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“A Remarkable Experience of God, Shaping us as a Family”: Parents’ Use of Faith Following Child’s Rare Disease Diagnosis

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Abstract

A child’s chronic illness can lead parents to utilize different types of coping, including religious beliefs and practices. Previous studies have generally focused on life-shortening diagnoses. The present study explored parental use of faith when the diagnosis was not life-shortening, using grounded-theory qualitative methodology. Data were collected using semi-structured telephone interviews with N=12 parents of children diagnosed with Neuroendocrine Hyperplasia of Infancy (NEHI); approximately 50% of the diagnosed population in the US at the time of the interview. Participants used faith to cope and make meaning in five ways: parents believed NEHI happened for a reason; beliefs provided resilience; parents were sustained by faith communities; beliefs affected parents’ behavior; and beliefs developed over time. The results suggest that chaplains develop means for universal screening for spiritual struggle; educating congregational clergy how to support families in which a child has a chronic illness; and assisting parents construct meaning of their experience.

Keywords

NEHI; spirituality; religious coping; chronic disease; parents

Introduction

Parents of children with a chronic disease may experience stress from the time when the search for a diagnosis begins and for many years afterwards. Many parents use faith to cope with the stress of their child's illness (Baldacchino, Borg, Muscat, & Sturgeon, 2012; Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011; Marshall et al., 2003; Schneider & Mannell, 2006; Wilson & Miles, 2001). Spirituality and religion provide frameworks for meaning (Pargament, 1997) and practices that increase resilience (Womble, Labbé, & Cochran, 2013) and also may provide social and emotional support from others (Krause & Wulff, 2005). Faith and spirituality are common among Americans (Newport, 2012).

This study interviewed parents of children with a rare pediatric lung disease called Neuroendocrine Hyperplasia of Infancy (shortened to the acronym NEHI and pronounced "knee high"), which was first reported in the medical literature in 2005 (Deterding, Pye, Fan, & Langston, 2005). NEHI is a type of children's interstitial lung disease (chILD) that typically presents with chronic fast and labored breathing, low oxygen levels and often poor weight gain in infants. Delays in diagnosis are common since these symptoms overlap with many more common disorders (Kurland et al., 2013). The diagnosis of NEHI is ultimately established by computerized tomography (CT) scan of the chest and or an invasive surgical lung biopsy. The prevalence of NEHI is unknown and difficult to estimate, though NEHI cases are increasingly being recognized worldwide (Gomes et al., 2013; Lukkarinen et al., 2012; Soares et al., 2013).

Medications do not generally provide symptom relief (Lukkarinen et al., 2012). The required supportive treatment of NEHI patients is perceived by some parents to be burdensome, since it may include months to years of supplemental oxygen and optimized nutrient therapy, such as the placement of a gastrostomy tube, for patients with failure-to-thrive symptoms. Almost all patients diagnosed with NEHI improve within the first two years of life, and there have been no reports of NEHI-associated mortality, which is significantly different from other chILD diseases (Popler, Lesnick, Dishop, & Deterding, 2012). The cause of NEHI is unknown, but recent studies suggest that genetic mechanisms, including mutations in the NKX2.1 gene, play a role (Young, Deutsch, Bokulic, Brody, & Noguee, 2013). Other studies have not identified host factors or an environmental basis for NEHI (Popler et al., 2010).

Most studies of the use of faith in healthcare are with adults, and those in pediatric settings are substantially fewer. Research attention in pediatric health care is important, since parental health behaviors have been shown to relate to their use of faith (Daniel H Grosseohme, Ragsdale, Wooldridge, Cotton, & Seid, 2010; Pendleton, Cavalli, Pargament, & Nasr, 2002). Most published studies of parental faith in pediatric chronic health care have been conducted on patient samples in which disease is chronic and life-shortening. NEHI was chosen as an example of a chronic disease perceived to be severe enough to lead to parental coping even though NEHI is not necessarily a life-shortening condition. This

sample was also selected to serve as an approximately age-matched comparison group to determine similarities and differences in parental use of faith compared with parents of children with life-shortening diseases. The present study was undertaken to develop a qualitative model of how parents of children with NEHI used faith to cope with their child's diagnosis; the extent to which that model differed from previously published models in life-shortening diseases; and to suggest potential chaplaincy interventions for parents of children with chronic diseases.

Method

This study was conducted in the Rare Lung Diseases Clinic at an academic pediatric medical center in the Midwest and was approved by the institutional review board at Cincinnati Children's Hospital Medical Center (IRB 2010-2741). All participants completed the informed consent process during their child's outpatient clinic appointment, which included being informed of the study's purpose, how their data would be used and how their identity would be protected. The physician who treated the children provided a list of eligible parents to the second and last authors. At the time of this study, approximately 30 children in the US had been diagnosed with NEHI.

Participants

Eligibility was based on having a child diagnosed with NEHI, and whose NEHI-related medical care was provided at this clinic and spoke English sufficient to participate in the interview. The second author contacted eligible parents in clinic or by telephone to inform them of their eligibility, answer any questions and obtain informed consent if they decided to participate. Participants then were scheduled for a telephone interview, which was audio-recorded. Recruitment ceased when no new data was obtained (saturation) (Morse, 1995). The interviews took place between January and March; all occurred after the child's diagnosis was confirmed.

Procedure

A semi-structured interview guide was used to elicit participant narratives about their coping during the time leading to their child's diagnosis with NEHI and thereafter. This interview guide was modified for use in this study based on previous studies by the senior author (Daniel H Grosseohme et al., 2010; Daniel H. Grosseohme et al., 2012) and was modeled on work by Ekedahl and Wengstrom (Ekedahl & Wengstrom, 2007). Example questions included, "How much control do you feel you have over your child's NEHI, or life in general?"; "Have your religious or spiritual beliefs changed because of your experience?"; In addition, the interview guide was modified to ask demographic questions; questions related to the child's diagnostic process (e.g., "What diagnoses did your child receive prior to NEHI that were not correct or not the whole problem for your child?"); and their experience of medical care (e.g., "What have been helpful and unhelpful ways in which difficult news was delivered to you?"). Telephone interviews were used for two reasons; first, there was a wide geographic dispersion among eligible parents (11 states in the Midwest and mid-Atlantic regions. The second reason was that telephone interviews often are utilized when the topic is sensitive, such as questions related to one's faith and religious

practices (Midanik, Greenfield, & Rogers, 2001). The interviewer (second author) was a psychosocial clinician with over five years' experience talking about related topics with parents and who was trained by the senior author on this interview guide to ensure rigor. Interviews were audio-recorded, transcribed by a commercial vendor and verified for accuracy by the second author.

Analysis

Grounded theory was chosen *a priori* as the interpretive framework for this study because there was no existing theory of how parents might use faith in this situation, and therefore no hypothesis to test (D. H. Grosseohme, 2014). Using grounded-theory methodology (Charmaz, 2006), the first, third and last authors completed initial coding of the transcripts independently, using the participants' words. Coding consists of identifying seemingly important words, phrases or sentences that relate to the study question. Differences in coding were resolved by consensus. Focused coding was again done independently, during which the individual codes were grouped together according to themes. Differences were again resolved by consensus. Axial coding was done by the first and last authors together; at this stage, the emerging themes were grouped together in ways that explained the core theory that emerged from the data. Due to constraints in the protocol, it was not possible to show the model to the participants for their insights (known in grounded theory methodology as "member checking"). However, validity in grounded theory methodology also stems from its requirement that codes utilize the participants' own words. Grounded theorists do not name categories in their words until axial coding begins.

Results

A total of 12 parents (9 female) of 10 different children with NEHI completed semi-structured interviews (average duration, 70 minutes). Recruitment and interviewing was stopped at that point because saturation had been reached (no new data was being obtained). Four of the children of the parents interviewed were female. See Table 1 for demographic characteristics of the sample. Parents generally indicated appreciation for the opportunity to describe their experience, as the study seemed to acknowledge to them that despite their child having a rare condition, the research interest validated their struggles.

The emergent theory was that the parents of children with NEHI used faith in five ways during and after the diagnostic process to cope with their child's NEHI and make meaning of their situation. Their strategies and experiences with faith-based coping were arranged into several main categories. This model is depicted in Figure 1 and each of these components is discussed in the following sections.

Parents believed NEHI happens for a reason

One of the most-common sentiments expressed by the parents was the belief that their child's NEHI diagnosis happened for a specific purpose and that God was in control of the disease. While the parents did not necessarily know what this purpose might be, they trusted that God was using the situation to bring about some positive end result. For example, one parent expressed the belief that his daughter was chosen by God to have NEHI so that "He

can have more glory through her, through her life, dealing with this NEHI, giving her opportunity to testify for Him to His faithfulness.” Other parents viewed the diagnostic process as a test meant to ultimately strengthen their faith. According to one mother, “...it’s another one of those trials that allows us to become more trusting of God, more strengthened in our faith.” Interestingly, while these parents did ascribe responsibility for their child’s illness to God, they did not blame God or consider Him to be directly culpable for the diagnosis. They accepted that NEHI was God’s will for their child, but didn’t see it as a malicious action or punishment; rather, they took solace in the belief that their child’s illness served some higher purpose and was part of God’s plan for their family.

Beliefs provided resilience

Most of the parents also commented that their faith and religious practices gave them comfort and a sense of strength during the difficult diagnosis process. For many parents, this comfort came through time spent in individual prayer as well as through the knowledge that others also were praying for their child. In the words of one parent, “more than anything, having prayer support was what held us together,” while another said “I make sure to get my alone time with God each day, that really helps me.” For many, the difficulty of their situation resulted in a strengthened faith stemming from an increased sense of reliance on God. According to one parent, “...Really hard times help us rely on Him.” Another said that their child’s illness “makes us see our need for Him, because we see how little we can do on our own.” In addition, the belief that a benevolent God was in control of their child’s life and illness was comforting to many parents. The diagnostic process was fraught with uncertainty and a sense of helplessness for many parents, so this sense of God’s sovereignty over their child’s life was a key source of comfort. In the words of one participant, “there is a point, especially with one of your children, that you are out of control, and then it is sustaining to know that there is one who is in control.”

Parents were sustained by faith communities

In addition to the strength derived from their individual faith beliefs, half of the parents commented on the important role their faith community played in their coping process. Church communities provided crucial tangible support for families; one parent mentioned church members bringing her family meals at the hospital, while another said their church collected financial donations to help cover expenses related to their child’s NEHI. According to one parent, his fellow churchgoers “...stepped right up and do what they can to bless us and help out... I think we’ve really drawn closer to our church family because of that.” Many others expressed the importance of social and emotional support from their church communities. Parents of children with NEHI sometimes expressed feelings of isolation because their children don’t tolerate upper respiratory infections (the common “cold”) as well as children without a chronic lung disease, and they felt that this increased susceptibility frequently prevented them from leaving the house. Participating in church worship or other events thus provided a key social outlet for parents. Fellow churchgoers supported the parents by expressing concern for their ill child and asking after their well-being if they didn’t attend church, which “helps us feel like we’re not alone,” in the words of one parent. These tangible acts of compassion, along with prayer support, eased the strain of

caring for an ill child and gave parents the much-needed time and resources to better care for their own needs.

Beliefs affected behavior

While many of the parents attended church in spite of the infection risk to their child, some also expressed a belief that their child would be protected from infection in church. These parents derived peace of mind from their belief in a supernatural form of protection that applied to their child only while in church. This was so important that one parent who had chosen to miss important family gatherings due to infection risk still felt safe enough to bring their child to church regularly, saying "...unless he was just really, really sick, I would take him to church and we would sit in the back...I just felt like that that was a place where he will be protected and that was...yes, absolutely that was critical."

Beliefs developed over time

Many of the parents interviewed found that their faith and religious beliefs changed or developed throughout the lengthy diagnostic process. For some parents, the difficult diagnostic period resulted in an increased sense of faith and, in the words of one parent, a "stronger sense of connectedness with God." Many parents also said that the diagnostic process led them to believe that God had equipped them with the skills and resources to deal with NEHI. According to these parents, God gave them the tools to make sense of their experience themselves, rather than giving them easy answers or intervening directly. One parent expressed this by saying "God gives us um, minds to think with...He gives us the resources to look at and explore and so we try to use those things that He gives us to make sense of things." Similarly, some parents expressed a change in their conception of God's power to intervene in their child's life. While these parents initially prayed for a miracle or some other direct intervention in their child's life, they eventually came to believe that God intervenes in more-subtle or nuanced ways. One father stated that the diagnosis process helped him realize that "...you can't just tell God to perform, He's not Santa Claus."

All but one parent described how their faith had deepened because of their experience of going through the lengthy diagnostic process and then coping with having a child with a chronic disease. The only parent who did not say their faith was deepened stated that their faith had always been strong and constant, and was not threatened or lessened by their experience. Four parents attributed their child's NEHI to a genetic or scientific cause; three described not focusing on why their child had a disease but on living with it; the remaining five had sacred attributions, including "It happens for a reason (known only to God)" and this being a way God "tests" them.

Discussion

Studying a rare population can be a useful means of comparing similarities and differences to more common populations. The parents in this sample had children in similar age ranges as those described in published studies on the use of parental faith (Baldacchino et al., 2012; Daniel H Grosseohme et al., 2010; Hexem et al., 2011; Marshall et al., 2003; Schneider & Mannell, 2006; Wilson & Miles, 2001). This model has several implications for clinical

chaplaincy. Based on the results of this study, we present a model of how parents used faith to cope with their child's diagnosis of NEHI in which they used faith in five ways during and after the diagnostic process to cope with their child's NEHI and make meaning of their situation.

The one way in which parents used faith to cope differently in this rare disease group compared to more common childhood chronic diseases was the largely absent sense of spiritual struggle associated with the diagnosis. For example, Schneider and Mannell noted that most parents reported questioning their beliefs or being angry with God for a period of time post-diagnosis, although they noted their struggles generally resolved (Schneider & Mannell, 2006). Grossoehme and colleagues noted a similar pattern among parents of children diagnosed with cystic fibrosis. Marshall and colleagues noted the distress parents of children with Down syndrome expressed concerning the child's ability to fit into the Latter Day Saints faith community, another theme not present among the NEHI parents (Marshall et al., 2003). Such a concern may be more salient in smaller, more homogeneous communities than the heterogeneous sample of parents of children with NEHI in this study. The lack of struggle expressed by parents in the present study may be related to the lengthy diagnostic process for NEHI at that time, and the extremely poor outcomes associated with most other interstitial lung diseases. One parent remarked, "It was a relief to get the NEHI diagnosis." This sense of relief after a prolonged period of uncertainty may account for the lack of post-diagnosis spiritual struggle. It is unknown whether increased awareness and recent progress in the diagnostic approach to childhood interstitial lung diseases may alter the impact on families in coping and spiritual domains (Kurland et al., 2013).

Pargament has written of spiritual struggle due to illness or trauma as presenting a "fork in the road", at which point spiritual struggle may become chronic for some people, while others experience spiritual growth (Pargament, 2008; Pargament, Murray-Swank, Magyar, & Ano, 2006). The proportion of parents in this study that reported a deepened faith, or spiritual growth, is remarkable and may be due to the non-life-shortening nature of NEHI. Despite this, two findings strongly suggest the need for spiritual screening for parents of children with chronic illnesses (and those in a process that may lead to a chronic-illness diagnosis). First, parents in this study reported spiritual growth and evolved beliefs. Other similar studies also report an evolution of parental beliefs over time (Baldacchino et al., 2012; Daniel H. Grossoehme, Ragsdale, Snow, & Seid, 2011; Marshall et al., 2003; Wilson & Miles, 2001). Early, universal screening permits chaplains to identify persons in potential need of professional spiritual care to minimize the negative health outcomes associated with spiritual struggle (Fitchett et al., 2004; Pargament, Koenig, Tarakeshwar, & Hahn, 2001) and to assist those for whom struggle induces growth. Second, the multi-faceted ways in which parents in this study used faith suggests that chaplains need to explore the breadth of how parents use faith. The evolution of how faith was used over time by the NEHI parents points to the need to re-assess and revise care plans accordingly.

Spiritual history-taking includes queries about one's supportive communities, which may include congregational support. Given the relatively short duration of time in which the family interacts with the health care system, facilitating the connection between family and their congregation may be helpful. Such an intervention implies more than just encouraging

parents to participate in a congregation if they are not already; it implies reaching out to the congregation to educate the clergy and others about the needs of children with chronic illness and their families.

The support described by parents in this study from their congregation was significant. The role of faith communities as sources of religious, emotional and instrumental support also has been found in some, though not all, studies of parents whose children have a chronic disease (Hexem et al., 2011; Marshall et al., 2003; Schneider & Mannell, 2006; Wilson & Miles, 2001). Szczesniak and colleagues have also documented the importance of congregational support to parents of children with cystic fibrosis, although the study did not focus on coping shortly after diagnosis, as have other studies discussed (Szczesniak, Zou, Wetzel, Krause, & Grosseohme, 2014). This suggests that chaplains may be well-suited to be mediators between the healthcare system and congregational life, from being a direct pastoral caregiver to coaching congregational clergy. Chaplains may sponsor educational programs for local clergy to accomplish at least two things. First, they can provide reliable information about chronic diseases of childhood and pastoral responses. Physicians and other clinicians can be conversation partners with chaplains when communicating with congregational clergy. Such an educational “program” might consist of educational content presented on the chaplaincy department webpage or other social media outlet to which congregational clergy could be directed. Second, such programs increase clergy familiarity with the hospital and may decrease their anxiety when they are asked to come to a pediatric unit.

Chaplains have a significant role in helping people in distress construct meaning of their experience. Parents in this study used faith to create the meaning that their child’s NEHI was, “for a reason” and usually ascribed a religious or spiritual significance to the reason. Other studies have documented the constructed meaning by parents of chronically ill children (Daniel H. Grosseohme et al., 2011; Marshall et al., 2003). In particular, the attribution, “It happens for a reason” was also noted by Hexem and colleagues, and Marshall and colleagues documented that the meaning of their child’s Down syndrome diagnosis by Latter Day Saints parents was for a special metaphysical purpose (Hexem et al., 2011; Marshall et al., 2003). Chaplains could facilitate spiritual meaning making with parents. The parents in a study by Baldacchino and colleagues reported that finding meaning in the experience of their child’s disease motivated their coping with the child’s illness (Baldacchino et al., 2012). When constructed meaning—or the search for it—provides hope, supporting parents in their search for meaning, may help them continue to trust healthcare providers when they are presenting primarily pessimistic views of the outcome, (Wilson & Miles, 2001). Trust in one’s healthcare providers is influenced by religious beliefs and relates to health behaviors that include adhering to prescribed therapies for chronic illness (Benjamins, 2006). While often thought of as a “downstream effect”, a chaplain who supports parents’ search for meaning in the face of their child’s illness may contribute to parental health behaviors and thus the child’s health outcomes.

Religious and spiritual beliefs influencing parents’ behaviors have been noted previously, including differences in treatment behavior by parents of children with cystic fibrosis (Daniel H. Grosseohme, Cotton, Ragsdale, et al., 2013; Daniel H Grosseohme et al., 2010).

In those studies, parents described how faith allowed them do painful but necessary care for their child, guided medical decisions, and was related to the extent to which parents actually completed their child's daily home treatments for cystic fibrosis. Schneider and Mannell report differences in prayer behavior among parents of children with cancer (Schneider & Mannell, 2006). Parents of children with NEHI reported beliefs strong enough that they overcame fears of their child developing a community-acquired infection and took the child to public worship believing the child would be "protected" in such sacred space, even though they reportedly avoided family gatherings due to this fear. Despite these examples of ways in which parental faith influences their behavior, they do not frequently share these influences with their child's healthcare providers (Daniel H. Grosseohme, Cotton, & McPhail, 2013; Marshall et al., 2003), although this may be because such beliefs are tacitly held. Chaplains often devote time to creating relationships and maintaining an emotionally and spiritually safe place in which parents may articulate ways that their beliefs relate to their behavior. This practice may help people make the relationship between belief and praxis explicit for the first time, and it may be a bridge to sharing their practices with healthcare providers when appropriate.

This study manifests a limitation inherent in any qualitative study in which persons are asked to relate past events; namely, recall bias. Although the sample size in this study is numerically low, it represents approximately half of the available, known population in the US at the time of the study (unusual for a qualitative study), and permits cautious generalizations about the findings and implications. Future research efforts could undertake a meta-analytic qualitative study as a step toward developing evidence-based practices for chaplains encountering parents of a child with a chronic condition. Identification about genetic factors was not available at the time the children of these parents were diagnosed, and the diagnostic process for NEHI has changed (such that many children no longer undergo lung biopsy). A future study could explore how the different diagnostic process and different information about the disease's mechanism might influence religious struggle or religious coping among parents of children diagnosed with NEHI.

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Figure 1.
 Conceptual model of parental use of faith to cope with child's NEHI diagnosis

Table 1

Demographic Characteristics of Participants and Their Children

		N (%)	Mean (SD)
Parent			
Gender	Female	9 (75)	
Race	Caucasian	11 (92)	
Religious Affiliation			
	Roman Catholic	4 (33)	
	Non-denominational Christian	4 (33)	
	Protestant	3 (25)	
	Jehovah's Witness	1 (9)	
Child			
Gender	Female	4 (40)	
Race	Caucasian	9 (90)	
Age (Months)	Symptom appearance		2.6 (14)
	Diagnosed with NEHI		11.2 (6.2)