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Patient Perceptions of Illness Identity in Cancer Clinical Trial Decision-Making

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Abstract

When patients are diagnosed with cancer, they begin to negotiate their illness identity in relation to their past and future selves, their relationships, and their group memberships. Thus, how patients view their cancer in relation to their other identities may affect how and why they make particular decisions about treatment options. Using the Communication Theory of Identity (CTI), the current study explores: (1) how and why illness identity is framed across identity layers in relation to one particular cancer treatment: participation in a cancer clinical trial (CT); and (2) how and why patients experience identity conflicts while making their treatment decisions. Semi-structured, in-depth interviews were analyzed for 46 cancer patients who were offered a CT. Results of a grounded theory analysis indicated that patients expressed separate identity frames (e.g., personal, relational, and communal), aligned identity frames (e.g., personal *and* communal), and identity conflicts (e.g., personal-personal). This study theoretically shows how and why patient illness identity relates to cancer treatment decision-making as well as how and why patients relate (and conflict) with the cancer communal identity frame. Practical implications include how health care providers and family members can support patient decision-making through awareness of and accommodating to identity shifts.

Keywords

illness identity; identity conflict; cancer; communication theory of identity; clinical trial decision-making

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Cancer is defined as a “collection of related diseases in which some of the body’s cells begin to divide without stopping and spread to surrounding tissues” (National Cancer Institute [NCI], 2015). With increased knowledge, detection, and treatment advancements, approximately 70% of U.S. cancer patients live beyond 5 years after diagnosis (Howlader et al., 2015). Although cancer mortality rates vary according to patients’ cancer type and treatment decisions, many patients living with cancer face considerable challenges as they cope with identity and lifestyle changes—from diagnosis through survivorship (CDC, 2016). Patients’ view of their cancer may have both positive and negative consequences for their well-being, including how they seek and receive care and make decisions about treatment options (Krieger et al., 2015a). Patients constantly negotiate their illness identity (i.e., how they understand their cancer as a part of themselves) in relation to their past and future selves (Charmaz, 1995), their relationships (Miller & Caughlin, 2013), and their group memberships (Harwood & Sparks, 2003). Thus, illness identity changes across the illness trajectory and results in different needs and goals for well-being, depending upon how patients view cancer in relation to their experiences and other identities (Mathieson and Stam, 1995).

A key challenge for patients during the cancer experience is treatment decision-making. Newly diagnosed patients may have a difficult time deciding which treatment is best and often rely on families and their health care provider(s) (HCPs) for guidance, though some patients prefer to make the decision themselves (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007). A research study, in the form of a clinical trial (CT), is one type of treatment option that may be introduced alongside other options. Because the purpose of a CT is to evaluate the effectiveness of at least one new treatment in comparison with the current standard treatment, patients’ anxiety and uncertainty while evaluating options may increase—especially as they struggle to process their diagnosis (Krieger et al., 2015a). The CT treatment decision may highlight identity conflicts (e.g., individual cancer patient vs. communal cancer patient), and depending on how patients view their cancer illness identity, they may respond differently to a CT option.

The current study examines patients’ illness identity during CT decision-making through the Communication Theory of Identity (CTI) (Hecht, 1993). CTI posits that identity is made of four layers (i.e., personal, enacted, relational, and communal) and that each layer combines with the others to create identity consistency or gaps (Jung & Hecht, 2004). In cancer treatment decision-making conversations, patients and HCPs try to negotiate similar meaning of discussions about patient health and particularly treatment goals to improve patient health. However, patients are often accompanied by caregivers who sometimes have their own goals for, and opinions about, the patient’s health, resulting in relational conflict and stress (Krieger et al., 2015b). Thus, we examined how patients considered CTs in relation to their illness identity so that all decision-making parties (i.e., patients, caregivers, HCPs) can negotiate meaning that enhances patients’ well-being and satisfaction with their cancer care during the treatment decision-making phase.

Illness as Identity

Illness Identity

Two common definitions of illness identity are Hayden's (1993) illness as "a deviant, abnormal state" (p. 264) and Charmaz's (1995) "incorporation of chronic illness or disability into one's sense of self." Of course, not all illness is the same. Visible illness (e.g., hair loss due to chemotherapy) is easily detectable by others through physical markers while invisible or hidden illness is not (Kundrat & Nussbaum, 2003). However, all identities, including visible and invisible illness, are negotiated through self-reflection and interactions with others (Hecht, 1993).

A chronic illness diagnosis is often considered an identity crisis for patients because they perceive changes in themselves and their roles, relationships, and abilities (Martin, 2016). In negotiating their illness identity, individuals experience identity conflicts between their past, present, and future selves (Hayden, 1993). As they struggle to redefine themselves in the context of their illness, individuals must learn to manage symptoms and others' expectations for them (Townsend, Wyke, & Hunt, 2006). This identity negotiation process is ongoing and plastic; as patients' illness experience changes, so do their needs and goals (Miller & Caughlin, 2013). For example, cancer patients have reported that after treatment, they struggle to negotiate a new patient identity—one where patients continue to seek follow-up care but cancer is no longer present in their bodies (Arora et al., 2007).

Additionally, Harwood and Sparks (2003) discuss three important levels of cancer identity for patients in relation to others: (1) primary identities, in which patients identify with large cultural groups (e.g., ethnicity and age); (2) secondary identities, in which patients identify with healthy and unhealthy behaviors that they share with others (e.g., smoking); and (3) tertiary identities, in which patients define themselves by their illness (e.g., cancer patient, survivor, or victim). The authors propose that these identities relate to specific health outcomes and behaviors. For example, cancer patients who identify as runners will find it easier to maintain this part of their identity during cancer if it is already a part of a person's self-concept. If running is not a part of patients' self-concept, then individuals will find it harder to maintain this identity during cancer (Harwood & Sparks, 2003).

Thus, how patients relate to the identity of 'cancer patient' has implications for their well-being. If patients negatively identify as a cancer patient, they may feel that cancer conflicts with their self-concept, resulting in perceptions of little control over the illness and lower participation in treatment discussions (Harwood & Sparks, 2003). Ai et al. (2010) found that individuals who struggled with incorporating their illness into their identity experienced increased depression, risk for co-morbidity, and spiritual struggle, as well as decreased hope. On the other hand, Sulik (2011) showed that patients who viewed their cancer as part of themselves (i.e., identity coordination) were 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. In the following sections, we show how CTI applies to illness identity and CT decision-making.

Communication Theory of Identity and Health

One theoretical lens to view illness and identity is the *communication theory of identity* (CTI) (Hecht, 1993). According to CTI, identity is comprised of four layers: *personal*, *enacted*, *relational*, and *communal*. The *personal* layer is one's view of oneself, or self-concept. *Enacted* is the performance of an identity through a role of some kind in social interactions. *Relational* is identity that is mutually negotiated between individuals. Finally, the *communal* layer is the identity of a group or community. All identity layers are intertwined with one another; however, one layer may be more salient than others depending upon the context and individuals. Identity gaps are created when one or more identity layers contradict each other (Jung & Hecht, 2004). These gaps may occur (1) *between* layers (11 possible gaps) or (2) *within* layers (Colaner, Halliwell, & Guignon, 2014). Within CTI, identity is viewed as inherently social, negotiable, and fluid over time (Hecht et al., 2004).

Applying CTI to illness identity involves a negotiation of the illness experience, resulting in changes in cognitions, emotions, and behaviors that can help people return to a satisfying way of life (Sulik, 2011). Health and identity are interconnected (Haslam, Jetten, Postmes, & Haslam, 2009). 'Healthy' is culturally defined and people absorb messages from their environment to inform what it means to be healthy. Historically, healthy has meant the absence of illness; however, health as an identity has also come to encompass individuals' behavioral choices and beliefs about fitness and nutrition (Hecht & Choi, 2012). In a cancer context, the personal cancer identity layer can conflict with the relational identity layer when someone's self-concept of cancer identity is different from that individual's perception of how others (e.g., family members) view him or her. For example, a patient may view herself as healing from cancer and want to return to work; however, her husband and children may want her to take more time off work because they still view her as 'sick'. Likewise, patients may have a personal-personal identity conflict that fluctuates often if they primarily view themselves as 'healthy' on days when they feel well and 'ill' on the days when they feel tired or nauseous (Higgins, 1999).

In the health and illness contexts, researchers have primarily examined the personal and relational identity layers as opposed to other identity layers (Hecht & Choi, 2012). The current study addresses this gap by examining these layers and communal identity within the cancer CT treatment decision-making context. These results may inform future interventions that hope to improve communication about CTs, patient informed decision-making, overall patient satisfaction, and patient distress while managing conflicting identities.

Cancer Clinical Trial Decision-Making

CTs are an important resource in cancer control and prevention (Mills et al., 2006). The success of CTs depends upon high and widespread patient enrollment and low dropout (Mills et al., 2006). CT enrollment numbers, however, are low, with only 3–5% of cancer patients enrolling (Umutyan et al., 2008). The CT context is important to study from a decision-making perspective because research studies are usually offered to patients immediately after receiving a cancer diagnosis. This is a period when time-related pressure, uncertainty, and stress are particularly high as patients and their family members cope with

their diagnosis and evaluate treatment options (Krieger, 2014). Communication factors such as physician responsiveness, framing of the CT (e.g., positive, negative, neutral), and supportive communication (e.g., emotional, informational support) have been found to influence patients' CT decision (Albrecht et al., 2008). Other studies have found that family members' communication (e.g., decisional support through asking questions and giving advice) to be influential in the patient's decision (e.g., Krieger et al., 2015b). Scholars have called for more research that focuses on patient and family informed decision-making and patient satisfaction with the decision-making process, including the support they receive for their decision (Stepan et al., 2011). Thus, this study examines the ways in which patients perceive cancer in relation to their identity during CT decision-making. Thus, the following research questions are proposed:

RQ1: How did patients perceive their illness identity when explaining their decision-making about CTs?

RQ2: What illness identity gaps did patients perceive when explaining their decision-making about CTs?

Method

Participants

Patients were recruited by partnering with health professionals at four community cancer clinics and a large, urban Comprehensive Cancer Center. Participants were 49 cancer patients who were *offered* a randomized cancer CT within the last two years. Of the 49 patients, three were eliminated after it was determined that they were not offered a randomized cancer CT. The final sample included 46 participants from 4 clinics: an urban clinic ($n = 17$, 37%), and three rural clinics ($n = 17$, $n = 9$, $n = 3$). The majority of participants were female ($n = 28$, 61%) and ages for all participants ranged from 33 to 79 years ($M = 59.67$, $SD = 11.46$).

Nearly all participants were White ($n = 44$, 96%) with one patient of Asian ethnicity and one patient declining to respond. Approximately 75% of patients enrolled in a CT ($n = 35$). The three most common types of patient cancer were breast ($n = 19$, 41%), multiple myeloma ($n = 9$, 20%), and prostate ($n = 7$, 15%). The highest levels of education among most participants was a high school diploma ($n = 17$, 37%) and some college ($n = 15$, 33%). Half of all participants reported annual household incomes of \$49,000 or lower ($n = 23$) with 5 patients reporting "don't know" and one patient declining to respond. The most common sources of health insurance were through an employer ($n = 22$, 48%) and Medicare ($n = 14$, 30%).

Procedures

Clinics identified patients who had been offered a randomized cancer CT (i.e., standard treatment compared to newer treatment) and were mailed a recruitment letter signed by their treating physician. A researcher conducted follow-up phone calls to give patients more information about the study and schedule interviews for those who agreed to participate.

Interviews were conducted until data saturation (i.e., no new information appeared in the data) was reached (Charmaz, 2006).

The interviews for this Institutional Review Board-approved study were semi-structured to allow for a discussion of similar topics but also to explore unique participant responses (Patton, 2002). A researcher was trained in interviewing techniques and conducted two practice interviews with medical professionals, after which interview questions were revised for clarity and sensitivity. Specific questions included, but were not limited to: (1) *What was your initial reaction to the treatment options you were given?* (2) *What was the initial reaction to the treatment options for the people who were with you?* (3) *What were the factors that you considered when you were deciding which type of treatment to receive?* (4) *What was your initial reaction to the clinical trial when it was presented?* (5) *Did your perception of the clinical trial change over time—why or why not?*

Patient interviews were audio-recorded and ranged from around 30 minutes to 3 hours in length. They were conducted in-person and at a location of the participant's choice. Whenever possible, interviews were conducted privately; however, four individuals were interviewed with others present. Following the interview, participants were asked a series of basic socio-demographic questions and given a \$30.00 gift card.

Interview Analysis

After interviews were conducted, they were uploaded to a password-protected computer and transcribed verbatim. Coders used NVivo 10 to conduct analyses and check reliability. Grounded theory analysis occurred in three phases (Charmaz, 2006). In the *initial (open) coding phase*, four independent coders read over each transcript several times while remaining open to all themes present in the data. It was in this first phase that multiple identity concepts emerged in the data. Researchers were not initially searching for CTI concepts; however, once the identity concepts emerged, coders agreed that CTI seemed to best capture and make sense of the multiple identity units present in the data. Thus in the following *focused coding phase*, researchers coded according to main themes related to perceived illness identity layers (i.e., personal, relational, and communal), identity gaps, and CT decision-making; and identified each unit of analysis based on these themes (Charmaz, 2006). Enacted identity was removed from analysis when researchers agreed to focus on perceived identity and identity shifts—what, how, and why patients felt about their illness when making their CT decisions. A unit of analysis was defined as any thought or idea related to the above themes, ranging from a phrase to several paragraphs. Modeled after CTI, *illness identity* was based upon the operationalization of identity within CTI in past qualitative research (e.g., Colaner, Halliwell, & Guignon, 2014) and thus defined as “an understanding of what it means to be a patient with cancer”. Analysis included any reference to cancer perceptions during CT decision-making through personal (i.e., references to own body or perceptions of illness); relational (i.e., mutually created perceptions of cancer within specific relationships, such as partner or family); or communal identity (i.e., group identity regarding cancer) (Hecht & Choi, 2012). *Illness identity gaps* were defined as any gap within or between identity layers during CT decision-making in relation to cancer (e.g., personal vs. communal) (Jung & Hecht, 2004). Coders verified each other's units and met to

discuss any discrepancies. A code book was created based on these themes¹ (Creswell, 2007). Two of these coders then re-coded all data according to the codebook to verify reliability.

In the third phase of coding (i.e., axial coding), coders identified the nature of the relationships between illness identity and illness identity gaps in relation to patients' CT decision (e.g., how they connected to each other to inform patients' decision-making) (Charmaz, 2006). Only units that pertained to CT treatment decision-making were included in analysis. Data about patients' identity during other stages of their cancer experience (e.g., diagnosis, recovery) were not included in the dataset *unless* patients deliberately related those experiences to the treatment decision-making stage, as can sometimes happen during the cancer experience (Krieger, 2014). Examples of information related to identity, but not coded, were when patients referred to aspects of themselves (e.g., previous hospitalization experiences, past occupational roles) that they did not relate to their current experience of cancer treatment decision-making. However, because our study focused on cancer and treatment decision-making, most units of identity data were included when coding for illness identity and treatment decision-making.

Results

Overall, participants made their decisions about CT enrollment based on illness identity perceptions, goals, and conflicts in reference to themselves, close relationships, and communal others (e.g., other cancer patients). Within each unit of analysis, participants related illness identity to their CT decision by referring to one layer of identity, by coordinating two layers of identity at the same time, and/or by referring to identity gaps.

Individual Layers of Identity (RQ₁)

All participants ($n = 46$) referred to one frame of illness identity when discussing their CT offer ($n = 458$ utterances): personal (42 participants; $n = 212$ utterances), relational (39 participants; $n = 161$ units), and communal identity (34 participants; $n = 85$ units). Unit totals are reported in Table 1.

Personal identity.—Four subthemes existed for participants ($n = 42$) who framed their CT decision within a personal identity frame: (1) *self as the locus of illness*; (2) *self as the locus of decision-making responsibility*; (3) *health identity in relation to illness identity*; and (4) *other aspects of self in relation to illness identity* (see Table 1). For people who described their personal illness identity as the *locus of their illness*, they described cancer as physically existing within their bodies. Additionally, they related the CT treatment to personal-level identity attributes, such as personal beliefs and opinions about cancer, treatment, and their bodies (*best treatment for me*; *it affects me*; *it's my body*). For example, Anna, a 50-year-old patient with breast cancer, was nervous about the harmful side effects of radiation to her body. However, she was offered a CT that would test whether ingesting heavy doses of cumin could reduce burning from radiation treatment, she agreed to participate: "If it was gonna help me get through it, you know, even the slim chance of it making it better . . .

¹Contact the corresponding author for a copy of the codebook.

Yeah, anything I could do to not have to burn or not go through anything, I was willing to try.” Anna, a medical lab technician, said she understood that she may get the control arm of the blinded CT (i.e., no cumin); however, she said she perceived the CT as having the potential to alleviate radiation’s harmful side effects to her body.

Another way participants used personal identity was as the *locus of their decision-making responsibility* in relation to their CT decision by claiming ownership of the CT decision (e.g., *my decision*). For example, George, a 68-year-old prostate cancer, said he did not remember receiving advice from anyone about his CT option, including his wife and children, but he said, “It wouldn’t have made no difference. I am in command of this,” reflecting his psychological ownership over his CT decision. Later in the interview, he, like Anna, related the CT back to his cancer identity, which, for him, was the physical presence of disease in his body: “I felt like there was things that, for instance, that they had found that hormonal injections and so forth, would make the cancer actually retreat, and those kinds of things I think was important.” For George, he connected the CT to his personal cancer identity and hoped the CT would make his cancer less present in his body. He later enrolled in the CT.

The third way participants used personal identity to frame their CT decision-making was through discussion about their *cancer illness identity in relation to their overall health identity*. For example, some participants explained that they were “good” and “perfect candidates” for the CT because they were “young” and “healthy” even with a diagnosis of cancer. Other participants explained that because they were “healthy”, they wanted to “get [cancer treatment] over with” and not be “sick” any longer than they had to be. In this theme, patients seemed to have accepted their cancer diagnosis by accepting the reality of cancer and cancer treatment on their bodies, but only as a temporary part of their personal identity that existed alongside their overall more permanent “healthy” identity. These patients described themselves through evaluations of strength, absence of other illness, and overall activity levels. Because some CTs could possibly extend the number of treatments in comparison to the standard treatment, many patients perceived the CT as also extending their sickness. For example, Madeline, a 65-year-old, two-time breast cancer patient, said, “I remember seeing another woman there in a chair – in a wheelchair, looking, you know, she had the scarf on, the hat, looking very, um, very ill. You know, I’m sure with cancer. And I remember thinking how lucky I was that I – you know I was okay. My borders were clear. I was okay.” Even though Madeline was offered a CT that day, she said she declined it because she considered herself healthier than other cancer patients and “just wanted to get out of there.”

Finally, patients used personal identity to describe their CT offer in relation to *other aspects of self and their illness identity*. Some patients had previous experience with CTs while others used their occupational roles or personality traits to explain their (dis)comfort-level with a CT. For example, Alice, 79, a retired medical lab technician, said she was interested in research. She said she had enrolled in her current CT for breast cancer treatment because “I’ve been in other clinical studies for things and I’m very interested in science and I have a background in science with medical technology.” Another example is Kristy, 52, a nurse anesthetist, who explained her decision to participate in a breast cancer CT as primarily an

evaluation of personality traits. Kristy said, “I think it’s whether they’re a risk-taker or not ... I’m willing to take risks.” These patients viewed their cancer CTs as fitting (or not fitting) within their overall self-concept.

Relational identity.—Patients ($n = 39$) who referred to their relational identity during their CT decision-making referred to their relational identity in two ways: (1) *relationships as the locus of illness identity* and (2) *relationships as the locus of decision-making* (see Table 1). For patients who viewed their cancer as being shared with others, they referred to relational identity in present, past, and future tenses. When describing a present relational identity, patients used language such as ‘we’ and ‘our’ to describe their illness. For example, Frank, 47, was diagnosed with multiple myeloma, but continually referred to his wife as sharing in his illness identity:

We were getting sick daily, you know, throwing up. So our quality of life was very low at that point. And like now, mid-February, we came down with shingles in our right eye and we just now, here it is April, and we’re just now getting over that. We had gyrations in our liver enzymes so they took us off all medication in the first part of February and that led us to be exposed to shingles. And to have the virus activated in our body.

For Frank, his wife, who was his primary caregiver, not only shared in the psychological experience of cancer, she actually shared in the physical experience of cancer even though she had never been diagnosed with cancer. This is juxtaposed with other sections of the transcript when he described his Army status (e.g., “I’m still in the United States army, I’m currently receiving Social Security benefits”). Thus, he primarily used “I” or “you” when describing other identities, such as his army or disability status, and “we” (referring to his wife/mother/sister who are involved in caring for him) when discussing his cancer treatment. This framing of ‘we’ in the shared experience of cancer appeared in several patients’ accounts (even though only the patient had the physical presence of cancer), using phrases such as “our markers have decreased”, “we’re so young, they gave us this cancer drug,” and “this was the place for us to be treated because of the high level of care”.

Some participants described their cancer in their CT decision-making as existing in their past and the future relationship identities, which have informed their present illness identity. Several participants, like Peggy, 54, reflected on their family history of cancer as they made their treatment decision: “My mom’s cancer is probably the largest influence on my attitude. But that was kinda like ‘cause I grew up with it basically. You figure I’ve lived around this stuff for almost 50 years.” Peggy’s mother died of breast cancer, and she remembers her mother’s treatment as being difficult. She said because of her family experience—both past (mom) and future (she has two daughters)—she is supportive of CTs and the improvement of cancer treatment for current and future patients.

The second way patients used relational identity to explain their CT decision-making was through *relationships as the locus of decision-making responsibility*. These patients used words such as “we”, “our”, and “us” when talking about the CT and the decision-making process. Laurie, 67, said “we didn’t know what to do” after her doctor told her and her husband about a breast cancer CT. Although Laurie was the one who physically had cancer,

she viewed her husband as sharing in the CT decision-making experience with her, including feeling uncertain and over-whelmed, because “we have a really good relationship”. Gilbert, a 58-year-old patient and physician with multiple myeloma, said he viewed his wife as sharing in the CT decision-making with him even though “she’s got a nursing home administrator background, but she doesn’t really have a medical background...so all the medical stuff was brand new for her.” When asked why he valued her opinions when he already possessed a high level of knowledge about his cancer and CT, he said, “she’s my wife, she’s my partner.”

Communal identity.—Participants ($n = 34$) who used communal identity to explain their CT decision-making used one main theme: *illness identity as cancer patient*. Patients referred to themselves as one of many cancer patients, one of many CT patients, and/or wanting to help other cancer patients through CT participation (see Table 1). They used language to frame their CT decision in terms of the anonymity of CT participants (e.g., *numbers used instead of names; no one knows what treatment we get*), and perceptions of CT participation among other cancer patients (e.g., *national study, two or three thousand people are part of this*).

Additionally, patients who viewed themselves as cancer patients in the communal frame focused on wanting to “help others”, referring to future cancer patients. Gloria, 50, who had lung cancer, said she enrolled in her CT because she believed that researchers would be able to “study something new that can help speed up the attack on the cancer and you know, help the people so they don’t have to go through such a long regimen of chemo or whatever and help get ‘em back on their feet.” Gloria, like many other patients, acknowledged that she was grateful to cancer patients who previously volunteered for CTs, which enabled her to have the benefits of her current treatment. Before enrolling, she thought about how she liked the CT because she viewed it as an opportunity to “give back” to cancer research. Emma, 55, before enrolling in her CT for multiple myeloma treatment, said she felt the same way. She explained:

I knew that I wanted to be a part of it and it was a good thing... Someday, even if not in my lifetime, there being a cure and just, you know, helping somebody else. That’s the main thing--helping somebody else, you know, it really is. I mean it’s not about you. It’s about somebody else.

Aligned layers of identity.—When explaining their CT decision-making, some participants ($n = 27$) referred to aligned layers of identity within the same unit of analysis ($n = 51$ utterances): (1) personal and relational; (2) personal and communal; and (3) relational and communal (see Table 1).

Personal and relational identity.—For this theme, patients mentioned moving back and forth from a *personal to relational locus of illness identity and decision-making*. Within the same unit of analysis, participants sometimes used “I” and other times “we.” For example, a prostate cancer patient, Eddie, 58, was offered a CT (surgery vs. surgery plus chemotherapy), but was unsure of participating in the CT because of a fear of chemotherapy. After discussing the trial with his wife for three hours, they decided that he should enroll.

Eddie described the confidence and relief he had in their decision: “Once we decided to do this, the fear was gone. I didn’t have any more fears. It was just, okay, we’re gonna make a decision, we’re gonna do this and let’s move on, let’s march forward.” Here, his use of language showed his psychological movement from cancer-related fears residing within himself (e.g., treatment effects in his body) to a decision/treatment solution residing psychologically within both of them. Even though Eddie viewed the aggressiveness of chemotherapy as a risk instead of a benefit like Larry, they both explained how the decision moved them from a personal identity to a relational identity with their spouses.

Personal and communal identity.—In this theme, participants framed their cancer as *illness identity existing within themselves and other cancer patients*. For example, Betty, 43, said she enrolled in her breast cancer CT because “you know, why not, why not give it a chance? You know, it might work. And if it does, it would benefit other people too, in the long run.” Hannah, a 36-year-old breast cancer patient, said she enrolled in her CT for similar reasons: “Basically, if I’m on it, [and] the research is correct or what they’re saying is correct, that I would have less chance of having a reoccurrence if I’m on it. If, within the study, they do find that it is true, then I’ll be immediately switched and be put on it [and] just the benefit of knowing that you’re part of something bigger.” Patients with these aligned identity frames, such as Betty and Hannah, distinctly related the CT to their cancer identity both personally as a potential treatment for their present cancer and with communal others who will have their same cancer in the future.

Relational and communal identity.—For this theme, participants focused on their family as well as larger, communal identities, such as religion and cancer patient. For example, Alice, 79, explained that she hoped her participation in a breast cancer CT would “help researchers and help them come up with a vaccine or a cure for cancer. And besides, I have three daughters of my own and three granddaughters. So I hope down the road that they won’t have to worry about getting breast cancer or other kinds of cancers.” Alice knew that the CT would not benefit her breast cancer; however, she believed her illness experience might help her female family members and other cancer patients. Likewise, Tim, 65, used relational-communal identity to explain his ability to navigate the fear and uncertainty that came with his prostate cancer and his CT decision through his deep faith and close connection with family:

You got to have belief that there’s something out there more than just us. And, uh, I’m not saying if you’re Catholic, Jews, or Jehovah Witness or what. I’m not picking on anybody’s religion. But I’m saying you need something to have some faith in. And you need a strong family. That’s the whole key to all of this stuff. And I’m telling you, you know, it would’ve hurt me if they’d said, ‘You got six months.’ Yeah, it’d hurt you. You, you’d probably cry for the six months. But at least you know that you did everything that was possible to stay with them, and they’ve made the right decisions with you. You know, so that’s all you can do.

Tim aligned his cancer identity with his faith and his family, and his perceptions of a ‘right decision’ was anything that could prolong his time with his family. He explained that even if he would not live long after his participation in his CT, he had peace within himself that he

had a foundation of faith and family to support him, and that they were part of his treatment decision-making process.

Illness Identity Gaps (RQ2)

Illness identity gaps existed when participants ($n = 33$) experienced an identity conflict that was present within layers or between two layers ($n = 137$ utterances). Sometimes these conflicts were resolved by the time patients made their CT decisions; other times the conflicts remained during patients' participation in their CTs. The three most common illness identity gaps were *personal-personal*, *personal-relational*, and *personal-communal* (see Table 1).

Personal-personal identity gap.—Patients experienced personal-personal identity gaps in two ways. For some patients, it was a conflict between a cancer identity and their overall health identity. For example, Bill, a 67-year-old prostate cancer patient who enrolled in a CT to hopefully improve cancer treatment for himself and others, admitted to still struggling with coming to terms with the fluidity of his past, present, and future cancer identity, especially after ensuring that he was eating healthy and exercising often before his diagnosis:

And, it didn't mean anything. Still got it. ... I find that interesting and I find out how little, how – we've come a long way with cancer. ... but nobody knows. All these doctors, they just – and they're not wrong. They don't know. I'd rather hear that. You know? There's no magic.

For patients like Bill, the cancer experience was intertwined with his CT decision because of the uncertainty behind his cancer diagnosis as well as his CT efficacy—"no one knows" and "there's no magic". Although he appreciated that doctors were honest with him about his prognosis with the CT, he was unsure if his past health identity would be restored or if his current illness identity would also be his future illness identity, even after participating in the CT.

Another example of personal-personal identity conflict is when patients wanted to participate in a CT to possibly improve their cancer but could not because of other health reasons. For example, Caleb, 55, had to delay treatment through the colon cancer CT by two weeks because he developed a life-threatening blood clot:

It really upset me because I was really wanting to get this taken care of. ... I had to wait two more weeks before I could have a treatment. So, that really upset me because I guess when you're dying, time's limited. You only got a certain amount of time to take care of it.

For Caleb, his struggle was not with accepting his cancer; it was with accepting that the health complications from his cancer were preventing him from moving forward with the CT, his preferred treatment for his cancer.

Personal-relational identity gap.—When participants experienced a personal and relational identity conflict, they were often relating how their personal illness identity

conflicted with their family identity. For example, Samantha, 52, declined a breast cancer CT because she wanted to focus only on healing and taking care of her children:

I think when you're first diagnosed, you're not in denial but you're just, I want it out of me. I want it gone. You know. I just want this - you know, I don't wanna take a chance that I'm not gonna get something that I need. I was just into that mode of I need to survive. I've got two little children.

Samantha acknowledged that she had cancer; however, she did not incorporate it into her identity as a mother. Rather than viewing a CT as a way to benefit her family's future health identity, she primarily identified with her present relational identity as a mother with two children, and viewed the CT as something extra that did not contribute to her identity as a mother.

Another type of personal-relational identity gap during CT decision-making existed when patients viewed their cancer identity differently than their families. For example, Frank said he wished his family accepted that the CT was not prolonging his life and that his cancer would not be cured.

The problem I run into with my family - with [my wife] and my mom and my sister - they think that we're going to be cured with this thing and I know in the heart of hearts we probably won't... It would make things easier on me if they would face that reality. Because I think they have a harder time dealing with me having terminal cancer than I do.

Frank identified his cancer partially with his family (e.g., "we're not going to get cured"); however, when talking about the conflict in perceptions, he reverted back to his personal identity (e.g., "me having terminal cancer"). This statement showed his desire to experience cancer together with similar perceptions about his CT. However, his family viewed his illness identity as temporary while he viewed his illness identity as permanent.

Personal-communal identity gap.—A common personal-communal identity gap was declining treatment because the communal goal of helping other cancer patients conflicted with the personal identity goal of healing from cancer in one's own body. For example, Cathy, 65, a lung cancer patient declined enrollment in a CT because it would have extended her chemotherapy treatment from 6 months to a year:

I know they have to have these in order to help others down the, the road. You know, I know this has to be. Um, and I'm not doing this. I mean, if it's six months, maybe. But a year? I'm not gonna be committed for a year. I'm not gonna make myself sick for - because I'm a healthy person. And I think that's, I think that's the whole thing. Being healthy and being sick and definitely we want, we all want the health. And, um, when you think of life, it's short. And why make me sick or, or committed for a year when I'm gonna be fine after this is over? After, after my chemo is over, after, I'm gonna be fine.

For Cathy, her illness conflict existed between personal vs. communal. She did not want to be sick any longer than she had to be (personal identity) and she believed that longer treatment meant being sicker longer; yet she struggled because she saw herself as someone

who helped others (communal identity). She eventually resolved her conflict by declining the CT, but while she was deciding, she kept going back and forth between her personal identity goals (quick treatment, restoration of health) and communal identity goals (help others).

Discussion

The purpose of the current study was to explore patients' perceptions of their illness identity and their CT offer, using the Communication Theory of Identity (CTI). Analyses were limited to communication about the cancer treatment phase to explore how people related what their cancer meant to them (i.e., illness identity) to a CT. Patients described their cancer identity as existing in (1) separate identity frames (i.e., personal, relational, or communal), (2) aligned identity frames (e.g., personal-relational), or (3) conflict with other aspects of their identity (e.g., personal-communal). Illness identity was found to be complex; varying with participants' experiences, values, and goals; and sometimes evolving over the decision-making period to include intersection with other identity frames (e.g., personal to the relational). Some of the results replicate extant literature (e.g., desire to help others), while other findings are novel. For example, new findings indicated that during CT decision-making, some patients considered themselves to be healthy while experiencing cancer and some patients moved from a personal identity of cancer to more of a relational identity. Thus, by using CTI to connect illness identity to patients' perceptions of CTs, we may be able to enhance recognition of patients' values, validate patients' unique view of their cancer, and help them to make sense of their diagnosis/treatment options in relation to their other unique identities.

Theoretical Implications

The challenge of understanding and improving cancer patient decision-making about CTs has been examined from different angles. While past research has focused on issues such as patient demographics and cultural identities, knowledge, transportation, uncertainty, motivations, HCP communication, and family decisional support, (e.g., Baquet, Commiskey, Mullins, & Mishra, 2006), the current study illuminates the fluid nature of patient identity frames and how they align with or contradict each other during treatment decision-making. Our findings theoretically connect patients' illness identity to their treatment decision-making process, which may suggest an additional way to understand patients' CT decision-making while also suggesting HCPs and supportive others consider illness identity when talking to patients about CTs.

Some patients used negative group stereotypes to view 'other' cancer patients as weaker, sicker, and needing more help than they personally did because they were "stronger" and "healthier". Thus, this study also furthers the work of identity communication research (Harwood & Sparks, 2003) by using illness identity to explain why some patients may relate negatively or positively to the communal 'cancer patient' group identity. For example, our findings suggest that if patients primarily identify with cancer in the personal frame, receiving messages from others in the communal frame may create identity conflict and result in negative affect, such as increased guilt, if they believe they 'should' be like other

cancer patients by either enrolling in a CT to benefit others or doing everything they should to ‘fight cancer’. However, if patients relate their cancer with others’ experiences of cancer, then receiving messages aimed at the communal frame of cancer identity may create or reinforce positive affect toward a shared group-level identity (e.g., provide comfort and support by reinforcing patients are not alone).

Additionally, some patients were initially concerned about their personal identity (e.g., personalized treatment for cancer), but then moved toward a relational identity (e.g., recognition that cancer affected their relationships) over the decision-making period. This finding may have implications for Temporal Comparison Theory (Klauer, Ferring, & Filipp, 1998), which explains how individuals struggle to maintain self-consistency during severe illness, and may have more positive views of their illness identity when they perceive change in multiple areas of life functioning (i.e., physical, self, family, work). Likewise, our study suggests that illness identity may fluctuate even during a short period of time (e.g., one week). Because HCPs and supportive others were sometimes involved in these identity negotiations, future studies should develop theoretical explanations for how social support influences the relationship between illness identity and higher or lower well-being.

Practical Implications

The study has implications for effective patient-centered care and communication. In patient-centered care, health care providers (HCPs) focus on patients’ emotional, psychological, and medical needs. If decision-making is an extension of patient identity, HCP awareness of and communication accommodation toward the ways in which patients relate their identity to CT cancer treatments could enhance patient-centered communication (Hajek, Villagran, & Wittenberg-Lyles, 2007). By examining patients’ perceived illness identity within the personal, relational, and communal identity frames, HCPs could better understand how to legitimize patients’ perspectives of their cancer while also tailoring their CT offer to what cancer uniquely means to individuals. Future studies could develop an illness identity and decision-making aid to identify patients’ main identity frames to help them sort out the identity changes and conflicts that often accompany a cancer diagnosis. Further, by becoming aware of how patients’ explain their cancer illness identity, HCPs and family members could better support patients by finding ways to support the patients’ holistic health—other aspects of patients’ identity that matter to them, such as finding ways to incorporate patients’ past selves into their changing selves (e.g., encouraging engagement in past hobbies, such as running, while also making sure to take the necessary time to rest; and asking patients how much family input they want). Thus, patients and supportive others can empower themselves to seek and provide effective support by attuning themselves to patients’ identity needs as their illness changes from diagnosis through survivorship (Epstein & Street, 2007).

Strengths and Limitations

Key strengths of the current paper include effective recruitment of a difficult-to-reach population (i.e., patients who were offered a CT) and robust coding analysis across two coding stages and four coders. Likewise, patients experienced different cancers and were offered different CTs at different times in their illness trajectories. This particular data set

allowed for a deep exploration of identity-related issues across a broad range of cancer experiences, further contributing to its strength. No systematic differences by cancer type were found, thus identity seems to be an important feature across different types of cancer and CT decision-making.

However, limitations exist. First, illness identity strength was not measured in this study, so it is not possible to explain how the strength of identity relates to patient perceptions of CTs. However, results may suggest that identity when it is aligned across multiple frames may produce stronger identity strength (e.g., personal, relational, and communal) and future studies should investigate strength of illness identity and group identification/participation as it relates to treatment decisions (Haslam, et al., 2009). Another study limitation is excluding enacted identity codes in our data because our study focused on perceptions of illness identity (i.e., what cancer *meant* to patients when they were making their decisions about a CT, rather than what they *did*). Finally, the results of the current study do not predict enrollment in a CT, rather a way of theoretically explaining patients' processing of a cancer CT in relation to their identity. Thus, the results of this study may suggest ways to improve patient-centered communication about CTs, which ultimately may affect CT enrollment and patient satisfaction with decision-making.

Conclusion

This study is a step forward in theoretically and practically connecting cancer illness identity to CT treatment decision-making. The current findings uniquely contribute to research by providing a more complete understanding of how and why patients (1) make CT decisions based on what cancer means to them, and (2) compare themselves to other cancer patients during the CT decision-making phase. These findings could help to improve patient-centered communication between patients, health care providers, and supportive others during the cancer CT decision-making phase by ensuring patients are receiving messages that align with their unique illness identity perspectives and shifts.

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Table 1

Coding Results for Primary Illness Identity (Conflict) Themes

Illness Identity (Conflict)	Number of Participants (%)	Number of Utterances (% of total utterances)
Identity	46	458
Personal	42 (91.3)	212 (46.3)
Locus of illness	37 (80.4)	97 (21.2)
Locus of decision-making	21 (45.7)	34 (7.4)
Health identity	24 (52.2)	49 (10.7)
Other aspects of self	19 (41.3)	32 (7.0)
Relational	39 (84.8)	161 (35.2)
Locus of illness	17 (37.0)	45 (9.8)
Locus of decision-making	31 (67.4)	84 (18.3)
With HCP	14 (30.4)	21 (4.6)
With supportive others	27 (58.7)	63 (13.8)
Close relationship with HCP	17 (37.0)	32 (7.0)
Communal	34 (73.9)	85 (18.6)
Cancer patient	34 (73.9)	85 (18.6)
One of many cancer patients	13 (28.3)	20 (4.4)
One of many CT patients	19 (41.3)	23 (5.0)
Help others	26 (56.5)	42 (9.2)
Identity Alignment	27 (52.2)	51 (11.1)
Personal/Relational	8 (17.4)	10 (2.2)
Personal/Communal	22 (47.8)	34 (7.4)
Relational/Communal	4 (8.7)	6 (1.3)
Identity Conflict	33 (71.7)	137 (30.0)
Personal vs. Personal	14 (30.4)	25 (5.5)
Personal vs. Relational	20 (43.5)	47 (10.3)
Personal vs. Communal	23 (50.0)	56 (12.2)
Relational vs. Relational	2 (4.3)	2 (0.4)
Relational vs. Communal	2 (4.3)	3 (0.7)
Communal vs. Communal	1 (2.2)	1 (0.2)