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# Caregiver Perceptions of Their Influence on Cancer Treatment Decision Making: Intersections of Language, Identity, and Illness

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# Caregiver Perceptions of Their Influence on Cancer Treatment Decision Making: Intersections of Language, Identity, and Illness

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## Abstract

Serious illness of a loved one can disrupt a caregiver's sense of self and relationships. We examined the language caregivers use to describe the cancer treatment decision making of a loved one to understand how caregivers frame their own identity relative to a patient's illness. We analyzed transcripts from in-depth interviews conducted with caregivers ( $N = 58$ ) of cancer patients to examine the intersection among language, identity, and illness. Caregivers with a patient-level personal identity frame used phrases such as *their body*, *their decision*. Caregivers with a relational identity frame used plural pronouns such as *we* or *our* when describing the treatment decision. Importantly, some caregivers perceived an illness identity gap in that the patients' perceptions of their illness identity differed from their own. Illness identity gaps are theorized to be associated with treatment decision making more closely aligned with intergroup, rather than interpersonal, processes.

**Keywords:** communication theory of identity, illness identity, family decision making, cancer clinical trials

A loved one's diagnosis of a chronic or serious illness can create new communication challenges for caregivers (for a review, see Goldsmith, Miller, & Caughlin, 2008). These challenges are due, at least in part, to the illness disrupting an individual's sense of self and his or her relationships (Hecht, Warren, Jung, & Krieger, 2005). For some, this disruption results in the development of a caregiver illness identity, while others attempt to separate their identity from caregiving (Blanchard, Albrecht, & Ruckdeschel, 1997; Hayes, Boylstein, & Zimmerman, 2009; Miller, Shoemaker, Willyard, & Addison, 2008). Language is the primary means by which caregivers socially construct and enact their illness identity in response to self and others' expectations (Chou, Hunt, Folkers, & Augustson, 2011; Koski, 2014).

Caregiver illness identity is useful for understanding patient and caregiver outcomes because the influence of caregivers is now widely accepted as a factor influential in patient treatment decision making (Venetis, Greene, Checton, & Magsamen-Conrad, 2015; Weber, Solomon, & Meyer, 2013; Zhang & Siminoff, 2003). However, it is yet unclear how caregivers conceptualize and communicate about their role in the treatment decision-making process. The current study fills this gap in theory and practice by examining the intersection of language and illness identity in the context of medical treatment decision making. Specifically, we examine caregiver narratives describing the cancer treatment decision-making process of a loved one. The results show that some caregivers frame illness as a characteristic of the patient, while others frame the illness as part of their relational identity. Furthermore, the way caregivers frame illness may be associated with important medical decisionmaking outcomes, such as relational conflict and satisfaction with the decisional process. We draw on the communication theory of identity (CTI) as a framework for understanding how identity is reflected through language and how identity gaps can result in communication that aligns more closely with intergroup, rather than interpersonal, processes.

## Identity and Language

Identity can be broadly conceptualized as the categories individuals use to define who they are and to locate themselves in relation to others (Owens, 2003). Identity is subsumed within the broader and more historically examined concept of "self." The self is distinguished from identity in that it is primarily born out of self-reflection, whereas identity is viewed as a socially constructed categorization tool by which individuals group themselves and present themselves to others (Owens, 2003). Unlike other identity theories that view communication as a product or outcome of identity, the CTI is unique in that communication is viewed as identity (Hecht, 1993; Hecht et al., 2005).

CTI posits that identity is an inherently communicative process, such that all social behavior can be viewed as a function of identity through communication (Collier & Thomas, 1988; Hecht et al., 2005). The term *enactment* or *enacted identity* is used to denote the idea of identity as performance or expression. One example of enacted identity is the way people adapt their linguistic behavior to accentuate either the similarities (convergence) or the differences

(divergence) between themselves and an interactional partner as a function of identity (Gallois, Ogay, & Giles, 2006). People converge as a means of garnering approval from one another. A caregiver who uses convergence strategies to discuss a patient's treatment choices communicates the importance of having the patient view him or her in a positive light. Conversely, a caregiver who uses divergence strategies in the same situation highlights the differences in their social group (i.e., health) status.

In addition to enactment, there are three additional frames of identity: personal, relational, and communal (Hecht et al., 2005; Jung & Hecht, 2004). *Personal* identity is an individual's self-concept or image. For example, the notion of being "healthy" or "ill" can be conceived of as an identity (Hecht & Choi, 2012). *Relational* identity is mutually negotiated in relationships through communication (Hecht et al., 2005). Relational identities encompass internalizations of how others view us (i.e., *ascribed relational identity*), identities formed through relationship to important others (e.g., lover, wife), and the relationship itself (e.g., the couple as a unit). The fourth frame, *communal*, refers to how the larger identity group collectively defines itself (e.g., breast cancer survivors). Identity frames are theorized to be interpenetrated, meaning they intersect in various combinations (Hecht et al., 2005; Jung & Hecht, 2004). In some cases identity frames work cooperatively, but other times they conflict. CTI refers to conflict between two or more frames of identity as an identity gap (Jung & Hecht, 2004, 2008). Next, we examine illness as a specific type of identity with potential for the development of identity gaps (Hecht et al., 2005).

### **Illness Identity**

When individuals' lives are disrupted by a chronic illness, they experience identity changes because their view of themselves, their relationships, and their abilities has changed (Charmaz, 1994). Individuals must learn to manage symptoms while also managing role responsibilities and societal expectations (e.g., what they *should* be able to do; Townsend, Wyke, & Hunt, 2006). Patients who effectively incorporate illness into their identity, meaning identity frames are working in coordination, experience better outcomes than those who do not. They are better able to cope with medical uncertainty, experience life changes, connect with others, become more knowledgeable, challenge medical diagnoses, and gain access to medical treatments (Sulik, 2011). In contrast, individuals for whom illness causes identity conflict experience increased depression, spiritual struggle, decreased hope, and increased risk for comorbidity (Ai, Pargament, Appel, & Kronfol, 2010). Patients are vulnerable to experiencing identity gaps as a result of conflict among the various identity frames across all stages of disease management (Jung & Hecht, 2004; Miller & Caughlin, 2013; Siminoff & Step, 2005).

Serious illness, such as cancer, affects not only patients but also the family system. Families in which a loved one is diagnosed with cancer also experience changes in their roles, identities, and daily activities (Blanchard et al., 1997). Some families may respond to these identity changes by integrating illness into their relational identity (Soliz & Rittenour, 2012). Others may experience anxi-

ety as a result of the enactment of divergent social identities (Hecht, 1993; Soliz & Rittenour, 2012). For example, one study found that wives whose husbands had dementia reported frustration when their spouses expressed interest in physical intimacy because sexual activity was associated with their identities as wives rather than as caregivers (Hayes et al., 2009). Their husband's initiation of sexual activity highlighted the gap between their enacted identities (i.e., caregiving activities) and their relational identity as a wife. While some individuals report high amounts of stress as a result of family caregiving, others perceive the experience more positively (Badr, Acitelli, & Taylor, 2007; Blanchard et al., 1997; Miller et al., 2008). There is some evidence that a strong relational identity, or seeing the relationship as an extension of oneself, helps buffer the association between caregiving and poor mental health (Badr et al., 2007). In other words, individuals feel more positively about caregiving and experience fewer negative outcomes when their personal identity is aligned with their relational and enacted identities. Although identity is an important component of the illness experience for both patients and caregivers, the ways in which caregivers frame their identity relative to the patient and the illness have not been explored. Building on this logic, we propose the following research questions:

**Research Question 1:** How do caregivers frame their identity as related to a patient's illness and treatment decision making?

**Research Question 2:** How do caregivers perceive that patients frame their identity as related to illness and treatment decision making?

### Family DECIDE Typology

Communication between patients and family caregivers is typically considered a form of interpersonal communication because messages are adapted to the unique characteristics of the individuals involved. While this may be true in some cases, there are other situations in which patients and caregivers enact divergent social identities, resulting in conflict (Dragojevic & Giles, 2014; Soliz & Rittenour, 2012). One common source of family conflict in the illness experience is illness identity gaps relative to the locus of treatment decision making. The Family DECIDE (Determinants of Clinical Decision Making) Typology is a conceptual framework for understanding how identities intersect in the treatment decision-making context (Krieger, 2014).

According to the Family DECIDE Typology, some caregivers perceive illness as a personal identity of the patient and, as such, are unwilling to be involved in treatment decision making. Such an approach can cause conflict if the patient perceives the illness, and thus the locus of decision making, to be part of the relational identity (Zhang & Siminoff, 2003). Patients' desire to have others co-own important medical decisions may be particularly strong in situations characterized by high uncertainty, such as participating in clinical trials (CTs; Krieger et al., in press). Similarly, conflict would be expected to result in situations where a patient conceptualizes his or her illness as a personal identity but the caregiver perceives the illness, and the associated decision, to be part of their relational identity. As such, the final research question is as follows:

**Research Question 3:** How does congruity (or lack of congruity) in the way illness identity is framed relate to the treatment decision-making process?

## Method

### *Participants*

Participants ( $N = 60$ ) were individuals referred by cancer patients who participated in a related study (Krieger et al., in press). Specifically, cancer patients living or receiving treatment in Ohio Appalachia were asked to refer caregivers who were influential in their decision-making process regarding whether to participate in a CT. Patients referred a total of 110 caregivers, of which 60 (54.5%) participated (range: 0-3 caregivers/ patient). Two participants were removed from analysis because their referring patients had not been offered a CT, for a total of 58 participants. A majority of caregivers were female (65.5%), White (89.7%), and an Appalachian county resident (79.3%). Most participants identified as a spouse (41.4%) or an adult child (29.3%) of the patient. The average age of caregivers was 55.1 years ( $SD = 15.0$ ), ranging from 19 to 85 years.

### *Procedure*

Caregivers referred to the study were called by a research team member and invited to participate in an interview. Those who agreed were scheduled to complete the interview at a time and place that was most convenient (e.g., home, hospital, coffee shop). In-depth, semistructured interviews were conducted to allow for similar questioning but unique probing of responses (Patton, 2002). All interviews were audio recorded, were conducted over 11 months, and ranged from 30 minutes to 3 hours in duration. Efforts were made to interview participants in a separate private location; however, for five interviews, the referring patient was present. On completion of the interview, participants completed a demographic survey and were remunerated \$30.00 (see Palmer-Wackerly, Krok, Dailey, Kight, & Krieger, 2014, for in-depth description of methods). All procedures were approved by the institutional review board.

### *Interview Analysis*

All interview audio files were uploaded to a password-protected computer and transcribed verbatim. Data analysis of the transcripts occurred in two phases. In the first phase, four members of the research team defined each unit of analysis as a meaningful thought about the decision-making process, ranging from a phrase to several paragraphs. The researchers coded each thought unit as reflecting how caregivers framed their identity with respect to the illness and the treatment decision (i.e., personal, relational) and the caregivers' perception of how the patients framed their illness and the decision (i.e., personal, relational). Each transcript was read by at least two members of the research team to establish agreement about number and coding of units.

In the second phase of analysis, three undergraduate research assistants were trained on the coding scheme for 30 hours over a 3-week period. After completing the training, raters independently read each transcript in the data set, created a brief memo summarizing the decision-making context, and applied the coding scheme. After all transcripts were coded, Cohen's kappa was used to assess intercoder reliability. Reliability for each code is as follows: illness framed as personal identity ( $\alpha = .81$ ), illness framed as relational identity ( $\alpha = .92$ ), patient framing of illness as personal identity ( $\alpha = .72$ ), and patient framing of illness as relational identity ( $\alpha = .74$ ).

## Results and Interpretations

### *Framing Illness Identity (Research Question 1)*

*Framing Illness as Personal Identity.* There were 164 utterances by caregivers in which illness identity, as related to treatment decision making, was framed as a personal characteristic of the patient ( $M = 2.91$ ,  $SD = 2.84$ ). These utterances demonstrate the ways in which caregivers frame a loved one's illness as separate (as opposed to embedded) from their relationship with the patient. Caregivers often talked about illness and the associated treatment decision-making process from the perspective of a patient's rights and associated responsibilities. Patient rights were discussed in terms of ownership of the body, and hence, the illness, with ownership explicitly linked to the responsibility for decision making. For example, Linda explained her lack of involvement in her husband's decision about how to treat his colorectal cancer this way: "I left the decision up to him since it's his body. And it's what he wants to do." Another caregiver, Allie, explained her lack of involvement in her sister's lung cancer treatment decision in a similar manner. She said, "I think it's very important for her . . . to get to do what she wants to do. You know, it's not my body. It's her body." These examples illustrate caregiver statements in which illness identity was framed as *their body*, *their decision*. In other words, illness identity was seen as a characteristic of the patients' identity because of the physical relationship between their body and the cancer.

There were two unique twists in the language caregivers used when describing the *their body*, *their decision* approach. The first was to use language that further reinforced their separateness from the illness and the associated treatment decision. One example is use of the term *whatever* to signal a lack of personal preference regarding the outcome of the decision. Marlene described her hands-off approach to her mother's decision about how to treat her breast cancer. She said, "I didn't want her to do anything that she didn't want to do . . . Go to Ohio State? That was fine. *Whatever*. It's her body." John took a similar approach to his wife's breast cancer treatment decision, "Whether she was going to just have [her breasts] both removed or *whatever*. I left that up to her. I mean, it's her body. She was the one that was battling [cancer]." Importantly, these caregivers were not being dismissive; rather, they were shifting the responsibility of decision making to the patient. Thus, caregivers viewed their role in the treatment decision-making process as supporting whatever decision the patient felt was best.



The second was the way that some caregivers used tentative language to downplay, rather than emphasize, the separation of identities. For example, Will described his father's prostate cancer treatment decision making this way: "It was his decision, and it's *basically* his body, his decision, so I supported him in it." Helen, whose daughter was diagnosed with lung cancer, described the decision-making process in this way:

She's her own person and she had made up her mind what she was going to do and I would never try to talk her out of anything because it's *sorta* her body and she *sorta* had her mind made up.

In these cases, caregivers used hedges (e.g., *sorta*, *basically*) to soften statements asserting patient ownership of the body and hence responsibility for the treatment decision making.

*Framing Illness as Relational Identity.* There were 249 utterances by caregivers in which illness identity was framed as a characteristic or extension of the relationship with the patient ( $M = 4.37$ ,  $SD = 4.44$ ). In these utterances, caregivers positioned the cancer experience and the treatment decision-making process as embedded in their relationship with the patient. A relational illness identity was expressed in a variety of ways, from explicit statements of opinion (whether in agreement or disagreement with the patient) to the strategic use of silence. Caregivers expressing a preference for patient interdependence reflected some level of a shared illness identity and a perceived duty or desire to adopt some of the rights and responsibilities associated with medical decision making. This preference was often expressed linguistically, such as using terms like *we need to* or *our decision* as a way of communicating about the experience. For example, Danny described the openness with which he and his wife discussed her treatment options for multiple myeloma. He said, "Hell, *we're* in this thing together."

In some cases, framing illness as a shared identity was consistent with relational norms. Phil describes himself as an advocate for his wife, who is often sick from her treatments. Phil reported regularly communicating with health care providers on her behalf and that she would consistently seek out his opinion. He said, "She usually asks me and what I say, she agrees with a lot of it." With respect to whether his wife should participate in the CT, he told her, "*We* gotta be aggressive . . . *we* gotta do it right now." Likewise, Steve described how he used relational norms to persuade a close friend to follow through with treatment:

I just told him that we wasn't ready to lose him and he was going to have to go get fixed. We needed—everybody needed him around. Of course, he said he wasn't going to go through with it and he wasn't this and he wasn't that. And I just looked at him and said, "Well, if the shoe was on the other foot, what would you tell me?" And he started to say, "I'd tell you to go get fixed." Then he just started grinning.

In other cases, the shared illness identity emerged as a direct result of a caregiver having some level of medical experience. Caregivers in this situation reported a perceived duty to actively participate in the decision-making process

by providing information or opinions. As a certified nursing assistant, Shelly said, "I just come out and told [my father] what I'd heard about [CTs] through my health care years. I've known patients who've done that and—Yeah, my opinion about it was positive." Another participant, Jennifer, who was in the medical field, felt it was important for her mother to participate in the CT she was offered. Jennifer explained, "First, she was like, 'I'm not sure.' And I said, 'Well, Mom, I really think that you probably should do it.'" This latter example demonstrates the delicate balance between social support and social influence when illness is framed as a shared identity.

### *Perceptions of Patient Framing of Illness Identity (Research Question 2)*

*Illness as a Patient-Level Personal Identity.* There were 147 utterances by caregivers indicating that patients framed their illness as a personal identity by excluding the caregiver in the treatment decision-making process ( $M = 2.58$ ,  $SD = 3.16$ ). The primary way caregivers perceived that patients communicated ownership of the illness was by informing caregivers of the treatment they would be receiving after the decision had been made. Caregivers interpreted this strategy of informing caregivers after the fact as preempting any potential for unwanted input. For instance, Lydia described her efforts to persuade her father to get a second opinion on the best treatment for his prostate cancer. She realized her efforts were in vain when, "He just came home and he said I think I'm going to do this trial."

Another caregiver described her sister as "impatient" with her attempts to ask questions about her treatment options. Ultimately, the patient came home one day and reported that "[the doctor] had asked her and she agreed [to the CT] because she felt that if whatever she could do that would maybe help her daughter or granddaughters and everybody else, that she would be willing to try." The caregiver was disappointed that her sister had not consulted her before making such an important decision. In short, caregivers felt that the patient communicated illness as a personal identity when they were informed of the treatment decision after it had been made.

*Illness as Ascribed Relational Identity.* There were 136 utterances by caregivers indicating that patients framed their illness, at least in part, in terms of their relational identity ( $M = 2.39$ ,  $SD = 2.27$ ). In contrast to behaviors that communicated caregiver involvement in the decision-making process was unwelcome, this code consisted of statements in which patients communicated to the caregiver that their opinion or participation in the decision-making process was desired. Frank, a physician, recalls talking with his father about his prostate cancer treatment decision, "He wanted to know if I thought that [the CT] was the best way to go." Connie a daughter of a lung cancer patient, reported that her mother wanted her complete involvement in her treatment decision making. She said, "I think my mom wanted my perspective and opinion [on the CT] because . . . I'm very straightforward, there's no sugar coating it. I think that's what she wanted to hear." Other caregivers reported that the patient situated the decision within the relationship because they regularly made important decisions together. For instance, one caregiver stated, "[My wife] wouldn't do any decision like that without talking to me."

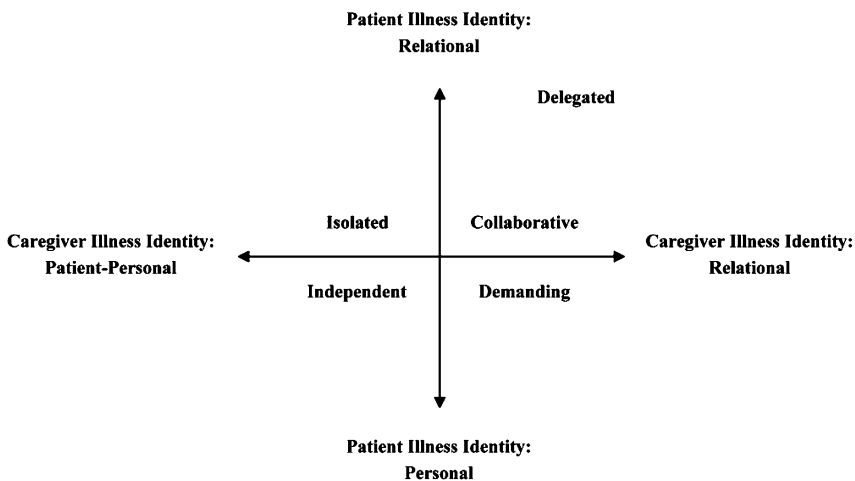


Figure 1. Typology of family decision-making styles.

Some caregivers specifically used the term *sounding board* to refer to the idea that the patient needed approval from the caregiver or trusted their opinion about what he or she should do. Amanda, whose mother had colon cancer, described her role in the treatment decision-making process as, “Maybe like a sounding board or an approver or disapprover. I think maybe she was almost looking for validation, like, ‘Did *we* do the right thing?’” Maggie believed that her mother talked with her about her treatment choices for her lung cancer for a similar reason. She said, “I think I was more of a sounding board than anything. She knows she can trust that I’m not going to pander to her. If I thought that it was a bad idea, she knows I would tell her.” These examples illustrate how caregivers interpreted particular messages to indicate that the patient viewed the illness identity and associated decision as shared.

### *Illness Identity Gaps and Treatment Decision-Making Styles (Research Question 3)*

The third research question asked to what extent caregivers perceive that their illness identity corresponds with patient framing of their illness identity. We analyzed utterances reflecting a caregiver’s framing of illness versus his or her perceptions of a patient’s framing. The results are mapped onto an a priori conceptual framework of family medical decision-making styles (see Figure 1). First, we describe family decision-making styles where the caregiver and patient framed the illness identity similarly (i.e., as either a patient-level personal identity or a relational identity). Then, we describe family decision-making styles where the caregiver and patient frame the illness identity differently, indicating potential identity gaps.

### *Congruent Framing of Illness Identity*

*Independent: Caregiver and Patient Frame Illness as Personal Identity.* The first family decision-making style is one in which caregivers framed illness as a patient-level personal identity of the patient and perceived that the patient viewed the illness similarly. Caregivers in this style perceived their primary role as supporting the patient's health care decision making. In some cases, this perspective was as a result of the patient not disclosing to the caregiver his or her treatment decision-making opportunities. In other cases, caregivers did not expect or desire involvement in the decision-making process. Some reported that the patient had already made the decision, causing their opinion to be obsolete. Other caregivers believed the patient did not wish to discuss their treatment options. For example, Michael described his role in his wife's decision-making process this way, "I figured that if she wanted to ask the questions, I would talk to her about it and she didn't. So, I just let it go." In this example, Michael believed that his wife did not attempt to involve him in the decision making and he did not want to initiate involvement.

*Collaborative: Caregiver and Patient Frame Illness as Relational Identity.* The collaborative decision-making style refers to contexts where caregivers and patients both frame the illness as part of the relational identity. For example, Connie, the daughter of a lung cancer patient, said, "We've always, we're always a close family, and whatever problems we have, it's always out in the open. It's never hush-hush. It's never quiet. It's never, 'don't say anything . . . It's never been like that.'" Other caregivers echoed the sentiment that both the caregiver and patient have a say in treatment decision making. One caregiver described their collaborative decision-making process as, "We talked about the experimental [treatment] and we thought it was good."

Caregivers negotiated different degrees of collaboration in treatment decisions. On one extreme were caregivers who mutually negotiated a very high degree of collaboration. Family members employed in medical fields commonly reported that patients expected a high degree of involvement and caregivers were willing to provide this level of decisional support. Jennifer described how her mother asked her to go with her to every medical visit and provide input on every decision. Jennifer was confident that if she had not attended her mother's medical appointment, her mother would not have participated in the CT because, "She wouldn't do any decision like that without talking to me." Like many caregivers, Jennifer provided her mother with a high level of decisional support, particularly related to the CT.

Caregivers also negotiated different degrees of collaboration across time. One participant, Deborah, described a different level of involvement in her mother's treatment decision making the second time she was diagnosed with breast cancer. The first time her mother was diagnosed, she was completing her medical residency and had little involvement in the treatment decisions. She said, "I just wanted to be the daughter." The decisional process was consistent with a more independent approach wherein her mother informed Deborah of her medical decisions.

The second time Deborah's mother was diagnosed with cancer, she took a much more active role. She said, "What we learned from that [first experi-

ence] is . . . [my mother] can't go into major medical decision making by herself anymore. There has to be someone else to hear it as well." Deborah helped coordinate a second opinion about the diagnosis, helped her mother understand the details of the CT, and even called her mother's physician about her treatment options. She described her mother's openness to her involvement because, "We're a family and we're pretty tight knit." In the end, Deborah and her mother discussed the options and made a final decision jointly.

### *Incongruent Framing of Illness Identity and Identity Gaps*

*Isolated: Personal–Relational Identity Gaps.* The isolated decision-making style occurred when caregivers framed the illness as a patient-level personal identity but the patients communicated in ways that framed the illness and decision in relational terms. This can be thought of as an identity gap between the personal (i.e., no perceived illness identity) and relational (i.e., ascribed illness identity) frames. Caregivers gave various reasons for avoiding participation in the patient's medical decision making. Some did not want to talk about treatment because they felt it was inconsistent with their personality. For example, George described his wife as a person who "talked about everything" related to her breast cancer. George reported avoiding conversations on the topic to try to stay positive. George stated, "I don't want to hear about it. . . . Just the way I am. I don't wanna face up to reality probably."

Other caregivers cited a lack of medical knowledge as the reason they did not want to be involved in treatment decision making. One participant, Jason says he would not talk with his wife about her treatment decisions, "because I'm not an authority on it." However, Jason admitted his wife would have felt more confident in her decision if he had been willing to discuss it with her. Thus, the isolated decision-making style is characterized by a caregiver framing the illness in terms of a patient identity but acknowledges that the patient's communication frames the illness in terms of a relational identity. The isolated decision-making style represents a form of intergroup communication because caregivers are engaging in a communication style wherein the social identities of *healthy* versus *ill* are highly salient.

*Demanding: Enacted–Relational Identity Gaps.* Demanding decision making refers to situations in which members of the social network initiated and enforced an active role in the treatment decision-making process without the patient desiring that they do so. In the demanding style, caregivers framed the illness as a relational identity but perceived that the patient constrained their attempts to enact this identity. In other words, caregivers did not feel as though they had adequate opportunity to share in the rights associated with treatment decision making. In an attempt to actively participate, caregivers in the demanding style attempted to convince (or coerce) patients to make the decision the caregiver believed was correct. Like the isolated family decision-making style, this type of identity gap resulted in communication that increased the salience of a *healthy* versus *ill* social identity between the caregiver and the cancer patient.

Communication in the demanding decision-making style was characterized by messages designed to take control of the medical decision making. Alyssa was a caregiver whose father had prostate cancer. Alyssa felt it was her role

to demand her father comply with what she felt was appropriate medical decisions in any given interaction. She gave the following example: "One time he was having chest pains and I told him, 'I said you have two options. Either ride with me in the car or the squad. Those are your only two options, I'll leave them up to you.'" In this situation, Alyssa was determining all possible courses of action (i.e., receiving treatment) but negotiated her demanding role through the illusion of patient choices (i.e., which car to ride in).

This approach extended to pressuring patients to make a specific CT decision. Typically, caregivers reported convincing patients to participate in the CT rather than the opposite. April described an interaction with her husband about whether he should enroll in the CT. She said, "Well, I flat out told him that I was selfish, that yes, this is what I want you to do . . . that's just the only way to do it." Another example is Hank, who was very supportive of the CT his wife was offered. He explained that she was not in favor of the CT, so he felt it was his job to convince her. He said, "She was even hard to convince after she talked to the doctor." Hank felt solely responsible for her enrollment in the CT, stating, "Because if I hadn't [expressed my opinion], she probably wouldn't have done it."

One interesting twist on the demanding style was how some caregivers constructed the illness as a patient identity if the caregiver and patient were in agreement about the treatment decision but as a shared identity if they disagreed. For example, Heather, the wife of a multiple myeloma patient, put it this way: "It's not my body. He asks my opinion, but if I feel like [his decision's] gonna hurt him—then I will step in." In other words, Heather draws on the identity of an illness as a personal identity when she refers to the idea of *his body*, *his decision*. However, she admits that she would become involved if there is any indication that she disagrees. Thus, this example is a demanding style because the patient only has choices to the extent that those choices correspond with the wishes of the caregiver.

## Discussion

The language used by caregivers to describe the cancer treatment decision-making process support and extend existing theory on the various ways the experience of illness can influence caregiver identity and their involvement in patient care. Several findings are particularly noteworthy. One is that caregivers are a heterogeneous group with regard to how illness of a loved one is incorporated in their personal and relational identity. Some caregivers framed their loved one's cancer as a feature of their shared identity using terms such as *we need to* and *our decision*. These participants felt co-ownership of the rights and responsibilities of medical decision making and viewed participation in the process as part of their caregiving role (Badr et al., 2007; Miller et al., 2008). Caregivers felt this approach was appropriate for various reasons. First, some caregivers perceived that the patient ascribed a relational illness identity through directly asking the caregiver to provide input. Second, caregivers often feared that the patient would make a poor choice without their participation. The final reason for perceiving co-ownership of decision making involved caregivers' perceptions of a relational norm for openness. If caregivers reported that

they were normally direct with the patient about other important life topics, they generally felt the patient would expect them to offer input on the CT decision (even absent a direct or indirect request from the patient that they do so).

Conversely, some caregivers viewed the illness as a personal identity of the patient. These caregivers expressed a preference for the patient to maintain all rights and responsibilities of medical decision making using the phrase, *their body, their decision*. By relinquishing rights to provide input, caregivers were simultaneously absolving themselves of any perceived responsibility associated with any negative treatment outcomes. In other words, some caregivers felt they could not participate in decision making because they could not live with the guilt of recommending a treatment decision that resulted in a poor health outcome.

Another contribution of this article involves providing preliminary evidence for the association between illness identity gaps and intergroup communication processes, particularly in the context of cancer treatment decision making. Illness identity gaps in this study were medical decision-making scenarios in which caregivers perceived that their own view of their illness identity differed from patients' perceptions. Two types of caregiver identity gaps were identified. The first is the *personal-relational* identity gap and aligns with the isolated family decision-making style. The personal-relational identity gap refers to situations in which a caregiver framed the illness as a personal identity of the patient but perceived that the patient framed the illness as a relational identity. Caregivers were often willing to provide patients with emotional support but did not want to participate in medical decision-making processes for a range of reasons, from having a reserved personality to lacking medical expertise. However, caregivers perceived that the patient ascribed a relational illness identity and wanted the caregiver to provide input on the decision. Caregivers reported feeling uncomfortable by patient expectations that they become involved in the cancer CT decision-making process.

The second is an *enacted-relational* identity gap, which aligns with the demanding family decision-making style. The enacted-relational gap refers to situations in which a caregiver framed the illness as a relational identity but perceived that the patient constrained his or her attempts to enact this identity. These caregivers felt that a serious decision like cancer CT participation, which affected the health of the patient and consequently the entire family, required their involvement. Caregivers reported feeling frustrated by patient perceptions that the illness was a personal identity when patients ignored or rebuffed caregiver attempts to participate in medical decision making. A common source of the enacted-relational gap was differing perceptions on whether or not the patient should participate in the cancer CT. Caregivers in the demanding style often felt it was their job to convince the patient to make the "right" decision.

## Conclusion

These findings have practical implications for improving family communication in cases when illness reshapes individual perceptions of the self and relationship roles. From a clinical perspective, health care providers should lis-

ten for clues as to whether patients and their caregivers have similar views of illness identity and the decisionmaking process. Situations in which patients discuss treatment decisions using “I” language and caregivers are using “we” language could signal the potential for conflict within the family. Caregivers in the demanding style may use significant social influence tactics in order to encourage patients to undergo certain types of medical treatment. In the current study, some caregivers convinced patients to participate in medical research because they believed it would provide a miracle cure. It is important to be sensitive to the potential for patients to agree to treatments they do not want in order to please caregivers. The opposite was also true in some cases. Some patients turned down the opportunity to participate in a medical research study because family members perceived research participation as risky. Providers should recognize that caregivers are often an important source of emotional, esteem, instrumental, and informational support for patients (Goldsmith, 2004). Patients may have difficulty making a decision a caregiver disagrees with if they are relying on that person for various types of social support. Family-based interventions may be useful for helping patients and family members identify their expectations of the decision-making process and identify a mutually satisfactory solution to differing desires.

The current study, as with all research, has limitations that should be noted. The study was designed to answer the call for research on the ways in which health decision making is commutatively constructed within families (Epstein, 2013). While this study explores the richness of the diversity of caregiver perspectives, including patient perspectives would also be useful. Future research could build on the current investigation by comparing patient and caregiver data on a more narrow set of criteria. Nonresponse bias is another potential limitation. Some of the referred caregivers declined to participate. Although it is unlikely that such a bias would influence the development of themes, it does preclude any generalizations about the prevalence of family decision-making styles.

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