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Using Online Health Communication to Manage Chronic Sorrow: Mothers of Children with Rare Diseases Speak



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Families affected by rare disease experience psychosocial reactions similar to families with prevalent chronic diseases. The ability to respond and manage the condition depends on psychosocial factors. This phenomenological study of 16 mothers of children with Alagille syndrome explored their lived experience in using online health communications to manage their chronic sorrow. Data consisted of semi-structured interviews analyzed using techniques described by van Manen. Analysis yielded four essential themes: connectedness, online triggers, empowerment, and seasons of online use contributed to online communication essential to a rare disease community. Findings suggest mothers need emotional support and help accessing appropriate online resources.

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RARE DISEASES POSE a significant and under-researched problem in health care. Almost 7000 rare diseases affect 25–30 million Americans, although each disease affects fewer than 200,000 Americans (National Institutes of Health, 2011). Children comprise approximately half of those individuals affected with rare diseases (National Institutes of Health, 2012). Rare diseases by their isolating nature make it difficult for parents of such children to find support (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006).

Families affected by rare diseases experience reactions similar to families with more prevalent chronic diseases, including shock, confusion, relief and grief/sadness (Hatton, Canam, Thorne, & Hughes, 1995). The isolating nature of rare disease and the unfamiliarity of many health care providers complicate the management of the condition and psychosocial experiences. Parents caring for a child with chronic illness generally seek and use social support from health professionals, family, friends and faith (Coffey, 2006;

Croezen et al., 2012; Wang, Wu, & Liu, 2003). Online communication provides the critical mass of people needed for support and facilitates finding information about rare conditions. Women are more likely to search the Internet for health related information and use online support groups (Pew Internet and American Life Project, 2007).

This study explores the lived experience of mothers of children with Alagille syndrome (ALGS) in using online health communications to manage their chronic sorrow. It seeks to inform nurses about these issues so they can consider how mothers manage their daily experiences. ALGS is a complex disease (Spinner et al., 2001) involving mutations at numerous different loci of the JAG-1 and NOTCH-2 genes on chromosome 20 and affecting approximately 1 in 70,000 live births. Almost all patients have a reduction in liver bile ducts (ALGS National Digestive Diseases Information Clearing House, 2009) and congenital heart defects (McElhinney et al., 2002). The disease also can affect numerous other organs, including the vascular system, kidneys, and spine, as disease severity varies widely. No cure exists for ALGS, but common treatments target improving

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the heart function and reducing effects of impaired liver function, with liver transplants being necessary for many patients (National Digestive Diseases Information Clearing House, 2009).

Chronic Sorrow

Mothers caring for a child with a chronic illness experience increased distress (Isaacs & Sewell, 2003), similar to grief reactions (Eakes, 1995; Vickers, 2005). Unlike grieving mothers, they also face the recurring disparity between their expectations for their child and the constraints imposed by the disease (Eakes, Burke, & Hainsworth, 1998) and ongoing loss with periodic triggering events (Northington, 2000).

Chronic sorrow theory addresses the ongoing disparity between hopes and reality. Chronic sorrow is cyclical sadness that is “pervasive, permanent, periodic and potentially progressive in nature” (Eakes et al., 1998, p. 180). It is a normal response as parents adjust to life with a child with a rare disease. The chronic sorrow literature emphasizes the importance of coping and social support, since many health care providers do not regard chronic sorrow as a normal response (Bowes, Lowes, Warner, & Gregory, 2009) and view the mother’s optimism and advocacy as denial of reality (Bettle & Latimer, 2009).

Maternal and Parental Coping

Researchers define coping as adaptive/constructive behaviors that can be classified into three types: appraisal focused, problem focused, and emotion focused (Weiten, Dunn, & Hammer, 2011). Mothers tend to use appraisal and problem focused strategies when caring for a chronically ill child (Coffey, 2006). The most helpful coping behavior is the problem focused strategy of seeking social support from others (Hodgkinson & Lester, 2002). Four types of social support activities exist: emotional, informational, appraisal, and material/instrumental (Eastin & LaRose, 2005). Parents of children with chronic illness identify the need for emotional, informational and material/instrumental support (Liu, Chao, Huang, Wei, & Chien, 2010).

Online communication encompasses social support activities that differ based on parental needs. Parents of children with more common chronic health conditions use various forms of online communication to supplement information from physicians, develop knowledge and increase advocacy (Coulson & Greenwood, 2011; Roche & Skinner, 2009). These parents do not readily turn to the Internet for health information, but preferred receiving information from their health provider (Gage & Panagaskis, 2011; Nordfeldt, Angarne-Lindberg, Nordwell, & Krevers, 2013). In contrast, emerging research suggests that parents of children with a rare chronic disease often turn to the Internet first to gain access to information regarding the disease and resources (Schaffer, Kuczynski, & Skinner, 2008; Skinner & Schaffer, 2006). We

lack a significant research base that explains other uses of online communication by these parents.

Methodology

The researcher employed a phenomenological approach rooted in a hermeneutic orientation to study the experiences/feelings of mothers using online health communications. Hermeneutic phenomenology involves interpreting the “texts” of life and lived experiences (van Manen, 1990). Chronic sorrow theory aided in forming questions with regard to lived experiences of mothers using online communication and can best be described metaphorically as a “spotlight”. “Theory is a spotlight, it illuminates what you see” (Maxwell, 2013). Furthermore, its use facilitated cohesion of the interview process.

The researcher recruited a purposive sample of mothers of children diagnosed with ALGS using an informational flyer on Facebook and in the ALGS Alliance’s newsletter. The researcher was known to the ALGS community because her daughter died from complications related to ALGS.

The sample included 16 mothers, aged 31 to 53 years. Participants were White (81%; $n = 13$) or Black (19%; $n = 3$). Most were college educated (88%; $n = 14$), married (75%; $n = 12$), and employed outside the home (88%; $n = 14$). Fifteen participants resided across the United States; one participant was from Europe.

Their children with ALGS ranged in age from 6 months to 17 years and had a variety of medical diagnoses associated with ALGS. The predominant diagnoses associated with ALGS, in addition to liver problems, included peripheral pulmonary stenosis and congenital heart disease. Five children had additional medical diagnoses not generally associated with ALGS. Five children were liver transplant recipients.

Data Collection Procedures and Instrumentation

The researcher developed a two part interview guide. Part one gathered demographic information. Part two consisted of 10 open-ended questions related to the mother’s experiences with online communication and her thoughts/feelings since the child’s diagnosis. Given the centrality of chronic sorrow emerging from the literature, the researcher used some questions contained in the Chronic Sorrow Questionnaire–Caregiver Version (Burke, Hainsworth, Eakes, & Lingren, 1992) in part 2. Two content experts reviewed the interview guide to address possible researcher bias, a validity threat often identified in qualitative research (Maxwell, 2013).

Mothers participated in one audio-recorded interview. Fifteen were interviewed by telephone, while one used Skype. The researcher transcribed interviews verbatim, reflected upon her beliefs, preconceptions, theories, motives, interview experiences, and personal biases, and documented her reflections in a journal after each interview. The researcher addressed concerns of potential biases/beliefs through “decentering”, an approach advocated by Munhall (2012), that creates

an awareness of beliefs, values and ideas and constructs an “unknowing” environment to properly interpret the lived experience. The researcher’s personal experience with ALGS required her to be acutely aware of her personal biases.

Data Analysis

The researcher uploaded transcriptions into the Web application *Dedoose Version 4.5, 2013* to organize and code the data. Following *van Manen (1990)*, the researcher engaged in “hermeneutic phenomenological reflection” (p. 77) by reflecting on and analyzing the lived experiences of the mothers. Next, she conducted thematic analysis via reflection on essential themes in relation to the lived experiences within the context of four life world existentials: “lived space, lived body, lived time and lived human relation” (p. 101). The researcher then incorporated *Munhall’s (2012)* approach by using decentering to aid in phenomenological thinking and returning to the participants for validation of the descriptions of the phenomenon. The researcher also used the reflective journal discussed above during data analysis to enhance the description of the phenomena. These techniques proved critical for the researcher due to her experiences with ALGS.

Lincoln and Guba’s (1985) naturalistic perspective was used to establish trustworthiness of data based on the elements of credibility, transferability, dependability, and confirmability. After data analysis, the researcher presented a summary of essential themes, interpretations and findings to one mother who experienced chronic sorrow and one mother who experienced “unpleasant feelings” (but not chronic sorrow). These mothers verified the researcher’s representation of their lived experience.

Results

Surprisingly, only half of the mothers experienced chronic sorrow. The other half experienced feelings of fright, anger or being overwhelmed that the researcher classified as “unpleasant feelings”. Differences in maternal support networks appeared to explain the different lived experiences. Mothers experiencing chronic sorrow had strong and consistent support from three groups: the online community, family/friends, and health care providers, while mothers experiencing unpleasant feelings lacked support from at least one of these groups. Lee experienced both feelings over time.

Initially... I was angry at the doctor as well because they had tested me for Down syndrome, [and] the typically things they test women for when they’re pregnant. I just could not understand for the life of me how come they had not tested me for ALGS. It was not until I went to genetic testing, realized that it was rare... your OB/GYN doesn’t test for those things.

Lee’s main support came from her mother at that time. She lacked online support or support from others in a similar

situation. However, the feelings of anger were not permanent. Lee slowly developed support networks in online communities, with other similarly-situated mothers, and with medical professionals. Lee states, “Now at times I feel more sad.” The evolution of Lee’s feelings shows how impairment in component (s) of support inhibits the experience of chronic sorrow.

Mothers who experienced chronic sorrow coped with different feelings than mothers who experienced unpleasant feelings, but the same communication themes emerged from the data connected to both sets of mothers. One overarching theme emerged in the interviews: online communication was essential to the mothers in managing chronic sorrow or unpleasant feelings. Mothers’ experiences were overwhelming, scary, and lonely, with little information or support from health care providers immediately after diagnosis. Mothers learned new ways of building relationships/connections, in addition to coping with their child’s illness. They shared their joy about meeting others and establishing a “personal connection” online, however most preferred in-person meetings with other parents. Kate who reported a chronic sorrow experience stated, “I wish there was somebody closer I could get together with, talk and share our experiences, but I am very fortunate for the online part of it.” Clare, a mother who reported an unpleasant feelings experience described online communication was “incredibly important” yet she wished there was a better way to communicate because “you are sharing so much and learn things you don’t need to know”. However, Clare ultimately shares because of the need “to know that other people are going through similar things.” The overwhelming need to share experiences with others in similar situations necessitated the use of online communication for these mothers, as an imperfect substitute for in person support.

Table 1 shows the four essential themes and nine sub-themes that contributed to the development of the overarching theme. The four themes were connectedness, online triggers, empowerment, and seasons of online use.

Connectedness

Isolation is predominant in the rare disease community, so mothers viewed connections to an online community for support as critical, “like a lifeline for a lot of us”. Numerous

Table 1 Essential themes and sub-themes.

Essential themes	Sub-themes
Connectedness	There is hope Being part of the community
Online triggers	We could lose our child Overload via social media Medical piece
Empowerment	Deciding the best place for information We’re the experts
Seasons of online communication	Using online communication more Using online communication less

comments reflected this sentiment: “Community is incredibly important to know that other people are going through similar things.” “It’s such a rare disease there is nobody local, nobody around me, at least ever heard of it. They are always like ‘What the heck is that?’” “The personal connection with other parents and the personal experiences, that’s what gets you through. [Online communication] was just key in me feeling connected and not being alone in it.” The mothers made social comparisons, as do parents with chronically ill children:

Your child always looks a little different than everyone else’s child or they don’t progress at the same rate and I guess that sort of solidarity is really important because it make it feel like you’re not, not something so terribly wrong with you child. When you look at them compared to other Alagille children, they’re doing fine, they’re doing just what Alagille kids do instead of looking at the world at large and other’s kids and how they progress.

Mothers indicated they used online communication for multiple purposes. They often began searching using a search engine like Google and eventually became able to access information, increase knowledge and empowerment, advocate for their child, and establish relationships with others going through a similar experience.

Lee started with message boards and transitioned to social media. She captured a global view of connectedness mothers experience through the evolution of online communication:

the Internet [social media] give you more of a personal touch with individuals, you can always chat with them, ‘Hey how’s your kid?’ and they can ask you...the Internet has been a wealth of knowledge, resources, information and connection

The Internet enabled mothers to communicate, seek support and information, and feel connected with other mothers. Currently, mothers use social media, specifically Facebook and Google, most frequently to feel connected and to obtain information regarding ALGS.

Online Triggers

Online communication can trigger chronic sorrow and unpleasant feelings. Common triggers include: negative information (especially early deaths), extraneous information overload, and the “medical piece”. Mothers seeking information and mothers heavily involved in social media experienced the negative triggers.

All mothers experienced triggers when learning of children who died from complications of ALGS, mostly on Facebook posts and YouTube, when seeking other information or support. Some mothers wondered why they subjected themselves to Facebook groups related to ALGS:

Sometimes a child will die and I’m in tears every time. Every time a little angel dies I’m distraught because I think of the parents and what they must be feeling. I’ve

been, wondering if I should be on that Facebook group at all. Every time that [a child’s death] happened I wonder what I am doing here?

One mother looking for videos of older children shared, “Don’t YouTube Alagille, then you see the kids that have passed away and then it makes you sad.... You wanna see what kind of future they’re gonna have and you see all the sad stuff too.”

Child loss reminded them of the fragility of their children and the unpredictability of ALGS. Lee described a child she followed on Facebook who seemed healthy, but died suddenly:

Last year we lost one and I cried. I was at work and I actually had to leave work it bothered me so bad. For one, I had no idea that anything was going on and so it just, just made me cry because it was just like sudden and why?

Most mothers avoided reading blogs about ALGS. They perceived blogs as generally containing negative information about children in poor health, “I try really not to [view blogs] that much because sometimes they sound so dire. I kinda don’t want put myself in that kind of mind set like ‘oh this is a possibility’. Alagille affects every child differently.”

Facebook “friends” can cause extraneous information overload. Mothers expressed the challenges associated with supporting other parents with whom they may share little in common.

I know them because I am friends with them on Facebook. They post tons of stuff that is of no pertinence to me and so then that gets like almost overload for me. But, I don’t want to defriend them because I know them; they have a child with ALGS and you know somewhere you can support each other too. It’s like I know too many people. I know of them, but I don’t really KNOW them.

The final common trigger related to online searches for medical information. Sometimes when mothers found information regarding ALGS or a specific procedure, the information triggered sadness or unpleasant feelings. Kate reports, “I did read this one article and I remember reading about the survival rate age and that really kinda scared me.”

Empowerment

Mothers recognized the value of information with statements such as “online sources for making yourself literate—it’s a must; if you’re gonna advocate for your child” and “I wanted information.” The knowledge, information and resulting empowerment helped in providing a sense of relief and some level of control. Online communications provided immediate emotional support and empathy mothers needed to feel empowered and capable.

Many mothers wrestled with the best places to get information. “It’s hard to tell who’s really the go-to people; where really is the best place to engage”. Oftentimes, health

care providers could not provide them with information or provided unhelpful/inaccurate information. “We had a hard time getting information from doctors.”

[Physician] was very technical and he was also very certain about the path of Alagille and what it entails. He was like [my son] was going to have a feeding tube, and he was going to have this issue and he is going to have that issue. You know the path of Alagille is different for each child. He was kinda setting up those expectations for us and that WASN'T necessarily our path.

Sometimes health care providers withheld information, complicating the mothers' online searches and their decision making ability. Mothers experienced frustration because of the professionals' lack of assistance.

The worst feeling is when I have been managed by a doctor or a nurse; where they decide that they are going to give me a limited amount of information instead of all the information. I think from the medical community, for me that's the worst possible feeling. We can take it, we can understand it.

Mothers developed high levels of health literacy due to the complexity involved in managing ALGS, including interactions with specialists, interpreting diagnoses, understanding medical instructions/recommendations, and engaging in complex conversations with providers. Mothers spoke of the determination and tenacity necessary to insure meaningful interactions with providers. “I remember reading the medical articles and then having to look up every other word because I didn't know what they were”.

Although mothers acquired more knowledge and confidence in managing their child's disease, providers often remained uninterested in collaborating or partnering with them in managing their child's disease. “There have been a few times when I have been discounted; like my opinions and thoughts were discounted because I don't have a medical degree.”

Seasons of Online Communication

Mothers described “seasons”, a term coined by Faith. She noted with ALGS “there are good seasons and there are bad seasons”. Faith explained seasons encompassed all the experiences families have with this disease. “You'll have a good season or two and then boom here comes this. It's like ‘really one more thing.’” She tells herself, “It is not overwhelming, this is just something we are gonna look into [get ALGS-related information] and we're gonna go with whatever it is”.

Mothers' engagement in online communication varied by “season”. They used more online communications during bad seasons, including the initial diagnosis, pending labs, medical procedures or changes in routine. “We get about 3 good weeks anytime we change her medicine and then it starts to get worse. So that's when I started doing more research with the Alagille on the Internet and the ALGS Alliance”.

Mothers of older children noted that generally as the child aged, bad seasons were less frequent and their lives stabilized. Older children enjoyed less complicated and better health.

As the kids get older, their health kind of stabilizes and so for a lot of the kids it stabilizes and then your need for information and support becomes less and less. You're still connected, but I think those early years until about 8, 9, 10 are really tough years because there's still so much going on. I see myself online it's less and less for the older he gets. It's not as all-consuming.

The mothers' “seasons of online communication” and information seeking behaviors changed over time based on their child's development and illness trajectory. The mothers' choice and frequency of using online communication were based on previous experiences and knowledge about what matched their situation.

Discussion

Online communication profoundly impacted how mothers of children with ALGS managed chronic sorrow or unpleasant feelings. Their child's diagnosis became a stressor leading them to engage in online communications, “even if the information being sought could prove scary and increase their anxiety” (Gundersen, 2011, p. 92). Consistent with the literature, mothers sought emotional and informational support (Coulson & Greenwood, 2011). Obtaining information about ALGS was essential for understanding and adjusting to a distressing situation (Gundersen, 2011). Mothers felt isolated and unable to rely on health care providers for information/guidance. Online communication provided the knowledge to manage the disease and educate others, including health care providers, as found by Leonard et al. (2004).

Mothers needed to meet others coping with ALGS, as documented in studies of parents with chronically ill children (Hodges & Dibb, 2010; Tozzi et al., 2013) and longed for understanding and knowledge. Mothers' hard-earned expertise on ALGS allowed them to manage emotions and gain a sense of control that enabled them to be their child's advocate (Gundersen, 2011). They enjoyed being part of the online community and meeting others in similar circumstances, particularly in support groups and social media, but felt an online community could not completely replace in-person interactions. Mothers felt online support was critical to managing feelings and increasing their knowledge of ALGS. Several mothers of older children evolved from being supported to supporting others, which likely leads to empowerment (Kerr & McIntosh, 2000).

Common online communication sources initially served mothers' needs better than ALGS specific sites. Most mothers initially used Google to find information. Other studies have found that individuals seeking health

information often use familiar sources because of unfamiliarity with online data bases (Roche & Skinner, 2009). Mothers eventually improved their ability to find information and assess its relevance and trustworthiness. Similarly, most mothers began feeling connected to others after replacing asynchronous formats with Facebook, which facilitated immediate responses, thereby overcoming complaints about the lack of responses on message boards and list servs (Coulson & Greenwood, 2011).

Despite the benefits of online communication, mothers acknowledged it sometimes triggered unpleasant feelings or chronic sorrow. In addition to traditional triggers, such as the diagnosis of a new condition, the development of a new symptom, or a pending procedure (Roche & Skinner, 2009), this study identified online triggers that caused unpleasant feelings or chronic sorrow. These online triggers included learning about the death of a child with ALGS, extraneous information overload, and the medical piece, which caused mothers to experience increased anxiety (Tozzi et al., 2013) and hampered their ability to judge the amount of information they needed (Gundersen, 2011).

Mothers risked information overload because most providers offered inadequate information about ALGS. The providers' lack of knowledge led the mothers to engage in online communication shortly after their child's diagnosis, as do parents of children with other rare diseases (Tozzi et al., 2013). The rarity of ALGS led mothers to engage in heavier online communication than mothers of children with common chronic conditions.

Empowerment developed as the mothers amassed information and acquired knowledge through online communication resources, consistent with the literature (Dolce, 2011; Margalit & Raskind, 2009). Developing parents' competence and empowerment might reduce stress related to parental incompetence (Dellve et al., 2006).

Mothers felt that their expertise was not valued by health care providers. Similarly, Swallow and Jacoby (2001) found that mothers' voices were "unheard" until they developed strategies for communicating and negotiating with health care professionals. Providers must acknowledge parents as experts in the care of their child, as parents provide care to their child and manage situations that could invoke stress and compromise their emotional health (Resendez, Quisti, & Matashazi, 2000).

The mothers predominantly used online communications for informational and emotional support, consistent with the two main types cited in online social support research (Margalit & Raskind, 2009). Mothers of younger children used less online communication when their child was stable, as opposed to when their child experienced a new symptom or was scheduled for a procedure. Mothers of older children used online communication less for information and more to support parents of newly diagnosed children. The mothers' frequency in using online communication depended on previous experience and knowledge, consistent with research (Nordfeldt et al., 2013).

Limitations

The limitations of this study include purposive sampling, use of one telephone/Skype interview and a demographically homogeneous sample. In-person and additional interviews may have yielded additional data from non-verbal cues or about experiences that the mothers may not have recalled.

Implications for Practice

This study advances our understanding of how mothers use online health communication to manage their sorrow and unpleasant feelings in response to a rare medical condition. Mothers' did not perceive themselves as getting the support/information afforded to mothers with children diagnosed with common chronic conditions. The complexity and unfamiliarity of ALGS among many health care providers led these mothers to explore online communication almost immediately.

Nurses should understand a diagnosis of a rare disease requires special care in guiding mothers with managing the associated feelings. Nurses must assist mothers with accessing appropriate online communication. Increasingly, individuals view themselves as active partners in their health care decision making (Boyer & Lutfey, 2010), so providers should assess mothers for information/computer literacy, which can help clinicians guide mothers to better resources and help clinicians anticipate mothers' informational needs. Nurses also should take a more active role in online communities to support accurate and valid information.

The researcher received the following recommendations from mothers regarding how health care providers could support their emotional needs.

- Automatically provide a health care professional to assist with the emotions experienced at diagnosis
- "Recognize when we are struggling and help us" (provide compassion, empathy, information, consideration, knowledge)
- Take an interest in the disease and helping the parents
- Help the parents find an online community
- "Respecting how much mothers know"

Nurses in community health care settings should recognize the value the Internet brings in expanding health care. Telehealth services for parents of children with special health needs may increase access to care for those in rural/medically underserved areas at no additional cost (Hooshmand, 2010). Nurses must implement technology strategies that promote optimal outcomes for children and their families.

Implications for Research

Research regarding online communication in the context of chronic illness is substantial, but remains limited in the realm of rare disease. More research should be conducted in

the rare disease context because these mothers depended on online communications more than mothers of children with common chronic illnesses. Mothers' experiences in this study suggested they did not perceive themselves as receiving typical support and information. The complexity of ALGS coupled with the unfamiliarity among providers involved in their child's care led them to pursue online communication almost immediately. These notable experiences may require providers to explore the impact of online communication on the dynamics of their relationship/consultation, including selecting optimal times to follow up with mothers to determine if they have identified helpful online resources. More research also is needed regarding fathers, adolescents and adults with rare disease. In addition, the impact of online support on coping and feelings parents have experienced over time should be explored. Lastly, assessment tools allowing for quick identification of chronic sorrow/unpleasant feelings would help clinicians provide appropriate resources.

Conclusion

The researcher's experiences led her to study how mothers of children with ALGS used online communication in managing chronic sorrow. The mothers spoke about their experiences using online communication in managing psychosocial issues. These descriptions should help nurses better understand how they can provide support and resources to mothers of children with rare diseases.

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