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“It Was an Overwhelming Thing”: Parents' Needs After Infant Diagnosis With CAH¹

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Abstract

This study characterizes the experiences and expressed needs of parents following diagnosis of their newborn with congenital adrenal hyperplasia (CAH). Six parents (four mothers and two fathers) were interviewed about how they learned about CAH and its management, followed by qualitative data analysis. Coding of transcripts revealed several themes, including health communication problems, a lack of medical home and decision support, and a desire for parent-to-parent social support. Findings have implications for how family-centered health care is delivered following an unexpected newborn diagnosis.

Keywords

Primary care providers; Qualitative; Retrospective; Interview; Infants; Parents; Children with special health care needs; Chronic conditions; Congenital adrenal hyperplasia; Health communication; Health literacy; Social support; Research report; Endocrinology; Newborn screening; Pediatrics; Medical home; Decision support; Disorders of sex development

“Most families enter the world of illness and disability without a psychosocial map to navigate the normative (i.e., common and expectable) strains.” (Rolland & Walsh, 2006, p. 529).

Background

Parenting a newborn with a complex health condition presents special challenges. The process of establishing the parent–child relationship in infancy can be complicated by a NICU admission and uncertainties about future growth and development. How parents adapt

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ultimately affects the child's and family's well-being (Fisher, 2001; Rolland & Walsh, 2006). Contextual factors, including the family's interactions with the child's health care providers and their personal social network, influence how parents accomplish adaptive tasks (Knafl, Deatrick, & Havill, 2012).

Newborn screening (NBS) represents a major accomplishment in health care implementation. Current recommendations for all U.S. states and territories are to screen for a uniform panel of 31 conditions (Watson, Mann, Lloyd-Puryear, Rinaldo, & Howell, 2006; U. S. Department of Health and Human Services, Health Resources and Services Administration, Discretionary Advisory Committee on Heritable Disorders in Newborns and Children, 2013). With the benefits that accompany early detection of serious medical conditions also come the challenges to parents of having their infant unexpectedly diagnosed, shortly after birth, with a life-threatening or life-limiting condition. Ideally, the medical home would coordinate the care of infants identified through NBS and work with specialists to assist the family in understanding and managing their child's condition (American Academy of Pediatrics, Newborn Screening Authoring Committee, 2008). However, in reality, primary care physicians do not always feel prepared to manage follow-up after a positive NBS (Kemper, Uren, Moseley, & Clark, 2006). As a result, positive adaptation for these infants and families may be compromised (McAllister, Sherrieb, & Cooley, 2009).

One of the conditions in the uniform NBS panel is congenital adrenal hyperplasia (CAH), which is typically identified through NBS and confirmatory diagnostic testing or, in the case of affected girls, due to masculinization of the genitalia. "Classic" CAH, inherited as an autosomal recessive genetic disorder, affects males and females in equal numbers and is potentially life-threatening. Mutations of genes for enzymes that mediate the biochemical steps of adrenal gland steroidogenesis result in insufficient cortisol and aldosterone production, and excessive androgen production (Speiser et al., 2010). The resulting hormonal imbalances, if untreated, can lead to electrolyte imbalances, dehydration, vomiting, cardiac arrest and shock. Incidence of the classic form of CAH ranges from 1:10,000 to 1:20,000 births (Speiser et al., 2010). Medical treatment of CAH involves hormone replacement of glucocorticoids and mineralocorticoids. Clinical management has been described as a "difficult balance between hyperandrogenism and hypercortisolism" (Speiser et al., 2010, p.4140). Yet, when a newborn is diagnosed with CAH, parents are expected to quickly learn about the required routine and emergency medical management so they can care for their child at home. Parents of girls may also experience pressure to decide whether to opt for genital surgery.

Although much is known about parents caring for children with special health care needs in general, little is known about parents' experiences and needs in learning to care for their infant after his or her unexpected diagnosis with CAH. The aim of this qualitative study was to characterize early parent caregiver experiences and needs in CAH, with a focus on contextual factors that can be modulated through education and support delivered by health care providers or via the NBS system.

Method

Participants

Four mothers and two fathers from four separate families agreed to participate in, and completed, a larger study to pilot Web-based educational resources for parents of newborns and young children identified by NBS. Participants were recruited through one state's NBS program via an invitation letter sent to families by the medical director of the program. At the time of enrollment, two of the four families also had an older child with CAH. The first affected child (two girls, ages 5 and 6 and two boys, ages 8 and 11) was the focus of the current study in order to investigate the parents' experiences when CAH was completely unfamiliar to them.

Five parents identified as “White” and “non-Hispanic,” and one as “Asian or Pacific Islander.” One parent had a high school education, two had some college, two were college graduates, and one had a graduate degree. Three worked as paid employees, two were self-employed, and one was a fulltime parent and caregiver in the home.

Design

The study's qualitative descriptive design (Sandelowski, 2000) was well suited to the aim of characterizing parents' experiences and needs. While not strictly adhering to the phenomenological methodology, the design had what Sandelowski described as “phenomenological overtones,” in that the aim was to describe parents' common experiences in receiving their newborn's CAH diagnosis and learning to care for their baby. To that end, both what parents experienced and the context in which they experienced it were emphasized in data collection (Creswell, 2007). The design was retrospective, with parents reflecting on the time after the birth of their first affected child.

Procedure

In individual, semi-structured telephone interviews that lasted 45–90 minutes, parents were asked how they learned about CAH and its management, including contextual factors in the process. They were also asked to comment on how they feel their needs could have been better met during that time. Interviews were audio-recorded, transcribed and coded. Study procedures were approved by the institutional review board, and all participants provided signed informed consent.

Data Analysis

Conventional content analysis (Hsieh & Shannon, 2005) was used to produce a description of parents' experiences organized by theme. Data analysis consisted of identifying significant statements and then developing “clusters of meaning” or themes (Creswell, 2007; Sandelowski, 2000). Coding categories were developed inductively and were derived directly from the raw data.

Two coders, the interviewer (KLB) and the transcriber, independently read the transcripts, noted important statements that emerged on repeated readings, and assigned preliminary codes. In subsequent readings, each independently consolidated and refined the coding

scheme, and categorized codes to form meaningful clusters. Coding schemes were then compared and contrasted, referencing the transcripts to inform joint decisions about how to reconcile minor differences. Inter-rater agreement was high with no substantive discrepancies, and consensus on the initial coding scheme was easily reached. The coders then employed the resulting coding scheme to independently code the transcripts. Subsequent meetings resulted in agreement on coding for all six interview transcripts. Member checking, a technique meant to enhance trustworthiness of qualitative analysis (Sandelowski, 1993), was deemed unnecessary due to the clarity of the data, the agreement between coders, and the strength with which themes emerged.

Results

Three main themes were identified in the content analysis. Communicating health information covered the challenges experienced by parents in understanding provider explanations of their child's condition and associated medical needs. Under the theme unmet needs, parents suggested strategies for improving experiences in the medical setting that attended to both informational and emotional needs at the time of diagnosis. Additional unmet needs were identified by the research team and are captured here. The final theme, social support, covered the particular benefits that come from communicating with other parents who have experienced similar circumstances.

Communicating Health Information

In describing how they learned about how to care for their child, participants talked about difficulties with the way in which information was communicated to them. Parents reported experiencing many strong emotions after learning their newborn had CAH. Common to all were feeling overwhelmed in facing the prospect of caring for their infant, and a limited ability to absorb the information provided. One parent recounted, "The endocrinologist started spitting out all of this information and it was all in technical terms and it was just flat out too much for me. I couldn't handle having that much information...." Another said, "He [the endocrinologist] spoke way above our heads, and I mean, we're educated parents you know what I mean? But...it was so hard to understand him at times, and we got the basic gist, and we knew what we needed to do,...but I just remember it being very, very frustrating." Two parents reported they could not understand the medical jargon used and had to find definitions for these terms on their own. A parent with a science background expressed surprise that she was unable to grasp the information provided, "...I remember... thinking 'this makes no sense to me at all!'"

All parents reported supplementing teaching through books, Internet searches and asking questions of health care providers. However, only two parents from a single family felt comfortable asking every question they had. Four parents came across material while searching online that frightened them. One parent, when exploring a CAH discussion board, encountered the term "intersex," which she had not previously heard, did not understand, and found distressing and confusing: "...it was the most horrible thing and I was like, "Are you kidding me?" No parents received guidance from health care providers on evaluating the quality of Internet health information sources. Four parents reported that the most

difficult time was before they understood the situation and what they had to do. Understanding is important: “When you understand what's going on, it's not as scary....any knowledge is power.”

Unmet Needs

Unmet needs can be characterized as either: a) those that parents verbalized in the interview or b) those that emerged from the interviews and were identified by the research team. Participants offered many ideas about how they would have preferred to receive information about their child's CAH. At initial diagnosis, parents stated that they wanted “easy-to-digest” information and “just the facts, because you can't handle anything else.” They wanted CAH explained without medical jargon or too much detail, and to learn how to give medication at home. Three parents said they wished that at their child's diagnosis they had been given a written “survival guide” or “playbook,” and they wanted it to contain illustrations and practical, how-to information, such as “what's going to happen now,” how to give medicine, and “what if the baby spits up.” They also wished for referral to trustworthy sources for further information, both print and Web-based, and an after-hours phone number to call with questions. The majority expressed the need for additional, more in-depth, information to be available as time since diagnosis progressed, including information on financial matters, such as paying for care or missing work. As one parent said, “there's just so much, there's so much to CAH, and everything you have to deal with and things you don't even think about until it happens.” Importantly, parents needed information to be accompanied by reassurance that many babies are born with CAH or other congenital conditions, their parents successfully learn to care for them, and the children have the potential to grow up healthy and happy. One parent felt she needed someone to tell her, “You're going to be okay, just breathe.”

Two other issues emerged from the data, though the participants themselves did not identify these as issues. First, all four families lacked a true medical home for their child; their child's care was neither routinely delivered nor coordinated by their child's primary care provider. In three families, the endocrinologist took the lead in managing routine and specialty care (e.g., general illness). With regard to coordination of care, parents in two families felt that they were the de facto care coordinators for their child: “...honestly, we coordinate all the care,” while in the other two, the endocrinologist was identified as the main coordinator of care.

The second issue that emerged from the data involved parents of girls. These parents viewed genital surgery as a necessary part of treatment rather than as a decision point in the care of their child. One parent stated that, “It's close to no choice” and that “we figured that it had to be done.” Another parent stated that deciding “what to do, and when to do it, and how to do it, and what doctor” was a “tough process,” but they never had any question about whether their daughter would have surgery in the first year.

Social Support

The parents in this study received instrumental (practical) and emotional support from family and friends. However, they described support from other parents of children with

CAH as fundamentally different. “We have a great family and friends but sometimes it's like we're the outsiders, because, I don't know, you feel like you got to put on this big front and keep it together...” One mother had the chance to meet another mother of a child with CAH: “It was awesome! Just to share experiences and see her little guy.” Five parents expressed a desire to help new parents of children with CAH, including by meeting with families of newly diagnosed children. One parent expressed the desire to reassure: “...I'll go to the endocrinologist and see brand new parents and I just want to walk up to them and hug them and tell them it's going to be all right.” All six parents found the CARES Foundation: Congenital Adrenal Hyperplasia Research Education and Support (2011) to be an important resource for information and support, specifically for a way to connect with similar others.

Discussion

For parents, the unexpected diagnosis of their newborn with a serious medical condition, like CAH, presents profound adaptive challenges. Early on, parents rely principally on health care providers, particularly the pediatric endocrinologist, to teach them what they need to know to care for their child and to support their informed decisions about their child's care. The findings highlight shortcomings in this process, including parent dissatisfaction with health communication about their child's CAH, a lack of process for fully-informed genital surgery decisions, absence of a medical home and thus care coordination, and an unmet desire to receive and give social support with similar others.

The small sample size recruited from a single state's NBS program challenges the potential generalizability of the findings. However, the high degree of overlap across the four families' experiences suggests that commonalities exist. Due to the retrospective nature of the design, there is a potential for recall bias, but in such salient life events, participants likely recall their experiences more vividly. For three of the four families, the birth of a subsequent CAH-affected child prior to the interview poses the risk of confounding recollections of the first affected child.

Parents emphasized the importance of knowing and understanding, though most of them described leaving appointments without fully understanding everything the endocrinologist had explained. Endocrinologists did not always take into account how parents' capacity to absorb complex and novel information was affected by emotional states, volume of information provided, and health literacy. Knowledge has been described as a means for parents of children with chronic conditions to feel empowered, to regain control, and to partner with health care providers (Fisher, 2001), yet after diagnosis through NBS, the number of questions parents ask varies widely (Dillard, Shen, Robinson, & Farrell, 2010), and providers do not always check for parents' understanding (Farrell & Kuruvilla, 2008). In diverse child conditions, many parents are dissatisfied around the time of diagnosis with the amount of information provided and its comprehensibility (Starke, Wikland, & Möller, 2002). They often feel they are given too much information at once and become overloaded (Hummelinck & Pollock, 2006; Starke et al., 2002). This is particularly true for parents whose child has a condition for which specialty care and an interdisciplinary team is required (Hummelinck & Pollock, 2006).

Parents shared concrete ideas about how the initial information provided after their child's diagnosis could have been improved. Similar recommendations have been made for diverse chronic conditions. Parents want to understand the day-to-day care for their child and the implications of their child's diagnosis for family daily life (Hummelinck & Pollock, 2006; Starke et al., 2002). Practical information, such as medication administration strategies, services available, insurance coverage, and information to share with others is valued (Hummelinck & Pollock, 2006; Jackson et al., 2008; Ray, 2002). Giving information on several occasions over a period of time makes it easier to understand, accept and reflect upon (Hedov, Wikblad, & Annerén, 2002; Starke et al., 2002). Information needs depend on time since diagnosis and parents' confidence in managing the child's care (Hummelinck & Pollock, 2006). In addition to verbal communication, parents want written information (Starke et al., 2002) as they find it difficult to retain information presented only verbally (Jackson et al., 2008). Parents also want referral to vetted, reliable sources for further information (Jackson et al., 2008). This should include both referral to vetted Web resources, such as the CARES Foundation, the National Newborn Screening and Global Resource Center (2013), and Web sites sponsored by academic medical centers (e.g., YourChild at the University of Michigan Health System, 2014), together with basic skills/tools for how to evaluate results of online searches, because caregivers are heavy users of the Web for information and coping (Fox, Duggan, & Purcell, 2013). Providing information in a variety of ways will help meet the needs of parents who may have different preferences due to variations in learning styles.

Parents expressed a desire for parent-to-parent contact. Parents of infants diagnosed with diverse congenital conditions benefit from social support and having contact with other families with a child with the same diagnosis (e.g., Hedov et al., 2002; Starke et al., 2002). Feelings of isolation and/or stigmatization are reduced by meeting similar others (Davies & Hall, 2005). Other parents can also provide appraisal support, defined as reassuring information related to self-evaluation through social comparison (Gottlieb, 1978; House, 1981), and can model positive coping. Relationships with similar others help parents put their challenges in perspective. Reciprocity, which is positively associated with health status (House, Kahn, McLeod, & Williams, 1985), is valued by parents, as they progress from receiving support to providing it (Davies & Hall, 2005). Through helping others, parents can find meaning in their child's condition (Case-Smith, 2004), which facilitates healthy family adjustment (Rolland & Walsh, 2006). However, opportunities for new and experienced parents to interact are not common; barriers may include the relative rarity of conditions like CAH, providers lacking confidence in such referrals, and parents feeling overloaded and unable to take on another commitment.

The ideal of the medical home coordinating care and facilitating teaching after positive NBS (American Academy of Pediatrics, Newborn Screening Authoring Committee, 2008) did not exist for the families in the current study. Yet, the family-centered medical home has the potential to improve outcomes for these children and families (McAllister et al., 2009). The current results may be consistent with the finding of Kemper et al. (2006) that many primary care physicians feel unprepared to assist families in navigating the diagnosis and care of infants identified through NBS. Alternatively, specialists may not adequately emphasize the

importance of the medical home, leaving parents with the impression that the specialty practice will fill that role.

Another important aspect of patient- and family-centered care touched on by this investigation is decision-making. The two families with girls in this study never decided whether their daughters would have genital surgery; they assumed it was the only option. Parents of children with other conditions associated with atypical genitalia similarly perceived surgery to be necessary (Crissman et al., 2011). Parents' instincts are often to try to protect their child through early "normalizing" surgery (Sanders, Carter, & Goodacre, 2012), though advocates have argued that parents' fears for their child could be addressed by simpler solutions and parent-to-parent support (Magritte, 2012). Effective health communication is an essential part of decision support, which should include not only ensuring understanding of the condition, but also addressing emotions, values, and evidence about all possible options (Karkazis, Tamar-Mattis, & Kon, 2010).

Overall, the current findings point to opportunities for improvements in how health information is provided to parents after their infant's diagnosis through NBS. Teaching should take parent emotional state, health literacy and learning style into account, be followed by assessment of understanding and supplemented with trustworthy Web, print and multimedia resources. A multimedia, evidence-based Web resource created for these parents would be particularly well-suited to delivering educational materials that meet their needs.

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