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# Explorations of uncertainty management: internet based behaviors of caregivers in the context of clubfoot

Florin Ilie Oprescu  
*University of Iowa*

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EXPLORATIONS OF UNCERTAINTY MANAGEMENT:  
INTERNET BASED BEHAVIORS OF CAREGIVERS IN THE CONTEXT OF  
CLUBFOOT

by  
Florin Ilie Oprescu

An Abstract

Of a thesis submitted in partial fulfillment  
of the requirements for the Doctor of  
Philosophy degree in Community and Behavioral Health  
in the Graduate College of  
The University of Iowa

December 2009

Thesis Supervisors: Associate Professor Michelle L. Campo  
Professor John B. Lowe

## ABSTRACT

The availability of online support communities creates new opportunities for caregivers of children affected by health conditions to manage their illness-related uncertainty. This dissertation includes two studies that examined the presence of uncertainty management behaviors in online interactions among parents (caregivers) of children with clubfeet, and empirically tested the applicability of the uncertainty management theory to online behaviors. The Uncertainty Management Theory provided the theoretical foundation for both studies. For the first study, a content analysis of messages exchanged in an online support community dedicated to parents of children with clubfeet was conducted. Most messages were authored by women. The majority of the emotions expressed in the messages were positive. The most frequent information-seeking behaviors were direct questioning and self-disclosure. Information exchanges as a strategy to manage uncertainty included names of health care professionals and medical information. Five major types of social support (informational, tangible, network, esteem, and emotional) were identified. Informational support was the most frequent type of support provided, followed by emotional and esteem support. A third of the messages included combinations of two or more types of social support. For the second study an online survey was distributed using a snow-balling technique. Based on the survey data structural equation modeling was used to empirically test the uncertainty management framework. Positive relationships were identified between knowledge and information seeking, information seeking and social support, social support and sense of virtual community, uncertainty and stress. The results suggested that the uncertainty management theory may need to be adapted for use in online contexts. Uncertainty seems to be an important part of the experience of parents caring for children with clubfoot. Online communities dedicated to these parents represent a promising setting for studying illness-related uncertainty and its potential causes. Such studies can be a critical source of

information to inform priorities for research and practice. This dissertation is the first step in better understanding the audience and provides an initial exploration of uncertainty management and communication processes present in an online support community. As we learn more about the parent audience, the importance of communicating with them becomes increasingly clear.

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CERTIFICATE OF APPROVAL

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PH.D. THESIS

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To my dear ones

When parents are faced with this disaster of seeing a baby born with clubfeet, they get to be very depressed. But when they can see that this deformity is nothing, that is a very easy thing to correct and the child is normal, they have hope.

Dr. Ignacio Ponseti

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The availability of online support communities creates new opportunities for caregivers of children affected by health conditions to manage their illness-related uncertainty. This dissertation includes two studies that examined the presence of uncertainty management behaviors in online interactions among parents (caregivers) of children with clubfeet, and empirically tested the applicability of the uncertainty management theory to online behaviors. The Uncertainty Management Theory provided the theoretical foundation for both studies. For the first study, a content analysis of messages exchanged in an online support community dedicated to parents of children with clubfeet was conducted. Most messages were authored by women. The majority of the emotions expressed in the messages were positive. The most frequent information-seeking behaviors were direct questioning and self-disclosure. Information exchanges as a strategy to manage uncertainty included names of health care professionals and medical information. Five major types of social support (informational, tangible, network, esteem, and emotional) were identified. Informational support was the most frequent type of support provided, followed by emotional and esteem support. A third of the messages included combinations of two or more types of social support. For the second study an online survey was distributed using a snow-balling technique. Based on the survey data structural equation modeling was used to empirically test the uncertainty management framework. Positive relationships were identified between knowledge and information seeking, information seeking and social support, social support and sense of virtual community, uncertainty and stress. The results suggested that the uncertainty management theory may need to be adapted for use in online contexts. Uncertainty seems to be an important part of the experience of parents caring for children with clubfoot. Online communities dedicated to these parents represent a promising setting for studying illness-related uncertainty and its potential causes. Such studies can be a critical source of

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## CHAPTER 1

### INTRODUCTION

Health communication research is dominated by a provider-patient or provider-caregiver focus that views the patient or caregiver as a recipient of information rather than a generator of information and an agent for health promotion. With the increasing penetration of the Internet, patients and caregivers have more options for generating and seeking information, providing and receiving support and becoming agents of change. Information and social support are generally pursued to manage uncertainty. This is quite visible in the world of clubfoot, where caregivers (parents or guardians) of patients (children) with clubfoot are generators and consumers of health information, providers and receivers of support and agents of change. Given geographical distances between caregivers, a large number of exchanges occur today in online environments and outside of hospitals. Because of these external interactions, health professionals have a limited access to and understanding of the experiences, activities and communication taking place online by caregivers.

The purpose of this dissertation was to explore caregivers' experiences of uncertainty and social support in the context of clubfoot with a focus on Internet-based interactions. The objectives of the project were to describe caregiver's experiences of uncertainty (lack of sureness) and social support (help an individual receives from social network members), to identify key types of social support available online, and to evaluate the relationship between online social support and uncertainty in the context of clubfoot. Such knowledge is needed to develop effective, caregiver-centered, health-promotion programs designed to enhance health communication, caregiver well-being and caregiver support. This dissertation used Uncertainty Management Theory as a theoretical framework.

## Introduction to clubfoot and the Ponseti method of clubfoot treatment

Clubfoot, or Talipes Equinovarus (TEV), is a complex deformity in which the foot is completely turned inwards at birth. The term clubfoot originates from the way the foot is positioned at an angle to the ankle, like the head of a golf club. Idiopathic clubfoot is the most common musculoskeletal birth defect and occurs worldwide with an incidence varying from 0.39 to eight per 1000 live births (Ester, Tyerman, Wise, Blanton, & Hecht, 2007). Clubfoot can be classified in mild or severe, typical or atypical and in some cases it can be associated with other congenital abnormalities. Males are more commonly affected than females (2:1 ratio), and up to 50% of the cases affect both feet (Mosca, 2001; Ponseti, 1996).

The exact causes of clubfoot are not known, yet it is believed that genetics and environmental factors may play an important role in clubfoot development (Ester et al., 2007). Diagnosis of clubfoot is usually made at birth; however, it can be discovered through ultrasound in the third trimester of pregnancy. Clubfoot in itself does not produce discomfort or pain, however the calf muscles on the affected side may be underdeveloped. If untreated by the time the child is ready to walk, the positioning of the foot may result in the child walking on the outside edge or even on the top of his/her feet in severe cases. The goal of the treatment in clubfoot is to restore the look and the function of the foot (Morcuende, Dolan, Dietz, & Ponseti, 2004).

The standard of clubfoot treatment today is the Ponseti method (Dobbs & Gurnett, 2009). The Ponseti method is a non-invasive technique consisting of precise manipulation and serial casting (Ponseti, 1996; Ponseti & Smoley, 2009). The method is effective, safe and economical in correcting the deformity even in challenging and severe cases (Ponseti et al., 2006). Performed correctly, the Ponseti method delivers complete clubfoot correction in greater than 95% of patients, often in less than six weeks (Morcuende et al., 2004; Morcuende, Abbasi, Dolan, & Ponseti, 2005; Ponseti & Smoley, 2009). Long-term

follow up demonstrates satisfactory clinical and functional results in most of the patients (Cooper & Dietz, 1995; Laaveg & Ponseti, 1980). Other treatment options for clubfoot include physiotherapy, serial casting (Kite) or extensive intraarticular surgical release (Turco). Physiotherapy requires daily manipulations for six months, thus a large time commitment from parents with varied rates of success. The Kite method of casting results in incomplete correction. Extensive surgery results in many cases in poor long-term foot function including stiff feet, high level of arthritis and high incidence of pain (Dobbs, Nunley, Schoenecker, 2006; Ippolito, Farsetti, Caterini & Tudisco, 2003).

One of the major driving forces in the diffusion of the Ponseti method has been the effort of parents of children with clubfoot and their use of the Internet. Given that the prospects of surgical treatment for clubfoot can be discouraging, parents seek alternative treatments. Traditionally, parents would have relied on health care professionals for advice and treatment. However, the development of the Internet and the explosion of health care information have allowed them to obtain disease-specific information in a timely manner and from sources other than physicians (Bader & Braude, 1998; Ball & Lillis, 2001; Beall, Beall, Greenfield, & Biermann, 2002; Beall, Golladay, Greenfield, Hensinger, & Biermann, 2002).

From information available on the Internet, parents can become aware of the Ponseti method and of the potential disadvantages of extensive surgical treatment. The fact that the Ponseti method allows full correction of the deformity in most cases in a very short period of time, and without the need for extensive surgery, seems to be of critical importance in the minds of parents considering treatment. Parents realized the benefits of this treatment modality and shared their experience with others through various channels, including the Internet. This sharing of experiences also resulted in many parents educating their child's physician about the Ponseti method (Morcuende, Egbert, & Ponseti, 2003). Parents have created and actively used Internet support groups focused on clubfoot to find and proffer information, share experiences, and provide

encouragement to other parents. One of the most active online communities related to clubfoot is the Yahoo-based nosurgery4clubfoot (NS4CF) group which was founded in 1999 by a parent who could not find information related to the Ponseti method of clubfoot treatment. The community had in 2009 over 2,300 members with 20 new members joining weekly. Over the years the group has accumulated over 75,000 individual messages in electronic format and it is the largest and oldest support group for parents of children with clubfeet.

The online community is an important source of information and social support for parents of children with clubfeet. Through their messages, the individuals on the board are presenting their stories (before, during and after treatment), requesting information, and offering comfort, encouragement, or advice. One of the major roles of the online community seems to be the management of uncertainty through various tactics.

#### Theoretical framework - Uncertainty Management Theory

Based on a preliminary analysis of randomly selected messages from NS4CF, the Uncertainty Management Theory (UMT) (Babrow, Kasch, & Ford, 1998; Bradac, 2001; Brashers, 2001; Brashers et al., 2000; Ford, Babrow, & Stohl, 1996) seemed to be the best fit for the research topic of interest - online communication and social support among parents of children with clubfeet. UMT addresses various ways in which people manage uncertainty, including attempts to reduce, maintain and even increase the level of uncertainty. UMT posits that the uncertainty experience is different from person to person and challenges the assumption that people will always try to reduce uncertainty. According to UMT the state of uncertainty can result in both increases and decreases in uncertainty-reducing behaviors based on the person and situation, behaviors that will produce an optimal level of uncertainty. As an example sometimes people will seek clarifying information and sometimes people will reject increased clarity.

The major uncertainty management behaviors proposed by UMT are information seeking and social support. Information seeking behavior ranges from direct methods (e.g. asking direct questions) to passive methods (e.g. hesitations). Information acquired can be used to influence knowledge, attitudes and behaviors. An example is information provided as a form of social support – informational support. Other forms of social support include tangible assistance, network support, esteem support and emotional support (Cutrona & Suhr, 1992). Both information and social support can be used strategically to manipulate uncertainty.

Uncertainty is a core construct of the Uncertainty Management Theory. Online interactions, such as those in online communities, may increase, maintain or decrease uncertainty. Following such online interactions, some parents would like to get a second opinion on the situation of their child, while not jeopardizing the relationship with their current physician by what could be seen as an act of distrust (another source of uncertainty). Furthermore, the information offered by parents may be different than that offered by the provider (another source of uncertainty). Confronting the existing provider can be a source of uncertainty in itself due to power issues.

Uncertainty management theory has been used in studies of HIV/AIDS patients (Brashers et al, 2000), advanced planning (Hines, 2001; Hines, Babrow, Badzek, & Moss, 1997), and cancer (Ford, Babrow, & Stohl, 1996). However the application of UMT to research online interactions among caregivers is novel. Furthermore, while physician-patient communication has received a significant amount of attention in health communication, patient-patient and especially caregiver-caregiver communication remain understudied. One interesting, important and unexamined aspect of parent-parent communication is the experience of uncertainty.

### Experience of uncertainty

Uncertainty is a state of mind generated when situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure with their current state of knowledge or with the state of knowledge in general (Babrow, Hines, & Kasch, 2000; Babrow, Kasch, & Ford, 1998). Uncertainty is a matter of perception. Despite acquiring a great deal of information on a given topic, some people will still be uncertain (Brashers, 2001). Uncertainty is also experienced when an individual assesses the probability of an event, the valence of the outcome (good vs. bad) or the combination of the two (Babrow, 1992). In the context of health and health care, uncertainty is experienced in situations related to illnesses (Babrow et al., 1998; Brashers, 2001, 2006). Sources of uncertainty include stigma of the disease, future prospects, trajectory of illness, effectiveness of treatment and relapses (Brashers, Neidig, Reynolds, & Haas, 1998; Brashers et al., 1999). Uncertainty is typical in medical decision making (Babrow et al., 1998; Hines, 2001). For certain illnesses (e.g., clubfoot), treatment options vary and their efficacy will depend on the experience of the health care provider.

Most parents of children with clubfoot are facing uncertainty starting with the moment of diagnosis. Clubfoot is diagnosed either during the third semester of the pregnancy at ultrasound or at birth. Given the visible nature of the illness, the child's clubfoot will be a source of uncertainty/anxiety for years for most of the parents. Pre-treatment sources of uncertainty include diagnosis, severity of the affection, the functional/emotional future of the child, treatment availability, selection of the treatment, selection of the provider, and competing sources of information. Treatment sources of uncertainty include development of the child, complications, parent-provider communication, cast care, competing sources of information, and the child's reactions. Post-treatment sources of uncertainty include bracing protocol (e.g., What is the correct procedure for bracing? How long do we need to use the braces?), the child's reactions/compliance, risk of relapse, and competing sources of information. Competing

sources of information are various sources providing relatively different answers to the same questions (i.e., nurse, physician, other parents, Internet, and articles in journals and magazines).

Parents in online communities are constantly managing uncertainty (their own and that of the others). Some messages are intended to increase uncertainty (e.g., about the success of surgery). Some messages increase uncertainty unintentionally through the stories presented or questions asked by some parents (e.g., relapses). Some messages are intended to maintain uncertainty (e.g., about the probability of relapses) by providing contradictory information. Other messages are intended to increase certainty about various topics, such as selection of a treatment method, follow-up protocol and child development. Finally, some parents manage their own uncertainty by communicating with other caregivers about their experiences in order to create coherence in their lives and to validate their choices (Plantin & Daneback, 2009).

As presented above clubfeet may generate multiple sources of uncertainty over time (e.g., diagnosis, selection of treatment, selection of provider, or follow up), and the information related to these sources is appraised differently based on a number of factors. As a result, uncertainty can become chronic. In this case, uncertainty acceptance can be employed as an adaptive mechanism (Mishel, 1990). Thus, individuals may come to appreciate uncertainty and even use it to their advantage through various appraisal processes and behavioral responses (Emmers & Canary, 1996).

#### Emotions and appraisal processes in uncertainty management

Behavioral and psychological responses to uncertainty are influenced by appraisals and emotional reactions to the personal experience. There is a two-way relationship between uncertainty and emotions. Responses to uncertainty are shaped by appraisals and emotional reactions to the experience. In addition, the experience of some

emotions is accompanied by feeling certain, understanding what is happening in the current situation, and feeling able to predict what will happen next. Other emotions are characterized by feeling uncertain, not understanding what is happening, and being unsure about what will happen next (Ellsworth & Smith, 1988; Smith & Ellsworth, 1985). Emotions such as anger, disgust, happiness, and contentment are associated with the sense of certainty; the emotions of hope, surprise, fear, worry, and sadness are associated with the sense of uncertainty (Roseman, 1984; Scherer, 1984; Smith & Ellsworth, 1985). These expressions are important because the experience of certainty-associated emotions may lead to more certainty in subsequent judgments than the experience of uncertainty-associated emotions (Tiedens & Linton, 2001).

Individuals judge an event based on its relevance to their lives (Mishel, 1990). One can certainly assume that the birth of a child with a visible birth defect (clubfoot) has a high relevance for the lives of the parents. It is clear from encounters with parents that the process of diagnosis, treatment and follow up of a child with clubfoot is an emotionally charged process for the parents. Thus, affective responses may be associated with uncertainty appraisals and subsequent behaviors (Babrow, 1992; Brashers et al., 2000). Emotional responses to uncertainty can be negative when uncertainty is viewed as a threat (e.g., the child may need some surgery), positive when uncertainty is framed as beneficial (e.g., the child will be fully functional), neutral when the outcome is indifferent and combined when negative/positive affects coexist (Brashers, 2001). Given the high emotional charge experienced by a caregiver (parent) of a child with clubfoot, the population of interest seems to be an ideal choice to better understand the relationships between expressed emotions, uncertainty and other factors influencing uncertainty management behaviors. Reframing of a problem (e.g. situation appraisal) or acceptance of uncertainty (e.g. through validation by peer group) are examples of uncertainty management behaviors.

Behaviors that attempt to bring uncertainty to a comfortable level (normalization) may include sharing of personal experiences, provision of information, requests for information, provision of empathy, provision of other types of support, gratitude, humor, creative expression (e.g., poetry, signature lines) and small talk (Perron, 2002; Braithwaite, Waldron, & Finn, 1999). Such behaviors may provide validation (of information and of the person), normalization of the personal situation/experience and a way to express/release various feelings and emotions. Two major uncertainty management behaviors (information seeking and social support) represent the main focus of the proposed project. A brief review of the two constructs and their relationship with uncertainty follows.

#### Information seeking and uncertainty management

Information seeking is one of the major ways to deal with uncertainty and one of the major indicators of uncertainty presence. Information can be used to manipulate uncertainty (i.e. increase, decrease, maintain) (Brashers et al., 2000). Acquiring information allows individuals to identify, create and compare options (Brashers, 2001). This may be one of the major reasons why parents are joining online communities. Individuals may seek information online to acquire knowledge, to validate their current knowledge and beliefs, and to use the information acquired to manage uncertainty (Brashers, 2001). Information-seeking behaviors include: a) question asking (Berger & Kellerman, 1983; Douglas, 1987); b) self disclosure or relaxing the target (Kellermann & Berger, 1984; Shaw, Hawkins, McTavish, Pingree, & Gustafson, 2006); c) offering a candidate answer (Pomerantz, 1988); and d) second guessing (Hewes, Graham, Monsour, & Doelger, 1989). Language styles such as hedges, hesitations, tag questions or expressions of probabilities may indicate a state of uncertainty (Fox & Irwin, 1998), which translates into passive information seeking (Brashers, 2001). It is important to

understand what types of information-seeking behavior are most prevalent in the context of clubfoot in order to produce relevant health communication messages.

Information seeking is a complex process. It can be further complicated by the nature of information available (e.g., inconsistent, contradictory, increasing/decreasing uncertainty). Individuals may evolve into "experts" who are vigilant, know how to assess the credibility of new information sources and know how to accommodate others in their efforts (Brashers, 2001). Furthermore, through the messages they post, participants in online communities manage and manipulate the uncertainty of others in addition to their own uncertainty, thus influencing the stress levels of other members.

#### Social support and uncertainty management

Social support is defined as, "aid and assistance exchanged through social relationships and interpersonal transactions" (Heaney & Israel, 2008, p201). Social support is intended to have a positive impact on the receiver and it may include activities such as expression of affect, social reinforcement, provision of tangible or symbolic aid, provision of information and advice (Scharer, 2005). There are four types of social support described in the literature: emotional (affective – love, caring, empathy), instrumental (tangible – aid, service), informational (cognitive – information, advice, suggestions), and appraisal (evaluative – constructive feedback, affirmation of beliefs, social comparison) (Birch, 1998).

The physical and psychological benefits of receiving social support have been widely documented (Antonucci, 1990; Israel, 1982; Israel, 1987; Logsdon, 2004; Prochaska, 2000; Vandervoort, 1999). Social support has been associated with reduction in risky health behaviors, as well as reduced depression, reduced anxiety, reduced stress, improved self-esteem, improved self-efficacy, improved social behavior and improved compliance with treatment (Berkman, 2000; Houston, Cooper, & Ford, 2002). The World Health Organization recognized the importance of social support for health and well-

being almost a decade ago (World Health Organization, 1998). Social support, especially for medical conditions, is often accessible through support groups.

Support groups have been used with and by clients for many types of health issues and had positive impact in reducing stress and assisting with adjustment to illness/disability for both clients and families (Badger, 1989; Dougherty, 1997). A direct link between social support and mental health (anxiety/depression) of mothers has been documented (Naerde, 2000). Parents and caregivers of children with various health problems often identify the need for more social support (Failla, 1991; Mayers, 1992; Norbeck, 1991; Reidy, 1991; Scharer, 2005). Furthermore, parent-to-parent communication has been identified specifically as needed by parents of children with disabilities or chronic medical conditions (Hartman, 1992; Scharer, 2005). Availability of strong social networks and social support are good predictors of health and well-being for families that have children with disabilities (Dunst, 1988; Dunst, 1990).

In some cases, acquisition of face-to-face social support may be problematic, especially when a health condition is rare. With increasing access to the Internet by a larger percentage of the population, Internet-based support groups, also known as online communities (OCs), have become an attractive alternative for many populations (Hoffman-Goetz & Donelle, 2007; Nahm, Resnick, & Mills, 2003; Nahm, Resnick, & Gaines, 2004). Advantages of online support groups may include: overcoming mobility (geographic) barriers, the possibility of developing coherent and complete messages in a written format, the potential for a great number of participants translating into a larger pool of information, a sense of community, twenty-four hours per day access, anonymity and multiple learning opportunities (Braithwaite et al., 1999). Despite a lack of many nonverbal and contextual cues, computer-mediated support groups can become as effective as face-to-face groups because individuals dedicate more time to online interactions and provide more thought-out messages (Wright, 1999). Examples of computer-mediated support groups include ones for breast cancer (Shaw, Hawkins,

McTavish, Pingree, & Gustafson, 2006), children with cancer (Han & Belcher, 2001), mental illness (Rajendran, Mitchell, & Rickards, 2005), substance abuse (Budman, 2000), digestive illness (Coulson, 2005), HIV/AIDS (Gustafson, 1999; Kalichman, 2003) and disabilities (Braithwaite et al., 1999; Dunham, 1998; Mickelson, 1997).

Active computer-mediated support groups are also referred to as virtual communities. Virtual communities are, “self-sustaining social systems in which members engage and connect with each other” (Blanchard, 2008; Rheingold, 1993; Schuler, 1996). While sense of community is considered an important characteristic of face-to-face communities (Chipuer & Pretty, 1999; Fisher, Sonn, & Bishop, 2002; Obst & White, 2004), sense of virtual community (SOVC) is proposed as the equivalent in virtual communities (Blanchard, 2008; Blanchard & Markus, 2004; Forster, 2004; Koh & Kim, 2003). SOVC is defined as, “members’ feelings of membership, identity, belonging, and attachment to a group that interacts primarily through electronic communication” (Blanchard, 2007).

Potentially offensive and damaging communication is a concern in OCs (Ginossar, 2008; Braithwaite et al., 1999). Such communication may include negative, aggressive and socially inappropriate remarks, or “flaming” (Finn, 1999; Finfgeld, 2000). The prevalence of potentially offensive communication was not previously examined in the online community of interest. Furthermore, such concerns are in line with the assumptions of many computer-mediated communication theories’ that online communication may be perceived as hostile due to a lack of nonverbal cues (Walther, Anderson, & Park, 1994). Hence, an examination of potential conflicts in the particular context of clubfoot OC is important for understanding its prevalence and the solutions that OC members may have found for such occurrences.

Through social support, others facilitate uncertainty management with messages and behaviors that increase, maintain or decrease certainty and uncertainty (Ford, Babrow, & Stohl, 1996). Socially supportive messages and behaviors influence the

experience of uncertainty, appraisal processes and uncertainty management behaviors (Brashers, Neidig, & Goldsmith, 2004). Social support can influence the experience of uncertainty by creating relationships, validating concerns, offering opportunities for ventilation, providing tangible and intangible support. Social support influences appraisal processes by helping individuals focus on salient questions, re-appraise uncertainty, or even reframe uncertainty. It is important to understand what types of social support (behaviors) are present in the OC of interest in order to properly deploy future communication.

Emotional and informational support are reported to be the most prevalent types of support in OCs (Braithwaite et al., 1999; Klemm, Hurst, Dearholt, & Trone, 1999; Klemm, Reppert, & Visich, 1998; Sharf, 1997; Shaw et al., 2000; Sullivan, 2003; Turner, Grube, & Mayers, 2001; White, 2000; Wright, 2002). Of the two types, emotional support seems to be especially important for women (Ginossar, 2008; Sullivan, 2003; Klemm et al., 1999). It is important to explore if the same types of support and gender differences are present in the OC of interest in order to create gender-tailored communications.

The other prevalent type of social support is informational support. Informational support influences the management of uncertainty through provision of information, collaborative information gathering, collaborative sense making, evaluation of information or even filtration of information (Brashers, 2001). For the community of interest some important types of information are medical information and evaluation of health care services.

Medical information is defined as factual information about diagnoses, symptoms, regular and alternative treatments, and relapses. However, the credibility of online information and its sources is an issue of concern (Culver, Gerr, & Frumkin, 1997; Evans, 2001; Wright, 2000). It has been suggested that members of an OC may receive misinformation or be directed to false health information (Klemm, Reppert & Visich,

1998; Finn, 1999; Wright, 2002). It is important to note that information acquired by a person does not need to be correct to reduce uncertainty, it just needs to give the perception of coherence (Brashers, 2001). In online support groups, trained and qualified persons may offer medical advice, but so may anyone else who participates. Information provided in the OC may not be peer reviewed and may even be harmful. Controversial information may be presented in a biased manner and the sources for medical information may be cited in less than 20% of the cases (Culver, Gerr & Frumkin, 1997). For development of evidence-based health communication interventions it is important to understand the types of medical information provided in an online environment and the sources from which such information come. Finally, the actual access to medical services may be influenced by informal evaluations of providers and health care services provided through informational support mechanisms.

Uncertainty may cause caregivers to employ redefinition of tasks, use of heuristics to make choices, or use of minimal information for decision making (Pierce, 1996). One interesting fact about physician-patient relations is that both groups employ stereotyping (heuristics and minimal information) in their relationships (Hines, Babrow, Badzek, & Moss, 1997). In the online communities there may be a tendency to label physicians (e.g. good or bad) in an attempt to find the best care for a child.

As a result, informal evaluations of the health care services may include negative, positive or neutral comments related to health care providers, health care facilities or the overall treatment experience. Such comments may have an influence on the uncertainty levels of the recipients and subsequently on their access of medical services (Finn, 1995). As treatment provision is critical for a caregiver, it is important to understand what information is requested and provided in terms of health care services evaluation.

As documented in this chapter, the Internet provides new ways for health communication through virtual communities. These communities have the potential to influence the way health information is managed, shared and utilized. At the same time

these communities have the potential to deliver much needed social support outside the medical act, thus influencing the well-being of the participants in online interactions. Through information exchanges and other types of social support, participants in online interactions are managing their own uncertainty and the uncertainty of others in the same situation with the purpose of reducing the burden of challenges they have to face as caregivers of children with clubfeet. The community of interest (caregivers of children with clubfeet) provides great promise in terms of potential findings as related to theoretical and practical contributions to the existing body of knowledge.

#### Stress and uncertainty management

For many parents, caring for an ill child is a highly stressful experience because of increased demands on their time and energy, worries about the long-term functioning of the child, and limited time for recreation (Wallander & Venters, 1995). Caring for a child with an illness affects family functioning through a number of mechanisms, such as increasing parental stress and depression, marital role strain, and the occurrence of differential treatment of siblings (Holden, Chmielewski, Nelson, Kager, & Foltz, 1997; Quittner et al., 1998; Quittner & Opipari, 1994). Mothers, given traditional family roles, typically assume much of the emotional and practical responsibility of caring for the child with a chronic illness (Hodgkinson & Lester, 2002; Quittner et al., 1998).

It is reported that mothers of children with health problems appear to be at risk for psychological distress, particularly depression (Mohlman & Patterson, 2004; Silver, Bauman, & Weiss, 1999). More symptoms of distress are reported by mothers who perceive their children to have more functional limitations (Jessop, Riessma, & Stein, 1988). Maternal emotional distress is reported to cause, in some cases, hostile and less responsive parenting practices (Cox, Puckering, Pound & Mills, 1987; Lovejoy, Graczyk, O'Hare, & Neuman, 2000).

Both parents are affected by the child's health condition. In general, fathers use more problem-solving coping skills, while mothers use more emotion-based coping skills (Hovey, 2003; 2005). Given traditional child-caring roles in the family, the perceived impact is higher on mothers than on fathers (Mohlman & Patterson, 2004; Hovey, 2005). Furthermore, differences in the child-caring load and perceived caregiving role differences between the two parents may result in increased conflicts and reduced marital satisfaction (Mohlman & Patterson, 2004). Interestingly, fathers may be more vulnerable than mothers when it comes to dealing with the stress of an ill child. Overall, men use fewer coping strategies and feel less confident in their caregiver abilities than women (Grant & Whittell, 2000). Furthermore, it has been documented that social support is more important for fathers when coping with stressful situations than for mothers, since for fathers, social support is strongly related to self esteem (Katz & Krulik, 1999).

However, studies evaluating the impact of family functioning have produced inconsistent findings, with some studies reporting high rates of parental stress and depression (Pipp-Sigel, Sedey, & Yoshinaga-Itano, 2002; Quittner, DiGirolamo, Michel, & Eigen, 1992; Quittner et al., 1998), while others have shown that parents are coping fairly well with their child's illness (Geiss, Hammersley-Maercklein, Hobbs, Kramer, & Henley, 1992; Walker, Van Slyke, & Newbrough, 1992).

#### Social support and stress

Parents who were satisfied with the support offered by those within their network reported fewer emotional problems (Dunst, Trivette, & Cross, 1986). In addition, perceptions of social support were found to be correlated to maternal stress with some differences across chronic illness populations. Mothers of children with asthma perceived their support networks as less adequate than did mothers of children with diabetes and healthy children, and these negative perceptions were associated with mothers reporting a greater number of stressful events (Hamlett, Pellegrini, & Katz, 1992).

Social support has been proposed as a mediator of stress, with high levels of parental stress associated with limited social support, which is, in turn, associated with higher levels of parental distress and depression (Quittner & DiGirolamo, 1998; Thompson, Gustafson, Hamlett, & Spock, 1992). In families of children with spina bifida, social support mediates the relationship between chronic illness-related stress and outcomes including parent and child adjustment (Barakat & Linney, 1992). The study found that a larger support network, a large proportion of family members in that network, and high satisfaction with perceived support were associated with improved maternal psychological adjustment. Furthermore, for mothers of deaf children, higher levels of general and disease-specific parenting stress were associated with lower levels of perceived social support, which mediated the relationship between parental stress and depression (Quittner, Glueckauf, & Jackson, 1990).

By evaluating social support in the population of interest, and providing additional support for its importance within models of parental adaptation, a greater understanding of the variability in the adjustment of parents of children with clubfoot will be gained. This is important because interventions focused on enhancing the social support networks of parents of children with illnesses have shown promise for reducing negative health effects (Ireys, Sills, Kolodner, & Walsh, 1996; Kirschbaum, Klauer, Filipp, & Hellhammer, 1995; Lieberman et al, 2003).

In the next section, I will present a description of the dissertation including: dissertation localization, study goal, dissertation significance, and chapter distribution.

#### Dissertation overview

This dissertation is an interdisciplinary research project located in the health communication area. The theoretical stream of research is Uncertainty Management Theory. The study area is uncertainty management and online behaviors of caregivers in the context of clubfoot. The *project goal* is to determine the applicability of the

Uncertainty Management Theory constructs to online behaviors and interactions of caregivers in the context of clubfoot. In this context, the dissertation provides insight into information-seeking behaviors of caregivers, identifies and describes the key types of social support available online (in OCs), and explores the relationships between uncertainty management-related constructs.

The project is *significant* because it elicited a wealth of valuable data that may inform priorities for research, health communication, and education. The implications are both theoretical and practical. From a theoretical perspective, the research provides needed detail on the relevance of the theory of interest to caregivers' behaviors. Furthermore, this research resulted in recommendations directed to theoretical improvements needed to extend and apply the Uncertainty Management Theory to online behaviors. Finally, the dissertation explores social support as one component of uncertainty management, rather than as an independent entity.

Practical implications include generating new and improved evidence regarding experiences and preferences of caregivers in regards to health communication and support, the first step in better understanding the audience. From a practical perspective, the information presented herein can be used to address communication gaps (between providers and caregivers), can help identify priorities for education and can identify issues that are important for caregivers. For the field of health communication, this dissertation adds to the growing body of literature that describes uncertainty management in health contexts and online interactions of health consumers, while focusing on a specific group with specific needs: caregivers.

The dissertation is based on two studies. Study 1 is a content analysis of existing messages within an Internet-based support group and study 2 is a survey of parents of children with clubfoot who use online support groups. The purposes of study 1 were to determine the applicability of the UM framework, to confirm the presence/absence of various UMT constructs and to describe their contribution to the uncertainty management

framework in the context of an online community (OC). The purposes of study 2 were to explore the relationships between UMT constructs and to test the contributions of a new construct – the Sense of Virtual Community (SOVC) – to the UMT framework.

Study 1 results are presented in chapters two and three of the dissertation (Figure 1.1). Chapter two examines and describes characteristics of the online communication, information-seeking and information-provision behaviors in an online support group for caregivers of children with clubfoot. Chapter three examines the provision of social support through messages posted to an online support group for caregivers of children with clubfoot. Study 2 results are presented in chapter four. Chapter four tests the relationships between UMT constructs and the potential contribution of SOVC to the UMT framework when applied to online communities (Figure 1.2). The final chapter summarizes the findings across the entire dissertation and addresses implications for practice and future research.

Figure 1.1 Conceptual model for study 1

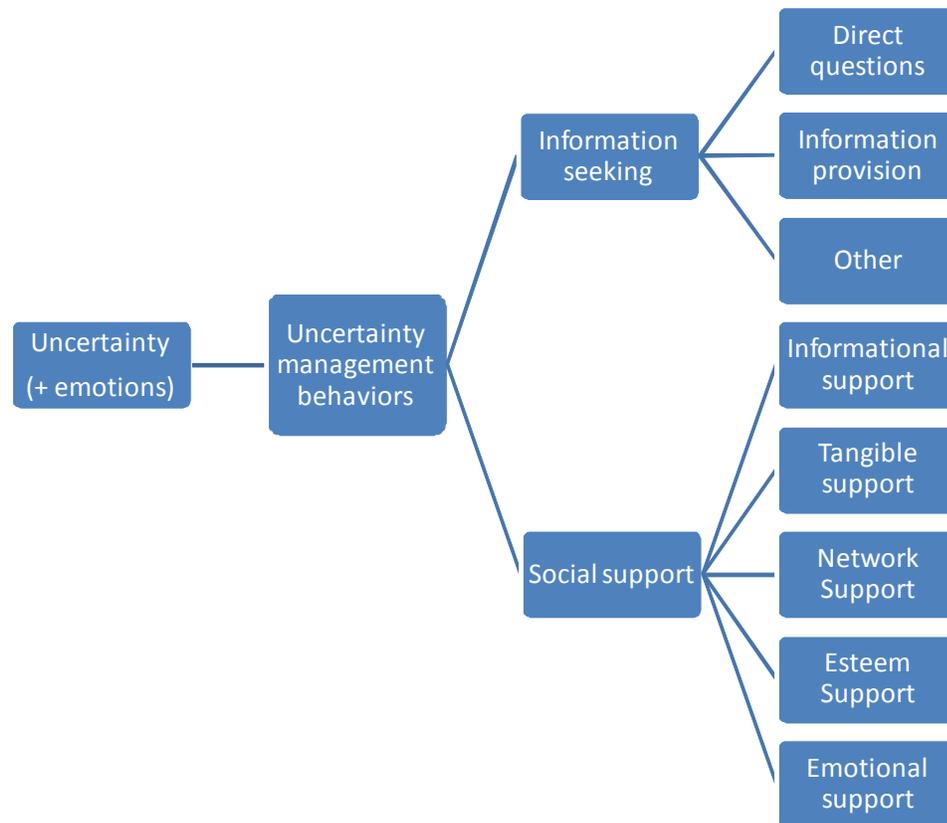
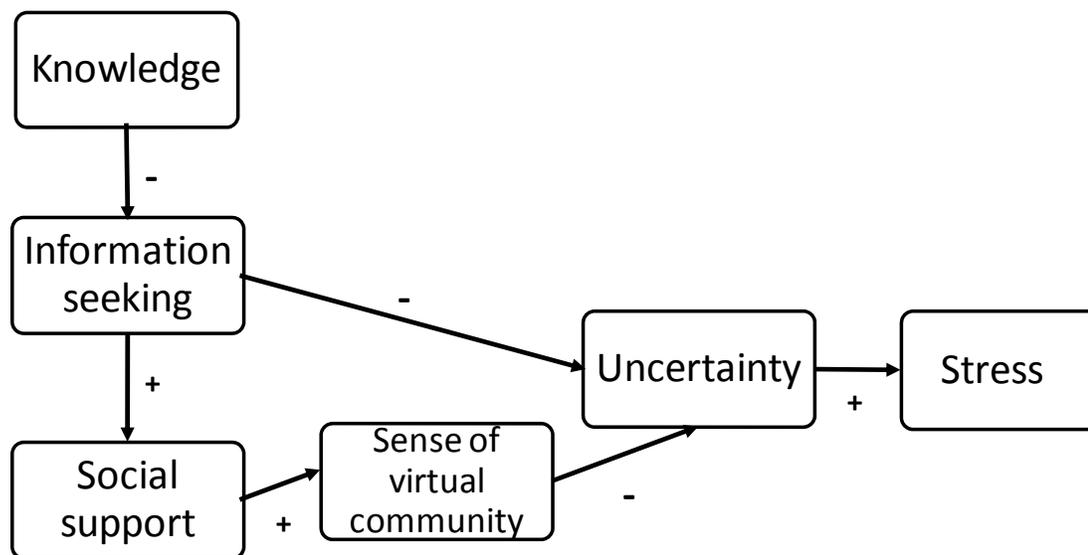


Figure 1.2 Conceptual model for study 2



## CHAPTER 2

### INFORMATION SEEKING AND OTHER UNCERTAINTY MANAGEMENT BEHAVIORS

#### Introduction

When caring for a child affected by illness or disability, the parent/caregiver experiences uncertainty (Babrow, Kasch, & Ford, 1998; Brashers, 2001; Mishel, 1990). Clubfoot is a developmental disability affecting the lower limb with an incidence of approximately 1 per 1000 live births (Morcuende, Dolan, Dietz, & Ponseti, 2004). Given its visual nature, clubfoot is a major source of uncertainty for the parents of the children affected starting with the moment of diagnosis. Furthermore, clubfoot treatment options vary, and their efficacy depends on the experience of the health care provider (Cooper & Dietz, 1995; Dobbs, Morcuende, Gurnett, & Ponseti, 2000; Laaveg & Ponseti, 1980; Morcuende et al., 2004; Ponseti et al., 2006). Uncertainty is defined as a psychological state characterized by insecurity and lack of clear information (Brashers, 2001). As with other serious health conditions, when a child is diagnosed with clubfoot, the parents are faced with a situation that is ambiguous and complex; information about treatment may be unavailable and inconsistent; and some parents may begin to feel insecure with their knowledge about clubfoot or with the state of medical knowledge in general (Babrow, Hines, & Kasch, 2000; Babrow et al., 1998). Sources of uncertainty may also include potential stigma of the health condition, child development (including long term effects of illness), and selection and effectiveness of treatment (Brashers, Neidig, Reynolds, & Haas, 1998; Brashers et al., 1999). Faced with such a condition, the parent/caregiver employs various behaviors to manage uncertainty. The aim of this study was to explore and describe processes of communication and uncertainty management in an online support community serving the needs of parents of children with clubfoot. In order to create effective health communication programs or health interventions to provide

support, reduce uncertainty and stress it is imperative to understand the audience. This study is a first step in this important direction.

*Uncertainty Management Theory.* The Uncertainty Management Theory (UMT) (Babrow et al., 1998; Brashers, 2001; Brashers et al., 2000; Ford, Babrow, & Stohl, 1996) addresses a number of ways in which people attempt to reduce, maintain, or increase their level of uncertainty. Individuals manage uncertainty (theirs and others) through appraisal processes and behavioral responses. Situation appraisals influence the magnitude of uncertainty and its impact on the individual. A situation seen as dangerous or undesirable (e.g., relapse) can generate feelings of anxiety and worry, while a situation seen as an opportunity for positive results (e.g., seeing progress after each treatment phase) can generate feelings of hope or optimism (Thompson & O’Hair, 2008). Situation appraisal may vary with the phase of treatment. Behavioral responses may include information seeking, information provision, emotional support provision, expressions of emotions and even chit chat (Braithwaite, Waldron, & Finn, 1999; Emmers & Canary, 1996; Perron, 2002). In addition to fulfilling the need for acquiring and sharing information (including emotions), such behaviors may help parents feel validated and more secure in their role as a caregiver of a child with clubfoot.

*Information seeking and uncertainty management.* Information is one of the major tools available to manipulate uncertainty, and information seeking is an indicator of uncertainty presence (Brashers et al., 2000). Information seeking is one of the major constructs present in the Uncertainty Management Theory (Brashers, 2001). Information-seeking behaviors include question asking, self disclosure, offering a candidate answer, second guessing, and passive information seeking (Brashers, 2001; Berger & Kellerman, 1983; Douglas, 1987; Hewes, Graham, Monsour, & Doelger, 1989; Kellermann & Berger, 1984; Pomerantz, 1988).

*Health information seeking on the Internet.* All people seek information; yet in health-related situations, the high stakes may lead to a large number of venues and styles

of information seeking to ensure that the individual gains access to as much information as possible regarding a certain health issue (Derdiarian, 1986; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Satterlund, McCaul, & Sandgren, 2003). A venue of increasing importance for health information exchanges is the Internet. A recent report from the Pew Internet Research Institute (2009) indicates that due to the increase in Internet access (75% of American adults use the Internet), there has been an explosion of health-related information online – both in terms of production and consumption. The Pew survey found that 10% of the American adult Internet users look for health information online each day, 80% of Internet users have searched online for health information, 7% of the Internet users participate in online discussions and groups, and over half of those surveyed indicate that the availability of health information on the Internet had a significant impact on the way they care for themselves or for others.

*Parents on the Internet.* Today's parents may not be satisfied with the information they receive during medical encounters, but instead require large amounts of information which cannot usually be made available to them in the limited time of a medical encounter. As a result, a large proportion of new parents use the Internet as a major source of information (Plantin & Daneback, 2009). More than half of the parents who use the Internet for seeking information about caring for their children report that what they find through Internet channels has a positive influence on them (Yahoo, 2005). Most parental Internet users are women (Madge & O'Connor, 2006, Sarkadi & Bremberg, 2005). Their mean age is less than 35 years and many are first-time parents (Graber, Roller, & Kaeble, 1999). More white adults have access to Internet at home than do Hispanics or Afro-American (Brodie et al., 2000; Fox & Livingston, 2007). Thus, the frequent health-oriented Internet users can be characterized as young, white, middle class women who use the Internet mostly for finding information related to health and parenting issues (Allen & Rainie, 2002; Fox, 2005).

The use of Internet as an information and support source is of particular importance for parents of children with various illnesses (Plantin & Daneback, 2009), including clubfoot (Morcuende, Egbert, & Ponseti, 2003). A child affected by illness or disability increases the need for support and information (Plantin & Daneback, 2009), and, often parents who need to care for such a child become active seekers of information and other types of social support (Brazy, Anderson, Becker, & Becker, 2001). These parents attempt to find as much information as possible about the health condition of interest including the best treatments, the best doctors, and the best facilities available (Derdiarian, 1986; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002). Information is primarily found using search engines, websites recommended by friends, advertisements in parental magazines and online support groups (Cotten & Gupta, 2004; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2003; Morcuende et al., 2003; Plantin & Daneback, 2009).

Given the increased availability of medical information, more parents want to be part of the treatment related decision making (McMullan, 2006; Morcuende et al., 2003). If not given sufficient attention or access to resources clients may become dissatisfied with the medical encounter (Chen & Siu, 2001; Jenkins, Fallowfield, & Saul, 2001) and leave the consult feeling they can search for, find and use medical information that is superior to the recommendations of the physician (McMullan, 2006). In order to manage uncertainty regarding the health care provider, parents may attempt to identify and recommend the physicians and medical institutions that provide the best care while steering away from those who provide less than satisfactory care. Messages including clear identifying information of health care professionals and institutions may be used to manage the uncertainty of the recipient (reduce, increase or maintain) regarding selection of the medical care provider (Hickson, Stewart, Altemeier, & Perin, 1988). Thus it is important to understand whether health care providers, institutions and services are mentioned by parents in informational exchanges within online support groups.

*Information seeking in online support groups.* Yahoo alone hosts over 137,000 online groups created around health & wellness topics and over 100,000 groups directed to parents (groups.yahoo.com, April 29, 2009). Many of the aforementioned groups allow individuals to engage in exchanges of information with others dealing with similar challenges. Repeat visits to monitor the online groups and obtain updates may be considered as part of the ongoing process of managing uncertainty by having the most up-to-date information and confirming that the information acquired so far is still valid (Ellis, 1989; Foster, 2004).

Online support groups have a number of advantages such as 24/7 availability, lack of geographical barriers, a greater degree of anonymity, and ability for people to carefully read and compose messages (Coulson, Buchanan, & Aubeeluck, 2007; Williams, 2006). In the context of clubfoot, given the relative rarity of the condition, another advantage is the ability to find or even meet other parents who face similar challenges. Some disadvantages may include lack of physical contact, potential of negative experiences, and lack of formal information quality control mechanisms (Dornan & Oermann, 2006; Han & Belcher, 2001; Hardwick & MacKenzie, 2005; Kildea, Barclay, & Brodie, 2006;). The lack of quality control in online communities, especially when discussing medical issues, may result in information that could be conflicting, misleading, or even invalid (Eysenbach, Power, Kuss, & Sa, 2002; Pandolfini, 2000). An initial step toward assessing the quality of the medical information exchanged is to identify its source.

#### Aim of the study

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 information. The study focus was an online support community serving the needs of parents of children with clubfoot. Special attention was given to information seeking and provision behaviors and other modalities of uncertainty management in addition to feelings and

emotions expressed in the support group. The purpose of the study was to better understand how parents use the Internet-based support groups (OSC – online support communities) to seek information and to manage uncertainty when caring for a child with a rare health condition. The following research questions were addressed:

RQ1: What is the prevalence and distribution of information-seeking, information provision, and of other types of uncertainty management behaviors?

RQ2: What is the prevalence and distribution of emotions expressed in the OC of interest?

RQ3: What is the prevalence and distribution of messages that provide clear identifying information of a medical professional or medical institution?

RQ4: What is the prevalence and distribution of messages that deal with medical information, and what are the most frequent sources of medical information?

### Methods

The methods section describes the study population, the study sample, the study methodology, variables of interest and statistical analysis.

*Study population.* The study population was represented by messages posted to the Yahoo-based nosurgery4clubfoot (NS4CF) group, the oldest, largest and most active online support group dedicated to informational and social support needs of parents of children with clubfoot. In 10 years of existence the group members exchanged over 76,000 messages. Currently the group has over 2,300 members and is joined by 10-20 new members each week. Between 50 and 400 new messages are posted every week. Active members post messages to the group, either seeking information or providing information and other types of support. Through their messages the individuals active in

the group are providing information, requesting information, offering comfort, encouragement, and other types of support as a way to manage their uncertainty.

*Study sample.* The study sample consisted of randomly selected messages posted to the OSC of interest. The sampling methodology was systematic random sampling (Neuendorf, 2002, p84). A sampling rate of 100 (every 100th message) starting with a randomly selected message was used. A total of 775 messages posted between January 2000 and December 2008 were collected, coded, and analyzed. Permission to collect the messages was secured from the group owner. The study methodology was approved by the Institutional Review Board at the University of Iowa.

*Study methodology.* Messages were analyzed and coded using content analysis. Content analysis has been previously used to study exchanges in online support groups (Ginossar, 2008; Sharf, 1997; Weinberg, Schmale, Uken, & Wessel, 1996; Winzelberg, Classen & Alper, 2003). Variables of interest are detailed below.

*Variables.* The *gender* of the author was identified using three options of response: female, male, and unknown. The *type of message* was coded as original message if it was the first message in the thread or response to a previous message if not the first message in the thread. The *intended recipient* was classified as individual if the message was clearly addressed to an individual (i.e., addressed by name) or group if the message was not addressed to a specific person.

*The types of information-seeking behavior* were coded following the schema proposed by Brashers (2001): question asking, self-disclosure, offering a candidate answer (possible response), second guessing, and passive information seeking. Finally, postings were coded for the presence of *emotions and feelings* (hope, happiness, contentment, worry, sadness, anger, surprise, fear, disgust) as indicators of uncertainty related to the caregiving experience (Emmers & Canary, 1996). A message could contain more than one category.

Messages with *identifying information* were those that included a clear identification of a facility or medical professional, either by name or by a description. These messages were categorized based on their valence as related to the overall experience of the poster: negative (“I have to admit I have been left to feel rather neglected through this recent experience with the hospital.”), neutral and positive (“We could not be happier with our doc. He is outstanding and caring...”). Messages *urging for other professional, treatment, or second opinion* were those urging the intended recipient of the message to seek a second opinion or a different medical care provider. Messages dealing with *medical information* were those including information about diagnoses, symptoms, regular and alternative treatments, relapses, and other medical issues. The *source of medical information* was classified as personal if it was based on the author’s experience, medical professional if a health care provider was mentioned as source, hospital/institutional website if a link was provided, and medical textbook/journal if the title was provided. The *type of medical information* was categorized based on clubfoot-related information such as diagnosis, casting, and bracing.

*Statistical analysis.* Statistical analyses, including intercoder reliability, were conducted using SPSS 15. Krippendorff’s alpha coefficients were computed for each variable. In order to compute intercoder reliability, out of the analytical sample, 15% (N=116) messages were randomly selected and independently coded by two coders following the methodology proposed by Neuendorf (2002, p158) for intercoder reliability computations. Messages where disagreements occurred were discussed, and where possible a consensus opinion was used. To ensure validity, disagreements were documented prior to achieving consensus in order to reduce potential biases (Ginossar, 2008; Weber, 1985). Krippendorff’s alpha can be used with multiple coders, accounts for different sample sizes and missing data, and can be used for ordinal-, interval-, and ratio-level variables (Hayes & Krippendorff, 2007; Krippendorff, 2004). Krippendorff’s alpha ranged between .84 and .98. A Krippendorff alpha above .80 is considered acceptable

(Neuendorf, 2002; Riffe, Lacy, & Fico, 1998). Descriptive statistics were used to present the prevalence and distribution of the variables of interest.

### Results

A total of 775 messages were randomly selected and coded. Women authored 85.7% (N=664) messages, and men authored 6.1% (N=47). The gender of the author was unknown for 64 (9.2%) of the messages. Eighty percent (N=616) of the messages were responses to a previous message and 20% (N=148) were original messages for a ratio of 4:1, indicating an average number of four responses for each original message posted to the board. In 73% (N=559) of the messages the intended recipient was an individual, while in 27% (N=210) of the messages the intended recipient was the online support group as a whole.

The most frequent information-seeking behaviors were direct questions (25.3% of all messages), followed by self-disclosure (15%). Other types of information-seeking behaviors were identified in less than 5% of the messages (see Table 2.1 for details). To determine the correlation between various types of information seeking behavior, five Pearson product-moment correlations were conducted. Information seeking using direct questions was found to be positively correlated to self disclosure, provision of a candidate answer, and passive information seeking. Self disclosure was found to be positively correlated to provision of a candidate answer, second guessing, and passive information seeking. Provision of a candidate answer was found to be positively correlated with second guessing and passive information seeking. Second guessing was found to be positively correlated to passive information seeking. All correlations reported were significant at the 0.01 level (2-tailed). More detail is provided in Table 2.2.

Emotions were classified in positive, negative and neutral (Brashers, 2001). Positive emotions (21.5%, N=166) were represented by hope, happiness and contentment. Hope was the most prevalent of the feelings/emotions articulated in online

communication (13.2% of the messages), followed by happiness (5.3%). Negative emotions (worry, sadness, anger, fear, and disgust) were identified in 4.7% (N=43) of all messages. Neutral emotions such as surprise were identified in 2.5% (N=19) messages.

A quarter of the messages included names of health care professionals, and less than 4% of the messages included the name or description of medical institutions, or description of the medical care provider. Comments about health care professionals were present in 74 (9.5%) of the messages. Over 75% of the comments related to health care professionals were positive. In less than 4% of the messages the recipient was strongly urged to seek a second opinion or to change their medical care provider.

The last research questions addressed the prevalence of messages that included medical information, as well as the source of the information. Detailed medical information was provided in 12.8% of the messages. Of the messages containing medical information, 45% addressed bracing (special shoes the child wears after the casting is completed), 13% provided general information about clubfoot and the Ponseti method of treatment, 11% addressed relapses and 11% addressed casting. Less than 10% of the messages addressed tenotomy (cutting of the Achille's tendon required in 80% of the cases), diagnosis, and other medical issues. Of those messages the major source of information was personal experience in 60% of the postings, followed by a medical professional as a source of medical information in 27.1% of the postings. Medical textbooks/journals and hospitals/institutional websites represented 4.5% of medical information sources.

### Discussion

This study examined information seeking behaviors and uncertainty management behaviors observed in an online support community dedicated to caregivers of children with clubfeet. The discussion will be divided in seven sections corresponding to the research questions: online group characteristics, information-seeking behaviors, emotions

as expressions of uncertainty, other types of uncertainty management behaviors, messages identifying health care providers, messages providing medical information, and sources of medical information.

*Online group characteristics.* During the study period, the OC of interest was an active discussion forum covering various issues related to caring for a child with clubfoot. The majority of active members are mothers of children with clubfoot indicating that in the case of clubfoot care the parent more likely to engage in online support groups to find and share information is the mother. This is in line with other literature that suggest mothers take the main responsibility for the health care of the family in general and of the children in particular (Cotten & Gupta, 2004). It also suggests the idea that women may be more likely than men to use support groups, both face-to-face and online (Harrison, Maguire, & Pitceathly, 1995; Klemm et al., 1999; Mo, Malik, & Coulson, 2009). Yet, it is possible that fathers do their own information seeking using other means such as search engines, websites, and literature without becoming actively involved in online communities (Soanes, Hargrave, Smith, & Gibson, 2009).

*Information-seeking behaviors.* In the health arena, information-seeking behaviors are a critical component of the uncertainty management framework (Brashers, 2001). In the online community the most frequently used types of information-seeking behavior were direct questions and self disclosure, both of them linked with attempts to manage uncertainty. This suggests that when involved in information seeking, community members use a combination of direct questioning and trust building. This allows them to manage both knowledge related uncertainty and interpersonal related uncertainty, supporting the idea of multilayered and interconnected uncertainties (Babrow, 1998). Information-seeking behaviors are the starting point for exchanges of information in online communities, allowing for an efficient and effective chaining of information from multiple sources such as individuals, health care professionals, and Internet-based resources (Ellis, 1989).

*Emotions as expression of uncertainty.* Expression of both positive and negative emotions has a positive impact on psychological wellbeing (Han et al., 2008). However, the findings of this study indicate that the online environment may not be very conducive to expressing feelings/emotions. This may be due to the OC being seen as a (semi) public place in addition to the restrictions of the online environment where most interactions are limited to written messages. Even though individuals adapt and explicitly express their emotions either through detailed descriptions of their emotional states or through use of emoticons as replacement for non-verbal language, expressing emotions on line seems to be a challenge. It is critical to note the general positive atmosphere characterized by mentions of positive emotions far surpassing the expressions of negative emotions such as worry, sadness, anger, fear and disgust (ratio of four to one). First, existing members may deliberately express positive emotions to create a welcoming and friendly environment as a way to manage interpersonal uncertainty. Second, expressing positive emotions may be a method of self-reassurance and self-validation. Third, expressing positive emotions may strengthen their situation appraisals (positive framing). It is possible that once new members see the results other parents had with the clubfoot treatment, their situation appraisal also changes from undesirable to opportunity. Future research could address this temporal aspect of uncertainty management by using the individual as unit of analysis and following posts across time.

*Messages identifying health care providers.* According to UMT (Brashers et al., 2001) individuals use information and other means to increase, maintain, or decrease their uncertainty levels. Based on the results, the main purpose of the clubfoot community is to allow individuals to request and exchange information and other types of support. Much of the information provided is generated from the personal experience of caring for a child with clubfoot. Such information, in addition to providing solutions to various issues encountered over the course of the treatment, also included names of health care professionals and accounts of hospital visits. It was encouraging to see that

~75% of the comments regarding physicians and clubfoot treatment were positive. However, it is clear that the purpose of the community is not to serve as a score board for physicians or medical care institutions even though where necessary group members will urge for second opinions or even for changing medical care providers if the accounts of medical visits do not fit the standards of Ponseti treatment or if some members of the board had negative experiences with a particular physician/hospital.

*Medical information.* The fact that hospital and institutional websites are rarely the source of medical information posted in online messages is an important finding since health information is one of the top subjects that people are looking for on the Internet, with over 12.5 million searches per day focusing on health issues (McMullan, 2006; Eysenbach, 2003). Additionally, more and more parents want to have as much information as possible about the health condition of their child (Derdiarian, 1986, Fogel et al., 2002).

One major reason for illness related uncertainty is the lack of clear, accurate, complete information from a trusted source (Babrow et al., 1998). Hospitals and medical care providers represent a trusted source of medical information (McMullan, 2006). However it is important to note the limited reliance on and reference to medical information available on the websites of medical institutions. This may have three potential explanations: the information is not available, reliable information is difficult to find, or physicians do not encourage their patients to take advantage of the existing reliable Internet-based information. While some hospital websites may provide clear and accurate information, such information seems to be difficult to find.

Critical evaluations of contributions are relatively rare even for messages dealing with medical information, similar to the observations of Culver et al. (1997). It seems that community members have a high level of trust in various contributions (reduced interpersonal uncertainty) even when the source of information is personal experience. For the future this aspect is important to analyze especially in messages dealing with

medical information since the OC has the potential to disseminate information to a large audience with great ease and speed regardless of the quality of information.

#### Practical and theoretical implications

This study supports the statement that in many cases mothers assume the main responsibility for the health of their children (Cotten & Gupta, 2004). Furthermore, women seem to be more likely to seek information on the Internet in general and in online support groups in particular. Finally, it seems that the exchanges that occur naturally in the process of uncertainty management through online communication include combinations of informational, esteem and emotional support. This finding may inform future health communication initiatives, and ensure that messages directed to parents include the aforementioned categories.

The lack of high quality information is a major source of uncertainty. Furthermore, the quality of medical information on the Internet is an issue of concern for health communication scholars and health care practitioners (Coulter, 1998). In order to increase the quality of information available to parents and to better manage their uncertainty, in the context of clubfoot management, and other similar health conditions, it is suggested that physicians become familiar with high quality and reliable information websites. In that direction it is recommended that medical institutions dedicate resources to create high-quality websites providing information on various aspects of the health condition from etiology to long-term follow up. In general existing institutional websites providing health information are perceived as less attractive and difficult to use so when providing information on the Internet special attention to usability and reading level is needed (Bernhardt & Felter, 2004). Further, it is suggested that physicians recommend reliable websites to their clients during the medical encounter as an Internet prescription (Gerber & Eiser, 2001) in order to increase client satisfaction and use the available consultation time more efficiently by answering critical care questions and directing

clients to additional online readings/resources including online support groups for additional informational needs (Hart, Henwood, & Wyatt, 2004).

In this context both the medical encounter and the online support groups can be used as efficient diffusion mechanisms for high-quality medical information. Information seeking has been used as a measure of target receptiveness, which is positively related to uncertainty-management processes in illness (MacGeorge et al., 2004; Thompson & O'Hair, 2008). The online environment seems to offer an excellent opportunity for health care professionals and health communication professionals to provide high-quality medical information to caregivers who are clearly in information-seeking mode. At the same time in the online environment the information is provided in writing, is archived and the parents have access to it as long as they need it.

This study supports the statement that information seeking is an important construct of the UMT. Furthermore the UMT theoretical framework was applicable to studying online activities of parents of children with clubfoot. Finally, the non-linear model of information seeking (Foster, 2004) may be a relevant framework for subsequent research initiatives. The non-linear model of information seeking includes core concepts such as opening, orientation and consolidation in relationship with cognitive approaches and internal/external contexts.

#### Study limitations and future research

There is limited demographic information on the members of the OC thus one cannot claim a full characterization of the board. There is also the potential issue of self-selection as members of this board have a vested interest in finding additional information about clubfoot treatment. Future studies should explore ways to collect additional demographic information, potentially through a survey. Future research should also examine if there are perceived differences between online information exchanges

and face to face information exchanges, and how online exchanges of information and support influence or complement medical encounters.

It is important to note that the members of the online community differ in their levels of participation. There are members who write messages almost every day, members who write occasionally, and members who only read messages (lurkers). This study only covers exchanges between members who are active on the board. Future research needs to examine the impact of the online community on those members who are passive, yet benefit from being exposed to the information and discussions generated in OC. Future research may also focus on the reasons why the passive members do not get involved in the discussion.

Given the large number of messages (75,000+) posted to the OC of interest it can be assumed that online support groups are popular and their members become quite involved in exchanging information. The activity in this particular group indicates that each original message is followed by an average of four replies. This is particularly important because it indicates that for each request of information or support approximately four people will respond with one or more attempts to manage the uncertainty of the recipient. Physician to patient interactions are one-to-one interactions, while interactions in the context of OCs are one-to-many and many-to-one. In contrast to face-to-face interaction, the online environment allows one-to-many and many-to-one interactions to be relatively easy, efficient, and effective by combining the knowledge and intelligence of the group members and preserving the output in a written, persistent format. This is an advantage of online communities that has been given limited attention until now and that will require further research modeling the communication pathways and individual involvement in the online exchanges, in line with the research pioneered by Bambina (2007). Such research could provide direction for ways in which medical care providers could become more involved in the fabric and activities of online communities.

Finally, access to health information on the Internet may be more an issue of health literacy than of access to Internet since the reading level on many health-oriented sites is high school level or higher, too high for a great proportion of the population (Berland et al, 2001; Graber, Roller, & Kaeble, 1999). It will be important and interesting to study what is the overall reading level of the message board especially in regards to medical information. As described in the discussion section, additional research is needed to better understand information-seeking behaviors in the health context both inside and outside the OC in addition to making reliable and readable information available to information seekers and the potential impact this approach would have on their uncertainty levels.

### Conclusion

There is an increasing interest among health communication practitioners and scholars in the Internet-based behaviors of parents of ill children because of the need to increase the effectiveness of health communication initiatives (Plantin & Daneback, 2009). Currently there is limited information on the processes occurring in online communities especially how uncertainty, as related to a health issue, is expressed and managed in online interactions. This article highlighted how the Internet facilitates information exchanges in the context of an online support community created and managed by parents of children with clubfoot. The study provided an initial exploration of information seeking and information provision processes present in an OSC, an area of great potential for health communication research and practice. A special attention was given to medical information sources.

This study presented a detailed description of an online community of parents of children with clubfoot. Special attention was given to information seeking behaviors and other modalities of uncertainty management in addition to feelings and emotions expressed in the support group. Furthermore, the discussion implies a need to reconsider

the attention and resources dedicated to Internet based medical information including the use of Internet prescriptions during medical encounters to guide the clients to high quality information sources. The findings of the present study regarding information seeking behaviors are important and they can be seen as directional for future research. It is recommended that the concept of information seeking as presented in the Uncertainty Management Theory is a critical one and deserves additional scientific inquiry by itself.

Table 2.1 Prevalence of information seeking behaviors and emotions

| <b>Item</b>                          | <b>Count</b> | <b>Percent</b> |
|--------------------------------------|--------------|----------------|
| <b>Information seeking behaviors</b> |              |                |
| Question asking                      | 196          | 25.3%          |
| Self-disclosure                      | 116          | 15.0%          |
| Offering a candidate answer          | 33           | 4.3%           |
| Passive information seeking          | 30           | 3.9%           |
| Second guessing                      | 3            | 0.4%           |
| <b>Emotions</b>                      |              |                |
| Positive emotions                    | 166          | 21.50%         |
| Negative emotions                    | 43           | 4.70%          |
| Neutral (other) emotions             | 19           | 2.50%          |

Table 2.2 Correlations between types of information seeking behaviors

|                  | Direct question | Self disclosure | Candidate answer | Second guessing | Passive |
|------------------|-----------------|-----------------|------------------|-----------------|---------|
| Direct question  | 1.000           | .538**          | .318**           | .059            | .253**  |
| Self disclosure  | .538**          | 1.000           | .324**           | .149**          | .366**  |
| Candidate answer | .318**          | .324**          | 1.000            | .193**          | .223**  |
| Second guessing  | .059            | .149**          | .193**           | 1.000           | .311**  |
| Passive          | .253**          | .366**          | .223**           | .311**          | 1.000   |

\*\* . Correlation is significant at the 0.01 level (2-tailed).

CHAPTER 3  
SOCIAL SUPPORT BEHAVIORS IN AN ONLINE SUPPORT  
COMMUNITY FOR PARENTS OF CHILDREN WITH CLUBFOOT

Introduction

While the field of social support research is well developed, the scientific field of online social support is still in its early stages (Baum, 2004; Scharer, 2005). 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 initial steps have been taken in studying online social support include mental illness (Fleischmann, 2005), neurological disorders (Leonard et al., 2004), skin disease (Lawton, Roberts, & Gibb, 2005), cancer (Han & Belcher, 2001; Lewis, Gunawardena, & El Saadawi, 2005), traumatic brain injury (Wade, Wolfe, & Pestian, 2004), spina bifida (Nicholas, McNeill, Montgomery, Stapleford, & McLure, 2003), and asthma (Oermann, Gerich, Ostosh, & Zaleski, 2003). However, much of the research in this area has been carried out to evaluate interventions set up by or linked to health institutions. Currently, there is limited information on caregiver-managed online social support initiatives.

Thus, this study addresses an important gap in scientific knowledge as identified by Heany and Israel (2008, p 201): “Research is needed to identify important components of Internet support groups, and for whom and under what circumstances they can have health-promoting effects.” This study explores what types of social support are exchanged between caregivers in an online environment. This is important because it reveals what social support behaviors or combinations of social support behaviors members of the OSC exhibit as a result of requests from their peers, thus indicating what type of communication is most necessary in such a setting for this type of audience. Using established categories of social support (Cutrona & Suhr, 1992) within the framework of the Uncertainty Management Theory (Brashers, 2001), this study describes

the types of social support exchanged by caregivers in a virtual online support community dedicated to parents of children with clubfoot.

Clubfoot is a 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 standard method of treatment is currently the Ponseti method (Morcuende, Dolan, Dietz, & Ponseti, 2004). 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. 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; Eysenbach, 2005). The aim of this study is to examine the provision of social support in messages posted to a clubfoot online support group.

Access to personal computers and the Internet has fundamentally changed the ways in which information is exchanged and relationships are fostered. Email lists, Facebook, Twitter, and Yahoo groups are just a few of the many possibilities to communicate and build relationships around health issues using information technology. Today's information technologies allow for easy creation of virtual communities (Eysenbach, 2005). Virtual communities were in existence before the official birth of the Internet (as we know it) as online bulletin boards. The first definitions of virtual communities present them as "social aggregations that emerge from the Net when enough people carry on . . . public discussions long enough, with sufficient human feeling, to

form webs of personal relationships in cyberspace” (Rheingold, 1993, p5). The first virtual communities focused on health issues were social networks formed through electronic mailing lists (Landro, 1999; Wellman, 1997).

A subset of virtual communities is represented by online support communities (OSCs). OSCs are defined as grassroots phenomena using services freely available on the Internet, are free and open to individuals, and have similar characteristics to self-help groups, including management by group members (Fernsler & Manchester, 1997; Ginossar, 2008). OSCs allow for and encourage exchanges of other types of support (i.e., emotional) in addition to informational support (Eysenbach, 2005). OSCs are of great importance for parents, particularly for those caring for children with rare health conditions such as clubfoot (Morcuende et al., 2004; Ponseti et al., 2006).

Today’s parents face 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 (Beck-Gernsheim, 2002; Plantin & 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 & Moren-Cross, 2005; O’Connor & Madge, 2004). 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 (Lamp & Howard, 1999; Plantin & 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 new parents face (Persson & Dykes, 2002; Persson, Fridlund, & Dykes, 2007).

The need for online information and support is greatly amplified for parents of children affected by various health conditions (Bernhardt & Felter, 2004; Plantin & Daneback, 2009). Many of these parents become active seekers of information and support (Brazy et al., 2001; Lawton, Roberts & Gibb, 2005). 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). Disadvantages include: large volume of electronic exchanges, including an important amount of messages that may not be relevant to the entire audience; lack of physical contact and proximity (Han & Belcher, 2001); potential for misinformation because of the non-evidence-based type of information exchanged and lack of quality control (Culver, Gerr, & Frumkin, 1997; Desai, Dole, Yeatman, & Troutman, 1997; White & Dorman, 2000) 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; Fleishman et al., 2000). Despite the above disadvantages, it has been documented that online communities allow for effective exchanges of social support, not only informational but also emotional, 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” (Heany & Israel, 2008, p.191). Cutrona and Suhr (1992) describe 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 (Heany & Israel, 2008; MaloneBeach & Zarit, 1995). High levels of perceived social support result in increased psychological well-being (Eastin & LaRose, 2005). It has been documented that social support can reduce depression, stress and overall psychological impact in traumatic and illness-related situations (Winzelberg et al, 2003). Social support is acquired and offered through social networks (Heany & Israel, 2008).

Two major mechanisms of acquiring social support are described in the literature: the main effects model and the buffering model (Aneshensel & Stone, 1982; Cohen & Wills, 1985). In the main effects support model, the social network of a person is characterized by a large number of members with strong interpersonal ties, resulting in intense and frequent interactions on multiple topics (Walther & Boyd, 2002). In addition to access to resources provided by network members (e.g. information, esteem, and emotional support) the participation of the individuals in the network fulfills their needs for affiliation, respect, belonging, and social recognition (Aneshensel & Stone, 1982).

In the buffering model, specific stressful events push individuals to seek support (Cohen & Wills, 1985; Wright, 2000). As is the case with clubfoot in particular, available resources of information and support (i.e. medical personnel) may be deemed inadequate by parents who seek outside resources to cope with their situation. The buffering model assumes a relatively small network (Rooks, 1990) and limited access to resources (especially information). Limited information seems to be applicable to the case of clubfoot as well as to other rare diseases and birth defects. However, thanks to the access to Internet and OSC, once parents actively begin to seek support from others than close family and friends (who have no experience with clubfoot) they can gain access to large virtual communities (over 2,300 members for the Yahoo group nosurgery4clubfoot -

NS4CF) of people who face the same problems, many of whom are familiar with solutions to those problems. And while some argue that buffering sources results in superficial interpersonal relationships (Walther & Boyd, 2002), because of the online environment, the existing common memory of the group, and the experiences that network members bring to the discussion, for this particular health condition and everything surrounding it (including parenting issues), the online sources may become essential for the well-being of the caregiver (Eastin & LaRose, 2005) and are actively used/sought after (Cummings, Sproull, & Kiesler, 2002; Gross, Juvonen, & Gable, 2002).

The Internet is becoming an increasingly important avenue for acquiring social support (Lieberman et al., 2003; Shaw & Gant, 2002; Tichon & Saphiro, 2003; Turner, Grube & Meyers, 2001). Social support online is secured through complex mechanisms (Eastin & LaRose, 2005). Some studies suggest that electronic social networks benefit their members similar to face-to-face groups (Robinson & Turner, 2003; Turner, Grube & Meyers, 2001; Wright, 2000). At the same time some scholars suggest that electronic social networks can increase isolation, including isolation from family members (Kraut, 1998; Nie, 2001; Sanders, Field, Diego, & Kaplan, 2000). The types of social support documented in online interactions are similar to those observed in face to face exchanges and include: informational, esteem, emotional, tangible, and network support (Braithwaite, Waldron, & Finn, 1999; Muncer, Loader, Burrows, Pleace, & Nettleton, 2000; Tichon & Saphiro, 2003).

#### Aim of the study

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 provide social support in

order to manage uncertainty. Based on the literature review, the following research questions are proposed:

RQ: What types of supportive behaviors are present in the OSC serving caregivers of children with clubfoot?

RQ: Are various types of social support behaviors correlated?

RQ: What is the prevalence and distribution of social support behaviors present in the OSC serving caregivers of children with clubfoot?

RQ: What is the frequency of non-supportive behaviors in the OSC?

### Methods

This project is part of a larger content analysis which examined information seeking behaviors and other types of uncertainty management behaviors in an OSC. The unit of analysis consists of messages posted to the Yahoo Group nosurgery4clubfoot (NS4CF) [ $N = 76,000+$ ]. Permission to access the messages board and to collect the data was secured from the group administrator/owner. Secondly, the group has over 2,000 members and, based on its size, it is categorized as a public space (Coulter, 2005). The Institutional Review Board at the University of Iowa reviewed and approved the study methodology.

The data for the study were collected using systematic random sampling. Beginning with a randomly selected message, each 100<sup>th</sup> message was selected. The coding scheme was developed using the Cutrona & Suhr (1992) social support behavior categories. These categories have been previously used to code and analyze communication in online support groups (Braithwaite, Waldron, & Finn, 1999; Coulson, 2005; Coulson, Buchanan, & Aubeeluck, 2007). Messages were coded for the presence of informational support, tangible support, network support, esteem support, and emotional support. Messages were also coded for non-supportive communication (lack of

understanding of fellow participants, criticism, and scolding). The following section describes the operational definitions of the variables under consideration.

Informational support was represented by text units providing information related to the stressors affecting the individual (Krause, 1987). Informational support has four subcategories: advice, referral, situation appraisal and teaching (Cutrona & 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 & Suhr, 1992). Text units offering to lend the recipient money or objects were coded as loans. Messages including direct support offers were coded as perform direct tasks. 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 & 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 has three subcategories: compliment, validation and relief of blame (Cutrona & 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 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 has five subcategories: relationship, physical affection, confidentiality, sympathy, understanding/empathy, encouragement and prayer (Cutrona & 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. A non-supportive behavior was defined as an "open expression of anger and aggression and generally conflicted interactions" (Moos & Schaefer, 1984, pp. 300).

Statistical analysis. Statistical analyses, including intercoder reliability, were conducted using SPSS 15. To compute Krippendorff's alpha coefficients in order to assess intercoder reliability, out of the analytical sample (N=775), 15% (N=116)

messages were randomly selected and independently coded by two coders following the methodology proposed by Neuendorf (2002, p158). Where possible, disagreements in coding were resolved through discussion as suggested by Hayes (2005). To ensure validity, disagreements were documented prior to achieving consensus in order to reduce potential biases (Ginossar, 2008; Weber, 1985). Krippendorff's alpha is one of the more flexible coefficients available for this type of computations (Hayes & Krippendorff, 2007; Krippendorff, 2004). An acceptable Krippendorff alpha is above .80 (Neuendorf, 2002; Riffe, Lacy, & Fico, 1998). The inter-coder reliability coefficients for the six major variables of interest ranged from .88 to 1.0. Descriptive statistics were used to present the prevalence and distribution of the variables of interest.

### Results

Table 3.1 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. To examine the relationships between categories of social support, five Pearson product-moment correlations were conducted (see Table 3.2). Informational support was found to be negatively correlated to esteem support,  $r(775) = -.23, p < .0001$ , and positively correlated to emotional support,  $r(775) = .1, p < .05$ . In addition, network support was found to be positively correlated to emotional support,  $r(775) = .23, p < .0001$ . Informational, esteem and emotional support were the most frequent categories, with network support and tangible assistance being less frequent. In the next section each type of social support is exemplified with actual quotes from the messages. All identifying information was removed from the quotes.

#### Informational support

Advice. The following examples of advice address 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 American Prosthetics at the U of Iowa at (319) 3....0."

In some cases parents need to secure accommodation for 4-6 weeks close to the location of the treatment. Thus, group members can refer 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 the situation. Personal experience seems to be a powerful way to present things because it increases 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."

Humor was also used by parents to reframe their status of parents of a child with clubfoot as illustrated in the following signature: "JK, bilateral [clubfeet] (and one heck of a cutie!)"

Teaching. The following examples of teaching include the description of clubfoot as an illness explained for a non-medical audience and a step by step solution to dealing with the braces. While various medical terms (i.e., clubfoot, talipes, abduction, equinus) are used in message exchanges, not all parents have a good understanding of these terms. One of the group members took on the task of converting medical information related to clubfoot from a medical dictionary (Tabers Medical) into a lower reading level text:

"The term for clubfoot is Talipes Equinovarus. If you take that term and look it up, it tells you that it is actually a combination of 2 different deformities. One being Talipes (from here on in referred to as t.) Equinus, which is a bending downward of the the foot in a plantar flexion position, and the other being t. valgus, where the heel and foot are abducted from the midline of the body. The abduction from the body, meaning away from, and midline meaning middle, breaks down into the heel and foot being turned away from the body. However, and I remember there were some others here with kids with the next condition, Metatarsus Varsus is the turning in of the foot."

Detailed explanations are also provided to help others address daily issues such as use of braces in a way that is comfortable for the child:

"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 wiggling room. Just thought we'd let you in on what has worked for us!"

#### Tangible assistance

Loans. There were no messages offering loans observed in the data sample.

Perform direct tasks. The following examples include 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 provides information that allows the 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 Iowa City on Sunday is welcome to join us."; "We will be heading out to Iowa City 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 represent 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

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

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

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 various issues the recipient faces 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."

Non-supportive behaviors. Two instances (0.1%) of non-supportive behaviors were identified in the data sample.

### Discussion

One of the major 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, Babrow, & Stohl, 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 health conditions, OSCs seem to be a viable platform to expand their existing social network and obtain meaningful social support (Eastin & 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 et al., 2007; Eastin & LaRose, 2005; Tichon & Shapiro, 2003).

Informational support was the most frequent type of support provided in the community. Most information was exchanged as advice to a particular situation or problem encountered by the caregiver. 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 et al., 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 et al., 1997; Desai et al., 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 et al., 1998).

People may be distressed by large quantities of information stored and exchanged in an online support community. Thus 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 (Bottoroff et al., 1998).

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 et al., 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 was used to create the sense of a common and friendly "meeting place" destined to increase trust in the community and reduce social uncertainty (Coulson et al., 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 & 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, Mehl & Niederhoffer, 2003). Once new group members understand the value of the community, contributions to the OSCs are further encouraged through esteem support (Cutrona & 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 can be hypothesized 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 will be. Furthermore, compliments are 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 (Steinfeld, Ellison & Lampe, 2008).

Provision of emotional support is a key characteristic of the online support community of interest and has an important impact on uncertainty levels (Brashers, 2001). The most frequent type of emotional support observed was encouragement. Parents encourage those who are dealing with difficult or confusing stages in the process – especially around milestones: diagnosis, beginning and end of casting, beginning of bracing, relapses. Encouragement is a key tactic in reducing uncertainty related to

negative outcomes (Heaman, Gupton, & Gregory, 2004). Encouragements range 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. Parents acknowledge 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 is 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 emphasize the importance of close relationships even in the online environment represent 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 indicating that due to the large number of members, most parents may perceive the group as a public place (Eysenbach, 2005).

While non-supportive behaviors are a concern in online communities, they were minimal in this community. It seems that most users of the group follow some etiquette rules that ensure minimal conflict and respectful communication (Kouri, Turunen, Tossavainen, & Saarikoski, 2006; O’Connor & Madge, 2004). The group norms are 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 indicate that acquiring more information reduces uncertainty: “We put up his information on the web at [www....com](http://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 health care professionals do get involved in major OSCs for parents of children with health conditions. 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 & O’Hair, 2008).

There are additional reasons for health care practitioners to encourage parent participation in OSCs. Frequent online participation increases perceived social support and reduces feelings of loneliness and depression (Morgan & 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, 1997). 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 regiment “Who's idea was it to stop the braces at 6 months old? Another huge red flag. They should stay on till the kids are 4-5 yrs old.”. Uncertainty management by well informed parents in their online interactions with other parents could be the key 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 & Suhr's (1992) support behavior schema as a coding framework for the study of uncertainty management in online communities.

#### Study limitations and future research

Some limitations need to be noted. 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 needs to assess recipient responses as well. 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 (over 2,100) suggesting that the main effect model of social support acquiring may be at play, 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 – lurkers (Preece, Nonnecke, , & 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 acquiring 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 is the first to examine 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. Furthermore, by using data already existing, the burden on the study population is minimized together with the response bias. The study of OSCs is a critical source of information to inform priorities for research, health communication and even medical practice.

Table 3.1 Prevalence and distribution of study variables of interest

| <b>Support categories</b>     | <b>Count</b> | <b>Percentage</b> |
|-------------------------------|--------------|-------------------|
| <b>Informational Support</b>  |              |                   |
| Advice                        | 262          | 33.8%             |
| Referral                      | 49           | 6.3%              |
| Situation appraisal           | 38           | 4.9%              |
| Teaching                      | 22           | 2.8%              |
| <b>Tangible Assistance</b>    |              |                   |
| Loan                          | 0            | 0.0%              |
| Perform direct task           | 17           | 2.2%              |
| Perform indirect task         | 15           | 1.9%              |
| Active participation          | 13           | 1.7%              |
| Express willingness           | 23           | 3.0%              |
| <b>Network Support</b>        |              |                   |
| Access                        | 10           | 1.3%              |
| Presence                      | 49           | 6.3%              |
| Companions                    | 31           | 4.0%              |
| <b>Esteem Support</b>         |              |                   |
| Compliment                    | 37           | 4.8%              |
| Validation                    | 186          | 24.0%             |
| Relief of blame               | 5            | 0.6%              |
| <b>Emotional Support</b>      |              |                   |
| Relationship                  | 79           | 10.2%             |
| Physical affection (i.e. hug) | 4            | 0.5%              |
| Confidentiality               | 0            | 0.0%              |
| Sympathy                      | 21           | 2.7%              |
| Understanding/empathy         | 106          | 13.7%             |
| Encouragement                 | 161          | 20.8%             |
| Prayer                        | 11           | 1.4%              |

Table 3.2 Correlations between categories of social support

|               | Informational | Tangible | Network | Esteem  | Emotional |
|---------------|---------------|----------|---------|---------|-----------|
| Informational | 1.000         | .049     | .022    | -.234** | .103**    |
| Tangible      | .049          | 1.000    | .031    | -.082*  | -.018     |
| Network       | .022          | .031     | 1.000   | .030    | .235**    |
| Esteem        | -.234**       | -.082*   | .030    | 1.000   | .020      |
| Emotional     | .103**        | -.018    | .235**  | .020    | 1.000     |

\*\* . Correlation is significant at the 0.01 level (2-tailed).

\* . Correlation is significant at the 0.05 level (2-tailed).

CHAPTER 4  
UNCERTAINTY MANAGEMENT THEORY AND SENSE OF  
VIRTUAL COMMUNITY APPLIED IN THE CONTEXT OF  
CLUBFOOT

Introduction

The ill health of a child is a matter of great importance for the parents, the medical system and the society in general. It is generally recognized that serious health conditions affecting children are a major source of uncertainty and stress for the parents (Nuutila & Salanterä, 2006; Mishel, 1993). How parents deal with uncertainty and stress as related to their child's health condition is a matter of interest for medical professionals and health communicators alike. Until 1990s health professionals were the major source of information related to health conditions and close family and friends the major source of support for parents of children affected by rare diseases. The development of information technologies, in general, and of Internet, in particular, provide new ways for parents to search for and find information, as well as to request and receive support from individuals facing similar challenges (Eysenbach, 2005). The manuscript explores the relationships between Uncertainty Management Theory (UMT) constructs and the potential contribution of the sense of virtual community (SOVC) to the UMT framework.

This study investigates the relationships between the constructs of the Uncertainty Management Theory applied to online interactions among caregivers of children with clubfoot. Understanding these relationships may provide critical information necessary in addressing uncertainty faced by parents and thus reducing the magnitude and impact of illness related stress on their wellbeing. Furthermore, the study provides a theoretical and analytical framework for the potential therapeutic effect of online activities (impact of online activities on uncertainty and stress). In addition to information seeking behavior, the study explores the underlying psycho-social dynamics (sense of virtual community,

perceived social support) of the exchanges that occur in online support groups. To our knowledge this is the first investigation of this type in the context of clubfoot. While this is the first application of structural equation modeling (SEM) to Uncertainty Management Theory in this context, SEM has previously been used to test a similar theory, the theory of motivated information management (Afifi et al., 2006; Afifi & Weiner, 2006).

Together with improvements in the medical knowledge, diagnosis and treatment great progress has been made in providing state of the art treatment options for children affected by various health conditions. A relevant example in this direction is clubfoot. Clubfoot is a common birth defect where the foot is twisted at a sharp angle, in a shape similar to a golf club (MayoClinic, 2008). Clubfoot can affect one or both feet and without proper treatment the child will start walking on the outside edge or even on the top of his/her feet. Much progress has been made in regards to clubfoot diagnosis, treatment and follow-up in the last decade (Keret et al., 2002). Thanks to scientific advancements and to advocacy by parents using the Internet (Morcuende, Egbert, & Ponseti, 2003) the Ponseti method of clubfoot treatment has become the standard of care in US. Using a series of precise manipulations and castings, the Ponseti method has a success rate of over 95% in correcting clubfoot with no need for extensive surgical interventions (Morcuende, Abbasi, Dolan, & Ponseti, 2004). Long term studies show that the feet of patients treated with the Ponseti method have functionality close to those born with "normal" feet (Morcuende et al., 2004).

Clubfoot is not one of the health conditions routinely covered in genetic counseling, thus the majority of parents would have limited or no knowledge related to clubfoot at the moment of diagnosis (Chitayat & Babul-Hirji, 2000). During the communication with medical professionals parents may receive limited information on cause and varied opinions on treatment options (Barker, Chesney, Miedzybrodzka, & Maffulli, 2003; Bor, Coplan, & Herzenberg, 2009; Ippolito, Farsetti, Caterini, & Tudisco, 2003; Morcuende et al., 2004; Mukerjee, 2004; Thompson, Hoyen, & Barthel, 2009).

Since parents are already going through an emotionally charged period with a newborn (Foster, Furness, & Mulpuri, 2002; Skari et al., 2006), it is hypothesized that low levels of knowledge regarding clubfoot will compel them to seek information and support from both formal and informal sources.

While physicians remain a preferred source of health information (during medical encounters or via phone and email communication) many individuals seek out health information on the Internet probably because they can access large quantities of information quickly and on their own schedule (Hesse et al., 2005). Parents of young children in general and parents of children with health conditions use the Internet in a number of ways, the most important ones being information seeking and social support, two core constructs in the Uncertainty Management Theory (Brashers, 2001). UMT states that individuals employ various behaviors to decrease, maintain or increase their uncertainty. Uncertainty management behaviors include seeking, acquiring or exchanging information and other types of social support.

Seeking and acquiring information on the Internet is reported to increase the ability of individuals to manage various health conditions (Murray et al., 2003). Today, those affected by illness, either as a patient or as a caregiver, have access to an increasing number of websites presenting information on many health conditions (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Ball & Lillis, 2001; Beall, Beall, Greenfield, & Biermann, 2002; Hesse et al., 2005). Websites that provide medical information can be divided into two major categories: personal websites (includes blogs) and institutional websites. Anyone with access to the Internet can generate and publish information related to a health condition, especially personal experiences, using tools readily available and easy to use ([www.caringbridge.org](http://www.caringbridge.org)). Medical oriented institutional websites are generated and updated by medical institutions or medical organizations. Some examples with information on clubfoot include the Mayo Clinic ([www.mayoclinic.com](http://www.mayoclinic.com)), American

Academy of Orthopaedic Surgeons ([www.aaos.org](http://www.aaos.org)), and MedlinePlus ([www.medlineplus.gov](http://www.medlineplus.gov)).

Another characteristic of the Internet space is the availability of online social support groups for caregivers of children with various health conditions such as cancer, mental illness and dermatologic conditions (Han & Belcher, 2001; Lawton, Roberts, & Gibb, 2005; Leonard et al., 2004; Lin, Tsai, & Chang, 2008; Scharer, 2005). Online support groups are usually found during information seeking on the Internet. Evidence indicates that the support received in online support communities (OSCs) is highly valued by the parents caring for ill children (Plantin & Daneback, 2009; Scharer, 2005). Social support and supportive communication have been shown to have a positive impact on both the psychological adjustment of the recipient and on the course of medical treatment (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; van Dam et al., 2005). Exchanges in OSCs allow individuals not only to acquire information, but also to assess the quality of information found on various websites (Landro, 1999). Furthermore, OSCs allow for exchanges of various types of social support needed to deal with uncertainty and stress (Cutrona & Russell, 1987).

In the case of clubfoot, after the diagnosis, most parents face a great deal of uncertainty. Uncertainty in illness has been defined as “inability to determine the meaning of illness-related events” and can be divided into four categories: “a) ambiguity concerning the state of the illness, b) complexity regarding treatment and system of care, c) lack of information about the diagnosis and seriousness of the illness, and (d) unpredictability for the course of the disease and prognosis” (Mishel, 1988, p. 225). To summarize the above, one may face uncertainty due to incomplete information, due to inability to process information, and due to the emotional impact of the situation. Since clubfoot is usually observed during ultrasound or at birth, the diagnosis has a high emotional impact on the parents, resulting in significant psychological distress (Detraux et al., 1998; Skari et al., 2006). The information received about clubfoot immediately

after diagnosis is just one of the many sets of information that parents need to process in a short amount of time and with limited cognitive resources (Murray, Cooper, & Hipwell, 2003; Murray & Cooper, 1997). Finally, clubfoot related information that parents receive immediately after diagnosis may be incomplete or confusing because of missing empirical data or conflicting recommendations from medical professionals (Politi, Han, & Col, 2007). Given the above it is not surprising that many parents indicate the need for psychological support (Detraux et al., 1998).

The diagnosis of a birth defect and the process of caring for a child with a health condition result in high levels of stress for parents (Bailey et al., 2009; Skari et al, 2006). Evidence indicates that mothers report more psychological stress than fathers (Skari et al., 2002; Skari et al, 2006). Stress can add additional burden on the parent, decrease their quality of life and may have a negative effect on early child development (Murray et al., 2001; Murray et al., 1999). Considerable effort needs to be exerted to deal with the stress generated by having a newborn with a health condition in addition to the stress generated by having a newborn (Skari et al., 2002). Stress is the major dependent variable of this study.

Although there is increasing interest in understanding online support communities, studies focusing on the underlying processes in OSCs remain scarce. Furthermore, relatively few studies have addressed online support communities that are initiated and managed without input from health institutions (Eysenbach et al., 2004). In the context of online support communities Eysenbach (2005) suggested that information seeking (websites, online groups and direct communication), social support, knowledge, uncertainty (confusion) and stress are inter-related and affect health outcomes. Individuals with lower knowledge may engage in more information seeking than those with high knowledge. As individuals search for information they may find online support communities and become members of those communities. Both information seeking and perceived social support from other members of the online community may have an

effect on uncertainty. Finally uncertainty may have a direct impact on stress. The Path model proposed in Figure 4.1 indicates how the constructs under study may be related to each other. The following research question and hypothesis will be explored

RQ1: Is UMT applicable to interactions in online environments in the context of clubfoot (PATH/SEM)? (See Figure 1)

H1.1: There will be a negative relationship between knowledge and information seeking

H1.2: There will be a positive relationship between information seeking and perceived social support

H1.3: There will be a negative relationship between information seeking and uncertainty

H1.4: There will be a negative relationship between perceived social support and uncertainty

H1.5: There will be a positive relationship between uncertainty and stress

Since existing theoretical frameworks such as the Uncertainty Management Theory were not created specifically to explore online communities, new constructs (such as sense of virtual community) may be a necessary addition. Sense of virtual community represents an important feature of virtual communities. It is defined as: “members’ feelings of membership, identity, belonging, and attachment to a group that interacts primarily through electronic communication” (Blanchard, 2007). While a new measure, SOVC has been documented to be superior to the Sense of Community Index (SCI), used to measure Sense of Community (SOC) in physical communities (Blanchard, 2007). SOVC has been used to analyze various online groups including groups related to infertility and pregnancy (Cheon & Ahn, 2009; Ellonen, Kosonen, & Henttonen, 2007; Welbourne, Blanchard, & Boughton, 2009). It is hypothesized that SOVC would be a valid construct in the case of online communities for caregivers of children with clubfoot.

Adding the SOVC in the equation as proposed in the Path model illustrated in Figure 4.2 allowed us to explore the following research question and hypothesis.

RQ2: Does adding SOVC improve UMT (PATH/SEM)? (Figure 2)

H2.1: There will be a positive relationship between perceived social support and SOVC

H2.2: There will be a negative relationship between SOVC and uncertainty

H2.3: SOVC mediates the relationship between virtual social support and uncertainty

### Methods

The study participants were parents of children with clubfoot. Participants were recruited using a snowballing technique. An invitation to take the survey was posted to an online support group dedicated to parents of children with clubfoot. Potential participants were invited to complete an anonymous survey concerning their uncertainty related to clubfoot and their use of Internet for information seeking and social support. The invitation to participate in the study was posted by the administrator/moderator of the group. The text of the invitation encouraged parents to share the link to the survey with other parents caring for children with clubfeet (snowballing). The study methodology was approved by the Institutional Review Board. Data was collected using an Internet based survey. The survey was developed and administered using an on-line survey tool (WebSurveyor). The survey was pilot tested with a group of parents of children with clubfoot that did not participate in the actual data collection.

The following measures were collected as part of the survey: uncertainty, stress and knowledge, information seeking behavior, perceived social support and sense of virtual community. Three items adapted from the Hilton Uncertainty Stress Scale were used for assessing current global uncertainty, stress and knowledge (Hilton, 1994).

Uncertainty was defined overall uncertainty the parent feels due to clubfoot related issues. Global uncertainty was measured using a score ranging from 0 (no uncertainty) to 100 (very high uncertainty). Stress was defined as the overall stress the parent feels due to clubfoot related issues. Global stress was measured using a score ranging from 0 (no stress) to 100 (very high stress). Knowledge about clubfoot was assessed using a self-report measure asking the parent to rate his/her general knowledge level about clubfoot related issues on a scale from 0 (no knowledge) to 100 (very high knowledge). This approach is consistent with Bandura's methodology (2006).

Measures of information seeking behavior. Respondents were asked to indicate how often they used various information sources related to clubfoot over the last twelve months. Sources of information were online group, hospital/clinic website, personal website/blog, health professional (via email, face to face or by phone), medical oriented websites (i.e. WebMD, Dr Greene), professional medical organization websites (i.e. American Academy of Orthopedic Surgeons, American Academy of Orthopedics), medical journals (i.e. through PubMed), and family and friends outside an online group. The aforementioned are all the sources were parents could find information about clubfoot. Options of response were never, less than once per month, several times a month, several days a week, and every day coded as 1 through 5. Responses were averaged to generate an information seeking score based on a similar methodology used to study patient information seeking behavior (Beisecker & Beisecker, 1990; Rains, 2007). See Table 4.1 for additional detail.

Measures of social support. Nine items adapted from Cutrona and Russell's (1987) Source Specific Social Provisions Scale ( $\alpha = .77$ ) were used to measure perceived social support. The dimensionality of the items was analyzed using a principal component factor analysis following the methodology described by Wrench, Thomas-Maddox, Richmond, & McCroskey (2008, p.428). Four criteria were used to determine the unidimensionality of the scale: sampling adequacy, the hypothesis that the measure

was unidimensional, the scree plot, and the interpretability of the factor solution. Kaiser's measure of sampling adequacy (MSA) was used to assess sampling adequacy. The MSA obtained was .8, which is considered acceptable for factor analysis (Kaiser, 1974). The scree plot indicated that the hypothesis of unidimensionality was supported. The principal component analysis revealed a strong primary factor with an eigen value of 2.951, explaining 33% of the variance. Sample items included “Are there people in the online group who enjoy the same social activities that you do?” “Do you feel your competence and skill are recognized by the people in the online group?” “Is there a trustworthy person in the online group you could turn to for advice if you were having problems?” Response options included “Yes”, “Sometimes”, and “No” coded as 2 through 0. Item responses were averaged to generate an overall perceived social support score. See Table 4.2 for additional detail.

Measures of sense of virtual community (SOVC). Seventeen Likert scale items adapted from Blanchard's (2007) SOVC scale ( $\alpha = .94$ ) were used to assess the sense of community in the online group. The dimensionality of the items was analyzed using a principal component factor analysis. Four criteria were used to determine the unidimensionality of the scale: sampling adequacy, the hypothesis that the measure was unidimensional, the scree plot, and the interpretability of the factor solution. Kaiser's measure of sampling adequacy (MSA) was used to assess sampling adequacy. The MSA obtained was .91, which is considered excellent for factor analysis (Kaiser, 1974). The scree plot indicated that the hypothesis of unidimensionality was supported. The principal component analysis revealed a strong primary factor with an eigen value of 8.891, explaining 52% of the variance. Sample items included: “I expect to stay in this group for a long time”; “Some members of this group can be counted on to help others” and “This group means a lot to me.” Responses ranged from 1 = strongly disagree to 4 = strongly agree. Item responses were averaged up to generate an overall sense of virtual community score. See Table 4.3 for additional detail.

Data analysis. The Statistical package for the Social Sciences (SPSS) version 17.0 was used to run descriptive analyses and correlations. The AMOS 17 software was used to conduct Path analysis (structural equation modeling - SEM) and to test direct and indirect relationships. The analysis aim was to explore the applicability of UMT to caregiver online behaviors and interactions in the context of clubfoot. The components of the theory were treated as observed variables. As suggested by the theory it was believed that knowledge, information seeking, social support, uncertainty and stress are inter-related.

To address RQ1 & RQ2, two SEM analyses were conducted. The first Path model (without SOVC) was tested for goodness of fit in the initial step. The second Path model (with SOVC) was tested for goodness of fit in the next step. Maximum likelihood imputation available in AMOS 17 was used to handle missing data as recommended by Byrne (2001). There are several goodness-of-fit indexes computed by AMOS to evaluate the fit of the model such as root mean squared error of approximation (RMSEA) , Bentler's Comparative Fit Index (CFI) and the incremental index of fit (Byrne, 2001). RMSEA takes population error into consideration, while CFI compares the hypothesized model with the independence model (Byrne, 2001; MacCallum & Austin, 2000). A RMSEA value of 0.05 is indicative of a good fit, a value of 0.08 a reasonable fit and values greater than .10 a poor fit (Byrne, 2001). Bentler (1990) suggest CFI as the index of choice with a cutoff value around .95 or more (Hu & Bentler, 1999). The incremental index of fit (IFI) indicates a good fit over .95 and accounts for issues of parsimony and sample size that may influence CFI. Furthermore SEM is considered as an appropriate statistical method for testing mediation models and was used to test H2.3 (Preacher & Hayes, 2008). According to James Stevens' Applied Multivariate Statistics for the Social Sciences (1996), 15 cases per predictor in a standard ordinary least squares multiple regression analysis is reasonable. Since SEM is closely related to multiple regression in some respects, a minimum of 15 cases per measured variable in SEM was considered

reasonable. Furthermore, Mitchell (1993) indicates that having at least twenty times as many cases as variables is recommended for SEM. The study sample size (N= 203) exceeded the aforementioned limits for both path analysis models proposed.

### Results

The mean age of the respondents was 33.4 years (SD=5). The respondents were predominantly women (94%). Ninety percent of the respondents had college level education and 87% had an income level of over \$35,000. In terms of ethnicity 81% of the respondents identified themselves as non-Hispanic White, 6% Hispanic/Latino, 6.5% Asian and 6.5% mixed ethnicity. See Table 4.4 for additional detail.

Table 4.5 illustrates the correlations among variables under investigation. One sample t-test for all variables in the model indicated that all mean scores were statistically significantly different from the scale means. The uncertainty score mean was 31.26 (SD = 29). The stress score mean was 30.42 (SD=30). The knowledge score mean was 76.87 (SD = 18.79). The information seeking score mean was 2.05 (SD=.45). The perceived social support score mean was 1.45 (SD=.37).

For the first research question and Path model, using structural equation modeling, the relationships were examined between knowledge, information seeking, perceived social support, uncertainty and stress as proposed by UMT. Figure 4.3 presents the results of the structural equation modeling. The structural model proposed approached the criteria of fit, but did not meet them. The model was not a good fit according to the chi-square test results:  $X^2 (5, N = 203) = 16.68, p = .005$ . The RMSEA of .108 (PCLOSE=.042), being above .1, suggested a relatively poor fit as well (Hu & Bentler, 1999). The comparative fit index (CFI) = .904 and the incremental index of fit (IFI) = .91 were both under .95 supporting the above conclusion (Bollen, 1989; Hu & Bentler, 1999).

The SEM analysis results did not support H1.1 - there was a positive relationship between knowledge and information seeking at the .05 significance level (estimated regression weight = .14,  $p=.049$ ). The results provided support for H1.2 – there was a positive relationship between information seeking and perceived social support (estimated regression weight = .185,  $p=.013$ ). The results did not support H1.3 – there was a non-significant relationship between information seeking and uncertainty (estimated regression weight = .124,  $p = .083$ ). The results did not support H1.4 – there was a non-significant relationship between perceived social support and uncertainty (estimated regression weight = -.05,  $p=.511$ ). The results supported H1.5 – there was a statistically significant positive relationship between uncertainty and stress (estimated regression weight = .646,  $p<.001$ ).

For the second Path model, using structural equation modeling, the relationships were examined between knowledge, information seeking, perceived social support, sense of virtual community, uncertainty and stress. The sense of virtual community score mean was 3.18 (SD=.51). Figure 4.4 presents the results of the second structural equation model. Results indicated that the modified structural model, after the inclusion of SOVC, was a reasonable fit:  $X^2 (9, N = 203) = 20.44$ ,  $p = .015$ . The goodness-of-fit indices are at or above the recommended levels (Hu & Bentler, 1999): RMSEA = .079 (PCLOSE=.128), comparative fit index (CFI) = .95 and incremental index of fit (IFI) = .95. These results suggest that the structural model including SOVC fits the data better than the one without SOVC.

The SEM analysis results did support H2.1 – there was a positive relationship between social support and SOVC (estimated regression weight = .703,  $p<.001$ ). The results did not support H2.2 – there was a non significant relationship between SOVC and uncertainty (estimated regression weight = -.014,  $p=.851$ ). The results did not provide support for H2.3 as the direct effect of SOVC on uncertainty was not statistically significant and the indirect effect of perceived social support on uncertainty was null. The

result was confirmed using an SPSS macro for testing mediation models developed by Preacher & Hayes (2008). While there was a positive relationship between perceived social support and SOVC, the total effect of perceived social support on uncertainty was not significant and the direct effect of SOVC on uncertainty was not significant. Controlling for age, gender, education, income, race and phase of treatment did not result in a statistically significant mediational model.

### Discussion

Although considerable research attention has been devoted to studying illness related uncertainty, less has been done on researching uncertainty management in online contexts. One way we might help caregivers deal with uncertainty is by better understanding their uncertainty management processes. Toward that effort, this study offers an empirical test of Uncertainty Management Theory, applying it to caregivers of children with clubfoot online behaviors. The results contribute to our understanding of the uncertainty management processes in three primary ways: a) lending insight into the relationships between constructs, b) supporting the applicability of the Uncertainty Management Theory to the population and context of interest and c) identifying the need for constructs and theoretical models adapted to online contexts. The results also uncover new directions for future research focused in uncertainty management in online contexts.

The results of this study suggest that the Uncertainty Management Theory needs to be adapted for use in online contexts. One way is to include theoretical constructs (i.e. sense of virtual community) specifically developed to measure online interactions. This study demonstrated that such an addition may result in a more appropriate theoretical model. Furthermore, especially for populations of parents additional theoretical constructs (i.e. self-efficacy) may need to be considered. Such constructs could better explain the connection between the original UMT items.

Analysis revealed statistically significant relationships between knowledge and information seeking, information seeking and perceived social support, perceived social support and sense of virtual community as well as between uncertainty and stress. Judging by the relationships between variables in the second proposed structural model, the results indicated that knowledge, information seeking, perceived social support and sense of virtual community are closely interconnected. However, the connection between the aforementioned constructs and uncertainty/stress has not been supported. The following paragraphs discuss the observed relationships.

### Knowledge

Knowledge was found to be positively related to information seeking behavior. This may have a few explanations. First it supports the idea that for some individuals the more they know, the more they want to know (Back & Arnold, 2006). There may be an underlying need to validate one's body of knowledge as a way to deal with uncertainty (Thompson & O'Hair, 2008). Second, one's knowledge has probably been accumulated over a period of time and from multiple sources including Internet based ones. One of the documented drawbacks of Internet based information is the large quantity of information available combined with lack of quality control which may lead to increased uncertainty due to confusion or misinformation (Arora et al., 2008; Eysenbach, Powell, Kuss, & Sa, 2002). Thus the parents of children with clubfoot with a high level of knowledge may have been exposed to multiple sources of information, some of which may have been conflicting (Morcuende et al., 2003). Third, clubfoot related information such as causes of clubfoot and long term effects on child development are still incomplete and require additional scientific inquiry. Considerably more work is required to examine the conditions under which knowledge influences the information seeking behaviors.

### Information seeking

Information seeking behavior was found to be positively related to perceived social support. A potential explanation is that the more parents seek for information related to the health condition of their children, the more likely they are to come across an online support community and become members of such a community. Evidence indicates that online support communities are an important source of information for parents (Eysenbach, 2005). Of the survey respondents, over 60% visit an online support community few times a week or even daily. Over 98% of the survey respondents indicated that they used a search engine in their information seeking. It is important to note that the largest online support community for parents of children with clubfoot - nosurgery4clubfoot - is usually in the top ten search results and thus a likely group to join. This has important practical implications because it suggests that an effective online support initiative needs to have a top presence in the results of various online search engines such as Google and Yahoo. Future investigations should more closely examine how online information seeking, may or may not influence participation in online support communities.

### Uncertainty and stress

The study results provided support for a strong relationship between uncertainty and stress, indicating the fact that illness related uncertainty may be a major cause of stress (Nolan, Camfield, & Camfield, 2006). There are two implications of this finding both theoretical and practical. From a theoretical perspective, stress seems to be a valuable construct to include in the Uncertainty Management Theory. The evidence indicates that stress is an important factor in caregiver psychological and behavioral functioning and further supports that its inclusion as a construct related to uncertainty management is an important consideration for future studies (Streisand, Swift, Wickmark, Chen, & Holmes, 2005). The need to cope with stress may be an important

reason why parents try to manage their uncertainty. A grounded theory approach in this direction may provide valuable (Stratton, 2004). From a practical perspective, the study results suggested that uncertainty may be a good locus of intervention in order to reduce the stress faced by a caregiver, thus potentially increasing individual wellbeing (quality of life). Identifying and addressing uncertainty causes before, during and after medical encounters may allow caregivers to better cope with stress (Raina et al., 2005). Furthermore, such an approach may also increase compliance with treatment by increasing the trust between parents and medical care providers (Lynn-McHale & Deatrack, 2000).

#### Perceived social support and sense of virtual community

Perceived social support was found to be positively related to the sense of virtual community. The strong relationship between perceived social support and sense of virtual community indicates that both of them may need to be considered in theory and in practice. This study indicated that a theoretical model including SOVC fits the data much better than one without SOVC. From a practical standpoint, developers and administrators of online communities may need to pay attention not only to the support exchanged in a community, but also to the sense of belonging to the community. This may be particularly important especially because members with a low SOVC may be more likely to leave the community as soon as their support needs have been fulfilled, instead of becoming active contributors. If people who have been through the experience of caring for a child with clubfoot leave when they have accumulated most experience and knowledge, it represents an important loss for the community and new members of the community. The active involvement of experienced members in an online community of support represents a critical factor in the success of such a community (Arguello et al., 2006; Joyce & Kraut, 2006). The sense of virtual community as a predictor of active membership longevity requires further exploration.

### Practical and theoretical implications

Clearly, health communication has expanded in parallel with the Internet expansion. Treatment of clubfoot remains important, but much more emphasis is needed on communication efforts in order to reduce unnecessary stress on the parents. Future advances in health communication have to be achieved through a combination of research and practice addressing multiple categories of stakeholders, the most important one in the case of clubfoot being parents. This study provides a theory based origin for future research initiatives in this direction.

The results of this study produced mixed success for the UMT framework. On one hand, we were able to measure through a survey all the constructs of UMT and to observe a significant relationship between information seeking and social support. Furthermore, with the addition of SOVC, the UMT framework fit the data well, suggesting it as a promising tool for future research in online environments. However, the results did not observe significant relationships between information seeking and uncertainty, nor between social support and uncertainty. These results suggest the need to consider other constructs that may be at play such as self-efficacy (Afifi & Weiner, 2006; Streisand et al., 2005). Furthermore, the connection between information seeking, social support and uncertainty may be more complex than originally proposed (Brashers, 2001).

This study offers a unique look at illness-related uncertainty management processes. Previous studies on the topic had more of a qualitative approach to them. Therefore, this study is one of the first to empirically test the Uncertainty Management Theory in an online context. No other research to date has employed a sophisticated analysis such as this structural equation modeling in order to understand uncertainty management processes in relationship to the Internet. The use of a theoretical framework provides a solid base for future research.

### Study limitations and future research

Some limitations of this study need to be noted. The results did not indicate a statistically significant relationship between perceived social support and uncertainty, nor between information seeking behavior and uncertainty, nor between SOVC and uncertainty. A potential explanation is that other constructs that have not been captured in the present study may influence uncertainty and stress. It is important to note that knowledge was negatively correlated to stress ( $-0.208, p < .01$ ), indicating that increased knowledge may result in decreased stress while not having a direct impact on uncertainty. Such an influence may be possible through other pathways such as self-efficacy (Afifi & Weiner, 2006; Streisand et al., 2005). Second, data collected is self-reported and thus may be subject to response bias and other limitations of surveys as noted in other caregiver studies (Kross et al., 2009). Third, this was a cross-sectional study, thus it does not allow for causal inferences. Longitudinal data would be necessary for making causal inferences. Finally, most of the respondents are White, suggesting that other ethnicities may not use the online support resources as much due to reasons that require further inquiry.

Despite the limitations noted above, this study uncovered some important relationships between constructs that have both theoretical and practical applications. One of the major critiques of research related to online support communities is the lack of theoretical frameworks (Wright & Bell, 2003). This study specifically explored the applicability of a theoretical framework (UMT) to analyzing individual and interpersonal constructs in the context of online behaviors of caregivers of children with clubfoot. Furthermore, this study brings an important theoretical contribution by identifying the importance of adding the sense of virtual community to the uncertainty management theoretical framework.

Although it is generally held that information seeking and social support are crucial constructs in uncertainty management for confronting the diversity of challenges

that a caregiver may face, much remains to be learned about the internal organizational functioning of an online community. With respect to online communities, understanding individual level variables (i.e., information seeking), interpersonal level variables (i.e. social support), and community level variables (i.e. sense of virtual community) is a valuable endeavor from both theoretical and practical perspectives. Joint consideration of information seeking, social support and sense of virtual community has the potential to increase understanding of all three constructs (Bambina, 2007; Blanchard, 2007). It is clear that securing information and social support in order to deal with illness related uncertainty is a complex process (Brashers, 2001). The study results suggest that with some additions Uncertainty Management Theory could be a valuable framework in exploring caregivers' experiences. Furthermore, online communities of caregivers of children with health conditions provide an appropriate setting for this type of research.

An interesting finding was that increased knowledge may be associated with increased uncertainty. A potential important conclusion from this study was that caregivers who have more knowledge on a health topic may be high information seekers. This pattern, the positive direct effect between knowledge and information seeking, may indicate that even this association could be a complex one. Under certain circumstances, less knowledge may lead to increased information seeking, yet more knowledge may not result in less information seeking. However it is important to note that this study cannot empirically establish a causal direction. The above results offer some support for the UMT stating that in some cases individuals employ behaviors that increase uncertainty (Brashers, 2001). Those behaviors that result in increased uncertainty remain understudied and future investigations should examine the factors influencing information seeking behavior and their impact on uncertainty levels.

Furthermore, the results of this study suggested that sense of virtual community (Blanchard, 2007) is a critical construct to be considered in future studies and theoretical models. There are various levels of participation in an online support community such as

stars, prime givers, moderate users, and takers (Bambina, 2007). Thus it is important to consider not only if a person is a member in an online support group, but also their sense of belonging to the virtual community (Blanchard, 2007). Future research of online support communities should pay more attention to the identification and promotion of sense of virtual community mechanisms. With the increasing access to Internet based health information and online support communities, it is important to understand the factors that drive online based behaviors and the constructs that may influence uncertainty and stress.

### Conclusion

In conclusion, this study offers an original exploration of the relationship between uncertainty management constructs and stress as the outcome variable, as well as the contribution of the sense of virtual community to the aforementioned relationships. The study population was represented by caregivers of children with clubfoot. Four constructs were identified and examined in relationship to caregiver uncertainty and stress: knowledge, information seeking, perceived social support and sense of virtual community. Structural equation modeling indicated that the theoretical model including uncertainty management constructs alone (knowledge, information seeking and social support) does not fit the data very well. However, the inclusion of the sense of virtual community in the model provides a much better model. The study provided support for the suggestion that measures of sense of community and social support do need to be adapted to the online environment if a study is to be conducted in such a context (Blanchard, 2007). The use of a theoretical framework was crucial for studying the individual and interpersonal processes related to uncertainty. The Uncertainty Management Theory could potentially be used to explore, analyze and understand various online behaviors related to health conditions such as clubfoot and thus contribute in important ways to what we know about caregivers in their role as uncertainty managers.

Table 4.1 Information seeking score by information source

| <b>Information sources</b>              | <b>Mean</b> | <b>SD</b>   |
|---|-------------|-------------|
| Online Support Community                | 3.60        | 1.26        |
| Hospital website                        | 1.98        | 0.70        |
| Personal website                        | 1.85        | 0.99        |
| Physician email                         | 1.68        | 0.70        |
| Physician verbal communication          | 2.18        | 0.63        |
| WebMD or similar                        | 1.71        | 0.76        |
| American Academy of Orthopedic Surgeons | 1.53        | 0.71        |
| Medical journals                        | 1.60        | 0.77        |
| Family and friends                      | 1.78        | 1.05        |
| <b>Information Seeking Score</b>        | <b>2.05</b> | <b>0.45</b> |

Table 4.2 Measures of virtual social support

| <b>Questions</b>   | <b>Mean</b> | <b>SD</b>   | <b>Loading</b> |
|--|-------------|-------------|----------------|
| Are there people (in the online group) that you can depend on to help you if you really need it?               | 1.61        | 0.64        | 0.71           |
| Do you feel you could not turn to other online group members for guidance in times of stress?*                 | 1.43        | 0.84        | 0.16           |
| Are there people in the online group who enjoy the same social activities that you do?                         | 1.30        | 0.66        | 0.71           |
| Do you feel personally responsible for the well-being of the members of the online group?                      | 0.71        | 0.77        | 0.73           |
| Do your relationships with online group members provide you with a sense of emotional security and well-being? | 1.27        | 0.73        | 0.66           |
| Do you feel your competence and skill are recognized by the people in the online group?                        | 1.43        | 0.70        | 0.73           |
| Do you feel none of the online group members really rely on you for their well-being?*                         | 1.51        | 0.77        | 0.12           |
| Is there a trustworthy person in the online group you could turn to for advice if you were having problems?    | 1.61        | 0.68        | 0.78           |
| Do you feel you lack emotional closeness with members of the online group?*                                    | 1.38        | 0.83        | 0.61           |
| <b>Perceived social support score</b>  | <b>1.45</b> | <b>0.37</b> |                |

\* For analysis the results were reverse coded

(N = 203) (No=0, Sometimes=1, Yes=2)

Table 4.3 Measures of sense of virtual community

| <b>Question</b>  | <b>Mean</b> | <b>SD</b>  | <b>Loading</b> |
|--|-------------|------------|----------------|
| I think this group is a good place for me to be a member.                              | 3.52        | 0.58       | 0.76           |
| Other members and I want the same thing from this group.                               | 3.41        | 0.61       | 0.68           |
| I can recognize the names of many members in this group.                               | 2.99        | 0.88       | 0.79           |
| I feel at home in this group.  | 3.19        | 0.68       | 0.85           |
| I care about what other group members think of my actions.                             | 2.80        | 0.84       | 0.58           |
| If there is a problem in this group, there are members here who can solve it.          | 3.26        | 0.60       | 0.74           |
| It is very important to me to be a member of this group.                               | 3.14        | 0.82       | 0.85           |
| I expect to stay in this group for a long time.  | 3.24        | 0.71       | 0.79           |
| I anticipate how some members will react to certain questions or issues in this group. | 2.82        | 0.84       | 0.61           |
| I've had questions that have been answered by this group.                              | 3.40        | 0.72       | 0.74           |
| I've gotten support from this group.   | 3.42        | 0.69       | 0.68           |
| Some members of this group have friendships with each other.                           | 3.36        | 0.61       | 0.59           |
| I have friends in this group.  | 2.61        | 0.90       | 0.66           |
| Some members of this group can be counted on to help others.                           | 3.44        | 0.60       | 0.68           |
| I feel obligated to help others in his group.  | 2.81        | 0.79       | 0.64           |
| I really like this group.  | 3.40        | 0.63       | 0.78           |
| This group means a lot to me.  | 3.22        | 0.73       | 0.84           |
| <b>Sense of virtual community score</b>  | <b>3.18</b> | <b>.51</b> |                |

(N=203) (1-4 Likert Scale, 1 = strongly disagree to 4=strongly agree)

Table 4.4 Socio-demographic variables of survey respondents

| <b>Socio-Demographic variables</b>                           | <b>Percent</b> |
|--|----------------|
| Education  |                |
| Grades 1 through 8 (Elementary)                              | 0.5%           |
| Grades 9 through 11 (Some high school)                       | 1.5%           |
| Grade 12 or GED (High school graduate)                       | 7.9%           |
| College 1 year to 3 years (Some college or technical school) | 27.1%          |
| College 4 years or more (College graduate)                   | 62.6%          |
| Income   |                |
| Less than \$25,000   | 7.4%           |
| \$25,000 to less than \$35,000                               | 5.4%           |
| \$35,000 to less than \$50,000                               | 16.7%          |
| \$50,000 to less than \$75,000                               | 16.3%          |
| \$75,000 or more   | 38.9%          |
| Prefer not to answer   | 14.3%          |
| Race   |                |
| Non-Hispanic White   | 81%            |
| Latino/Hispanic White  | 6%             |
| Other  | 13%            |

(N=203)

Table 4.5 Correlation matrix of variables under investigation

|                     | Uncertainty | Stress  | Knowledge | Information seeking | SOVC   |
|---------------------|-------------|---------|-----------|---------------------|--------|
| Uncertainty         |             |         |           |                     |        |
| Stress              | .646**      |         |           |                     |        |
| Knowledge           | -0.056      | -.208** |           |                     |        |
| Information seeking | 0.115       | 0.13    | .139*     |                     |        |
| SOVC                | 0.014       | 0.002   | 0.142     | .216**              |        |
| Social support      | -0.024      | -0.06   | 0.113     | .175*               | .692** |

\*\*Correlation is significant at the 0.01 level (2-tailed).

\*Correlation is significant at the 0.05 level (2-tailed).

Figure 4.1 Proposed Path model

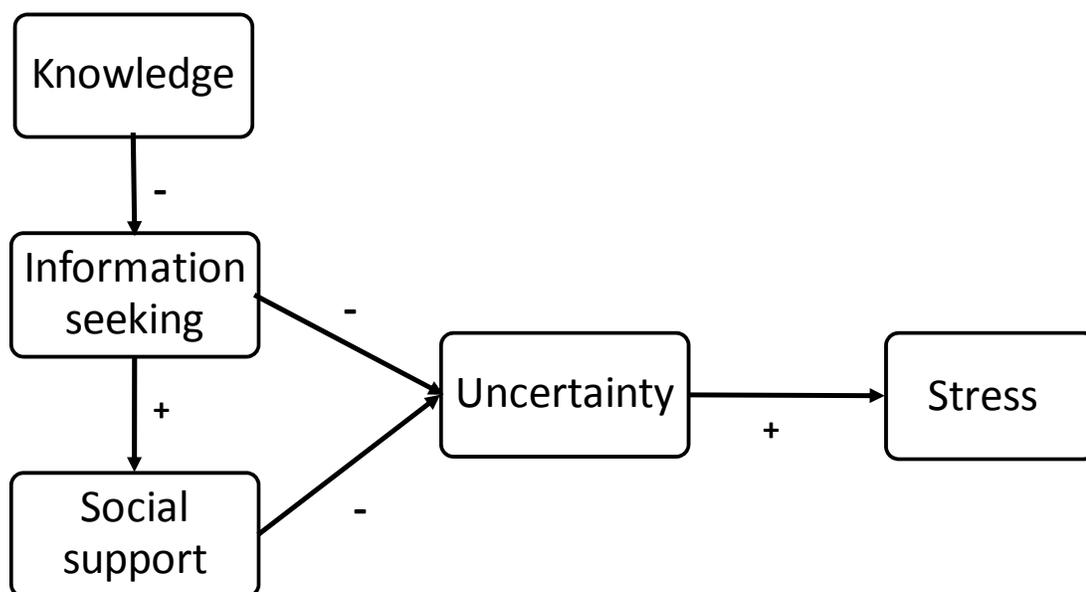


Figure 4.2 Alternative Path model including sense of virtual community (SOVC)

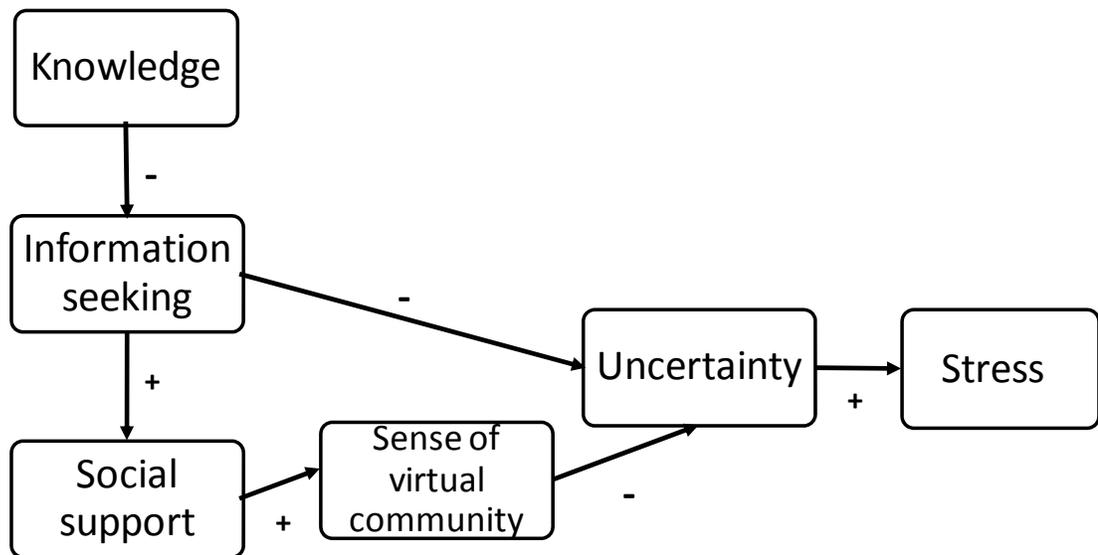
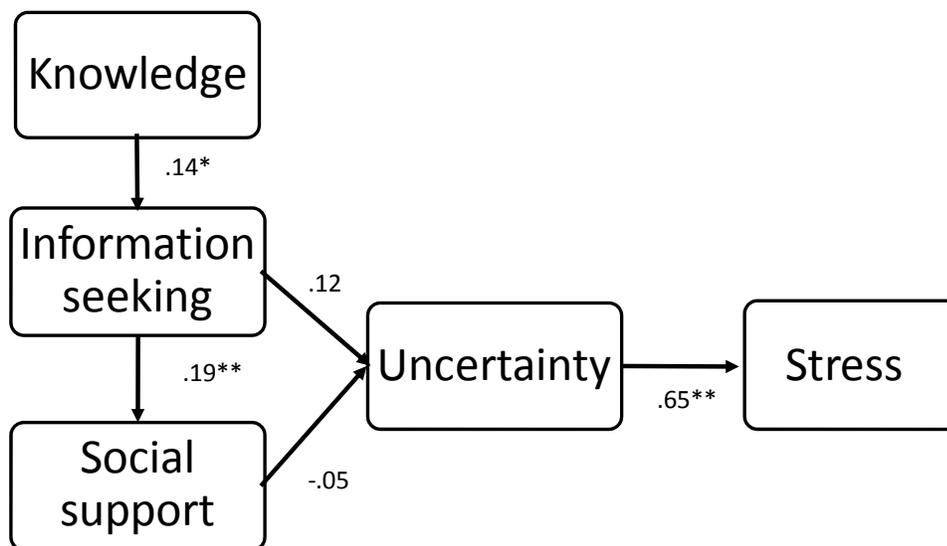


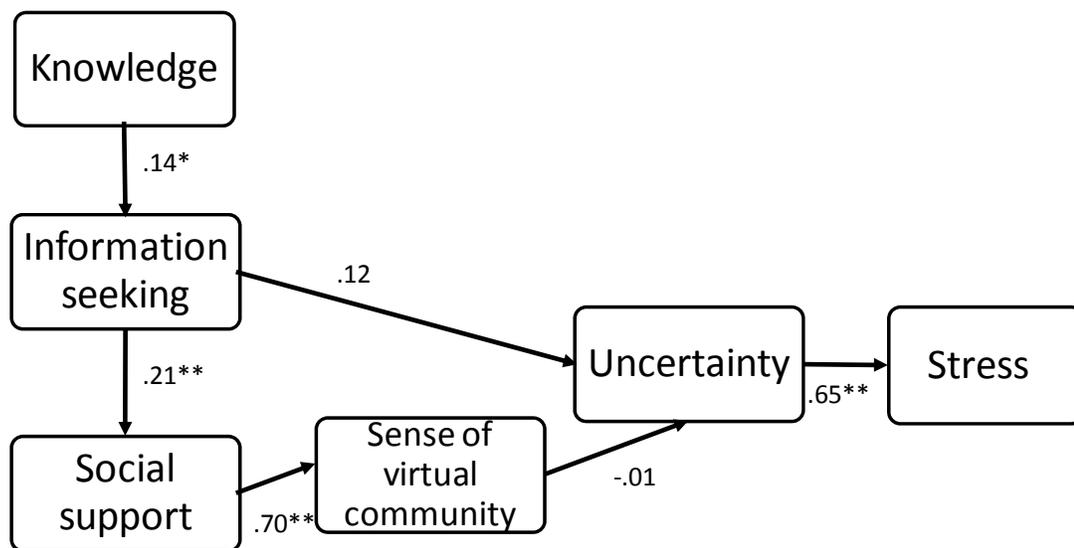
Figure 4.3 Path model without SOVC including estimated regression weights



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\*  $p < .05$ , \*\*  $p < .01$

Figure 4.4 Path model including SOVC and estimated regression weights



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\* p<.05, \*\* p<.01

## CHAPTER 5

### DISCUSSION AND CONCLUSION

The previous chapters have explored in detail the applicability of Uncertainty Management Theory (information seeking, social support and other related constructs) to an online context. This chapter covers a synthesis of the results, the findings, research limitations, directions for future research, and outlines practical and theoretical implications for uncertainty management research and health communication.

#### Synthesis of results

The purpose of this dissertation was to be a first step in better understanding the processes of uncertainty management and online communication in the context of clubfoot. The study population was caregivers (parents) of children with clubfoot. The dissertation was unique compared to past uncertainty management research for three reasons. First, it was the first research project addressing uncertainty management in the context of clubfoot. Second, it is the first research project to empirically test the Uncertainty Management Theory (UMT) using structural equation modeling (SEM). Previous studies have taken mostly a qualitative focused approach (Brashers, Goldsmith, & Hsieh, 2002; Brashers, Neidig, & Goldsmith, 2004). Third, two research methodologies were used in a complementary manner, an original approach for this topic of research (Brashers, 2006). It also represents a valuable contribution to the clubfoot literature since most of the previous research is medically and patient oriented, with only one study focused on the impact of Internet on clubfoot treatment (Morcuende, Egbert, & Ponseti, 2004).

For the first two studies, I conducted a content analysis of 775 messages from the nosurgery4clubfoot Yahoo group, the largest and most active online support community (OSC) dedicated to parents of children affected by clubfoot. For the third study I used structural equation modeling (SEM) with data from an online survey in order to analyze the relationship between uncertainty related constructs in the context of online communication and to test the applicability of the Uncertainty Management Theory (UMT) to online behaviors and interactions.

The content analysis addressed two major constructs of the UMT: information seeking and social support. The results showed that the major information seeking behaviors in the OSC are direct questioning and self-disclosure. The information seeking by some community members resulted in information provision by other community members. The most frequent source for the information provided was personal experience. Some of the responses to inquiries included medical information and clearly identified medical care providers. Similar findings regarding information seeking and provision have been reported in other studies of online behaviors (Bernhardt & Felter, 2004; Coulson, 2005; Coulson, Buchanan, & Aubeeluck, 2007; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Plantin & Daneback, 2009; Scharer, 2005). Some replies to inquiries were classified as informational support, one of five categories of social support explored in this research. Additional detail is available in chapter two.

Social support is a core construct of the UMT. In the OSC of interest instances of all five major categories of social support as described by Cutrona & Suhr (1992) were identified: informational, tangible, network, esteem and emotional. The results suggested that the aforementioned coding framework may be appropriate for the study of online

communication and uncertainty management. The results indicated that in the online environment the most frequent uncertainty management behaviors are provision of informational, esteem and emotional support. Additionally, various types of social support are often provided in combination (e.g. informational support and esteem support, informational support and emotional support). These findings are aligned with other studies of online communities (Baum, 2004; Drentea & Moren-Cross, 2005; Han & Belcher, 2001; Lawton, Roberts, & Gibb, 2005; Nystrom & Ohrling, 2006; Scharer, 2005), yet this is the first study to clearly link social support and uncertainty management in the context of clubfoot. Additional detail is available in chapter three.

To further explore the applicability of the UMT framework a structural equation modeling procedure was conducted using data from an online survey of parents of children with clubfoot. A similar approach has been employed to test the theory of motivated information management (Afifi et al., 2006; Afifi & Weiner, 2006), yet this is the first foray in empirically testing the UMT. The results indicated that the original UMT constructs may not fully explain online behaviors and interactions. However the addition of the sense of virtual community (Blanchard, 2007) improved the UMT model. Additionally, the findings of the analysis suggest that there may be other endogenous constructs that connect information seeking and social support with uncertainty such as self-efficacy. Additional detail is available in chapter four.

#### Discussion of findings across the entire dissertation

There was a fair amount of overlap and complementarity among the three research projects that form this dissertation. In this section I will focus on three critical uncertainty management constructs and how they were addressed: information seeking

and provision, social support and the role of appraisals and emotions in uncertainty management.

### Information seeking and provision

The content analysis was used as a common methodology for chapters two and three. In chapter two I identified both information seeking and information provision behaviors in the OSC. While the chapter two analyzed the sources of information for information provision as well as some types of content of information included in the messages (medical information and identification of health care providers), chapter three further detailed the types of information provision behaviors (advice, teaching, situation appraisal and referral) from a social support perspective. It seems that information seeking and information provision are in a close interplay that addresses two main targets (self and others) of uncertainty management (Brashers, 2001; Babrow, Kasch, & Ford, 1998).

Some individuals provided information as part of the information seeking process (as self-disclosure with the goal of obtaining relevant information from other community members). Some individuals used information provision as passive information seeking (posting a candidate answer with the goal of having their knowledge validated or invalidated by other community members). Some individuals seem to provide information as a result of direct inquiries with the explicit or implicit goal of managing the uncertainty of the recipient regarding various topics such as physician selection, treatment progress, child care and more. Similar findings related to information seeking and provision have been reported in recent research (Buchanan, Joinson, Paine, & Reips, 2007; Ramirez, Walther, Burgoon, & Sunnafrank, 2002). Specific to the online context

some individuals send unsolicited messages to the community documenting their experiences with medical encounters or with various solutions they identify while caring for their child, either with the goal of validating their acquired knowledge or to manage the uncertainty of others. These findings are critical for understanding interpersonal communication online and how it may influence physician-caregiver interactions (Duggan, 2006; Hay, Strathmann, Lieber, Wick, & Giesser, 2008; Kivits, 2006). Chapter four takes the analysis one step further by computing an individual information seeking score. The information seeking score was based on the frequency of use of various information sources relevant to clubfoot. Looking across all three studies it seems that information behavior, a theoretical construct from information science, may be relevant for UMT since it includes giving and sharing of information in addition to information seeking (Case, 2006; Wilson, 1997).

### Social support

Other uncertainty management behaviors such as social support were under study. Chapter three focused on attempts to manage the uncertainty of others through provision of social support. The findings of chapter three suggest that solicited and unsolicited informational support was a frequent occurrence in the OSC (Bambina, 2007; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Nicholas, McNeill, Montgomery, Stapleford, & McLure, 2004; Plantin & Daneback, 2009). To complement that, chapter two findings indicate that about half of the information provided was based on personal experiences (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2001). Furthermore, chapter three indicates that informational support was often provided in combination with other types of support, mainly esteem and emotional support. While chapter two indicates that combinations of

information seeking behaviors are employed to manage one's own uncertainty, chapter three suggests that combinations of social support behaviors are used to manage other's uncertainty (Brashers, 2001). Finally, while manuscripts one and two identify the presence of social support in the OSC, chapter four also measures the perceived social support at the individual level using a source specific scale. This findings related to social support bring to attention the fact that in health communication endeavors directed to parents of children with clubfoot other types of support such as emotional and esteem may need to be communicated in addition to information. Overall, it seems that parents who have access to the Internet are using it as the major source of information and social support. This indicates a trend shift from a few years ago when families and nurses were the primary source of support (Brazy, Anderson, Becker, & Becker, 2001).

#### Role of appraisals and emotions in uncertainty management

Emotions are considered an indicator of uncertainty and can influence the appraisals of one's situation and subsequently one's uncertainty (Brashers, 2001). Chapter two identified that most emotions expressed in the OSC were positive. Chapter three results suggested a potential explanation for the above finding: frequent provision of informational, esteem and emotional support among group members. As highlighted in chapter three, informational support included situation appraisals where group members reframe a perceived negative situation in a more positive manner. Furthermore, the provision of esteem and emotional support may also have a positive impact on the appraisal processes that influence perception of uncertainty (Babrow, Kasch, & Ford, 1998). Another potential explanation, particularly relevant for new group members, is the fact that they find themselves among a large group of parents who are or have been in a

similar situation. Finding the OSC may produce an important positive shift in the emotional and appraisal responses of the parents. Furthermore, emotions and appraisals may be influenced by the stage of child's treatment and many of the community members seem to be in advanced stages of the treatment. Finally, existing group members seem to give great attention to making new group members feel welcome and part of the community (Arguello et al., 2006). To further our understanding in this direction, the sense of virtual community (SOVC) was measured in chapter four as a construct that could influence uncertainty (Blanchard, 2007).

To summarize, manuscripts one and two identified the existence of uncertainty management constructs in the OSC, while chapter four explored the relationship among the UM constructs. Both manuscripts one and two explored the range of behavioral and psychological responses to uncertainty with the goal of better understanding the parents (Brashers, 2001). While chapter two explored the experiences of uncertainty and the reflection of emotions (Brashers, 2001), chapter three explored the social support behaviors present in an online community (Bambina, 2007; Cutrona & Suhr, 1982; Eastin & LaRose, 2004). Given that the major UMT constructs were identified in manuscripts one and two, chapter four tested the applicability of UMT on a new set of data with the purpose of exploring it as a promising theoretical framework for future studies of online communities (Blanchard, 2007; Brashers, 2001; Eysenbach, 2005).

There were some inconsistent findings that may require further exploration. In spite of the fact that all uncertainty management construct of interest were identified in the OSC, not all the relationships among them were statistically significant as initially hypothesized. First, the original UMT framework did not fit the data very well. Second,

while the addition of SOVC seems to result in a better theoretical model to study uncertainty management in online communities, the chapter four results indicated that there is no significant relationship between information seeking and uncertainty, nor between perceived social support and uncertainty. In addition to the inherent biases related to self-reporting, these results may be explained by the potential existence of other uncertainty related constructs that were not captured in the data collection. Potential candidates include self-efficacy and satisfaction with physician-caregiver communication (Dutta-Bergman, 2005; Galil et al., 2006; Hall & Irvine, 2009; Horky, Kleinman, & Firth, 2007; McRae et al., 2009).

#### Research limitations

There are a few limitations that need to be noted. The first limitation is the relatively narrow focus on one specific caregiver population. A potential critique is that clubfoot is one type of birth defect and the findings of the dissertation may not be generalized to other birth defects. Thus it may be necessary to conduct similar studies with online communities dedicated to parents of children affected by other health conditions. Such research may be able to identify commonalities and differences between uncertainty experiences related to different health conditions affecting children. An interesting topic to address would be the impact of the visibility of the health condition. Some of the messages indicate that attribution errors by general public (e.g. you broke your kids legs) may represent a cause of distress and uncertainty for parents.

Second, information was collected mostly from the members of an online group. Survey respondents were relatively high income, highly educated and high health information seekers (see chapter four for details). The research of Dutta-Bergman (2003)

suggests that information seeking behaviors and information sources are different for different socio-economic levels and health orientations. Thus lower income and less health-oriented caregivers may manage their uncertainty quite differently. Since the aforementioned segment was not captured in this research this may be another potential explanation of why no significant relationships between information seeking, social support and uncertainty were found. Future research needs to collect information from caregivers from multiple socio-economic strata, in addition to assessing their health orientation.

Third, the content analysis only revealed the information exchanged by active members of the community. It was not possible to assess the social support received by lurkers or to that effect their information seeking behavior. It is possible that over half of the community members do not get actively involved in the community (Nonnecke & Preece et al., 2004). Other research methodologies may be needed to obtain information from this category of community members. It would be interesting to explore the reasons why lurkers do not get actively involved, and what would be some incentives for them to become active participants. Future research may attempt to measure the perceived social support for all members in an online community either by identifying smaller size networks or by finding an incentive for all community members, including lurkers, to provide this type of information to the researchers.

Fourth, the study design does not allow us to draw causal inferences. For that goal, a longitudinal design is needed. However, the relationships identified provide sufficient information for designing such a longitudinal study that could follow the progress and interactions of a selected group of parents, from the moment of diagnosis

until they cease activity in the online community. In that regard, an interesting area to explore would be a social network analysis that clearly identifies the relationships between members of the group. It is suggested that a network social structure may have an impact on the transmission of social support (Bambina, 2007). Such an analysis would also reveal different levels of involvement in community, from those who post a lot of messages to those who post only occasionally. The level of involvement in the community may have an impact on a number of constructs such as perceived social support, sense of virtual community, uncertainty, and empowerment (Blanchard, 2007; Demiris, 2006; Winkelman, 2003). Such a research could potentially identify processes and predictors leading to empowerment of caregivers.

#### Future research

The common experience of caring for a child with clubfoot and the online support group provides parents with access to a new social network. Given the availability of relevant information, the availability of support and the 24 hours unrestricted access, at times the online support community may be more relevant and relied upon than close family and friends, or even than the treating physician. Parents with newly diagnosed children join the list to seek information and advice from parents who have more experience with clubfoot, while some of the parents who are in a more advanced phase of treatment share their knowledge, be it of medical nature, be it of practical nature (i.e. how to deal with braces in the first three weeks or what to feed the child). The parents use each other's experiences to learn how to cope with various challenges they face while caring for a child with clubfoot, from diagnosis to the long term follow up. The support goes well beyond information. In addition to sustained emotional support, parents also

provide much esteem support as the “experienced” ones recognize the impact of having a child with a birth defect on a new parent. It has been suggested that “experienced” group members sustain and increase their self-esteem by providing support (Hoybye, Johansen, & Tjornhoj-Thomsen, 2005). By giving support “experienced” parents may improve their own wellbeing by making their experiences, including negative ones, meaningful. A number of parents who are new to the group express great joy to find a place where they can talk with people in the same situation. Thus the issue of isolation faced by parents who are not part of an OSC deserves further exploration (Hoybye, Johansen & Tjornhoj-Thomsen, 2005). It may be valuable to compare knowledge, uncertainty, stress and quality of life levels between those caregivers who are part of an OSC and those who are not.

Since online support communities are based on written word, and trust is built through self-disclosure, it would be interesting to explore the effect of narratives on self-esteem, uncertainty and empowerment. Medical anthropology provides the theoretical basis for exploring the therapeutic potential of narratives (Kreuter et al., 2007). Narratives can be of illness or of caregiving-related experiences. Narratives may be used for validation of the information one possesses or for providing social support (informational and emotional). In the online community of interest, narratives were used to build trust, facilitate information exchange and to address emotional and practical issues (Kreuter et al., 2007).

While there are many potential future research directions, if I were to choose one based on the experience acquired during the dissertation research it would be the meaning of uncertainty.

### Meaning of uncertainty

The meaning of uncertainty as related to clubfoot requires a more in-depth exploration and may be the next logical step in better understanding the parent audience. The following two dimensions of uncertainty may be worth exploring as they are relevant to clubfoot and online communities of support: complexity and quality of information (Babrow, Kasch, & Ford, 1998). Because the exact causes of clubfoot and its long term effects are still unknown communicating information about clubfoot may be a complex endeavor especially for individuals with limited medical knowledge. The quality of information communicated in an online community could potentially be assessed by measuring clarity, accuracy, completeness, volume, ambiguity, consistency, applicability and confidence in the source.

Messages posted in online communities may have imprecise or incomplete wording and the resulting lack of clarity may produce uncertainty (Sheer & Cline, 1995). The accuracy of the information through online messages is another issue of concern, especially when medical information is exchanged. While assessing the accuracy of medical information exchanged in the online community of interest was not one of the aims of this dissertation, this is a critical topic to address in any online community (Culver, Gerr, & Frumkin, 1997). Future studies need to look closer at the quality of health information available in the online communities as some of it may result in a false sense of knowledge (van Lankveld, 2006; Suarez-Almazor, 2001; Fogel et al., 2001)

A closely related construct to accuracy is completeness of information (Babrow et al., 1998; Klir, 2006; Mishel, 1990). Completeness of information could be assessed at the level of the community by piecing together all the information that was produced over

the life of the community (a rather resource consuming endeavor) or by measuring the completeness of information at individual level (practically measuring individual knowledge as related to the topic of clubfoot). The second option would be a more appropriate choice as uncertainty is an individual construct. The volume of information may also be an important source of uncertainty. Since the community of interest for this research has over seventy five thousand messages posted the issue of volume seems as an appropriate construct to address with future research.

While uncertainty may be reduced by information seeking, an overload of information may result in increased uncertainty (Babrow et al., 1998). Finding the relevant information in a large amount of messages may be a daunting task. The results of chapter two indicate that group members may use frequently direct questioning to find information instead of seeking for past messages that may have the answer to their question. As the amount of information available increases in a community, the ability of individuals to process that information may decrease (Babrow et al., 1998). Research suggests that for some individuals increased knowledge is positively related to increased uncertainty. A potential explanation is that after the amount of information available to an individual passes a certain threshold, the resulting information gain overload results in increased uncertainty. This is particularly important for health communication initiatives where the amount of information made available to the audience should not pass the aforementioned threshold of processing capacity.

Another dimension of quality is ambiguity of information. If messages posted to the online community are ambiguous they may be interpreted in multiple ways and result in confusion. Instances of confusion have been observed during the content analysis.

Examples include what types of braces are better or what is the appropriate bracing schedule or even the meaning of clubfoot. Some parents perceive the clubfoot as a punishment while others perceive it as an opportunity to create a stronger bond with their children. Hence the interpretations and words used in messages may deserve a special analysis to identify instances of ambiguity as a potential cause for uncertainty. Another cause of uncertainty is the inconsistency of messages. The chapter two results indicate that for each request of information, on average there are four replies. Such replies may be consistent with each other or provide contradictory information. The online community is an appropriate setting for studying consistency because messages could be analyzed in clusters, each cluster being represented by a thread (topic). Thus the consistency of messages could be assessed thread by thread. Such an analysis could reveal what topics or questions generate inconsistent responses. A potential health communication intervention to address consistency issues would be to bring in one or more experts to respond to problematic areas.

The last two dimensions related to information quality as a source of uncertainty are applicability and confidence in the source. The research methodologies employed in this dissertation do not allow an assessment of the perceived applicability of the responses to the person who asked the question in the first place (information seeker). If the response received is relevant, the uncertainty level of the recipient may be reduced. If the response is irrelevant or too complex (i.e. many medical terms) it could either be ignored or could potentially increase uncertainty because the information seeker is not able to process the information received. Confidence in the source of information is another potential cause for uncertainty (Atkinson, 1995; Hesse et al., 2005). The results

of chapter two indicate that most of the information exchanged in the online community of interest comes from personal experience. However no critiques of the posts have been observed. Thus it would be interesting to assess if the individual experience as a source of information increases or decreases uncertainty (Babrow, 2007).

### Theoretical implications

There is a fine line between practice and theory in this dissertation thus I will address the practical implications through the lens of the Uncertainty Management Theory. Uncertainty Management Theory was present in all three manuscripts of this dissertation. It served as the overarching theoretical framework for the content analysis for both manuscripts one and two and it provided the basis for the structural equation models used in chapter four. For the content analysis, UMT was used to select and operationalize the major processes of communication and uncertainty management to be studied: information seeking and social support. While a content analysis can determine the presence of UMT constructs, it may not be an appropriate method to test the relationships between them. Thus UMT was used to inform the development of two structural equation models that tested relationships between uncertainty related constructs using data from a survey of parents of children with clubfoot.

Understanding the meaning and experience of (child) illness related uncertainty will allow the development of strategies and programs for improving the lives of parents. From a theoretical perspective online support communities as research settings, caregivers/parents as a research population and clubfoot as a research context hold great promise in that direction. I will address the three aforementioned categories based on their relevance for studying processes of communication and uncertainty management

such as experience of uncertainty, meanings and causes of uncertainty, appraisals in uncertainty management, behavioral responses and psychological responses in uncertainty management.

#### Online support communities as research settings

Online support communities are a practical setting for studying processes of communication and uncertainty management. First most OSC members have an explicit or implicit goal of managing uncertainty (their own and/or of others). Second, all the messages exchanged in an OSC are archived, easy to retrieve and can be studied using content analysis. This setting gives scholars and practitioners access to an invaluable source of information while putting no burden on the study population. Third, the information available is likely high quality as it is not prone to recall or self-report bias as it would be the case with surveys or interviews. The unit of analysis for content analysis was a message. Future studies could have as unit of analysis the individual author or a conversational thread. By analyzing the messages of one or more individuals, scholars could observe the multiple layers of uncertainty, the connections between uncertainties and the evolution in time of the overall uncertainty (Babrow, 1995; Babrow, 2007). Chapter two identified direct questioning and self-disclosure as the most frequent information seeking behaviors. By analyzing the information seeking messages, scholars could identify the major causes of uncertainty for the members of the OSC in particular and for parents in general. Finally as it was documented in manuscripts one and two, using content analysis, communication scholars can identify the most frequent behavioral and psychological responses to uncertainty (Brashers, 2001).

### Caregivers (parents) as a research population

Caregivers/parents of children affected by health conditions such as clubfoot are a convenient study population. The experience of this dissertation suggests that parents are interested in being participants in this type of research, especially if their required involvement is within reasonable limits of time and effort. After all, the research findings are supposed to benefit them as well. Parents are also a study population that has received limited attention from a research perspective thus they may not suffer from study fatigue. Most of the studies done on online communities are focused on patients not on caregivers. It is important to note that the experience of uncertainty for caregivers may be different than for patients (Cox, Smith, Brown, & Fitzpatrick, 2008; Griffiths, Lindenmeyer, Power, Lowe, & Thorogood, 2006). However, given the fact that the child is affected by illness, the health condition is very relevant for most of the parents and thus a potential source of uncertainty. However, since they are not physically affected, parents may have more resources to participate in online interactions than patients. Yet they may have less resources as they need to care for one or more children. As a caregiver, the meaning and sources of uncertainty may also be different than for a patient (Holm, Patterson, Rueter, & Wamboldt, 2008; Streisand, Swift, Wickmark, Chen, & Holmes, 2005).

### Clubfoot as a research context

Clubfoot seems to be an excellent context for studying processes of communication and uncertainty management. Given its appearance and relative ambiguity in regards to etiology (causes), clubfoot creates conditions for multilayered and interconnected uncertainties that evolve in time (Babrow, 1995). Sources of

uncertainty may include decisions about the treatment, decisions about the treatment facility, treatment effectiveness, follow up, child development, etc. Even the radical improvements obtained through the Ponseti method can be causes of uncertainty (Brashers et al., 1999). This is because some parents may begin to worry about relapses when they see the results of the treatment (loss frame). As in the previous example the meanings and causes of uncertainty may vary with the individual characteristics of the caregiver and his/her appraisal processes. Appraisal processes and psychological processes may be amplified especially by the high emotional charge of the diagnosis. Diagnosis of clubfoot is often done at birth.

#### Uncertainty management as a theoretical framework

UMT is a promising theoretical framework for studying online interactions among parents of children with clubfoot. The findings suggest that by using UMT as a base and including constructs that are adapted to online environments, health communication scholars can extend the use of the UMT to new contexts such as the Internet. Thus, this research makes the case for improving existing theoretical models that could address new theoretical and methodological challenges generated by the use of the Internet for health communication research and programs.

#### Practical implications

The findings of this dissertation may be useful to health communication scholars and practitioners, medical care providers and administrators of online communities dedicated to caregivers/parents. These findings may assist in developing effective health communication programs for parents of children with birth defects in addition to informing theory driven research initiatives.

Overall, this research provides a comprehensive analysis of online activities of parents of children with clubfoot, with the long-term goal of developing effective health communication interventions. Uncertainty experiences and the associated behaviors have a great impact on the well-being of parents. However, uncertainty experiences may be influenced by communication. The interesting thing about interactions in OSCs is that basically all of them are communication acts carried using written words. Online there is no verbal communication, and just very limited nonverbal communication. One might say that the communication act should be heavily impaired. Yet, the parents seem to be able to effectively exchange through acts of written communication not only information, but also other types of social support. This supports the argument that those who write messages online give more attention and thought to what they communicate. To truly understand the underlying processes in an online community, we need to expand existing theories of communication and of uncertainty management, and adapt them for the online context. Uncertainty management and other communication theories that account for online related factors will have important consequences for physician-caregiver interaction, for institutional health communication, and for developing and sustaining relationships with critical audiences (Brashers, 2001). The first step in these important directions is to better understand the audience. In the next paragraph I list a few more practical arguments of why scholars and practitioners need to better understand the parents.

First, the voice of the parents on the Internet has played a major role in the diffusion of the Ponseti method of clubfoot treatment (Morcuende et al., 2003). Thus it is critical to foster good relationships between medical care providers and caregivers

because of their advocacy potential. Second, a strong relationship between parents and physicians is essential for good medical outcomes, especially in long-term illnesses (Nuutila & Salanterä, 2006). Third, there may well be lessons to be learned from parents. This is because they have to care for their children, many hours a day. They have the possibility to observe how children react to braces, treatment, and what the best ways to deal with day-to-day challenges are. Such information could be very valuable for both nurses and physicians in their interactions with new patients and their caregivers. Unfortunately, physicians, during medical encounters may not think it is important to share their trust and respect in the knowledge and skills that parents have acquired (Lynn-McHale & Deatrck, 2000). Online communities may provide a unique opportunity for physicians to get involved in informal conversations and to build a trust based relationship with parents, a relationship that extends beyond the medical facility (Nuutila & Salanterä, 2006). However, communication begins with the first encounter between a parent and a medical care provider.

The first contact with the parent audience is the moment of diagnosis. The diagnosis of clubfoot is a critical physician-caregiver interaction. Effective health communication could ease the burden of illness a great deal and transform the initial consultation into an opportunity for caregiver empowerment (Werner & Malterud, 2005). Recent advances in biological, clinical and epidemiological research have begun to clarify some of the potential causes of clubfoot, as well as the best treatment options available (Morcuende, Dolan, Dietz, & Ponseti, 2004). Medical care providers could use the Internet to help parents cope with the many issues they face after such a diagnosis. First, medical care providers need to recognize the role that the Internet may play in the

information seeking behaviors of parents and direct parents to reputable sources of information online as a critical component of a comprehensive physician-caregiver communication strategy (Gerber & Eiser, 2001). Second, while physicians may not be able to provide other types of support that parents need, they can direct parents to online support communities.

The dissertation findings suggest that the members of the clubfoot parent community are capable of conveying not only relevant informational support, but also emotional and esteem support among people who may have never met and possibly will never meet face to face. For rare health conditions OSCs may be the only way caregivers/parents can interact with others in a similar situation. This type of support could also be ideal for rural areas where travel is difficult and access to specialized medical care is limited (Hall & Irvine, 2009).

Individuals from all over United States and some from other countries are finding on the Internet a source of support that would be difficult to recreate by any health-related institution currently in existence. Access to good quality information is known to reduce uncertainty (Babrow, Kasch & Ford, 1998; Babrow, 2007; Eysenbach, 2005). Thus, health-related institutions could provide critical information to online communities of parents and thus insure that the medical information spread through such a peer-to-peer network is of good quality and coming from a trusted source (Dutta-Bergman, 2003; Hesse et al., 2005). Utilizing the credibility of peers institutional health communication programs could be designed in order to disseminate correct information related to a health condition.

As we learn more about the parent audience, the importance of communicating with them becomes increasingly clear. As the burden of illness changes, the informational needs of parents change as well and the physicians and nurses may not have the resources or knowledge to deal with this shift in needs (Nuutila & Salanterä, 2006). Close to the diagnosis phase parents need information – high quality (clear, accurate, complete, consistent and applicable) instead of high quantity would be preferable (Babrow, 2007; Babrow et al., 1998). Such information needs to be communicated in an empathetic manner. As parents progress through the treatment they begin to learn and may become a valuable partner in the treatment of their child and in supporting other parents. The online community is a great setting for parent-to-parent interaction. In the online community some of the parents select the empowerment path and stay on board, actively involved, in the life of the online community. By sharing their previous experience they contribute to the well-being of other parents and they feel empowered. Some of the highly contributing parents become recognized experts in the online community, and their knowledge may be a great complement to formal medical advice.

This dissertation is just the first step in better understanding the audience and in finding or developing an appropriate theoretical framework to support future research and interventions. While the results of this research are valuable, we will need a deeper understanding of the causes and meanings of uncertainty. Furthermore a deeper understanding of the psychosocial processes and experiences that parents go through is needed in order to create an effective partnership between health care providers and caregivers. The constructs explored in this dissertation provide a promising theoretical framework for future research.

### Conclusion

In conclusion, uncertainty seems to be an important part of the experience of parents caring for children with clubfoot. Furthermore, online communities dedicated to these parents represent a promising setting for studying illness-related uncertainty and its potential causes. I have presented a number of future research directions that could be pursued in regards to the causes and meanings of uncertainty, using online communities as a research setting.

Today's world is characterized by enormous complexities, rapid technological advancements, and great opportunities for health communication practice and research. Clubfoot is not merely a medical problem, but a context that could foster a wide spectrum of research. Clubfoot oriented research has the potential to cross many disciplines such as social science, medicine, information technology, biology, and genetics. Most importantly such research could have an immediate impact on improving the lives of children and their parents. Clubfoot is an opportunity for research and practice that we cannot afford to overlook.

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APPENDIX  
INSTRUMENTS

Coding Sheet

**1) ID**

**2) Type of message**

- NA
- Original message
- Response to previous message

**3) Intended recipient**

- NA
- Individual
- Group

**4) Main topic of message**

- NA
- information request reply
- information seeking
- provision of unsolicited information
- request for emotional support
- provision of emotional support
- conflict
- advocacy
- Other (please specify)

If you selected other, please specify:

Additional comments:

### 5) Information seeking

- NA
- Question asking
- self-disclosure (relaxing the target)
- Offering a candidate answer
- Second guessing
- Passive information seeking (hedges, hesitations, tag questions, expression of probabilities)

Additional comments:

### 6) Mentions of health care services (any comment related to hospitals, physicians, nurses or experiences related to office visits)

- Yes

### 7) Tone of evaluation of health care services

|  | negative              | neutral               | positive              |
|--|-----------------------|-----------------------|-----------------------|
| Comments on health care professionals  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Comments on (the results) of treatment | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Comments on health care services       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Additional comments:

### 8) Postings with identifying information

- Name of health care professional
- Description of health care professional
- Name of medical institution
- Description of medical institution

Additional comments:

### 9) Urging for other professional, treatment or second opinion

- Yes

Additional comments:

### 10) Message provides medical information (i.e. casting, relapse, diagnosis, bracing, tenotomy)

- Yes

Additional comments:

### 11) Type of source of medical information

- |   |   |
|---|---|
| <input type="checkbox"/> personal                       | <input type="checkbox"/> Medical Professional             |
| <input type="checkbox"/> friend or other lay person     | <input type="checkbox"/> medical textbook/journal article |
| <input type="checkbox"/> hospital/institutional website | <input type="checkbox"/> Other (please specify)           |

If you selected other, please specify:

### 12) SOCIAL SUPPORT Information support

- Advice
- Referral
- Situation appraisal

- Teaching

Additional comments:

### **13) Tangible assistance**

- Loan
- Perform direct task
- Perform indirect task
- Active participation
- Express willingness

Additional comments:

### **14) Network support**

- Access
- Presence
- Companions

Additional comments:

### **15) Esteem Support**

- Compliment
- Validation
- Relief of blame

Additional comments:

### **16) Emotional support**

- Relationship
- Physical affection (i.e. hug)
- Confidentiality
- Sympathy
- Understanding/empathy
- Encouragement
- Prayer

Additional comments:

**17) Other means of uncertainty management**

- Sharing personal experiences
- provision of information
- requests for information
- provision of empathy
- gratitude
- humor
- creative expression (poetry, signature lines)
- chit chat
- non-verbal
- Request for empathy

Additional comments:

**18) Feelings expressed**

- Anger
- Disgust

- Happiness
- Contentment
- Hope
- Surprise
- Fear
- Worry
- Sadness
- Other (please specify)

If you selected other, please specify:

Additional comments:

**19) Negative remarks directed at other members**

- Lack of understanding
- Criticism
- Scolding

Additional comments:

Parent survey

What is your age?

What is your gender?

Female  Male

What is the highest grade or year of school you completed?

Never attended school
  Grades 1 through 8 (Elementary)
  Grades 9 through 11 (Some high school)
  Grade 12 or GED (High school graduate)
  College 1 year to 3 years (Some college or technical school)
  College 4 years or more (College graduate)

What is your annual pre-tax household income from all sources?

Less than \$25,000
  \$25,000 to less than \$35,000
  \$35,000 to less than \$50,000
  \$50,000 to less than \$75,000
  \$75,000 or more
  Prefer not to answer

Are you Hispanic or Latino?

Yes  No

Which one of these groups would you say best represents your race?

White
  Black or African American
  Asian
  Native Hawaiian or Other Pacific Islander
  American Indian or Alaska Native
  Other (please specify)

If you selected other, please specify:

**Clubfoot questions**

If you have more than one child with clubfoot please answer the following questions referring to the oldest child diagnosed with clubfoot.

What is the date of birth (Month/Year) of your child with clubfoot?

MM/YYYY   
Format: 99/9999

**What is the date of the first treatment (Month/Year) for your child diagnosed with clubfoot?**

MM/YYYY   
Format: 99/9999

**Which side is the clubfoot?**

right foot  left foot  both feet

**What is the present status of your (oldest) child with clubfoot?**

- no treatment started yet
- in treatment with normal progress toward correction
- doctor could not complete correction with initial treatment and currently looking to find another provider for additional correction
- relapse (child currently in a relapse and needs additional treatment)
- fully corrected after experiencing one or more relapses
- fully corrected with no relapses

Additional comments:



---

**The following questions relate to your overall perception of uncertainty and stress related to your child having clubfoot (available information, support, diagnosis, treatment, relapses, long term results etc).**

*Uncertainty is not being able to foretell the future; a lack of clarity about the present; being in doubt; being undecided; not being able to rely, count or depend on someone or something; and having a sense of vagueness about what to do, expect, know and ask as related to clubfoot.*

**Overall, my uncertainty level about my child's clubfoot right now is:**

Please enter a number between 0 (no uncertainty) and 100 (very high uncertainty) which best indicates your level of uncertainty

**Please list below the major reasons/topics that cause uncertainty for you:**

-----

Overall, the stress I feel from my uncertainty is:

Please enter a number between 0 (no stress) and 100 (very high stress) describing your level of stress right now

Please list below the major reasons/topics related to clubfoot that make you feel stressed:

-----  
Some people find that uncertainty can sometimes be associated with positive feelings (such as hope) because of the possibility that things will work out well even if one does not have all the answers.

Overall, the level of my positive feelings associated with uncertainty is:

Please enter a number between 0 (no positive feelings) and 100 (only positive feelings)

Please list below the reasons for having positive feelings related to caring for a child with clubfoot (and the associated uncertainty)



---

Given all the information you collected, how knowledgeable would you say you are about clubfoot today?

Please enter a number between 0 (no clue) and 100 (I know all that can be known)

Have you ever used a search engine to find information about clubfoot?

Yes  No

If yes please list keywords you may have used to search for clubfoot information

The matrix below refers to major sources that you may have used to collect information about clubfoot.

Please answer both the frequency and the quality questions for each category.

|  | How often have you used each information source over the last 12 months (or since diagnosis if less than a year) |                          |                          |                          |                          | What is the perceived quality of information for each source in general |                          |                          |                          |                          |
|--|--|--------------------------|--------------------------|--------------------------|--------------------------|---|--------------------------|--------------------------|--------------------------|--------------------------|
|  | never  | less than once per month | several times a month    | several days a week      | every day                | very poor   | poor                     | acceptable               | good                     | excellent                |
| Online group (Internet based community)                            | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Hospital/clinic website  | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Personal website/blog  | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Health professional via email                                      | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Health professional (face to face or by phone)                     | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| General medical website (As WebMD, Dr Greene..)                    | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Professional Medical Organization website (as AAOS, POSNA, AAP...) | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Medical journals/collections website (as PubMed...)                | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Family and friends (outside an online group)                       | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Additional comments  | <input type="text"/>   |                          |                          |                          |                          | <input type="text"/>  |                          |                          |                          |                          |

**Please answer to the best of your knowledge to the next questions**

The exact causes of clubfoot are known:

True  False

The percentage of cases of clubfoot in which both feet are affected is:

15%  30%  50%  70%  85%

Clubfoot is more common in girls than in boys:

True  False

In clubfeet treated with the Ponseti method, the percutaneous tenotomy is recommended in:

20% of the cases  40% of the cases  60% of the cases  80% of the cases  100% of the cases

If done correctly, the Ponseti method will result in good clubfoot correction in:

65% of the cases  75% of the cases  85% of the cases  95% of the cases

The following type of casts are used in the Ponseti method:

Short leg casts  Long leg casts

In a clubfoot treatment involving casting is it OK to remove a baby's cast the night before the appointment?

Yes  No

Have you ever joined an online community to find, share and discuss information about clubfoot?

Yes  No

If yes, please list the name(s) of the online groups you joined and proceed to the next page

**What is your level of participation in the clubfoot online group where you spend most time?**

Read only  I rarely post messages to the group  I occasionally post messages to the group  I often post messages to the group

-----

**The following questions are part of nationally recognized standardized questionnaires. Perceptions of online clubfoot support communities will be compared to online communities dealing with other medical conditions.**

**In answering these questions, please think about your current relationships with the members of the online group dealing with clubfoot where you spend significant amounts of time**

|  | Yes                      | Sometimes                | No                       | Not Applicable           |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| Are there people (in the online group) that you can depend on to help you if you really need it? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you feel you could not turn to other online group members for guidance in times of stress?    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Are there people in the online group who enjoy the same social activities that you do?           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

|  |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you feel personally responsible for the well-being of the members of the online group?                      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that members of the online group do not respect your skills and abilities?                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| If something went wrong, do you feel that none of the online group members would come to your assistance?      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do your relationships with online group members provide you with a sense of emotional security and well-being? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel your competence and skill are recognized by the people in the online group?                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel none of the online group members share your interests and concerns?                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel none of the online group members really rely on you for their well-being?                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is there a trustworthy person in the online group you could turn to for advice if you were having problems?    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel you lack emotional closeness with members of the online group?                                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Additional comments:

In answering the following questions please think of your sense of community with the clubfoot online group where you spend most time

|  | Strongly disagree     | Disagree              | Agree                 | Strongly agree        |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| I think this group is a good place for me to be a member.                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other members and I want the same thing from this group.                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can recognize the names of many members in this group.                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel at home in this group.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I care about what other group members think of my actions.                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| If there is a problem in this group, there are members here who can solve it.          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| It is very important to me to be a member of this group.                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I expect to stay in this group for a long time.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I anticipate how some members will react to certain questions or issues in this group. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've had questions that have been answered by this group.                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've gotten support from this group.   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Some members of this group have friendships with each other.                           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have friends in this group.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Some members of this group can be counted on to help others.                           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel obligated to help others in his group.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I really like this group.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| This group means a lot to me.  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Additional comments:







|   |                          |                          |                          |                          |                          |                          |                          |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Whether I can depend on people who are important to me to be there when I need them | <input type="checkbox"/> |
| Whether I can manage financially given my child's clubfoot                          | <input type="checkbox"/> |
| What symptoms I should be aware of  | <input type="checkbox"/> |
| What to look for to check the status of my child's feet                             | <input type="checkbox"/> |
| Additional comments   | <input type="text"/>     |                          |                          |                          |                          | <input type="text"/>     |                          |                          |                          |                          |

**How many doctors/clinics did you seek opinions from before starting the first treatment for clubfoot?**

**[Enter 0 if the first doctor you consulted also provided treatment]**

**How did you select the doctor that initially treated your child (select all that apply):**

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> internet research                                       | <input type="checkbox"/> in-network for insurance                          | <input type="checkbox"/> reputation as a good orthopedic surgeon |
| <input type="checkbox"/> referral from other parents with children with clubfoot | <input type="checkbox"/> doctor worked at facility that provided free care | <input type="checkbox"/> reputation as a good "Ponseti" doctor   |
| <input type="checkbox"/> referred by other physician                             | <input type="checkbox"/> location/proximity to my home                     | <input type="checkbox"/> Other (please specify)                  |
| <input type="checkbox"/> financial reasons                                       | <input type="checkbox"/> location/proximity to a relative/friend's home    |  |

If you selected other, please specify:

**How satisfied are you with the treatments for clubfoot your child has received so far?**

|   | Didn't get this treatment | Very satisfied        | Somewhat satisfied    | Neither satisfied nor dissatisfied | Somewhat dissatisfied | Very dissatisfied     |
|---|---------------------------|-----------------------|-----------------------|------------------------------------|-----------------------|-----------------------|
| Ponseti method (including tenotomy)   | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>              | <input type="radio"/> | <input type="radio"/> |
| Modified Ponseti method (including Botox)                                       | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>              | <input type="radio"/> | <input type="radio"/> |
| Serial casting (not Ponseti)  | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>              | <input type="radio"/> | <input type="radio"/> |
| Physiotherapy   | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>              | <input type="radio"/> | <input type="radio"/> |
| ATTT (Anterior Tibial Tendon Transfer)  | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>              | <input type="radio"/> | <input type="radio"/> |
| Extensive surgical release (Tenotomy and ATTT are NOT considered major surgery) | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>              | <input type="radio"/> | <input type="radio"/> |
| Other (please write method name in the Comments field)                          | <input type="radio"/>     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>              | <input type="radio"/> | <input type="radio"/> |

Additional comments:

**How many different clinics/hospitals has your child received clubfoot treatment from?**

**Overall, my certainty level about my child's clubfoot is:**

please enter a number between 0 - completely uncertain and 100 - certain beyond any doubt that my child is and will be all right

**Please write below any comments or additional information that you would like to be included in this analysis or in future studies. Thank you**