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**Uncertainty of Social Network Members
in the Case of Communication-Debilitating Illness or Injury**

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Abstract

Uncertainty is a consequential aspect of chronic illness for patients as well as family and friends, yet little research has focused on how non-ill individuals experience uncertainty about the condition of someone in their social network. Thirty-one individuals with loved ones who had a communication-debilitating illness or injury (CDI) participated in one-on-one interviews about their experiences. We analyzed transcripts for participants' sources of uncertainty and for ways that they managed the uncertainty. Participants' experiences with uncertainty included questions about the condition itself, and involved the impaired communication resulting from the CDI. Participants described managing uncertainty through information seeking, changing the ways they communicated with the person with the CDI, and creating schemata to help reduce uncertainty. We discuss the findings in terms of predominant conceptualizations of uncertainty in illness, and we address the prevalence of communication as both a significant source of uncertainty and an important means of managing uncertainty.

Keywords: uncertainty; communication; chronic illness; close relationships; stroke

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Uncertainty has been identified as a pervasive and significant accompaniment of illness and treatment, and a key feature of both acute and chronic illness (Babrow, 2001; Babrow & Mattson, 2003; Brashers et al., 2000; Mast, 1995; Mishel, 1993). A great deal of scholarly interest in uncertainty has led to an extensive body of research on people's experiences of uncertainty as they pertain to their experiences with illness. One primary assumption of research and theory about uncertainty and illness is that patients and their social network members can use communication as a means to cope with the illness and to manage their uncertainty (Babrow & Mattson, 2003; Brashers et al., 2000). What typifies uncertainty, however, when the patient's condition is characterized by a resultant impairment in the ability to communicate? This issue has both theoretical and practical implications, yet has received relatively little scholarly attention. Thus, in this article, we intend to begin to fill that gap in the literature. Our goal was to examine the uncertainty of social network members when a loved one experiences a communication-debilitating illness or injury.

Communication-debilitating Illness or Injury

The focus of this study is on the uncertainty experienced by friends and family members of patients whose communication abilities have been impaired. The term communication-debilitating illness or injury, or CDI, has been used to describe a chronic condition yielding an incapacity to use language in a standard manner (Bute, Donovan-Kicken, & Martins, 2007). This term describes the loss of communication ability that existed prior to the onset of the illness or condition, or prior to the occurrence of the injury. By language, we mean a system of symbols that is governed by syntax, phonology, semantics, and pragmatics, and by communication, we mean the verbal and nonverbal exchange of symbols in order to create meaning and achieve

goals (Bradac & Giles, 2005; Canary, Cody, & Manusov, 2000). A person's communication could be affected by a variety of conditions, for example, stroke (Sundin, Jansson, & Norberg, 2000), multiple sclerosis (Pring, 1999), Alzheimer's disease (Williamson & Schulz, 1990), and traumatic brain injury (Allen, Linn, Gutierrez, & Willer, 1994). Communication impairments and language disorders can range from slightly slurred words and occasional memory lapses to being "locked in" (i.e., able to construct lucid thoughts but unable to communicate them by mouth) to suddenly being incapable of reading simple sentences.

Impact of a CDI. Previous research has shown that a CDI presents significant challenges not only for patients but also for their non-caregiving family and friends (Bute et al., 2007). Social network members of a person with a CDI have reported a variety of positive and negative changes to their relationship with CDI patients and to the way they communicate with the patient, and have indicated the distressing effects of a patient's impaired communication. Family and friends of CDI patients have also described making adjustments to the way that they interact with the patients to compensate for the communication disability (Bute et al., 2007). This research is similar to previous research which has indicated that people with chronic illness experience changes in their relationships and their interactions (Lyons, Sullivan, Ritvo, & Coyne, 1995; Wells, 1999). As patients deal with pain, the rehabilitation process, and changes in relationships, those experiences unfold concomitantly with social network members' own experiences, many of which potentially entail a great deal of uncertainty.

The Uncertainty of Social Network Members

For the most part, the research on uncertainty and illness has focused on the prominence of uncertainty in the experiences of patients alone, or on patients and their primary caregivers. For example, recent research has examined uncertainty in the context of many illnesses, some of which fall under the classification of CDI, including brain injury (Man, 2002); asthma (Mullins,

Chaney, Balderson, & Hommel, 2000; Sexton, Calcasola, Bottomley, & Funk, 1999); cancer (Beach & Good, 2004; Sammarco, 2001; Wallace, 2003); multiple sclerosis (Gold-Spink, Sher, & Theodos, 2000; Mullins et al., 2001); HIV/AIDS (Brashers et al., 1999; Brashers et al., 2000; Brashers et al., 2003); and stroke (Becker & Kaufman, 1995; Brereton & Nolan, 2002; Close & Procter, 1999; O'Connell, Baker, & Prosser, 2003; Scholte op Reimer, de Haan, Rijnders, Limburg, van den Bos, 1998). This corpus of research has demonstrated that uncertainty has implications for how people receive and understand diagnoses, cope with symptoms, adhere to treatment regimens, and maintain relationships.

Understanding the uncertainty experienced by social network members is important for a number of reasons. First of all, a study like this can contribute to the literature on uncertainty and illness by providing descriptions of the nature of illness-related uncertainty as it pertains to non-injured or non-ill individuals. Currently, little is known about the uncertainty of family and friends of patients, especially if those family and friends are not the patients' caregivers. In a review of the literature on uncertainty and illness, Mishel (1999) called for more research on how uncertainty is experienced in diverse relationships. This lacuna in the literature merits attention, considering that the limited research has indicated that a patient's social network members are faced with their own feelings of uncertainty and unpredictability (e.g., Mitchell, Courtney, & Coyer, 2003; Northouse et al., 2002). Furthermore, as much as scholars have acknowledged the importance of studying interaction in health contexts, most health communication research has focused on patient-provider relationships, and it is important to consider members of the patient's social network who may influence patient outcomes (Acton & Miller, 2003; Lyons et al., 1995). Second, looking at social network members' uncertainty creates opportunities to test and extend current conceptual frameworks of uncertainty and illness, which, again, tend to focus on uncertainty from the patient's point of view. It is yet to be determined how the uncertainty of

family and friends fits into these theories, and how broader understanding of the processes involved with uncertainty can be better understood by attending to the experiences of non-caregiving family and friends. Mishel (1997, 1999) has argued that much of the research on uncertainty in illness is atheoretical; the present study attempts to answer questions about the uncertainty of social network members of CDI patients in not only a systematic, but also a theoretical manner.

Finally, this area of research is consequential for practical reasons. Especially in the case of critical or chronic illnesses, family members' and close friends' uncertainty may affect their ability to cope with the illness situation. Research already indicates that relationships can suffer after the onset of an illness, because family and friends experience discomfort, distress, and anxiety about what to say and how to act (Lyons et al., 1995). This, in turn, has implications for how likely they are to maintain a relational bond with the patient at all, and can alter how effectively they can help the patient adapt as well (Mitchell et al., 2003). Factoring communication disabilities into uncertainty processes can provide additional insight, because communication has been linked so closely with uncertainty (e.g., Babrow, 2001). Another area of practical import is that family and friends are often key links between health care providers and patients. Managing any chronic illness cannot be effectively accomplished without taking into consideration the rest of a patient's family (Strauss & Glaser, 1975), and the complexity of illness management is compounded when not all parties are able to communicate. Knowing more about network members' perceptions has the potential to improve the care of patients, because communication with CDI patients is difficult even for experienced health care providers, and family and friends are often some of the most important liaisons and sources of information between patients and health care staff (Hokenstad, Hart, Gould, Halper, & Levine, 2006; Sundin, Norberg, & Jansson, 2001). Family and friends' interpretations of what CDI patients think, need,

and want often get communicated to health care workers at home, in hospital, and in skilled nursing facilities.

For all of these reasons, the uncertainty experiences of social network members during this type of illness experience warrant exploration. The following section outlines the conceptualizations of uncertainty that provide a framework for this study of family and friends of CDI patients.

Conceptualizing Uncertainty

Uncertainty can be defined as the perception that one lacks knowledge about, or lacks the ability to establish meaning of, illness-related circumstances (Brashers, 2001; Mishel, 1998). Mishel's (1988) original model of uncertainty in illness, which has guided much of the research in this area, encompassed the following sources of uncertainty: ambiguous symptom patterns, complex systems of treatment and care, insufficient information about diagnosis, and unpredictable disease progression or prognosis (Mishel, 1988). The severity of the illness, specificity of diagnosis, personality factors, social support, health care providers, and demographic variables have frequently been explored as causes of uncertainty (Mishel, 1997). The original model of uncertainty in illness was specific to acute illness; Mishel (1990) reconceptualized her theory of uncertainty in illness to address the ongoing nature of chronic illness. The unique characteristics of a chronic condition, such as a CDI, include unpredictability and inconsistency in symptoms, looming questions about recurrence or aggravation, and an indefinite future. The sources of uncertainty in chronic illness often include the nature of the illness, perceptions about the future, concept of self, lack of information, social support, and health care providers (Mishel, 1999).

Uncertainty is typically conceptualized as a psychological state (Babrow, Kasch, & Ford, 1998), with emphasis on individuals' first perceiving uncertainty, and then reacting according to

their assessment of how the uncertainty will affect them. Uncertainty, then, is itself a neutral experience, neither inherently bad nor good (Brashers, 2001; Mishel, 1988). Rather, it is the appraisal of uncertainty that determines one's affective response to the uncertainty, depending on whether uncertainty is viewed as beneficial or harmful (Brashers et al., 2000; Mishel, 1988). To that end, it is possible that social network members of CDI patients might perceive uncertainty in different ways. Some may interpret a lack of information as a threat to receiving more effective treatment, whereas others might embrace uncertainty as a way to avoid finding out even more bad news. After a stroke, for instance, when language use has been impaired, family and friends will likely wonder about the severity and the permanence of the communication disability. Social network members may experience uncertainty for similar reasons but may manage their uncertainty differently: Some may be vigilant about seeking several professional opinions of how much speech recovery might be expected, whereas others may be more comfortable not knowing, and may take more of a watch-and-wait approach.

Especially when an illness is chronic, the ongoing nature of the illness makes uncertainty a part of life (Brashers et al., 2000; Mishel, 1999). Whereas in the case of acute illness, people often desire to reduce uncertainty (e.g., seeing a physician in order to receive the proper medication), individuals who are dealing with a chronic illness may shift from uncertainty reduction to uncertainty management. Family and friends may adjust over time as their uncertainty becomes a constant presence in their relationship with the CDI patient. A grounded theory of parents of seriously ill children has indicated that they live under conditions of sustained uncertainty, with intermittent upsurges when something newly unusual occurs (Cohen, 1995). Even seemingly positive events can be sources of uncertainty that may or may not be welcome, as in the case of persons with HIV/AIDS who experience uncertainty due to "revival," when their health unexpectedly improves after they have already come to terms with their

terminal illness (Brashers et al., 1999). It is also useful to point out that uncertainty may include questions about matters other than the medical aspects of the experience: Brashers et al. (2003) extended Mishel's (1990) model of uncertainty in illness beyond medical uncertainty to include personal and social sources of uncertainty. The findings from their qualitative study corroborated Mishel's (1999) earlier prediction that uncertainty in chronic illness is not limited to diagnosis, prognosis, and treatment, but that it penetrates a person's entire life because the illness experience creates ongoing uncertainty about life in general—including uncertainty about what illness means in terms of personal identity, what to expect from relationships, and the implications of illness for professional and financial goals (Brashers et al., 2003). This research considered the uncertainty of patients, but it stands to reason that social network members of CDI patients likely experience uncertainty about issues beyond the diagnosis of, treatment for, and recovery from the CDI itself.

Research Questions

The limited research on the uncertainty experienced by friends and family members of a chronically ill person has indicated that social network members are likely to encounter uncertainty about a number of issues. For instance, Mishel and Murdaugh (1987) found that healthy spouses reported elevated uncertainty about their relationship with spouses who had had heart transplants. Uncertainty has been identified as an issue for families with loved ones in hospital intensive care units (Mitchell et al., 2003), family members of people with traumatic brain injury (Jumisko, 2005), and family members of people with esophageal cancer (Andreassen, Randers, Näslund, Stockeld, & Mattiasson, 2005). Results of a study by Northouse et al. (2002) revealed that family members of women with recurrent breast cancer reported more uncertainty about the illness than the patients themselves. Family members of patients with end stage renal disease have reported uncertainty as a major source of stress (Pelletier-Hibbert &

Sohi, 2001), and even those who did not live with the patient experienced uncertainty regarding long-term issues. Notably, the current study is one of the few investigations to our knowledge that focuses mainly on family and friends who do not reside with the patient. In addition, we are studying a constellation of illnesses with the common characteristic of being marked by dramatic loss of communication ability, an illness context that has not been explored in this way before.

Our goal, then, was to examine uncertainty experienced by friends and family members of CDI patients, both in general and with regard to how the chronic condition has affected communication. We posed the following research questions:

RQ1: What are the sources of uncertainty for family and friends of CDI patients?

RQ2: Which sources, if any, pertain to the patient's impaired communication ability?

RQ3: How is uncertainty managed by these social network members?

In the following section, we describe our data collection procedures and data analysis techniques.

Method

Methodological Approach

Using one-on-one interviews, we asked family and friends of CDI patients about their experiences since the onset of the CDI. We collected these data as part of a study designed to broadly explore the issues faced by friends and family members when a loved one experiences a CDI, including the stresses and changes they had experienced, and how the CDI affected communication. We collected data with the use of a semi-structured interview schedule and analyzed data in accordance with constant comparative techniques in an effort to extract information that was “embedded in individual's experiences” (Michallet, LeDorze, & Tetreault, 2001, p. 733). This method follows Mishel's (1999) recommendation for giving priority to qualitative work in new areas of research on uncertainty in illness. A qualitative approach permitted participants to share a wide array of complex responses about their uncertainty

experiences, and imbue their responses with illustrative details about sources of uncertainty and management of uncertainty. In the paragraphs that follow, we describe in greater detail the sample and procedures.

Participants

Volunteers from a medium-sized Midwestern city agreed to participate in face-to-face interviews to discuss their experiences with a friend or family member who had a CDI. We employed purposive, non-probability sampling to recruit participants in multiple ways: through flyers distributed at local support groups related to brain injury and stroke; with a notice for the study posted in a university-wide email newsletter; and with an announcement of the study in a newspaper for university staff and faculty. We advertised for volunteers with close friends or family members who had an illness or injury that changed how they spoke or otherwise used language. We provided examples of conditions (“Related illnesses or injuries include, but are not limited to, stroke, Alzheimer’s disease, and brain trauma”). We screened potential participants who contacted us by confirming that they understood what we meant by CDI. Each participant received \$15 for his or her participation. All recruitment, remuneration, and data collection procedures, including the interview protocol, received Institutional Review Board approval.

Thirty-one volunteers (8 men and 23 women) participated in the study.¹ We solicited participants who had dealt with a variety of illnesses and injuries, because we were interested in conditions which had in common a communication disability, but we did not want to limit the scope of this exploratory effort to one particular condition. The most common CDI reported by participants was stroke ($n = 18$), followed by brain injury ($n = 3$), brain tumor ($n = 3$), autism ($n = 2$), and Alzheimer’s disease ($n = 2$). The rest of the conditions were each reported only once; these were AIDS, bleeding in the brain, dementia, and throat cancer. The number of participants

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reporting on stroke was not surprising because language disabilities occur most often with stroke patients (Sundin et al., 2000). The length of time patients had experienced the CDI ranged from approximately six months to 12 years ($M = 4.2$).²

CDI patients on whom participants reported represented a variety of relationships, including parents ($n = 18$), nephews/nieces ($n = 3$), siblings ($n = 2$), grandparents ($n = 2$), spouses ($n = 2$), close friends ($n = 3$), and a mother-in-law ($n = 1$). Twenty-one participants reported communicating with the patient on at least a weekly basis. Of these, nine participants, or almost one-third of our sample, reported daily communication with the patient.³ Not every respondent described the patient's current living situation, but among those who did, they reported that patients lived at home with caregivers ($n = 10$), in a nursing home/skilled nursing facility ($n = 9$), or in an assisted living community ($n = 2$). Participants in our study ranged in age from 25 to 75 years ($M = 42.6$), and at the time of the CDI diagnosis, patients were between the ages of 15 to 96 years ($M = 61.5$ years), excluding one especially young case, an 18-month-old child. Most participants in our sample held an advanced degree ($n = 18$) or a four-year college degree ($n = 7$). Our participants also included those with a two-year college degree ($n = 2$) and those who had completed some college ($n = 3$) or some graduate school ($n = 1$).

Interview Schedule

Based on the goals of the broader study and a review of the literature on interpersonal communication and chronic illness, the authors and two other researchers generated, revised, and agreed upon a series of interview questions. A pilot interview was then conducted to gauge the appropriateness and progression of the questions. After the pilot interview, the interview schedule was revised to enhance comprehensibility and completeness during data collection. Throughout the data collection and analysis processes, we met to discuss the suitability of the interview protocol. We continued to work from the same topics and range of questions to

maintain consistency, while allowing for flexibility during the interviews themselves to enhance comfortable communication between researcher and respondent and to make probing both possible and effective (Lloyd, Gatherer, & Kalsy, 2006; May, 1991). The pilot interview was transcribed and analyzed as part of the final sample. These procedures are similar to those followed by Kuyper & Wester (1998), who conducted interviews with partners of people who were chronically ill.

The interview schedule included four topic areas. First, we asked for background information about the CDI patient, including the onset and progression of the condition. Next, we asked about changes and stresses that the participant had experienced in conjunction with his or her loved one's condition. Then we inquired about the nature of the relationship between the participant and the CDI patient. Finally, we asked specifically about communication between the participant and the injured person, including times when they were alone and instances when other people were involved. In closing, we asked participants what, if anything, they had learned from their experiences knowing someone with a CDI, and invited them to share any remaining thoughts. The complete interview schedule can be found in the Appendix.

Data Collection and Analysis

To ensure voluntary participation, potential participants called or emailed one of the researchers to express interest in the study, in response to advertising aimed at support groups and community members. We screened potential participants to ensure that their loved one's condition corresponded with our general definition of a CDI. We then scheduled one-on-one interview sessions with participants. During the first part of the interview, participants completed a consent form and a brief open-ended questionnaire regarding background information about themselves (e.g., education level and their relationship with the patient) and the person they planned to discuss (e.g., what condition the patient had). We explained the purpose of the study

and previewed the interview schedule, and we reminded participants that they could stop the interview at any time without penalty and still receive their monetary incentive for participating. Each interview lasted approximately one hour and was audio recorded with the participant's permission. Each interviewer also took brief notes during the interview. Audio tapes were transcribed for the purposes of data analysis.⁴ After data collection began, we continued to interview additional participants in an effort to increase the scope and adequacy of the data (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Uncertainty about various aspects of the patient's illness and communicative ability emerged as a dominant theme in participants' responses. Our goal in data analysis was to carefully analyze the patterns prominent in the underlying meaning of participants' responses to interview questions. We used latent content analysis (Babbie, 2001) and constant comparative techniques (Strauss & Corbin, 1990) to detect themes in the ways that participants conceptualized, experienced, and communicated uncertainty. This method of analysis has been used to examine uncertainty in transcripts of focus group interviews with HIV patients (Brashers et al., 1999). Analyzing the data in this way follows grounded theory methodology guidelines which emphasize identifying categories that emerge from data and inductively giving meaning to the emergent themes (Strauss & Corbin, 1990). In an initial reading of the transcripts, uncertainty emerged as a prominent theme in participants' experiences, even though the interview protocol did not include a series of questions focused on the topic of uncertainty. To explore themes of uncertainty, we began by independently analyzing a random sample of 25% of the transcripts to identify general preliminary categories of uncertainty in the data. We then met to discuss and compare our interpretations and negotiate a series of categories that we used to give structure to our analysis. We returned to the transcripts several times, to find and develop more conceptual themes relevant to respondents' perceptions of feeling uncertain, having questions, perceiving

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that they lacked sufficient knowledge, what created uncertainty, and how uncertainty was managed. We met to refine categories and reach consensus on exemplars of categories. In the next section, we report the major findings.

Results

All of our participants discussed uncertainty to some extent. Some participants mentioned uncertainty as just one of the many aspects of their experience with their friend or family member's CDI. For many participants, however, it was clear that uncertainty was an especially prevalent facet of their narratives. From our interview transcripts, we identified both sources of uncertainty and ways of managing uncertainty. In this section, we discuss the overarching themes in each of these areas.

Sources of Uncertainty

Participants reported two prominent sources of uncertainty: (a) the condition itself, and (b) communication with the patient. Uncertainty about the condition included questions about the patient's initial diagnosis, the cause of the CDI, the patient's long-term prognosis, and general questions about why this had to happen at all. Uncertainty about communication with the patient comprised understanding the patient, knowing the patient's thoughts and feelings, wondering about the patient's cognitive abilities, and figuring out how to communicate with the patient.

Uncertainty about the condition. Participants reported experiencing uncertainty about the patient's initial diagnosis when they learned that the friend or family member had fallen ill or had an accident, or when they first started noticing significant symptoms of a potential medical problem. Most participants were concerned with learning an actual diagnosis (e.g., Did Dad have a stroke?; Why does Grandma keep forgetting things?). The attention of some participants was fixed on the extent of the damage caused by the illness or injury, as in the case of one woman,

whose grandmother had a stroke. This woman was not at the hospital and was receiving information from other relatives: “I didn't know how bad it was. I heard she can talk. She sleeps most of the time. When she's awake she talks to you. I didn't know how bad. I didn't know how good.” An immediate question that many participants had was whether the patient would live or die. This was especially true for participants whose friends or family members were admitted to the hospital after a sudden incident, such as a stroke or an accident, when the patient's life was threatened.

Another area of uncertainty for participants was the cause of the condition. In some cases, after months or even years, it was unclear what had precipitated the onset of the CDI. One participant was unsure of the cause of her father's stroke, and she could not identify any telling signs. Her father was a practicing physician, in seemingly good health, and he exercised regularly. She said:

He was just too young and they could never find a source for it. By the time they got him and did all the scans, there was no evidence of it. All they could say is that maybe a clot formed under his left ear.

In this woman's case, no one had suspected her father's impending health problem. Other participants reflected back on the time leading up to the onset of their friends' and family members' CDIs and expressed uncertainty about the meaning of ambiguous symptoms. One respondent talked about how she and her relatives were curious about her aunt's suddenly searching for words, which was atypical for her: “She's a very well-read person and she does crossword puzzles all the time and she's usually well spoken. And when you notice that, you don't know if it is anything of significance.” She was curious about her aunt's behavior for some time before eventually learning that her aunt had a series of mini strokes.

In contrast to the previous examples, which demonstrate participants' uncertainty about the physiological cause of the CDI, some participants also questioned who may have been responsible for contributing to the onset of the condition. Some participants wondered if the patient's poor health habits were to blame; others considered the possibility of inadequate medical care; for instance, following her mother's stroke, one woman said:

We always questioned if [the doctors] hadn't done some things, like the medication they put her on. Did that put her into the stroke? Who would ever know that? The hospital that let her go to the bathroom while she was just learning to walk again, and now she would never walk again. Whose fault was all that? Who dropped the ball?

A third theme related to the condition was the uncertainty of the patient's long-term prognosis. This included questions about the possibility for, and extent of, physical and mental recovery:

They said a complete recovery for him would be one to two years. I don't know what the word "complete" means. My question to them was how long would it take to get [my friend] back to the way he was...How long will it take for him to be completely normal? What is "normal"? Better than what?

Uncertainty about long-term prognosis also included more general questions about the patient's future and quality of life. Said one participant of her husband, who had a brain tumor removed, "[He has] no problems driving...He can use his power tools again...He can read to our daughter...It's just a question of what to do with the rest of his life."

Finally, some participants had general philosophical questions: They asked themselves whether there was some larger, spiritual reason for the CDI happening. They discussed the entire experience in terms of "Why him? Why now? Does he deserve this?"

Uncertainty about communication with the patient. A prominent source of uncertainty reported by our participants was understanding the patient. Participants were often unsure of what words patients were trying to communicate because the CDI had impaired the patients' ability to speak. This idea was expressed by a person whose father had throat cancer:

You really couldn't understand him or anything he was saying because his speech was so slurred. And then when they found the cancer and he had the operation, it just went downhill from there. It is very, very difficult to understand what he is saying.

Sometimes, patients retained the ability to articulate or enunciate words with clarity; however, participants still expressed uncertainty about what those words meant, and about the message the patient was trying to convey. One particularly confusing episode was recounted as follows:

There was one time in August I said, "How is your speech therapy going?" and she showed me that she's practicing words and she showed me the lists [of words]. I said, "Are you supposed to practice these?" and she said, "Yes." And then I didn't get it, we were going down to the elevator and she'd go, "Bird." And then I didn't get it. I didn't know that subject was something she was practicing.

Communication is by no means limited to verbal messages. Some uncertainty about being able to understand the patient was related to difficulty interpreting the patient's nonverbal cues. This was especially true in cases where the patient had lost all ability to make sounds.

Another aspect of uncertainty, closely tied to the patient's CDI and impaired communication, was not knowing the patient's thoughts and feelings. This included not knowing what the patient wanted, or whether the patient was stressed, upset, happy, excited, in pain, and so on. This source of uncertainty refers to participants' not knowing what a patient was thinking because the patient was unable to communicate it. One man put this feeling into words when talking about his friend who had AIDS-related dementia:

I would see tears rolling down his cheeks sometimes. I didn't know whether that was from he was touched and he was pleased to be remembering something that I was talking about, or whether he was angry that he wasn't out there doing stuff still, too.

Many participants voiced uncertainty about the patient's cognitive abilities—whether the patient could comprehend what was being said, what was happening around him or her, or what was wrong with him or her. One respondent said about his friend, “It had gotten to the point where it wasn't just the speech, it was probably also his cognition...you weren't sure if he even understood the question.” After her grandfather had a stroke, one woman explained,

I wondered how much he knew, and how much he understood. When he heard me did he hear jumble or did he hear words? That was something I was very curious about, because he would say things jumbled, so did he hear things jumbled? How much did he understand?

Sometimes participants tried to explain important information or a noteworthy event to their friends and family members, and they could not tell if the patient understood what they meant or what was happening:

Well, there are times when I say things to her and I'm not sure she understands. I think she understands a lot of what I say, I'm just not sure she understands everything. For instance, recently, my father died, and she had been divorced from him for many years, but they had reconciled. I told her after a delay of a few weeks, and I wasn't 100% sure that she understood because she didn't have a whole lot of reaction. I'm not really sure all of the time.

A final theme that emerged around uncertainty about communication was wondering how to communicate with the patient. Because patients were unable to communicate as before, and could not provide feedback about what worked best for them, participants were often uncertain

about what topics of conversation were appropriate and what strategies for communication were most successful. Choosing topics to discuss could be difficult: “It’s kind of hard because, not that I don’t feel relaxed around him, but at the same time, it’s like, ‘Well, what can I do? What do I have in common with him really anymore?’” Uncertainty about communication mechanics was expressed by many participants, for example: “I am not always sure if it is helpful when we try to guess what she is trying to say or if we should let her struggle along with it.” Overall, as is described in the various sources of uncertainty above, participants found that communication with their loved one was rife with uncertainty.

Management of Uncertainty

Participants reported responding to uncertainty in a variety of ways. In an effort to manage their uncertainty about the CDI and about communication, participants used information seeking, changed their communication mechanics, tried to create answers to their questions by inferring or speculating, and maintained or accepted their uncertainty.

Information seeking included various means of gaining knowledge about the CDI: researching via the Internet, medical journals, or mainstream periodicals; talking to health care providers; joining support groups; and talking to other members of the patient’s social network about the patient’s condition and how to communicate with him or her. Participants sought information for themselves as well as on behalf of the patient. One respondent’s husband had a brain tumor removed, and lost some of his cognitive capacity and communicative abilities. This person reported that she looked for information about their situation: “I joined the Brain Advocacy Association, I get the Heads Up! newsletter, and looked into patient advocacy. I was the one looking into all the health insurance stuff...I’m still reading about brains.”

By changing the mechanics of communication, participants used specific communication strategies, and worked with patients to communicate more effectively, in order to manage their

uncertainty. Examples included asking “yes” or “no” questions, writing things down or using pictures, using repetition, avoiding too much detail or complexity, and contextualizing the conversation. We were told of the effort involved in interacting with the CDI patients:

Sometimes we have to kind of get her physically engaged first. Sometimes she’ll be kind of dozing off and we have to rouse her a little bit. We ask her how she’s doing and if she knows who is here today. We try to establish first if she is alert enough to have a conversation. Then we talk to her about the weather and the seasons and try to remind her what time of year it is, and put her in the right place in time. Get her to think about the larger situation outside the nursing home, and where she is in time and space.

Over time, this particular participant learned to establish this type of routine with her mother-in-law in order to feel more confident that her mother-in-law would understand her.

A prominent theme in our findings was that participants would often try to create answers to their own questions as a means of managing their uncertainty about various issues. Sometimes this was an immediate response to uncertainty, which we have termed inferring, wherein participants read cues to try to understand the patient during the context of an interaction (e.g., concluding that Dad is unhappy based on the way he blinks his eyes). Inferring occurred in a number of instances; participants used strategies that they developed to reduce their uncertainty about what patients were trying to say, or about patients’ thoughts or feelings. Participants learned to draw conclusions about patients’ thoughts and feelings by recognizing signs and patterns. They had to spend time learning how to read the patient’s body language and understand what certain utterances meant. When asked how they could tell that the patient was upset, or how they could tell that the patient understood them, participants often said simply, “You could just tell.” Sometimes participants learned to look for a particular response to verify

that the patient understood them. By watching for her mother's physical response to her words, one woman could tell whether her mother understood her:

If you tell somebody that they have to go now or that it's time for dinner and then they get up and go, you know then. So it would be, the only things ever really you could tell she understood was when she physically responded to.

In addition to gauging nonverbals, participants also sometimes just relied on their past experiences with the patient, or their longtime familiarity with the patient. One man spoke of his wife of 52 years, who had a brain tumor: "We don't have to talk much. I know what she means."

Another way that participants reported creating answers to their questions involved more global evaluations of the situation at hand. Rather than trying to decipher a certain word during a given interaction, they answered questions they had about the condition or about the patient's frame of mind by hypothesizing and attributing—we termed this speculating:

And now, I think that he is becoming...well, he has accepted where he is right now. He says, "I'm fine, I go fishing every day. I am retired," that kind of thing. He will tell you when you don't even ask. I think that maybe he is trying to talk himself into it that he is okay; it is good to be alive and that kind of thing.

This respondent was uncertain about her father's feelings about his illness. In this example, she drew her own conclusions about her father's acceptance of it, even though he had never articulated his thoughts to her. When asked whether she discussed her mother's health condition with her, another woman indicated that it was ineffective to try to talk to her mother; instead, she had her own opinions and speculated about her mother's understanding:

There wasn't anything [to really talk about], and I certainly didn't want to depress her by saying, "This is it; this is what your life is." I think she knew that. Nobody had to tell her that.

A final means by which participants managed their uncertainty was to maintain and accept uncertainty. In other words, not all responses to uncertainty were directed toward reducing uncertainty; rather, sometimes participants chose to maintain their uncertainty. One person, who had engaged in a great deal of information seeking about her husband's condition, also acknowledged occasionally blunting negative information when interacting with speech therapy professionals: "There's part of me that doesn't want to get the answer I don't want, so I don't ask." In this case, uncertainty was maintained by actively avoiding information. Some participants just accepted the fact that they could not always understand what the patient was trying to communicate to them. A certain tolerance for uncertainty was sometimes articulated by our participants: "I had no idea what she was talking about and she was trying to tell me something very persistently. I just needed to move on in the conversation because I didn't know what she was saying." In addition, some participants seemed to actually embrace uncertainty. For instance, one man recalled feeling more optimistic when he did not know whether his mother would recover her speech after her stroke; before he realized that she would never recover it, he was able to cling to the hope that she would regain her ability.

Discussion

In conducting this analysis, our objective was to bring to light the uncertainty experiences of friends and family members of an individual with a CDI. Looking at this particular illness context in this way has provided some new insight into how people experience uncertainty when a loved one is seriously ill. Previously, much of the research related to our study has examined the experiences of spouses (Baxter, Braithwaite, Golish & Olson, 2002) or parents with ill children (Cohen, 1995; Mishel, 1999). In this research, we cast a broader net with regard to relationship type, by including participants who were nieces, cousins, adult children, friends, and coworkers of CDI patients. Moreover, whereas early research on family and friends

acknowledged the probable existence of their uncertainty, we have offered an indication of the specific ways in which friends and family members experience uncertainty, what triggers their uncertainty, and how they attempt to manage it. For instance, participants in our sample were uncertain about the patient's diagnosis, the progression of the illness, and the meaning of ambiguous symptoms.

In many ways, friends and family members of CDI patients experienced sources of uncertainty that parallel the medical sources of uncertainty described in previous qualitative research (Brashers, 2003; Mishel, 1988). At the same time, the distinct categories we identified in this article indicate that different types of information and assistance might be helpful at different points in the course of the illness or injury. Perhaps initially, family and friends are likely to have questions mainly about the patient's chances of survival, whereas over time, they might experience uncertainty about how the condition will manifest and change. It is possible that social network members experience rises and falls in uncertainty, as they become skillful at interpreting patients' limited communicative cues and yet are challenged by unexpected changes in patients' (dis)abilities. Awareness of the variety of ways that family and friends experience uncertainty could be useful for health care professionals who are trying to help loved ones cope. The early days and weeks following the onset of a CDI seemed to be fraught with uncertainty, however, even after a long-term prognosis and care plan have been established, questions remain. As Cohen (1995) has pointed out, the stability of a serious condition does not eliminate uncertainty; it may be useful for health care providers to bear in mind that family and friends' uncertainty exists even years after onset.

Additionally, we see in our findings a reinforcement of the intrinsic link that has been identified between uncertainty and communication (e.g., Babrow, 1992; 2001), albeit in a unique way. Specifically, based on our findings we wish to emphasize the importance of considering

communication ability. In the case of many illnesses, network members can rely on communication with the patient both to express and to manage their uncertainty. For instance, they may discuss information from health care providers, or talk about treatment options with the patient. The ability to carry out such tasks is compromised when a patient experiences a CDI; therefore, customary methods of managing uncertainty about the illness itself (e.g., seeking information together) may be inadequate or impossible. The approaches that our participants discussed provide some insight into how patients and their loved ones negotiate the processes of uncertainty appraisal and management together in uncommon ways.

Furthermore, recognizing communication impairment as a specific source of uncertainty adds to the current theorizing on sources and management of uncertainty (Brashers et al., 2003; Mishel, 1988; 1999). When impaired, communication may in itself comprise an aspect of medical, personal, and social uncertainty, and the traditional means of managing uncertainty become limited. Mishel's (1988) model of uncertainty in illness identified cognitive ability as a resource that can reduce people's uncertainty; we would propose that communicative ability can affect how people reduce or maintain uncertainty as well. We are reminded by the findings of this research that theories which assume unimpaired communication ability may not always be adequately equipped to explain the experiences of people who are in a situation in which a person's capacity to communicate normally has been compromised.

The original goal of our study was to broadly explore the overall experiences of friends and family members of CDI patients, and not just their feelings of uncertainty; therefore, we did not ask a series of questions pertaining specifically to uncertainty. Yet the robust nature of our results would indicate that even without prompting, uncertainty still emerged as a prominent theme in the responses of our participants. In addition, the collaborative nature of the data analysis enhances the validity of these findings (Pyett, 2003). Other researchers have noted the

value of carefully analyzing participants' experiences and detecting recurrent themes which emerge from responses to questions which do not specifically address that particular concept (Hinton, 1981). Thorne, Hislop, Kuo, and Armstrong (2006) demonstrated that among people who recounted their experiences with cancer, one specific aspect which stood out as salient and meaningful to them was being confronted with numerical information (e.g., likelihood of recurrence): "Although we asked no specific question intended to draw out this particular form of communication, its prevalence among and between participant accounts became evident as a powerful theme characterizing a shared element in the experience of our research participants" (Thorne et al., p. 322). We observed several themes related to uncertainty among the narratives of participants in our sample, and it seemed apparent that uncertainty was a significant facet of their overall experiences with a relative or friend who had a CDI.

Limitations and Suggestions for Future Research

Our data that suggest the value of examining social network members' uncertainty experience. However, there are some limitations to this study. First of all, it does not reflect an exhaustive sample of CDIs, and the majority of participants in our study discussed stroke. Therefore, our sample does not include a comprehensive representation of different types of conditions. It is also important to recognize that the types of conditions associated with communication impairment, like stroke and brain tumor, for instance, are highly variable in nature. The uncertainty surrounding them could be quite different from the uncertainty accompanying other chronic illnesses; these findings may not accurately reflect the experiences of family and friends of patients with other conditions. The participants in our sample were highly educated, and it is possible that their experiences are not characteristic of a more diverse population. For instance, education level may impact how individuals manage uncertainty: people with more education may be better equipped to obtain useful information from health care

providers, literature, and other sources, and they may also be better able to understand information that they receive.

We have contributed to current understanding of uncertainty in illness by exploring the experiences of friends and family members and by studying communication-debilitating illness and injury. However, the exploratory nature of this study indicates a need for additional research. Future research could explore further how the impairment of communication affects uncertainty by examining individual illnesses in greater depth, and by probing with more specific questions about how a loved one's communication disability might contribute to one's uncertainty. We need to know more about how communication loss affects appraisal and management of uncertainty. Some scholars have advocated abandoning notions of uncertainty that conceptualize it as always negative, as something that people are always driven to reduce (Brashers, 2001). Empirical findings have supported this position. For example, people may avoid receiving test results if they fear being diagnosed with a serious condition, or may avoid consuming health information pertinent to their own or their loved ones' health, because not knowing may actually be less threatening and less distressing than the potentially bad news (Brashers, Goldsmith, & Hsieh, 2002; Brashers, Neidig, & Goldsmith, 2004; Brashers et al., 2000). However, participants in our sample seemed to have a tendency to want to reduce their uncertainty, and the reasons for this were not entirely clear. According to Mishel's (1988) model, uncertainty that is sensed as upsetting, or dangerous, typically compels people to reduce their uncertainty. It is possible that the combination of serious illness or injury and communication loss creates a particularly distressing situation for friends and family members, which motivates them to reduce their uncertainty. Further research is needed to examine this relationship.

Conclusion

The literature on uncertainty in illness includes many studies that examine how patients experience uncertainty. In the present study, we extend this past research through an investigation of the sources of uncertainty reported by friends and family members following a loved one's CDI, as well as their methods for managing that uncertainty. We also discuss the impact of a patient's communication loss as a prominent finding, which has significant implications for the study of uncertainty in illness. This work represents a contribution to the efforts of researchers who are working to advance theories of uncertainty in illness, by laying some groundwork for future research that can explore the experiences of friends and family members, and the experiences of people whose uncertainty is linked to communication disability, in greater depth.

Notes

¹ One participant discussed two people with different conditions; therefore, the data comprise thirty-two unique transcripts from thirty-one participants.

² One participant did not report on the duration of the patient's condition, and in another case two participants reported on the same person. Thus, $n = 29$ for this calculation.

³ At the time of the interview, some patients were deceased ($n = 8$), so in those cases participants reported on the frequency of contact they had when the patient was living.

⁴ Equipment failure prevented audio recording in two interviews. In these cases, a partial transcript was created from the researcher's notes.

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Appendix: CDI Interview Questions

Note. Interviewers adapted these questions and deviated from this schedule when necessary as interviews unfolded.

Questions about the Patient's Background

Can you tell me a little bit about [the patient] and what your relationship is with him/her?
 When did the condition start?
 What changes has [the patient] undergone?
 What has the progression been like physically? Mentally?

Questions about Changes and Stress After the CDI

Do you experience stress because of [the patient]'s condition? What causes it?
 How do you deal with the stress?
 Does it seem to you that [the patient] experiences stress?
 What do you think causes this stress on [him/her]?
 How can you tell when [the patient] is feeling stressed?
 How does he/she might deal with this stress?
 Do you help him/her deal with the stress? How?

Questions about Relationships

How has your relationship changed as a result of the condition?
 Have you changed the way you act around [the patient]? How so?
 Do you think that other people treat [the patient] differently now that he/she has this condition?
 In what ways?
 Have people's reactions to [the patient]'s condition been positive or negative?
 How do you handle people's reactions?
 How do you think [the patient] handles people's reactions?

Questions about Communication – Changes

How has communication changed between the two of you since the onset of the condition?
 In what positive ways has the way you talk changed? Negative ways?
 Do you talk about the condition? How often? What do you talk about?
 What is your most frequent topic of conversation?
 What was the first conversation you had with [the patient] after the onset of his/her condition like? How did it compare to what you had expected?

Questions about Communication – Facilitating

What are some things you do that you find to be helpful in communicating with [the patient]?
 How do you know that [he/she] understands you?
 Can you describe a specific situation in which you and [the patient] had a problem or problems during a conversation?
 Can you describe a situation in which you and [the patient] had a conversation that went really well?

Questions about Communication – with Others

Can you describe a positive experience that you and [the patient] had with other people?

What about a situation in which you and [the patient] had difficulty communicating with other people?

Questions about Communication – Needs and Support

Did you have any questions or concerns regarding communication with [the patient] after the onset of the condition? What were they?

Did you look for help or information about how to communicate with [the patient]?

Where did you find it? How helpful was it?

Is there one in particular that you found most helpful?

Have you been involved in a support group because of [the patient]'s condition?

How does/did this help you?

Wrap-Up Questions

What would you say you've learned from this experience with [the patient]?

Is there anything else that you would like to add?