

Cybersupport: Empowering Asthma Caregivers

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In the United States, an estimated 6.5 million children have asthma (Akinbami, 2005). Due to the chronic and unpredictable nature of asthma, the condition places excessive demands on the primary caregiver. The complexity of asthma management has required parents to take increased responsibility for the assessment and treatment of their child's asthma (Dickinson & Dignam, 2002). Many families are turning to the Internet for information and support. The purpose of this study was to gain insight into the "lived" experiences of an online asthma caregivers support group. Archived messages posted to an online discussion list were analyzed using phenomenological thematic analysis. Five themes emerged providing insight into the meaning of caregiving and the provision of social support. Online support narratives provide a unique way to gain insight and understanding of the experiences of mother's enacting the caregiver role. Understanding the everyday lives of asthma caregivers can help nurses and other health care providers better meet caregiver needs.

Asthma is a chronic respiratory disease characterized by attacks or episodes of inflammation and narrowing of the airways in response to asthma triggers (Akinbami, 2005; Centers for Disease Control and Prevention, 2002). An estimated 6.5 million children in the United States have asthma, making asthma the most prevalent long-term childhood disease (Akinbami, 2005). Between 1980 and 1996, rates increased for children under the age of 5 years by more than 80% (National Institute of Allergy and Infectious Diseases, 2005). The vast majority of children with asthma also suffer from various allergies (Kieckhefer & Ratcliffe, 2004). Asthma treatment is a complex and ongoing process involving numerous, often time-consuming activities, such as monitoring a child's respiratory status, administering various medications, identifying and removing asthma triggers, and promoting others' understanding of the child's needs through repeated and ongoing communication (Dalheim-Englund, Rasmussen, Moller, & Sandman, 2004). Because the dis-

ease affects one's ability to breathe without warning, there is a great deal of uncertainty and danger involved in caring for a child with asthma (Englund, Rydstrom, & Norberg, 2001; MacDonald, 1996; Rydstrom, Dalheim-Englund, Segesten, & Ramussen, 2004).

Asthma has a significant impact on the quality of life of families affected by the disease (Dalheim-Englund et al., 2004; Juniper et al., 1996; Newacheck & Halfon, 2000). Families report concerns about time management, financial strain, and family relations (Kurnat & Moore, 1999). It is widely accepted that the extent to which parents adapt to living with their chronically ill child ultimately has an impact on the health of the ill child and any siblings (Green, 1994; Kurnat & Moore, 1999; Wertlieb, 2003).

It has become increasingly important for nurses and other health care professionals to understand the experiences of parents who have one or more children with asthma. New roles, responsibilities, and skills must be learned and used by families in managing and coping with the illness (Donnelly, 1994). Palmer (2001) stated, "The caregiver is usually put in the position of the 'fighter' or 'vigilante' for the child, required to always be available and on guard, ready to fight for the child's fair and equitable treatment" (p. 8). Lack of effective communication, underutilization of coping resources, and the absence of adequate support systems can create

unbalanced caregiver responsibilities (Englund et al., 2001). Responsibilities are frequently shifted more heavily to one parent, typically the mother (Dickinson & Dignam, 2002; Englund et al., 2001; Juniper et al., 1996; Townsend et al., 1991). Perrin, Lewkowicz, and Young, (2000) found that mothers of children with chronic health conditions were more likely to identify a need for contact with other families experiencing similar life situations for networking, discussion, and support compared with fathers. Many mothers are turning to the Internet for emotional support and information.

Online Support Groups

The Internet has changed the way people communicate and form support networks. More than 1,000 online support groups have recently become available (White & Madera, 2000). Online support groups facilitate coping through the sending and receiving of text-based messages. According to the Pew Internet Project survey, 73% of respondents (about 147 million adults) were Internet users (Fallows, 2005). As more people gain access, more families are using the Internet for health information and support. Millions of people are logging on and finding support from similar others familiar with their day-to-day struggles and triumphs.

Online support groups can help people overcome mobility, access, or communication-related challenges associated with face-to-face groups

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Objectives and the CNE Posttest can be found on pages 228-229.

(Braithwaite, Waldron, & Finn, 1999; Finn, 1999; Fullmer & Walls, 1994; Wright, 1999). Unlike face-to-face groups, online groups take place without the constraints of time and geographical distance (Braithwaite et al., 1999). Interaction within online groups can promote empathy and emotional integration into a community, becoming part of one's "lived dimension" (Preece, 2000).

Computers may promote greater relatedness by reducing barriers of time, distance, and social status through the formation of virtual communities (Finn, 1999; Jones, 1997). Online groups may actually engage in higher rates of emotional support and self-disclosure compared with face-to-face groups (Salem, Bogar & Reid, 1997). The support received typically comes from a broader array of people with a variety of experiences, views, and opinions. Sharing of information about health care professionals, Web sites, articles, and other resources provide a starting point for one's own research, saving time and decreasing feelings of being overwhelmed from the vast amounts of information and advice available. Interacting with other parents online soon after a child's diagnosis appears to be an important coping strategy for caregivers.

Cutrona and Suhr (1992) used a five-category system for coding face-to-face social support – emotional support, esteem support, network support (nurturing support), informational support, and tangible assistance (action-facilitating). Four of these types of support can be provided in online text-based messages without the physical presence of the provider.

Online participants may choose how much time and involvement they would like to dedicate to the group. For example, some may choose to "lurk," learning about the norms of the group and the types of issues discussed before ever writing a message. Some may subscribe to ask a single question and then unsubscribe from the group. Others may choose to be a "core member," participating daily or on a regular basis. Face-to-face support groups typically have a group facilitator and meet for 60 to 90 minutes once a week, often disbanding after 10 weeks. While face-to-face support groups are often unavailable especially in rural areas, online groups can provide a valuable resource for families dealing with chronic health problems.

Online group participants are not limited to a particular time period to gain support. Ferguson (1996) report-

ed that the largest proportion of online support occurs between 7:00 p.m. and 1:00 a.m. Participants can log on and ask for advice or receive emotional support when they need it most, without the added worry of travel or family commitments. They may choose to meet in person, and/or exchange private emails, letters, photos, and telephone calls. This type of access and communication has been shown to be therapeutic (Perron, 2002).

Support does not have to be "managed" in the same way as it does in face-to-face support group settings. For example, physical absences may produce heavier feelings of guilt and expectations for stronger accountability in face-to-face groups. Group attrition will not be as noticeable in online groups as it is in face-to-face groups. Uncomfortable interactions in face-to-face settings, especially when groups are just forming, often occur without participants knowing how to appropriately respond. It is likely that online support provides a less-threatening way to make social contacts and receive help. Online support participants do not have to worry about what to say when all eyes are upon them. Participants have opportunities to edit their messages before sending or may choose not to respond, without the same type of social sanctions.

The written narrative is unique in providing a memory aid for participants. This aid is not only available for one's own life experiences, but also in helping to remember the life situations of others. Online group messages are often available in archives that can be saved and downloaded for future reference. Archived messages can be read to "catch up" on other's lives when they find themselves too busy or stressed to log on daily. Also, search features and threaded messages provide a quick way to scan for topics of primary interest. Online group participants can choose to receive their support in a daily digest form. The digest makes it convenient to browse through the messages and choose the ones they desire to read or are most relevant to their own situations. This type of tracking is not available in face-to-face exchanges.

Online narratives are valuable tools for providing insights into the lives and experiences of support group members (Christian, 2005; Galegher, Sproull, & Kiesler, 1998). Yet, the "lived" experiences of cybersupport groups are relatively unexplored (Sullivan, 2003). According to Baum's (2004) review, only four Internet sup-

port groups involving parents of a child with health needs were located in the literature. The purpose of this study was to understand the everyday lives of those caring for one or more children with chronic asthma. Messages posted to an online asthma caregivers support group were analyzed. Understanding the everyday lives of asthma caregivers can help nurses and other health care providers to better meet the needs of caregivers and aim to reduce their various life stressors.

Method

A phenomenological thematic analysis was conducted of the archived messages of an online asthma caregiver group. Phenomenology attempts to describe and interpret meanings with depth and richness (van Manen, 1990). Sunwolf and Frey (2001) contend that stories are used, "both to give order to human experience and to share experience with others" (p. 120). To protect confidentiality of the online participants, the name of the group is not revealed and pseudonyms are used when quoting messages (Finn, 1999; Perron, 2002).

The online parent support group analyzed was started by a parent and is part of an extensive Web site aimed at providing information for parents of children with asthma. It was initiated in December 1998, with 9 posted messages. Hundreds of messages are now posted each month. There are currently 435 subscribers to the discussion list. All archived messages are easily accessible to the public. In this study, participants posting messages are referred to as "posters."

During the analysis period (October, 2004 through March 2005), messages were collected and stored on computer disks. The number of messages posted per month were as follows: October, 555; November, 657; December, 590; January, 770; February, 682; and March, 796. Data from another six months were reviewed. Participants lived in numerous locations throughout the United States, in both rural and urban settings. Several participants lived outside the United States in countries such as Australia, Russia, and Canada. Each month, only a fraction of those subscribers post messages, and a core group of subscribers are frequent posters. In November 2004, there were 26 different posters; 23 in December; 21 in January; 26 in February; 31 in March. The remaining subscribers, lurkers, received the messages but chose not to write.

Posts were primarily kept in their original form. Spelling errors were corrected when meaning was compromised. Messages identified the sender, intended recipient, topic of each message, and date and time of original post, followed by the actual text message itself. Some messages were addressed to all users, but the majority were addressed to specific individuals.

Stages of data analysis. ‘Virtual’ lived experiences were analyzed using thematic analysis based on the guidelines presented by Colaizzi (1978) and Osborne (1990). This phenomenological inquiry involved a three-step process – (1) Description: gathering messages of virtual lived experience, (2) Reduction: reviewing data to reveal essential themes, and (3) Interpretation: determining the interrelatedness of the themes and how they reflect the essence of the experience (Lanigan, 1988). This process is helpful in setting aside researchers’ preconceived ideas, thus focusing on description of the lived experiences of the group participants (Sullivan, 2003).

Description began with the gathering of archived posted messages from an online asthma caregiver’s group. To gain familiarity with the messages sent, several months of posts were read and reviewed (October 2004 through March 2005). The reduction process began with the messages for each thread starting January 2005. Threaded messages included the original posted message and all responses to it. Threads were read and reviewed twice to gain familiarity and to begin to think about commonalities and possible themes. A third reading was conducted in which messages were put on index cards and bracketed or highlighted. These bracketed messages were believed to be important and significant statements that reflected the essence of the posters’ communication (Sullivan, 2003). The cards were then sorted and clustered into themes. Messages directly relevant to a child’s asthma, including all caregiving aspects, were analyzed and bracketed. The process of analyzing messages by threads continued. When it appeared unlikely that new themes would be revealed, a saturation point was believed to have been reached and the collection phase of the study ended. A total of 2,042 messages were sorted.

Some demographic data were spontaneously offered within the posted messages and organized. Participants were distributed across the United States.

Table 1.
Online Asthma Caregivers Support Group Themes

1. Monitoring: “Seems we never get a break.”
2. Fitting the pieces together: “Who can keep it all straight?!”
3. Second-guessing: “Having to second guess the doctor and having him second guess you.”
4. Sense of responsibility: “I just do it because if I don’t, nobody else will.”
5. Bonding: “We are here for support when you need it.”

All messages by group participants were sent by mothers who had one or more children diagnosed with asthma. In most cases, asthma was combined with other health problems. Many children had various asthma-related conditions, such as allergies, skin conditions, and urinary tract reflux problems. Others had other non-asthma related health conditions. Mothers self-reported their own health conditions, including both asthma and allergies.

Posters developed shorthand methods of communicating, often using abbreviations. Some of the common abbreviations were ped (pediatrician), pp (pediatric pulmonologist), aa (asthma/allergist), neb/nebbing (nebulizer use), and dh (deadbeat husband). Common online symbols of expression were also used, most frequently LOL (laugh out loud) and :, expressing humor within their strenuous lives.

Results

This online support group provided an opportunity for asthma caregivers to tell their story and establish ongoing connections with other mothers who understood their fears and frustrations. The women in this study shared what it meant to them to be a mother of a child with asthma, focusing on the everyday stresses and worries brought on by this role. Five themes emerged in the process of analyzing support group messages that brought insight into the complex issues related to fulfilling the caregiver role and the provision of social support (see Table 1).

Monitoring: “Seems we never get a break.” Mothers monitored the lives of their children, while attempting to adhere to a complex asthma plan. Consistent with MacDonald’s (1996) “mastering uncertainty,” this monitoring process required constant surveillance. These women paid careful attention to the details of their children’s environment, being alert to possible and known triggers. Different seasons brought about different trig-

ger worries, including smoke season (such as chimney fires and wild fires), flu season, extreme temperature changes, and springtime pollen. One mother expressed her frustrations when she wrote, “We thought we would be okay in the winter, but it is so cold, and the spring is windy and pollen, and the summer we have lots of smoke in the air from forest fires, so it seems we never get a break.” Mothers were able to distinguish between various types of coughs, such as barky coughs, low coughs, wet coughs, and wheezes. Activities and triggers surrounding the cough were remembered and put into the mother’s asthma schema.

Even with safety precautions in place, at times these mothers had little control over the child’s exposure to certain triggers, especially in other’s homes and in the school environment. A simple play date was a potential threat and required interviews about the home environment. They expressed their worries that others would pass on germs to their children and jokingly wished for “airtight houses.” Anxiety, plus the children’s health status, influenced decisions to keep children home from school. Many told stories, relaying their frustration with school personnel, especially teachers. For these and other reasons, some mothers opted to homeschool their children.

Although sometimes decisions had to be made quickly, at other times, these parents took a wait and see approach. This approach required mothers to begin a treatment regimen and carefully monitor their child’s health status in response to particular medication. Some wrote about the difficulty of waiting to see how a child would be affected during flu season. As one mother wrote, “Well it is officially hitting here hard, as of the headlines today. Ugh, I really hate waiting to see how bad it is going to be in our family. It is so scary every year.” The desire to protect the child and seek out some level of control was met with the reality of uncertainty.

In trying to prevent asthma flares, these caregivers often tried to anticipate the future. A pregnant mother revealed her anxiety about the future when stating, "Having this happen made us go through the 'what ifs' again just 'what if' something like this happens when baby is due, and 'what if' after baby, how are we going to handle it all. I guess there is nothing we can do but just hope and pray for a smooth winter season. It's still is a big fear for me." Mothering a child with asthma required understanding of how the illness affected multiple aspects of their daily lives.

Even when symptoms subsided, these mothers were fearful of putting their guard down. One stated, "Well, I hear nothing! No coughing, no wheezing, no nebulizer humming! I hate to jinx myself, but I've been walking on egg shells the past 4 weeks and I am finally exhaling." Participants expressed empathy and wished each other moments of reprieve, "Hope you get a minute to think about nothing. Isn't that the greatest when you are constantly worried about everything."

Fitting the pieces together: "Who can keep it all straight?!" Decisions regarding medications and medical testing presented widespread anxiety and confusion. During the pre-diagnosis phase, children were subjected to a host of medical tests and procedures. One mother stated, "the asthma/allergy specialist ran Mark through a grueling battery of tests his first two years...we ruled out [cystic fibrosis] CF, immunodeficiencies, and allergies...and ruled in ear infections and reflux as bad triggers in addition to the usual viral suspects." Mothers expressed their concern with the particular diagnosis and pain a child was experiencing and the impact of medical testing on the child's development.

These women voiced their worries about the taste, form, texture, and dyes in medicines; equipment use; and insurance coverage. They expressed their frustrations over the number and types of medications used. It appeared that weekends and evenings were particularly vulnerable times. They vented about lack of sleep, the trauma or emergency rooms visits, and behavioral impacts of various medications. As one mother stated, "I am a mother of two with asthma. My oldest son is 5 years old. He is on pulimort, xopenex, foradil, singulair, Claritin, rhinocort...I am very frustrated with all the medications. He also takes predisone when he needs it, every month or so. I also worry about all the steroids used between all the medications. He seems

moody and aggressive when using predisone." Another responded, "I too am hugely frustrated. My 3 year old is on Flovent and Singulair. He has been in the hospital and on steroids twice since September. I am so tired of it! The 'ROID Rage,' the nebs, the ER trips at 1:00 a.m." They also expressed concerns about the impact of various medications on their children's long-term health and the dilemma it imposed for them. "I worry what these meds are doing to her long term, but at the same time, I know she has to breathe now." Sometimes the mothers reported being absent minded. One mother wrote, "All those meds just get exhausting, don't they? I could not find Mark's new bottle of Singulair for two whole days, was looking everywhere, even under the car seats etc.! And then the drugstore called to say there was a prescription waiting to be picked up...whew! They didn't give it to me when I got the other one I called in. So...who can keep it all straight?!"

Because different specialists often recommended different treatment regimens, caregivers had to be educated on the various approaches to treatment. Misunderstandings about proper use of equipment could have severe ramifications. One mother was told that she was not using pulmicort properly by a new doctor and angrily stated, "Our first PP never asked how we administered medicine, obviously, a pretty critical piece of the puzzle." One expressed worry about the damage caused to the child's eyes when nebulizing. Mothers informed one another about the importance of a properly fitted nebulizer mask to ensure that solution does not escape into the eyes. Swimming goggles were used by some to decrease chances of ocular complications. For periods of time, some mothers nebulized one or more children every four hours all day and through the night. One mother expressed her feelings of exhaustion: "Mary is still needing 4-hour nebs, almost on the dot. I'm thinking she still might need orals and boy are they hard to keep up. I'm sooo tired, cause I have such a hard time falling back to sleep after I give her treatment at 3:00 a.m." Mothers tried to make the best of these late night sessions by offering young children the chance to watch their favorite DVDs/videos and/or television shows.

It was clear that additional caregiving responsibilities led to fatigue and high levels of stress for these mothers. One woman informed a new member that "it takes a while to find the perfect combo, and right when you find it,

something else goes on so it is a lot to deal with." In spite of the influx of stressors on their lives, these caregivers were able to help one another sort through the "pieces of the puzzle" and provide some sense of direction and guidance.

Second-guessing: "Having to second guess the doctor and having him second guess you. Grrr." Another major decision involved choosing appropriate medical personnel for their child. These mothers reported difficulties communicating with their doctors and often spoke negatively about the health care received, especially from pediatricians. Most families began care with pediatricians and as they became more knowledgeable, they asked about specialists, such as asthma, allergy doctors, and pulmonary specialists. Mothers shared stories and appeared to prefer doctors who took control and aggressively treated their child's asthma. One stated, "I definitely think we need to find another doc who's more savvy at treating asthma...our ped told us at the end of last week that we might need to use orals...I just think she's willing to wait too long." Further, it appeared to be important for some mothers to be confirmed and "believed" by the doctors. Anger and frustration could be heard in many messages. One mother wrote, "Oh I feel for you, having to second guess the doctor and having him second guess you. Grrr."

Asthma plans require changing dosages and medications with different symptoms. Some were looking for that "miracle cure" while others wished to get their child off a certain drug.

Based on prior experiences, these mothers were not afraid of revealing to each other that they had occasionally made their own medical decisions or altered protocols in hope of relief for their child. Tracy wrote, "No fevers for either of them but they sound congested, and I am upping the nebs just in case."

When a week or two would go by and there were no symptoms, some began to question the asthma diagnosis. This thought process is illustrated in the following quote, "Each time things clear up I think 'maybe it is gone, maybe he does not have asthma...but not anymore.' Until the symptoms kick in again. And each time it does, I still seem to feel surprised that it is back. I'll take what I can and hope that it does not rear its ugly head again for awhile." Prevention medications can give the illusion that "asthma is cured" and provide a sense of optimism that is conducive to experimentation.

Guilt and self-blame also occurred when mothers took their child off a medication too soon or tested the need for a particular medication and watched child's health quickly deteriorate. As one stated, "She had that cold and I stopped too early and then when winter started, I stopped the Singulair and the Zyrtec just to see if they really worked and everything went haywire it seemed." Some mothers expressed disbelief in having missed asthma warning signs. One revealed, "When we took him to the ER the first time, the triage nurse PANICKED and ran down the hall yelling with him in her arms. I was floored (after I got over my own panic), I kept asking the doctors, HOW could I not realize my son was in respiratory distress when I myself have asthma?" Having others who understood the daily stressors and frustrations allowed these caregivers to open up and present their vulnerabilities without the fear of being negatively judged.

Sense of responsibility: "I just do it because if I don't, nobody else will."

At times, fulfilling their multiple roles and responsibilities became overwhelming and seemingly insurmountable. Their children were susceptible to colds, flu, eczema, and ear infections. They often passed their colds on to their mothers, making caregiving even more difficult. Several mothers reported just making it through the day fulfilling certain tasks, while letting others slide. "The house is a wreck and things are being put off but there are clean clothes and plates and food in the house." It was important for these mothers to be highly organized to normalize the everyday lives of family members. They often turned to each other for support when they felt overwhelmed and looked for ways to settle into a routine, for as long as possible. One woman referred to this type of role fulfillment as the "curse of motherhood," while another responded, "I just do it because if I don't, nobody else will." Similar to the Englund et al. (2001) finding, these mothers reported shouldering the responsibility for the care of their asthmatic children.

In this study, husbands were sometimes referred to as "dh," deadbeat husbands. Even though at times these messages could be read in a light-hearted fashion, there appeared to be an underlying frustration with the way in which the caregiving workload was distributed as well as lack of trust in fathers' caregiving abilities. This resulted in some disparaging talk about their husbands' lack of participation and/or inadequacies. Concern over the hus-

band taking responsibility for a child's care was clearly illustrated in the following posts. One mother stated, "It seems as though our DH's trying hard to help, but never get it exactly right when it comes to meds and treatments...I try not to complain, but sometimes it's easier not to leave him alone with Daddy." Another replied, "I hear you on the dad thing. Amazing how they can FORGET meds when the kids are hacking and wheezing loud enough for the neighbors to hear!" When attempts were made by fathers to become more involved, it appeared to have been met with negative feedback and scrutiny. It may be the case that mothers' sense of responsibility for fulfilling the childcare role may prevent the fathers from participating more fully. When responsibility is shifted heavily toward the mother, fathers appear to lack the essential knowledge to perform caregiving duties. One mother stated, "I think when the mommies are the ones always doing it, the men folk just never learn what to watch for or how to treat it."

Bonding: "We are here for support when you need it." Knowing there are others going through similar circumstances can help to reduce feelings of isolation and build a sense of community (Sullivan, 2003). This online group of women provided both emotional and information support, letting each other know that they were there when help was needed.

These mothers supported one another by providing information about their own experiences with asthma. They often reported the decisions and regimens they gave to their children in hope that it might provide suggestions or empower other mothers to ask their doctors about certain medications. They advised each other to keep a daily journal. They helped others become educated by answering questions, giving advice, and notifying each other of helpful resources, Web sites, and news articles.

Participating in this group provided an important emotional resource. These mothers encouraged each other, validated feelings, and affirmed efforts in mothering. One stated, "Please don't be too discouraged, asthma is a long, hard road to walk along. It twists and turns in surprising and often unpleasant ways, but there are good developments, too. Good management takes a long time to achieve..." They reminded each other that there was no cure and tried to keep each other optimistic. "The sad part of this, there is no cure for asthma, none, we have to learn as much as we can, be

proactive in their care, find a great doctor, and keep on going." They provided compliments and confirmation. One wrote, "You are such a source of great info and inspiration. That is clearly why you are the Mayor of Asthmaville!" Another wrote, "I continue to underestimate the power of mothers. You have to pat yourself on the back and know you are doing a great job and have been given a challenging task of taking care of your family. If it's not one thing, it's another, and I feel so bad for you during this difficult time." They empathized with each others' hardships, with a level of understanding that only those who had gone through similar circumstances could provide. They did their best to stay up on each other's situations. They gave each other updates on their own lives and the lives of all family members. Although the emphasis was on the children, they did support each other in their individual lives. "I am sorry you have to go through all these medical things right now, and we are here for support when you need it. Take care of yourself in these stressful times, okay?" This online support group provided a place where these mothers could vent their fears, worries, concerns, and life experiences. "Feel free to vent anytime you want."

The group was described as a "family" and new members were quickly welcomed into the community. The group itself was clearly appreciated. "Thank God for you, fabulous 'asthma women!' I'm constantly sharing with my husband all insights I get from my 'asthma moms' online." As these mothers learned, they educated others and asserted themselves to receive the best care for their children. Mothers with adopted children shared advice on medical information and records to obtain from foreign doctors and orphanages. Through venting and sharing day-to-day experiences, these mothers were able to develop a bond that helped fulfill multiple needs – the need for belonging, the need to self-disclose, and the need for advice.

Discussion

Messages provided insight into the benefits of these groups and what it means to be a mother of a child with asthma. Analysis revealed several stressors and challenges encountered by these caregivers, including making sense of the illness, coping with demanding treatment regimens, role strain, interacting with health care professionals, and decision making. Five themes emerged. The first theme, monitoring, reflected actions taken by

these mothers to cope with the illness experience on a day-to-day basis. The participants in this online caregivers' support group used active coping strategies to handle the numerous, ongoing concerns and anxieties experienced (Sullivan, 2003). They became intimately familiar with the details of their children's everyday lives. This type of daily monitoring brought about high levels of stress and fatigue.

Theme two involved, putting all the pieces of the puzzle together. Numerous and ongoing medical decisions had to be made. Each new medicine and medical test brought with it its own set of concerns. It was difficult for these mothers to feel secure in reaching a satisfactory asthma plan. Frustration with all the medication and testing was clearly heard throughout the posts. It was apparent that these mothers felt the burden of the caregiving role.

The third theme dealt with second-guessing themselves and the care their children were receiving. At times, mothers altered the recommended protocol and second-guessed their doctor's decision-making. They desired aggressive treatment plans and sought out specialists. Questioning the care received appeared to have contributed to high levels of guilt and feelings of self-blame. Sharing this type of information with others who are not intimately involved in the day-to-day care of a child with asthma would likely strain those relationships. Individuals in one's face-to-face support network may tire of the expressions of guilt and frustrations, feeling unable to problem-solve. Having persons who understand and welcome such communication appears to be important to the health and well-being of the caregiver. Available at all hours of the day and night, this online group provided much needed network support. Traditional, face-to-face support groups can not match the availability of the provision of support. The act of writing messages to a group of similar others who understood the daily stressors and shared their own stories appeared to be an important coping mechanism for these women.

Theme four (sense of responsibility) emphasized the overarching meaning associated with mothering a child with a chronic illness. Mothers were able to vent their feelings and express their frustrations in fulfilling the caregiving role. There are few other opportunities where women can openly express the frustrating aspects of mothering with such ease and understanding. In our society, it is often considered taboo for mothers to express any feelings associated with the

negative aspects of mothering.

The final theme to emerge went beyond the experience of mothering and caregiving for a child with asthma. "Bonding" centered around the experiences of connecting with other women who were sharing similar life experiences. This theme emphasized the altruistic aspect of the online support group. It was apparent that parents of children with asthma help support and educate each other on the disease and its various treatments. Posted messages appeared to help these women recognize the signs of poorly controlled asthma and understand what optimal asthma control meant. They shared the ups and downs of everyday life while gaining crucial knowledge and support, all within the comforts of their own homes. These women bonded with each other in providing emotional and informational support in such a way as to perceive the group as an extended family.

Limitations

Some limitations were noted. First, this study was limited to a single caregivers support group, composed entirely of mothers. It is not known if the messages analyzed are truly representative of all mothers of children with asthma. The characteristics of the participants were not fully known. Limited demographic information was ascertained through the posts. In the future, along with thematic analysis of posted messages, survey research could be conducted to gain direct information and perspectives from the participants.

Implications

The Internet is providing opportunities for patients and caregivers to participate more fully in their health care, leading to feelings of empowerment and partnerships with health care professionals. Nurses may encourage this active participation by including Internet support group recommendations into their resource referrals. Parents of children who have been newly diagnosed are likely to find this type of resource particularly helpful and informative (Mailick, Holden, & Walther, 1994). Problems of time, geographical distance, illness, physical disability, and lack of child care can prevent caregivers from participating in face-to-face groups.

Participation in online support groups may be beneficial for the health and well being of mothers caring for a child with asthma. Online support groups are one way to decrease feelings of isolation, to give and receive

support, and to be part of a community of others facing similar circumstances. Cybersupport groups can empower caregivers by building confidence and competence in the management of the illness, while helping others. Online "helper therapy" taps into a "deep altruistic impulse" that may be more therapeutic than receiving help for oneself (Baum, 2004; White & Madera, 2000). Altruism may be a major coping strategy that should be explored further (Sullivan, 1997).

According to Green (1994), a child's health begins with the health of his or her parents. Parental emotional distress and amount of social support are the most important predictors of how much impact a child's asthma has on the family (Wamboldt, 1998). Findings have indicated that mothers shown to have high levels of depressive symptoms reported less confidence in their own ability to manage their child's asthma as well as decreased child adherence with asthma medication (Bartlett et al., 2004). The therapeutic value of writing may alleviate symptoms of depression and loneliness and help to reduce stress (Smyth, Stone, Hurewitz, & Kaell, 1999; White & Dorman, 2001).

As the Internet becomes more accessible, knowledge about ways to use Internet resources is becoming increasingly important to the provision of optimal health care services. Nurses may benefit from participating or lurking in online groups to help in understanding caregivers' perspectives and the range of issues and concerns they face in their day-to-day lives. Nurses can also help spread the word and offer suggestions and quick tutorials to caregivers on how to locate and subscribe to online support groups.

Future Research

Further research is needed to determine the impact of Internet health resources on social support and caregiving. Mothers have consistently taken on family caregiving responsibilities (Juniper, et al., 1996; Townsend et al., 1991). It is important to note that involvement of a father or father-figure in a child's life has been shown to have important health benefits for the child (Moore & Kotelchuck, 2004). Fathers have indicated an interest in participating more fully in their children's health care (Moore & Kotelchuck, 2004) as well as a desire for support in fulfilling the caregiving role (Perrin et al., 2000). In the literature, mothers of children with asthma have been presented, as "over-protective," while fathers are viewed as more "liberating" (Englund et al.,

2001). These style differences were cited as a source of conflict and resentment between the parents, contributing to the stress level for the couple (Ahmann, 2006). May (1996) emphasized that men must be allowed to be "Mr. Dad" and not "Mr. Mom." Although fathers were not prohibited from participating in the online caregivers group studied, no father chose to participate, and no online groups were geared specifically for fathers of children with asthma. Investigating ways to encourage participation in and the promotion of online support for fathers should receive research attention. It is important for nurses to understand both the strengths and limitations of various parental caregiving styles and various ways to provide needed support to each parental figure.

Understanding how online groups function and the benefits and drawbacks of this resource will become increasingly important. Despite some noted disadvantages, such as the dissemination of misinformation, pressure to adopt a distorted group belief, and the possibility of hostile encounters (Baum, 2004; Finn, 1999), online support groups may be the next major advance in e-health services for patients and caregivers.

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ASSIGNMENT

- Sullivan, C. (2008). Cybersupport: Empowering asthma caregivers. *Pediatric Nursing*, 34(3), 217-224.
- Green, J., & Thomas, J. (2008). Interdisciplinary collaboration and the electronic medical record *Pediatric Nursing*, 34(3), 225-227, 240.

Earn 1.6 Contact Hours

OBJECTIVES

1. Discuss the importance of using available technology to meet the needs of children and their families.
2. Describe the experiences of members of an online asthma caregivers support group.
3. List three findings regarding physicians' perceptions of electronic nursing documentation.
4. Identify opportunities for pediatric nurses to keep current on the use of technology in pediatric health care.

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Statement of Disclosure

The authors reported no actual or potential conflict of interest in relation to this continuing nursing education series.

All *Pediatric Nursing* Editorial Board members reported no actual or potential conflict of interest in relation to this continuing nursing education series.

QUESTIONS

1. According to Ferguson, (1996) the largest proportion of online support messages are sent between the hours of ____?
 - a. 7:00 a.m. and 10:00 a.m.
 - b. Noon and 3:00 p.m.
 - c. 4:00 p.m. and 6:00 p.m.
 - d. 7:00 p.m. and 1:00 a.m.
 - e. 3:00 a.m. and 6:00 a.m.
2. The analysis in the article "Cybersupport: Empowering Asthma Caregivers" revealed several stressors and challenges encountered by caregivers of children with asthma. These included all of the following EXCEPT:
 - a. making sense of the illness.
 - b. coping with demanding treatment regimens.
 - c. role strain.
 - d. interacting with health care professionals.
 - e. peak flow assessment.
3. Which theme best reflected actions taken by the mothers to cope with the illness experience on a day-to-day basis, thus becoming intimately familiar with the details of their children's everyday lives?
 - a. Monitoring
 - b. Fitting the pieces together
 - c. Second-guessing
 - d. Sense of responsibility
 - e. Bonding
4. Which theme emphasized the overarching meaning associated with mothering a child with a chronic illness, having the opportunity to vent feelings and express frustrations in fulfilling the caregiver role?
 - a. Monitoring
 - b. Fitting the pieces together
 - c. Second-guessing
 - d. Sense of responsibility
 - e. Bonding
5. Which theme went beyond the experience of mothering and caregiving for a child with asthma and centered around the experiences of concerns with other women who were sharing similar life experiences? This theme emphasized the altruistic aspect of the online support group.
 - a. Monitoring
 - b. Fitting the pieces together
 - c. Bonding
 - d. Sense of responsibility
 - e. Second-guessing
6. Electronic medical records increase accuracy and precision of patient data for all of the following reasons EXCEPT:
 - a. enhanced accessibility.
 - b. diverse formatting.
 - c. electronic imaging.
 - d. increased buy-in by staff.
7. The purpose of the nursing addendum form is to document:
 - a. additional assessment data.
 - b. interactions with physicians.
 - c. narrative data not include checklists.
 - d. discharge plans.
8. Physician users of the electronic medical records desired nursing documentation with additional:
 - a. information and greater clarity.
 - b. patient-teaching data.
 - c. discharge planning.
 - d. details about nurse-physician communications.
9. The electronic medical record was largely a checklist system that reflected patient changes from normal physical states.
 - a. True
 - b. False
10. Which of the following is NOT considered minimal legal documentation?
 - a. Patient's baseline status
 - b. Patient's history prior to hospitalization
 - c. Changes in patient status
 - d. Interventions used to respond to changes in patient status

Answer Form: Technology in Pediatric Care

***PED J804**

Check the box next to the correct answer.

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Evaluation	Strongly disagree			Strongly agree
1. The objectives relate to the overall purpose/goals of the education activity.	1	2	3	4 5
2. The activity met the stated objectives.				
a. Discuss the importance of using available technology to meet the needs of children and their families.	1	2	3	4 5
b. Describe the experiences of members of an online asthma caregivers support group.	1	2	3	4 5
c. List three findings regarding physicians' perceptions of electronic nursing documentation.	1	2	3	4 5
d. Identify opportunities for pediatric nurses to keep current on the use of technology in pediatric health care.	1	2	3	4 5
3. Home study format was appropriate.	1	2	3	4 5
4. The content was relevant to my practice.	1	2	3	4 5
5. The content met my needs.	1	2	3	4 5
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