Parents Managing Clubfoot: A Content Analysis of Internet-based Social Support Behaviors with a Focus on Uncertainty Management and Health Communication

Florin Oprescu, University of the Sunshine Coast, Australia
Shelly Campo, University of Iowa, USA
John Lowe, University of the Sunshine Coast, Australia
Julie Andsager, University of Iowa, USA
Jose A. Morcuende, University of Iowa, USA

Abstract: Using established categories of social support and the Uncertainty Management Theory, this interdisciplinary study situated at the intersection of social science, medicine, information technology and health communication explored the types of social support exchanged by caregivers in a virtual online support community for parents of children with clubfoot. A systematic content analysis of 775 messages indicated that the online environment allows participants to receive and provide a wide range of social support, particularly informational, emotional and esteem support. Results reveal what social support behaviors members of the online support community (OSC) exhibit as a result of requests from their peers, thus identifying what types of health communication may be effective in such settings. Furthermore, OSCs provide a great opportunity for scholars and practitioners to learn about the experiences of caregivers of children with health conditions and explore where gaps in health communication may exist. It is suggested that online support communities are key channels for future health research, communication and interdisciplinary practice.

Keywords: Uncertainty Management Theory, Online Social Support, Caregivers, Birth Defects, Clubfoot, Information Technology, Online Support Communities, Health Communication

Introduction

While the field of social support research is well developed, the systematic research of online social support is still in development (Baum 2004; Scharer 2005). Compared with other areas of research a relatively limited number of studies dealing with various online social support mechanisms used by parents of children affected by illness are available. The pediatric health conditions where some steps have been taken in studying online social support include mental illness (Fleischmann 2005; Scharer et al. 2009), neurological disorders (Leonard et al. 2004), skin disease (Lawton, Roberts, and Gibb 2005), cancer (Bragadóttir 2008; Gage and Panagakis 2011; Han and Belcher 2001; Lewis, Gunawardena, and El Saadawi 2005), traumatic brain injury (Wade, Wolfe, and Pestian 2004), spina bifida (Nicholas et al. 2004), autism (Jordan 2010), and asthma (Jordan 2010; Oermann et al. 2003; Stewart et al. 2011; Sullivan 2008). However, much of the research in this area has been carried out to evaluate online communities set up by or linked to health institutions. Currently, there is a gap in the literature related to information on caregiver-managed online social support communities.

Thus, this study addresses a gap in scientific knowledge by exploring and reporting on types of social support exchanged in a caregiver-managed online communities. This is important because it reveals what social support behaviors members of the online support community (OSC) exhibit as a result of interactions with peers in the absence of health professionals. Using established categories of social support (Cutrona and Suhr 1992) and the Uncertainty Management Theory (Brashers 2001) this study explored the types of social support exchanged...
by caregivers in a virtual online support community dedicated to parents of children with clubfoot. The next sections will describe clubfoot, online support communities and social support for parents of ill children.

Clubfoot is a common developmental disability, characterized by the foot of a child being turned inwards, similar to a golf club. Clubfoot is present in approximately 1 in 1,000 live births, and the preferred method of treatment in many orthopaedic centers is currently the Ponseti method (Morcuende et al. 2004; Zionts et al. 2012). The Ponseti method consists of precise manipulations and serial casting of the feet, resulting in a 95% correction rate (Morcuende et al. 2004). Following casting the child wears a special pair of shoes (braces) in order to prevent relapses (McKay, Dolan, and Morcuende 2012). Due to the highly visible nature of the feet, parents of children with clubfeet may experience considerable uncertainty. The Uncertainty Management Theory (UMT) states that individuals employ behaviors that may decrease uncertainty (information seeking and social support), maintain uncertainty (information avoidance), or even increase uncertainty (Brashers 2001). Thanks to the increasing penetration of the Internet, parents of children with clubfoot and their family members have new opportunities for information management and social support, both of them critical for uncertainty management (Brashers 2001; Donovan–Kicken and Bute 2008; Eysenbach 2005; Oprescu et al. 2013). The aim of this study is to explore and describe the provision of social support in messages posted to a clubfoot online support community (OSC).

OSCs can be defined as grassroots phenomena using services freely available on the Internet, that are free and open to individuals, and that have similar characteristics to self-help groups, including management by group members (Fernsler and Manchester 1997; Ginossar 2008; Kinnane and Milne 2010). OSCs allow for and encourage exchanges of other types of support (i.e., emotional) in addition to informational support (Coulson, Buchanan, and Aubeeluck 2007; Eysenbach 2005; Kinnane and Milne 2010). OSCs are of great importance for parents, particularly for those caring for children with rare or difficult to manage health conditions such as clubfoot (Morcuende et al. 2004; Ponseti et al. 2006).

Today’s parents may deal with decreased traditional social support and increased informational needs. The modern society, characterized by globalization, increase in divorce rates, and increase in the number of step-family members, creates conditions for a decrease in the support provided to parents by their immediate friends and family (Plantin and Daneback 2009). Direct and sustained support from close friends and family is becoming difficult to acquire due to frequent geographical moves required by the job market (Drentea and Moren-Cross 2005; Madge and O’Connor 2006). As a consequence the modern family is becoming an evolving social network of relationships rather than one social unit, with the Internet as a critical tool used to acquire information and support (Plantin and Daneback 2009). Today’s parents are comfortable with the Internet not only for finding information but also for fostering new or existing relationships, especially around important issues such as birth and illness. Fostering online relationships is a way to deal with the need for support and for reliable information that many parents face (Persson, Fridlund, and Dykes 2007; Plantin and Daneback 2009).

The need for online information and support is greatly amplified for parents of children affected by various health conditions (Barker 2008; Gundersen 2011; Plantin and Daneback 2009; Schaffer, Kuczynski, and Skinner 2008). Many of these parents become active seekers of information and support (Lawton, Roberts, and Gibb 2005; Schaffer, Kuczynski, and Skinner 2008). An important part of this much-needed support is acquired using the Internet, either through websites or through participation in online support communities. OSCs have many advantages, including: absence of geographic and time barriers; increased anonymity, often resulting in increased self-disclosure, honesty and intimacy; ability to find other families affected by rare diseases; access to a group of individuals who have become experts through experience; access to a large amount of information specific to the health condition of interest; and access to a group of individuals with a high capacity for empathy (Bambina 2007; Han et al. 2010; Plantin
and Daneback 2009; Schaffer, Kuczynski, and Skinner 2008; Zaidman-Zait and Jamieson 2007). Disadvantages include: large volume of electronic exchanges, including an important amount of messages that may not be relevant to the entire audience (Zaidman-Zait and Jamieson 2007); lack of physical contact and proximity (Han and Belcher 2001); potential for misinformation because of the non-evidence-based type of information exchanged and lack of quality control (Culver, Gerr, and Frumkin 1997; Gundersen 2011; Gustafson et al. 2008; Schaffer, Kuczynski, and Skinner 2008; Sullivan 2008; Zaidman-Zait and Jamieson 2007) and potential for spamming and unsupportive behaviors (Eysenbach 2005). Specifically, unsupportive behaviors (angry criticism, lack of understanding, hassling) have been linked to negative mood and depression (Cranford 2004). Despite the above disadvantages, it has been proposed that online communities may allow for effective exchanges of social support, beyond information, even in the absence of direct physical contact (Bambina 2007).

Social support is defined as “aid and assistance exchanged through social relationships and interpersonal transactions” (Heaney and Israel 2008). Cutrona and Suhr (1992) described five categories of social support: informational (provision of information related to the stressor), tangible (provision of items or services to deal with the stressor), network (intended to create a sense of belonging to the social network), esteem (intended to increase recipients’ self-esteem), and emotional (communication of caring and understanding of the other person) support. Social support is intended to have positive effects on the recipient (Heaney and Israel 2008; MaloneBeach and Zarit 1995). High levels of perceived social support can impact psychological well-being (Eastin and LaRose 2005). It has been documented that social support can reduce depression, stress and overall psychological impact in traumatic and illness-related situations (Namkoong et al. 2011; Winzelberg, Classen, and Alpers 2003). Social support can be acquired and offered through social networks (Han et al. 2010; Heaney and Israel 2008; Jordan 2010; Plantin and Daneback 2009; Zaidman-Zait and Jamieson 2007).

The Internet is becoming an increasingly important avenue for acquiring social support (Gundersen 2011; Gustafson et al. 2008; Jordan 2010; Lieberman and Goldstein 2006; Rains and Young 2009; Shaw and Gant 2002; Sullivan 2008; Tichon and Shapiro 2003; Turner, Grube, and Meyers 2001; Zaidman-Zait and Jamieson 2007). However, social support online is secured through complex mechanisms that are yet to be fully understood (Eastin and LaRose 2005).

Study Aims

The aim of this study was to explore and describe processes of communication and uncertainty management in an online context with a special emphasis on social support provision. The goal was to better understand how parents caring for a child with a rare health condition may use an online support community to acquire and provide social support in order to manage uncertainty. The following research questions were addressed:

- RQ: What types of supportive behaviors are present in the OSC serving caregivers of children with clubfoot?
- RQ: What is the prevalence and distribution of social support behaviors present in the OSC serving caregivers of children with clubfoot?
- RQ: Are various types of social support behaviors present online correlated?

Methods

A systematic content analysis examined information seeking behaviors and other types of uncertainty management behaviors in an OSC for parents of children with clubfoot. As the group of interest had over 2,000 members and, based on its size, it can be categorized as a public space (Coulson 2005). Permission to access the messages board and to collect data was secured from
the group administrator/owner. The University Institutional Review Board reviewed and approved the study methodology.

**Data Collection**

The data for the study were collected using systematic random sampling. Beginning with a randomly selected message, each 100th message was selected. The coding scheme was developed using the (Cutrona and Suhr 1992) social support behavior categories. These categories have been previously used to code and analyze online communication (Coulson 2005; Coulson, Buchanan, and Aubeeluck 2007). Messages were coded for the presence of informational support, tangible support, network support, esteem support, and emotional support. The following section describes the operational definitions of the variables under consideration.

**Measures**

Informational support was represented by text units providing information related to the stressors affecting the individual (Krause 1987). Informational support had four subcategories: advice, referral, situation appraisal and teaching (Cutrona and Suhr 1992). Suggestions or guidance for coping with challenges were coded as advice. Efforts to introduce the recipient to new relationships and resources outside the network (i.e., physicians, websites, articles) were coded as referrals. Text units that explicitly redefined or reframed a specific situation, sometimes in a positive way were coded as situation appraisals. Text units providing detailed information in order to clarify an issue or step-by-step instructions on how to solve a problem were coded as teaching.

Tangible assistance was defined as provision or offer to provide goods or services that could help the recipient deal with the stressor. Tangible assistance has five subcategories: loan, direct task, indirect task, active participation, and willingness (Cutrona and Suhr 1992). Text units offering to lend the recipient money or objects were coded as loans. Messages including direct support offers were coded as direct task. Messages that included information directly helpful for the recipient to secure a tangible object with no further intervention from sender were coded as indirect task. Offers to meet or get involved in activities requiring physical presence were coded as active participation. Text units expressing willingness to help were coded as willingness.

Text units meant to create a sense of community among individuals with similar concerns were coded as network support. Network support includes three subcategories: access, presence and companions (Cutrona and Suhr 1992). Text units that explicitly introduced the recipient to new relationships and resources within the network were coded as access. Text units indicating presence of listeners and encourage the use of the group were coded as presence. Text units reminding the recipient of supportive others in a similar situation who express readiness to actively assist the recipient were coded under companions.

Text units communicating respect and confidence in the abilities of the message recipient were coded as esteem support. Esteem support had three subcategories: compliment, validation and relief of blame (Cutrona and Suhr 1992). Text units that conveyed positive assessments of the individuals such their level of expertise or strength were coded as compliment. Text units that conveyed positive assessments of the individuals such their level of expertise or strength were coded as compliment. Text units acknowledging agreement or common ground with the recipient’s perspective were coded as validation. Text units attempting to get rid of feelings of guilt were coded as relief of blame.

Text units communicating love, caring and understanding of others were coded as emotional support. Emotional support had five subcategories: relationship, physical affection, confidentiality, sympathy, understanding/empathy, encouragement and prayer (Cutrona and Suhr 1992). Text units that stressed the importance of closeness and love between individuals were coded as relationship. Text units indicating offers for physical contact such as hugs, kisses and
hand-holding were coded as physical affection. Text units indicating regret for the recipient’s situation were coded as sympathy. Text units indicating identification with and understanding of the feelings, thoughts, or attitudes of the recipient were coded as understanding/empathy. Text units providing the recipient with hope and confidence were coded as encouragement. The potential of exposure to negative messages is mentioned by scholars as an issue of concern in online exchanges.

Statistical Analysis

Statistical analysis was conducted using the Statistical Package for Social Sciences - SPSS 15. Krippendorff alpha coefficients were used to compare intercoder reliability. Fifteen percent (N=116) of the messages from the analytical sample were randomly selected for independent coding by two researchers (Neuendorf 2002). Where possible, disagreements in coding were documented and resolved through discussion (Hayes 2005; Ginossar 2008). Krippendorff’s alpha is one of the more flexible coefficients available for this type of computations (Krippendorff 2004; Hayes and Krippendorff 2007). An acceptable Krippendorff alpha is above .80 (Neuendorf 2002; Riffe, Lacy, and Fico 1998) and for the six major variables of interest it ranged from .88 to 1.0. Descriptive statistics were used to present the prevalence and distribution of the variables of interest.

Results

Table 1 reports the frequency of the categories and types of support observed in the data sample. Forty-four percent of the messages included one category of social support, and 34% of the messages included two or more categories of social support. Informational, esteem and emotional support were the most frequent, with network support and tangible assistance being less frequent.

Table 1: Prevalence and Distribution of Social Support Categories

<table>
<thead>
<tr>
<th>Support categories</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Informational Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advice</td>
<td>262</td>
<td>33.8%</td>
</tr>
<tr>
<td>Referral</td>
<td>49</td>
<td>6.3%</td>
</tr>
<tr>
<td>Situation appraisal</td>
<td>38</td>
<td>4.9%</td>
</tr>
<tr>
<td>Teaching</td>
<td>22</td>
<td>2.8%</td>
</tr>
<tr>
<td><strong>Tangible Assistance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loan</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Perform direct task</td>
<td>17</td>
<td>2.2%</td>
</tr>
<tr>
<td>Perform indirect task</td>
<td>15</td>
<td>1.9%</td>
</tr>
<tr>
<td>Active participation</td>
<td>13</td>
<td>1.7%</td>
</tr>
<tr>
<td>Express willingness</td>
<td>23</td>
<td>3.0%</td>
</tr>
<tr>
<td><strong>Network Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access</td>
<td>10</td>
<td>1.3%</td>
</tr>
<tr>
<td>Presence</td>
<td>49</td>
<td>6.3%</td>
</tr>
<tr>
<td>Companions</td>
<td>31</td>
<td>4.0%</td>
</tr>
<tr>
<td><strong>Esteem Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compliment</td>
<td>37</td>
<td>4.8%</td>
</tr>
</tbody>
</table>
To examine the relationships between categories of social support, five Pearson product-moment correlations were conducted (see Table 2). Informational support was found to be negatively correlated to esteem support, $r(775) = -0.23, p< .0001$, and positively correlated to emotional support, $r(775)= .1, p<.05$. In addition, network support was found to be positively correlated to emotional support, $r(775)= .23, p<.0001$.

**Table 2: Correlations between Categories of Social Support**

<table>
<thead>
<tr>
<th></th>
<th>Informational</th>
<th>Tangible</th>
<th>Network</th>
<th>Esteem</th>
<th>Emotional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational</td>
<td>1.000</td>
<td>0.049</td>
<td>0.022</td>
<td>-0.234**</td>
<td>0.103**</td>
</tr>
<tr>
<td>Tangible</td>
<td>1.000</td>
<td></td>
<td>0.031</td>
<td>-0.082*</td>
<td>-0.018</td>
</tr>
<tr>
<td>Network</td>
<td></td>
<td>1.000</td>
<td>0.030</td>
<td></td>
<td>0.235**</td>
</tr>
<tr>
<td>Esteem</td>
<td></td>
<td></td>
<td>1.000</td>
<td>0.020</td>
<td></td>
</tr>
<tr>
<td>Emotional</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.000</td>
</tr>
</tbody>
</table>

**. Significant at 0.01 level (2-tailed).  
*. Significant at 0.05 level (2-tailed).**

In the next section each type of social support is exemplified with actual quotes from the messages. Identifying information was removed from the quotes.

**Informational Support**

All four subcategories of informational support (advice, referral, situation appraisal and teaching) were identified in the sample of messages analyzed. Specific examples are provided next.

**Advice**

The following examples of advice indicate challenges such as finding information, caring for the child, and hospital visits. Advice was provided to help the recipient find more information in the group, better care for a child with clubfeet or even matters related to hospital visits:

“I suggest that you also make another post here, and put ‘Need Help In Florida’ in your title line so that you will attract the attention of any other parents in your neck of the woods.”
“Until the feet get used to the shoes it is possible to develop red spots or blisters where they are rubbing. We had that happen and put a doctor Scholls corn pad (with a hole in it) over the area and it healed within a few days. Others here have used band-aids, mole skin or other things to help reduce the rubbing until the shoes and feet get used to each other.”

“Just a hint, be sure to take your parking ticket up with you. There is a desk as soon as you get off the elevator where you will check in and the ladies will stamp it for you so you don’t have to pay for parking.”

Referrals

The following examples include referrals to obtain braces (special shoes needed after the serial casting is complete) and to find places to stay. An important issue for parents of children with clubfoot is acquiring braces. Thus many referrals were specifically directed at obtaining braces:

“I don’t know who the manufacturer of the bar is. My suggestion would be to contact KZ at (...) 3….0.”

In some cases parents need to secure accommodation close to the location of the treatment. Group members directed them to such temporary housing:

“If you want to go to Kingston instead there is a similar place called ‘Almost Home’ close to clinic (about 2 blocks away).”

Situation Appraisals

The following examples include situation appraisals using personal experience and humor to reframe difficult and uncertain situations. Personal experiences seemed to increase the persuasiveness of the message:

“When he was born I was upset by the fact that he had clubfeet (knowing we would have a long road to get them taken care of), but I was never upset by the way they looked. When I looked at them they were just his precious little baby feet. He would put the sole of his feet up against his diaper and just fold them up there. I thought that even though they weren’t right they were some of the most precious feet I had ever seen.”

Teaching

The following example of teaching includes a step by step solution to dealing with the braces.

“Hello everyone, When K is in her DBB [braces] we have socks that go well past the ankle and we pull them over the shoes and hook them under the heel of the shoe plate (or just around the shoe if it won’t go that far), also covering the laces. We also pull the socks at the toes to insert the feet, and after they are inserted we pull them again to give the toes wigging room. Just thought we’d let you in on what has worked for us!”

Tangible Assistance

Four subcategories of tangible assistance (direct task, indirect task, active participation, and willingness) were identified in the sample of messages analyzed. There were no messages offering loans observed in the data sample. Specific examples are provided next.
Perform Direct Tasks

The following examples included direct offers to post pictures to the board and to find contact information for health care providers: “You could send me the pics and I’ll post them in the photos section over there”; “I can get you his [doctor’s] info tomorrow”; “Do you have his [doctor’s] email address? If not, let me know and I can send it to you.”

Indirect Task

The following example provided information that allows recipients to purchase leg warmers (used by parents during winter for easier change of the diaper without having to remove the brace): “I was browsing online at Target and they carry the Babylegs brand of leg warmers...but are MUCH cheaper and can be returned at the store.”

Active Participation

The following exchanges were intended to facilitate face-to-face meetings of parents who are visiting the same medical facility: “Our appointment was rescheduled to next Tuesday so we might be at the hospital at the same time.”; “Anyone else in the XYZ on Sunday is welcome to join us.”; “We will be heading out to XYZ for the annual checkup! Wondering if anyone else plans to be out there June 16th? Would be so nice to meet some of you!”

Willingness

The following examples represented various offers of help, from general to particular such as assisting the recipient in finding suitable care: “If there is anything else I could help you with just ask.”; “I am willing to help out any way possible with information if you would like.”; “If that is the case we are ready and very willing to help you find the appropriate care.”

Network Support

All three subcategories of network support (access, presence and companions) were identified in the sample of messages analyzed. Specific examples are provided next.

Access

The following examples include access to materials already available in the online support group such as older messages and word documents: “Here is a link to an earlier message that K posted with the text of an article Dr. Ponseti wrote on relapsing, and its treatment. “It might be helpful.”, “As far as his screaming, check the Files section under “Shoes” by K. After reading her pages, if you have done everything you can, then maybe something could be wrong. I think many of your questions will be answered at your appointment (at least I hope so). I know you are worried and hope you will have peace of mind soon.”

Presence

The following quotes exemplify instances of social support observed in this category: “You will be having some exciting times ahead when you are removing the casts and start using the DBB. Good luck and keep us posted on that too!”; “My thoughts are with you and remember you have this board of wonderful people to refer to.”; “Please feel free to ask any questions, there is a
tremendous amount of support on this site with so many parents either going through the treatment or have already been through it.”

**Companions**

The following quotes are examples of group members clearly expressing their availability to help: “Feel free to post any questions or concerns and we’ll help you the best we can.”, “Good luck! Let me know if I can answer any more q’s.”, “Feel free to ask lots of questions (we’re here to help) and vent anytime you need to.”

**Esteem Support**

All three subcategories of esteem support (compliment, validation and relief of blame) were identified in the sample of messages analyzed. Specific examples are provided next.

**Compliment**

The following examples include compliments directed to the individuals and to the group: Compliments directed to the individual can include both references to the well being of the child (first quote) and references to parents being experts by experience (second quote): “I think you’re so wise and right to see the need to be strong and secure to help your daughter feel that way too.”; “To any of you “pro’s” with the shoes, how long were your kids in 14-16 a day with the DBB [brace].” In addition to compliments directed to individuals, compliments directed to all members of the group were also observed: “I wish that all children had the love and concern from their parents like the ones I see on this board.”

**Validation**

Many messages included in this category underline the importance of the sender’s communication through expressions of gratitude (thank you) as exemplified by the following quotes: “I want to thank those of you who responded to my post about my concern about having taken a medication during pregnancy. You gave me some comfort and some things to think about, and I appreciate it. It helps a lot.”, “I can’t thank you enough for your reply and suggestions. I will try anything at this point.”, “I want to thank you again so much for replying. You made me feel so much better.”

**Relief of Blame**

Messages included in this category included words such as guilt and blame as exemplified by the following quotes: “But, you know what, you sound like an awesome parent and you are doing the best for your daughter that you possibly can, and you can’t beat yourself up about the past.”, “Do not look for blaming yourself; I do not think it was your fault.”, “By doing all you have for G, you have done what is best for her and your family. All of us here can only do what we feel is the best for our families. I hope this makes you feel a little better.”

**Emotional Support**

All five subcategories of emotional support (relationship, physical affection, confidentiality, sympathy, understanding/empathy, encouragement and prayer) were identified in the sample of messages analyzed. Specific examples are provided next.
Relationship

Messages included in this category attempted to create and strengthen relationship by expressing joy due to positive events in the life of the recipient: “HUGE congrats on your new addition!”, “CONGRATULATIONS! That is just wonderful about your new baby girl!”, “I cannot think of a better surprise, I’m so happy for your family!”

Physical Affection

The following quotes exemplify symbolical expressions of physical contact: “Hugs to little K…”, “**hugs**”, “Sending you my hugs over the net”. Symbolic promises to keep issues the recipient deals with in confidentiality were not identified in the data sample.

Sympathy

The following quotes exemplify instances of social support in this category: “I am sorry that the first night with K didn’t go so hot. Sleep deprivation for mom can be the worse.” “Just wanted to say that I sympathize!”; “I’m very sorry to hear about your disappointing visit. It must’ve been frustrating, after having traveled so far, and right before your husband had to leave, too. That’s a lot to be dealing with.”

Understanding/empathy

Some messages in this category included personal experiences paralleling recipient’s situation and reactions as exemplified by the following quotes: “I know it’s been a rollercoaster of emotions for you…and I’m sure making another long trip is no small matter for you and your family.”; “I also want to say that I know how you feel with the wasted time and the fears that you are having right now. Every time I read one of your e-mails, I want to say “Amen sister!” at the end of it.”, “I completely understand how daunting it seems to be hearing the number of years go up. It seems like forever. But it really is not.”

Encouragement

The following quotes exemplify instances of encouragement using personal experience and emotional appeals as persuasive mechanisms: “She is now 2 1/2 and has beautifully corrected feet. She still wears the shoe brace at night but will be discontinuing it at Christmas time.”, “I would like to encourage you to continue educating yourself so that you can make informed decisions about your daughter’s treatment.”, “…your child will always appreciate the time and sacrifices that you have made for her and her little foot.” Text units that made direct reference to prayer for others were coded as prayer as exemplified by the following quotes: “I pray for you”, “You and K are in my prayers”, “You and M will be in my prayers.”

Discussion

One of the constructs of the Uncertainty Management Theory is social support, also labeled as assisted uncertainty management (Brashers 2001). Supportive behaviors expressed through messages may increase or decrease uncertainty (Ford et al. 1996). This study examined categories and types of social support provided in an online community for caregivers of children with clubfeet. The results indicate that a wide range of social support types are exchanged among members of the OSC. For caregivers of children with rare or difficult to manage health conditions, OSCs seem to be a viable platform to expand their existing social network and obtain meaningful social support (Eastin and LaRose 2005). Informational, esteem and emotional
support were the most frequently categories of support provided. This finding is consistent with other studies of online communities and of face to face support groups (Coulson, Buchanan, and Aubeeluck 2007; Eastin and LaRose 2005; Tichon and Shapiro 2003). Informational support was the most frequent type of support provided in the community, which is expected due to the nature of the environment. Most information was exchanged as advice to a particular situation or problem encountered by the caregiver (Oprescu et al. 2013). In general the advice was based on the author’s experience, was individualized to the need of the recipient and was combined with other types of support, particularly emotional. This is particularly important for uncertainty management because information that is applicable and clear has a positive effect on the recipient (Babrow, Kasch, and Ford 1998). Through referrals, members manage the uncertainty of others by providing information related to resources outside the online community that parents could use to facilitate their search for additional knowledge and treatment options. Situation appraisals have a direct effect on uncertainty by encouraging the readers to focus on more important issues or to analyze their situation from a more positive perspective (Brashers 2001). Situation appraisal was closely linked to encouragement and validation, both of them designed to foster stable relationships between group members. Highly technical teaching was relatively rare possibly because the more technical materials were already available in the files section of the message board and thus offered as network support. Some messages in the information support category included medical information. Further research is needed to determine the quality of medical information exchanged as this is a topic of interest and concern for health communication scholars and medical professionals (Culver, Gerr, and Frumkin 1997; White 2000). Medical information may result in increased uncertainty if it is ambiguous, incomplete, and inconsistent or if it comes from a source that the recipient does not trust (Babrow, Kasch, and Ford 1998). New users may be distressed by large quantities of information stored and exchanged in an online support community. It seems that some group members, especially the ones who have been active for a longer time in the community, may function as buffers against high volumes of information as a cause of uncertainty (Brashers 2001). These lay experts may respond questions with their own synthesis of messages they read over time in addition to their own experience, thus reducing the recipient’s burden of information processing and the related stress. Instances of tangible assistance were relatively rare, supporting the proposition that the online interactions are not intended to generate physical contact, but rather they are mostly used for exchanges of intangibles such as information, esteem and emotional support (Coulson, Buchanan, and Aubeeluck 2007; Eysenbach 2005; Ginossar 2008) Interestingly there were no instances of loans provided observed, not even for braces. They either occur outside the community or they are rarely a consideration. Network support seems to be used to create a sense of a friendly “meeting place” destined to increase trust in the community and reduce social uncertainty (Coulson, Buchanan, and Aubeeluck 2007). While all members are constantly reminded of the presence of others who have been through the same situation and of the availability of support, many network support instances were directed to new members by informing them about existing resources (documents, pictures, and links) in addition to availability of “unending support”. This suggests that network support is particularly important in reducing the uncertainty of new members in regards to the value of the community and in sustaining the lively exchanges in the community since new members are more likely to return and post again if they receive responses to their requests (Joyce and Kraut 2006). Furthermore, the use of first person plural: “We are here for you”, “You can count on us” may be an indication of the sense of community and an invitation to the recipient to become active in the group (Pennebaker et al. 2003). Once new group members understand the value of the community, contributions to the OSCs were further encouraged through instances of esteem support (Cutrona and Suhr 1992).
Esteem support was frequently encountered in the community of interest, with validation being present in almost a quarter of the messages. In addition to increased self-esteem as a direct benefit (Kim 2000), validation may be used as a mechanism to foster participation in the community by reinforcing the fact that contributions are important, useful and appreciated. It is possible that the more an individual contributes to the community, the more s/he is likely to become a long term active participant. The longer a person participates in the community, through acquired information and experience, the more valuable his/her contributions may be. Furthermore, compliments were used to make members, especially the new ones, feel good about themselves and their children, a mechanism often used in reducing uncertainty while establishing new interpersonal relationships. There were few instances of relief of blame which may indicate the fact that most parents do not blame themselves for their child being affected by clubfoot or do not blame others for the way they are caring for the child. However, guilt could be a reason for frequent utilization of the community: “My son was treated for five months before we found Dr. Ponseti and I felt so guilty. He had a surgery that didn’t work before hand – and I still cringe about that.” Increasing individual’s self-esteem through esteem support may result in more frequent contribution to the online community and in increased social capital (Steinfield, Ellison, and Lampe 2008).

Provision of emotional support was a key characteristic of the online support community of interest and seems to be used to manage uncertainty levels (Brashers 2001). Parents encouraged those who were dealing with difficult or confusing stages in the process – especially around milestones: diagnosis, beginning and end of casting, beginning of bracing, relapses. Encouragement was a key tactic in reducing uncertainty related to negative outcomes (Heaman, Gupton, and Gregory 2004). Encouragements ranged from general ones: “This will make you stronger” to specific examples of parents and children who have been in a very similar situation and who had excellent results: “She is now 2 1/2 and has beautifully corrected feet.” Understanding/empathy and sympathy are of critical importance in emotionally draining situation such as caring for a child with a health condition. Some parents acknowledged each other’s feelings and may present their own opinions and experiences when they were in a similar situation. For some parents this online community may be the only place where they can get the support they need due to tensions with their close family including their spouse or partner. Messages that emphasized the importance of close relationships even in the online environment represented 10% of the data sample indicating that parents do not perceive the online environment as being a barrier to strong connections. No instances of confidentiality were observed potentially indicating that due to the large number of members, most parents may perceive the group as a public place (Eysenbach 2005).

It seems that most users of the group follow some etiquette rules that ensure minimal conflict and respectful communication (Kouri et al. 2006; Madge and O’Connor 2006). The group norms were presented upfront through an automated welcome email that outlines some of the basic rules of the group. Written in an easy to read format and not overly long, this initial email sets up the stage for the subsequent communication. This tactic ensures faster integration of new members by familiarizing them with the group rules, and minimizes the probability of non-supportive communication.

Practical and Theoretical Implications

Parents active on the OSC indicated that acquiring more information reduces uncertainty: “We put up his information on the web at www….com to help others like us that are trying to learn about clubfeet. We found that the more we learned the better we felt. It is a treatable condition with great outcomes”. It is suggested that involvement of health care professionals in major OSCs for parents of children with health conditions could be beneficial. Professionals could relatively easy point the group members to reliable sources of information and correct erroneous
information that may be circulating in the community since physicians remain the most trusted source for medical information (Hesse et al. 2005). Because parents, especially the new group members, are in information seeking mode, they are more receptive to any type of information, be it correct or incorrect (Thompson and O’Hair 2008).

Health care practitioners could also encourage parent participation in OSCs. Frequent online participation increases perceived social support and reduces feelings of loneliness and depression (Morgan and Cotton 2003). Furthermore, there is indication that participation in OSCs may result in decreased perceived stress and could create strong relationships (Wright 2000). Finally, participation of parents in OSC could result in increased compliance with the recommended treatment thus minimizing future complications.

One of the critical issues in the treatment of clubfoot using the Ponseti method and the greatest risk for relapse is compliance with bracing (Ponseti et al. 2006). Bracing is a great exemplification of the Uncertainty Management Theory. Bracing is a long term process, carried with limited medical supervision, that is critical for successful outcomes. However, parents have various levels of uncertainty about the correct bracing protocol, various types of braces, and how to deal with daily challenges generated by the use of braces: “This decision weighs on me. I’d rather have her wear it till 5 to be safe. But we may take her out at 4 and closely monitor her.”. In the online community information about bracing from experienced parents is used both to decrease uncertainty about complying with the bracing regimen “I intend to continue my daughter in the 12 hour wear till at least 5 years old.” and to increase uncertainty about non-compliance with the bracing regimen “Who’s idea was it to stop the braces at 6 months old? Another huge red flag…” Uncertainty management by well-informed parents in their online interactions with other parents could be important in achieving a high level of compliance with treatment. Recommending parents seen in the hospital to use the online community may be a solution to increase compliance with bracing as they would benefit from the support of group members that are in the same stage of treatment or that have completed the treatment.

Communication scholars and health practitioners need to understand the causes and meaning of uncertainty for the parents before, during and after medical encounters, as well as the behaviors employed by parents to manage their own uncertainty as well as the uncertainty of others. OSCs provide a great amount of data to analyze, data that does not require to be recreated, data that is not affected by recall bias or other types of response biases. Finally, this study provides additional evidence for the use of (Cutrona and Suhr 1992) support behavior schema as a coding framework for the study of uncertainty management in online communities.

**Study Limitations and Future Research**

The study analyzed messages posted to a single online support group for parents of children with clubfeet interested in the Ponseti method of clubfoot treatment. The generalizability of the findings to other OSCs dedicated to parents of children with other health conditions needs to be tested. The study represents an assessment of the provision of support. Future research is needs to assess the direct and indirect impact of that support. Finally, the actual impact of social support on the recipient is difficult to measure using only content analysis. Surveying OSC members could provide some insights into the relationship between social support and uncertainty for parents.

While the community of interest has many registered members the current study design did not allow for categorization of members based on their group activity level. It may be possible that only a small number of parents are providing social support, while many may be passive recipients – also known as lurkers (Preece, Nonnecke, and Andrews 2004). Thus future research may employ social network analysis to better understand the actual social support exchanges and interpersonal relationships in the OSC of interest and how they may impact the uncertainty of both receivers and givers (Bambina 2007). Such a research may reveal if the acquiring of social
support in an online community is done through a main effects model (large network, strong ties, and frequent interactions) or a buffering model (small active network and limited access to information). Furthermore, such a classification may allow an exploration of which of the two models of social support acquisition online has greater impact on individual uncertainty. Despite the aforementioned limitations, the results of the study provide a critical overview of the online exchanges that may benefit caregivers of children with clubfeet and sets up the stage for future research.

Conclusion

The present study examined social support provision in an online community for caregivers of children with clubfoot from the perspective of uncertainty management. The results suggest that the online environment is conducive to receiving and providing a wide range of social support, particularly informational, emotional and esteem support. Furthermore, OSCs provide a great opportunity for health communication scholars and practitioners to learn about the experiences of caregivers of children with health conditions and explore where gaps in communication exist. Finally, the burden on the study population and the response biases could be minimized by using already existing data. In conclusion, online support communities could be seen as critical sources of information and action for future health research, communication and interdisciplinary practice.

Acknowledgements

We acknowledge the parents of children with clubfoot for the extraordinary work they do to support each other. Saloni Nayar provided coding support. The Research Cluster for Health Improvement provided support during the production of the manuscript.
REFERENCES


ABOUT THE AUTHORS

**Dr. Florin Oprescu:** Dr. Florin Oprescu is a health promotion and communication specialist. He works on initiatives including health promotion education, health communication, injury prevention, and translation of scientific findings into practical and accessible public health content, especially for at risk populations and limited resource settings.

**Shelly Campo:** University of Iowa, USA

**John Lowe:** University of the Sunshine Coast, Australia

**Julie Andsager:** University of Iowa, USA

**Jose A. Morcuende:** University of Iowa, USA