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# Using Information to Manage Uncertainty During Organ Transplantation

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People living with a chronic illness can experience uncertainty about their physical conditions, identities, and relationships. One way individuals cope with this uncertainty is through managing information related to their illness. We conducted in-depth interviews with 38 pretransplant and posttransplant patients and analyzed the transcripts using grounded theory techniques. Participants reported that they managed their uncertainty related to transplantation by seeking and avoiding specific information and by strategically handling personal and social information. Participants also described a number of challenges associated with their information use. We discuss the theoretical implications of these findings for literature on information management, uncertainty in illness, and organ transplantation. In addition, we highlight practical implications for medical professionals as well as transplant patients and their loved ones, and we suggest that future research might usefully address what role uncertainty appraisal plays for people coping with chronic illness.

*Keywords*: uncertainty; information; communication; transplantation

The number of individuals who have received an organ transplant is steadily increasing, and the number of people who are added to the waiting list to receive an organ is growing at an even faster rate (United Network for Organ Sharing, 2012). Like many other illness experiences, the process of waiting for and receiving a transplant is marked by considerable anxiety, including uncertainty about one's physical conditions, identities, and relationships with others (Martin, Stone, Scott, & Brashers, 2010). Such uncertainty is not inherently good or bad, but how the uncertainty is managed can have far-reaching implications for persons coping with illness (Brashers, 2001; Brashers & Hogan, in press). When uncertainty is managed poorly, a person's physical, personal, and social well-being can be severely compromised, whereas when uncertainty is managed well, he or she is better able to adjust physically and psychologically to the illness experience (Brashers, 2001; Mishel, 1988).

## Uncertainty in Illness

Uncertainty has long been studied as an important aspect of illness experiences (see Babrow, Kasch, & Ford, 1998; Brashers et al., 2003; Mishel, 1988, 1990). According to Mishel (1988), people experience uncertainty when they are unable "to determine the meaning of illness related events" (p. 225). This experience of uncertainty is influenced by a person's stimulus frame (i.e., perceived stimuli relating to symptom patterns, familiarity with events, and congruence between expected and actual experiences), which, in turn, is affected by a person's cognitive capacity (i.e., the ability to process information) and structure providers (i.e., resources, including information). Mishel (1990) later reconceptualized the theory to account for the experiences of people living with chronic illness, arguing that chronic illness and its accompanying uncertainty affects daily routines and general well-being.

The experience of uncertainty is related to particular illness contexts (e.g., Brashers et al., 2003; Martin et al., 2010; Stone & Jones, 2009), and considerable research has identified various ways in which uncertainty manifests in the context of transplantation. For pretransplant patients, deteriorating quality of life, questions about the availability of organs, or concerns about their physical or relational capabilities following the transplant can cause uncertainty (Bjork & Naden, 2008; Brown, Sorrell, McClaren, & Creswell, 2006; Karam et al., 2003; Kierans, 2005; Wainwright, 1997; Young et al., 2008). Posttransplant

patients may feel unsure about the possibility of organ rejection, the side effects of immunosuppressive therapy, or their revived physical health (Baines, Joseph, & Jindal, 2002; Buldukoglu et al., 2005; Dudley, Chaplin, Clifford, & Mutimer, 2007; Forsberg, Backman, & Moller, 2000; Hsieh, 2004; Martin et al., 2010; Nilsson, Persson, & Forsberg, 2008; Starzomski & Hilton, 2000; Wainwright, 1995).

## Uncertainty and Information

Many theoretical approaches to uncertainty assume that people always want to reduce uncertainty (e.g., Berger & Calabrese, 1975; Gudykunst, 1995). In his theory of communication and uncertainty management, Brashers (2001, 2007) challenged this assumption by proposing that people may want to reduce, maintain, or even increase their uncertainty, depending on their appraisals of and emotional responses to experiences characterized by uncertainty (e.g., chronic illness). For example, an individual who experiences uncertainty that causes distress may try to reduce that uncertainty. Research has suggested that information management is one significant way that people respond to illness-related uncertainty (Brashers & Hogan, in press; Hogan & Brashers, 2009; Mishel, 1988, 1990), and a number of scholars have described the role of information seeking and avoiding as a communicative means of managing uncertainty (Afifi & Weiner, 2002; Brashers, Goldsmith, & Hsieh, 2002; Hogan & Brashers, 2009; Knobloch & Solomon, 2002; Morrison, 2002; Rosen & Knauper, 2009; Sweeny, Melnyk, Miller, & Shepperd, 2010; Sweeny & Miller, 2012). Brashers et al. (2000) found that information can decrease uncertainty for individuals who are able to use that information to develop meaning around an illness event. Alternatively, individuals may wish to maintain uncertainty when they appraise it positively. People may try to avoid information as a way to manage uncertainty when it conflicts with information they already have (Babrow, 2001; Sweeny et al., 2010). Posttransplant patients, for instance, may decide not to ask about the likelihood of rejection after transplantation as a way of maintaining hope that the transplant will be successful.

Despite valuable research about information seeking and avoiding, less is known about how people assess and utilize particular sources of information or the challenges that can arise in managing uncertainty through information. Individuals may assess and utilize multiple sources

of information over the course of an illness. For instance, people coping with illness may turn to healthcare providers (e.g., physicians and nurses), friends, family, the Internet, or health-related pamphlets for information (Brashers, Haas, Neidig, & Rintamaki, 2002). Furthermore, although seeking or avoiding information sources is one way that people manage their illness-related uncertainty, there may be challenges and dilemmas associated with these information management behaviors (Hogan & Brashers, 2009). Brashers, Goldsmith, and Hsieh (2002) suggested that the collaborative nature of information management (i.e., goals must be coordinated among individuals) and contextual features of information management (e.g., varying cultures and channels of communication) can present significant challenges, but less is known about how such challenges are communicatively addressed in the context of transplantation.

Theories of uncertainty management have been described in particular illness contexts (e.g., HIV; Brashers, Goldsmith, & Hsieh, 2002), and it is likewise important to examine the role that illness context plays in information management. Understanding the processes associated with information management in a specific illness context (e.g., transplantation) will bolster our confidence in generalizing claims about information and uncertainty across illness types. Further, practical suggestions for how to manage information and cope with potential challenges and dilemmas associated with information management may be context specific. Thus, the specific aims of the present study were to investigate: (a) What kinds of information behaviors do transplant patients engage in? and (b) What challenges do transplant patients face in using information to manage their uncertainty?

## Method

### Sample

We conducted in-depth interviews with 38 pretransplant ($n = 8$) and posttransplant ($n = 30$) patients (16 men, 22 women). Participants were between 28 and 76 years old and had a mean age of 49.9 years ($SD = 12.1$ years). The sample included 37 white participants and 1 African American participant. Pretransplant patients had been waiting for an organ between 2 and 36 months ($M = 1.4$ years, $SD = 1.2$ years), and three pretransplant participants were waiting for a kidney transplant, two were waiting for a heart, and three were waiting for a liver.

Posttransplant participants reported waiting between 1 day and 6 years for an organ ($M = .8$ years, $SD = 1.1$ years), and had been transplanted between 6 weeks and 14 years at the time of the interview ($M = 5.6$ years, $SD = 4.1$ years). Eleven posttransplant participants had received a kidney transplant (4 from living donors), eight received a heart, seven received a liver, three received a kidney-pancreas transplant, and one received a kidney and liver. Most posttransplant patients had received only one transplant, but three participants were receiving their second transplant, and one her third transplant.

### Data Collection

After receiving approval from the Institutional Review Board, we recruited participants through an advertisement in a local newspaper and through handouts distributed in support groups for transplant patients in several Midwestern states. People who were interested in the study contacted a member of the research team and were scheduled for a one-on-one interview at a location of their choice (e.g., library, restaurant, campus office). At the start of each interview, the interviewer described the purpose of the study and previewed the interview protocol for the participant. In addition, informed consent procedures were followed, with each participant being told that participation was entirely voluntary, that pseudonyms would be used in place of names in all reporting of results, and that he or she could opt to skip questions or withdraw from the study at any time. Interviews ranged in length from 30 minutes to 2 hours. After the interview, participants completed a short demographic questionnaire. Participants received $25 for their involvement in the research.

### Interview Guide

We prepared two versions of the interview guide with questions designed to elicit experiences from pretransplant patients and posttransplant patients. Both pretransplant and posttransplant interviews began with several questions about the participant's general transplant experience, which helped us orient our interview to the particular experiences of the pretransplant and posttransplant patients and provided context for the narratives that followed. After discussing the participant's general transplant experience, we asked a number of questions about experiences of uncertainty. We invited each participant to describe

"what uncertainty means to you" in the context of the transplant experience and how they responded to their feelings of uncertainty. If a participant described information seeking behaviors as a way he or she managed the uncertainty he or she experienced, we asked follow-up questions about what the sources of information were for each area of uncertainty previously described. For posttransplant patients, we also asked, "Was there any information or part of the transplant experience that people told you about or told you to expect that ended up not being true?" to learn about whether misinformation was a source of uncertainty. At the end of each interview, we gave participants the chance to talk about anything that we did not cover that they wanted to discuss.

During the first stage of data collection, three of the authors led in-depth interviews in which participants answered questions related to their experiences with information and transplantation. After conducting these initial interviews, all authors met to discuss preliminary themes in participants' responses to refine the interview protocol. Based on our preliminary findings, the interview protocol was revised to explore participants' experiences with uncertainty and information in greater detail. After this first stage of data collection, we conducted the remaining in-depth interviews.

## Data Analysis

We conducted preliminary analyses using a grounded theory approach, which involved refining research questions during the course of the study to pursue fruitful lines of inquiry (Charmaz, 2000; Corbin & Strauss, 2008). Digital recordings of the interviews were transcribed verbatim and distributed to each author for coding. Interview transcripts were analyzed using latent content (Lincoln & Guba, 1985) and constant comparative techniques (Glaser & Strauss, 1967). Our analysis was influenced by our understanding of relevant literature and theoretical concepts (Alvesson & Skoldberg, 2000). We used an iterative analysis process to constantly check each other's assumptions about the data against interview transcripts and to ensure that our conceptual categories faithfully accounted for the experiences of our participants.

First, at least three authors independently coded each transcript for themes. After this initial coding, we met to compare and compile our findings. Our initial coding led us to further examine the sources of information that participants described. We did this by returning to the

transcripts and focusing on participants' specific examples of, and stories about, the ways in which they used (and did not use) information throughout the transplant process. We then developed a detailed categorical system for describing the sources, behaviors, and challenges associated with information management described by participants. In the second stage of analysis, all authors returned to the transcripts to code using the refined categorical system. After the second stage of coding, we met to further refine the conceptual categories in terms of relevant literature, particularly work by Hogan and Brashers (2009) that categorized information behavior in terms of information acquisition and information use. Finally, we reached consensus about the interrelationships among these categories.

## Results

Participants reported coping with uncertainty through a variety of information management behaviors and discussed several information-related challenges in managing their uncertainty. Although participants focused primarily on information acquisition in their narratives, they also discussed the ways in which information was used as a tool for managing uncertainty.

### Information Acquisition

We follow Hogan and Brashers's (2009) definition of information acquisition which "reflect[s] the diverse means by which people come into contact with information in the course of their daily lives" (p. 49). Transplant patients reported a number of ways in which they acquired information for managing their uncertainty, including strategically (a) selecting sources of information, (b) seeking information, and (c) avoiding information.

#### Selecting sources of information

Patients mentioned many different sources of information they consulted in managing their uncertainty about transplantation, including medical professionals (e.g., doctors, nurses, transplant coordinators, pharmacists), the Internet, peers (i.e., other people who were waiting for, or who had experienced, a transplant), books, and transplant conferences and seminars.

Although patients expressed different preferences for sources of information, getting information from other people was generally preferred to getting information from print or online sources. Vanessa liked getting information from other people more than searching online: "I hated the Internet; I didn't bother with the Internet. I'd rather talk to someone. So I interviewed a bunch of different transplant groups, and I pestered the hell out of the doctors, and I'd keep asking them questions." Furthermore, patients expressed preferences for information from some groups of people over others. For instance, Walker explained why he would rather get information from peers than from doctors: "I find that the patient that's going through the stuff, they know more than what the doctors do." Some participants, though, preferred the Internet as a source of information. For example, several patients noted the helpfulness of being able to look up medical terminology or potential side effects of their medication on the Internet, as Rosemary did: "Anytime somebody tells me something I don't know, something medical, I go online." For many participants, information from preferred sources provided them with a way of reducing their uncertainty about the transplant experience.

However, some participants described how sources of information created additional uncertainty. For instance, the lack of knowledge exhibited by medical professionals who did not specialize in transplantation was a concern for Andy: "I'll probably never go to a non-transplant hospital again because I ended up having to do most of my care and explaining how the medications worked and all that because they just had no clue." Others expressed reservation at using the Internet. Louis explained why he was wary of the Internet as a source of information:

> They were developing WebMD back when I got sick. So I started reading the same stuff that the doctors are reading. I did that for about two weeks and [it] scared me so much that I quit reading it. They get into too much detail and start talking about survival rates.

For Louis, then, the Internet was not a useful source of information because of the content as well as the volume of information it offered.

Several patients mentioned the importance of assessing the quality of information sources. Andy explained that the Internet was helpful for learning about other people's transplant experiences, but not for learning medical information:

> I will take personal stories from the Internet and believe it—medical diagnoses from people in their blogs, not so much. You can have some stuff out there that they just don't know what they're talking about, so I didn't really look at anything for medical facts or percentages, but outside of that you can read people's stories.

Bob expressed a similar reason for his preference for getting information from medical journals: "You get a lot [of] information about that reading medical journals. You get a lot more stuff. They're not so worried about painting such a nice picture."

### Seeking information

Participants frequently named information seeking as a valuable tool for managing uncertainty. Rosemary explained that she "wanted to know what was going on all of the time" and constantly gathered information to diminish uncertainty about the transplant process. She advised other patients to, "Read everything. Get all the information you can get. Be totally aware of everything." Vanessa similarly described how seeking information allowed her to develop a clearer understanding of her medical choices:

> I would rather know what's out there, what options I have. Even if I can't choose that option or shouldn't choose that option, at least I want to know about it because I want to know my right to try this or try that. So I found the information to be helpful, even though it's hard to swallow.

Other transplant patients echoed Vanessa's desire to receive as much information as possible, regardless of its valence.

### Avoiding information

Although some participants reported seeking as much information as possible, others acknowledged that they avoided particular types of information. Avoiding information was a strategy utilized by patients to maintain uncertainty about possible negative outcomes associated with transplantation. In addition, participants avoided information to stave off the possibility that it would invoke new, undesirable uncertainties. Gene explained:

> I don't want to hear all the negative things that could happen because, when you're in a situation like mine where you need [a transplant]

anyways and you're going to do it, what's the use? I don't want to hear the bad parts of it because I really don't have a choice in the matter, so I've learned—I've kind of thought that helps with the uncertainties, if you don't know all of the consequences.

For some patients, like Gene, avoiding information and, in effect, maintaining uncertainty about some of the potential dangers of transplantation was a form of self-protection. In a similar vein, several people mentioned that they had learned to avoid information about transplant patients who did not survive to protect themselves from negative thoughts and feelings.

In summary, participants reported that they mindfully selected information sources based on their assessment of the credibility and utility of the sources. Participants also reported that seeking information can facilitate uncertainty management by providing an understanding of what is occurring and clarifying their options. By contrast, through information avoidance, participants were able to maintain uncertainty about some of the risks associated with transplantation as well as prevent the development of other uncertainties that could threaten their psychological well-being.

## Challenges of Information Use

Although seeking or avoiding information may facilitate uncertainty management, our data also illuminated several challenges related to the ways in which information was used by participants. Specifically, participants recounted difficulties regarding (a) the quantity and quality of information, (b) seeking and processing information under stressful circumstances, (c) the distressing nature of certain information, and (d) information that leads to conflict.

The quantity and quality of information may not be optimal. Some participants discussed feeling burdened by an overabundance of information. Elizabeth explained, "There's this massive amount of information about meds that you have to keep straight. And even now, that's a little overwhelming." Similarly, Audrey described the amount of available information about transplantation as "information overload." Sorting through a vast amount of material can be a time-consuming task, complicated by the fact that patients may have difficulty assessing the quality of the information. Sharon recalled:

> The way I dealt with my uncertainty was to absorb any and every bit of information I could get. I talked to people; I spent a lot of time re-searching online—hours and hours. There were times when I said [to my doctor], "Oh, I heard about this new stem cell research and they are injecting your own stem cells back into your heart and it's working." And my doctor said, "No, it's a lot of media hype. You have to be careful. As of today, we still don't know what they are doing. I certainly don't recommend it."

Some participants, like Sharon, turned to their doctors for help in evaluating the validity of the information they encountered, but others complained that the information conveyed by medical professionals sometimes lacked clarity. Bob lamented, "It's tedious keeping up with it [the latest information], and the doctors can always talk over your head. And they use that. If you start prying too much, 'medical-ese' just comes pouring out of 'em."

By contrast, a smaller number of participants felt that not enough information was available to them. Walker hoped that an upcoming visit to a hospital in a larger city would provide him with more infor-mation. He explained, "I don't know if it's just here or what, but the doctors and the nurses don't know much about the transplant. They're not really keeping me informed about what's going on." His frustration became increasingly evident as he listed several of the questions that he had been unable to get answered:

> And what does that mean for my immune system? Am I going to be a convalescent for six months or six days? When I get up there, what is the average wait time? Is it six months, a year? See, I don't get anything down here.

A lack of information exacerbated Walker's uncertainties about trans-plantation; an excess of information, however, had a similar effect on other individuals.

It can be difficult to seek or process information under stressful circumstances. Another challenge reported by participants was difficulty in seeking or processing information in the context of transplant-related stressors. For example, posttransplant patients may have trouble seeking information due to the fatigue that can mark the recovery period. Meredith explained:

> If I had felt better, I would have liked all the information I could get. You are extremely tired. I am still tired. I suppose it's because I'm older as well. I imagine I napped for six months after the surgery—I mean heavy napping, not just falling asleep in your chair; I slept.

In addition, several people noted that medical information sometimes became too overwhelming to absorb fully. For this reason, Matilda realized that she needed to bring friends and family members with her to appointments. In recognizing that their capabilities to absorb information were temporarily limited, some patients, including Matilda, turned to others for aid in these uncertainty management processes.

Some information is upsetting. A third challenge associated with information is that, inevitably, patients encounter disturbing news. Jerry described how reading about the deaths of individuals with similar health problems sometimes invoked doubts about his own long-term prognosis:

> You see someone in [the obituaries] that had kidney problems. They are about your age, but you don't know what other problems they had. I read that and think, "Is this going to be me in four or five years?"

Moreover, friends and family members can interfere with patients' attempts at avoiding distressing information, as evidenced by Isabel's account:

> Sometimes you don't want to know too much, and I already had people telling me stories, "Oh, so-and-so had complications like this and couple of years later they did this, and this happened." I don't want to know that stuff!

Information can lead to conflict. Although participants predominantly described the utility of information for making decisions, some participants noted that their information management strategies led them to situations where the information created conflict. Bob described his information-seeking behaviors as important to his care because he needed to be his own advocate. He said, "I found out that everybody's a better advocate for themselves." As he continued his story of the importance of acquiring and using information to make health-care decisions, he noted that this often led to conflict, saying, "I had nurses that hated me because I was always prying, always questioning everything." Having acquired information, Bob was confronted with

challenges in using it. However, conflict over information did not always result in a negative outcome. For participants in the current study, conflict over information often allowed for relationships to build between healthcare providers and patients based on trust and mutual understanding. More active participants who used information to question their healthcare providers thought they received better medical care. In short, although information seeking and avoiding can serve as tools for uncertainty management, several difficulties may be associated with these processes. Even if transplant patients are aware of their preferences for specific sources, types, or amounts of information, they may not always be able to access such information. In addition, the very uncertainty that patients seek to manage through information can compromise their capacity to process that information. Alternatively, information meant to manage uncertainty may actually exacerbate uncertainty (e.g., if the information is distressing or conflict-inducing).

## Discussion

Research demonstrates that uncertainty characterizes many aspects of the transplantation experience, and we sought to examine information management as one mechanism by which transplant patients manage this uncertainty. These findings have important theoretical and practical implications for the literature on uncertainty management, information management, and transplantation. The present study extends existing theory and research in several ways by providing further evidence for the role of information in managing uncertainty. First, the sources of information noted in this study overlap with the information sources noted in previous research on other health concerns (e.g., Brashers, Haas, Neidig, & Rintamaki, 2002). The current study builds on this extant work by identifying not only the various sources of information that transplant patients use to manage uncertainty, but also the ways patients go about strategically selecting information sources. Participants described some information sources as preferable to others because of factors such as the source's credibility (e.g., peers or doctors) and accessibility (e.g., the Internet or transplant seminars). No information sources emerged as universally preferred, and many participants recognized that certain information sources were valuable in some circumstances, but not in others. Moreover, the sources that were helpful to some participants in certain circumstances were not useful to others in

similar circumstances. This finding suggests that there is no one-size-fits-all solution for using information to manage uncertainty.

The challenges that participants in our study identified warrant further investigation in light of research that has examined direct and indirect methods for seeking information (Miller & Jablin, 1991). Researchers have argued that people should consider the balance between what is considered socially appropriate and what is effective when seeking information from others, suggesting that indirect methods might be more appropriate and effective when the information sought is considered sensitive (Berger & Kellerman, 1983). Although participants in this study described the importance of information seeking, they also described how assessing the quality of the information posed a challenge. Perhaps more attention to the relative benefits and risks of direct and indirect information seeking strategies would help to alleviate some of the difficulty of information management. Further, narratives from participants' experiences bolster recent research that has called for a closer look at information behaviors (Hogan & Brashers, 2009).

This study also has several notable practical implications for those involved in transplantation. In the case of healthcare providers, participants suggested that knowledge of transplant patients' ability to evaluate the validity of information is essential for providers to consider when describing the transplantation process. This is especially important considering how participants described using the Internet as a source of information. Because both reliable and unreliable health information is available online, healthcare providers might consider assessing the patient's knowledge level and sources of that knowledge before discussing plans for treatment or providing information about adjustments that should be made to daily activities. Moreover, participants described the importance of healthcare providers avoiding jargon when communicating with patients.

## Directions for Future Research

Our findings provide evidence that information is an important part of the uncertainty experience of pretransplant and posttransplant patients. This investigation focused on the experience of patients only, but supportive others typically share in the uncertainty and information management experiences during illness experiences (Stone & Jones, 2009; Ullrich, Jansch, Schmidet, Struber, & Niedermeyer, 2004). The

findings from this study also yield recommendations for close others who are providing support for transplant patients (see also Scott, Martin, Stone, & Brashers, 2011). As Goldsmith (2009) argued, uncertainty is a complex experience for close others, with clear implications for management strategies. Participants described how important it was for others, particularly peers, to be sensitive about not providing "bad news" stories when the patient may be trying to avoid negative information. It may be that close friends and family members could also serve as information filters, screening out unwanted or distressing information to relieve some of the challenges transplant patients face in managing information and uncertainty. Scholars might examine the information behavior of supportive others in the transplantation context. Furthermore, our findings related to the challenges of information management underscore the importance of examining the appraisal process for people coping with illness (Mishel, 1988). The data from this study provides a starting place for future research that can more directly examine these aspects of the transplantation experience.

## Conclusion

The ability of transplant patients to manage information and thus uncertainty can have implications for the person's physical and psychosocial health. The connection between uncertainty and information is complex, and the present study represents an important first step toward discovering how people assess and utilize particular sources of information as well as the challenges that can arise in managing uncertainty through information in the context of transplantation.

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