Illness Identity, Social Support and Cancer Treatment Decision-Making

Dissertation

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

Angela L. Palmer-Wackerly, M.A.

Graduate Program in Communication

The Ohio State University

2015

Dissertation Committee:

Nancy D. Rhodes, Advisor

Shelly Hovick

Janice Krieger

Abigail Norris-Turner

Joyce Wang
Abstract

Approximately 40% of U.S. adults will be diagnosed with cancer during their lifetime. Because of improved diagnostic tests and cancer treatment, patients are living longer with cancer than in the past. In recent years, cancer researchers have called for more attention on patients’ well-being throughout their illness trajectory. Thus, the current paper offers three manuscripts focusing on enhancing patient well-being during the cancer experience. Combined, these manuscripts highlight the importance of support providers’ recognition of patients’ illness identity in order to provide support that meets the needs of patients.

The first manuscript examines patients’ illness identity and illness identity gaps as they relate to cancer clinical trial decision-making. In-depth interviews were conducted with 46 patients who were offered a clinical trial as part of their cancer treatment. Qualitative analysis indicated that participants made their decisions about clinical trial enrollment based on (1) illness identity perceptions and goals, and (2) comparisons with ‘other’ cancer patients.

The second manuscript examines another part of the cancer experience: treatment decision-making and two key influential support sources for patients: partners and health care providers. Participants included 479 cancer patients who had a significant other when making their treatment decisions. In a web-based survey, participants rated how
influential their partners’ and health care providers’ support was in their treatment decisions. Mediated regression results indicated both a direct effect of partner support on higher decision-making satisfaction and an indirect effect of health care provider support on the relationship between partner support and decision-making satisfaction. Thus, patients reported higher decision-making satisfaction when they reported influential partner support and influential health care provider support in their cancer treatment decision-making.

Finally, the third manuscript builds on the findings of the two previous studies by proposing a theoretical model explaining the influence of social support on the relationship between illness identity and patient well-being. Using the Communication Theory of Identity as a foundation, the third paper outlines a process whereby patients seek to resolve their illness identity gaps through strategic support seeking. If patients receive support messages that are aligned with patients’ identity perspective and goals, then patients will rate support as effective, patient identity will re-align, and patients will achieve well-being. Conversely, if patients receive support messages that are not aligned with their identity perspective and goals, then patients will rate support as ineffective, identity conflicts will be reinforced and patients will experience negative well-being. A proposed test of the model as well as future directions for the model in other illness contexts are discussed. In all manuscripts, theoretical implications and future research directions are discussed.

Key words: illness identity, social support source, cancer treatment decision-making, patient well-being, communication theory of identity
Dedicated to my husband, Matt; my graduate school mentors; and all of the men and women who generously shared their cancer experiences with me.
Acknowledgements

I would like to thank my advisor, Dr. Nancy Rhodes, and all of my committee members, Drs. Janice Krieger, Abigail Norris Turner, Shelly Hovick, and Joyce Wang, for their time and energy spent guiding and encouraging me in the completion of this research project as well as all of my graduate school endeavors. I would also like to thank Tricia Hengehold, Kevin Kramer, and David Gatarano, for their qualitative coding assistance; and Julie Wojno for her assistance with creating the survey.
Vita

June 1995 ............................................. Lexington High School

June 2000 ............................................. B.S. Human Development & Family

Science; B.A. Political Science, The Ohio

State University

2001-2003 ............................................. Staff/Communications Assistant, The

Committee on Financial Services, U.S.

House of Representatives

August 2004 ............................................. M.A. Journalism, Northeastern University

2003-2008 ............................................. Journalist, Cape Cod Life Publications

and Columbus C.E.O. magazine

2008-2010 ............................................. Instructor, English Composition/Magazine

Writing, Capital University and Columbus

State Community College

2012 ................................................. M.A., Communication, The Ohio State

University

2010 to present .................................... Graduate Associate, The Ohio State

University
Publications


Fields of Study

Major Field: Communication

Specializations: Health Communication; Interdisciplinary Global Health
# Table of Contents

Abstract .......................................................................................................................ii

Dedication ....................................................................................................................iv

Acknowledgements .......................................................................................................v

Vita ..............................................................................................................................vi

List of Tables ................................................................................................................x

List of Figures ..............................................................................................................xi

Chapter 1: Patient Perceptions of Illness Identity in Cancer Clinical Trial Decision-Making..................................................................................................................1

Method ........................................................................................................................9

Results .......................................................................................................................13

Discussion ...............................................................................................................28

References ..............................................................................................................36

Chapter 2: The Role of Partner and Provider Decisional Support in Patients’ Cancer Treatment Decision-Making Satisfaction ..................................................................................42

Methods ..................................................................................................................51

Results .....................................................................................................................56

Discussion .............................................................................................................58

References .............................................................................................................68
Chapter 3: Effective Identity Support Communication during Chronic Illness .......... 81

Conclusion ............................................................................................................. 118

References ............................................................................................................. 126

Chapter 4: Conclusion ......................................................................................... 136

Bibliography ........................................................................................................... 139

Appendices ............................................................................................................ 158

Appendix A: Codebook .......................................................................................... 158

Appendix B: Personal-Enacted Identity Gap Scale ................................................. 159

Appendix C: Personal-Relational Identity Gap Scale ............................................. 160

Appendix D: Relational-Enacted Identity Gap Scale ............................................. 161

Appendix E: Effective Support Scale ................................................................. 162
List of Tables

Table 1. Coding Results for Primary Illness Identity (Conflict) Themes ..................40
Table 2: Participant Statistics .................................................................73
Table 3: Descriptive Statistics and Pearson’s Correlation between Variables ........75
Table 4: Regression Results for Mediation .............................................76
Table 5: Regression Results for Moderation ..........................................78
Table 6: Regression Results for Moderated Mediation ..............................80
List of Figures

Figure 1. Theoretical Model of Mediation of Social Support and Decision-Making Satisfaction……………………………………………………………………………74

Figure 2: Theoretical Model of Moderation of HCP Support on Partner Support and Decision-Making Satisfaction…………………………………………………………77

Figure 3: Theoretical Model of Moderated Mediation of Clinical Trial Enrollment on Social Support and Decision-Making Satisfaction……………………………79

Figure 4: The Communication of Chronic Illness Identity Support Model………………..135
CHAPTER 1: PATIENT PERCEPTIONS OF ILLNESS IDENTITY IN CANCER

CLINICAL TRIAL DECISION-MAKING

According to the U.S. National Cancer Institute, approximately 40% of Americans will develop cancer in their lifetime (Howlader et al., 2015). Because of increased awareness, detection, and treatment advances, survivor rates (i.e., patients living 5 years or more after their initial diagnosis) have steadily increased from 48.7% in 1975 to 69.0% in 2007 (NCI, 2015). With this increase in survivorship, cancer is viewed as an acute chronic illness that even after remission, may return in 5 years or more (Howlader et al., 2015). As a result, cancer patients continually cope with identity and lifestyle changes throughout their illness experience—from diagnosis through survivorship (CDC, 2015).

When patients are diagnosed with cancer, they are often overwhelmed with uncertainty and fear regarding their future health and relationships (Epstein & Street, 2007; Howlader et al., 2015). As with any chronic illness, patients must come to terms with how their illness affects their lives. How patients view their cancer illness identity may have both positive and negative consequences for their well-being, including how they seek and receive care and make decisions about treatment options (Harwood & Sparks, 2003; Krieger et al., in press). 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, 2004), their relationships (Miller & Caughlin, 2013;
Siminoff, 2013), and their group memberships (Harwood & Sparks, 2003). Illness identity also changes across the illness trajectory and results in different identity needs and goals for well-being, depending upon how patients view cancer in relation to their experiences and other identities (Blackford & Arrington, 2011; Mathieson and Stam, 1995).

One way to increase patient well-being throughout the entire illness experience is through patient-centered communication (PCC) (Epstein & Street, 2007). In patient-centered communication, health care providers (HCPs) focus on patients’ emotional, psychological, and medical needs. By focusing on patients’ needs, providers try to incorporate patients’ values and goals for treatment in their discussions, thereby empowering patients to actively participate in all aspects of their health care (Epstein & Street, 2007). A key challenge for patients during the cancer experience is treatment decision-making. HCPs typically discuss cancer treatment options immediately following diagnosis. Because processing a cancer diagnosis is emotionally and psychologically stressful, patients may have a difficult time deciding which treatment is best and often rely on families and their HCPs for guidance (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007). One particular treatment, a cancer clinical trial (CT), is sometimes introduced alongside other treatment 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 (e.g. Krieger et al., 2015). This 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 paper examines patients’ illness identity during CT decision-making through the Communication Theory of Identity (CTI) (Hecht, 1993). CTI posits that identity is made of 4 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; Krieger, et al., in press). A crucial part of patient-centered communication is negotiating similar meaning between patients and providers in discussions about patient health and particularly treatment goals for their health (Epstein & Street, 2007). However, cancer is considered a relational illness and patients are often accompanied by caregivers who sometimes have their own goals for the patient’s health (Krieger et al., in press; Siminoff, Zyzanski, Rose, & Zhang, 2008). Thus, in order to empower patients to choose treatments that are consistent with their values and preferences, it is helpful to examine how patients consider CTs in relation to their illness identity so that all decision-making parties (i.e., caregivers, HCPs) can negotiate meaning that enhances patients’ well-being and satisfaction with their care during this stressful decision-making phase.

**Illness as Identity**

**Illness Identity**

Illness identity has been defined in various ways. Hayden (1993) defines illness as “a deviant, abnormal state” (p. 264). Charmaz (1995) defines it as the “incorporation of chronic illness or disability into one’s sense of self”. Of course, not all illness is the same. Visible illness is easily detectable by others through physical markers while invisible or hidden illness is not easily detectable to others (Kundrat & Nussbaum, 2003). Examples
of visible chronic illness include some forms of cancer (e.g., loss of hair and/or weight with chemotherapy) and disability (e.g., paraplegia) while invisible illness includes such conditions as inflammatory bowel disease (Defenbaugh, 2013), infertility (Bute, 2009), chronic fatigue syndrome (Edwards, Thompson, & Blair, 2007), and HIV (Baumgartner, 2007). However, all identities, including illness, are negotiated through self-reflection and interactions with others (Hecht, 1993).

A chronic illness diagnosis is often considered an identity crisis because individuals’ view of themselves, their relationships, and their abilities has changed (Charmaz, 1994). In negotiating their illness identity, individuals experience identity conflicts between their past, present, and future selves (Charmaz, 1994; 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; as patients’ illness experience changes, so do their needs and goals (Blackford & Arrington, 2011; 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. They may still require support in helping them define new relationship roles yet support starts to decline for patients after treatment because others view them as cancer-free (Arora et al., 2007; Miller & Caughlin, 2013). Additionally after treatment, caregivers sometimes struggle with losing the ‘caregiver’ role and feel that patients no longer need them (Miller & Caughlin, 2013). Thus, patients and supportive others continually negotiate identities in relation to the roles and expectations that came with the patient’s illness.
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 (ethnicity and age); (2) secondary identities, in which patients identify with health 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’s 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).

How patients relate to the identity of ‘cancer patient’ may have implications for their well-being. If patients primarily identify as a cancer patient, they may feel that this illness 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 themselves experienced increased depression, spiritual struggle, decreased hope, and increased risk for co-morbidity. However, patients may also positively identify as a cancer patient when it is in alignment with other identities in their self-concept (Harwood & Sparks, 2003). Sulik (2011) showed that patients who successfully viewed their cancer identity as part of themselves 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. Thus, to improve individuals’ quality of life, it is important to understand how individuals’ illness identity is changed
and managed across the lifespan. The current paper examines illness identity during the treatment decision-making phase and how patients relate their identity to a clinical trial option.

**Communication Theory of Identity and Health**

One appropriate 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). This theory is appropriate for the current paper because identity is viewed as inherently social, negotiable, and constantly shifting over time (Hecht et al., 2004).

Applying CTI to illness identity involves the negotiation process during chronic illness, 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; Hecht & Choi, 2012). ‘Healthy’ is culturally defined and people absorb messages from their environment to inform what it means to be healthy. Healthy has historically 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). For example, in the health 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 view him or her. A patient may view herself as healing from cancer and want to return to working as a nurse; 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 if they primarily view themselves as ‘healthy’ when not undergoing cancer treatment and ‘ill’ when undergoing treatment (e.g., chemotherapy).

In the health and illness context, personal and relational identity layers have been primarily examined as opposed to other identity layers (Hecht & Choi, 2012), and the current study fills this gap by examining all applicable illness identity layers within the cancer context. This study also uniquely contributes to the literature by examining cancer as illness identity specifically within the decision-making context of clinical trials. This is an important contribution because identity changes throughout the illness trajectory and identifying how patients’ identity during this specific treatment decision-making phase relates to the communication about clinical trials would inform future interventions that hope to both improve clinical trial enrollment rates as well as patient informed decision-making.

**Cancer Clinical Trial Decision-Making**

Clinical trials (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); however, CT enrollment numbers are low, with only 3-5% of cancer patients enrolling (Umutyan et al., 2008). For medically underserved communities (e.g., African Americans, rural individuals, low-income), participants are even fewer (Baquet, Commiskey, Mullins, & Mishra, 2003). Common barriers include elderly age, patient-provider communication, and poor access to care (Baquet et al., 2003).

The CT context is unique in that a CT is usually offered immediately after cancer diagnosis, thus high levels of time-related pressure, uncertainty, and stress are involved as patients and their family members cope with their diagnosis while also trying to evaluate treatment options (Politi, Clark, Ombao, Dizon, & Elwyn, 2011; Krieger et al., 2015). In this context, communication factors have been found to influence patients’ CT decision, such as physician responsiveness, physician framing of the CT (i.e., positive, negative, neutral), and supportive communication (e.g., emotional, informational support) from the provider (Albrecht et al., 2003). Other studies have found family members’ communication (e.g., decisional support through asking questions and giving advice) to be influential in the patient’s decision (e.g., Krieger, in press).

Most extant research focuses on patient barriers and facilitators to CT enrollment and few studies focus on patient well-being during the CT decision-making process. 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; Yang et al., 2010). Albrecht et al. (2008) found that patients felt more confident about their CT decision when they perceived HCPs and family members to support the same decision. Thus, the current
paper examines how patients view the cancer CT treatment option as contributing or detracting from their well-being through their negotiation of illness identity. As a result, the following research questions are proposed:

RQ1: How do patients describe their illness identity when explaining their decision-making about clinical trials (CTs)?

RQ2: What, if any, illness identity gaps are present for patients during CT decision-making?

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 (1) were offered a randomized clinical cancer trial within the last two years and (2) lived in and/or were treated for cancer in one of Ohio’s 32 rural Appalachian counties. Of the 49 patients, were eliminated after it has been discovered that they were not offered a randomized clinical cancer trial. 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 provide a response. Approximately 75% of patients agreed to participate in a CT \( (n=35) \). The three most common forms of cancer among patients are breast \( (n=19, 41\%) \), multiple myeloma \( (n=9, 20\%) \), and prostate \( (n=7, 15\%) \). The highest level of education among most participants is a high school diploma \( (n=17, \)
37%) and some college ($n=15, 33\%$). Half of participants have reported annual household incomes of $49,000$ or lower ($n=23$) with $5$ patients reporting “don’t know” and one patient declining to provide a response. The most common sources of health insurance are through their employer ($n=22, 48\%$) and Medicare ($n=14, 30\%$).

**Procedures**

Clinics identified patients who had been offered an opportunity to participate in a Phase III cancer CT and were mailed a recruitment letter signed by their treating physician. Follow-up phone calls were conducted by a researcher 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 who work extensively in Appalachia. The interview questions were then revised for clarity and cultural sensitivity. Questions focused on (1) the goals of patients when discussing cancer treatment and CTs with their medical providers and family members, (2) how those goals shape family communication about CTs, (3) outcomes of family conversations (e.g., in what ways do family members serve as barriers and facilitators to CT enrollment), and (4) factors that were important in patients’ treatment decision-making.

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 (e.g., participant’s home, coffee shop, hospital waiting or treatment room). Whenever possible, interviews were conducted privately; however, four individuals were interviewed with others present. Following the interview, participants were asked a series of socio-demographic questions (e.g., health status, household structure, family history of cancer). Following the interview, participants were given a $30.00 gift card.

**Interview Analysis**

After interviews were conducted, they were uploaded to a password-protected computer and transcribed verbatim. Analyses occurred in three phases. In the initial coding phase, two independent coders read over each transcript several times; created a memo describing main themes related to illness identity, identity gaps, and clinical trial (CT) decision-making; and identified each unit of analysis based on these themes (Charmaz, 2006). A unit of analysis was defined as any thought or idea related to the above themes, ranging from a phrase to several paragraphs. Coders verified each other’s units and met to discuss any discrepancies. A code book was created based on these themes (see Appendix A) (Creswell, 2007).

Based on theoretical guidance and previous research about CTI, *illness identity* was defined as “an understanding of what it means to be a patient with cancer”. Thus, analysis included any reference to cancer perceptions during CT decision-making through personal (i.e., references to own body or perceptions of illness), enacted (i.e., behaviors communicated to others based on perceptions of cancer), 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* are 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).

Because the current study was a secondary analysis of data exploring cancer decision-making, illness identity was not explicitly asked about in interview questions. Thus, analysis in the current study was based upon operationalization of identity within CTI in past qualitative research. For example, in their investigation of ‘adoptive identity’, Colaner, Halliwell, and Guignon (2014) defined adoptive identity as “an understanding of what it means to be an adoptive person” (p. 470). Additionally, in their analysis of caregiver and patient cancer identity, Krieger et al. (in press) coded units for personal and relational illness identity when caregivers referred to cancer as a personal characteristic of the patient (i.e., personal identity) or as an extension of the caregiver’s relationship with the patient (i.e, relational identity). Because the current study explored all illness identity layers (e.g., enacted, communal), the resultant dataset was large and included nearly all information patients gave when talking themselves and their treatment decision-making experience. However, data about patients’ identity during other stages of their cancer experience (e.g., diagnosis) was usually not included in the dataset as the current study focused on illness identity during treatment decision-making only. Exceptions were made, and information from other illness stages included, only if patients deliberately related those experiences with their treatment decisions in the current cancer experience. Examples of information related to identity, but not coded, were when patients referred to aspects of themselves that they did not relate to cancer and treatment decision-making (e.g., previous hospitalization experiences, poor relationships with family, past occupational roles). Because the initial study focused on cancer,
however, few units of identity data were excluded when coding for illness identity and treatment decision-making.

In the second phase of analysis (i.e., focused coding), a researcher analyzed and connected the themes based on how they related to each other (Charmaz, 2006). In the third phase of coding (i.e., axial coding), a researcher identified the nature of the relationships between illness identity and illness identity gaps in relation to patients’ CT decision (e.g., how they connect to each other to inform patients’ decision-making). Only units that pertained to CT treatment decision-making were included.

**Results**

**Illness Identity (RQ1)**

Participants discussed their illness identity in relation to their clinical trial (CT) offers by focusing on individual levels of identity (i.e., personal, enacted, relational, communal) and by combining levels of identity (e.g., personal and relational; relational and communal).

**Individual layers of identity.** All participants (n=46) referred to at least one frame of illness identity when discussing their CT offer (n=513 utterances). Below is a discussion of the most prominent layers (n>5 utterances). Participants related the CTs to singular levels of their identity: personal identity (42 participants; n=212 utterances), relational identity (39 participants; n=161 units), and communal identity (34 participants; n=85 units) (see Appendix B).

**Personal identity.** Four subthemes existed for participants (n=42) who framed their CT decision in the context of their personal identity: (1) *self as locus of illness*; (2) *self as 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 Appendix B). For people who described their personal illness identity as the locus of their illness, they related the CT treatment to beliefs and opinions about cancer, treatment, and their bodies (best treatment for me; it affects me; it’s my body). Anna, a 50-year-old patient with breast cancer, enrolled in a clinical trial to test whether heavy doses of cumin could reduce burning from radiation treatment. She had previously been against radiation because of a fear of side effects, but when she found out the CT might reduce the harmful effects to her body, she participated: “If it was gonna help me get through it, you know, even the slim chance of it making it better . . . Yeah, anything I could do to not have to burn or not go through anything, I was willing to try.” A medical lab technician, Anna said she understood that she may get the placebo arm of the CT (i.e., no cumin) and that she would not find out about her CT arm until after the study was over; however, she said she wanted to do anything that might help reduce radiation’s harmful side effects to her body.

Another way participants used personal identity was as locus of their decision-making responsibility in relation to their CT decision was by claiming ownership of the CT decision (my decision). For example, Elsie, a 78-year old breast cancer patient, enrolled in a CT that studied whether the standard number of radiation treatments (33 treatments) was equally effective at reducing cancerous tumors as the comparison treatments (16 and 22 treatments). Elsie, said, “I didn’t discuss the CT with anyone . . . because it was my decision. I made that decision.” She said she informed her son and her daughter (who is a nurse) that she enrolled in a CT only after she made the decision to update them about her health and her treatment. Similarly, Torie, 50, a lung
cancer patient, described her decision to enroll in a CT as: “I pretty much made the decision myself ‘cause I just told [my family] this is what I was gonna do, and like I said, nobody argued with me or said, “No, I don’t think you should do that.”

The third way participants used personal identity to frame their CT decision-making was through discussion about their overall health identity in relation to their cancer identity. For example, some participants explained that they were “good” and “perfect candidates” for the CT because they were “healthy” even though they had 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, so this perception of their health and illness identities influenced their CT decision. 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 (e.g., “why make me sick when I’m a healthy person?”). For example, Mae, a 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.” Mae said the doctor introduced the study to her and that the nurse talked to her about it, but at 65 years old, she said, “All I could think of was how fortunate I was that I did not have – you know that it was gone and I shouldn’t take up any more of his time. I was fortunate. I just needed to go home and be grateful and get on with my life.” As a result, she declined the CT for that round of cancer.

Another patient, Edith, 73, was diagnosed with breast cancer and chose to decline a CT because she was worried about the side effects to her major organs, such as heart,
kidneys, and liver. Originally an immigrant to the U.S., she had not had health issues previously, but because of her age, she was worried that she might be at a greater risk for the side effects. Thus, she preferred what she perceived as a lower risk treatment for her overall healthy identity: the standard treatment, which she described as a more tailored type of treatment for her particular cancer as opposed to the CT. She said she wanted: “Easy way and what is, what’s the doctor say is good for me. Not the, you know, chop off of that whatever I need. I suppose to need it but that’s not . . . I want basic care from doctor now . . . My kind of, you know, cancer.” Edith also had a strong patient identity and viewed her perspective as unique to only her situation. She said it was impossible to compare her situation to others or vice versa because each patient experience is unique, again highlighting her personal illness identity frame:

People have the right, everybody different and the different kind of cancers and stuff. You can’t say, you know, ‘Don’t do this and don’t do that.’ Because you might wanna do it. You know, I, I don’t wanna do it, but you might wanna try. But, I’m not, but I’m not gonna say, ‘Hey you try the new kind or something.’ I’m not gonna say that either. Because I’m not a study and I’m not a doctor, I’m, you know – I’m only the patient who [been] what I been through.

Finally, patients also used personal identity to describe the CT in relation to other aspects of self and their illness identity. Some patients had previous experience with CTs while others used their occupational roles to explain their (dis)comfort-level with a CT. For example, Betty, 79, said she was a retired medical lab technician and 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 Adaline, a breast cancer patient, who explained her decision to participate in a CT as primarily an evaluation of personal risk. A 52-year-old nurse anesthetist, Adaline said, “I think it’s whether they’re a risk-taker or not … I’m willing to take risks.”

**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 locus of illness identity* and (2) *relationships as locus of decision-making* (see Appendix B). For patients who viewed their cancer as being shared with others (e.g., spouse, children), they referred to relational identity in both present and past/future tense. When describing a present relational identity, patients used language such as ‘we’ and ‘our’ to describe their illness. For example, Jude, 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 Jude, his wife 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 manuscript when he describes his Army status (e.g., “I’m still in the United States army, and I’m currently receiving
social security benefits).” Thus, he primarily uses “‘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.

Some participants described their cancer in their CT decision-making as existing in their past and the future relationships, which has informed their sense of illness identity. Several participants, like Cora Jo, 54, reflected on their family history of cancer as they made their decision about treatment. She was open to CTs because of her family history: “You know, my mom’s – probably 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.” A breast cancer patient, Cora Jo had a mother who 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 present (she has two daughters)—she is supportive of clinical trials and their improvement of cancer treatment for patients. Other participants who used the relational identity frame to describe their CT decision-making referred to the future cancer identity of their families. For example, Bobbie, 67, has a daughter and two granddaughters. When she was considering her breast cancer CT, she said she thought only about improving life and possible future cancer treatments for them. “It was kind of selfish. It was just about my family.”

The second way patients used relational identity to explain their CT decision-making was through relationships as locus of decision-making responsibility. These patients used words such as “we”, “our”, and “us”. Joe, a patient with prostate cancer,
said he and his wife sought the guidance from his children and grandchildren when they made the decision to enroll in a CT:

I talked to the family. I mean, we get around the table, sitting in the living room or wherever, all three of the girls, the grandkids, and we said, “Hey. Do we” – ‘cause [the CT nurse] said, “You don’t have to do this. You don’t have to.”—And, we said, “Hey. What do you guys think?” Instead of me saying yes or no. Well, no, soon as it’s done, it’s over. We all get – And we’ve never made decisions, even my kids don’t make a decision on their own. Everybody kind of – a major decision, everybody gets together.

In this section, Joe explained that he viewed his participation in the CT as a family decision, framing his question of enrollment with “do we…?” instead of “do I?”. Further, when he speaks about how he approached his family, he uses the phrase: “we said”, instead of “I said” to give relational importance to him and his wife as a couple instead of his role as the patient. He even contrasts this language of unity with “instead of me saying yes or no”, showing that he perceived his cancer treatment decision-making as a process that involved his entire family, led by him and his wife as a couple.

**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 who referred to themselves with communal identity 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 Appendix B). They used language to frame their CT decision in terms 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. Torie, 50, who had lung cancer, said she enrolled in her CT because she knew that if she participated, 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.” Torie, like many other patients, acknowledged that she was grateful to cancer patients that came before her and volunteered for past CTs, which enabled her to have the benefits of her current treatment. Now she wanted to “give back” to cancer research. Jenna, 55, enrolled in a CT for multiple myeloma treatment, and 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.

Patients who expressed their CT decision-making in terms of communal identity were primarily focused on their identity as a cancer patient and invested in treatments that would benefit future patients with their particular type of cancer.

**Multiple levels of identity.** When explaining their CT decision-making, some participants (\(n=27\)) referred to multiple levels of identity with the same unit of analysis
(n=51 utterances): (1) personal and relational; (2) personal and communal; and (3) relational and communal (see Appendix B).

**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, Vincent, 74, who enrolled in a prostate cancer CT, wanted to be randomly selected into the chemotherapy and surgery arm of the CT (as opposed to surgery only). He said, “I just said I’m going to do the chemotherapy. And they said well, you have to be randomly selected. And [my wife] and I just said well, that’s what’s going to happen. We’re going to be in that group. And we were.” Vincent, a college research professor, understood randomization; however, Vincent had a spiritual belief that he was going to get the chemotherapy arm and said his wife reinforced this belief, which resulted in a shared illness identity—he viewed it like they were both placed in the chemotherapy CT arm.

Another prostate cancer patient, Luke, 58, was offered the same CT (surgery vs. surgery plus chemotherapy) as Vincent, but was not sure he wanted to participate in the CT because of a fear of chemotherapy. But, after discussing the trial with his wife for three hours on the way home from the clinic, they decided that he should enroll. Luke 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.” This sentence illustrates how 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 Luke viewed the aggressiveness as chemo as a risk instead of a benefit like Vincent, 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, one multiple myeloma patient, Peter, 47, said he enrolled in a clinical trial because “if they’re trying to cure my disease, I want to do everything I can to help them, you know? If giving extra blood will help, then more power to them, you know? That was my thoughts behind it anyway.” Likewise, Mary, 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.” Both of these patients explained how they wanted to try to help improve illness for themselves as well as for others experiencing the same cancer.

Another way participants referred to both personal and communal identities was by framing their specific illness identity as complex and extending their personal experience to others who may have similar complex illness identities. For example, Gena, 57, enrolled in a CT because she hoped her participation would not only help future lung cancer patients, but also cancer patients who suffered from chronic depression and anxiety like she did.

I really hope it helped – see, I have, you know, I suffer from depression and anxiety and I was hoping anything I went through maybe could help
somebody in the same condition I’m in. You know. Physically, I’m doing okay. Mentally and emotionally, I’m not too sure.

**Relational and communal identity.** For this theme, participants focused on their family as well as larger, communal identities, such as religion or cancer patient. For example, Betty 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.” Betty knew that the CT would not benefit her breast cancer; however, she wanted to use her illness to help her female family members as well as other cancer patients. Likewise, Joe used relational-communal identity to explain his ability to navigate the fear and uncertainty that comes with cancer:

> 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.

In the above statement, Joe explained that he incorporated his cancer identity into his faith and his family and that together, they were able to navigate the stress and decision-making process.

**Illness Identity Gaps (RQ2)**

Illness identity gaps existed when participants \((n=33)\) experienced a conflict that was present within layers or between two or more layers \((n=137\) utterances). Sometimes
these conflicts were resolved by the time patients made their CT decisions; other times the conflicts remained even after patients participated in CTs. The three most common were personal-personal, personal-relational, and personal-communal (see Appendix B).

**Personal-personal identity gap.** Patients who experienced a personal-personal identity gap primarily struggled with incorporating their personal cancer identity into other aspects of their personal identity (e.g., health). For example, Matt, a prostate cancer patient, who enrolled in a CT to hopefully improve treatment for himself and others, also expressed that he was still surprised he had been diagnosed with cancer because he and his wife worked so hard to maintain a healthy lifestyle:

I think the most interesting – I should share this with you. The most interesting thing to me about getting cancer is that we have made, we think, great efforts in being healthy. You know, eating blueberries, eating fish. Eat everything, you know, that we think is healthy. You know, walking, running you know, all the, all the food we – we’ve done all that. And it didn’t mean anything. Still got it.

Another example of personal-personal identity conflict is when patients wanted to participate in a CT but could not because of other health reasons. For example, Caleb, 55, had to drop out of his colon cancer CT and delay treatment by 2 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.
**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, Eve, 52, declined a breast cancer CT because she could only focus 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.

Eve acknowledged that she had cancer; however, she did not incorporate it into the rest of her identity. Cancer does not fit in her life right now and rather than viewing a CT as a way to benefit her family’s future health identity, she primarily identified with her need to provide for them.

Another type of personal-relational identity gap during CT decision-making existed when patients viewed their cancer identity differently than their families. For example, Jude said he wished his family accepted that the CT was not prolonging his life and 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. And I need to – it’s frustrating to me to hear all this going on and know that we’re not going to get cured and I wish they would see the reality of the situation that we’re not going to be cured and that we are going to die in 5 to 10 years. 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.

Jude locates his cancer in some of the above statement with his family (e.g., “we’re not going to get cured”); however, when talking about the conflict in perceptions, he reverts back to his personal identity (e.g., “me having terminal cancer”). This statement shows his desire to experience cancer together with similar perceptions about his CT. However, his family views his cancer identity as temporary while he views his illness identity as permanent.

Finally, a third type of personal-relational identity gap involved when patients viewed others (i.e., supportive others who were in the medical field, HCPs) as having more or less knowledge than they did as patients when considering the CT decision. Joe said he had to trust the medical information HCPs were telling him because he did not have the medical knowledge that they did:

If you’re a septic installer and you’ve worked construction and concrete, I know nothing about medical. Or clinical trials. Yeah, if they’d a said, “Hey, this is an experiment.” They didn’t say it. They said – Everything they told me was good stuff. They never said, you know, “Things can really go horrible wrong, but now are you willing to take that chance?”

There was none of that said. It was all good stuff.

**Personal-communal identity gap.** A common personal-communal identity gap is declining treatment because the communal goal of helping other cancer patients conflicts 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 clinical trial because it would have extended her chemotherapy treatment from 6 months to a year.

I had the guilt trip of helping others. You know, I would, I mean, if you needed a Coke, I would give you my last Coke, you know. That's just the way I am. And, and I thought, you know, “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 trial, 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).

Now, I was offered this clinical trial and I really, really, really—I cried. I prayed. I talked to everybody. And, um, I felt I, I'm not a sick person so I didn't wanna be sick for a year. Do you understand where I'm coming
from? And, um, I, when I went in that day, I still did not know what I was
gonna do. I felt for sure I wasn't going to. But had there been one thing
that might have helped, I would have probably. But that, they didn't know
that. You know, that's why it's a trial. And, um, I didn't wanna be sick for
a year. … Now, grant you, if, if I was in the fourth stage, I might have
done it because, you know, I didn't have much hope there. But my stage
was only two. And I'm not gonna be sick for a year. Now, if I have to, I
will, but I'm not going to. So I decided no.

Discussion

The purpose of the current study was to explore illness identity during treatment
decision-making about a CT. Analyses were limited to communication in the treatment
phase to explore how people perceived CTs before a CT decision is made, while they are
enrolled in a CT, and after they have finished their participation. Results indicate that
most patients (n=33; 71%) initially reported identity conflicts in relation to a CT decision
and they may or may not be resolved by time they make their final decision. Patients who
found a way to incorporate the CT into one or more of their identity layers experienced
identity re-alignment and thus higher well-being. Conversely, those patients who still
struggled with resolving their identity conflicts (even after a decision was made)
expressed how misaligned identity communication (e.g., personal vs. relational identity)
was associated with negative well-being (e.g., more identity conflict). Results also
indicate that patients view their illness identity as only part of their identity (e.g., in
relation to their family roles, occupational roles, or other illnesses), though it may take a
central role in identity renegotiation more so in the diagnosis and treatment phases,
during which patients are confronted with daily reminders (e.g., side effects, bodily limitations) of their illness. Thus, illness identity was found to be complex, varying with participants’ experiences, and changing across the treatment phase of illness. Regardless, however, all patients expressed their CT decisions in context of how they viewed their illness identity (e.g., personal, relational, personal vs. relational).

**Theoretical Implications**

The current study built upon the findings of Krieger et al. (in press) that found that caregivers related their perceptions of patients’ illness identity to caregivers’ roles and responsibilities in cancer treatment decision-making. The current results extend those findings by focusing on patient perceptions of their illness identity (including decision-making roles) as well as how the identity frames combine to align or contradict each other, resulting in higher or lower well-being (i.e., absence or presence of identity conflict) for patients. Past studies have examined facilitators and barriers to CT enrollment (e.g., Umutyan, 2008). Patients have been shown to enroll in CTs because they trust their oncologist, they believe the CT may offer a beneficial treatment, and they have a desire to help others. Barriers to CT enrollment include transportation, time involved, lack of knowledge, and uncertainty about treatment effectiveness (Baquet, Commiskey, Mullins, & Mishra, 2006). Other facilitators and barriers include HCP communication (e.g., thorough discussion of options, focus on patient choice, or physician’s use of persuasive techniques, such as presenting more information about the benefits of CTs) (e.g., Albrecht et al., 2008; O’Brien, et al., 2013). The current study offers a way to theoretically examine and understand these patient choices by relating them to patient illness identity and illness identity conflict. Thus, unique findings in this
study include exploring how patient illness identity relates to (1) CT decisions, (2) patients’ health identity, (3) illness identity changes during the cancer treatment phase (e.g., from personal to relational identity), and (4) patients’ overall identity.

Enacted identity was not found to be prevalent in the current study with the exception of a few participants, who mentioned that they behaved in identity consistent or contradictory ways in comparison with how they viewed others’ perceptions of them. For example, one patient mentioned that she “just had the attitude that [the HCPs] were going to make her well” and that her oncologist told her, “That’s a great attitude to have.” She said she displayed her positive attitude by smiling whenever she came in for treatment, a behavior that she said the doctors and nurses mentioned to her. She remembered her oncologist saying to her at her last appointment to one of his nurses, “She’s got a great attitude. Every time she came in, she had a smile.” One reason for this study’s paucity of enacted identity data might be that most patients in this sample seemed to be still adjusting to their new personal identity of cancer, thus, their illness identity may contain a mix of uncertainty, fear, and sometimes hope. As a result, their behaviors may not be as salient to them as their thoughts and attitudes toward cancer during the treatment stage of cancer identity.

This study also furthers the work of Harwood and 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, if patients primarily identify with cancer in the personal frame, receiving messages in the communal frame from family members and HCPs may create identity conflict and result in negative well-being, such as increased guilt and victim perceptions, if they perceive they ‘should’ be like other cancer
patients by either enrolling in a CT to benefit others or they ‘should’ be stronger when ‘fighting cancer’. However, if patients associate their cancer with others’ experiences of cancer, then messages aimed at the communal frame of identity may be more effective at providing comfort and support during this stressful time for patients and their families. It also might be that some patients may eventually move to the communal frame over time (e.g., once they complete treatment). For some patients, perhaps the side effects of treatment make personal identity the most salient during this phase, but after patients enter remission, they take on the ‘survivor’ group mentality, as one patient described. Thus, some patients may only be ready to assume one primary identity at a time (e.g., personal, then communal), suggesting that some patients have more complex illness identities (i.e., multiple layers of primary identities) than others.

This study also adds to intergroup theory by showing when and how group identity differences are most salient during cancer treatment decision-making (Soliz & Rittenour, 2012). For example, one patient used age-based stereotypes (i.e., a young doctor was better than an older doctor because of increased knowledge of advanced cancer treatments) when choosing her oncologist. However, this same patient then later declined enrollment in a CT because she viewed the younger doctor as not considering her age when describing the risk involved in her particular CT. This patient felt that at 73 years old, she should be given ‘regular’ treatments (i.e., standard treatments), which she defined as safer to someone from her age group because of the lowered risk of damage to her major organs. These group-based differences were also at play when patients chose to rely solely on HCPs for treatment guidance because their family members and friends did not have the medical knowledge the physicians had.
Finally, as mentioned above, patients used negative stereotypes to view ‘other’ cancer patients as weaker, sicker, and needing more help than they themselves did because they were “stronger” and “healthier”. This finding shows that even within the cancer group, no matter what cancer stage they experienced, some patients distinguished themselves from ‘other’ cancer patients, and this social comparison resulted in positive and negative implications for their well-being (i.e., more or less identity conflict). Because HCPs and supportive others were involved in these identity negotiations, future studies should build on the relationship between illness identity and social support to develop theoretical explanations for how social support influences the relationship between illness identity and higher or lower well-being.

**Practical Implications**

The study also has implications for effective patient-centered communication (PCC). A key aspect of PCC is negotiating similar meaning between patients, family members, and HCPs (Street, 2013). Results suggest that effective PCC may be achieved through HCP awareness of and communication accommodation toward the ways in which patients relate their identity to cancer treatments, including a CT (Hajek, Villagran, & Wittenberg-Lyles, 2007; Watson, Hewett, & Gallois, 2012). Future treatment decision-making and support interventions could test whether alignment in illness identity from all key players in cancer support—patients, family members, and HCPs—could increase patients’ informed decision-making (i.e., patients’ understanding of how treatments resolve or do not resolve their identity goal conflicts) as well as patient satisfaction with their decisions and overall care (i.e., how well their values, emotions, needs, and identity goals were considered in their medical interactions). Further, by becoming aware of
patients’ identity needs (e.g., need to feel healthy), HCPs and family members could better support patients by finding ways to communicate ‘health’—diet and fitness choices, as well as finding ways to incorporate patients’ past self into their changing self (e.g., engaging in past hobbies, such as shopping, while also making sure to take the necessary time to rest). Thus, patients (as well as supportive others) can empower themselves to seek and receive emotion-based and information-based ways of coping by attuning themselves to patients’ identity needs as their illness changes from diagnosis through survivorship (CDC, 2015; Epstein & Street, 2007; Miller & Caughlin, 2013).

**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 clinical trial) and robust coding analysis across three stages and four coders. However, limitations exist. First, identity strength was not measured in this study, so it is not possible to say how the strength of identity relates to patient well-being. However, results may suggest that identity that 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 well-being (Haslam, et al., 2009).

Second, participants shared their experiences through self-report, which can be susceptible to memory changes and inaccuracies (enhanced by a possible side effect of cancer treatment), nor were these accounts were not corroborated by HCPs and their supportive others. However, people often have different perceptions of an experience, especially during conflict, no matter the context (Barki & Hartwick, 2004). It is possible
that accounts from all conversational partners would conflict especially during a period of stress, such as cancer treatment. Likewise, patient well-being was the focus of this study, which primarily involves patient perspectives.

Third, as mentioned earlier, patients were not explicitly asked about their illness identity or identity changes; however, all patients mentioned at least one illness identity frame (e.g., personal, relational, communal) even though they were not prompted to do so. This unintentional finding is now viewed as a strength because illness identity was prominent in the data, showing what sometimes can be the difference between patients’ definition of a problem (e.g., identity changes) and researchers’ definition (e.g., informed decision-making). However, studies such as the current one have merged the two problems by connecting patients’ illness identity to patients’ decision-making and consequential well-being (Palmer-Wackerly, et al., 2014). Because this study was intended as a pilot study in exploring illness identity and treatment decision-making, future studies should focus specifically on illness identity to ensure that this concept and related processes are defined and measured appropriately. Finally, patients experienced different cancers and were offered different CTs at different times in their illness trajectories. Though generalization to a population-based sample is not possible through qualitative research, 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.

**Conclusion**

The current paper is a step forward in theoretically and practically connecting illness identity and communication to patient well-being during chronic illness. By
examining a patient’s illness identity during CT decision-making, the current paper accomplishes the following goals: (1) identifies a more complete understanding of why, how, and with whom patients make decisions about cancer treatments, particularly CTs; and (2) examines more thoroughly the difference between health and illness identity and how this identity alignment or conflict contributes to group distinctions within cancer treatment decisions. Taken together, these findings provide insight into how patients negotiate meaning about CTs through perceptions of their illness in relation to their well-being throughout the cancer treatment phase.
References


<table>
<thead>
<tr>
<th>Illness Identity (Conflict)</th>
<th>Number of Participants (%)</th>
<th>Number of Utterances (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Identity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Personal</strong></td>
<td>46 (91.3)</td>
<td>513 (41.3)</td>
</tr>
<tr>
<td>Locus of illness</td>
<td>37 (80.4)</td>
<td>97 (18.9)</td>
</tr>
<tr>
<td>Locus of decision-making</td>
<td>21 (45.7)</td>
<td>34 (6.6)</td>
</tr>
<tr>
<td>Health identity</td>
<td>24 (52.2)</td>
<td>49 (9.6)</td>
</tr>
<tr>
<td>Other aspects of self</td>
<td>19 (41.3)</td>
<td>32 (6.2)</td>
</tr>
<tr>
<td><strong>Enacted</strong></td>
<td>3 (6.5)</td>
<td>4 (0.8)</td>
</tr>
<tr>
<td><strong>Relational</strong></td>
<td>39 (84.8)</td>
<td>161 (31.4)</td>
</tr>
<tr>
<td>Locus of illness</td>
<td>17 (37.0)</td>
<td>45 (8.8)</td>
</tr>
<tr>
<td>Locus of decision-making</td>
<td>31 (67.4)</td>
<td>84 (16.4)</td>
</tr>
<tr>
<td>With HCP</td>
<td>14 (30.4)</td>
<td>21 (4.1)</td>
</tr>
<tr>
<td>With supportive others</td>
<td>27 (58.7)</td>
<td>63 (12.3)</td>
</tr>
<tr>
<td>Close relationship with HCP</td>
<td>17 (37.0)</td>
<td>32 (6.2)</td>
</tr>
<tr>
<td><strong>Communal</strong></td>
<td>34 (73.9)</td>
<td>85 (16.6)</td>
</tr>
<tr>
<td>Cancer patient</td>
<td>34 (73.9)</td>
<td>85 (16.6)</td>
</tr>
<tr>
<td>One of many cancer patients</td>
<td>13 (28.3)</td>
<td>20 (3.9)</td>
</tr>
<tr>
<td>One of many CT patients</td>
<td>19 (41.3)</td>
<td>23 (27.1)</td>
</tr>
<tr>
<td>Help others</td>
<td>26 (56.5)</td>
<td>42 (8.2)</td>
</tr>
<tr>
<td><strong>Identity Consistency</strong></td>
<td>27 (52.2)</td>
<td>51 (9.9)</td>
</tr>
<tr>
<td>Personal/Relational</td>
<td>8 (17.4)</td>
<td>10 (0.9)</td>
</tr>
<tr>
<td>Personal/Communal</td>
<td>22 (47.8)</td>
<td>34 (6.6)</td>
</tr>
<tr>
<td>Enacted/Relational</td>
<td>1 (2.2)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Relational/Communal</td>
<td>4 (8.7)</td>
<td>6 (1.2)</td>
</tr>
<tr>
<td><strong>Identity Conflict</strong></td>
<td>33 (71.7)</td>
<td>137 (26.7)</td>
</tr>
<tr>
<td>Personal vs. Personal</td>
<td>14 (30.4)</td>
<td>25 (4.9)</td>
</tr>
<tr>
<td>Personal vs. Enacted</td>
<td>1 (2.2)</td>
<td>2 (0.4)</td>
</tr>
<tr>
<td>Personal vs. Relational</td>
<td>20 (43.5)</td>
<td>47 (9.2)</td>
</tr>
<tr>
<td>Personal vs. Communal</td>
<td>23 (50.0)</td>
<td>56 (10.9)</td>
</tr>
<tr>
<td>Enacted vs. Relational</td>
<td>1 (2.2)</td>
<td>1 (0.2)</td>
</tr>
<tr>
<td>Relational vs. Relational</td>
<td>2 (4.3)</td>
<td>2 (0.4)</td>
</tr>
<tr>
<td>Relational vs. Communal</td>
<td>2 (4.3)</td>
<td>3 (0.6)</td>
</tr>
<tr>
<td>Communal vs. Communal</td>
<td>1 (2.2)</td>
<td>1 (0.2)</td>
</tr>
</tbody>
</table>
In the United States, cancer is the second leading cause of death behind heart disease (American Cancer Society (ACS), 2015a) with 40% of American adults estimated to develop cancer in their lifetime (National Cancer Institute (NCI), 2014). While 1,600 people per day are estimated to die from cancer in 2015 (ACS, 2015a), survivorship is expected to increase within the next 10 years from 14.5 million people today to nearly 19 million (ACS, 2015a). With more people expected to live longer with a history of cancer, research is needed to ensure patients’ overall well-being throughout their illness trajectory.

Cancer is considered both a life crisis and a relational illness, one that affects patients’ family and friends (NCI, 2014). After a diagnosis, patients are often consumed with thoughts of fear and uncertainty about the future (Epstein & Street, 2007). Patients turn to health care providers (HCPs) and loved ones as sources of support when considering information about their diagnosis and treatment options (Arora, Finney, Gustafson, Moser, & Hawkins, 2007; Siminoff, Zyzanski, Rose, & Zhang, 2008). The decision making process is stressful for patients as they consider types of available treatment (including clinical trials), weigh benefits and risks of treatments, deal with uncertainty, and manage the impact to themselves as well as to their families (e.g.,
treatment side effects, transportation costs, financial concerns) (Siminoff, 2013). As a result, family members often accompany patients to appointments to discuss treatment options with HCPs (Siminoff, 2013). Communication about treatment options, however, reaches far beyond clinical encounters. Patients talk to their loved ones and HCPs both before and after medical visits as they consider their options and care (Arora, et al., 2007). In particular, spouses have been shown to be an important source of support for patients as they adjust to their illness (Miller & Caughlin, 2013). Evidence suggests that family communication about cancer care may influence how and what types of treatment options patients discuss with their HCPs (Krieger, 2014; Siminoff, 2013). Thus, communication about cancer care commonly consists of a decision-making team made up of patients, family members, and HCPs.

Although patients often rely on several sources of support while making decisions about their care both inside and outside of the clinical encounter, research has shown that patients report receiving inadequate support during their medical decision making (O’Connor et al., 2003; Zikmund-Fisher et al., 2010). If support is ineffective, patients’ health outcomes may be worsened (Goldsmith & Albrecht, 2011). Patients who disagree with family members about best treatment options report higher stress, lower psychological well-being and quality of life (Siminoff, Rose, Zhang, & Ayzanski, 2006). One study found that a patient’s family disagreed with a patient about a treatment decision about a third of the time (Hauke, Reiter-Theil, Hoster, Hiddemann, & Winkler, 2011). Conversely, patients who are involved in their treatment decision making with HCPs have reported higher satisfaction with their decisions and lower decisional conflict (Glass et al., 2012). Additionally, patients who are more satisfied with their decisions
report better health outcomes, such as higher treatment adherence (Glass et al., 2012). Thus, patients’ satisfaction with decision making is an important indicator of patient well-being during the cancer treatment decision phase.

Despite the team-centered nature of cancer care communication, medical decision-making research has historically focused on the patient and HCP (Street, 2013). The role of communication from both family members and HCPs during this decision-making process is understudied, and scholars have called for the inclusion of other members in health decision-making research (Arora, Street, Epstein, & Butow, 2009; Epstein & Street, 2007), such as families (Krieger, 2014) and the entire medical team (Quashning, Korner, & Wirtz, 2013). Thus, the current manuscript examines the influence of social support from patients’ partners (i.e., significant others) in addition to HCPs regarding patients’ satisfaction with decision making.

**Family Decisional Support**

Cancer is no longer viewed as an individual illness, rather one that affects the entire family (NCI, 2014); approximately three in four families have a family member who is a cancer survivor (ACS, 2015b). One way to examine family influence in patients’ treatment decision-making is to consider enacted social support, or how supportive messages are communicated (Goldsmith, 2004). This definition of support is different from other definitions of social support that focus on the quantity, frequency, structure, and availability of perceived social support, which unlike enacted support, do not consider the quality and appropriateness of support (Goldsmith, 2004).

Enacted social support consists of four dimensions: emotional support (i.e., expressions of caring, concern, and empathy); informational support (i.e., information
and advice); tangible support (i.e., offers of goods and services); and appraisal support (i.e., providing new perspectives on problems) (Goldsmith & Albrecht, 2011). Support given by the social network has been shown to facilitate patients’ adjustment to illness through increased empathy, respect, and ‘constructive discussions’ (Friedman & DiMatteo, 1982; Funch & Marshall, 1983). Patients want family members to allow them to express their worries and fears honestly while also feeling valued, loved, and cared for (Friedman & DiMatteo, 1982; Gotcher, 1993). Emotional support has been particularly important in facilitating patients’ psychological adjustment to illness (Gotcher, 1993). Social support has also been shown to increase individuals’ adherence to community healthful norms, perceptions of personal control, and intent to comply with healthful behaviors later (Goldsmith & Albrecht, 2011).

Social support (e.g., informational, emotional) given and received during a decision-making context has been defined as decisional support (Krieger, 2014). Decisional support has been found to differ according to individual preferences of patients and families. According to Krieger’s (2014) DECIDE typology for family communication about cancer treatment decision making, decisional support in the family context consists of five decision-making styles on a continuum ranging from patient autonomy (patient assumes/controls all decisional rights and responsibilities) to patient interdependence (patient gives some/all decisional rights and responsibilities to others). The styles include (1) independent (both patient and family desire patient autonomy in decision); (2) isolated (i.e., patient desires interdependence, but family desires patient autonomy); (3) collaborated (i.e., both patient and family desire interdependence); (4) delegated (i.e., both patient and family desire family autonomy); and (5) demanding (i.e.,
patient desires autonomy and family desires interdependence). Using this typology, Krieger et al. (in press) found that caregivers of cancer patients described their decisional support efforts as both aligning and conflicting with patient needs for support. When aligned between patients and family members, decisional support can result in positive health outcomes (e.g., less distress for patient); however, it can also increase patients’ distress if this support leads to conflicts between decisional partners about treatment preferences (Siminoff, et al., 2006).

Ways in which family members have provided decisional support to patients include assisting patients in seeking, sifting through, and processing information for health decisions, including finding an HCP, receiving advice about cancer treatment, and describing symptoms to providers (Krieger et al., in press; Siminoff et al., 2006). One study found that family members accompanied cancer patients on 2/3 of their visits with their oncologist and these family members play a role in seeking and receiving information (Shields et al., 2005). Family members have also been shown to influence patients’ decision making by pressuring patients to choose treatments that are less burdensome to the family as well as treatments that adhere to patients’ family’s values instead of HCP recommendations (e.g., vitamin supplements) (Siminoff, 2013). Likewise, before and after clinical visits, patients reported talking with other members of their social network—even before a decision is made (Meegan & Berg, 2002). Thus, decisions about health care and treatment are considered relationally imbedded—they contain much more than the preferences and values of conversation partners, but are also influenced by outside sources, such as friends and siblings (Lown, Hanson, & Clark, 2009).
In cancer decision making, spouses are an important, if not the primary, source of support, and extant research acknowledges the link between spousal communication and psychosocial outcomes, such as distress and adjustment to diagnosis (for review, see Harris et al., 2009). A primary finding in this research is that patients prefer more support than they receive from their partners (Harris et al., 2009). In comparison with other support sources (e.g., HCPs), research on partner communication in health decision making and health outcomes is understudied (Siminoff, 2013). Likewise, research about family support in other cancer contexts outside of breast and prostate is limited. Harris et al. (2009) calls for studies that focus and include other cancers that affect all genders and have lower survival rates (e.g., lung cancer, colon cancer). The current study addresses these gaps by focusing on partner (instead of only married couples) provision of four main types of enacted support (i.e., emotional, informational, advice, and appraisal) in treatment decisions for cancers of multiple sites. Thus, based on the above research that predicts family and spousal influence in clinical conversations about treatment decisions, the following hypothesis is presented:

H1: Social support from partners will be positively related to social support from HCPs in patients’ cancer treatment decision-making.

**Influence of Providers**

In the past, the dominant role of communication in health decision-making research focused on ensuring the clinician’s medical goals are met (i.e., treatment compliance, medication adherence). Although clinician goals are important to examine, there has been a move to focus on the treatment goals of patients through patient-centered communication (PCC) (Arora et al., 2009). The six main tenets of PCC include fostering
healing relationships, exchanging information, responding to emotions, making decisions, managing uncertainty, and enabling patient self-management (Arora et al., 2009). In other words, to promote healing and patient well-being, HCPs should support the needs of the ‘whole’ person, rather than only the biophysical needs, which includes considering the influence of family members in the decision-making process (Epstein & Street, 2007).

Ways in which HCPs have been shown to give support to patients include validating patients’ emotions; soliciting the patient’s beliefs, values, and preferences; asking about family and social context; providing sufficient information; and offering encouragement and support (Epstein & Street, 2007). Research has indicated that patients who report more informational support from the HCP, a discussion of patients’ preference for treatment in the clinical encounter, and the joint processing of risks/benefits of each treatment with HCPs report higher satisfaction with decision making (Bot et al., 2014; Glass et al., 2012). Thus, the second hypothesis predicts that support from one type of HCP (i.e., oncologist) will be related to patient satisfaction with decision making:

H2: Social support from HCPs will be positively related to patient decision-making satisfaction in patients’ cancer treatment decision making.

**Combined Support Influence**

Few studies, however, consider the combined influence of families and HCPs on patients’ decision making (Siminoff, 2013). Scholars have called for research in determining the role of family support on (1) patient/provider communication and (2) patient’s psychosocial outcomes (e.g., Ballard-Reisch & Letner, 2003; Street, 2013). Thus, we explore the influence of four main types of decisional support from the two
primary sources of patient support—partners and HCPs—on patients’ satisfaction with decision making. To our knowledge, this is the first study to quantitatively examine both family and HCP support on patient satisfaction with decision making.

Because this study is cross-sectional, the current paper is intended to be exploratory in nature when investigating possible linkages between partner support, HCP support, and patient decision-making satisfaction. Based on past research, two pathways are tested below. Some studies suggest that family members are likely to influence the treatment conversations with providers, which are likely to influence decision-making satisfaction (e.g., Epstein, 2013; Siminoff, et al., 2006). Further, Krieger (2014) argues in her empirically-derived family cancer treatment decision-making typology that families have static health decision-making styles that patients rely on when making medical decisions. These patterns then influence how the patient makes medical decisions (i.e., how much they rely on family support vs. HCP support). In contrast, one could hypothesize that the HCP relationship might influence how much patients rely on family support; however, that seems unlikely in light of Krieger’s work. Thus, it is possible that one type of family support—partner support—has a stronger relationship with patient decision-making satisfaction when it occurs through the process of HCP support. Thus the first research question is presented:

RQ1: Will HCP support mediate the effects of partner support on decision-making satisfaction?

Additionally, it may be possible that partner support relates to decision-making satisfaction differently at different levels of HCP support. For example, it may be that
partner support relates to higher decision-making satisfaction when HCP support is higher as opposed to lower. Thus, the second research question is presented:

RQ2: Will HCP support moderate the effect between partner support and decision-making satisfaction?

Clinical Trial Decision-Making

Clinical trials (CTs) are viewed as a critical resource to improving cancer care through treatment advances (Baquet, Commiskey, Mullins, & Mishra, 2006); however, approximately 5% of cancer patients enroll in a CT (Umutyan et al., 2008). Research has primarily focused on the identifying barriers to enrollment, yet scholars agree that patient and family informed decision making (and HCP support of those decisions) should be the goal of clinical trial research (Stepan et al., 2011; Yang et al., 2010). However, contexts which involve scientific or medical uncertainty (i.e., unknown effectiveness of treatment) or risk (i.e., unknown side effects), such as clinical trials, can be especially problematic for patients’ decision-making satisfaction (Politi, Clark, Ombao, Dizon, & Elwyn, 2011).

Within the decisional network, both family and HCP communication have been associated with CT enrollment. For example, Albrecht et al. (2008) found that patients who had greater trust in their HCPs and agreed with both HCPs and family members about treatment options had a higher likelihood of enrolling in a clinical trial. Patients felt more confident about their CT decision when they had more information and alliance with HCPs and family members (Albrecht et al., 2008). As a result, patients who enroll in a clinical trial might have increased satisfaction with decision making when patients view all members of their decision-making team (i.e. family and HCPs) as participating in their treatment decisions (i.e., giving support). In this study, we examine whether or not the
relationship between social support and patient decision-making satisfaction varies with a specific treatment decision—a clinical trial decision. Thus, we present our final research question:

RQ3: Does a patient’s specific clinical trial decision moderate the effects of partner and HCP support on decision-making satisfaction?

**Methods**

**Participants**

Participants ($N=667$) are included in this study if they were 18 years or older and received a cancer diagnosis within the last 2 years (see Table 1). Ages ranged from 18-89 ($M=48.9$, $SD=17.0$). A subsample of participants ($n=481$) reported that they had a significant other (e.g., spouse partner) at the time they were making their cancer treatment decisions. A majority of participants were female (61.1%) and white (85.2%) with ages ranging from 20-89 years old ($M=48.2$, $SD=16.6$). A majority of participants reported incomes of $50,000 or more (63.8%) and reported at least some college education (76.5%). Of the total sample, around 20% ($n=133$) of patients were offered a clinical trial. Nearly half of these participants had enrolled in a clinical trial ($n=83$, 59%) (see Table 1). Ages ranged from 21-78 ($M=43.2$, $SD=13.2$).

**Procedures**

For one week in May 2014, participants were recruited from the Qualtrics survey software web panel (i.e., a pool of U.S. adults who have volunteered to participate in online survey research via Qualtrics). Participants were randomly selected to participate through an email invitation with an embedded, secure individualized link to the survey. Survey questions focused on the attitudes and experiences of cancer survivors. Responses
were anonymous and confidential, and no personal identifiers were linked to participants. The researchers did not have access to any of participants’ identifiable information.

Participants who chose to opt-in to the study read an introductory page that (1) described the study and its purpose and (2) requested their consent to participate. Once they gave their consent, participants completed the survey, skipping any questions that they did not want to answer. After completion of the study, participants received a debriefing statement, which provided contact information for the principle investigators should they have any questions about the survey or their participation. All study participants, regardless of survey completion, received a cash value reward that is credited to their member account on the site. Reward amount is based on recruiting incentives, which are adjusted for survey length and target audience. In this study, higher incentive awards were given to minorities. Once their account value exceeds $10, panelists may redeem for an Amazon.com gift card, a Payoneer prepaid debit card, or a restaurants.com gift certificate.

Measures

Social support measures were adapted from established definitions of enacted support (Goldsmith, 2004) and were repeated across two separate support sources: HCP (i.e., oncologist) and partner (i.e., significant other). Social support was measured using a 5-point Likert scale asking if patients had received any treatment decision-making help by others (1) showing care and concern for me (i.e., emotional support); (2) giving me valuable information about my treatment options (i.e., informational support); (3) giving me advice about which treatment option would be better for me (i.e., informational-advice support); and (4) giving me a different point of view (i.e., appraisal support).
Responses ranged from strongly disagree (1) to strongly agree (5). Scale items resulted in reliability for partner support ($\alpha = 0.84$) and HCP support ($\alpha = 0.85$).

For each support source, a principal components analysis was conducted for support survey items. All coefficients in the correlation matrix reported coefficients of .3 and above. The Kaiser-Meyer-Olkin value was 0.781 (HCP) and 0.775 (partner) and Barlett’s Test of Sphericity was significant for both sources, thus making factor analysis appropriate for both of these source scales (Pallant, 2013). Analysis for both scales resulted in one component with eigenvalues exceeding 1: 2.848 (HCP) and 2.726 (partner), which explained 71% (HCP) and 68% (partner) of the variance. Thus, scale items for each source were combined separately into two variables (HCP and Partner) by using the mean score across each case for each support source.

Clinical trial participation was measured by asking patients who were offered a clinical trial: Did you agree to participate in the cancer research study you were offered? Responses were yes or no.

Decision-making satisfaction was measured using a 5-point Likert scale created from four questions from the Satisfaction with Decision Scale (Holmes-Rovner et al., 1996): (1) I am satisfied that I was adequately informed about the issues important to my decision; (2) The treatment decision I made was the best decision possible for me personally; (3) I am satisfied with the outcome of my decision; and (4) I am satisfied that my decision was consistent with my personal values. Possible responses ranged from strongly disagree (1) to strongly agree (5). Scale reliability was calculated for decision-making satisfaction ($\alpha = 0.88$).
Using the guidelines above for PCA (Pallant, 2013), results showed that the test was appropriate and that one component was present with an eigenvalue exceeding 1: 2.968, which explained 74% of the variance. Thus, scale items were combined into one variable by using the mean score of scale items for each case.

**Data Analysis**

A secondary analysis was conducted of survey information about cancer treatment attitudes. All analyses were conducted in SPSS (version 22, IBM, New York). First, frequencies and distributions of demographic and behavioral variables (Table 1) and reliability of scale items were assessed. In addition, three key variables (i.e., partner support, HCP support, and decision-making satisfaction) were negatively skewed, thus, they were transformed by reflecting and inversing the scores. This technique allows for the creation of new variables with more normally distributed responses in order to meet the statistical assumptions of the techniques below (Tabachnick & Fidell, 2014, p. 87).

Participants \((n=481)\) were included if they had completed the HCP, partner, and decision-making satisfaction scales. Two participants were eliminated because one did not report income and one did not report health care provider influence for a total sample of 479. To estimate the relationship between the predictor (i.e., partner support; HCP support) and outcome variables (decision-making satisfaction), a correlation test was conducted using Pearson’s correlation (Table 2).

To estimate the mediation model (i.e., RQ1), a test of significance for the indirect effect was conducted using the PROCESS macro (Model 4) in SPSS to estimate Path(a) from the predictor variable to mediating variable; Path(b) from the mediating variable to the outcome variable; and Path(c) from the predictor variable to the outcome variable...
(Figure 1). The indirect effect was tested using the Process macro for SPSS (Model 4). Bootstrapping was conducted in order to generate a valid confidence interval for statistical inference. In bootstrapping, indirect effects are estimated from repeated resampling (Preacher & Hayes, 2004). The indirect effect is quantified as the product of the direct effect of partner support on HCP support and the direct effect of HCP support on SWD.

To estimate the moderation model (i.e., RQ2), a test of significance for the interaction effect was conducted using multiple regression analysis through the PROCESS macro (Model 1) in SPSS. For both mediation and moderation analyses, bootstrapping was conducted with 5,000 samples to test significance and obtain a valid 95% confidence interval (Preacher and Hayes, 2004). The regression was controlled for age, sex, race, education, and income (see Table 1 for frequencies).

For RQ3, participants for moderated-mediation (Preacher, Rucker & Hayes, 2007) included only those participants offered a clinical trial (n=133). A test of significance for the indirect and conditional effects was conducted using the PROCESS macro (Model 14) to estimate Path(a) from the predictor variable to mediating variable; Path(b) from the mediating variable to the outcome variable; Path(c) from the predictor variable to the outcome variable; and the conditional effect of a clinical trial decision on decision-making satisfaction (Figure 2). Bootstrapping was conducted with 5,000 samples to test significance and obtain a valid 95% confidence interval (Preacher and Hayes, 2004).
Results

Partner Support and HCP Support (H1)

The first hypothesis predicted that social support from partners will be positively related to social support from HCPs in patients’ cancer treatment decision-making. Table 2 provides descriptive statistics and the Pearson’s correlation for these variables. As hypothesized, a significant positive relationship exists between partner support and HCP support ($r=0.481$). The results show that H1 is supported.

HCP Support and Satisfaction with Decision Making (H2)

Hypothesis 2 predicted that HCP support would be positively related to satisfaction with decision making. To explore this relationship, a Pearson’s correlation was conducted (Table 2). Results indicate that a positive significant relationship exists between HCP support and SWD ($r=0.456$, $p < .001$).

HCP Mediation of Partner Support and Satisfaction with Decision Making (RQ1)

RQ1 asked if higher partner support would be associated with higher HCP support, and higher patient decision-making satisfaction (Figure 1). Using the unstandardized regression coefficients in an OLS model, the estimated effect for the direct effect of partner support on HCP support (path a in Preacher and Hayes [2004]) is 0.450, and is statistically different from zero (see Table 3). For the direct effect of hcp support on SWD (path b in Preacher and Hayes [2004]), the estimated effect is 0.420 and is also significantly different from zero.

The indirect effect is the product of these two paths: $(0.450) \times (0.420) = 0.189$. This means that a patient who reports one unit higher on the partner support scale is estimated to report 0.189 units higher in SWD through the effect of health care support,
which then affects the likelihood of achieving SWD. The indirect effect is statistically different from zero as evidenced by the 95 percent confidence interval for the indirect effect created by the 5,000 bootstrap samples (0.1359-0.2539). As a result, HCP support significantly mediates the relationship between partner support and overall decision-making satisfaction.

The model also shows a significant direct effect of partner support and the likelihood of reporting overall SWD ($b=0.090, p=0.047$). This direct effect (path $c'$ in Preacher & Hayes [2004]) is statistically different from zero (see Table 3). Thus, a direct effect exists between partner support and likelihood of reporting SWD, independent of HCP support. This means that as partner support increased, the likelihood of reporting SWD also increased. The total effect of partner support on SWD is estimated by adding the direct effect and indirect effect (path $c$ in Preacher & Hayes [2004]): $0.090 + 0.189 = 0.279$. The total effect is the unstandardized regression coefficient estimating likelihood of reporting SWD from partner support. Thus, RQ1 is supported through a partial, and significant, mediation effect of HCP support on the relationship between partner support and decision-making satisfaction.

**HCP Moderation of Partner Support and Satisfaction with Decision Making (RQ2)**

A moderated multiple regression analysis was conducted to estimate overall decision-making satisfaction from HCP support and partner support and their product (i.e., HCP x Partner) (Figure 2). The regression analysis, when controlled for sex, age, education, ethnicity, and income, showed that the interaction was negative; however, it was not statistically significant from zero ($b = -0.156, p=0.34$). Thus, HCP support does
not moderate the relationship between partner support and decision-making satisfaction (Table 5).

**Clinical Trial Enrollment Interaction Effect (RQ3)**

In addition to above analyses, I examined the conditional effect of a clinical trial decision to explore whether the relationship between support and SWD varied by participation in a clinical trial. In other words, does social support from partners and HCPs predict overall SWD for clinical trial enrollment (i.e., yes/no)? Table 1 provides the frequencies for CT offer and enrollment. A correlation matrix was run to measure the strength and significance of source of support on CT decision (Table 3). Both HCP and partner support were positively correlated with CT decision, though the relationships were not significant (Table 2). As expected after the correlational analyses, a moderated-mediation multiple regression analysis was conducted (Process Model 14) and the regression analysis shows that the interaction between HCP support and CT decision is positive though not significantly different from zero ($b=0.203, p=0.16$) (Table 6). Thus, partner support that leads to HCP support does not depend upon CT enrollment when patients report overall SWD.

**Discussion**

The purpose of this study was to examine the role of social support provided from partners and HCPs in determining patient satisfaction with decision making in the cancer treatment context. Additionally, we examined the conditional effect of clinical trial enrollment on the relationship between support and satisfaction. To our knowledge, this was the first study to quantitatively explore the relationship between partner and HCP support and patient satisfaction with decision making.
The results indicated that after adjusting for demographic factors, both partner and HCP support were significantly and positively related to patient decision-making satisfaction. This means that as HCP and partner support increased, patients reported higher decision-making satisfaction. Results further indicated that higher partner support was associated with higher HCP support, which also increases patient decision-making satisfaction. In contrast, results also showed that the relationship between support and decision satisfaction did not vary with CT enrollment. In fact, there were no significant associations between CT enrollment and partner and HCP support and satisfaction with decision making. These findings show that clinical trial enrollment did not affect the relationship between decisional support and patient decisional satisfaction. This result is promising for patient well-being in that it may suggest that patients are feeling supported in their treatment decision from both partners and HCPs, no matter what their CT decision.

Theoretical and Practical Implications

Few studies exist that examine both the influence from both HCPs and family members in health decision-making encounters. The present research sought to fill this gap by examining these sources together in relation to patient satisfaction with decision making—an important indicator of patient well-being. Because research findings are mixed in how HCPs affect health outcomes, scholars (e.g., Ballard-Reisch & Letner, 2003; Epstein, 2013; Street, 2013) have called for research that identifies how additional factors, such as family social support, affect the relationship between health care HCP communication and subsequent treatment outcomes (Street, 2013). Because spouses are considered a key source of support in the cancer context (Miller & Caughlin, 2013), we
chose to include partner support in our first exploratory analysis with HCP support on patient decision satisfaction.

**Partner support.** Partner support was shown to be influential in patients’ medical decision-making; however, variability existed among patients to what extent this support influenced their decision (Table 2). Partner support was positively correlated with HCP support and satisfaction with decision-making, and the direct effect in mediation regression analysis was small ($b=0.090$) but significant. This finding supports previous research (e.g., Krieger, 2014) that found that in cancer treatment decision making, patients do not always seek and/or value the support from their family and that conversely, families do not always give the support that a patient desires from them (e.g., Krieger et al., in press). Even if partner support was given to and received by patients at a high level, patients may value partner support more if they have an interdependent style of family decision making and less if they have an autonomous style of family decision making. Thus, it follows that partners are significant sources of information; however, their effect on decision making satisfaction may be small.

One possible reason for a difference in patients’ value of partner support could be patients’ illness identity (i.e., what it means to patients to have cancer). Couples have been shown to negotiate and change relational identities based on caregiving roles that extend beyond the cancer treatment phase (Miller & Caughlin, 2013). In addition, Krieger et al. (in press) found that when caregivers perceived patients to be viewing patients’ cancer illness identity in similar identity frames (i.e., relational or personal), caregivers were more likely to give effective decisional support to patients. Conversely, when caregivers perceived patients to be viewing patients’ cancer illness identity in
different identity frames (i.e., relational versus personal), caregivers were less likely to give effective decisional support.

Future research could investigate the extent to which patients construct and view their illness as existing solely within themselves and/or with others, such as their HCP, families, or larger groups, such as cancer survivors. These studies would be important because they could potentially illuminate when support from family members as opposed to solely HCPs are influential in the treatment process. Focusing on illness identity could also allow HCPs to ensure that they are aligning their identities with the patient’s preference for family involvement (autonomy vs. interdependent) and also identify when patients are receiving adequate decisional support from their family members that they desire. This may also help to identify when patients are in need of psychosocial services, such as counseling or a support group to adjust to changes in their personal and relational identities.

**HCP support.** In contrast, most patients reported that their HCP was highly influential in their decision-making satisfaction. HCP support was positively correlated with satisfaction with decision making, and the direct effect in mediation regression analysis was moderate ($b=0.420$) and significant. This finding for HCP support is encouraging given the focus on patient-centered care in medical decision-making and patient perceptions of HCP credibility and knowledge. This finding shows that for cancer treatment decision making, patients value the support their HCP gives them, and when effective, it influences patient satisfaction.

An interesting finding in the current study is that patients viewed types of support as similarly influential to their treatment decision (e.g., emotional, informational, advice,
and appraisal) for both partners and HCPs. As shown in their reliability scores, the types of support blended together for the patients even though they had different associations with decisional satisfaction. This finding could mean that patients want to receive information but also wanted to feel cared for by their HCP and/or it could mean that by communicating information, HCPs were also communicating they cared for patients. The need for support is bound to be different among patients; however, the finding here may suggest that when they do value support in their decision-making, they value the types of support similarly. This finding could also suggest that single item measures are not distinct enough to identify unique differences among types of support; thus, improved scales for decisional support could be developed and used in the future. For the purposes of this study, we wanted to explore the influence of support source more so than support type as well as explore the utility of a shortened social support scale; thus, the current scale was sufficient for the current analysis.

**Combined source support.** Past research suggested that clinical encounters are relationally imbedded and scholars have called for analyses that integrate more than one source of influence on patients’ medical decision making (Epstein, 2013; Street, 2013). Thus, the current study examined how the support of HCPs and partners combine to influence decisional satisfaction. Our results confirmed that through mediation regression analysis, HCP support is a stronger predictor of decision-making satisfaction than partner support, but that higher partner support also encourages more HCP support, which influences decision satisfaction. Though a causal relationship cannot be inferred from the cross sectional data provided in this study, the results from the current mediated regression possibly suggest an explanation for a process through which family members
influence patients’ decision-making satisfaction (i.e., partner support leads to HCP support which leads to decision-making satisfaction) (MacKinnon, 2008). Future studies should consider temporal study designs to appropriately test causal linkages.

Theoretical support for a future causal interpretation of these relationships make sense when considering that partners attend appointments with patients and seek and receive more information from HCPs (Shields et al., 2005). In addition to patients, partners may ask more questions than if patients had attended the appointment alone (Shields et al., 2005). Another possible explanation for this finding is that patients who receive more support from partners may feel more empowered and confident in seeking support from providers (Han et al., 2005). Finally, patients who have an interdependent decision-making style may value support from both family and HCPs as opposed to patients who have an autonomous family decision-making style and value support from the HCP only (Krieger, 2014). Future studies should investigate the relationship between sources of support in cancer and other illness contexts to more deeply explore these support relationships to health outcomes. Regardless, the results are encouraging that partner and HCP support is associated with patient satisfaction with their decisions.

Further supporting the possible causal relationship between partner support and HCP support is the result of the moderation analysis. No significant interaction was found between partner and HCP support, and interestingly, the interaction was negative, suggesting that when HCP and partner support interact, they are associated with lower decision-making satisfaction for patients. One possible mechanism to explain this negative relationship is a difference of opinion between partners and HCPs regarding patients’ treatment decisions, and future research should consider measuring the level of
agreement between decision-making team members as well as communication factors (e.g., perspective-taking) that allow for congruence among all members of the decision-making team.

These results also suggest that in addition to patient-centered communication with HCPs, patients could also benefit from patient-centered communication with family members—focusing on patient goals and values for treatment. Just as shared decision-making models between HCPs and patients have moved to a mutually influential style of communicating—one that respects patients’ goals and level of involvement (Arora et al., 2009)—so too could shared decision-making models with family members incorporate respect for patients’ goals and their level of involvement. Of course, this is more emotionally difficult for caregivers (as opposed to HCPs), who are personally and relationally invested and perceive cancer to be affecting the entire family (Hasson-Ohayon, Goldzweig, Braun, & Galinsky, 2010; Krieger et al., in press). Thus, future family cancer communication interventions could explore how to educate both patients and caregivers on the importance of patient-centered communication in shared illness identity, and its personal and relational implications, such as identifying and respecting the patients’ desire for the family’s level of involvement in decision making in order to increase patient wellbeing and lower decisional conflict for families.

**Satisfaction with decision-making.** Finally, we used satisfaction with decision making as an indicator of patient well-being. However, some researchers claim that quality decision making is more important than satisfaction with decision making in determining patients’ well-being. These reasons include the need to accurately assess patient’s knowledge about options, understanding of risk involved with treatments, and/or
how well the decision-making process matches their value system (Politi et al., 2011). In
consideration of these reasons, we chose Holmes-Rovner et al.’s (1996) satisfaction with
decision making scale because it privileges the patients’ perspective in asking the patient
to evaluate how informed they believed they were, how good the decision was for them,
how satisfied they were with the outcome, and how consistent the decision was with their
personal values.

Likewise, patients do not always engage in systematic processing when making
treatment decisions and instead engage in naturalistic (i.e., intuition-based) and/or
heuristic processing (Krieger, 2014). This makes sense when considering that patients
desire different levels of information depending upon where they are located in the illness
trajectory (Marcus et al., 2013). Specifically in the cancer context, patients have initially
reported feeling overwhelmed and experiencing difficulty processing information after
their diagnosis. However, it is precisely at this moment that treatment options are often
discussed because of medical concerns about cancer progression and often why it is
suggested that patients bring loved ones to their appointments. Likewise, these
appointments have also been shown to be overwhelming for caregivers and factors such
as motivation, knowledge, and communication skills been shown to influence how well
people understand and communicate with HCPs about health information (Epstein &
Street, 2007). Thus, satisfaction with decision-making, although not the only measure for
quality of decision-making, is an important indicator of decisional quality because it
indicates that patients have met their goals and considered their values (i.e., patient-
centered communication), which have been linked to less decisional conflict and
increased well-being (Glass et al., 2012).
Limitations

The current study examined the influence of significant others in relation to health care HCPs on decisional satisfaction. As other researchers have noted, many other relational influences (e.g., friends, siblings, children) influence the clinical encounter both before and after these visits (Harris et al., 2009). The original sample size contained 667 participants, which is a small sample size compared to the general cancer patient population. Further, patients who are surveyed through a Qualtrics web survey present a selection bias in any sample because they likely (1) have an interest in research; (2) are motivated to participate to receive monetary remuneration; and/or (3) have more advanced technological skills than the average cancer patient. However, collecting data through Qualtrics allows for oversampling of difficult-to-recruit populations, such as cancer patients who are ethnic minorities and who are offered clinical trials.

Although the original sample contained 667 participants, once partners were included in the analysis, participants dropped to 479. Although this subsample represents 72.0% of the original sample, the findings only represent cancer patients who have spouses. The current study specifically looked at partner support because partners and HCPs have been shown to be the most influential sources of support for cancer patients (e.g., Miller & Caughlin, 2013). However, findings cannot be generalized to cancer patients who rely on other caregivers, such as a close friend, sibling, or child because they are either not married, have lost a partner, or find more support in other relationships. Future studies should instead consider the influence of a primary support network source (as opposed to significant other) to account for these differences and increase generalizability among cancer patients.
Finally, another sample limitation is the smaller sample size for patients offered a clinical trial ($n=133$). However, in all of the above analyses, I attempted to address the sample size limitation through bootstrapping; however, sample selection bias remains (MacKinnon, 2008). Although a minority of cancer patients enroll in a CT (Umutyan, et al., 2008), approximately 20% of participants in the current sample were offered a CT, and 59% of those patients (11% of total sample) enrolled in a CT. Although this number is higher than clinical participation rates, the analyses in the current study remain informative in examining the relationship between decisional support and decisional satisfaction. Further, clinical trial participants are often difficult to recruit given their small percentages of enrollment; thus, the elevated percentage of CT enrollees can also be considered a strength of the study.

**Conclusions**

Partners and HCPs are key sources of decisional support and the current study is an initial step to examining the dual influences of both clinical and social network support. Future studies should continue to include the influence of multiple sources of decisional support to understand the influence of communication in patients’ health decision making. A need exists for theoretical models to predict and explain the relationships between decisional support and health outcomes that lead to patient well-being. With continued theoretical development, interventions can be developed and tested to ensure patients’ decisional needs for support are met from both the social network as well as health care HCPs.
References


Table 2
Participant Statistics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total Sample (n=667)</th>
<th>Partner &amp; HCP Support (n=479)</th>
<th>CT offer (n=133)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number (% )</td>
<td>Number (%)</td>
<td>Number (%)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>416 (62.4)</td>
<td>294 (61.1)</td>
<td>88 (66.2)</td>
</tr>
<tr>
<td>Male</td>
<td>251 (37.6)</td>
<td>187 (38.9)</td>
<td>45 (33.8)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>568 (85.2)</td>
<td>410 (85.2)</td>
<td>97 (72.9)</td>
</tr>
<tr>
<td>African-American</td>
<td>50 (7.5)</td>
<td>34 (7.1)</td>
<td>18 (13.5)</td>
</tr>
<tr>
<td>Asian/Asian-American/Pacific Islander</td>
<td>35 (5.2)</td>
<td>26 (5.4)</td>
<td>14 (10.5)</td>
</tr>
<tr>
<td>Native-American/Eskimo</td>
<td>4 (0.6)</td>
<td>3 (0.6)</td>
<td>1 (0.8)</td>
</tr>
<tr>
<td>Other</td>
<td>10 (1.5)</td>
<td>8 (1.7)</td>
<td>3 (2.3)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS incomplete</td>
<td>12 (1.8)</td>
<td>6 (1.2)</td>
<td>2 (1.5)</td>
</tr>
<tr>
<td>HS graduate</td>
<td>93 (13.9)</td>
<td>67 (13.9)</td>
<td>14 (10.5)</td>
</tr>
<tr>
<td>Technical/trade/vocational after HS</td>
<td>55 (8.2)</td>
<td>40 (8.3)</td>
<td>14 (10.5)</td>
</tr>
<tr>
<td>Some college</td>
<td>192 (28.8)</td>
<td>143 (29.7)</td>
<td>39 (29.3)</td>
</tr>
<tr>
<td>College graduate (4-yr degree)</td>
<td>233 (34.9)</td>
<td>171 (35.6)</td>
<td>47 (35.3)</td>
</tr>
<tr>
<td>Post-graduate</td>
<td>82 (12.3)</td>
<td>54 (11.2)</td>
<td>17 (12.8)</td>
</tr>
<tr>
<td>U.S. annual income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $10,000</td>
<td>18 (2.7)</td>
<td>9 (1.9)</td>
<td>2 (1.5)</td>
</tr>
<tr>
<td>$10,000 to under $20,000</td>
<td>47 (7.0)</td>
<td>15 (3.1)</td>
<td>9 (6.8)</td>
</tr>
<tr>
<td>$20,000 to under $30,000</td>
<td>73 (10.9)</td>
<td>44 (9.1)</td>
<td>6 (4.5)</td>
</tr>
<tr>
<td>$30,000 to under $40,000</td>
<td>87 (13.0)</td>
<td>59 (12.3)</td>
<td>21 (15.8)</td>
</tr>
<tr>
<td>$40,000 to under $50,000</td>
<td>64 (9.6)</td>
<td>47 (9.8)</td>
<td>12 (9.0)</td>
</tr>
<tr>
<td>$50,000 to under $75,000</td>
<td>160 (24.0)</td>
<td>123 (25.6)</td>
<td>33 (24.8)</td>
</tr>
<tr>
<td>$75,000 to under $100,000</td>
<td>113 (16.9)</td>
<td>92 (19.1)</td>
<td>25 (18.8)</td>
</tr>
<tr>
<td>$100,000-under $150,000</td>
<td>80 (12.0)</td>
<td>70 (14.6)</td>
<td>20 (15.0)</td>
</tr>
<tr>
<td>$150,000+</td>
<td>24 (3.6)</td>
<td>21 (4.4)</td>
<td>5 (3.8)</td>
</tr>
<tr>
<td>Clinical Trial Offer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>133 (20)</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>No</td>
<td>534 (80)</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Clinical Trial Enrollment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>-----</td>
<td>-----</td>
<td>78 (59)</td>
</tr>
<tr>
<td>No</td>
<td>-----</td>
<td>-----</td>
<td>55 (41)</td>
</tr>
</tbody>
</table>
Figure 1: Theoretical Model of Mediation of Social Support and Decision-Making Satisfaction
Table 3

*Descriptive Statistics and Pearson’s Correlation between Variables*

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>PS</th>
<th>HCP</th>
<th>CT</th>
<th>SWD</th>
<th>Pearson’s r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner Support (PS)</td>
<td>3.9</td>
<td>0.9</td>
<td>1.0-5.0</td>
<td>1.000</td>
<td>0.481**</td>
<td>0.156†</td>
<td>0.213**</td>
<td></td>
</tr>
<tr>
<td>HCP Support (HCP)</td>
<td>4.1</td>
<td>0.8</td>
<td>1.0-5.0</td>
<td>-----</td>
<td>1.000</td>
<td>0.064</td>
<td>0.429**</td>
<td></td>
</tr>
<tr>
<td>Clinical Trial Dec (CT)</td>
<td>-----</td>
<td></td>
<td>-----</td>
<td>-----</td>
<td>1.000</td>
<td>0.08</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dec-Making Satis (SWD)</td>
<td>4.4</td>
<td>0.7</td>
<td>1.0-5.0</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>48.2</td>
<td>16.6</td>
<td>20.0-89.0</td>
<td>-0.32**</td>
<td>-0.12**</td>
<td>-0.01</td>
<td>0.19**</td>
<td></td>
</tr>
<tr>
<td>Sex (1=Male, 2 = Female)</td>
<td>-----</td>
<td></td>
<td>-----</td>
<td>0.11*</td>
<td>0.11*</td>
<td>-0.18*</td>
<td>0.09†</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>0.02</td>
<td>-0.06</td>
<td>0.01</td>
<td>-0.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>0.06</td>
<td>0.03</td>
<td>-0.01</td>
<td>-0.08†</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>0.04</td>
<td>0.01</td>
<td>0.03</td>
<td>0.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**p<0.001
t† p<0.10
Table 4
Regression Results for Mediation

<table>
<thead>
<tr>
<th>Panel A: Variables</th>
<th>Coeff.</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision-Making Satis regressed on partner support (c)</td>
<td>0.279</td>
<td>6.439</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>HCP support regressed on partner support (a)</td>
<td>0.450</td>
<td>11.434</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>DM Satisfaction regressed on</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HCP support controlling for partner support (b)</td>
<td>0.420</td>
<td>8.950</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>DM Satisfaction regressed on partner support controlling for hcp support (c’)</td>
<td>0.090</td>
<td>1.989</td>
<td>0.047</td>
</tr>
</tbody>
</table>
Figure 2: Theoretical Model of Moderation of HCP Support on Partner Support and Decision-Making Satisfaction
Table 5
Regression Results for Moderation

Panel A: Variables

<table>
<thead>
<tr>
<th></th>
<th>Coeff.</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision-Making Satis regressed on:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>0.075</td>
<td>0.703</td>
<td>0.48</td>
</tr>
<tr>
<td>Partner Support</td>
<td>0.199</td>
<td>1.619</td>
<td>0.11</td>
</tr>
<tr>
<td>HCP Support</td>
<td>0.512</td>
<td>4.764</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Interaction (Partner x HCP support)</td>
<td>-0.156</td>
<td>-0.954</td>
<td>0.34</td>
</tr>
</tbody>
</table>
Figure 3: Theoretical Model of Moderated Mediation of Clinical Trial Enrollment on Social Support and Decision-Making Satisfaction
Table 6
*Regression Results for Mediated Moderation*

<table>
<thead>
<tr>
<th>Panel A: Variables</th>
<th>Coeff.</th>
<th>$t$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision-Making Satis regressed on:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>0.238</td>
<td>1.472</td>
<td>0.14</td>
</tr>
<tr>
<td>Partner Support</td>
<td>0.088</td>
<td>1.074</td>
<td>0.29</td>
</tr>
<tr>
<td>HCP Support</td>
<td>0.268</td>
<td>2.427</td>
<td>0.02</td>
</tr>
<tr>
<td>CT Enrollment</td>
<td>-0.136</td>
<td>-1.295</td>
<td>0.20</td>
</tr>
<tr>
<td>Interaction (HCPxCT)</td>
<td>0.203</td>
<td>1.405</td>
<td>0.16</td>
</tr>
</tbody>
</table>
CHAPTER 3: EFFECTIVE IDENTITY SUPPORT COMMUNICATION DURING CHRONIC ILLNESS

Chronic illness affects the health and economic well-being of every country in the world. As a result, the United Nations made chronic illness a key focus in its 2011 meeting (U.S. Institute of Medicine, 2012). In the U.S., approximately half of all adults (117 million people) are struggling with chronic illness (Ward et al., 2014); one in four Americans are living with two or more (U.S. Institute of Medicine, 2012). The two most common chronic health conditions, heart disease and cancer, account for nearly half of all deaths in the U.S. (Ward et al., 2014). Other non-life threatening diseases, such as arthritis, diabetes, and obesity, are leading causes of disability and significantly disrupt individuals’ quality of life. As a result, chronic illness is responsible for 84% of our nation’s health care costs (CDC, 2014). Recently, the U.S. Institute of Medicine (2012) concluded that improving quality of life for chronically ill individuals has not been given the research funding or attention that it requires to improve control of chronic illness and overall patient well-being.

Chronic illness has been defined as “setbacks, flare-ups, complications, impaired functions, and disabilities” (Charmaz, 1987, p. 283) that last for three months or longer (U.S. Institute of Medicine, 2012). To cope with changes in their lives as a result of these chronic illness, patients often turn to loved ones (i.e., family and close friends) and health care providers (HCPs) for support. These sources have been shown to provide advice and
assistance throughout the illness trajectory—from coping with illness symptoms to evaluating and choosing appropriate treatments (Arora, Finney, Gustafson, Moser, & Hawkins, 2007; Krieger et al., in press; Siminoff, Zyzanski, Rose, & Zhang, 2008). Research has shown mixed results for the effects of social support on health outcomes (for a review, see Goldsmith & Albrecht, 2011).

Effective support has been correlated with patients’ experience of lower stress, increased resilience, and higher well-being (e.g., Kim, Han, Shaw, McTavish, & Gustafson, 2010). Conversely, ineffective support has been linked to negative health outcomes, such as lower physical health and well-being, increased depression, and higher uncertainty (e.g., Uchino, 2009). However, more support sometimes leads to worse health because of inappropriate or poor quality of support (Goldsmith & Albrecht, 2011). As a result, Goldsmith and Albrecht (2011) call for communication scholars to move beyond relating types of support to outcomes, and instead further theoretical work by explaining the processes through which conversational elements relate to health outcomes (p. 337).

Thus, the current paper theoretically investigates how the role of illness identity may explain the effectiveness and ineffectiveness of social support throughout a patient’s illness trajectory. Currently, theoretical development around the concepts of illness identity, social support, and patient well-being is lacking. Researchers often examine health care providers and family members as separate support influences on a patient’s health. The current paper advances this body of work by examining two simultaneously influential sources of social support (HCPs and loved ones) for patients’ well-being during their illness experiences. The proposed model, The Communication of Chronic Illness Identity Support (CCIIS), also contributes to our practical understanding of social
support by meeting patients’ support and identity needs for well-being during chronic illness. Patients have reported that they would like to have been made aware of the changes that would come to their identity when they were first diagnosed in order to better cope with their disease (Karnilowicz, 2011). Patients have also reported receiving inadequate support during medical decision-making (Sloan & Knowles, 2013) and a lower level of helpful support after treatment (Arora et al., 2007). In recognition of these support gaps, the U.S. Institute of Medicine (2012) has called for more intervention-level research focused on concepts such as social support and coping resources and care and disease management. Thus, to lower health care costs and improve patients’ well-being, a need for theoretically-based solutions for support provision across the illness trajectory is needed.

**Chronic Illness Identity and Well-Being**

When individuals are diagnosed with a chronic illness, they experience identity changes because their view of their bodies, their relationships, and their abilities has changed (Charmaz, 1994). As a result of chronic illness, individuals’ lives are disrupted and they struggle to regain a sense of themselves (Charmaz, 1994). Scholars have defined this sense of illness identity differently. Hayden (1993) defines illness identity as “a deviant, abnormal state” (p. 264) and Charmaz (1995) defines it as an incorporation of chronic illness or disability into one’s sense of self (p. 658-659). Mathieson and Stam (1995) argue that when people incorporate illness into their identity, they are not merely adjusting or coping with disease; they are transforming their perspective about who they are. The authors explain that a chronic disease experience leads to a total reconstruction of individuals’ identity and the ways in which disease will change their life story.
Sociologists have typically studied illness identity through either crisis models (i.e., illness permanently changes one’s social identity and thus self-identity) or negotiation models (i.e., identity is fluid and changes as an individual tries to regain normalcy) (for a review, see Kelly & Field, 1996). Both models are useful, with crisis models used more in visible health contexts (e.g., physical disability) and negotiation models used more for private, hidden contexts (e.g., diabetes). However, it is possible for individuals to manage their identity using a combination of these models with patients negotiating their illness identity to fit within their current and future lives, regardless of the visible or hidden nature of their illness (e.g., cancer) (Kelly & Field, 1996).

During patients’ experience of chronic illness, 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 are negotiating a new identity, and these identity changes are constantly in flux because individuals’ experience of disease is ongoing and changes over time. As a result, these changes create identity dilemmas (also called identity transformations, identity shifts, or identity gaps), which contradict each other and continually change (Blackford & Arrington, 2011; Jung & Hecht, 2004; Miller & Caughlin, 2011; Siminoff & Step, 2005). As a result, individuals face questions about how to understand, manage, and ultimately communicate their newly formed illness identity to themselves and others (Hansford & Hattie, 1987). When patients effectively incorporate their illness into their identity, research has shown that they are able to better 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 who do not adjust to
their illness have been shown to experience increased depression, spiritual struggle, decreased hope, and increased risk for co-morbidity (Ai et al., 2010).

**Illness Identity Changes over Time**

Chronic illness identity, as with any identity, constantly changes across time in relation to experiences (Hecht et al., 2004). Even when a disease is controlled or no longer present in the body, identity changes can still occur because patients are still undergoing disease-related experiences, such as follow-up appointments, ongoing tests, and post treatment side effects (e.g., numbness, hormonal changes) (Miller & Caughlin, 2013). Based on extant research, I argue that three stages capture the most significant change: diagnosis, treatment, resolution/recovery. Several studies identify stages of identity transformation in disease and disability. For example, Karnilowicz (2011) examines his identity challenges during his experience with prostate cancer from diagnosis (i.e., psychological distress) to treatment (i.e., all-consuming learning process to try and understand disease) and recovery (“psychological ownership” of disease and identity reconstruction) (p. 277). Recovery might not exist in the physical sense if individuals are struggling with end-of-life care; however, recovery might be conceptualized as resolution to describe the process with which individuals may or may not come to terms with the ultimate outcome (i.e., death, disability).

In addition, Braithwaite and Braithwaite (2003) identify three stages individuals experience with disability onset: (1) redefining self as part of a new culture (i.e., stigma isolation, stigma recognition, and stigma incorporation); (2) redefining disability (i.e., as only part of one’s identity); and (3) redefining disability for the dominant culture (i.e., the education of others, advocacy). Although these stages are labeled differently, they map
onto the broader stages of diagnosis, treatment, and recovery by describing what type of identity changes happen during these three disease management stages (e.g., diagnosis = stigma isolation; treatment = redefining illness; recovery = illness advocacy). Of course, this process may not be linear for all patients and some patients may continue to experience stigma in the treatment or recovery stage and may depend on a number of factors (e.g., personality traits, culture).

Other scholars have examined identity changes through one phase of illness, such as diagnosis. For example, one longitudinal study that interviewed adolescents with cancer across four time points during their first year of diagnosis, were shown to vary across time in negotiating their cancer identity with their future identity. In the first and fourth time points, they were more concerned with their future identity as it related to their illness identity; however, at the second and third time point, they were more concerned with their present cancer identity (Stegenga & Macpherson, 2014). Similarly, Harwood and Sparks (2003) argue that after diagnosis, cancer patients seek information to understand their new disease and treatment options and begin the process of identification with their illness, including identifying with other cancer patients. This process occurs over time and depends on patients’ mental models of what it means to be a cancer patient.

Finally, Miller and Caughlin (2013) examine couples’ experience with cancer through treatment and survivorship. They found that relational challenges differed in each stage and couples sometimes struggled to redefine themselves in terms of caregiver-patient roles. For example, some caregivers liked caring for their spouse and felt a loss of that relational bond after the patient no longer needed them as much. Thus, for the
purposes of my model, it is useful to broadly conceptualize chronic illness identity across three stages: diagnosis, treatment, and control/recovery. However, to fully investigate illness identity changes, we must include the influence of others in patients’ identity formation. Thus, below I give a brief overview of theoretical work that informs how patients negotiate their illness identity with others.

**Social Support and Illness Identity**

In health contexts, social support is defined as communication designed to elicit comfort by assisting in managing uncertainty and enhancing perceptions of personal control (Albrecht & Adelman, 1987, p. 19). One type of social support, enacted support (or received support), is primarily comprised of 6 dimensions: emotional support (expressions of caring, concern, and empathy); informational support (information and advice); tangible support (offers of goods and services); appraisal support (providing new perspectives on problems) (Goldsmith & Albrecht, 2011); esteem support (reassurances of worth) and network support (relationships/connections to others) (Goldsmith, 2004). This type of support focuses on *how* these messages of support are communicated within conversations (Goldsmith, 2004). Support has also been shown to increase individuals’ adherence to community healthful norms, perceptions of personal control, and intent to comply with healthful behaviors (Goldsmith & Albrecht, 2011).

Throughout patients’ experience with illness, they have been found to both seek and receive support from others depending upon the stage of illness. For example, Arora et al. (2007) found that at diagnosis, breast cancer patients have been found to report helpful informational support from HCPs, emotional support from all supportive others (including HCPs), and helpful decision-making support from family and HCPs. Patients
have been shown to adjust to illness more readily when supportive others show increased empathy, respect and validation for their emotions (Friedman & DiMatteo, 1982). However, patients report receiving less available support and reduced quality of support as their illness progressed. Arora et al. (2007) found that in later stages of illness, patients reported receiving more emotional support from loved ones and more informational support from HCPs, even though the overall quality and amount had decreased.

Social support can be perceived as more effective by recipients when parties share similar social identities (Haslam, Jetten, Postmes, & Haslam, 2009). For example, people have been shown to be more willing to help strangers by giving support if a shared social identity is experienced (Haslam, Jetten, O’Brien, & Jacobs, 2004; Levine, Prosser, Evans, & Reicher, 2005). In the case of traumatic brain injury (TBI), patients’ identity strength was increased through support from others in their social network. Likewise, social identity has been shown to operate as a coping resource in that members of disadvantaged groups tend to help each other through emotional, informational, and tangible resources to “collectively resist” stigma and discrimination (Haslam et al., 2009, p. 13) by rejecting negative stereotypes and reaffirming positive evaluations of themselves, in contexts such as epilepsy (e.g., Jacoby, Snape, & Baker, 2005) and stroke (Shadden & Agan, 2004). Thus, Harwood and Sparks (2003) argue that individuals who strongly identify with a group who is at risk for certain diseases (e.g., cervical cancer, breast cancer) are more likely to engage in preventative health practices, such as pap smears or mammograms.

Support is not always effective or interpreted as genuine, however. For example, in cases of disability, individuals complain of others offering assistance in patronizing ways that are more about making themselves feel better than genuinely caring for another.
(i.e., asking to help with wheelchair) (Braithwaite & Japp, 2005). Likewise, caregivers have been shown to engage in activities that are seen as supportive (e.g., provide transportation to medical appointments); however, their primary intention is to ensure they are involved in the patients’ treatment decision-making and medical care, whether the patient desires their help or not (Krieger et al., in press). Social support efforts are further complicated by ambiguity in illness identity; some patients may view themselves as ill and request social recognition of this status, while others view themselves as healthy and having a medical condition that is viewed as less severe than an illness (Braithwaite & Japp, 2005; Palmer-Wackerly & Krieger, 2014). Finally, it is often difficult for supportive others to know what patients need or want when patients, themselves, may not be sure what support they desire (Palmer-Wackerly & Krieger, 2014).

**Intergroup Approach to Illness Identity**

Social identity has also been shown to affect health behavior, such as more serious evaluations of symptoms, likelihood of taking prescribed medicine, adhering to behavior group norms (e.g., smoking, unprotected sex, receiving vaccinations), participating in an aerobics class, and using contraception (for a review, see Haslam et al., 2009). Likewise, Oyserman, Fryberg, and Yoder (2007) found that African Americans and American Indians responded to out-group (i.e., White) health messages about dieting as non-normative for their groups and had lower intentions to pursue healthy lifestyles and higher expressions of health fatalism.

Social identity has also been shown to be associated with clinical outcomes. For example, HIV developed significantly faster among gay men who were sensitive to
rejection compared to gay men who were not (Cole, Kemeny, & Taylor, 1997). Likewise, social identity continuity has been shown to be important. For example, stroke patients who had multiple memberships in groups pre-stroke were better able to maintain cognitive well-being and life satisfaction post-stroke because of their increased likelihood of maintaining some “valued social identities” (Haslam, Holme, Haslam, Iyer, Jetten & Williams, 2008). Another study found that groups higher in collective self-esteem have less chronic illness (Bailis, Chipperfield, & Helgason, 2008). In an intervention study, Haslam, Haslam, Jetten, Bevins, Ravenscroft, & Tonks, (2010) found that group-based therapy resulted in improved memory performance and group play resulted in less depression and increased quality of life. Group membership participation improves the likelihood of well-being (Haslam, et al., 2009).

**Communication Theory of Identity**

One theoretical lens to view illness and identity is the *communication theory of identity* (CTI) (Hecht, 1993). This theory frames identities as inherently social, but also multiple and shifting, and developing over time (Hecht, et al., 2004). Specifically, CTI explains that 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. Each of these frames is intertwined and co-exists with one another (Hecht et al., 2004). One layer may be more prominent than others depending upon context and individuals; however, all layers are continually fluid and negotiable. Thus, they “interpenetrate” each other (Hecht et al., 2004, p. 268). Because
illness identity is transient in nature, consists of multiple layers (e.g., self, social) and exists across time, CTI is an ideal theoretical framework because of its interdependent and shifting view of identity.

The four layers of CTI overlap and sometimes contradict each other, resulting in “identity gaps” (Hecht et al., 2004; Jung & Hecht, 2004). Eleven identity gaps are possible when considering contradictions between two, three, and four layers. For example, the personal identity layer can conflict with the relational identity layer when someone’s individual identity is different from that individual’s perception of how others view him or her. Likewise, the personal identity layer can conflict with the enacted identity layer if an individual is communicating about oneself in ways that are different from one’s self-concept (Jung & Hecht, 2004; Kam & Hecht, 2009). People may also have within-frame identity gaps, such as two relational identities (e.g., adoptive and birth family identities) that are in conflict with each other (Colaner, Halliwell, & Guignon, 2014). For example, in the case of infertility, people may have a relational identity where others perceive them as being satisfied with not having a child; whereas, other infertile individuals in a support group may recognize that these same individuals are dissatisfied with not having a child. Thus, patients must often juggle multiple identities in relation to their illness while considering their impact on social relationships (Hecht, et al., 2005).

CTI is inherently an intergroup theory of identity, focusing on the social interactions and behaviors of individuals and how these interactions shape our identities. CTI has its roots in two primary theories: (1) social identity theory (SIT) and (2) identity theory (Hecht et al., 2004). SIT posits that identity primarily exists at the group level and is a result of social categories assigned to individuals when they are members of groups.
Groups have been defined as “relational structures with which we engage and which help to define who we are” (Haslam, et al., 2009, p. 2). Individuals’ group identity becomes salient when these individuals interact with others from another group, resulting in stereotypical, normative, and discriminatory communicative practices during intercultural contact (Hogg, Terry, & White, 1995). These categories then inform individuals’ beliefs, attitudes, and behaviors. Thus, individuals’ identity exists primarily at the group level (Hecht et al., 2004), and SIT focuses on the motivation, likelihood, and outcomes of intergroup communication.

In contrast, identity theory (theory focused on ‘self’) explains that identity primarily exists at the individual level though it is influenced by the social level (Hecht et al., 2004). Identity is based upon individuals’ roles within groups, and individuals enact different roles in different groups in response to others. CTI is different from these foundational theories in that identity itself is conceptualized as communication. In other words, identity is created through the process of communication instead of through social structures. For example, when someone is performing a social role (e.g., parent), she is communicating part of her identity through her behaviors (e.g., picking up kids from school, cooking). Likewise, identity is not simply dichotomous, or existing between two dialectical tensions: self and social. Rather it is complicated by other identity forces, such as in relationships, which combines the two ends of the identity continuum (Hecht, 1993). Thus, identity is then constantly negotiated, internalized and redefined in social interactions; thus, it is discursive (Hecht, et al., 2004).
CTI and Illness Identity

Applying CTI to illness identity involves the negotiation process during chronic illness (Hecht & Choi, 2012), resulting in changes in cognitions, emotions, and behaviors that can help people return to a satisfying way of life (Sulik, 2011). These changes occur across all four identity layers: In the personal layer, individuals focus on their perceptions of themselves and their bodies (e.g., Hamilton, Deemer, & Janata, 2003). Frank (1995) identified three illness narratives that patients used to describe their personal illness experiences: restoration (return to health), quest (journey to something new), and chaos (loss of hope). The first two types of narratives promote healing and coping; whereas, the chaos narrative portrays only an overall negative experience. However, illness contexts are different and some patients, such as those receiving an organ transplant, view their health event as a new start instead of the medical crisis that many non-patients do (Kundrat & Nussbaum, 2003). These patients focus on recovery, rather than diagnosis and treatment, and the changes to identity follow a negotiation process similar to Frank (2005). For organ transplant patients, the transplant signifies a new beginning because of a positive rather than negative life change (Blackford & Arrington, 2011).

In the enacted layer, individuals perform identities while interacting with others, and Newton (2001) found that patients with mental illness were able to enact an independent identity while living in communal contexts. The relational layer occurs when individuals disclose their illness with others and negotiate changes in the relationship because of their illness. Edwards, Donovan-Kicken, and Reis (2013) found that HIV-positive parents desired to be open and honest with their children, yet wanted their children to view them as responsible and wanted to maintain a healthy parent-child
relationship and avoid overburdening their children with the parents’ health concerns. Finally, the *communal* layer is activated when individuals consider themselves part of a health or illness community or group (e.g., cancer survivors, people with disabilities) (Harwood & Sparks, 2003). Illness identity has also been shown to be strengthened by in-group others who share similar experiences, resulting in collective identities that lead to social movements to improve the illness experience (e.g., Sulik, 2011). Such improvements have included informed decision-making, closer relationships with health care providers, and increased access to health information (Sulik, 2011). Thus, CTI is an ideal theoretical framework to analyze illness identity because of its focus on: (1) multiple, shifting layers—through the self, roles, relationships, and groups—across time and (2) the *communication* of identity instead of solely the existence of identity.

**Health Identity versus Illness Identity**

The term illness identity calls into question the definition of health identity. Health identity has been defined as the absence of illness, which is understood as “normalcy” (Defenbaugh, 2013). This definition implies a social and moral aspect to health, meaning that to have an illness is to not be in good health (Hayden, 1993). This term has been used in juxtaposition to illness identity. However, just because an individual has an illness, does not mean that that he or she views himself or herself as unhealthy, especially when considering identity transformations that occur during chronic illness. In other words, a medical diagnosis may not be an individual’s only evaluation of health (Penrod, Gueldner, & Poon, 2003; Roberto & McCann, 2011). These constructions of health identity also change as an individual ages when limitations are increasingly placed on the body in comparison with what individuals used to be able to do. For
example, Roberto and McCann (2011) found that older women with chronic health conditions used perceptions of everyday health and their ability function in their regular activities to evaluate their health identity. These studies found that how people interpret their bodies and their bodily experiences (i.e., embodiment) directly relates to how they conceptualize their health identity (Roberto & McCann, 2011).

This question of health identity versus illness identity is important when studying chronic illness. People with chronic illness must learn to adapt to their illness because it is most likely a permanent condition (e.g., diabetes, alcoholism, heart disease) (Hayden, 1993); thus the chronic illness context requires patients to incorporate elements of their medical condition into their overall identity if they are to manage their disease and relationships effectively. Charmaz (2006) found that people adapted to chronic illness more easily if they were (1) still able to maintain their regularly expected activities and (2) felt they were responsible for the illness (e.g., exercise to prevent health disease). Thus, the more disruptive to their lives an illness or limitation became, the more central that ‘health’ became to individuals’ personal identities (Roberto & McCann, 2011). This salience leads individuals with chronic illness to redefine themselves in order to accept their changed personal and social reality, which often involves a loss of some kind (Hayden, 1993).

The tension between health and illness identity is an important factor in how patients compare their ‘sick’ identity to others’ ‘healthy’ identity. For example, Krieger et al. (in press) found that caregivers who primarily viewed cancer as existing in the personal identity of the patient rather than the relational frame of the family, were less likely to offer support and advice to the patient because they believed that the patients
were responsible for decisions related to their bodies. Likewise, in the disability context, people often struggle how to present themselves to others in order to get the support they require; they are caught between proving they can do and they cannot do (Braithwaite & Japp, 2005). This presents a conflict between all layers. In the personal layer, people have a battle with themselves on how to define the ‘self’. In the enacted layer, people struggle in their performance of their illness or lack of illness. In the relational role, it is difficult to communicate to others what their needs are. And, in the communal role, they struggle to achieve social legitimacy for their identity, further contributing to confusion and uncertainty. For example, someone with an invisible handicap (e.g., chronic autoimmune disease) might not receive social acceptance for parking in a handicap spot though they do in fact need it (Braithwaite & Japp, 2005).

Because health and illness are also social identities, they are also influenced by other group memberships. For example, men and women are given different social scripts when it comes to dealing with chronic illness. Men may grieve more readily with anger and fear; however, because of more limited social networks, they may be much more at risk for depression than women. One personality trait that determines whether men will fall into a negative or positive self-identity is their evaluation of their future. Charmaz (1994) found that for men, a future identity must be active in some way, or the propensity for depression increased. Men worried about disclosing illness for how it affects their social identity at work (e.g., perceptions of inability and weakness), which led them to hide when they had to receive medical treatments, such as dialysis. When their illness had to be disclosed, men perceived others as pitying them or accusing them of receiving privileges.
In relation to identity transformation, Charmaz (1994) also found that initially, some men labeled their chronic illness as “an enemy” in order to separate themselves from the illness; however, it wasn’t until they saw the illness as “an ally” that they were able to transition into maintaining a consistent self-concept throughout their past, present, and future. In contrast, women have been shown to receive high levels of emotional support for chronic disease management even when they do not desire it. Further, women who accepted their changed identity as a result of their chronic illness were able to cope with the changes better than those who could not accept their new limitations (Roberto, Gigliotti, & Husser, 2005).

Other Illness Identity Influences and Gaps

In social interactions, people with chronic illness have reported limitations in others’ understanding of their perspective. Chronically ill patients are frustrated in conversations with others; however, they understand that people cannot always empathize unless they have lived through the experience themselves (Hayden, 1993). For example, infertile patients have described conversations in which others have not recognized the severity of the illness and life crisis that occurs with infertility with the inability to carry a biological child to term (Palmer-Wackerly & Krieger, 2014). In this study, patients reported that others often viewed infertility as a medical condition that was not as important as life-threatening illnesses, such as cancer or HIV. Thus, the social and cultural beliefs about an illness play into individuals’ re-conception of their identities and how they communicate these identities at all levels (i.e., personal, enacted, relational, and communal) through norms, language, cultural beliefs, and stigma.
Norms

Injunctive norms are prescriptions for what people should do with positive value-laden, moralistic language that dictates what is appropriate or expected for a situation. A certain type of injunctive norm, subjective norm, is a perceived belief about appropriate behaviors for situations according to the people closest to an individual and the individual’s motivation to comply with these behaviors (Rhodes & Ewoldsen, 2009). In contrast, descriptive norms are what people actually do—what is typical of a group that dictates what is appropriate for a situation (Kallgren, Reno, & Cialdini, 2000). These norms have powerful implications for identity and support during illness. For example, the more people positively and highly identify with their in-group, the more they should be motivated to comply with the norms of that group (Christensen et al., 2004). For example, men feel particularly threatened in relation to disease that affects their perceptions of productivity, sexual performance, domination, and independence (Charmaz, 1994). Many men believe they must remain tough, independent and stay active. Highly-identifying men, even when they know they are at risk for certain diseases (e.g., prostate cancer) may be less likely to prevent, seek or receive treatment and support for illness for fear of being perceived as weak (Harwood & Sparks, 2003). Thus, men are limited by their perceptions of what society views as ‘credible behavior’ (i.e., social legitimacy) when they are confronted with illness.

In decision-making, research suggests that people will evaluate and follow injunctive norms to the extent that they serve as reminders/regulations for who the person would like to be or become (Williams & Gilovich, 2008) and the social costs/rewards of certain behaviors (Rhodes et al., 2014). Focus theory of normative conducts states that
whichever norm is most salient to the individual (i.e., descriptive vs. injunctive), that norm will determine behavior (Cialdini & Goldstein, 2004). These health risk behaviors, if accompanied by strong norms and attitudes, may be hard to change because the attitudes and norms are developed early in individuals’ development (Rhodes et al., 2014). These findings, within the illness and treatment decision-making context, mean that the more accessible the norms of individuals’ individual and social identities (e.g., cultural, ethnic, illness, religious), the more likely the individual is to comply with the group’s norms for treatment options, treatment adherence and continuity, and recovery/resolution options (e.g., self-help support group, counseling, adoption, hospice).

**Language**

To give effective support, people with illness and people without that illness must share a common language with a common understanding (Bowker, 1996). Shared metaphors have been shown to both close and reinforce this language gap between conversational partners (Lakoff & Johnson, 1980). For example, health care providers use metaphors to increase patients’ understanding of complex medical treatments and diagnoses (Arroliga, Newman, Longworth, & Stoller). Likewise, infertile individuals have used metaphors (e.g., job, journey, dance) to disclose their infertility to others by strategically choosing metaphors that represent shared cultural experiences (Palmer-Wackerly & Krieger, 2014). However, a common language is not enough to achieve effective support; common understanding is just as important. For example, Bowker (1996) described others’ tendency to frame cancer as a battle when discussing her cancer experiences with her. She, however, did not like the term battle as it meant to her that cancer would be relentless and never-ending. Another study showed that patients in rural
cultural groups interpret metaphors differently in relation to cancer treatment risk, which may affect treatment decision-making, such as enrolling in a clinical trial (Krieger, Parrott, & Nussbaum, 2011).

**Cultural Beliefs**

Culture has been defined in more than 300 ways; however, seven commonalities have emerged (see Hecht, Jackson, & Pitts, 2005): structure/pattern (i.e., system of ideas, behavior, etc.); function (i.e., tool to accomplish tasks); process (i.e., social negotiation); product (i.e., artifacts); refinement (i.e., focused on evolving over time for a higher purpose); power/ideology (i.e., group power); and group membership (i.e., belonging to a place or group). Culture shapes how we perceive ourselves and how we see others. An intergroup perspective on culture and communication involves moving away from fixed categories (e.g., gender, race, ethnicity) to examining how communication creates and maintains membership in communities (Hecht et al., 2005). Culture can influence health on all levels, beginning with initial understanding and framing of illness. Depending on patients’ cultural group members, patients explain illness through explanatory models (EMs) consisting of different causes, symptoms, treatments, and effects (Shaw et al., 2012). EMs can influence treatment decision-making through understanding of risk and treatment adherence (Lee & Vang, 2010). Likewise cultural members extend support differently if a member of a communal culture (where focus is on maintaining group stability) or individual culture (where focus is on maintaining individual stability) (Mortenson, Liu, Burleson, & Liu, 2006).
Stigma

Stigma has been defined as “an attribute that is deeply discrediting” (Goffman, 1963, p. 3) with individuals being perceived as “tainted” and “discounted” (p. 3). Stigma can be applied by others, but also by the self (Defenbaugh, 2013). All illness can be viewed as stigmatizing, especially terminal illness (Harwood & Sparks, 2003); however, some may be more so than others. Individuals who struggle with highly stigmatizing diagnoses (e.g., mental illness, HIV, infertility) strategically interact with others about their illness when facing larger structural or cultural forces. These strategies include distancing (i.e., separating oneself from his or her illness), rejecting (i.e., failure to relate the meanings of the illness to oneself while also acknowledging the illness meanings for others), and normalizing (i.e., challenging the meanings of an illness) (Schneider, 2003). People with stigmatizing illnesses, often feel that they are being blamed for their illness. For example, others often blame patients with lung cancer for smoking and that their disease is a worthy punishment of an unhealthy choice. Likewise, patients with HIV also perceive others as blaming them for unhealthy choices, such as having unprotected sex or sharing needles. Thus, stigma extends through all layers of identity.

Contextual Age

Contextual age has been defined as individuals’ perception of “place within the life span . . . a transactional view of aging that incorporates physiological, psychological, social, and communication influences on life-position” (Rubin & Rubin, 1986, p. 30). Contextual age does not necessarily reflect one’s chronological age; thus, people diagnosed with the same illness (e.g., heart disease) are able to experience similar contextual ages even with different chronological ages because of common health
concerns (Kundrat & Nussbaum, 2003). Interestingly, contextual age was shown to remain stable across all ages in that they viewed themselves as older, possibly suggesting a maturity level that originates with the diagnosis and remains throughout the individuals’ illness experience. This same study showed that after patients disclosed their hidden illness, supportive others viewed invisibly ill patients as older in contextual age possibly because of a difference in patients’ perceived roles and abilities (Kundrat & Nussbaum, 2003).

Combined, the above influences contribute to patients’ illness identity both personally and socially. What is missing from the literature, however, are theoretical models that explain how patients’ illness identity and well-being are affected by the social support from both HCPs and the supportive network. Based on the above research and my work in this area, I propose the following theoretical model to examine illness identity change, supportive communication, and patient well-being: The Communication of Chronic Illness Identity Support (CCIIS).

**The Communication of Chronic Illness Identity Support (CCIIS)**

In their proposed conceptual framework about patient-centered communication and positive health outcomes *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*, Epstein and Street (2007) point out that one challenge in achieving patient-centered communication is that physicians often have difficulty gaining patients’ perspectives on their illness, treatments and thus often incorrectly evaluate patients’ needs. I propose that becoming aware of patients’ locus of illness identity (e.g., personal, relational, communal frame) will allow them to better understand patients’ needs and goals.
The purpose of the current theoretical model is to explain how patients’ illness identity relates to overall well-being through social support (see Figure 1). The model helps answer questions about the combined influence of HCPs and members of a patient’s social network to better explain why and how social support is effective and ineffective. This model takes into account illness identity from an intergroup perspective: ‘self’ versus ‘other’ and ways in which social support can highlight similarities and differences between patients and their supportive others. Based on previous research, three primary assumptions related to this model include:

(1) *Patients’ illness identity is constantly changing throughout the illness trajectory.*

(2) *Patients continually develop and communicate their identity by reflecting on the ‘self’ and ‘others’.*

(3) *From diagnosis to resolution/recovery, patients experience identity gaps to which they look to others for help in resolving.*

As a result of these assumptions, I propose that:

(1) *Patients choose supportive others based upon who can best help them with their particular identity conflict(s). This strategic choice depends upon (a) how they define their illness identity; and (b) who is available and willing to help.*

(2) *Patients will rate the support of others as effective to the extent that the support aligns with patients’ overall sense of who they are or want to be (i.e., identity-related goals: personal, enacted, relational, communal).*
(3) Patients’ well-being will be dependent upon the extent that they can re-negotiate an illness identity that is consistent with their overall sense of who they are and want to be (personally and socially). This re-negotiation depends upon how they and others define their illness (language, cultural beliefs, norms, age, stigma).

In the following sections, I give examples from my research about cancer decision-making, which includes the consideration of a clinical trial, to further explain how illness identity conflict is both resolved and reinforced through social support efforts. Examples of how to test the above propositions is also included.

**Patient Illness Identity**

Most, if not all, patients will experience some type of personal identity gap when diagnosed with a chronic illness (Jung & Hecht, 2004). These gaps, include but are not limited to, personal-personal (e.g., healthy vs. ill); personal-relational (e.g., individual cancer experience vs. relational cancer experience); and personal-communal (e.g., individual experience of cancer vs. the experience of other cancer patients) (Harwood & Sparks, 2003). As patients move to the treatment phase, they look to treatments that will resolve these conflicts; thus, they consider which treatments will most satisfy their identity goals (e.g., to restore health, to prolong survival) (Krieger, 2014). For example, if a patient’s goal is to ‘get through cancer as quickly as possible’ (e.g., personal identity), then he or she will try to pursue an aggressive treatment to eradicate cancer from their bodies without doing anything ‘extra’, that ‘they don’t have to do’. If a patient’s identity goal is to try and help find a cure for their disease (e.g., personal and communal identity), then he or she may be more likely to enroll in a cancer clinical trial, which is more
focused on helping others while also possibly helping themselves through improved treatment. Further, patients consider their past identity in relation to their present and future identities when considering treatments (Charmaz, 2004). If a patient’s illness conflicts with his or her abilities or hobbies (e.g., fitness), then he or she will most likely choose a treatment that aligns with their fitness identity. This is the first step in patient empowerment: seeking to create a cohesive narrative about their illness and who they are to themselves and others through “health stories” (Epstein & Street, 2007, p. 5). Patients are constructing and re-constructing their illness identities as they process its effect of loss on themselves and their relationships (Charmaz, 1995; Harwood & Sparks, 2003).

Thus, to improve patients’ well-being, patients’ identity goals must also be met in communication with others. Social support from others is one way which patients seek to meet these goals. Thus, if patients primarily identify their cancer as a personal illness, they will seek support to cope with their personal identity (e.g., as it relates to their bodies; disease symptoms and treatment side effects). Social support attempts will be effective if they align with patients’ identity goals. Conversely, social support attempts will be ineffective if they conflict with patients’ identity goals. Further, whoever communicates effective identity support (i.e., HCPs, family, and/or friends) will be who the patient primarily relies on to achieve well-being (re-alignment of identity). If all sources communicate effective identity support, then patients will presumably rely on all sources. The following sections explain patients’ identity and how it may be affected (resolved, re-enforced) by the social support from both HCPs and family members.
HCP Support and Illness Identity

An individual can have an illness (particularly a chronic illness) and still view himself or herself as healthy (e.g., Palmer-Wackerly & Krieger, 2014). This perspective can be in direct contradiction to the perspective of the physician, whose job it is to focus on eradicating or at least treating that illness (Epstein & Street, 2007). However, physicians sometimes communicate to patients that they are ‘healthy’ even when they are ‘ill’, particularly when they perform diagnostic tests to evaluate if patients are suitable candidates for clinical trials. Thus, HCPs communicate illness identities to patients depending upon HCP goals for treatment (e.g., enrollment in CT, medication adherence). As a result, these messages of support affect patients’ illness identity and decisions associated with their illness (i.e., coping and treatment) (Street, 2013).

Social Network Support and Illness Identity

Families have also been shown to influence individuals’ identity (Soliz & Rittenour, 2012). Illnesses, such as cancer, are now considered relational illnesses, meaning that profoundly impact the patient’s family and friends as well (National Cancer Institute, 2014). Patients often discuss aspects of their illness with their loved ones, including their treatment options and concerns about lifestyle changes (Miller & Caughlin, 2013; Siminoff, 2013). However, patients and family members may have different models for social support and may experience conflict over treatment decisions. Kreiger et al. (in press) found that caregivers of cancer patients sometimes view their support role differently than patients. For example, caregivers believed their support role for CT decision-making was dependent upon where the locus of illness was. If caregivers believed cancer was a relational illness, then they offered decisional support; if they
believed it was a personal illness, then they did not offer support, believing instead that it was the patient’s responsibility to make the decision. Thus support is not always available to patients when they desire it and conversely may not want support when others want to give it.

Identity Conflict Resolution and Reinforcement

Based on data from the DECIDE project (Krieger, 2014; Palmer-Wackerly et al., 2014), below are examples that show how patients’ communication with HCPs and family members can result in identity resolution (i.e., identity frame realignment (i.e., incorporation of illness into their overall identity); and identity conflict (i.e., inability to incorporate their illness into their overall identity). Those patients who received identity congruent messages (i.e., messages that were directed to their locus of illness identity) succeeded in realigning their illness identity with their overall identity (overall well-being). Those patients who did not receive identity congruent messages (messages that were directed to a different frame than their locus of illness identity) had their identity conflict(s) reinforced (overall well-being). The examples below illustrate both identity resolution and identity conflict reinforced in two types of identity conflicts: personal-personal and personal-relational.

Illness Identity Resolution

Illness identity resolution can occur in and between any or all identity frame(s). The following examples include a personal-personal identity conflict (i.e., Vickie) and a personal-relational identity conflict (i.e., Joe). Both were resolved when supportive others helped them realign their identity frames.
Personal-Personal identity realigned. Patients who frame their illness as part of their personal identity view their illness as how it affects their bodies, their personal health, or themselves as individuals (e.g., hobbies, etc.). Data from the DECIDE project showed that a common personal-personal identity conflict was health versus illness. One participant, Vickie, 78, had brain and lung cancer and enrolled in a clinical trial that had the chance to reduce the side effects of radiation to her brain. She said she knew her cancer was serious because it was labeled as Stage 4 and in multiple sites. However, she said when her oncologist talked to her about enrolling in a CT, her oncologist defined her as otherwise ‘healthy’. She said laughing, “I was a great candidate,” they said, because of my health. I said, “How can I be so healthy, and have this?” But that's it. My health was good.” For Vickie, her oncologist affected how she saw herself with cancer. Even though she had stage 4 cancer, she believed her doctors when they said she was in ‘good’ health. Vickie defined her health as primarily existing within her personal identity—how it related to her body—and her oncologist helped resolve that conflict that she was strong otherwise, giving her hope that she could survive this cancer. Her oncologist also explained that the CT could potentially lessen the harmful side effects of radiation (e.g., loss of hair and burning) by only treating part of the brain (instead of the entire brain as in standard treatment). Because she was very concerned about the effect of cancer in and to her body, this CT offer and informational and appraisal support by the oncologist aligned with her personal illness identity concerns and goals. She later enrolled in the CT.

Locating her illness in the personal frame of identity also had implications for who she relied on when seeking social support. She said her oncologist primarily influenced her treatment decisions, and as a result, she only informed (instead of
consulted with) her family about her decision to enroll in a CT. For example, one of her children wanted her to seek a second opinion for care in a city 3 hours away near his home where she could live during treatment; however, she believed that she was receiving quality medical care close to home that met her identity needs (focus on personal health concerns). Thus, she elected to rely primarily on the advice of her health care team who could best help her resolve her identity conflict (i.e., personal) and tangentially include her family in her illness experience.

**Personal-Relational identity realigned.** In contrast to the above example, patients who frame their illness as personal and relational primarily consider their illness identities as they relate to their bodies as well as to others close to them. A common example from the DECIDE data is a patient who identifies as a parent (e.g., mother, father) to his/her specific children. This patient may consider an identity goal for treatment as one that focuses on maintaining these family roles or relationships. For example, Joe, 65, said he wanted to undergo a cancer clinical trial because he wanted to ensure that one of his grandkids did not get prostate cancer in the future. He considered his illness identity goals to be relational more so than personal; however, both goals were involved in his treatment considerations: He wanted to heal himself because he loved his family.

What I’m saying is if one of the grandkids would have, would get cancer and it take my life to – They could treat them and give them my – Because right now if somebody walk, walk into right, right here with us and say, “[Patient], tell you what, what’s gotta happen, and that’s – It has to be this way. You gotta give your life right now or we’re gonna go take
one of the nine- or seven-year-old’s life. We have to do that.” I’d say, “Hey, take me back there and give me the shot or shoot me, whatever you need to do.” Because they come before me. My wife comes before me.

When Joe was diagnosed with cancer, he wanted to forgo treatment because he feared cancer, medical treatment, and the uncertainty of his survival; however, once his wife, his children, and grandchildren talked at length about his options, they convinced him that enrolling in a CT would be his best treatment option. They mentioned that a primary benefit would be that he was watched more closely by a team of doctors, and Joe said he wanted to do whatever would keep him living the longest with his family.

Because [the HCPs] would be a-watchin’ me longer, and then my opinion after [my family] said that, I said, “Yeah.” And mine was, reason was, wasn’t necessarily for me, but it was for them, the grandkids, and anybody else that, that would make a difference on, that’s fine. But you know, uh, first option was my immediate family, you know. And then second option was if it helped some other kid or an adult – ‘Cause we’re doing it for my family, but that don’t mean, well, don’t use it on nobody else.

To him, his illness belonged equally to all of his family members; it was in his body, but it was also within his family because he valued how much they wanted him to get the most aggressive treatment to live the longest he could with them.

His locus of identity also affected his source of support for his treatment decision. Because he identified with cancer in both the personal and relational identity frames, he relied on both his family and his oncologist when making his treatment decisions. At first he thought he would be a “guinea pig” with a CT that would look at treating the entire
prostate versus part of the prostate with radiation, but after he received information from this oncologist and CT nurse, he said, “The more they explained it, you’re like, “Okay. I’m – I could do that.” After multiple conversations with his family and CT nurse, he concluded that the CT would give him the most aggressive treatment for his cancer while having his body more closely monitored (i.e., personal identity), keep him longer with his family (i.e., relational identity), and also help inform future cancer treatment (i.e., communal identity). The communal identity goal was an added benefit, as he made clear in his statement above, but because it did not conflict with his personal and relational identity goals for treatment, it became part of his illness identity resolution as a cancer patient.

The above examples illustrate when support was effective from HCPs and family when it aligned with how patients defined their illness identity. Below are examples that illustrate when HCPs and families defined illness identity differently from patients, and patients’ identity conflict was reinforced, resulting in patients’ negative well-being.

**Illness Identity Conflict Reinforced**

**Personal-Personal identity conflict.** Some patients experienced more identity conflict when they received social support from HCPs and family. This was as a result of their identity needs not being met through a misalignment of identity support messages. For example, Terri, 52, was diagnosed with ovarian cancer and like most new cancer patients, was shocked when she heard her diagnosis. Terri had not been to a doctor in 40 years and only sought medical care after she experienced extreme swelling in her stomach, which resulted in blocked intestines. When she was diagnosed, she was fearful of treatment because when she was 14 years old, she witnessed her mother’s breast
cancer treatment and later death: “I'd seen that she got sick and everything and I was kind of terrified and worried about it because that's the only thing I had to go by was what my mom went through”. She ultimately agreed to surgery because she wanted to “get it over with”; however, she was concerned about getting a scar and losing her hair: “I just told them to take it, get it out. The only thing I told them, asked them [was] how they were going to cut me? They said, ‘From here down.’ And I said, ‘Well don't cut my belly button’, and they didn't, they went down around it.” Terri located her illness primarily in the personal frame—as it related to her body, and as a result experienced a personal-personal identity conflict (health vs. illness). She knew she had cancer, but she wanted to remove it from her body as quickly as possible with minimal damage to her body. Even when she reflected on her mother’s experience (relational experience of cancer), it was in relation to how it would affect her personal treatment experience.

When it came to social support during her experience, she relied mostly on her boyfriend, and her best friend, who had recently survived breast cancer. She said both sources gave her much-needed emotional support; they listened and expressed that they loved her and didn’t want anything to happen to her and would “stand by” her through it all, which helped her cope with her diagnosis. For the treatment decision stage, when it came to deciding on a CT, she declined it, saying no one influenced her but herself. Based on DECIde data and the propositions of the current paper, Terri located her illness primarily in her personal frame; thus, she would be expected to primarily seek support from her HCP when making her decision. However, the support from her HCP was ineffective because she said, the medical team “didn’t really pressure though they pushed
me” to enroll in the CT. She offered a suggestion for HCPs to offer more effective support:

They should try not to be so overwhelming. I mean it was like vultures on a dead body. It's just that was the main thing was too much, too fast. I mean I suppose if somebody was at the hospital every three months getting a surgery or having something done it wouldn't be too much for them but for me not having gone through anything in the past 45 years.

You're lucky I even saw a doctor; well I'm lucky I even saw a doctor.

She said she was not sure what she should do in terms of treatment so she turned to her best friend and boyfriend for advice though she said they were also unsure of the best option, so she relied only on herself to make the decision. Thus, Terri is an example of someone who desired support from her HCPs, having located her illness primarily in the personal frame; however, instead of giving her effective support, she felt the HCPs were not taking into account that she needed help processing the information in relation to her illness. Instead, she said they gave her “all kinds of literature”:

I didn't read it because I didn't want to know. Like the statistics on it, I didn't want to know how many people survived. I just wanted to know I'm going to survive. I mean not that I don't care about people, you know what I mean?”

As a result, she rated the HCP support as ineffective in helping her cope with her illness during the treatment-decision phase. They were helping her see how her illness related to other cancer patients (communal identity) through the offer of a CT and information related to her cancer (survival rates); however, she could not move past the personal
identity phase and needed to understand how cancer was going to personally affect her body and well-being. She described the informational support she received below regarding the CT:

[The nurse] explained things pretty thoroughly, but like I said it was overwhelming, and I was still trying to get it sunk in that I even had cancer, you know, so I kind of half listened, I was half listening to everybody, just kind of leave me alone with my thoughts, you know.

Terri said that her HCPs gave informational support through discussions and literature; however, the information did not meet her identity needs (personal identity: how the treatment would resolve her healthy vs. ill personal conflict). If it had, she might have rated the support as effective and possibly enrolled in the CT. Thus, it was not the case that she experienced a lack of support; on the contrary she admits to receiving plentiful support. However, the support she received was ineffective because it did not align with her illness identity needs.

**Personal-Relational identity conflict.** Support can sometimes become more complicated when the illness is shared within the relational frame with family members (Krieger et al., in press), and the family members understand the illness differently. This personal-relational identity conflict can have profound implications for a patient’s well-being and ability to incorporate his illness into his overall identity. For example, Jude, an army veteran, said he and his family viewed his CT option differently in relation to his cancer prognosis. His family viewed the CT as curing his multiple myeloma while he knew, at best, the CT would prolong his life by perhaps a decade:
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. And I need to—it’s frustrating to me to hear all this going on and know that we’re not going to get cured and I wish they would see the reality of the situation that we’re not going to be cured and that we are going to die in 5 to 10 years. 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.

Jude locates his cancer in some of the above sentences with his family (e.g., “we’re not going to get cured”); however, when talking about the conflict in illness perceptions, he reverts back to his personal identity (e.g., “me having terminal cancer”). He relates these relational identity concerns to his well-being when he said that “it would make things easier on me”. Jude said this personal-relational identity conflict is preventing him from preparing for his family’s future, something that he said would really help him cope with his disease (i.e. by allowing him to maintain his relational identity of providing for his family even after his death):

If they just—because we wouldn’t be living this fairytale Disney dream of that we’re going to be cured when I know we’re not. My wife gets upset at me because I always talk about dying. She says, ‘Do you want to die?’ No, I don’t want to die, but it’s a fact that we have cancer, and it’s a fact that the type of cancer that we have there’s no cure for and it’s something that we need to—I ain’t saying we need to be down and out about it, but
you need to discuss it and need to make plans beyond my departure from this planet.

In the above sections, he views his cancer to be both part of his personal and relational identity, and because they are remaining in conflict instead of approaching resolution, this identity conflict is preventing him from effectively coping with the changes to his body and his relationships.

Because he locates his cancer in both the personal and illness identity frames, he seeks support from both his HCPs and his family (i.e., wife, mother, and sister) in coping with cancer and making treatment decisions. Because his family is producing more identity conflict in their support efforts regarding the CT, Jude said his oncologist was most influential in his decision about enrolling in the CT. In contrast to his family, his oncologist gave him a realistic prognosis (i.e., personal identity) but also connected his illness to a communal identity with other cancer patients.

He laid [out] our ‘if I was to participate in this trial what it would lead to’, and he’s like, I didn’t have to participate—I can drop out anytime—but he basically told me what this would produce and basically gave us a reason to stick to it and move forward… to help him help others. … I felt that since I got this disease I might as well try to use whatever I can to help whoever’s researching for a cure to find a cure.

This new communal identity, although not initially where he located his illness, aligned with his “service mentality” from the army and allowed him to focus his efforts on helping others with cancer. Thus, he was able to maintain a part of his identity: Although he retired from the army because of his cancer, he could still serve others as a cancer CT
patient. Thus, Jude experienced effective support (i.e., identity resolution) from his HCP in terms of personal-communal identity (i.e., receiving the best treatment available to him and advice that helped him cope with it); however, he had not received effective support from his family (i.e., they have different goals for his treatment than he does) and continued to experience personal-relational identity conflict.

**Proposed Test of this Model**

The model described in this paper is designed to represent the illness trajectory from diagnosis (initial identity conflict: patient’s illness identity vs. a patient’s overall identity) through resolution (well-being: effective incorporation of illness identity into overall identity). To test the current model; however, it is first necessary to measure illness identity within each phase (e.g., diagnosis, treatment, resolution). Thus, for cancer patients, I propose testing at multiple time points over a 5-year period, which is the period a cancer patient may be considered in partial or complete remission if cancer is controlled or has disappeared (NCI, 2015). To establish a baseline measure for identity conflict, patients will complete adapted and shortened scales from established measures (see Appendix A, B, C) (Jung & Hecht, 2004; Kam & Hecht, 2009) at diagnosis or shortly after diagnosis. Scales not in existence will be created (e.g., personal-communal identity conflict) based on already existing scales (e.g., personal-relational identity conflict). Treatment length can vary the first year after diagnosis (i.e., 3 months to a year); thus, I propose measuring the change in illness identity conflict every three months the first year (i.e., 3 more times after initial baseline measure). After the first year, patients’ identity conflict will be measured twice a year (i.e., every six months). Thus, patients will complete identity conflict measures for a total of 12 time points.
Once patients’ initial identity conflicts are established, patients will be made aware of these identity conflicts and an intervention will help them seek support messages from the sources best able to help them realign their identity (e.g., personal identity with HCPs; relational identity with family members; communal identity with support groups). HCPs, family members, and support group members will also be informed about patients’ identity conflict status and will be trained to help give effective support to resolving patients’ identity conflicts (e.g., aligning their messages with patients’ identity goals).

Social support effectiveness should be measured by asking patients who were the most helpful sources in patients’ adjustment to cancer (e.g., HCPs, family, friends, support group). Measures for support effectiveness in alleviating cancer-related discomfort will be adapted from definitions of enacted support (Goldsmith, 2004) that has been tested in another study (author, under review) (see Appendix D). Finally well-being will be measured through the well-established Functional Assessment of Cancer Therapy-General (FACT-G) scale (Brucker, Yost, Cashy, Webster, & Cella, 2005). The scale, now in its fourth version, is comprised of four subscales: Physical well-being, social/family well-being, emotional well-being, and functional well-being.

**Conclusion**

The current theoretical model, *The Communication of Chronic Illness Identity Support (CCIIS)*, advances work in illness identity and social support between patients, HCPs, and supportive others. This model helps to answer some of the questions by scholars who have called for more work in the creation/maintenance of illness identity (Hecht et al., 2004); the effects of social support and health outcomes (Goldsmith &
Albrecht, 2011); and the influence of family members in conversations with patients and HCPs (Krieger, 2014; Street, 2013). In integrating these components, I attempt to explain how and why patients seek support from HCPs and social network members; and how and when support sources are effective in their communication with patients.

Support Source Choice

This theoretical model predicts that patients’ illness identity frame directly influences from whom they seek assistance. If patients primarily have personal identity concerns, then they may seek support from both HCPs and family, but will rely primarily on HCPs, who can give them information related to how treatments affect their bodies. Patients may still talk to loved ones for support, but are more likely to use loved ones to reinforce their understanding of their illness and treatments as discussed with the doctor. If however, patients have relational identity concerns, they will primarily look to those relationships (e.g., family) for support, and those relationships will have the most influence on their illness outlook and decisions. If they have both personal and relational identity concerns, they will look to both sources for help.

Support Effectiveness

It is well-established that social support is not always given when it is desired, resulting in support gaps for patients (Goldsmith & Albrecht, 2011; High & Steuber, 2014). However, support is sometimes given and patients still view it as unhelpful or inappropriate, and thus ineffective in eliciting comfort or assistance (Goldsmith & Albrecht, 2011). This result can occur when patients’ autonomy is not recognized (Palmer-Wackerly & Krieger, 2014) or when patients receive unwanted advice (e.g., Feng & MacGeorge, 2006). This paper suggests another underlying mechanism to the
evaluation of ineffective support: when the support fails to align with and produce resolution to patients’ illness identity conflict(s).

This model predicts that patient well-being results when patients’ identity frames (e.g., personal, relational) are aligned with one another. In other words, illness identity is incorporated into the patient’s overall identity. If one or more of patients’ identity frames are in conflict with one another, then patients experience lower well-being and illness identity is not part of patients’ overall identity. For example, if patients consider the illness to be personal, they are more likely to rate social support efforts as effective if the messages relate to their personal identity and help to resolve it. Conversely, if support providers offer support (e.g., communal identity-related support) that does not meet patients’ identity needs (e.g., personal), then the support is unlikely to be effective (i.e., comforting and helpful to the patient).

This model has wider implications for supportive communication and illness identity beyond cancer. With our longer lifespans, chronic illness is becoming increasingly more common and the well-being of patients will become even more important as we live longer lives with chronic illness. Future health interventions should continue to examine illness identity as a key factor that relates to how individuals approach their disease and management techniques.

**Future Directions**

Two particular areas of illness identity and social support theoretical development that are ripe for more attention and research within health and intergroup communication are: (1) invisible illness, and (2) health disparities.
**Invisible illness.** Kundrat and Nussbaum (2003) argue that the term illness identity (and illness identity formation) is more complicated in health contexts where illness is invisible, meaning when the disease or disability is not readily apparent to others. These diagnoses create challenges for invisible illness patients because the conditions and treatments may be complex, and HCPs may not fully understand the causes for the condition, such as infertility (Domar & Kelly, 2002) and chronic fatigue syndrome (Edwards, Thompson, & Blair, 2007). This lack of understanding of diagnosis may prolong uncertainty during disease management (Edwards, Thompson, & Blair, 2007) as well as influence self-efficacy in managing disease symptoms (Farrell et al., 2004). To supportive others and HCPs, hidden illnesses may also not be seen as real (i.e., legitimate) or severe as visible illnesses (Edwards, Thompson, & Blair, 2007). Thus, patients may struggle with communicating their needs to others and finding the appropriate social support resources to cope with their illness (Palmer-Wackerly & Krieger, 2014).

Even when supportive others are not aware of or fully recognize the severity of individuals’ illnesses, patients with invisible illness can still experience social identity changes. For example, Onken and Slaten (2000) define illness identity in the context of perceived stigma and shame for mental health patients as “identifiable states of transformation” similar to the changes in other identity constructs, such as race, ethnicity, and sexual orientation” (p. 104). Because illness is fluid and ongoing, the authors argue that patients must repeatedly redefine themselves in a process of a positive illness identity development. People with invisible illness are torn between accepting parts of their illness and eschewing others (Braithwaite & Japp, 2005). Just as a training program helps
people with disabilities, especially sudden onset disabilities, adjust to their new lifestyle and identities (Braithwaite & Braithwaite, 2003), a training program designed to help people with their illness identity would also help them adjust to treatment and their changing identities. This may be especially beneficial for contexts, such as infertility, where privacy and stigma are involved, and as a result, social support availability is perhaps more limited than in other disease contexts without stigma (e.g., breast cancer).

Other implications involve patients with invisible illness who sometimes want to be treated like their able-bodied peers (i.e., seen as capable, responsible, and independent) and other times receive accommodations that allow for difference in body ability (e.g., parking options, flexible work hours) (Braithwaite & Japp, 2005). This second part becomes more difficult because the illness cannot be verified by (i.e., seen as legitimate) by others. Thus, there are cultural norms and rules around relational responses to illness and we need to understand these in order to improve relationship and support processes during illness (Lyons, Sullivan, Ritvo, 1995).

**Health disparities.** Research to reduce health disparities, which is defined as social health disadvantages that are preventable, has mostly focused on race/ethnicity or social class/socioeconomic resources (Adler & Rehkoph, 2008). For example, African Americans and Native Americans have the highest mortality (e.g., homicide, hypertensive heart disease, diabetes) and poorest health status than any other group, while Hispanics and Asian Americans have lower overall mortality rates in comparison to non-Hispanic whites, though disparities exist for specific conditions (e.g., diabetes, heart disease). Individuals with lower education and income levels are more at risk for chronic health conditions, such as cancer (Clegg, et al., 2009), diabetes (Maty et al., 2005), and
heart disease (Roux et al., 2001). They have less health knowledge about screening and prevention (e.g., Ford, Coups, & Hay, 2006), and tend to seek less health information (Ramanadhan & Viswanath, 2006). African Americans have been shown to resist prevention-related behaviors, such as screening, changing diet, increasing exercise, reducing alcohol and tobacco use, and practicing safer sex (Kreps, 2006). Disparities are also influenced by the digital divide (e.g., differential access to the internet), which contributes to low levels of health literacy, information seeking, and health knowledge for people with low access to technology (Kreps, 2005). Typically, patient decision-making has focused on social influence through uncertainty management, information seeking, and social interaction (Ackerson & Viswanath, 2009). However, other macro-level variables are also important when seeking to improve health care and the communication involved. For example, Ackerson and Viswanath (2009) suggest increasing focus on racial/ethnic disparities, social capital, social support, and socioeconomic inequalities. Across the world, social determinants such as social class, education, material resources, and occupation influence health; and in the U.S., race and ethnicity are also strongly associated with health. Studies have shown other factors to mediate these associations through variables such as stress, prejudice, food, and clean environments.

Supportive communication between patients, their families, and providers is a promising area for health disparities intervention work. To combat these disparities, culturally grounded, community-based participatory research approaches are needed to in order for behavior change to be sustainable (Hecht & Krieger, 2006). Interpersonal communication campaigns focusing on supportive communication between providers,
patients, and family members can assist in decreasing barriers to health care. For example, race has been shown to influence provider-patient communication. Among concordant physician-patient race pairs, health-related conversations are longer in length and rated more positively than discordant pairs (Cooper et al., 2003). Likewise, in comparison with white patients, physicians speak more dominantly to African American patients and consider these patients less in their overall communication style. They perceive minority patients as less invested in their medical care. African Americans have been shown to be less trusting of the medical system, participate less in decision-making, and have less positive affect than White patients. Socio-economic status also influences communication with providers in that individuals with lower levels of income and education are least likely to seek, understand, and trust health information (Ackerson & Viswanath, 2009, p. 10). Many factors contribute to these behaviors, including information seeking norms, risk perceptions, and ability to process health information (Burnett, Jaeger, & Thompson, 2008).

Social support given through relationships in social networks has been shown to be beneficial to patients because of shared resources (e.g., emotional and informational support) and lowered stress and depression. Further, the larger one’s social network, the more likely a patient is exposed to beneficial health information (Ackerson & Viswanath, 2009). Social network ties can be advantageous and disadvantageous in health outcomes; both enhancing and harmful health information has been shown to come from strong ties and weak ties. For example, people may quit or start smoking depending on the normative behaviors of their family and peers (Rhodes & Ewoldsen, 2009). Social capital is also important. Defined as the trust, norms, and collective action of a social network,
social capital is available to members of a community and is linked to health outcomes such as lower mortality (Ackerson & Viswanath, 2009). However, Arora et al. (2007) reported that a support disparity exists for women of color, lower education, and less health insurance. This most likely exists because of uncertainty in seeking and receiving this social support and a possibility of weaker-tie social networks.

Thus, more work in supportive, chronic illness identity communication is needed and differs across social identities. The current paper’s model, The Communication of Chronic Illness Identity Support (CCIIS), is one step forward in understanding the theoretical and practical relationships between illness identity, social support, and patient well-being, and ultimately help empower individuals to manage their illness from diagnosis through resolution/recovery.
References


Figure 4. The Communication of Chronic Illness Identity Support Model

Patient Illness Identity

Patient Identity

Strategic Seeking of SS from specific source to resolve ID conflict

- Patient Personal Illness ID
- Patient Enacted Illness ID
- Patient Relational Illness ID
- Patient Communal Illness ID

HCP

Close Relational Others

Supportive Others w/ Similar Illness ID

If received support matches patient’s ID:

Patient Positive Well-being

If received support does not match patient’s ID:

Patient Negative Well-being
CHAPTER 4: CONCLUSION

The current document includes three manuscripts that combine to theoretically explain how illness identity and social support are related to patient well-being during the cancer experience. The first two chapters detail studies that are the building blocks for the theoretical model explained in the third chapter. As a result, my overall theoretical model combines two large concepts, illness identity and social support, to explain how they work to improve patient well-being. I argue that the process through which patient well-being occurs during chronic illness is through (1) patients’ strategically seeking social support to resolve identity conflicts brought about by a chronic illness diagnosis; (2) patients’ evaluation of received support as effective (i.e., social support message re-aligns patients’ identity); and (3) patients’ receipt of effective support, which leads to an incorporation of their illness into their overall identity, which resolves the original identity conflict.

The first manuscript contributes to this theoretical model by exploring ways in which cancer patients describe their illness identity and illness identity gaps during clinical trial decision-making. Although illness identity needs further conceptual clarification in future studies, this manuscript—through the study of illness identity—answered the call for further investigation of (1) illness identity in relation to health outcomes (Hecht et al., 2004) and for intergroup identity perceptions in relation to
‘cancer patient’ (Harwood & Sparks, 2003). Using the Communication Theory of Identity as a foundation, results of this study showed that certain identity layers (e.g., personal, communal) are more important to some patients’ illness experience while other patients situated their illness identity across multiple identity layers. This perception of patients’ illness identity is important because it shows which elements of the illness experience are most important (and concerning if experiencing identity conflict) to patients. Through continued study of how illness identity is communicated by patients in conversations with support network members and HCPs throughout the illness trajectory, researchers will be able to create interventions to improve the provision of effective support during different illness stages.

The second manuscript examined the relationship between partner support, health care provider support, and patients’ cancer treatment decision-making, including clinical trial participation. The contribution of this manuscript is its focus on how partner communication and HCP communication combine to relate to patient satisfaction with decision-making. Few studies have simultaneously looked at both sources of support influence when studying treatment decisions. Results indicated that HCP support partially mediated partner support in patients’ treatment decision-making satisfaction, suggesting a process through which support relates with patient satisfaction. There was no interaction effect between the two sources. Additionally, patients’ clinical trial enrollment did not affect their decision-making satisfaction. Together, these results suggest that there may be a causal relationship between partner support, HCP support, and satisfaction; however, the cross sectional design of this study does not allow for that interpretation. Further studies should investigate the temporal relationship between these supportive
conversations and how they influence one another before, after, and during the clinical encounter.

The third manuscript integrated the findings of the first two studies to explain that patients will (1) strategically seek supportive messages from others (e.g., health care providers, family members, support group members) to resolve illness identity gaps, (2) rate supportive messages from others as effective when they align with patients’ identity perspective and goals, and (3) experience well-being when identity conflicts are resolved and identity layers re-aligned with one another. This manuscript details the first theoretical model to explain the process through which illness identity and social support might influence patient well-being. The model can and should be tested over time to evaluate how and when the relationship between illness identity and social support changes patient well-being. For example, are certain illness identity layers more salient in certain stages of the illness (e.g., diagnosis vs. resolution) and/or do certain patients have specific identity layers that are more important to them across illness stages? Explication of these processes will lead to more precise identification of the social support needs of patients and their family members, which will allow health researchers to develop social support interventions that are tailored to patients across their illness experience.

Combined, these three manuscripts explain how and why patients rely on the support of specific sources to achieve health outcomes. These findings uniquely contribute to the current literature by offering a mechanism through which health care providers and family members can engage in patient-centered communication: through the recognition and validation of patients’ illness identity.
Bibliography

Chapter 1


Chapter 2


146


**Chapter 3**


Conclusion


Appendix A: Codebook

1) Illness Identity (relating to CT offer only): reference to self either through self-reflection or perceptions of how others view them
   i. PERS: Personal identity
      1. view of oneself, self-concept
      2. perceptions of themselves or their bodies
   ii. ENAC: Enacted identity (performance of an identity through a role in some kind of social interaction)
       1. communicating one's “real self”
       2. communicating only certain aspects of oneself to others
   iii. RELA: Relational identity (mutually negotiated between individuals, how others view them)
       1. changes in relationships because of illness
       2. concerns with how illness impacts their relationships with others
   iv. COMM: Communal identity (identity of a group or community)
       1. Ex: cultural group (Appalachian); religious group, etc.
       2. Health group (e.g., breast cancer patient, cancer survivor, etc.)
       3. Army is a communal identity when patients are talking about how the army views his treatment/identity

2) Illness Identity gaps (only related to CT): where one or more frames conflict with each other. Below are examples:
   b. Personal-personal: conflict in which patient struggles with two aspects of self in relation to illness
   c. Personal-relational: conflict in which patient struggles with self vs. supportive other about view of illness
   d. Personal-communal: conflict in which patient struggles with self vs. perceptions of a larger group identity
Appendix B: Personal-Enacted Identity Gap Scale (adapted for illness identity)

(Jung & Hecht, 2004)

1. *When I communicate with others, they get to know the “real me” with cancer.
2. *I feel that I can communicate with others in a way that is consistent with who I really am with cancer.
3. *I feel that I can be myself when communicating with others about my cancer.
4. I express myself in a certain way that is not the real me with cancer when communicating with others.
5. I do not reveal important aspects of myself with cancer in communication with others.
6. When communicating with others, I often lose sense of who I am with cancer.
7. I do not express the real me with cancer when my thoughts are different from others’ expectations of my behavior.
8. I sometimes mislead others about who I really am with cancer.
9. There is a difference between the real me with cancer and the impression I give others about me with cancer.
10. *I speak truthfully to others about myself with cancer.
11. *I freely express the real me with cancer in communication with others.

*Items are reverse coded
Appendix C: Personal-Relational Identity Gap Scale (adapted for illness identity)

(Jung & Hecht, 2004)

1. *I feel that my family members see me with cancer as I see myself with cancer.
2. I am different from the way my family members see me with cancer.
3. *I agree with how my family members describe me with cancer.
4. I feel that my family members have wrong images of me with cancer.
5. *I feel that my family members have correct information about me with cancer.
6. I feel that my family members portray me with cancer based on information provided by other sources, instead of information provided by me.
7. I feel that my family members stereotype me with cancer.
8. I feel that my family members do not realize that I have been changing because of cancer and still portray me based on my past images before cancer.
9. *I feel that my family members know who I used to be when they portray me with cancer.
10. When my family members talk about me with cancer, I often wonder if they are talking about me or someone else.
11. *I feel that there is no difference between who I think I am with cancer and who my family members think I am with cancer.

*Items that are reverse coded
Appendix D: Relational-Enacted Identity Gap Scale (adapted for illness identity)

(Kam & Hecht, 2009)

1. My family members have expectations of me with cancer that I do not follow.
2. My family members are often surprised by the things I say about my cancer.
3. Sometimes I don’t really act like I have cancer when I’m with my family.
Appendix E: Effective Support Scale

On a scale of 1 to 5, where 1 means you “strongly disagree” and 5 means you “strongly agree”, please tell us how much you agree or disagree with the following statements. My oncologist helped me adjust to my cancer by:

1. Showing care and concern for me.
2. Giving me valuable information about my cancer and my health.
3. Giving me advice about how best to take care of myself with cancer.
4. Giving me a different point of view about my cancer and my health.