MANAGING UNCERTAINTY IN THE CONTEXT OF CLUBFOOT CARE: EXPLORING THE VALUE OF UNCERTAINTY MANAGEMENT THEORY AND THE SENSE OF VIRTUAL COMMUNITY

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ABBSTRACT

Serious health conditions, such as clubfoot, could be a major source of uncertainty and stress for parents of children affected. How parents deal with uncertainty and stress as related to their child's health condition is of interest for medical professionals and health communicators alike. 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, including in online support communities. This study explored the connections between Uncertainty Management Theory (UMT) constructs and the potential contribution of the sense of virtual community (SOVC) to the UMT framework. The results of this research suggest that the UMT needs to be adapted for use in online contexts. One way is to include theoretical constructs, such as the sense of virtual community, specifically developed to measure online interactions. A modified and updated Uncertainty Management Theory could be useful in exploring, analyzing and understanding online behaviors related to health conditions such as clubfoot and thus contribute substantially to what we know about caregivers in their role as uncertainty managers.

INTRODUCTION

The health of a child is of great importance for parents, health services systems, and society in general. Serious health conditions, such as clubfoot, could be a major source of uncertainty and stress for parents¹,². How parents deal with uncertainty and stress as related to their child's health condition is of interest for medical professionals and health communicators alike. Until the 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 the Internet in particular, provides new ways for parents to search for and find information, as well as to request and receive support from individuals facing similar challenges³,⁴. 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 likely because they can access large quantities of information quickly and on their own schedule⁵,⁶,⁷. Parents of children with health conditions may use the Internet in a number of ways; the most important being information seeking and social support, two constructs of the Uncertainty Management Theory (UMT)⁸. UMT states that individuals employ various behaviors to decrease, maintain or increase their uncertainty. Uncertainty management behaviors include seeking, acquiring, and exchanging information in addition to other types of social support⁹,¹⁰.

The diagnosis of a birth defect and the process of caring for a child with such a condition may result in high levels of stress for parents⁷,¹⁵. Evidence indicates that mothers report more psychological stress than fathersª,¹⁵,¹⁶. Stress can add additional burden on the parent, decrease their quality of life, and may have a negative effect on early childhood development. Considerable effort needs to be exerted to cope with the stress generated, not only with the normal anxiety of having a newborn, but with a newborn with a health condition¹⁰,¹⁶. Some parents may turn to online support communities (OSCs) to manage their stress and uncertainty.

Studies focusing on the underlying processes in OSCs remain scarce despite the increasing interest in understanding online support communities. There have been relatively few studies addressing online support communities that are initiated and managed without input from health institutions¹⁷. In the context of online support communities, Eysenbach¹ suggested that information seeking (websites, online groups and direct communication), social support, knowledge, uncertainty (confusion) and stress may be inter-related.

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METHODS

This research explored the connections between Uncertainty Management Theory (UMT) constructs and the potential contribution of the sense of virtual community (SOVC) to the UMT framework. The PATH model proposed in Figure 1 indicates how the constructs under study may be related to each other according to UMT. The research question and hypothesis addressed in this study are listed next.

RQ1: Is UMT applicable to interactions in online environments in the context of clubfoot?

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

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

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

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

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

Because the Uncertainty Management Theory (UMT) was not created specifically to explore online communities, new constructs (such as Sense of Virtual Community or SOVC) 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”\textsuperscript{18}. SOVC has been used to analyze various online groups including groups related to infertility and pregnancy\textsuperscript{19,20}. 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 2 allowed us to explore the following research question and hypothesis.

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

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

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

Sample and procedure

The study participants were parents of children with clubfoot. Participants were recruited using a snowballing technique by posting an invitation in an online support community managed and used by 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 online support group. The text of the invitation encouraged parents to share the link to the survey with other parents caring for children with clubfeet. The study methodology was approved by the University of Iowa’s Institutional Review Board. Data was collected using an Internet-based survey, developed and administered via WebSurveyor. The survey was pilot tested before administration.

The following measures were collected as part of the survey: uncertainty, stress, 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\textsuperscript{21}. Uncertainty was defined overall as the anxiety the parent feels because of 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 as a result of 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 or her general knowledge level about clubfoot related issues on a scale from 0 (no knowledge) to 100 (very high knowledge). To measure information seeking behavior, respondents were asked to indicate how often they used various information sources related to clubfoot over the last twelve months. The responses were averaged to generate an information seeking score. Seventeen items adapted from Blanchard's SOVC scale were used to measure the sense of virtual community in the online group. Nine items were adapted from Cutrona and Russell's Source Specific Social Provisions Scale to measure perceived social support.

Data analysis

The Statistical Package for the Social Sciences (SPSS) was used to run descriptive analyses and correlations. The AMOS 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 application of UMT to caregiver online behaviors and interactions in the context of clubfoot. As suggested by the UMT theory, it was believed that knowledge, information seeking, social support, uncertainty and stress are inter-related. The aforementioned constructs were treated as observed variables.

To address RQ1 & RQ2, two SEM analyses were conducted. The first Path model (without SOVC) was tested for goodness of fit in the first phase. The second Path model (with SOVC) was tested for goodness of fit in the second phase. Maximum likelihood imputation was used to handle missing data as recommended by Byrne. 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. RMSEA takes population error into consideration, while CFI compares the hypothesized model with the independence model. A RMSEA value of 0.05 is indicative of a good fit, a value of 0.08 is a reasonable fit and values greater than 0.10 are a poor fit. Bentler suggested CFI as the index of choice with a cutoff value around 0.95 or more. The incremental index of fit (IFI) indicates a good fit over 0.95 and accounts for issues of parsimony and sample size that may influence CFI. Fifteen cases per predictor in a standard ordinary least squares multiple regression analysis is reasonable according to James Stevens’ Applied Multivariate Statistics for the Social Sciences. A minimum of 15 cases per measured variable in SEM was also considered reasonable since SEM is closely related to multiple regression in some respects. In addition, Mitchell 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). Ninety-four percent of the respondents were women. Ninety percent of the respondents had college level education and 87% had an income level of over $35,000. Eighty-one percent of the respondents identified themselves as non-Hispanic White, 6% Hispanic/Latino, 6.5% Asian and 6.5% mixed ethnicity. Table 1 illustrates the correlations among constructs under investigation.

<table>
<thead>
<tr>
<th>Uncertainty</th>
<th>Stress</th>
<th>Knowledge</th>
<th>Information seeking</th>
<th>SOVC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress</td>
<td>0.646**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledge</td>
<td>-0.056</td>
<td>-0.208**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information seeking</td>
<td>0.115</td>
<td>0.13</td>
<td>0.139*</td>
<td></td>
</tr>
<tr>
<td>SOVC</td>
<td>0.014</td>
<td>0.002</td>
<td>0.142</td>
<td>0.216**</td>
</tr>
<tr>
<td>Social support</td>
<td>-0.024</td>
<td>-0.06</td>
<td>0.113</td>
<td>0.175*</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed). *Correlation is significant at the 0.05 level (2-tailed).
comparative fit index (CFI) = 0.904 and the incremental index of fit (IFI) = 0.91 were both under 0.95 supporting the above conclusion28.

The SEM analysis results did not support H1.1 as there was a positive relationship between knowledge and information seeking at the 0.05 significance level (estimated regression weight = 0.14, p=0.049). The results provided support for H1.2 as there was a positive relationship between information seeking and perceived social support (estimated regression weight = 0.185, p=0.013). The results did not support H1.3 because there was a non-significant relationship between information seeking and uncertainty (estimated regression weight = 0.124, p = 0.083). The results did not support H1.4 because there was a non-significant relationship between perceived social support and uncertainty (estimated regression weight = -0.05, p=0.511). The results did not support H1.5 because there was a statistically significant positive relationship between uncertainty and stress (estimated regression weight = 0.646, p<0.001).

For the second Path model, the relationships were examined between knowledge, information seeking, perceived social support, sense of virtual community, uncertainty and stress using structural equation modeling. The sense of virtual community score mean was 3.18 (SD=0.51). Figure 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: X² (9, N = 203) = 20.44, p = 0.015. The goodness-of-fit indices are at or above the recommended levels of: RMSEA = 0.079; (PCLOSE=0.128); comparative fit index (CFI) = 0.95; and incremental index of fit (IFI) = 0.9528. These results suggest that the structural model that included SOVC fit the data better than the one without SOVC.

The SEM analysis results did support H2.1 because there was a positive relationship between social support and SOVC (estimated regression weight = 0.703, p<0.001). The results did not support H2.2 because there was a non-significant relationship between SOVC and uncertainty (estimated regression weight = -0.014, p=0.851).

**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 initial empirical test of Uncertainty Management Theory. The results contribute to current understandings of the uncertainty management processes in three primary ways: a) lending insight into the relationships between constructs, b) exploring 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 outcomes also uncover new directions for future research focused on uncertainty management in online contexts.

The results of this research suggest that the UMT 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.

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. The results indicated that knowledge, information seeking, perceived social support, and sense of virtual community are closely interconnected, judging by the relationships between variables in the second proposed structural model.
Knowledge was positively related to information seeking behavior. This supports the idea that for some parents the acquisition of information leads to more information seeking\cite{31}. There may be an underlying need to validate one’s body of knowledge as a way to deal with uncertainty\cite{32}.

Information seeking behavior was 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\cite{33,34,35}. Of the survey respondents, over 60% visit an online support community a few times a week or even daily. Over 98% of the survey respondents indicated that they used a search engine in their information seeking.

The study results provided support for a strong relationship between illness-related uncertainty and stress\cite{36,37}. Identifying and addressing uncertainty causes before, during, and after medical encounters may allow caregivers to better cope with stress\cite{38,39}. Furthermore, such an approach may also increase compliance with treatment by increasing the trust between parents and medical care providers\cite{31,40}.

Perceived social support was 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 shows that a theoretical model including SOVC may fit the data better than one without SOVC. 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 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. The active involvement of long-term members in an online community of support represents a critical factor in the success of such a community\cite{41,42}.

Some limitations of the study are noted next. First, 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. 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\cite{43}. Third, most of the respondents were reportedly white, suggesting that other ethnicities may not use the online support resources as much because of reasons that require further inquiry such as income and education status, access to a computer and so forth.

Despite the above, this research 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\cite{44}. 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. The study findings recommend adding the sense of virtual community to the uncertainty management theoretical framework.

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. Yet much remains to be learned about the internal organizational functioning of an online community. 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 with respect to online communities. The joint consideration of information seeking, social support, and a sense of virtual community have the potential to increase understanding of all three constructs\cite{45}. It is clear that securing information and social support in order to deal with illness related uncertainty is a complex process\cite{46}. The results suggest that, with some additions, Uncertainty Management Theory could be a valuable framework in exploring caregivers’ experiences and that online communities of caregivers of children with health conditions provide an appropriate setting for this type of research\cite{47}.

CONCLUSION

Health communication efforts designed to support parents of children with serious health conditions may need to expand in parallel with the Internet. Treatment of clubfoot remains critically important, yet much more emphasis is needed on communication efforts designed to reduce the stress experienced by parents. Future advances in health communication could be achieved through a combination of research and practice involving partnerships between parents, health professionals and scholars interested in clubfoot. A modified 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 substantially to what we know about caregivers in their role as uncertainty managers.
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