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**Effects of Communication-Debilitating Illnesses and Injuries  
On Close Relationships: A Relational Maintenance Perspective**

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Abstract

A communication-debilitating illness or injury (CDI) presents significant challenges for patients as well as for friends and family. In a qualitative study of the effects of a CDI on close relationships, twenty-eight individuals with loved ones who had experienced a CDI were interviewed. Participants described adjustments in communication with the patient and explained what it is like to experience a relationship with a CDI patient. Themes that emerged transcended the type of illness and relationship. Recommendations are made for further research that focuses on patients' relationships with a variety of social network members, beyond primary caregivers.

## Effects of Communication-Debilitating Illnesses and Injuries

## On Close Relationships: A Relational Maintenance Perspective

It's cruel that this was a person who was a great communicator. This was her forte and to watch that being robbed...it would have been better if she would have died or been blinded or deafened because this seems to be the cruelest hit. —Rachel, whose mother had a stroke.

This comment from Rachel is indicative of the impact that serious health conditions can have on people's interpersonal relationships. More specifically, it provides a glimpse of what it is like to know and care about someone who has lost certain fundamental communication abilities. The theories and definitions that guide our understanding of interpersonal communication and interpersonal relationships assume that when people interact, they are capable of exchanging messages. Although communication *skills* may vary from person to person, the basic *ability* to express, receive, and process information is taken for granted as fundamental to relationships, especially close ones. Communication is what helps people to perform relationships (Burlison, Metts, & Kirch, 2000). But how are relationships maintained when communication abilities are lacking? Sometimes a person's ability to communicate is damaged or destroyed, such as in the case of certain injuries and chronic illnesses that involve physical or cognitive disabilities. With a few notable exceptions (Baxter, Braithwaite, Golish & Olson, 2002; Kemper, Lyons & Anagnopoulos, 1995; Orange, Ven Gennep, Miller, & Johnson, 1998), research on communication in close relationships has overlooked the unique challenges confronted by relational partners when standard communicative facilities are compromised. The purpose of this study is to address this gap in the literature by examining how family and friends experience

relationships with persons who have faced a communication-debilitating illness or injury. We use relational maintenance as a theoretical framework to understand how relationships and communication change as a result of such a condition.

*CDI: Communication-Debilitating Illness or Injury*

The sometimes sudden onset of a chronic condition can be a great disruption to everyday life, and a tremendous source of anxiety for the patient as well as his or her friends and family (Bury, 1982). The disruption of chronic illness can be further exacerbated when the condition involves a communication disability. The focus of this investigation is on relationships in the context of communication impairment, so our interest is in conditions that, regardless of other symptoms or trajectories, are characterized by a patient's altered ability to communicate. For the purposes of this study, the term *communication-debilitating illness or injury*, or CDI, is used to broadly identify a chronic condition yielding an incapacity to use language in a standard manner, and almost exclusively<sup>1</sup> describes the loss of an ability that existed prior to the onset of the illness or condition, or prior to the occurrence of the injury. A variety of illnesses and injuries can result in impaired communication, including, but certainly not limited to, stroke (Sundin, Jansson, & Norberg, 2000; 2002), multiple sclerosis (Pring, 1999), Alzheimer's disease (Williamson & Schulz, 1990), and traumatic brain injury (Allen, Linn, Gutierrez, & Willer, 1994).

*Relationships and Chronic Illness*

In general, relationships are challenged by chronic illness because of changes to the ability to engage in shared interests and activities, as well as alterations of roles fulfilled by the relational partners (Lyons, Sullivan, Ritvo, & Coyne, 1995). The small amount of research on how people interact after the onset of a CDI has been devoted to the patient-spouse relationship,

usually in the context of one specific condition, like Alzheimer's disease (e.g., Kemper et al., 1995; Orange et al., 1998), or to family caregivers. Primary caregivers are typically classified as those people who bear the most responsibility for patients' day to day functioning (Grant, Elliott, Giger, & Bartolucci, 2001; Perlesz, Kinsella, & Crowe, 2000). The literature indicates that caregiving for patients who have sustained a CDI can be overwhelming (Anderson, Parmenter, & Mok, 2002; Brerton, 2000; Denman, 1998; Jongbloed, 1994; Santos, Farrajota, Castro-Caldas, & DeSousa, 1999; Smagt-Duijnste, Hamers, Abu-Saad, & Zuidhof, 2001).

The management of any chronic illness, however, cannot be effectively accomplished without taking into consideration the rest of a patient's family (Strauss & Glaser, 1975), *even when* communication abilities are adequate. It is logical to expect, then, that the interactions between CDI patients and their family and friends will change after the onset and progression of the CDI. Interpersonal communication between chronically ill patients and significant others can be problematic for a number of reasons, such as discomfort, anxiety about what to say or how to act, and difficulty in terms of concealing or revealing signs of distress or illness exacerbation (Lyons et al., 1995). A CDI can be particularly devastating to relationships because communication-debilitating conditions can physically or cognitively inhibit patients' abilities to express themselves or interpret messages from other people. This impaired ability naturally has consequences for the patient's family and friends when it comes to interacting and maintaining a stable, satisfying relationship.

The relationships that do endure following a CDI might take on a special level of significance, as those relational partners become primary agents in a limited network. Following the onset of an illness or disability, one's social network shrinks in size, the amount of social contact that one has with remaining members decreases, and feelings of social isolation and

loneliness increase (Guay, 1982; Lyons et. al, 1995). It is important to study social network members because they retain shared knowledge, memories, and experiences that are essential to close relationships, and their support is vital to the health of the patient (Morgan, Patrick, & Charlton, 1984; Planalp & Garvin-Doxas, 1994). These individuals are not responsible for helping the CDI patient with the tasks of living on an everyday basis, and therefore should be somewhat less likely to experience the well-documented experience of caregiver burden (Perlesz et al., 2000). However, even family members of CDI patients who do not bear the tasks of caregiving cannot escape the everyday challenges of communication when it comes to interacting with the patient. As scholars of relationships, illness, and disability have noted, the experiences of social network members have implications for their own well-being as well as that of the patient (Morse & Johnson, 1991).

A study of non-caregiving social network members can provide greater insight into the impact of a CDI on an understudied set of individuals who are close to the patient, and who may serve unique relational functions. A main goal of this research is to describe how family and friends of CDI patients interact in this distinctive health and relational context. This is in contrast to other studies, which have tended to focus either on describing what communication abilities patients are left with after the onset of a condition (e.g., Ellis, 1996), or on a particular type of speech event (e.g., constructing narratives; Kemper et al., 1995) rather than the general, everyday back-and-forth communication that is an integral component of relationships.

#### *A Relational Maintenance Perspective*

This study applies a relational maintenance perspective to describe how close relationships distinguished by a CDI, a distinctive relationship dilemma, are affected by the marked change in communication between partners, and how the ongoing nature of the

relationship—in other words, how the relationship is maintained—is reflected in the communication behaviors that are performed. A number of scholars have examined relationships based on the underlying principle that relationships do not simply exist; instead, they must be maintained through various behaviors (e.g., Canary & Zelley, 2000). One of the central questions of the relational maintenance perspective has been why people in some relationships engage in maintenance behaviors while others do not. Rusbult's (1987) investment model describes cognitive processes by which partners adjust their perspectives on their relationships, for example, valuing a relationship over alternatives as a function of commitment. It is possible that family and friends of CDI patients appraise these relationships in ways that help them to determine reasons to perpetuate them. The equity model of maintenance offers another explanation for why people engage in relational maintenance behaviors (Canary & Stafford, 1992, 1993; Stafford & Canary, 1991), and suggests that relational partners act in ways that attempt to strike a fair balance between what they provide and receive from the relationship. In the present study, our interest lies with relationships in which the distribution of rewards and costs would appear unfair, because we see potential to advance our understanding of how close relationships endure by learning more about what relationships are like when communicative resources are unequal.

A relational maintenance perspective recognizes that people keep their close relationships intact through the use of communication, and that the communication between relational partners serves as a reflection of how people attempt and achieve longevity and contentment in their relationships. We chose to use this framework because it allows us to describe people's enduring bonds after the onset of a serious health condition that dramatically alters their abilities to interact. We also anticipated an opportunity to build on the relational maintenance literature by

applying this theoretical perspective to a new relational context. The focal point of relational maintenance research and theory has been enduring heterosexual romantic relationships; however, many assumptions of this body of research are applicable to other close relationships (e.g., Canary, Stafford, Hause, & Wallace, 1993), which are also characterized by commitment, appraisals and comparisons, positivity and negativity, and strife. Although disabling conditions like a CDI can threaten relationships, “there is also evidence that through even the most severe, life-threatening illness, social relationships can be preserved, effectively restructured, and even improved” (Lyons et. al, 1995, p. 13).

### *Purposes of the Study*

To reiterate, little research has focused on friends and family members who are *not* spouses or caregivers of those living with chronic illness<sup>2</sup>. A main goal of this research is to describe how family and friends of CDI patients interact in this distinctive health and relational context when the communicative ability of the CDI patient is limited or non-existent. Therefore, the following research questions are posed. From the perspective of the non-injured friend or family member:

RQ1: What are relationships with CDI patients like?

RQ2: What communicative practices do people use to maintain relationships with CDI patients?

### Method

Individuals 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 recruited participants through flyers distributed at local support groups related to brain injury and stroke, a notice for the study posted in a university-wide email newsletter, and an announcement



of the study in a newspaper for university staff and faculty. Respondents received \$15 each for their participation.

### *Participants*

Twenty-eight volunteers (6 men and 22 women) took part in the study<sup>3</sup>. Participants who had dealt with a variety of illnesses were sought because we did not want to limit the scope of this study to one particular condition. The most common CDI reported by participants was stroke ( $n = 17$ ), followed by brain injury ( $n = 3$ ), autism ( $n = 2$ ), and Alzheimer's disease ( $n = 2$ ). Additional conditions, including AIDS, bleeding in the brain, dementia, and throat cancer were reported only once. The number of participants reporting a stroke was not surprising given that language disabilities occur most often with stroke patients (Sundin, Jansson, & Norberg, 2000). Participants in our study ranged in age from 25 to 61 years ( $M = 42.8$ ), and at the time of the CDI diagnosis, patients were between the ages of 18 to 94 years ( $M = 61.9$  years), excluding one outlier, an 18-month-old child. The length of time participants reported dealing with the CDI ranged from 6 months to 9 years ( $M = 4.5$ )—check—I got a different number than Nicole did<sup>4</sup>. Most participants in our sample held an advanced degree ( $n = 15$ ) 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 ( $n = 1$ ). CDI patients on whom participants reported represented a variety of relationships, including parents ( $n = 17$ ), nephews/nieces ( $n = 3$ ), siblings ( $n = 2$ ), grandparents ( $n=2$ ) close friends ( $n =3$ ), and a mother-in-law ( $n =1$ ).

### *Interview Protocol*

The semi-structured interview schedule included four sections of questions. First, 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 relationship between the participant and the CDI patient. Finally, we asked specifically about communication between the participant and the injured person. As a closing question, we asked participants if they had learned anything from their experiences knowing someone with a CDI, and invited them to share any remaining thoughts. A pilot interview was conducted to gauge the length of the interview and question progression. Based on the pilot interview, we revised the protocol to enhance comprehensibility and completeness.

### *Procedure*

Potential participants called or emailed one of the researchers to express interest in the study. Participants were screened to ensure that their loved one's condition corresponded with our definition of a CDI. We then scheduled one-on-one interview sessions. During the first part of the interview, participants completed a consent form and a brief 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). The researcher then briefly explained the purpose of the study and previewed the interview schedule before proceeding with the first question. Each interview took approximately one hour to complete and was audio recorded for purposes of transcription and analysis. Researchers also took notes during the interviews<sup>5</sup>.

### *Data Analysis*

Qualitative methods provide a process for extracting the meanings that are embedded in people's experiences, making them especially worthwhile for new areas of research (Michallet, Le Dorze, & Tetreault, 2001; Mishel, 1999). For these reasons, we believed that the objectives of our study would be best met using grounded theory techniques. A grounded theory approach

employs data analytic techniques that allow themes to emerge which are representative of aspects of the phenomenon of interest (Strauss & Corbin, 1990). Our goal was to systematically analyze the accounts that family and friends offered, so that the results of this study could be an important first piece in a grounded theory of family and friends' communication and relationships with people who have experienced a CDI.

We randomly selected 8 transcripts (approximately 25%) for category development. Each transcript was read twice by the authors, and coded using methods of constant comparison (Strauss & Corbin, 1990). We identified reoccurring themes and discrete ideas in the data. For example, one code was "nonverbal cues." We then compared codes, and generally reached agreement; we discussed any disagreement until a consensus was reached. Next, we grouped similar codes into single categories and assigned a conceptual label to each grouping. For example, the codes "nonverbal cues" and "written cues" were grouped under the category "communication mechanics." The remaining transcripts were then each read twice and coded to answer the research questions. We reconvened again to determine if the existing codes needed modification. Finally, we searched for representative examples for each of the categories across all 28 transcripts. All authors met to discuss the final category descriptions, to resolve differing interpretations, and to select exemplars for each category.

## Results

Our results offer insight into the experience of having a relationship with a family member or friend with a CDI, as well as how those relationships are enacted and sustained through communicative efforts. In this section, we outline our findings, first describing the nature of participants' relationships with the CDI patients, and then explaining what the communication between the participants and their loved ones entailed. Data from our interviews

are offered throughout as exemplars to illustrate the unique nature of these relationships and interactions.

### *Relationships with CDI Patients*

Friends and family members made explicit references to and comments about the relationship with the CDI patient, including whether and how it might have changed as a result of the CDI. In some cases, the relationship changed as a result of the CDI, and in some cases, the relationship remained the same. Some participants reported positive changes in the relationship, others reported negative changes, and some reported a combination of positive and negative change. These themes are developed in more depth below.

Some participants reported positive changes in their relationship with the CDI patient. They described what they found to be rewarding, albeit often unforeseen, changes. Although Heather's<sup>6</sup> mother had virtually lost the ability to carry on a conversation as a result of her brain tumor, Heather still enjoyed talking to her and even expressed a desire to talk to her more often. She said, "I think the positive thing about it is that I wanted to talk to her more, even if it was about nothing." Maria explained that she and her teenage brother got along better after he suffered a traumatic brain injury: "We never fight anymore and now there's a lovely relationship between us. You can tell. 'Like send me a kiss like [kissing sound],' he says to me always every day. He's always like, 'I miss you.'"

Other participants described negative changes in their relationship with the CDI patient. For these participants, the relationship had become frustrating or less fulfilling. Leslie, whose father had dementia, said, "It is a different relationship...I have lost the friend that I used to have before. But this is new, this is different and so you just adapt." Because her father's dementia limited his ability to talk, Leslie felt as though she had lost a friend. In a similar vein, Barb

described the change in her relationship with her father: “I don’t get to have my dad as my dad. There are so many things I’ve wanted to talk to him about, but I simply cannot. It’s just not an option.” Because he did not possess the cognitive ability to converse with her as a “father,” Barb felt as though her father’s stroke had left her without a dad.

Some participants indicated that even if communication had changed as a result of the CDI, the relationship with the patient was very much like how it had been before. Beatrice said that she had never had a good relationship with her father and that his stroke didn’t change that fact. She said, “I didn’t ever have a good relationship with him; it has always been frustrating.” Although her father was still a “chatty guy” after his stroke, his communicative ability did not seem to have an impact on the way Beatrice characterized their relationship. In a few cases, some aspects of the communication between a patient and a participant did not change as much as one might expect. When speaking about her mother-in-law, whom she described as often being “too drowsy” or slow to take part in conversations, Patty said, “We were never very close, so we never really discussed important things or had very deep conversations.” Even though her mother-in-law’s communicative ability was drastically altered, Patty did not feel that the condition had a major impact on their relationship.

Finally, some participants described a combination of both positive and negative changes to the relationship. Early in his interview, Kyle said that he missed having conversations with his friend who had dementia. Later in the interview, Kyle put a positive spin on the relationship:

Well in a way, it seems bizarre but it maybe deepened. I’ve never really talked about this before, I’ve never really thought about it, but...the fact that we couldn’t talk, I think there was still, that nonverbal communication...Even though he couldn’t say that or verbalize

it, I don't know how I got it. But there was just something about his manner that I felt like there was something that was just very good for the relationship.

Kyle mourned his friend's loss of communication, but also gained a greater appreciation for the power of nonverbal communication, and even attributed a positive change in the relationship to the fact that his friend could no longer speak. Kyle learned that "there is another layer of communication beyond words," a lesson that he claimed helped to deepen his relationship with his friend. This finding parallels previous research suggesting that wives of Alzheimer's patients might rely on deeper, relational level messages in the absence of coherent verbal communication (Baxter et al., 2002).

Notably, the changes to the relationship experienced by our participants do not appear to be directly related to the severity of the patient's impaired communication. For instance, Heather, whose mother could barely form a complete sentence and therefore could not fully participate in conversations, described wanting to talk to her mother even more after the onset of the CDI. In contrast, Beatrice, whose father retained a great deal of his verbal ability, still described her relationship with her father as frustrating. Brian, whose mother had a stroke, summarized his experience by saying this:

I think in terms of advice I would give someone, I would just say that this is really devastating and it's going to be really hard...it's not going to be easy but you can really do a lot to turn this into a positive situation.

Brian's advice indicates that having a relationship with someone who has suffered a CDI is an experience that can be incredibly challenging but that can be ultimately rewarding or valuable in some way.

### *Communication with CDI Patients*

Results of the study indicated that participants make intentional adjustments in order to communicate with loved ones who have experienced a CDI. Our participants described a large repertoire of communicative practices as they explained the details of facilitating interactions with the patient. Specifically, participants described adjusting the mechanics of communication and inferring meaning based on limited cues from the patient. Some of the adjustments described by our participants are similar to those reported in previous research, including those identified in studies by Baxter and colleagues (2002) and Kemper and colleagues (1995); however, our participants also described adjustments not mentioned in previous studies.

#### *Adjusting Mechanics of Communication*

Participants adjusted the mechanics of communication in various ways. Friends and family members described how they modified the way they interacted with the CDI patient. Some participants described using specific communication tactics to change their speech (e.g., speaking more clearly or more slowly, asking questions). Sometimes adjusting was a matter of being strategic about topics of conversation, and sometimes participants used a third party or acted as intermediaries to facilitate communication with the patient.

*Using communication tactics.* Participants described a variety of communication tactics they used to facilitate interactions with the CDI patient, including filling in words for or prompting the ill or injured person, having one-way conversations, and using guesswork or a process of elimination to fill in the blanks as they tried to understand what the patient was saying. Several participants described the challenges involved in striking a balance between filling in words for the patient and giving the patient the chance to speak. For instance, Patty, whose mother-in-law had a stroke, said, “I think what I continue to learn is that I want to prompt her to be engaged and not supply the conversation for her. I think that's a trap that many people

in the family fall into.” Leslie, whose father had dementia, described a similar experience: “I try to provide him enough little prompts to get him where he wants without saying it for him.”

Participants wanted to let the patient have a voice while still using tactics to help facilitate the interaction.

Other communication tactics described by our participants included speaking more slowly, distinctly, or loudly, using repetition, or using close-ended questions or questions with multiple choice answers to make it easier for the person with the CDI to respond. Kathy, whose great aunt had a stroke, described their interactions: “I probably animate a little more, probably use simpler words or words that I can enunciate. I’m probably repetitive, in that I’ll say it one way and then say it a separate way while she’s processing information.” When asked what she finds useful in talking with her father, who has dementia, Leslie said, “Speak slowly. Ask questions.” Both Kathy and Leslie used a combination of specific communication tactics to make conversations possible. Overall, our participants shared a great deal of detail in describing how they use certain communication tactics to facilitate conversations with the patient. Some of the tactics they described are similar to those reported in other studies, including emphasizing nonverbal communication (Baxter et al., 2002) and filling in details (Kemper et al., 1995).

*Managing topics.* Like wives of Alzheimer’s patients in the Baxter et al. (2002) study, our participants also described managing topics as a means of facilitating conversation. Participants explained that they sometimes selected specific topics of discussion because doing so made it easier for the patient with the CDI to understand and contribute to the conversation. For instance, several participants described discussing less complex topics with the patient. This simplification was sometimes related to the patient’s impaired cognitive ability. Alex, whose co-worker had a stroke, said, “I try not to get into complicated things, because it’s pretty clear that’s



she's confused by some things." Carol, whose father had Alzheimer's disease, said, "[The communication has changed] because you can't talk about complex things. You can't talk about what the activity is going to be for the day because he doesn't even understand that." By selecting simple topics, participants tried to ensure that the patient would be able to take part in the conversation.

In some cases, participants avoided discussion of certain topics to protect the person with the CDI from becoming upset. Protecting the patient from emotional distress made it easier for both parties to carry on communication. For instance, Andrea, whose grandmother had a stroke, said, "You don't talk about certain things. You don't get her too upset." In one instance, Andrea and her family did not tell her grandmother that they had sold her apartment and some of her belongings because they thought this information would devastate her. Other participants described more general forms of topic management, such as sticking to positive topics when communicating with the patient. After Maria's brother suffered a traumatic brain injury, she and other family members were careful about discussing only good things with him. She explained, "We always put that law in my house, always good things. So if you want to talk with him, always good things. Never, never bad things." Similarly, after her mother's stroke, Wanda was careful about the topics she mentioned in letters to her mother:

I'd always try to talk positive in the letters. Talk about the grandkids. For a long time, I would write her and say, "Don't give up. Try writing with your left hand." And try to promote her to try and do something, and then I got to where I just quit doing that. I thought it was depressing her more, so I just didn't talk about it anymore.

Participants described strategically selecting safe, neutral, or positive topics as a means of protecting the person with the CDI.

*Using a third party or acting as an intermediary.* Some participants reported using a third party or acting as an intermediary as a means of facilitating conversation with their loved one and with others. In some instances, participants used a third party as a means of maintaining communication with the patient. Wanda, whose mother's speaking ability was severely damaged by a stroke, used her mother's boyfriend as an intermediary when she called to check on her because she could no longer speak directly with her mother over the phone. Wanda explained: "I would call the gentleman that she was with and always ask him if the doctor had said any changes or anything different. I would communicate with him, probably twice a month I would call him and actually talk to him." In this way, Wanda relied on her mother's boyfriend to update her on her mother's condition, and thus play a role in sustaining their connection, because her mother lacked the physical ability to speak.

In other cases, participants relied on a third party to learn the best way to talk with the patient. When asked if she sought information about how to best communicate with her cousin after he had a stroke at the age of 15, Kristin explained, "I always talked with his brother and my uncle...they wouldn't say a lot, but basically what they would do we would do. So, basically their actions is what we tried to do." Kristin went on to explain that her well cousin and her uncle taught her how to use repetition to communicate with her cousin who was ill. In this case, Kristin learned how to use certain communication tactics by watching others communicate with her cousin.

Some participants reported that they themselves acted as intermediaries to facilitate communication between the patient and another person. In some instances, participants communicated on behalf of the person with the CDI because the patient was unable to effectively communicate for him or herself. These intermediary acts occurred with the patient's health care

provider and with other friends and family members. Sometimes participants spoke on behalf of a patient whose speaking ability was severely impaired. Wanda, for example, described a situation in which she spoke on behalf of her mother:

And, the nurse one time wouldn't give her morphine whenever she felt pain. She was rubbing her stomach, and I went to the nurse, and I said, "I think she is in pain." I asked her and she shook her head [yes].

In other cases, participants acted as an intermediary by modeling the best way to communicate with the patient. Kathy, for example, assisted her father by modeling how to communicate with her great aunt:

My dad has no patience with it. He can't figure it out, he just gives up. So it works better if we both go together. I can model a little bit of how to communicate with her...I handle it like I'm a teacher. You know I want to help him relate to her better.

For some participants, the opportunity to act as an intermediary and to help facilitate discussions between the patient and another friend or family member was a source of pride. Kelly, whose father had throat cancer, said, "And I understand him a lot better than my husband does, I am kind of proud of that...that I can help my husband understand or whomever is around. I feel good about that." Baxter and colleagues (2002) also reported the use of intermediaries as a communicative practice. Wives in their study described using nursing home staff members as information mediators who updated them on what their husbands said and did in their absence, relieving wives of the guilt they felt when unable to visit their husbands at the nursing home. Our results suggest that other network members (e.g., a patient's boyfriend) can serve as information mediators who not only relay information but also assist others in learning how to communicate with the person with the CDI (e.g., Kristin's uncle showing her how to talk to her cousin). In

some cases, our participants themselves served in this role by modeling communicative practices for others (e.g., Kathy showed her father how to talk to her great aunt).

### *Inferring Meaning from the Patient's Cues*

In addition to adjusting communication mechanics, participants also reported relying on specific cues when trying to communicate with the patient. Participants used cues to understand what the patient was trying to say (i.e., the patient's thoughts and feelings) and to determine whether the patient was able to understand and follow the conversation. Because patient's communicative abilities were altered as a result of the CDI, participants reported inferring meaning from patients' now limited behaviors. Cues reported by our participants included cues written by the patient, verbal cues spoken by the patient, and a variety of nonverbal cues. Participants also reported drawing meaning from multiple cues used in combination (e.g., the patient might speak while gesturing to something). The process of inferring meaning from these cues was sometimes challenging for participants.

*Writing by the patient.* Some participants reported that patients who retained the ability to write would use written communication to replace or supplement oral communication. Kathy's great aunt used written communication after her speaking ability was damaged by her stroke. Kathy described a specific interaction in which her aunt used writing to communicate her thoughts:

Okay, she had received something in the mail from [her bank] talking about one of her CDs. And I'm just getting involved in some of her financial stuff. And I read it and it made sense to me. It's just a normal legal notice that you get concerning this document. And she didn't understand it. So she'd write me a note and say "I do not understand." And then I would try

to explain to her verbally and she would just look at me and “I do not understand, why does it compare to this other CD?” she wrote.

In this situation, Kathy’s great aunt supplemented her limited speaking ability with written communication in an attempt to clear up her confusion regarding a recent bank statement.

*Interpreting verbal cues.* This category refers to how participants reported relying on oral cues from the patient to communicate. The patients described by our sample represented a range of communicative ability; some still retained the ability to speak coherently, and others did not. Beatrice, whose father had suffered a stroke, was able to understand her father because he retained much of his speaking ability. When asked how she could tell when her father understood, Beatrice said:

He usually replies...Right now, he is still very verbal and the dialogue goes back and forth and back and forth. So if I say something, he usually says something in response so he lets me know that he understood exactly what I was talking about. That is not an issue yet.

Notice that in the final line Beatrice anticipates that her father’s ability to express himself and to understand her might become an issue in the future.

Rachel’s mother had a stroke and Alzheimer’s disease, yet retained some limited verbal ability. Rachel described the process of trying to interpret her mother’s verbal cues in their interactions:

[I know she understands me because] she’ll say “oh”...those verbal cues that let you know. Sometimes she isn’t saying words necessarily but she will try and repeat what you say. In fact, it will come out all scrambled. But then I can kind of use her response. If she asks questions, she will sometimes repeat that weird word that was all scrambled up. She

will try to repeat my question or my answer when she is using the weird word. I try to figure it out. It's like trying to learn a second language at the same time.

Rachel's description highlights the challenges involved in interpreting cues, even when a patient has retained some verbal ability. Because her mother's words were often scrambled, Rachel compared interpreting these cues to learning a second language.

*Interpreting nonverbal cues.* Participants described deriving meaning from patients' nonverbal cues, including patients' facial expressions, eyes, gestures, and body movements. Rachel, for instance, read her mother's facial expressions to determine when her mother was frustrated. She explained, "She gets a really deep frown on her face. She has always been very expressive with her face, so she can still really show me how she is feeling with her facial expressions." Andrea<sup>7</sup>, whose grandfather had a stroke, could tell when her grandfather was upset and that he recognized people by the look in his eyes: "The emotional [part] was the fact he couldn't say what he wanted to say. You could tell it by his eyes. You could tell he wanted to say something. You could tell he knew who we were." Her grandfather's speaking ability was completely devastated by his stroke, so Andrea relied on his eyes to infer what her grandfather was thinking and feeling.

Participants also derived meaning from patients' gestures and body movement. Kyle, whose friend had dementia, said that he could tell when his friend wanted to be close to him: "He would kind of reach out for and you would just get the impression that he wanted that closeness." Miriam, whose mother had a stroke, said that she could tell her mother was upset because of the gestures she used. She explained, "[If] they said something she didn't agree with, she would shake her fist and let you know that she didn't want you talking about that. Yes, you knew when

she was not happy with what you were saying.” Clearly, Miriam had learned to read her mother’s gestures and to understand what her mother was feeling.

In a number of cases, participants described relying on a combination of cues to derive meaning. In describing conversations with her great aunt, Kathy said:

She’ll look directly and point her finger or she’ll say no, you know, no. She has trouble, actually she gets messed up in her “yes” and her “no.” So often when you ask a question like that you have to wait until she settles on one of the two answers. So she also, you can just read her eyes. And you know when she’s really angry.

In this passage, Kathy described interpreting her aunt’s gestures, using verbal cues, and reading her aunt’s eyes to determine when her aunt is angry.

In a few cases, participants reported deriving meaning when patients engaged in very specific behaviors. For instance, Leslie, whose father had dementia, knew that her father was frustrated during a telephone conversation when he would set down the phone and walk away. Andrea said that she knew her grandfather was ready to die when he stopped eating. She explained, “He stopped eating and that was a clear indication that he wanted to go. That was his communication.” Inferring meaning from these distinctive behaviors is yet another way participants tried to understand the patient’s thoughts and feelings.

All participants described making strategic adjustments in communication. For many, learning what tactics worked best and what cues were most useful was a process that occurred over time as the patient’s communicative ability continued to change or as the participant grew accustomed to the patient’s altered ability. Patty described this process of accommodation when discussing her mother-in-law’s stroke: “It’s not as though there was a single event that suddenly

changed her ability to communicate or her relationship with us. It's something that we've all kind of grown along with."

Making these adjustments was sometimes frustrating for participants and sometimes rewarding. Some participants indicated success in their endeavors and took pride in the fact that they had the ability to understand or communicate with the patient in a way that others could not. A few dealt with the patient's altered communication by redefining what counted as successful communication. Redefining success included instances where a simple communicative act took on greater meaning or was more momentous because of the patient's lack of communicative ability. Heather, whose mother had a brain tumor, described such an experience:

So I would call and she had deteriorated so that she couldn't carry a conversation; sometimes she would be there, at other times she wouldn't. She would usually be able to say "Hello, hi," My dad would have to say, "It's Cindy" and we would at least be able to say two lines. It was Chinese New Year, my father is Chinese and so my mom doesn't speak Chinese because she is Hawaiian and German. I said [Chinese phrase] and she said, "What is that?" And that was a full sentence! So that was about a month ago and that was just so encouraging for her to say a full sentence.

Her mother's ability to say a complete sentence, a mundane task prior to her CDI, created a memorable occasion for Heather and represents one way that participants adjusted to the patient's impaired ability.

Wives of Alzheimer's patients have also described increasing interpretive work when communicating with their husbands (Baxter et al., 2002). Specifically, wives in the Baxter et al. (2002) study described relying on their spouses' idiosyncratic behaviors, including reading eye messages and facial expressions. Other adjustments, including relying on written communication



and redefining what counts as successful communication, have not been reported in other studies and add to our knowledge of the many and varied ways family members and friends make continued efforts to communicate and maintain relationships with loved ones who have suffered a CDI.

### Discussion

The results of this study are an important first step in understanding the experiences of family members and friends whose loved one has experienced a CDI. To date, we know little about how people adjust when a friend or family member's physical and cognitive ability to communicate is altered. This study contributes to our limited knowledge by exploring what it is like to experience a relationship with a CDI patient and offers insight into the broader experience of family members and friends of a CDI patient. Participants in our sample characterized their relationship with the patient in various ways. For some the experience was positive, for some negative, and for some the experience included both positive and negative relational changes. These descriptions are somewhat different from relational changes described in previous research examining a CDI. For instance, Baxter and colleagues (2002) reported that wives of Alzheimer's patients found their husband's illness "enormously problematic" as they struggled to redefine their marital relationship (p. 9). The fact that wives tended to find the challenge of a CDI especially troublesome likely reflects the dynamics unique to marital relationships and highlights the importance of examining how people in other relational roles (e.g., children, cousins, friends, coworkers) might experience relationships with a CDI patient in ways that are similar to and different from spouses and full-time caregivers. For some participants in our study, the onset of the loved one's CDI was, indeed, enormously problematic, but others did not feel the same negative impact. Although nearly all of our participants acknowledged the challenges

associated with a CDI, many characterized relational changes in positive terms. The negative experience of Alzheimer's wives (Baxter et al., 2002) could also be accounted for by the unique nature of that particular condition; however, our results suggest some level of commonality among different types of CDIs. Future studies could tease out possible distinctions among CDIs by comparing and contrasting various conditions.

Our results also reveal how friends and relatives make adjustments that facilitate interaction and maintain relationships with CDI patients. We know from previous research (e.g., Lyons et al., 1995) that interactions with chronically ill individuals can be difficult and awkward. Our study extends previous research by exploring the unique challenges to communication that are posed when one person's ability to communicate is altered. In addition, our results reveal the specific adjustments people make in the course of a conversation to facilitate communication with a CDI patient. Although the severity of the communication impairment varied somewhat from one patient to the next, every participant in our sample described making some sort of strategic adjustment to accommodate the patient's altered ability. These adjustments included using certain communication tactics, managing topics, using a third party, acting as an intermediary, and inferring meaning from limited cues. Our results suggest that making such adjustments is a process that occurs over time and one that can present both obstacles and triumphs as family and friends learn to adapt. The process of adapting involves anticipating challenges, making necessary adjustments, and helping patients continue to contribute to conversations, even if those contributions are severely limited as a result of the CDI.

Our results can be interpreted in light of a few related studies. In their study of wives of elderly husbands with Alzheimer's disease and dementia, Baxter and colleagues (2002) identified communicative practices that wives used to manage dialectical tensions, including

emphasizing nonverbal communication, increasing interpretive work, using nursing home staff as mediators, and avoiding topics. Participants in our study described making similar adjustments when communicating with a CDI patient. Our study builds on Baxter and colleagues' (2002) research by identifying additional communicative practices, including using other network members (i.e., individuals other than health care providers) as information mediators, modeling communication for others, relying on written cues, and redefining successful communication.

Our study also explores adjustments to communication in a variety of relational contexts and highlights adjustment as a process of adaptation that affects various members of a patient's social network. Although we did find similarities in our data to the communicative practices reported by Baxter and colleagues (2002), our results also suggest that individuals in different relational roles might in some cases use different types of communicative practices to facilitate interactions. For instance, wives in the Baxter et al. (2002) study drew meaning from their husband's limited communication by focusing on idiosyncratic behaviors unique to the relationship. The authors claim that the couples' years together eased the process of making such adjustments (Baxter et al., 2002). Although other social network members might also share an intimate bond with a CDI patient, it is unlikely that all members of a CDI patients' social network are able to rely on the same relational history and emotional connection that spouses share when making accommodations. The results of our study suggest that there may be some differences in the way other network members (i.e., those who are not spouses or full-time caregivers) experience, adjust to, and maintain relationships with CDI patients. Future research could explore this idea by directly comparing caregivers and non-caregivers in the same study.

Our results also contribute to the existing literature by suggesting that adjustments such as using certain communication tactics and inferring meaning from limited cues can be useful

across a variety of CDI contexts, not just in the case of Alzheimer's disease and dementia. The results of our study mirror some of the findings of Sundin et al. (2002), who found that caregivers of stroke patients were careful to demonstrate to the stroke victims that they were attentive and patient and not irritated, so that patients would find it worthwhile to try to communicate. Also, these caregivers placed special importance on what they could read in the patients' eyes, just as many of our respondents did.

### *Theoretical Implications*

Participants in our study described engaging in a number of communicative behaviors to constitute their relationships. Applying a relational maintenance perspective to this particular context offers some theoretical implications for studying communication in close relationships. The case of a CDI is interesting because it challenges the assumptions of some explanations for relational maintenance behaviors, such as those posed by equity theory (e.g., Canary & Stafford, 2001); conversely, the CDI context might provide greater insight into other explanations, such as those that emphasize commitment (e.g., Rusbult, Olsen, Davis, & Hannon, 2001) over social exchange processes. Relational maintenance literature that focuses on equity (e.g., Canary and Stafford, 2001) argues that people will engage in more maintenance work when they see their relationships as equitable. In other words, individuals subjectively assess whether they are equitably treated, overbenefited, or underbenefited, and this assessment of equity either motivates or demotivates them to keep the relationship in its current state. However, the results of our study suggest that individuals who are theoretically underbenefited might still engage in communicative behaviors intended to maintain relationships. Many of the relationships described by our participants clearly do not fit the typical notion of equitable, but either through redefining what counts as equitable or by disregarding that principle, participants sometimes chose to

pursue relationships that they themselves described in negative terms. This finding suggests that relational maintenance might function somewhat differently in relationships outside the romantic context, or within the illness context. Our results indicate that friends and family members will sometimes make efforts to maintain a relationship with a loved one even when that person does not perceive an equitable relationship.

On the other hand, some relational maintenance scholars suggest that commitment to the relationship, rather than equity alone, determines relational maintenance, arguing that strong commitment encourages relationship maintenance mechanisms (Rusbult et al., 2001). The commitment perspective offers a possible explanation for why people in our sample sometimes made efforts to continue seemingly inequitable relationships. Theoretically, it will behoove scholars to continue applying concepts of relational maintenance to new and different contexts, including more like that of a CDI, to begin parsing out the relative import of equity and commitment processes, and to further elucidate what motivates people to sustain their relationships and find satisfaction in challenging circumstances like these.

### *Strengths and Limitations*

One strength of our study is that we have addressed the scarcity of literature on this issue by examining how non-caregiving friends and family members of CDI patients interact in this distinctive health and relational context. We solicited friends and family members' accounts via in-depth interviews to discover their interpretations of their own and others' communication. It is quite possible that our results would differ had we had the opportunity to observe actual interactions. However, the use of in-depth interviews is appropriate for understanding how people narrate and attach meaning to their lived experiences, especially in the case of individuals who interact with family members with CDIs (Geist-Martin & Dreyer, 2001). The sample

presented here is not intended to be comprehensive and might not be representative of all CDIs. However, it is noteworthy that the changes described by participants seemed to transcend specific illnesses and particular types of relationships. Even though we recognize that each disorder presents unique challenges, our findings suggest a commonality among various CDIs that should encourage other researchers to explore common threads among such conditions.

#### *Practical Implications and Directions for Future Research*

The current study suggests a number of practical implications. First, past research indicates that family caregivers have a need for social support to maintain life satisfaction (Grant et al., 2001), and that patients improve at a faster rate when they perceive empathy from those around them (Robertson & Suinn, 1968). These studies underscore the importance of maintaining a healthy family system and social network. The findings of our study indicate the possible strain of a CDI on these systems and suggest that coping resources (e.g., literature, support groups) should be made available to all members of a patient's social network. Healthcare professionals and social service agencies would be wise to recognize the impact of a CDI on relationships, family systems, and social networks and consider interventions that address the difficulty in managing communication and sustaining relationships when a loved one has a CDI. Of course, providing resources to members of a patient's social network can be difficult: Past research indicates that even caregivers who are often in regular contact with professionals do not always receive adequate information (Denman, 1998; Smagt-Duijnsteet et al., 2001). Future research should test the practicality and utility of these suggestions.

The results of this study begin to paint a picture of the CDI experience from the perspective of a patient's family member or friend, and indicate that there is more to be learned about what a communication-debilitating condition has in store for social networks. Additional

research directly comparing the experiences of caregivers and non-givers would be a logical next step in this line of research. Future work related to this issue would also benefit from larger samples and multimethod approaches. In addition, research questions could become more specialized to tease out similarities or differences among types of conditions and relationships.

Our findings suggest that family and friends continue to sustain their relationships with significant others who have a CDI, despite the changes and challenges that are involved in the experience of the condition. Although they are sometimes unable to have an ordinary conversation with their loved ones, many of our participants remarked upon the importance of the bond that they shared. Some of the CDI patients had already passed away by the time of the interview; participants whose family and friends were still alive indicated their intention to continue the relationship, albeit in its altered state. Some even noted that they were aware that further deterioration was inevitable. It is notable, even if not surprising, that family and friends desired to maintain their relationships with the CDI patients. What is beyond the scope of the present study is exactly how family and friends of CDI patients make choices to maintain their relationships, and what that process involves (how consciously the choice is made, for instance).

Another potentially worthwhile area for future research involves how family and friends of CDI patients make choices about becoming intermediaries. We noticed that some of our participants described instances of speaking on behalf of the patient. However, we know little about the way in which this decision to act as an intermediary is made. How is such a routine implemented? How is it discussed with the patient, if at all? Obviously, if the CDI patient's communicative ability is minimal, then as we have seen from our participants' experiences, family and friends might have to rely on their interpretation of ambiguous cues in order to assume that the patient agrees to being spoken for. It is possible that a patient might wish to be

addressed directly by health care providers, but the patient's friend or family member chooses to be the intermediary to facilitate conversation. At the same time, it is likely that the negotiation is shared by several members of a patient's network; it would be useful to know more about how family members decide among themselves who gets to speak for a patient. Continued exploration of the impact of a CDI will enable us to create a more cohesive understanding of what a CDI means to the social network as a whole.



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## Notes

<sup>1</sup> We say that the term almost exclusively describes the loss of an ability that existed prior to the onset of the illness or condition because two participants discussed a young child with autism. We recognize that some conditions inhibit language ability throughout childhood and into adulthood; however, the vast majority of the patients discussed in this study experienced the sudden onset and subsequent progression of a CDI due to an illness or injury.

<sup>2</sup> Although Baxter et al. (2002) examined spouses, all the husbands lived in nursing homes.

<sup>3</sup> Thirty-one interviews were conducted in total. It was discovered that three participants were the primary caregivers and consequently, they were dropped from the analysis.

<sup>4</sup> One participant failed to report the duration of the patient's CDI. Therefore,  $n = 27$  for this one question—check!.

<sup>5</sup> Equipment failure prevented audio recording in two interviews. In these cases, a partial transcript was created from the researcher's notes.

<sup>6</sup> Pseudonyms are used to protect the participants' identity.

<sup>7</sup> This participant reported on her grandmother and grandfather, who both suffered a stroke.