



5-2015

Making Meaning of the Illness Experience: Narratives of Partners of Cancer Survivors

Heather Nicole Tidwell
University of Tennessee - Knoxville, htidwell@vols.utk.edu

Follow this and additional works at: https://trace.tennessee.edu/utk_gradthes



Part of the [Health Communication Commons](#)

Recommended Citation

Tidwell, Heather Nicole, "Making Meaning of the Illness Experience: Narratives of Partners of Cancer Survivors." Master's Thesis, University of Tennessee, 2015.
https://trace.tennessee.edu/utk_gradthes/3339

This Thesis is brought to you for free and open access by the Graduate School at TRACE: Tennessee Research and Creative Exchange. It has been accepted for inclusion in Masters Theses by an authorized administrator of TRACE: Tennessee Research and Creative Exchange. For more information, please contact trace@utk.edu.

To the Graduate Council:

I am submitting herewith a thesis written by Heather Nicole Tidwell entitled "Making Meaning of the Illness Experience: Narratives of Partners of Cancer Survivors." I have examined the final electronic copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Communication and Information.

Laura E. Miller, Major Professor

We have read this thesis and recommend its acceptance:

Michelle T. Violanti, Jonathan Pettigrew, Jennifer M. Jabson

Accepted for the Council:

Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

**Making Meaning of the Illness Experience: Narratives of Partners of Cancer
Survivors**

A Thesis Presented for the
Master of Science
Degree
The University of Tennessee, Knoxville

Heather Nicole Tidwell
May 2015

Copyright © 2015 by Heather Nicole Tidwell
All rights reserved.

Dedication

“The purpose of life is to contribute in some way to making things better.”

– Robert F. Kennedy

The time has come for me to make my mark on this world. I'd like to think that the journey up to this point has prepared me for the inevitable challenges the future holds. I feel as though I've arrived not at the ultimate destination, but at an incredibly important and monumental station on the train track that is life – and I thank God everyday for my arrival. This thesis signifies the end of one phase of my life. It represents the valiant effort put forth over these past six years. I hope this research will make an impact, be it great or small, in the growing field of health communication research and practice.

I would like to dedicate this work to those who have stood by me throughout not only my graduate and undergraduate career, but who have loved and supported me through this crazy thing called life. If not for your constant words of encouragement and support, I can guarantee I would not be where I am today. I attribute my successes to you. First and foremost, I would like to thank my mother. Mom, you are undoubtedly the most inspirational person I know. So much of who I am as a person is due to your love and dedication. I appreciate what you have sacrificed in order to give your children the best shot at pursuing all of life's grand opportunities. Please know that the greatest recognition I can ever receive is to know you are proud of what I have accomplished. Thank you to my father and brother who have constantly reminded me that I can achieve anything I set out to do. Growing up with two wonderful male figures in my life has made me strong enough to handle the toughest moments – and for that, I am eternally grateful.

To my friends, where would I be without you? I thank you for your continuous words of encouragement and the occasional (perhaps more than occasional) shoulder upon which I've leaned and cried. Specific recognition goes to my graduate cohort without whom I would be completely and utterly lost. I am so proud of each and every one of you and how far we have come through this process. I cannot wait to celebrate this momentous occasion with you by my side.

To my future husband, Matt, I am most grateful for you. You have supported me unconditionally through the past eight years of my life. I thank you for your willingness to tackle two years of long distance, knowing that education is incredibly important to me. Long distance is not for the faint of heart, and I am so appreciative of every road trip, plane flight, and late night spent making our relationship work. You breathe life into my soul and encourage me to be the best person I can be. I am better because I am with you. I cannot wait to close this chapter of our lives and embark on our next adventure together.

Acknowledgements

I would like to express my profound gratitude for Dr. Laura Miller, my mentor, committee chair, and friend. We began this journey six years ago, and I am so thankful that you were my undergraduate advisor. You have opened my eyes to the world of health communication and the numerous opportunities it holds. I always knew that I wanted to make a difference in the lives of others and health communication enables us, as communication scholars, to make an impact. You may not know just how much your guidance has meant to me over these past several years. When faced with loss, I turned to you and your teachings to help me understand and make meaning of my own experiences with illness and coping. You have been so much more than just an advisor or chair, you are a role model, and I aspire to be like you. Words cannot express how thankful I am for your insight, advice, and support. I am the scholar I am because of your encouragement and faith in me.

To my other committee members, Dr. Michelle Violanti, I am grateful for your wisdom. Thank you for guiding me through this process and challenging me to reign in my often-extravagant research ideas and goals. To Dr. Jennifer Jabson, thank you for introducing me to the field of Public Health. I entered your class naïve and left with a deep-seated understanding of how society impacts health. I know that we are all part of the problem, but more importantly, we are all part of the *solution*, and it is my responsibility to impart change on the world and lead by example. Dr. Jonathan Pettigrew, I thank you for challenging me to become a better scholar. I appreciate your earnest criticism and willingness to guide.

Finally, to those who serve the College of Communication and Information, I applaud you. Your willingness to help your students succeed is ceaseless. If not for you working behind the scenes, day in and day out, I would not have made it this far. You are not given enough recognition for what you do yet you do it tirelessly, so I thank you.

As I transition into the next phase of my life, I look to my relationships with each of you to remind me that there are wonderful people dedicated to the success of others. Your guidance has kept me humble. I hope I have made you proud. Thank you.

Abstract

Receiving a cancer diagnosis not only uproots the life of the patient but also the lives of the patient's family members and loved ones. Adjustments in communication and disclosure as well as in identity must be made at various phases of the cancer trajectory. Survivorship, specifically, poses its own set of challenges as both cancer survivors and their partners must cope with perpetual uncertainty as to whether the cancer is truly over (Fife, 1994; Lethborg, Kissane, & Burns, 2003; Miller & Caughlin, 2012). Furthermore, although partners report being significantly impacted by a cancer diagnosis, they are often understudied when it comes to understanding the illness experience (Goldsmith, 2009). This study employs a symbolic interactionism perspective and a narrative methodology to uncover the interplay among identity, communication, and uncertainty as it relates to the meaning making process over the course of the cancer trajectory. Comparative analyses of 10 in-depth interviews with partners of cancer survivors suggest meaning making for partners of cancer survivors is complex and deeply interrelated with identity, communication, and uncertainty and changes over time. These findings are discussed as they pose implications for both theory and practice. Areas for future research are also proposed.

Table of Contents

CHAPTER ONE: INTRODUCTION	1
CHAPTER TWO: LITERATURE REVIEW	4
Cancer	5
Challenges	7
Identity	7
Communication	8
Uncertainty	9
Meaning Making	11
Narratives	12
Purpose and Research Questions	14
CHAPTER THREE: METHODOLOGY	16
Participants	16
Procedures	18
Analysis	20
CHAPTER FOUR: RESULTS	22
CHAPTER FIVE: DISCUSSION	41
Theoretical Implications	45
Practical Implications	49
Limitations and Future Directions	52
CHAPTER SIX: CONCLUSION	55
LIST OF REFERENCES	57
APPENDICES	62
Appendix A: Prescreening Telephone Script	63
Appendix B: Informed Consent Statement	64
Appendix C: Narrative Interview Guide	66
VITA	67

List of Tables

Table 1. Study Participants.....	18
----------------------------------	----

CHAPTER ONE: INTRODUCTION

As modern medicine advances, an increasing number of individuals are living longer. Contributing to the aging population is the ability to diagnose disease earlier and provide more supportive and effective treatments. As a result, there is also an “increasing number of individuals who are surviving *cancer* [emphasis added] and living for longer periods of time” (Hodgkinson et al., 2006, p. 405). With an increasing number of individuals living with and surviving cancer, it is inevitable that the disease will affect the majority of the population at some point in time, whether that be through personal diagnosis or indirectly via the diagnosis of a family member or loved one. The American Cancer Society reported that as of January 2014, “nearly 14.5 million Americans with a history of cancer were alive” (p. 1). Researchers are now looking deeper into the illness experience itself. “Illness can shake up our sense of self and reintroduce uncertainty about how each person thinks and acts in response to a new set of demands” (Goldsmith, 2009, p. 216). As with any other serious illness or disease, cancer significantly affects the lives of both the patient and his or her family.

Cancer, in particular, follows a unique pathway, often with multiple phases of the illness experience. Researchers are thus able to study how cancer impacts communication, uncertainty, and identity at the specific phases of diagnosis, treatment, completion of treatment, and throughout survivorship. Not surprisingly, however, the vast majority of research pertaining to the illness experience focuses on the perspective of the patient or survivor. “Although individuals may bodily experience the agony of a broken bone or the discomfort of chemotherapy, health care challenges are *inherently relational*

[emphasis added]” (Harter, Japp, & Beck, 2005, p. 12). It was not until the 1970s that researchers began to examine the nuances and needs of cancer patients’ families (Lethborg et al., 2003). Research has uncovered the ways in which couples experience illness and the communication patterns they employ to manage uncertainty, develop joint identities and cope with the inevitable life changes of such a diagnosis (Goldsmith, 2009). Although some studies have investigated the relational aspects of illness in general, there is a significant lack of information regarding solely the partner’s experience as he or she moves through and makes meaning of the illness process (Goldsmith, 2009). Previous studies that have explored the experience of partners have uncovered that spouses experience “sleep disturbances and eating disorders, heightened anxiety and depression, a pervasive sense of helplessness, and fears about cancer and its treatment” (Blanchard, Albrecht, & Ruckdeschel, 1997, p. 189). Moreover, the effects of a cancer diagnosis are significant, and partner narratives warrant their own dedicated body of research.

This study explores the nuances of the illness experience through the collection of health narratives via storytelling from the perspective of partners of cancer survivors who have been declared NED, standing for “no evidence of disease,” or who have completed all treatments. “Storytelling informs and is informed by temporal, relational, and spatial contexts” (Harter et al., 2005, p. 26). Through a narrative approach to data collection, partners are given the opportunity to disclose their own personal experience with cancer beginning with the initial diagnosis. The use of narratives enables researchers to uncover the “lived realities” (p. 9) of partners of cancer survivors.

Using a symbolic interactionism perspective, this study uncovers the nuances of how partners of cancer survivors ascribe meaning to the illness experience and how these meanings are related to identity, communication, and uncertainty over time. This study first reviews the literature on cancer and the challenges associated with a cancer diagnosis, in relation to partners of cancer survivors. Additionally, a review of symbolic interactionism is presented to provide a guiding framework for this study. Finally, this study reviews the literature on using narratives as a way to collect qualitative data.

CHAPTER TWO: LITERATURE REVIEW

Cancer is dynamic in that it encompasses various phases of prognosis. As the rate of individuals living with or surviving cancer is on the rise, the size of cancer's reach continues to grow – nearly everyone will experience cancer either directly or through a family member or loved one. Upon review of the literature, it is clear a cancer diagnosis can and will uproot both the patient and his or her family – especially the partner who is most often enlisted as the main caregiver (American Cancer Society, 2014). When faced with a cancer diagnosis, individuals employ sense making to give meaning to their experiences. Meaning is created via social interaction and is undoubtedly impacted by challenges in identity, communication, and uncertainty. The existing body of literature highlights these challenges faced by those traversing illness. However, partners of cancer survivors are often understudied (Goldsmith, 2009). Previous research does acknowledge that, for partners, the cancer is never really “over” even after all treatments have been completed (Goldsmith, 2009; Miller & Caughlin, 2012). Furthermore, these difficulties often manifest themselves in a physical manner. A cancer diagnosis will likely affect a partner's mental and physical wellbeing.

Though partners serve as essential supports for cancer survivors, some may become highly distressed and may develop affective disorders, or those related to moods, feelings, and attitudes (Pitceathly & Maguire, 2003). This high instance of distress is further magnified by the unlikelihood of partners disclosing their worries and concerns and seeking assistance with coping. These psychological issues often become chronic in nature and more severe as the partner moves through the illness experience thus having a

greater impact on physical health as well. Literature supports the notion that the mental health of caregivers (partners and family members) improves post diagnosis when the caregiver feels as though he or she has received adequate support (Pitceathly & Maguire, 2003). However, as noted previously, partners often feel as though their stress due to a cancer diagnosis is not acknowledged; therefore, there is a significant possibility that the partner will never feel satisfied with the support and their mental health may not improve.

Cancer

A cancer diagnosis is not only received as a one-time critical event but also often represents a prolonged, traumatic experience that is both unclear and uncertain (Keitel, Cramer, & Zevon, 1990). Furthermore, cancer is unique in its structure. There are several phases, each possessing unique attributes, relating to diagnosis, prognosis, treatment, and recovery that can be explored. In many cases, even when treatment has been completed, patients and partners alike must deal with the uncertainty of possible recurrence.

Lethborg et al. (2003), after studying the experiences of spouses of breast cancer patients, described the experience as never really being “over” for both the patient and the partner. As Miller and Caughlin (2012) discovered when interviewing couples in survivorship, the shift from patient to survivor creates its own issues. These issues often include challenges in communication and disclosure and the development of new identities and roles within the relationship.

At each phase of the disease, personal and relational adjustments must be made. Survivorship, defined by this study as having been declared NED, completing all treatments, or deemed in remission, is multidimensional in that it gives hope and is often

desired and celebrated; however, it also poses significant challenges to the lives of the survivor and his or her family. Most caregivers are partners of cancer patients (American Cancer Society, 2014). Often, the adjustments required of partners have been found to be more severe than the adjustments of cancer patients (Goldsmith, 2009; Keitel et al., 1990). Families and partners must proceed through multiple transitions when coping with the ever-changing demands of cancer - before during and after cancer treatment (Lewis, 1993). Keitel et al. (1990), upon review of prior literature focusing on the experience of spouses of cancer patients, determined the illness experience affects partners of cancer patients by impacting their relational satisfaction, their emotional states, and their household responsibilities.

Relational satisfaction often deteriorates after a cancer diagnosis is made due to a decrease in communication on the parts of both the patient and the partner (Keitel et al., 1990). Partners may limit communication after diagnosis or throughout treatment to prevent the patient from feeling burdened or uncomfortable. This decline in communication may lead to feelings of isolation and thus a decrease in overall relational satisfaction. Partners also endure extreme feelings of emotion. These emotions range from anger, helplessness, fear, and exhaustion to guilt (American Cancer Society, 2014; Blanchard et al., 1997; Keitel et al., 1990; Lethborg et al. 2003). Additionally, cancer can change previously established household roles and responsibilities of both the patient and his or her partner. In partners of breast cancer patients, while the patient was “still processing the diagnosis and could not take much else in, the significant others appeared to need to take control...in order to assume a supportive role that comforts, helps,

protects and cares” (Lethborg et al., 2003, p. 70). As such, the partner is often tasked with fulfilling multiple roles to keep the household running. These obligations cause inevitable stress and strain on the partner and the relationship.

Many partners of cancer patients and survivors report feeling as though their needs are not recognized. Lethborg et al. (2003) found “while the significant others described an experience of distress and trauma, there was a common theme that they did not feel their stress was acknowledged” (p. 76). In fact, the majority of the study’s participants felt extreme trauma, stating that diagnosis and treatment “represented a life transition for them in as genuine a manner as it did for their partner” (p. 76). A gap exists in what is known about cancer as a relational experience and what is provided in terms of resources and outlets for partners to utilize when attempting to cope. All too often, partners experience their own version of crisis and must navigate and make meaning of the process alone, facing challenges in identity, communication, and uncertainty.

Challenges

Identity. The concepts of identities and self are often discussed when considering serious illnesses like cancer. “Identities define, locate, characterize, categorize, and differentiate self from others” (Charmaz, 1994, p. 269). Over time, identities become a significant portion of one’s self-concept. Self-concept, although often used synonymously with identity, is defined as “the relatively stable, coherent organization of characteristics, evaluations, and sentiments that a person holds about self” (Charmaz, 1994, p. 269). Illness can threaten identity by inhibiting an individual’s ability to physically function the way he or she did before the illness. Illness also impacts identities

formed through social roles and through personal endeavors that shape the self (Charmaz, 1994; Goldsmith, 2009). Furthermore, identity is often formed through relationships and communication with others.

Communication. Not only do cancer patients have to decide what, to whom, and how much to tell about their illness, but partners also must battle with the decision of whether and how to voice their own experiences. More often than not, the stories partners describe are not their own but are those of their ill partners. Communicating about illness often poses the same risks to the partner as it does to the patient or survivor. “When one discloses illness, facts and feelings about it touch one’s self-concept and self-esteem” (Charmaz, 1991, p. 108). Telling often means exposing oneself, straining relationships, and risking control and autonomy (Charmaz, 1991). Particularly when it comes to survivorship or post illness, individuals often feel torn about how to communicate. “I don’t tend to say that I am sick now. I don’t tend to say it in terms of the present tense or in terms of an ongoing chronic illness,” stated an individual with an autoimmune disease known as mixed collagen disease. “I don’t think I do trust anybody in terms of letting them know about having been sick, even though I’m not sick now. That’s something like that is kind of a secret.” (Charmaz, 1991, p. 107). This quote is an example of the complications involved in knowing how to communicate about illness. It should be noted, however, the partners of patients must also navigate feelings of distrust and “keeping a secret” when deciding to whom and what to tell. Often, this encompasses taking extreme consideration of their ill partner’s preferences above their own needs.

How individuals communicate with others about illness may include elements that go beyond recounting and describing the medical prognosis; this process is known as disclosure. It often involves the feelings of the teller and the “feeling self is brought into the foreground” (Charmaz, 1991, p. 119). There are two forms of disclosure to be considered. One is protective disclosure which allows the teller to control, by planning, how, what, when and who is told about the illness. Spontaneous disclosure on the other hand “includes full expression of raw feelings, open exposure of self, and minimal or no control over how, when, where, what and whom to tell” (p. 119). Disclosing should not be confused with informing. Informing allows the teller to become a teacher who is in control. Informing often incorporates very technical terminology and the information is presented in a factual, organized manner. This form of telling allows individuals to control their emotions and also enables them to influence and control other people’s responses. More often than not, both patients and partners employ informing as a dominant method of telling because it allows for more control over potentially debilitating feelings of emotion. This control over communication is then translated into control over one’s life and influences his or her uncertainty.

Uncertainty. Research suggests that illness creates a multitude of uncertainties for both patients and their partners. Brashers (2001) proposed “uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge” (p. 478). Cancer, specifically, brings with it a heightened “sense of

unpredictability and heightened uncertainty” due to the ambiguity of the disease course (Blanchard et al., 1997, p. 190).

Although patient and survivor uncertainty has been investigated, we know less about the uncertainties faced by partners and how those uncertainties impact their meaning making (Goldsmith, 2009). Survivorship, specifically, poses unique uncertainties. Often, couples struggle to find a new normal after treatment has been completed (Miller & Caughlin, 2012). Uncertainties about new roles may arise for partners. For example, a spouse of a breast cancer survivor interviewed for Miller and Caughlin’s (2012) study stated that because his main focus had been his wife’s needs for so long, upon completion of treatment he felt as though he had “lost his place in the book,” (p. 75) and did not know how to find that place again or who he needed to be. This example illustrates the effect of uncertainty on identity.

Brashers (2001) describes the managing uncertainty process as an interconnection of three focal areas: experiencing uncertainty, evaluating emotional responses, and adapting behaviors to manage that uncertainty. Uncertainty is perceptual. Meaning, if an individual feels uncertain about a cancer diagnosis, he or she is indeed uncertain. In turn, that individual may make a negative meaning of the cancer diagnosis, or he or she may choose to reframe the situation and formulate a positive meaning. “The uncertainty that ripples outward from an individual’s illness experience is multifaceted and complex” (Goldsmith, 2009, p. 221). Managing uncertainty, whether through seeking information or avoiding it, impacts the meaning that individuals create to better cope with their experiences.

Meaning Making

In order to cope with a significant and traumatic life event, like a cancer diagnosis, individuals employ sense making to construct and ascribe meaning to their experience. Meaning is “defined as an individual’s perception of the potential significance of an event...for the self and one’s plan of action” (p. 310) and is constructed through the interactions between an individual and his or her world (Fife, 1994). One perspective used to describe meaning making is symbolic interactionism.

Symbolic interactionism proposes that human behavior is based on the meanings individuals assign to the objects of their behavior, and those meanings are founded in the social interactions in which individuals engage. These meanings are the product of an individual’s cognitive processing of their social interactions (Blumer, 1969). A symbolic interactionism perspective provides a guiding framework with which to uncover nuances of meaning making in partners of cancer survivors. In particular, investigating challenges in uncertainty and identity within the social interactions partners experience and how those challenges may impact meaning making and vice versa. Research shows that changes in identity and roles are associated with meanings of loss – loss of self and of control. Furthermore, this meaning of loss is perpetuated by uncertainty created by a cancer diagnosis (Fife, 1994).

The literature shows that meaning making is dynamic. “It changes over time as changes occur in the individual, in events, and in the contexts within which the events occur” (Fife, 1994, p. 315). Meaning, as individuals progress through the various phases of the cancer experience (diagnosis, treatment, survivorship), the meanings they make

can and will change. In order to gain insight about the lived experiences of partners of cancer survivors at each phase of the cancer continuum, it is critical to employ a approach that enables partners to recount their experiences in a logical progression – similar to a story. One such approach is to elicit a narrative.

Narratives

Narratives are often used to collect health related data. “Storytelling, as data collection, helps us more fully capture one’s experience so that responses are improved and interventions better designed” (Palacious, Salem, Hodge, Albarrán, Hayes-Bautista, 2014, p. 4). Narratives are particularly useful in exploring issues of health and healing because they uncover the subtleties and challenges that individuals face when dealing with health issues and concerns. These challenges include identity construction, order and disorder, autonomy and community, fixed and fluid experiences” (Harter et al., 2005, p. 8). Narratives serve as the building blocks of identity creation and maintenance (Rosenthal, 2004).

In seeking health narratives, researchers often employ the biographic research approach through which the researcher requests the entire life story of the participant - regardless of the context of the research itself. “The goal of biographical research is not only to understand individual cases in the context of individual life histories, but to gain an understanding of societal realities or of the interrelationship between society and life history” (Rosenthal, 2004, p. 62). Furthermore, narratives bring current life and past experiences together, often illustrating the impact the present may have on the meanings made of past experiences. This approach comes with several assumptions: (1) in order to

accurately understand a particular phenomena, the participant must recreate their origin, or steps in their “creation, reproduction and transformation” (p. 49), for the researcher, (2) to better understand actions taken by the participant, the researcher must uncover the subtleties of what and how they experienced events at the time of their occurrence and also how they experience those events now in the present, (3) to uncover the nuances of “how” a participant makes a statement about a past experience, the researcher must review and understand the context of their current life experiences.

The biographical narrative interview approach follows a structured sequence. The first phase of the interview session is devoted to the participant’s main narration. The main narration is prompted by an initial narrative question and is followed by the participant’s “self-structured biographical self-presentation” (Rosenthal, 2004, p. 50). Once the participant has completed his or her main narration, the researcher is then able to pose internal and external narrative questions, which are based on topics presented during the main narrative (internal) and topics of interest to the researcher, which have not already been discussed (external). Alternatively, Rosenthal (2004) recommends a more structured approach to the biographical narrative when researching phenomena as it relates to a specific context.

This tailored approach to the biographical narrative begins with a targeted initial question rather than the broad request of a participant’s entire life story. By using a targeted initial question, the researcher is able to present the participant with the topic of interest to ensure said topic is covered; at the same time, this approach still provides flexibility and allows the participant to explore other “biographical strands” during the

interview process. Although this targeted initial question seeks the participant's narrative within a specific context, the initial narrative is still open and often lasts for an extended period of time. During the initial narrative, the researcher does not interrupt the participant with questions; rather, the researcher will create memos from which internal questions are then formulated.

Internal questions may be oriented to address a particular time or situation, an emergent theme, or an extended narrative for clarification and further understanding of the participant's life. Internal questions do not cover topics that have not already been presented by the participant. Questions focusing on aspects not already covered are asked during the external questioning phase (Rosenthal, 2004).

Purpose and Research Questions

To determine the best way to support partners of cancer survivors, it is essential to first determine the ways in which partners make meaning of the illness experience and more specifically, the relationship among identity, communication, and uncertainty and the meaning making process. Using a symbolic interactionism perspective and narrative approach to data collection, this study uncovers the nuances of the illness experience from the partner's perspective. To explore these intricacies of meaning making as it relates to identity, communication, and uncertainty, the following research questions were proposed.

RQ1: How do identity, communication, and uncertainty relate to the meaning making process of partners of cancer survivors?

RQ2: How does meaning change throughout the different phases of the cancer experience (diagnosis, treatment, survivorship)?

CHAPTER THREE: METHODOLOGY

Using a symbolic interactionism framework, this study investigates the ways in which partners of cancer survivors navigate and make meaning of the illness experience. Qualitative data from a total of 10 one-on-one, semi-structured interviews with partners of cancer survivors were collected. By using a narrative approach to eliciting information, the collected data represents the nuances of the meanings ascribed to lived experiences (Palacios, Salem, Hodge, Albarrán, & Hayes-Bautista, 2014).

Participants

Partners involved in cohabitating, heterosexual, romantic partnerships with cancer survivors who had been deemed NED or who had completed all treatments at least six months prior to the interview were recruited for participation. These recruitment criteria were enforced in order to ensure the collection of similar narratives. Meaning, all participants were at a similar phase along the cancer trajectory and were of similar relationship type. Participants were identified via contacts made by the researcher and were also recruited from a large cancer-support organization located in the southeastern region of the United States. Recruitment was conducted via flyers, presenting participants with the opportunity to “tell their story” in order to facilitate rapport between the researcher and participant. No incentives were given and participation was voluntary. Snowball sampling was used as those who agreed to participate were asked to pass study and contact information along to others who met the recruitment criteria.

The final sample included a total of 10 participants. Ideally, recruitment would have continued through till saturation was reached; however, due to time constraints

imposed on the current study, interviews ceased once a total of 10 participants were interviewed. Participants represented a variety of cancer experiences, including one colon, one bladder, one prostate, and five breast cancer narratives as well as two non-Hodgkin's lymphoma narratives. Partners of survivors of non-melanoma skin cancer were not recruited for this study because the medical experience of individuals with non-melanoma skin cancer is unique (Main, Nowels, Cavender, Etschmaier, & Steiner, 2005). For the purpose of this study, it was important to compare narratives from similar medical experiences, thus partners of non-melanoma skin cancer survivors were excluded. The following demographic information describes the above-mentioned participants. A total of six males and four females were interviewed. Although the inclusion criteria did not exclude unmarried partners, all participants included in the final sample were married to a cancer survivor prior to diagnosis and lived with their partner through survivorship. Participants reported an average marriage length of 28 years. Participants ranged from 38 years of age to 69 with an average age of 54. For participant pseudonyms and additional demographic information, see Table 1.

Table 1 Study Participants

	Pseudonym	Age	Survivor Age	Relationship Length (years)	Cancer Type	Year Diagnosed	Year Cleared
1	Barry	52	52	27	Breast	2007	2007
2	Don	59	65	36	Breast	1991	1993
3	George	56	55	15	Breast	2009	2009
4	Jacob	45	39	13	Breast	2011	2011
5	Kelsey	38	42	13	Non-Hodgkin's Lymphoma	2013	2014
6	Larry	68	67	45	Non-Hodgkin's Lymphoma	2004	2009
7	Rebecca	48	50	24	Prostate	2014	2014
8	Samantha	69	69	47	Bladder	2005	2012
9	Sonya	46	46	18	Colon	2012	2013
10	Victor	64	60	41	Breast	2001	2002

Procedures

Prior to a face-to-face interview, all participants were prescreened via telephone to ensure recruitment criteria were met (for prescreening script see Appendix A). Once the participant was deemed an appropriate candidate for this study, the researcher arranged a face-to-face interview to take place in a private location and at a date and time mutually convenient to both the researcher and the participant. Participants were prompted to read and sign a consent form prior to the in-depth interview (for consent form see Appendix B). The consent form detailed the basic premise of the study, that

participation was voluntary and that the participant could withdraw at any time without penalty, the risks involved, confidentiality and privacy protocol, and contact information. Once consent was obtained, the participant was given a copy of the consent form and the interview began.

Each interview consisted of open-ended questions designed to elicit the participant's story and were audio recorded to ensure accuracy of transcription. Interviews lasted on average 65 minutes with a maximum time of 130 minutes and a minimum of 22 minutes. Interviews yielded a total of 102 pages of transcription. An interview guide containing sample questions to elicit the narrative was used. Based on participant responses, some of the internal and external interview questions were not asked if the topic was already covered during the initial narrative portion of the interview (for interview guide see Appendix C). The questions identified in the interview guide were chosen based on previous studies to allow for fluidity as the participant moved through his or her illness narrative (Palacios et al., 2014; Schenker et al., 2014). Using Rosenthal's (2004) biographical narrative interview approach, the researcher guided the participant through the stages of the cancer experience including the time before the diagnosis was made, throughout the treatment process, and during survivorship - beginning after the patient was deemed NED or completed all treatments. Verbal probes and prompts were used when necessary during the initial narrative portion of the interview. After the participant completed describing his or her initial narrative, a variety of internal questions based on the memos recorded during the participant's initial narrative were asked. Internal questions were designed to explore, in more detail, the

themes presented during the narrative (Rosenthal, 2004). Internal questions were followed by external questions adapted from previous studies investigating meaning making. These questions were designed to elicit information regarding topics of interest to the researcher not previously disclosed, including details related to communication, identity, uncertainty (Radcliffe, Lowton, & Morgan, 2013).

Analysis

Constant comparative methods were used to analyze the data for emergent themes (Strauss & Corbin, 1998). The key to constant comparative analysis is to compare data to other data. This process began by the researcher first transcribing all interviews. The researcher then reviewed each interview line by line and identified and labeled passages according to a priori codes taken from the research questions. These initial codes included identity, communication, uncertainty, and meaning making. During the second pass of each interview, the researcher reviewed the data for nuances related to the a priori codes and refined the categories to present more narrow codes. Codes assigned on the second pass were added to the existing codes and included new roles, caregiver, spouse, survivor, disclosure, telling, putting partner first, telling makes it real, shock of reality, meaning before diagnosis, meaning during, and meaning in survivorship. The researcher completed a third pass of the data to further refine these categories. These codes were again added to the existing codes and included keeping information, giving back to others, factual telling, creating a game plan, unexpected events, death sentence, old person's disease, battle/enemy, perspective taking, gratitude, and strength/bravery. Axial coding was completed to identify relationships among the aforementioned codes.

Categories were linked with one another based on their properties and characteristics. Passages that were labeled similarly within each interview were compared with one another to determine whether the information presented was novel or repetitive. Upon completion of the internal comparison, the researcher compared each interview to another to again identify whether passages that were labeled similarly were presenting novel or repetitive information. Coding processes were completed using the qualitative data analysis software, NVivo, in conjunction with hand-written memos recorded during the interviews. During the final stages of coding, the researcher reviewed categories and subcategories with a faculty advisor to discuss the relationship between codes and select exemplars of each subcategory. Through the process of coding and discussion, the finalized coding process was agreed upon. Exemplars representative of emergent themes are presented in the results. Pseudonyms were given to all participant exemplars to ensure confidentiality.

CHAPTER FOUR: RESULTS

Several themes emerged across the majority of participant responses. As partners of cancer survivors described their narratives, they unveiled the ascribed meanings of their experiences. These meanings altered perceptions of identity and impacted the communicative patterns participants engaged in with their partners, families, friends, and healthcare professionals. Comparatively, these communicative patterns also impacted the ways partners of cancer survivors interpreted and drew meaning from their illness experiences, which often presented changes in uncertainty. The narrative process allowed participants to move through the cancer trajectory as they lived it. Through these narratives, it was clear that meanings of cancer and life in general change over the course of the illness experience. These meanings included an evolving perception of cancer first as a death sentence and ultimately representing strength, bravery, and growth.

Meanings for Identity

Upon receiving a cancer diagnosis, both the patient as well as the partner must take on new responsibilities and roles. Changes to daily routines often precipitate shifts in identity. For partners of cancer survivors, changes in identity are founded in the meanings they assign to their new roles and responsibilities.

Caregiver means becoming keeper of the information. A cancer diagnosis involves total immersion into the medical world. Some participants acknowledged this immersion as an opportunity to become keeper of the medical information. For some, this meant seeking out information on behalf of their ill partner. For example, Sonya, a 46-

year-old wife of a colon cancer survivor, described her new role as a gatherer and keeper of information:

One of us had to know, in my mind, one of us had to know what was going on. And so knowledge sometimes can be a burden, and so I bore that for him, or for us. And um, he, what was really interesting, that he, part of the reason why I continued in that vain was that he would often want information from me. He would want me to tell him things, not the doctor.

Although she describes feeling burdened by taking on this new role, her meaning of being a caregiver meant doing whatever her partner needed, which included reiterating and explaining the medical information when her husband was ready to process it:

And then, having to feed it back to him a little bit, that was um, I'm not, it's kind of, I'm not saying that was necessarily bad, it was just part of the caregiver role. I guess I was trying to meet him where he was and giving him information as he could handle it and wanted it, and being sort of that, gatekeeper of information.

Similarly, both Barry and Jacob, 52 and 45 years old respectively and both husbands of breast cancer survivors, described the process of being diagnosed as too emotional an event for a cancer patient to process thus constituting a shift in identity towards information keeper. As Barry detailed:

It takes a team. Even though she, she took the pain you know. We always used the term we. We went to the doctor. We did this. And it's just as important to you as it is to your spouse...And I would say too, as far as the front end of it, always when I hear of other people who are going through it, to it the first thing I ask is

who's going with you? Who else? Who else can you, who else cares about you; who do you care about? If you can't find one, call me. I'll go with you. You're never going to take it all in. I mean it was like bullets flying. I could tell you I saw her face; all she kept thinking, all she heard was I'm going to die. She said, she'll tell you to this day, because we would circle back after. We would talk about it on the way home she had nothing to say. She didn't retain any of the ancillary information...

Jacob echoes this notion of not going alone and always accompanying your partner throughout the process:

I mean one thing that was always very interesting to me because my wife has a medical background so she always had a list of questions, every time you come in you need your list, and they [hospital personnel] knew she'd have them. But you need another person in the room to comprehend it. And I might hear one thing, she hears another thing, and then we get back home and we're like what do you think he said? This is not what I got out of it at all. Oh my gosh, okay. And then you're making another call. I think even if you have a medical background, I think the emotional aspect puts you into almost a fog where you think you're getting it all but you're not. Everything they're telling you, it's way too much to comprehend. And that's why I think it's a mistake when people do go and do these alone.

Noting the rapid influx of medical information, these partners took it upon themselves to absorb this information with the intention of remembering it and discussing it with their

spouse when they felt their spouse was able to grasp the novel information. They clearly identified this process of keeping information as an important responsibility and took their newfound role very seriously.

Cancer as your partner's disease. Taking on new roles may be a bit of a burden to some caregivers; however, participants described putting their needs second to their partner's. Many participants described cancer as their partner's disease and not their own. Most participants acknowledged that cancer had an effect on them as well, but also that their needs were insignificant in comparison. This shift was difficult for some. Rebecca, the 48-year-old wife of a prostate cancer survivor described her thought process while attempting to put herself second:

It made me question how, like, when it was tough, it made me question like, what kind of person are you that you want to like run from this? Or you want to like, you know. So it actually, as opposed to like ennobling me like, oh I'm so...it actually made me feel kind of bad about myself. Not terrible but like, you suck.

What the hell? Suck it up; deal with it, you know? Like, what's your problem?

Rebecca goes on to describe her difficulties in putting herself second when it came to sharing her feelings and emotions with others:

I actually haven't told anybody. You're the first person I've told about it. No, cause I felt like it was, he was the one going through something hard, and I was just like, let me be strong for you. That was my role.

Similarly, Kelsey, a 38-year-old wife of a non-Hodgkin's lymphoma survivor, described how she concealed her emotions in order to fulfill her new identity of putting herself second:

I mean of course it was hard, but I had enough friends who had, her husband has been through it, well I met her through this. But she's just like you cry in shower; you cry when you need to, but you remain strong for him.

When faced with a cancer diagnosis, participants quickly identified themselves as a support person for their partner. They began to identify with someone who is responsible for behind the scenes work, so to speak. This work included concealing emotions and focusing all attention on their spouse. For these participants, this most often involved stepping back and placing their partner's needs before their own.

Survivorship means giving back. Identities and roles also shift when transitioning into survivorship. Participants paralleled one another when describing their newfound responsibility to give back and serve as a resource to others. As Kelsey conveyed:

I really believe that God allowed all this because I mean it's amazing how many people Seth has just reached out to that's gone through cancer. People that have contacted him, they need him to go be with this person who's been diagnosed. And we gave our testimony at church one night. People, you know people that aren't even going through cancer just going through hard things, they realize we've been through hard things; we can relate. So we kind of feel like it's our calling to try and help others going through tough times.

Sonya also detailed this newfound component of her identity of wanting to reach out and inspire others:

Now in this day, in this part of the puzzle, it's part of our lives in the sense of, you know, he and I want to inspire other people and talk about how you can get through it, and you can get through it and you don't have to be bitter. You don't have to be negative about it. You can be positive.

Samantha, the 69-year-old wife of a bladder cancer survivor, shared her desire to help others because she and her husband did not have such a resource when her husband was diagnosed:

Because, like I said, we didn't have anybody who had this disease, we didn't know anything about this disease. And then he had the surgery and we really, you know, didn't know anybody who had gone through this. So now we have, um, a really good support group executive committee, we have meetings, we have a newsletter. We started all of this in the last two years. So, uh, that's how we've reached out to help other people, especially him. We don't give medical advice so much, but this is what you can expect when you go home, this is what you can expect here, and every so often. You know, that sort of thing.

She and her husband now organize and run a support group for bladder cancer patients, survivors and their loved ones. Correspondingly, Victor, 64 and a husband of a breast cancer survivor described sharing tangible resources with those in similar situations:

Books. Books that were given to me by friends. Just to, you know, reading up on it. What you can expect as a spouse. And I in turn have those books, and I give

them to people whose wives or husbands are diagnosed with something. You know so I just, if it was given to me, I would love to give it to them.

For partners like these, giving back tangible or emotional resources to others is a way to fulfill a newly formed identity. This sense of self that is created through the cancer experience prompts the desire to help others in whatever way possible. These partners even chose to support others in similar situations when nothing was expected of them and without recognition. Clearly, a cancer diagnosis presents a unique opportunity to step into new identities and roles based on the meanings they give to becoming a caregiver or a part of survivorship.

Meaning Making and Communication

As shifts in identity occur, the way partners of cancer survivors communicate also changes. In order to maintain a sense of coherence between actions and identity, partners communicated in such a way that reinforced the meanings they assigned to their identity. Additionally, the act of communicating with others about their partner's disease gave meaning to the experience and the cancer itself.

Meanings ascribed to roles influence communication. Cancer presents changes in the way partners of cancer survivors communicate with others. These changes are in part based on the meanings ascribed to their experiences. In disclosing information to friends and family, for example, the notion of putting yourself second again rings true. Participants recounted stories of when they were asked how they were doing, they interpreted the asking as an inquiry into how their ill partners were doing. As Sonya recounted:

And on one hand it's totally understandable, it's much more interesting. I mean I don't know how interesting this was to a lot of audiences, it's much more interesting to be the person with the diagnosis. And he's been asked to speak; he gets asked to speak, like at our church, and I remember thinking about it, wait a minute, why doesn't anyone ever want to hear from the caregiver? I think it's 50/50. For every person who's diagnosed, there's an equal number of caregivers. So it's not like you've got a lesser population to speak to, it's just not as, maybe it's not as interesting. I don't know. But it's, I guess maybe it's more inspiring to be the one with the diagnosis.

Furthermore, Rebecca uncovered her own realization when it came to how she communicated information to others:

Kind of medical. Like how's he doing and then how are you doing. Do you know what I mean? Like I know this is going to affect your relationship, you know, we've got to...I was just trying to think if anybody ever did ask me how I was doing. Maybe once or twice.

This realization came as a surprise as a result of the initial meaning Rebecca assigned to all inquiries, further reinforcing the concept that cancer is her partner's disease, not her own. In her reflection, she notes that she's never really considered why no one asked her how she was coping with the experience. This may signify that meanings are created and assigned to events and objects almost subconsciously.

Not only did meaning impact the ways in which partners communicated, but the reverse is also true in that communicating with others shaped meaning. Many participants

shared that the cancer only became real when telling others. For example, Jacob describes:

The only time I ever get emotional is surprisingly not about talking about telling the kids. It's about the first time I said it, and I told my mom. I don't know why. I mean even when you brought it up and I said it, I could feel a little something here (points to throat). It makes it real. All of the sudden you're, this is what's going on. Strangely enough, and I don't know why. I think it was just cause it was the first person. Could have been somebody else, and I may still have that same memory. But it just happened to be her.

Victor also described his difficulty in telling others about what he was going through for fear of bringing the cancer into reality:

My close friends that I mentioned I would tell, but I never gave them what I was feeling inside. I would just make a bland statement but never saying what I really felt. And I was, I was a nervous wreck. I probably should have gone for therapy; I did not. And, you know, a couple close friends that I would talk to, I would just, you know, let them know how things were. But other than that, no, I really didn't express myself...I didn't want to face the reality of what could happen...

Communicating with others about a cancer diagnosis or experience promotes the meaning making process for partners. By informing others about what is going on from a medical standpoint, partners fortify the meanings they've ascribed to their own roles. In addition, telling others brings the cancer diagnosis itself into reality, thus giving the cancer meaning.

Uncertainty and Meaning

Partners often described the situations and social interactions that incurred feelings of uncertainty. As a result of the communication that took place during these interactions, partners assigned meanings to these events and based on those meanings, uncertainties arose. Moreover, feelings of uncertainty caused partners to experience a sense of realness and severity not yet felt over the course of their experiences.

Uncertainty gives meaning to moments. As stated above, the mere act of telling another about a cancer diagnosis was often described by participants as bringing the diagnosis into reality. This new reality also meant the creation of a game plan or a clear and defined order of events to be followed. With this game plan, many participants described feelings of increased certainty as to the path the illness would take. However, when participants narrated stories within which things deviated from this plan, uncertainties increased and the meaning of these deviations implied an err of seriousness and potential life change. As Sonya described the possibility and ultimate reality of her husband having a permanent colostomy bag as a result of the surgeons not being able to get clear margins, it was clear the meaning behind having a bag on the left side created uncertainty for what life would be like. As she recounted:

So when he, um, so all leading up to surgery he had scans and test and other probing, whatever, and the doctor had talked to us about he was going to have a temporary colostomy. He was going to go in and clean up all that tumor mess, and you know, get clear margins, that's what they want, they want clean tissue around the tumor, and get all that cleaned up and have a temporary colostomy and in

three months or so he'd have a second surgery to put him all back together and he wouldn't have a colostomy. He'd be able to use the restroom like everyone else does. So that was the plan. So the morning of the surgery, the surgeon came in and spoke with us before the surgery started, and he had to mark on Mark's stomach where the temporary colostomy was going to be. Well when he was doing the marking, he said, if it's on the right side, it's temporary. But if it's on the left side, it's permanent. And he made two marks. And we were like what do you mean permanent? Permanent colostomy had never been talked about. We were like it might be permanent? Really?

And then after Sonya discovered the surgery had not gone as hoped and her husband had to have a permanent colostomy bag:

But the other part was, there, to me there's comfort in having a plan, and as long as we were on the plan we were fine. But man, when we deviated a little from the plan, and it really became really real. I don't really have the words for that exactly... That's when it became really real to me.

Similarly, the relationship between communication, meaning and uncertainty was clear when George, 56 years old and a husband of a breast cancer survivor detailed the meaning he interpreted after having a conversation with healthcare personnel regarding his wife's unplanned emergency surgery:

We went in to the doctor and she ended up having a blood clot. So we went to the doctor to ask about it, and he walked out of the room and said come back tomorrow. And I chased him down the hallway and said that's unacceptable. And

so he sent us across the street to the hospital. So when we got there, they asked if she had eaten that day. And she said, ‘Well yeah, I just had lunch. I didn’t think I would be having surgery today.’ The staff told us that this doctor never approves emergency surgery like that, and so when they came back and said that she was going to have surgery, I knew. I don’t know if she picked up on that, but I did. I knew it must be pretty bad because of that.

The deviation from the plan in conjunction with the way it was communicated clearly signified a shift in the meaning of their experience and almost always signified an increase in participant’s uncertainty. Victor described his feelings when his wife had a negative reaction to her third round of chemotherapy treatment. During this time, healthcare professionals told him that his wife might die from the complications. He recounted, “And as long as we did what they told us to do, I had no doubt in my mind that things were going to be okay. Except the third round of chemo and they had me prepared. I said, ‘Holy shit.’”

Another such story presented by Jacob illustrated that although his interpretation of the outcome of his wife’s surgery was ultimately inaccurate, in the moments where his interpreted meaning was that of a poor prognosis, his uncertainty dramatically increased. He recalled:

When they came in to me when she got out of surgery, he said everything went great. I said, ‘Was there any node involvement?’ He said, ‘Yes and we took eight nodes.’ And I said, ‘Okay, so how many does she have left?’ And he said, ‘Oh no, once we found it we took all of them.’ And all of the sudden I’m thinking it’s like

really riddled in her. She's really got it [cancer]. There wasn't a point...and my wife thought that too. And the only person in the waiting room was my mother-in-law, and she's just like, 'What are you so upset about?' And I'm going she's got it everywhere, crazy. We even talked to I think it wasn't him [surgeon] doing the rounds later, cause at that point I just don't understand. I didn't understand what this guy's telling me. And we talked to a couple other surgeons when they came by to see my wife, and I told them what I was thinking. They were like, 'Oh no.' And then the surgeon, he felt horrible. Like I had no idea that's what, I thought you understood that once we see node involvement in some of them, we just take all of them. Neither of us thought that, and I thought it was just me. When I told my wife she was like, 'What?' And I'm like yeah. She understood the same way I did, but we both got it wrong. I remember that being a moment where I was like oh crap.

Meanings are created via the interpretations of symbols or language within social interaction. Furthermore, these meanings impact feelings. In whichever way language is interpreted, partners will assign a particular meaning to the event or object being discussed. In these instances the interpretation of the social interaction was one of severity and thus constituted uncertainty.

Obviously meanings ascribed to the illness experience affect the level of uncertainty partners of cancer survivors feel. Most often, these meanings are first created via interaction and communication with others. These interactions and the way participants communicated with others during their experience are, in part, a result of the

new identities they adopt once a cancer diagnosis is made. Not only are these constructs of meaning, identity, communication and uncertainty deeply intertwined, they are also dynamic in that they change over time.

Meanings of Cancer and Life Change Over Cancer Trajectory

As partners move through each phase of the cancer trajectory, communication and social interactions surrounding their partner's diagnosis change. As a result, the meanings given to cancer and life itself also evolve as the partner moves through his or her illness experience.

Cancer as a death sentence, an old person's disease. Based on prior experiences with cancer, participants most often described the meaning of cancer prior to their partners' diagnoses as a death sentence. Jacob, for example, described what came to mind when someone said cancer prior to his wife's breast cancer diagnosis:

Everyone I knew from that point all died. I didn't know of really like cancer survivors no matter what it was. I didn't also have a lot of family involvement that I really remember with cancer. I did have an aunt and there was my dad but they all, I mean they passed away from it. He lived a few years and that was it. All my other close family were strokes, heart attacks, old. You don't think about it the same way.

In addition, Rebecca described the magnitude in her mind of what cancer entailed prior to her husband's diagnosis with prostate cancer:

Chemo. Loss of hair. Very weak. Radiation. I mean I really thought, I thought of what your people that are suffering for a year or two or it keeps coming back. And that's what I thought.

Kelsey went on to convey her belief that cancer was something only older people suffer from: "You know you think it's going to happen to older people, people that aren't healthy. But it doesn't."

Clearly, stemming from prior experience and knowledge of cancer there is a real severity present in the minds of partners of cancer survivors when it comes to receiving a cancer diagnosis.

Cancer as a fact of life, something to fight against. Throughout treatment and surgery, cancer takes on new meaning. Participants described cancer as something that had become a part of their lives. Commonly, participants described proceeding through the motions of doctor's visits and chemo treatments as simply part of the journey. For example, Sonya detailed her reflection back on the process:

Again it was, some things you just have to go through, and in my head this was just one of those things, I couldn't get out of it. I couldn't really change the reality of it, this was just something we had to go through and we were going through it and I was coping, I was relatively okay most of the time, and in my mind, there wasn't a lot to say.

Kelsey also disclosed how looking back, she and her family floated through the process and incorporated it into their journey:

It was kind of surreal the whole process. You know when I look back I'm like did that really all happen? It's almost like we were just floating through it, getting through it. And now I look back and it's just like, it really was like a surreal experience because now we're back in this normal life. You know we fought cancer. It's just crazy that that happened just out of nowhere. It wasn't easy, but we did have a lot of help.

This may mean that partners have trouble engaging in sense making during moments of treatment. It seems that it is only once a partner has entered survivorship, he or she can look back on the experience and really assign a meaning of cancer being something to "get through".

Participants also described cancer as an enemy or something to battle against during the course of treatment and surgery. Viewing cancer like this enabled couples and families to band together during this time. For example, Sonya stated:

It gave us a common enemy. You know when you're having marital problems the enemy is sometimes each other, so this gave us a common enemy, which is a cliché I know, too. But on some level I think it's true. We had something to fight against. And um, and take care of each other. And on some level he did take care of me too.

Rebecca echoed this notion when she described the impact cancer had on her relationship:

It's like okay; we're in this together. We fought through this. It's the first thing that we've really had to fight through. I mean we didn't, we haven't really had

any big marital problems or anything like that, so it's the first thing we ever had to fight through to get to the other side. So I think that's why it did make us stronger.

Kelsey explained a similar feeling of cancer as something to beat:

But that, it was just kind of like we had a series of all these tests coming up after that, so we kind of just got a game plan and went from there on Monday. We were anxious to start chemo; that was our main thing. We were just so ready to start it, but we had to get all these tests done first, and that was, that was hard. You're just ready to beat it.

Clearly there is a shift in the meaning partners of cancer survivors ascribe to their experience as it shifts from diagnosis to treatment. Viewing cancer as something to battle may also indicate a strengthening in their relationship with their spouse. The most profound shift, however, comes when partners move into the survivorship phase.

Survivorship means strength and growth. Most often, participants had a profound takeaway from their experience. They detailed how being a part of survivorship has shown them that cancer no longer signifies a death sentence. As Rebecca mentioned when reflecting on her view of cancer now that her husband is clear, "And then, my view after this is that sometimes it, it's something that you can get past." Rebecca goes on to identify the underlying reason as to why she doesn't view cancer as a death sentence:

And that's the other thing I'm learning so much. There's so many different forms of everything. And each one, and that's what's so amazing too with the medical advances they are making. Now they know so much more.

Additionally, participants detailed that survivorship represented a stronger sense of self and stronger relationships. Samantha disclosed how survivorship has meant strength:

I hope I've become a little stronger, a little more supportive. Uh, definitely stronger faith, you know, depending on higher power. We can't do it all. And um, but uh, yeah I think it's definitely changed my perspective.

Rebecca expressed a similar feeling of newfound strength and how it meant a closer bond with her family:

The fact that we pulled through it together. And the fact that we got closer even as a couple and as a family because we had faced some adversity together. Now, we were very lucky cause it was not the kind of adversity that can break you. Yeah, I mean doing that caretaker role a year or two through chemo. I'll, you know, I'll find the strength; it'll happen, but it'd be hard.

Finally, Barry described how cancer now symbolizes bravery rather than weakness:

And I do reflect because I thought she was incredibly brave. And when you see in those, in those rooms, in the oncology rooms, the IV center, is the incredible brave faces. And you ask yourself, could you be that brave? Every one of those people you seldom saw even when they were down, you never saw them not smiling. I drove home that first day, and I said man, what a room full of heroes. So I guess seeing it first hand gives you a reflection of hopefully how you would battle it.

These testimonies illustrate the transformation of the meaning of cancer over the course of time. Perhaps this change over time is best illustrated by Sonya's analogy conveying how as her relationship with cancer evolved, so did its meaning:

Like it moved from being my next-door neighbor to moving in the house with me. I'm very familiar with my next-door neighbor, but now my next-door neighbor was in the house with me, and that's totally different... But, yeah, that it's much different when it comes home to you. And you're actually having to do it. As with most things in life, it's different to have to talk about some things, it's different to have to say to someone who's going through it, "Oh that's hard." But to actually, do it, and to go through something like that is totally different.

CHAPTER FIVE: DISCUSSION

The study's results show how partners of cancer survivors engage in meaning making throughout the cancer trajectory. These findings reveal that meaning making is deeply intertwined with partner identity, communication, and uncertainty. They also show that these three constructs interrelate in the meaning making process.

Identity, for example, refers to an individual's perception of the self and the roles and responsibilities he or she performs (Fife, 1994). Partners of cancer survivors encounter an unavoidable shift in identity when presented with a cancer diagnosis. This shift often involves becoming a caregiver and ultimately a teammate to a survivor. The findings from this study illustrate that changes in identity are grounded in the meanings partners ascribe to their situations. Becoming a caregiver means adopting new responsibilities including becoming a keeper of information. Lethborg et al. (2003) describes the need to seek and keep information as an effort on the behalf of the caregiver to gain control. However, this study illustrates that this identity may be a product of the meaning partners ascribe to the term caregiver. As symbolic interactionism states, meaning is created via social interaction and communication with others (Blumer, 1969). Thus, in understanding these new meanings, this study uncovers how by observing and participating in medical interviews with their partner and healthcare professionals, partners of cancer survivors deduce that a cancer diagnosis means that their partner is on the receiving end of a whirlwind of medical terminology and decisions. As a result of these interactions, meaning is formed and partner identity is shaped in the form of taking on new roles, including keeping information on behalf of their overwhelmed partner.

Moreover, taking on the role of caregiver also means putting your partner first. Participants described cancer as their partner's disease, not their own. This meaning most likely stems from the way society communicates and interacts with reference to cancer. For example, when prompted with an inquiry about how they were doing post diagnosis, participants always received this question as an inquiry into how their spouse was doing. In fact, the majority of participants reflected that answers detailing how their spouses were doing were often sufficient for the inquirer and thus this interpretation reinforces meaning over time. This meaning is that cancer is a partner's disease and not your own. The repercussions of this interpretation in turn affect the ways in which partners of cancer survivors communicate about their illness experiences.

Previous literature has explored that telling or deflecting to factual information enables the teller to better control potentially uncomfortable feelings and emotions (Charmaz, 1991). However, this study uncovers that the act of telling factual information or deflecting to the partner's medical condition may in fact be due to the meaning partners have assigned to their role of caregiver and putting themselves second to their partner's needs. The current study also uncovers that the act of telling another about a cancer diagnosis gives the cancer itself meaning. As partners described, the most challenging part of their illness experience or the point in which it all became real was when they first chose to tell someone else about their partner's diagnosis. Therefore, communication plays a significant role in bringing the cancer into reality and giving it meaning.

Furthermore, as the couple moves into survivorship, additional responsibilities and components of the partner's identity are presented. As a result of the social interactions partners engage in with other cancer survivors and partners of cancer survivors over the course of treatment, survivorship holds its own unique meaning of giving back to others as others helped them. Participants responded that they felt like now that they are in the survivorship phase of the illness experience, there is a new set of responsibilities to provide for others in the form of advice, emotional support, or even tangible support as Jacob described:

Maybe more inclined to help people, which I always felt like I was a pretty helpful person. But when you have someone that's in a similar situation you go you know what, yeah having someone just go over and cut the grass was nice. Just opening up time to do whatever. So I find myself doing that sometimes. I'll have a neighbor whose mom's sick, and I'll just go over and cut their grass. It's just one less thing. Just little stuff but it's, you don't tell anybody; you just do it. I don't need, I've never been the type to need recognition for anything.

Clearly, meanings assigned to the roles of caregiver and of survivorship first and foremost begin with the social interactions partners of cancer survivors engage in both before and during the illness experience.

Meaning also impacts uncertainty. The results from this study suggest that levels of uncertainty often rise when meanings shift. For example, when complications occur over the course of the illness experience, the meanings ascribed to these complications dramatically influence how uncertain partners feel. By the same token, these meanings

are also impacted by social interaction and communication with others. To illustrate, by communicating with healthcare professionals involved in the treatment of their partner, partners of cancer survivors described assigning meanings to events such as complications. Due to the nature of complications often resulting in negative outcomes, the meanings that were assigned increased uncertainty.

Noticeably, the process of meaning making for partners of cancer survivors is complex and deeply intertwined with identity, communication, and uncertainty. It should be noted, however, that not only is this process complex, but it is also dynamic in that it changes over time. Drawing from participant narratives, it cannot be assumed that the meaning individuals ascribe to cancer and life in general will be the same upon diagnosis and throughout survivorship. This study reveals a positive shift in the meaning making process. As a result of their change in experiences and social interactions, participants reported that they experienced a shift from interpreting cancer's meaning as a death sentence or an old person's disease to ultimately representing strength and bravery. Fife (1994), in discussing the conception of meaning of illness, describes the notion of self-transcendence in that the illness experience broadens perspectives and encourages self-awareness. The cancer experience becomes much more complex over the course of time as partners broaden their perspectives, which incurs this shift in meaning. The evolution of meaning overtime among partners of cancer survivors is both influenced by and influences their identity, communication, and uncertainty. These findings pose significant implications for both theory and practice.

Theoretical Implications

The findings from the current study add to the literature on meaning making in that it reports on the meaning making processes of partners of cancer survivors specifically. Much of the research referencing meaning making focuses on the meaning making processes of cancer patients and survivors, not their loved ones (e.g. van der Spe et al., 2013). The findings from this study support and expound upon the tenants of symbolic interactionism. For example, in defining the basic premises of symbolic interactionism, Blumer (1969) details that humans assign meaning to objects via social interaction. Although objects do not change in actuality over the course of time, the meanings and social interactions surrounding those objects over the course of the cancer trajectory do evolve. Therefore, it may be beneficial to examine the nature of the social interactions surrounding an object or situation like cancer. More specifically, these interactions vary greatly depending upon the phase of the cancer trajectory and are thus bound to incur shifts in meaning over time. By employing a narrative approach, this study details these shifts in meaning making over the course of the illness trajectory and identifies contributing social interactions. This is illustrated by the analogy Sonya gave comparing cancer to a neighbor whom has moved into her house. As the relationship to an object changes, as do the social interactions surrounding it and thus the meanings assigned do change. This notion echoes Blumer's (1986) second tenant that meanings can and will be modified through continued social interaction. Most commonly, symbolic interactionism is discussed as it relates to identity. However, the findings from this study

illustrate the complexity of the relationship between meaning making and uncertainty and communication as well.

The findings also expand what is known about uncertainty among partners of cancer survivors. Brashers (2001) discusses how uncertainty is created by ambiguity and unpredictability. Significantly less attention has fallen on the meaning making processes behind uncertainty and uncertainty management. Some research focusing on the role of appraisal in uncertainty states that how individuals experience or manage uncertainty is based on their appraisal of the situation. However, this notion that appraisal comes after uncertainty is experienced leaves out the critical piece of how uncertainty is created in the first place. The results reported here expand Brashers' work in that it uncovers that the meaning created via social interactions first and foremost effects whether uncertainty is experienced. As previously described in the exemplar from George's narrative regarding his feelings about his wife's emergency surgery, his uncertainty arose from the social interaction with the nurses. Through this interaction, he ascribed meaning to the emergency surgery and from that meaning he felt uncertain. Therefore, it is possible that when studying uncertainty it is important to first investigate meaning making as the meaning first influences whether uncertainty is felt. From there how individuals appraise their situation is most often based on the resources available as well as their self-efficacy. Meaning making is not a result of self-evaluation but rather a result of the communication and social interactions surrounding the situation. Moving forward, if researchers and theorists alike know more about the meanings ascribed to uncertain events, practitioners may then be better equipped to facilitate the management of uncertainty.

The findings from this study also pose implications for research investigating other communication theories and constructs. For example, the tenants of communication privacy management theory (CPM) may lend an explanation for the ways in which partners of cancer survivors communicate about their illness experience (Petronio & Durham, 2015). The results from this study suggest that due to partner meanings of being a caregiver and a part of survivorship, partners may be engaging in boundary setting. One of the core principles of CPM is that co owners of information, like partners of cancer patients and survivors, must negotiate certain rules about to whom they can share that information and what exactly they can disclose. The process of negotiating rules may be influenced by the partner's feeling that cancer is their spouse's disease and not their own, thus rules or boundaries may be assumed. If these boundaries are not negotiated, meaning if co owners do not work together to create these boundaries, there is the potential for boundary turbulence, which may impact the relationship. Furthermore, in assuming the identity of information keeper, this process may have implications for the concept of ownership of private information. For instance, partners sometimes feel as though they need to conceal private information from their own spouse until he or she is ready to process it. In doing so, it may suggest a shift in ownership of private information from the cancer patient or survivor to their partner.

The findings may also impose meaning for the communication concept of face. The concept of face is referred to as the respect given or expected from others during social interaction. Face work or saving face is the idea that during interactions, individuals will communicate and behave in such a manner that avoids embarrassment

and promotes respect (Goffman, 1955). This concept is interesting in discussing the findings because partners of cancer survivors may be engaging in face work when fulfilling their newfound role of keeping information both from their spouse and from friends and family. In aims of respecting their spouse, partners of cancer patients and survivors may retain and reserve potentially debilitating information in order to preserve their spouse's sense of pride and avoid any sort of embarrassment. This could take place during interactions with healthcare professionals, with family or friends, with one another, or even during interactions with individuals who have had similar experiences.

Findings related to the ways in which partners engage in social interactions with their ill spouse may be of significance to research relating to relational uncertainty. Relational uncertainty is referred to as the extent to which an individual believes his or her partner is committed to the relationship or the extent to which he or she is committed to the relationship (Knobloch & Solomon, 1999). Although not reported in the findings for the purpose of this study, partners of cancer survivors, particularly of survivors with physical deformities or disabilities, may encounter feelings of relational uncertainty. Both patients and survivors and their spouses engage in relational uncertainty due to shifts in identity. These shifts may call into question the confidence with which a partner or a patient or survivor feels about the status and security of their relationship. Thus, the findings from this study may provide insight into the meanings and social interactions that underlie potential feelings of relational uncertainty.

Obviously, meanings underlie each of these constructs of identity, communication, and uncertainty; they are so deeply ingrained in one another it is difficult

to differentiate where one ends and another begins. Therefore, researchers and theorists must explore these meanings in addition to identity, communication, and uncertainty. It may be insufficient to conclude that all individuals experience the same shifts in identity, employ communication similarly, and manage uncertainty in the same ways without first understanding the meanings they ascribe to their experiences. Additionally, changes in the meaning making process over time must be considered.

Practical Implications

Partners of cancer survivors' illness experiences are complex and dynamic and different from the experience of the survivors. As a result, practitioners cannot treat both members of couples facing a cancer diagnosis in the same manner. Drawing from the findings, practitioners must support partners of survivors in a very particular way as their social interactions have an effect on their meaning making process in conjunction with their identities, communication, and uncertainties. For example, partners of cancer survivors revealed their desire to hear positive stories of other cancer experiences. Although most often partners' views of cancer initially begin as a death sentence, this meaning can shift in a positive direction over time. Therefore, others acting as support should work to convey positive stories when communicating with partners of cancer patients. For instance, Kelsey described:

You know that's one thing, you want to hear from the people who have had positive experiences. I mean honestly some people reached out that they had lost a loved one with cancer, and it's like, that was the hard ones to talk to. It's like I want to hear from the people with good stories. That's just how it is.

Moreover, the narrative process itself had a very positive impact on participant's cognitive processing. As Rebecca stated after sharing her story with the researcher:

It felt really good to talk about it. It made me like think about, think about things I didn't think about that I hadn't really, hadn't really considered at all what it did to me. Not I mean truly, like not at all.

Although many support programs do incorporate this narrative, storytelling process into their frameworks, support programs should consider the need for positivity in addition to the shift in identity that occurs when partners move into survivorship.

As mentioned before, partners of cancer survivors have a strong feeling of responsibility to give back and help others. Interestingly, when asked about traditional support group involvement, partners of cancer survivors reported negative feelings. For example, Sonya detailed her support group experience:

But what I found that was, the first few nights, because I feel everything everybody else feels. I am very perceptive and take on other people's emotions, and man, that was overwhelming to be honest. To be in a room full of people with varying stages of um, of cancer in a loved one, that was, wow, that was really overwhelming for me. And I probably wouldn't do it again. I didn't feel like - it was too much to be consumed by my own set of circumstances and then have to take on, it felt like I had to take on you know, hearing their burdens, their worries, it was a bit much, it was hard ... so I kept going for, well for the entire time, but I didn't really connect with anybody in there so much. Anyways that wasn't really quite the right fit for me.

Responses such as these come as a bit of a surprise; however, knowing this, public health professionals may reconsider their approach to social support.

Public health practitioners are familiar with working towards prevention and education regarding cancer; however, interventions in the way of support for partners of survivors are limited (LIVESTRONG, 2004). *The National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* was created to identify the needs among survivors and their loved ones. One of the plan's main objectives is to "implement effective and proven programs and policies to address survivorship more comprehensively" (LIVESTRONG, 2004, p. ES-2). Although objectives such as these are important and impactful, the majority of data and research focuses on aspects of care and access to information in order to promote healthy behavior. This study provides insight into the way partners make meaning of their experience. These results imply that perhaps education and information are not the answers to promoting effective coping with regards to survivorship. Rather than focusing on changing health behavior as public health so often aspires to do, public health practitioners could also consider the meanings that members of this population assign to their situation and provide opportunities and resources to facilitate their new roles and identities and manage any uncertainties they may encounter.

For example, the creation of a mentorship-type program in which partners of cancer survivors can serve as a mentor to families and partners of those recently diagnosed may be beneficial. This type of program would benefit this population twofold. First, partners of cancer survivors would be given the opportunity to fulfill their

newfound identity of giving back to others by sharing their stories. This in turn may help facilitate cognitive processing and increase emotional adjustment. Additionally, a program such as this would benefit those who are entering the beginning phases of the cancer trajectory by fulfilling their needs of hearing positive stories and engaging in positive social interactions to promote meaning making.

Limitations and Future Research

Although this study makes strides in discovering how the meaning making process is related to identity, communication, and uncertainty and how that process changes over time, the findings are not exhaustive. There is undoubtedly more research to be done. More specifically, by narrowing the scope of this research to the relationship between meaning making and each construct independently, researchers can better understand the intricacies of these relationships. Additionally, this study was broad in that it examined the narratives of a variety of cancer experiences including colon, bladder, prostate, and breast cancer, and non-Hodgkin's lymphoma. Future researchers should aim to investigate the experience of partners of survivors of different types of cancer separately. This may allow researchers to discover nuances about specific cancer experiences and determine whether some meanings are cancer-type specific.

In addition, the sample that was recruited may have a potential bias due to their involvement in cancer-based organizations. Although not all participants were members of a formalized support group, they were recruited through a local cancer support community and via snowball sample. Therefore, there may be a subpopulation(s) within

the much broader population of partners of cancer survivors that was not surveyed and thus a different set of experiences was not explored.

Due to the nature of a thesis study, there were significant time constraints. These time constraints impacted the sample size as well as the data analysis. The researcher ceased interviews once the participant sample reached 10 due to the need to begin the analysis process. Ideally, the interview process would have continued until saturation was reached. Additionally, in order to conduct a more thorough analysis of qualitative data, it is recommended that researchers take a step back, so to speak, and return to the data with a fresh lens (Strauss & Corbin, 1998). This process of returning to the data multiple times was not possible for this study. However, the researcher plans on returning to the data in the future to uncover nuances within the participant responses.

Furthermore, this study is retrospective in that it prompted participants to recall past experiences. Although the narrative approach used helped facilitate this recall, future studies should utilize a longitudinal study design to more accurately understand how the meaning making process changes and evolves over the cancer trajectory.

Another area of research of interest is to explore how partners of cancer survivors communicate with others using technology and social media. Many participants mentioned various forms of technology including blogging, group email, CaringBridge, and Facebook when describing their communication patterns with family and friends. This phenomenon is of interest as it may impact the meaning making process, as it is a different form of social interaction.

Similarly, the meaning making process of cohabitating partners versus married partners of cancer survivors may present interesting findings. Drawing from research investigating family communication, there are distinct differences in ideals regarding commitment between partners who cohabit versus those who marry before living together. Furthermore, cohabitating relationships in general are more likely to terminate or end in separation (National Marriage Project, 2002). All of the current study's participants were married to a cancer survivor and thus partners who are cohabitating may have different views of identity and engage in meaning making differently.

CHAPTER SIX: CONCLUSION

As medical advances continue to arise, more and more individuals are living with and surviving cancer. Consequently, there is an increasing number of partners who are living with and supporting cancer patients and survivors. Although many studies have examined meaning making as it pertains to the patient or survivor (e.g. Park, Edmondson, Fenster, & Blank, 2008), there are limited studies that investigate this process for partners of cancer survivors. Additionally, communication scholars often work to uncover nuances in identity, communication, and uncertainty as they relate to illness. However, literature investigating the relationship between the meaning making process and identity, communication, and uncertainty over the course of the cancer trajectory is limited. This study shows that this relationship is both complex and dynamic in that meanings shift and evolve over time. The social interactions in which partners engage both before and over the course of the illness experience impact the meanings they assign to objects and situations, including caregiver, cancer, and survivorship. These meanings in turn impact elements of partner identity and how they communicate with others about their experiences. Furthermore, partners draw meaning from their interactions, which affects how they experience and manage uncertainty. This process is recurrent in that these constructs of identity, uncertainty and communication influence future social interactions and thus reinforce or evoke changes in the meanings originally assigned.

This study poses theoretical and practical implications for health communication by illustrating how intricate the meaning making process is for partners of cancer survivors. It opens future research and practice to reconsider investigating identity,

communication, and uncertainty without first understanding the meanings given to the objects and situations surrounding these constructs. Using this knowledge, public health practitioners may be able to modify and reassess current support resources offered for partners of cancer survivors.

REFERENCES

- American Cancer Society. (2014). Cancer Treatment and Survivorship Facts & Figures. American Cancer Society. Retrieved from <http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-042801.pdf>
- Blanchard, C. G., Albrecht, T. L., & Ruckdeschel, J. C. (1997). The crisis of cancer: Psychological impact on family caregivers. *Oncology, 11*, 189–194. Retrieved from <http://www.cancernetwork.com/oncology-journal/crisis-cancer-psychological-impact-family-caregivers>
- Blumer, H. (1969). *Symbolic interactionism: perspective and method*. Englewood Cliffs, NJ: Prentice-Hall.
- Brashers, D. (2001). Communication and uncertainty management. *Journal of Communication, 51*, 477–497. doi:10.1111/j.1460-2466.2001.tb02892.x
- LIVESTRONG Foundation, & Centers for Disease Control and Prevention. (2004). *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Retrieved from <http://www.cdc.gov/cancer/survivorship/pdf/plan.pdf>
- Charmaz, K. (1991). Disclosing illness. In *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (1994). Identity dilemmas of chronically ill men. *The Sociological Quarterly, 35*(2), 269–288. doi:10.1111/j.1533-8525.1994.tb00410.x

- Fife, B. (1994). The conceptualization of meaning in illness. *Social Science & Medicine*, 38(2), 309–316. doi:10.1016/0277-9536(94)90400-6
- Goffman, E. (1955). On face-work: An analysis of ritual elements in social interaction. *Psychiatry: Interpersonal and Biological Processes*, 18, 213-231.
doi:10.15521/0032747.1955.11023008
- Goldsmith, D. J. (2009). Uncertainty and communication in couples coping with serious illness. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty and information regulation: Theories and applications* (pp. 203–225). New York, NY: Routledge.
- Harter, L. M., Japp, P. M., & Beck, C. S. (Eds.). (2005). *Narratives, health, and healing*. Mahwah, NJ: Lawrence Erlbaum Associates, Inc., Publishers.
- Hodgkinson, K., Butow, P., Hunt, G. E., Wyse, R., Hobbs, K. M., & Wain, G. (2007). Life after cancer: couples' and partners' psychological adjustment and supportive care needs. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 15, 405–415. doi:10.1007/s00520-006-0148-0
- Keitel, M. A., Cramer, S. H., & Zevon, M. A. (1990). Spouses of Cancer Patients: A Review of the Literature. *Journal of Counseling & Development*, 69, 163–163.
doi:10.1002/j.1556-6676.1990.tb01479.x
- Knobloch, L. K., & Solomon, D. H. (1999). Measuring the sources and content of relational uncertainty. *Communication Studies*, 50, 261-278.
- Lethborg, C. E., Kissane, D., & Burns, W. I. (2003). "It's not the easy part". *Social Work in Health Care*, 37, 63–85. doi:10.1300/J010v37n01_04

- Lewis, F. M. (1993). Psychosocial transitions and the family's work in adjusting to cancer. *Seminars in Oncology Nursing, 9*, 127–129. doi:10.1016/S0749-2081(05)80109-3
- Main, D. S., Nowels, C. T., Cavender, T. A., Etschmaier, M., & Steiner, F. (2005). A qualitative study of work and work return in cancer survivors. *Psycho-Oncology, 14*, 992-1004. doi:10.1002/pon.913
- Miller, L. E., & Caughlin, J. P. (2012). “We’re going to be survivors”: Couples’ identity challenges during and after cancer treatment. *Communication Monographs, 80*, 63–82. doi:10.1080/03637751.2012.739703
- Palacios, J. F., Salem, B., Hodge, F. S., Albarrán, A. A., & Hayes-Bautista, T. M. (2014). Storytelling: A qualitative tool to promote health among vulnerable populations. *Journal of Transcultural Nursing, 1*–8. doi:10.1177/1043659614524253
- Park, C. L., Edmondson, D., Fenster, J. R., & Blank, T. O. (2008). Meaning making and psychological adjustment following cancer: The mediating roles of growth, life meaning, and restored just-world beliefs. *Journal of Counseling and Clinical Psychology, 76*, 863-875. doi: 10.1037/a0013348
- Petronio, S., & Durham, W. T. (2015). Communication privacy management theory: Significance for interpersonal communication. In D. O. Braithwaite & P. Schrodtt (Eds.), *Engaging theories in interpersonal communication: Multiple perspectives* (pp. 335-348). Thousand Oaks, CA: Sage.
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients’ partners and other key relatives: a review. *European Journal of Cancer, 39*, 1517–1524. doi:10.1016/S0959-8049(03)00309-5

- National Marriage Project. (2002). *Should we live together? What young adults need to know about cohabitation before marriage: A comprehensive review of recent research* (2nd ed.). Piscataway, NJ: Popenoe, D., & Whitehead, B. D. Retrieved from <http://nationalmarriageproject.org/wp-content/uploads/2013/01/ShouldWeLiveTogether.pdf>
- Radcliffe, E., Lowton, K., & Morgan, M. (2013). Co-construction of chronic illness narratives by older stroke survivors and their spouses. *Sociology of Health and Illness*, 35, 993–1007. doi:10.1111/1467-9566.12012
- Rosenthal, G. (2004). Biographical research. In C. Seale, G. Gobo, J. F. Gubrium, & D. Silverman (Eds.), *Qualitative research practice* (pp. 48–64). Thousand Oaks, CA: Sage Publications.
- Schenker, Y., Dew, M. A., Reynolds, C. F., Arnold, R. M., Tiver, G. A., & Barnato, A. (2014). Development of a post-intensive care unit storytelling intervention for surrogates involved in decisions to limit life-sustaining treatment. *Palliative and Supportive Care*, 1–13. doi:10.1017/S1478951513001211
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage
- van de Spek, N., Vos, J., van Uden-Kraan, C. F., Breitbart, W., Tollenaar, R. A. E. M., Cuijper, P., & Verdonck-de Leeuw, I. M. (2013). Meaning making in cancer survivors: A focus group study. *PLOS ONE*, 8(9), 1-7. doi:10.1371/journal.pone.0076089

APPENDICES

Appendix A

Prescreening Telephone Script *Making Meaning of the Illness Experience*

“To introduce myself, my name is Heather Tidwell, and I am a master’s candidate of the College of Communication and Information at the University of Tennessee. For my master’s thesis, I have developed a research study designed to better understand the ways in which partners of cancer survivors navigate and make meaning of their illness experiences. By participating in this study, you will be contributing to the existing body of research investigating how partners of cancer survivors experience illness. The findings from this study may be used in the future to develop support resources for loved ones of cancer patients. Your participation in this study is purely voluntary. You may decline to participate without penalty. If you choose to participate, your participation will be kept completely confidential. No personally identifying information will be collected or used in the final write up. All names provided will be given a pseudonym to ensure confidentiality. If you decide to participate, you may withdraw from the study at any time. If you withdraw before data collection is completed, your data will be destroyed and will not be used for analysis.

If you so choose to participate in the proposed study, we will schedule a date and time convenient to you to arrange an interview. Interviews will take place in a private office/room to ensure confidentiality. All interviews will last approximately one hour. During the interview, you will be asked to tell your story beginning with the time just before your partner was diagnosed with cancer. It is important that you reference your personal story during this process rather than your partner’s story. At this time, do you have any additional questions? Would you like to participate in this study?”

If participant agrees to participate, prescreening questions include:

1. Are you involved in a heterosexual relationship with a cancer survivor?
2. How long have you and your partner been in a relationship?
3. Do you currently live with your partner?
4. Have you lived with your partner throughout the duration of the cancer experience?
5. What type of cancer was your partner diagnosed with?
6. When was your partner first diagnosed?
7. Has your partner been declared NED (no evidence of disease)?
8. When was your partner declared NED?
9. Has your partner completed all of his or her treatments?
10. When did your partner finish his or her last treatment?
11. What this your partner’s first and only cancer diagnosis?
12. Has there been any recurrence of the cancer (same or different)?
13. Have you yourself ever had or have cancer?

Appendix B

Informed Consent Statement

Making Meaning of the Illness Experience
College of Communication and Information
The University of Tennessee, Knoxville

Introduction

You are invited to participate in a research study investigating the ways in which partners of cancer survivors navigate the illness experience. To participate, you must be 18 years of age or older. Additionally, participants must be currently involved in a heterosexual, cohabitating, romantic partnership with a cancer survivor. Participants must have been with their partner at the time of cancer diagnosis, during treatment, and throughout survivorship. Cancer survivors must have been declared no evidence of disease (NED) or have completed all treatments at least six months prior to participation in this study.

Information about participation

During the following interview, the researcher will ask you to tell your story beginning with the time just before your partner was diagnosed with cancer. Please reference your personal story during this process rather than your partner's story.

All interviews will be audio taped to ensure accurate transcription.

Risks

There are minimal foreseeable risks to you with regards to participation in this study. As this study explores the illness experience, there is the possibility you may experience feelings of discomfort. If at anytime your level of discomfort escalates to the point you cannot or wish not to continue, please notify the researcher and the interview will stop immediately. If you choose to withdraw, all data collected pertaining to your story will be destroyed and will not be used in data analysis or final write up. Additionally, local counseling resource information is available and will be provided upon request.

Benefits

By participating in this study, you will be contributing to the existing body of research investigating how relational partners of cancer survivors experience illness. The findings from this study may be used to develop support resources for loved ones of cancer patients.

Compensation

There are no monetary or tangible incentives being offered for your participation.

Confidentiality

All audio recordings and documents obtained, including this consent form, through this study will be kept confidential. Consent documentation and data will be stored separately and will be secured in a locked office in 293 Communications Building, Knoxville, TN

37996. Consent documentation and data will be accessible only by the researcher. Direct quotes may be used in the final analysis and write up; however, all participants will be given a pseudonym and all personally identifiable information will be removed during the transcription process. Consent documentation will be kept for three years after the study has been closed.

Participation

Your participation in this study is purely voluntary. You may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time. If you withdraw before data collection is completed, your data will be destroyed and will not be used for analysis.

Contact Information

If you should have any questions at any time about the study, or if you experience any adverse effects as a result of participating in the study, you may contact the researcher, Heather Tidwell, at 678-372-2131. If you have questions pertaining to your rights as a participant, contact the University of Tennessee's Office of Research's Compliance Officer at 865-974-7697.

Consent

I have read and understand the above described information. I have received a copy of this consent form. I understand by signing my signature on the line below, I am agreeing to participate in this study.

Participant's Signature _____ Date _____

Investigator's Signature _____ Date _____

Appendix C

Narrative Interview Guide *Making Meaning of the Illness Experience*

Eliciting the participant's story:

“Can you tell me about what was going on in your life before your partner was diagnosed?”

Probes:

“And then what happened?”

“Tell me how that experience was for you.”

“What was it like for you to go through that?”

Possible Internal Questions/External Questions:

“How did you cope with your cancer experience?”

“How did you view life prior to your partner's cancer diagnosis?”

“How did your experience challenge or change the views you had of life before the diagnosis was made?”

“How has your experience affected the way you think about yourself?”

“What was your view of cancer prior to your partner's diagnosis?”

“How do you view cancer now that your partner is in survivorship?”

“How has your experience affected your relationships with family and friends?”

“Who did you communicate with during your cancer experience and why?”

Reflection

“Is there anything else you can think of that you want to share with me about your experience?”

“How do you feel after telling me about your experiences?”

“What did you feel was the most difficult part of telling me your story?”

“What did you feel was positive about the telling of your story?”

“What have you shared with others about your story?”

“Who have you shared your story with?”

Probe: “Why did you choose to share your story with ____?”

“What advice might you have for others in a similar situation?”

VITA

Heather Nicole Tidwell was born and raised just north of Atlanta, GA. She and her brother, Samuel Vincent Tidwell, Jr., are children of Marjory D. Tidwell and Samuel Vincent Tidwell, Sr. Pursuing her collegiate career early, Heather chose to forgo her senior year of high school and enrolled as a full time student at a local community college. She returned to attend her graduation ceremony with her peers in May of 2009. Heather entered the University of Tennessee in the fall of 2009 as a transfer student with 33 earned credits. She was able to apply to the School of Communication Studies early in her undergraduate career. While maintaining a high GPA, Heather worked part time at the University of Tennessee Veterinary Medical Center as an administrative assistant. It was there she realized her passion for health and the wellbeing of others. Heather graduated Cum Laude in the fall of 2012 with a Bachelor of Arts in Communication Studies and a minor in Animal Science. After graduation, Heather returned to Alpharetta, GA to work as a Special Education Paraprofessional at a nearby elementary school. During this time, she also applied and was accepted to the University of Tennessee College of Communication and Information graduate program. Heather returned to UT in the fall of 2013 and began her graduate career with a focus in Health Communication. During her graduate career, Heather was awarded a graduate teaching assistantship with the School of Communication Studies. She also received a graduate research assistantship with the UT Center for Advanced Medical Simulation under the Graduate School of Medicine. Heather will graduate with her Master's of Science in May of 2015 with highest honors and plans on pursuing her career in health communication.