down type of thing and then the first blow was, was finding out about [child]'s JIA. And then after that there's just been like, one kick after another, it feels like."</p> <p>"It [JIA] kinda consumes your life... until it's in remission, it really consumes your life."</p>
Domain 6: Being Hard on the Entire Household	<p>"Like we held, held back a little bit during that time 'cause for her to go and watch other kids having, being able to have all this fun, um, it's like we would rather stay home, rather than go there and be sad about it, you know."</p> <p>"It really hurt his brothers because they felt helpless also because seeing their brother in pain is never fun."</p> <p>"I know that there was resentment towards my husband because I was always the one that got up with [child] when he woke up during the night and always when I got up with him first thing in the morning when he woke up, and there was just building resentment that he didn't do more with, I was the one that was sleep deprived all the time instead of him taking a turn being sleep deprived sometimes taking turns with [child]."</p> <p>"It [sleep deprivation] affected me hugely. It, it still continues to affect me. I've totally come to understand why, why sleep deprivation is used as a torture tactic and it has been used as a torture tactic because it is just, you get to this, this state where you're so tired and you just wanna sleep and, and not have it disturbed. And so from the time [of the diagnosis], pretty much, I feel like I was constantly sleep deprived for over, for almost three years consecutive of my life."</p>