

Sociology Senior Exercise
Identity and Survivorship: The Impact of Cancer on the Construction of the Self

Kelly Adams
2008-2009

Over the past decade, progress in cancer research and treatment has steadily increased the number of patients who survive a cancer diagnosis. Advancing effective treatments for cancer has created a new, growing population: off-treatment patient survivor populations. With nearly 10 million cancer survivors in the United States alone, there is a demand for research regarding the effect of this illness on patients and what it means for the way they relate and interact with their social world. Specifically, how does this population incorporate their experiences with cancer into their new identities as survivors? In this paper I will argue that the cancer acts as (1) a disruption to the identity, (2) a threat to identity, (3) a means to develop and take on new roles of identity, and (4) an agent to create new meaning in the lives of cancer survivors. Grounded in the work of symbolic interaction social theorists and supported by in-depth interviews, I will argue that a continuing renegotiation of identity exists as a result of the impact of cancer treatment, recovery from treatment, effects from treatment, and the burden of living with anxiety over whether the cancer may return. Furthermore, individuals cope with and make sense of the cancer experience through both identity construction and a renegotiation of the self resulting in a renewed appreciation for life.

Introduction:

Advances in cancer detection, diagnosis and treatment over the past decade have resulted in more people surviving cancer and living longer. As cancer survivorship is a rather new concept, academia is now playing catch-up in understanding issues relevant to the long-term cancer survivor. While research on survivorship has increased exponentially in the last ten years, there is still the need to explore the effects of the experience of illness, specifically chronic illness, on identity and quality of life.

Identity is an open-ended process developing and evolving in response to socialization and experiences. The self, existing both as visible attributes and abstract ideas, can be transformed by an event. Illness, such as cancer, can both threaten and change the self by different degrees of physical, psychological, and social changes. In order to look at the ways in which survivors negotiate issues of identity post-treatment, I will focus specifically in terms of social reintegration, self-identification/self-categorization, support groups, lifestyle changes, self-awareness, body perception, and meaning. By assessing the cumulative effect of these changes, I will show the ways in which these factors relate to identity transformation.

In researching a patient's newly constructed sense of self, I will also examine the transition of cancer patients to cancer survivors and what this process means for identity and self-identification. Initially, a cancer diagnosis is a central part of an individual's life as treatment requires an indefinite amount of time. Once treatment is over, patients must adjust to a number of changes in terms of the role cancer plays in their lives. There can be a feeling of loss: loss of a regimen or schedule as was present with treatment, loss of a patient's social world (doctors, advocates), and the loss of a patient identity. Cancer moves from the foreground to the background of their life.

Identity Theory

Identity is a process of endless negotiations. Individual experiences symbolically transform into social meaning and the construction of the multidimensional identity. The assessment of self and evaluation of the self by others create a social and public identity respectively (Weigart: 1986). Symbolic interactionists emphasize the meanings and intentions people construct through their interactions as well as social and cultural experiences. Mead argues that the self arises through a process of socialization and social experience. Individual

experience of the social world is crucial and corresponding internal conversations serve as self interaction. Mead emphasizes that meanings about the self are created from social interactions between people: “The self is something which has a development; it is not initially there, at birth, but arises in the process of social experience and activity, that is, develops in the given individual as a result of his relations to that process as a whole and to other individuals within that process” (Mead: 1934: 135). The self emerges socially and through a reflexive process: The “me” is the social self, and the “I” is created as a response to the “me” (Mead: 1934: 178). The self is a constant process of combining the “I” and the “me”: “The ‘I’ is the response of the organism to the attitudes of the others; the ‘me’ is the organized set of attitudes of others which one himself assumes” (Mead: 1934: 175). Individuals actively respond to the social world by taking into consideration the attitudes of others (Mead: 1934). Mead suggests the existence of a generalized other: “an organized and generalized attitude” (Mead: 1934: 195). Mead asserts that individuals reference others to define their own conduct. By viewing themselves from the view of the generalized other, individuals become conscious of their self.

Having feedback from others allows individuals to perceive themselves from a different perspective. As stated by Cooley, “the social reference takes the form of a somewhat definite imagination of how one’s self- that is any idea he appropriates- appears in a particular mind, and then kind of self-feeling one has is determined by the attitude toward this attributed to that other mind” (Cooley: 1902: 185). Cooley calls this “the Looking Glass Self”, the self which is understood as a result of the information reflected back to the individual from the judgments of those with whom one interacts. Individuals first imagine how they appear and how others judge them subsequently developing feelings about their sense of self (Cooley: 1902).

Goffman's discussion of self-presentation and impression management is relevant in understanding symbolic interactionist explanations of identity. He argues that, "every person lives in a world of social encounters, involving him either in face-to face or mediated contact with other participations" (Goffman: 1955: 332). His concept of impression management focuses on the "ways in which the individual guides and controls the impression others form of him or her" (Wallace and Wolf: 2006: 238). Encounters between individuals are processed and create an assurance of an individual's place in society. Goffman also describes stigma as an impression, categorizing two types of individuals: discreditable and discredited (Goffman: 1986). Illness or having had an illness can be conceptualized as a stigma, rendering these individuals discredited. This may cause these groups to perceive themselves as "the other" and thus weaker than their healthy counterparts. Other stigmas may include the effects of chemotherapy, radiotherapy, hormonal treatment, or surgery: loss of hair, weight loss, "chemo brain", and loss of body parts.

Wuthnow (1994) asserts that identity is closely linked to personal relationships and support groups. The collective sharing of experiences serves as both a source for comfort and finding oneself: "many say their identity has changed as a result of extended involvement in their group" (Wuthnow: 1994: 5). Groups not only acted as a source of personal identity, but also created standards of behavior for group members to adhere to.

Health and Illness in Relation to Identity

The experience of illness is fundamental to the way in which identity is created, maintained, and renegotiated. The role of identity in coping with traumatic events such as an illness is crucial. Existing research indicates that part of successfully navigating the experience of a trauma, such as a cancer, is the construction of a new sense of self (Neimeyer: 2006). Illness can act as a disruption in identity, and ultimately a means of identity transformation. Managing

identity during a crisis such as illness is an open-ended process of “identity work” (Mathieson and Stam: 1995). Cancer, specifically, acts a “threat to formed self images” including “loss of productive function, financial strain, family stress, personal distress and stigma” (Mathieson and Stam: 1995: 287). As a result, individuals must transform their identities, losing their status as a healthy person. Their new status as a patient and survivor is a role that comes with an entirely new set of societal expectations. Individuals must internalize and integrate this role as survivor into their new identity. Charmaz (1983) indicates that in order to successfully integrate traumatic experiences into new roles, individuals feel compelled to create meaning around the illness in order to regain control and make sense of their lives.

Deimling et. al (2007) approaches survivorship through addressing the issue of self-identification. They investigate what factors influence identifying oneself as a survivor including amount of time in remission, how others view them, and the degree to which the cancer experience plays a role in their life. There also exists a significant amount of research on breast cancer survivors, and what their experiences mean for the way they view themselves and their bodies (Carpenter et. al, 1999), (English et. al 2008), (Kaiser, 2008), (Ucok, 2005). These authors agree that breast cancer is damaging to women’s self-esteem and perception of their own femininity. Price (1996), Mathieson and Stam (1995), Charmaz and Paterniti (1999), and Radley and Green (1987) explore the illness in the context of the sociology of health. Using concepts of identity work, these authors explore the idea that the ill renegotiate their identity and make meaning of their illness within the context of their social relationships.

Thoits (2003) explores the effects of trauma on the self, focusing on how illness threatens the healthy self. Corbin (1988) echoes the notion that illness threatens identity as a result of

awareness of one's mortality. Illness is presented as a source of distress for individual's identity, creating conflict for the healthy versus sick identity.

In exploring the impact of illness identity, limited research exists regarding the transition period between patient and survivor. Bridges (2004) speaks to general transitions and their impact on role-specific behaviors: "Divorces, death, job changes, moves, illness, and many lesser events disengage us from the context in which we have known ourselves. They break up the old cue-system which served to reinforce our roles and to pattern our behavior" (Bridge, 95-96). He suggests that transitioning involves mixing elements of one's old identity with aspects of the new one.

The existing literature highlights the difficulty of integrating an experience of trauma into one's sense of self. While complex and demanding, this process of incorporating aspects of the cancer experience and transitioning from one phase of life into another is vital in establishing a solid sense of self for cancer survivors. Drawing on these ideas, my study will contribute research on the specific ways in which cancer survivors cope with their experiences, make sense of them, and in turn construct a new identity.

Methodology

In order to investigate the impact of the cancer experience on identity, I conducted in-depth interviews with survivors of a variety of cancers. All subjects were at least one year post-treatment, ranging in ages and both male or female. Conducting in-depth interviews lends itself particularly well to self-reflection and narrative story-telling. I created interview questions focusing on issues of identity crisis, transformation, and renegotiation. The interview questions are Appendix I. Having spent the summer of 2007 working at the Dana Farber Cancer Institute in Boston in the Lance Armstrong Foundation Adult Survivorship Clinic and the David B. Perini

Jr., quality of Life Clinic for Childhood Cancer Survivors, I had a number of survivor contacts who agreed to participate. I took a dual approach by conducting the interviews both in person and via email. In person interviews were conducted both in Massachusetts and in Ohio. I contacted Matthew Zachary, the executive of a support network for young cancer survivors called of “I’m Too Young For This” to help recruit participants. On the group’s Facebook page, Zachary posted a note about my project and that I was looking for interviewees. He included my email and phone number. Within just a few hours, I had survivors contacting me agreeing to take part in my research. One of these was Kairol Rosenthal who, upon seeing my request for interviewees, agreed to write a blog about my project and solicit more volunteers. Another posting was made on the Ohio regional group of “I’m Too Young For This.” The volunteers from this group were interviewed in person at a neutral site. Those who offered to participate but were not within driving distance were emailed the interview questions and they completed them as they found time. Once completed and returned, I began compiling the interviews and in some cases sent a few follow up questions. I also made use of snowballing to increase my sample. I conducted 24 interviews total: 11 in person and 13 through email. My interviewees were as follows:

- **Aaron:** 35 year old survivor of advanced Non-Gonadal Mediastinal germ cell Seminoma
- **Amy:** 22 year old survivor of midrange Hodgkins Lymphoma
- **Danielle:** 33 year old survivor of AML (Acute Myelogenous Leukemia)
- **McKenzie:** 21 year old survivor of ALL (Acute Lymphoblastic Leukemia)
- **Rachel:** 36 year old survivor of breast cancer
- **Tia:** 25 year old survivor of Hodgkins Lymphoma
- **Amanda:** 26 year old survivor of breast cancer
- **Beth:** 35 year old survivor of Primary Mediastinal B Cell Lymphoma
- **Norman:** 23 year old survivor of Hodgkins Lymphoma
- **Eva:** 73 year old survivor of colon cancer
- **Michelle:** 30 year old survivor of Chondroblastic Osteosarcoma
- **Sandra:** 23 year old survivor of advanced ALL Acute Lymphoblastic Leukemia
- **Emily:** 30 year old survivor of Non-Hodgkins Lymphoma
- **Kelly:** 25 year old survivor of Hodgkins Lymphoma

- **Lisa:** 36 year old Breast Cancer survivor
- **Tom:** 29 year old survivor of Hodgkins Lymphoma
- **Sarah:** 30 year old survivor of Hodgkins Lymphoma
- **Brittany:** 18 year old survivor of AML (Acute Lymphoblastic Leukemia)
- **Sophia:** 20 year old survivor of Wilm's Tumor
- **Lindsay:** 22 year old survivor of Alveolar Soft Part Sarcoma
- **Leanne:** 31 year old survivor of Neuroblastoma
- **Adam:** 33 year old survivor of Chronic Myeloid Leukemia
- **Kelly B:** 31 year old survivor of AML (Acute Myelogenous Leukemia)
- **Sara:** 18 year old survivor of Optic Nerve Brain Tumor

Taking a dual approach was helpful but also had certain drawbacks. The face to face interviews were more in depth and allowed me to ask immediate follow up questions. Despite writing follow up questions to some of the email interviewees, the interviews were altogether more disjointed. Yet, taking this dual approach allowed me to collect a large quantity of original and rich data. Email-based interviews allowed flexibility both for the interviewees and for me. I believe this was the best method for approaching my research question because it allowed for interviewees to share with me their experiences in a narrative style.

Once my interviews were completed and transcribed, I did a content analysis. I coded for self-identification/self-categorization, social reintegration, support groups, lifestyle changes, body perception, healthcare, and meaning. These categories were generated both as a response to the existing literature on health and identity as well as through my previous experiences with survivors.

Limitations of this study

Results of sociological studies are often skewed by self-selecting; that is, only those outgoing enough to share their experiences participate. This is a problem with recruiting via cancer support organizations and online social networking groups. It creates a bias in the results because respondents are the ones who have certain attitudes about survivorship. They are more

likely to value support groups and survivorship contact. My study is limited as my qualitative research only begins to answer some questions about the complexity of the cancer experience and issues survivors face. As there continues to be a growing population of cancer survivors, it is important to consider how this experience has shaped their identity and their ability to reintegrate into society. Furthermore, the endemic nature of cancer is such that most, if not all, people have been, or will be affected by cancer. Whether or not one is stricken by cancer themselves, it is likely that in one's lifetime a family member, friend, or acquaintance will face this disease. Cancer prevalence and increasing curability demands more research in survivorship.

Analysis

Through analysis of my interviews, several themes emerged. First, many of my interviewees characterized cancer as a disruption or interruption to their life and identity. As a result, cancer threatened their identity in terms of physical changes, lifestyles changes, cancer taking over their identity, the difficulty in maintaining social roles, and the fear of relapse. Furthermore, cancer propelled individuals to take on new roles in terms of career, relationships, volunteering, and social participation as well as the adoption of the role of survivor. Although the evolution into this new role was a slow and difficult process, interviewees noted that support groups and the guidance of family, friends, and fellow survivors helped in this transition. The interviews also suggested that the cancer experience gave new meaning, renewed appreciation, and a sense of purpose for life.

Disruption to Identity: "I had to put a three year pause on my life where I could not do anything except focus on staying alive."

For many, the cancer experience caused a great deal of internal disorganization and disintegration. It was an interruption of identity and normal life, rendering it difficult to maintain

a coherent sense of self (Mathieson: 1995). Whether it meant putting plans, personal issues, career, or education on hold, existing relationships and circumstances were paused in order to deal with cancer. In speaking to this idea, Tia noted, “I feel like it [cancer] doesn’t fit very well. It is more of an event that interrupted my life as opposed to a part of my life.” Michelle found that cancer suspended the life she and her husband had built: “We had forged our careers, earned advanced degrees, purchased and furnished a home and had a dog and a baby. Life was a dream! Then, cancer. Now we are living in a very different situation than we had imagined.” 21-year old McKenzie, a high school junior at the time of her diagnosis, was forced to put her identity as a student on hold in order to battle leukemia: “I had to put a three year pause on my life where I could not do anything except focus on staying alive.” Amy, another student, described her treatment as a “stagnant” period in which she concentrated primarily on being a patient, casting other parts of her life and identity aside. The life threatening nature of cancer lent itself even to temporary suspension of other identity threatening issues. Beth spoke candidly of marital issues preceding her cancer diagnosis: “My husband and I were having marital issues beforehand – we are trying to work on them now. Cancer created an interlude where they didn’t matter, but health has them right back.” A diagnosis of cancer was not only an interruption to the patients themselves, but also to family and friends. Lisa, a single mother to a three year old boy, described how her inability to care for her son during treatment as a disruption to both of their lives: “Having to be in hospital for five days (and not seeing him) and then not being able to pick him up or cuddle him for a while afterwards was hard. He stayed with my mom while I was in hospital and then we stayed there until I could go back to work...his life was also disrupted and he was out of a routine.” Interviewees emphasized how cancer and the transition into survivorship acted as a disturbance to their former lives and the process of identity formation.

Threats to Identity: “I don’t feel like myself anymore”

In addition to interposing on the lives of individuals, identity was threatened by cancer. Physical changes, lifestyle changes, and fear of reoccurrence made it difficult to maintain roles key to their identity and at times overwhelmed the interviewees’ identity as a whole. Cancer results in threats to former self-images (Mathieson and Stam, 1995). The physical consequences and implications of post-treatment disability as well as health risks resulted in their loss of status as a healthy person. Furthermore, treatment left many of the interviewees impaired or disabled which made it impossible or at the least very difficult for them to carry out daily routines. In this way, they lost parts of their perceived self. These physical changes have resulted, for many, in a loss of sense of self. Emily noted that “With the weight gain, muscle loss, and thin hair, I feel like I look like a totally different person.” For Amy, weight gain, scars, and changes in her hair resulted in a decrease in self-esteem: “I don’t feel like myself at all in my body. I put weight on that I haven’t gotten rid of. I also have two scars that I am a bit nervous to show. My hair is also different. I look back on old pictures and think they are beautiful, I haven’t quite felt that since cancer.” Beth’s treatment left her with scars and dramatically changed her physical appearance to the point where she felt unrecognizable: “I have more scars. My hair used to be long straight and auburn – it came back in black and curly. I don’t recognize myself in the mirror anymore – so I’ve stopped looking!” This loss of confidence among female cancer survivors was a common theme. Many reported feeling unattractive, unhealthy, and vulnerable: “I no longer feel pretty or desirable, really. I had a very lovely, healthy body. I was strong and energetic. Now, I have terrible scars over much of my body and I am asymmetrical and do not move gracefully.” Aaron described how undergoing treatment has left him with debilitating side effects which impede the way he lives his life: “I still have personal demons with the fight. I still fight the side effects. In

the end it's not the disease that was the hard fight for me, it is the side effects and living with that which has become the tougher battle.” The repercussions of treatment often prompted individuals to separate their physical body from their sense of self. Kelly B thought of her cancer and post-cancer body as a “separate entity” from herself. In this way, the survivors were able to cope and accept the idea that their own bodies had betrayed them.

The physical changes due to treatment have resulted in lifestyle changes including an interference to daily routine and career. Michelle became disabled due to the resection of a tumor in her pelvis and spinal column. Her daily life is now physically demanding and she is no longer able to participate in hobbies that she very much identified with.

It's a whole different ballgame. I used to be very energetic and bubbly...loved to dance around and stuff. Now, I walk with a cane and have a pronounced limp. I am very weak in my left leg. There are a lot of things I cannot do that I used to adore (mountain biking, skiing, motorcycling, etc). That has been hard to accept.

Many interviewees reported working less and being less invested in their career. In forgoing career goals, individuals chose to focus on the relationships with their families.

Before [cancer], I was planning to work part-time and return full-time once my son went to school, at the very latest. Now, I really don't care to have a career. I prefer to focus on savoring the next precious years with my son, one day at a time. I still have interest in the professional world, but I hope to stay on disability and be able to volunteer my time to help others, rather than return to work. I want a low-stress future.

As a result of drastic physical and lifestyle changes, cancer survivors struggle with the way in which cancer and its impacts overwhelm their identity. Amy described the difficulty in not allowing cancer to take over her sense of self: “I’m trying not to lose the fact that I did have cancer and it influenced who I am today in all aspects, and trying not to rely on that fact too much either.” Amanda echoed these notions as a survivor having enduring cancer. She feels as though she has been stripped of her pre-cancer identity: “I feel like I’m not the same person

anymore... I don't feel like myself anymore." In trying to avoid this dilemma, Michelle described trying to separate herself from her experiences with cancer: "I almost prefer to leave my cancer experience behind me and move forward." The struggle for survivors to negotiate how to integrate cancer into their new lives will be further investigated later in this paper.

The experience of cancer and the transition into survivorship was problematical for maintaining roles key to identity. Role-identities both give individuals a sense of purpose and belonging and define the self (Thoits: 2003). The effects of illness on different roles control the degree to which an individual's physical, social, emotional, psychological, spiritual, and financial well-being is affected. When an individual is unable to maintain roles which are salient to identity, the overall identity associated with those roles are undermined (Thoits: 2003).

Michelle, a mother of a toddler who was became physically disabled as a result of her Chondroblastic Osteosarcoma, found that her role as a mother was threatened due to her treatment:

I feel shame. My husband's family tried to be supportive and moved in with us to help me care for our son. It ended up being a really negative experience for me because I felt like a lot of my motherhood was robbed from me. In addition to all I was going through, I lost the role I had as a mother. I was no longer the only one caring for my baby and raising him...I wish I could run alongside my son...Fortunately, I am able to care for him alone and be his Momma, which is what I most want in this world. I am limited and handicapped, but at least I am independent and functioning.

The experience of illness conflicted with Michelle's role and status as a mother. In the same way, McKenzie's identity as a high school student was threatened by cancer.

Norman, a former member of the Corps of Cadets at VT, also had to abandon this identity because his cancer took away his chances at becoming a naval officer.

Fear of reoccurrence prompted individuals to live in the moment and promoted a heightened self-awareness and consciousness of personal mortality. Life threatening illnesses

such as cancer yield shocking awareness of one's own mortality and can ultimately result in a discontinuity between past and future self (Corbin and Strauss: 1988). Subjects reported that paranoia, fear, and awareness changed the way they live their lives. Beth describes her perception as having one shot at everything "It makes me make sure that I do my best and fullest every day. I can't screw up because I might not have the chance to make it right again...It's an awful way to live because there is a lot of pressure to live right." Amanda experiences hypersensitivity in terms of any ailments which brings on a fear of relapse: "I'm now in this overly paranoid mode when it comes to everything about me. If I'm having chest pains, the back of my mind thinks, 'what if it's back'." Contrary to the majority of participants, Rachel noted that she did not allow her fear to change her behavior: "I am fearful I am not done with cancer altogether, although this does not change the way I live my life." For others, fear acted as an agent to propel individuals into new roles and a new purpose; "It's always in the back of my mind to not take for granted that I am standing above ground. It gives me purpose now."

In feeling grateful for surviving the treatment, cancer acted as means to taking on new roles and social reintegration. In order to renegotiate their identities, individuals must internalize these new roles and perceive them as having meaning (Charmaz, 1993). Survivors joined support groups, and online networks to stay connected with fellow survivors and provide encouragement for those undergoing treatment. They also became involved in cancer based organizations by volunteering or acting as mentors at events such as Camp Make-A-Dream, Relay for Life, American Cancer Society, and the Light in the Night Walk. Some even made career or educational changes. Danielle, for example, became the Director of Programs and Services for Bear Necessities, a pediatric cancer charity. Amy changed her major from interior design to psychology in order to pursue a career in helping those with cancer. Others felt the

need to reach out to others in similar positions and assume on the role of caretaker: “I am always very candid on my survivorship. Because I met a wonderful person the day I was diagnosed, I felt I needed to do the same for others.” Cancer impelled survivors to take on new roles, especially ones that involved the disease that they battled.

Physical setbacks from treatment result in the loss of the interviewees’ healthy identity. In response to changes in appearance and inability to engage in activities, they were forced to abandon pieces of the former self. As a result, individuals sought out new, meaningful roles in order to cope with the loss parts of their old identity.

Relationships and the Social Construction of Identity

The occurrence of cancer creates stress for both the patient and their loved ones. Many of the interviewees supported the notion that because of the role of the family and others in supporting those with cancer, they are all survivors of the experience. Some friendships were strong enough to withstand the stresses of cancer; “my old friends are still my best friends. Cancer can't change that.” Others were not able to endure the trials or tribulations of cancer: “Other friendships have disappeared because people have abandoned us. They were either too busy in their own lives to become involved in ours or too afraid to see me in that manner.” Romantic relationships were also changed through the experience of cancer. Tia felt a positive effect; “I think my boyfriend and I are closer after having gone through that.” The cancer experience interferes “having cancer disrupts intimate relationships, and generally reorganizes the geography of social function” (Mathieson et al.:1995: 300). Michelle felt that cancer changed the nature of her relationship with her husband: “we all bear the scars (emotional and physical) from this journey...I feel a lot of joy has been dampened. My hubby and I are no longer the footloose and fancy-free lovers of the past.”

How others responded to the interviewee's cancer was significant for their identity and the social construction of survivorship. People who were a part of the pre-cancer life often had trouble or caused trouble for the survivor in integrating cancer into their identity, while other people connected with cancer helped in this process.

Emily described how the support she received from family, friends, and even strangers gave her strength:

People I thought I would never hear from again have come out of the woodwork and have now become my best friends. During my first two weeks in the hospital I must have received at least 50 cards from co-workers and friends. They were all very encouraging and offered help. I had people bring me comfort food and games to play with during my hospital stay. Even complete strangers sent me stuff to pass the time... In retrospect, all of these things made me feel like I could beat cancer and it was not as bad as it could have been. Being surrounded by so much support made it feel like less of a death sentence."

On the other hand, Kelly B recalled that the overwhelming support of her community caused others to identify her as just a cancer patient:

I come from a small town, which has its benefits and drawbacks. People I had never met came to the hospital to pray for me. Churches I had never attended held fundraisers for me. An entire community rallied around me. But with that, I became 'cancer girl.' My friends joked that it had become like 'Ferris Bueller's Day Off' – Save Ferris!

Kelly B also describes how the judgments of those with whom she interacted with were reflected back onto herself as described by Cooley's "Looking-Glass Self." "Surviving cancer makes everyone look at you as a strong person, whether they were there through the process or not." The survivors internalized the judgments about their status from those around them (Cooley: 1902).

Cancer survivors were forced to manage other's impressions of their self. In losing their healthy identity, they were stigmatized not only for elements of their current self, but also for the

reasons why they got cancer in the first place. Post-cancer identities were socially constructed by those around them and internalized by the individuals themselves:

There is no known cause of leukemia. It can literally strike anyone from marathon runners to couch potatoes. However, I was overweight and had smoked cigarettes, drank alcohol and smoked marijuana a few times in college. At first, I felt that maybe if I had treated my body better it wouldn't have happened. And I thought that others might think that as well.

Because Kelly B believed others may judge and deem her unhealthy lifestyle the cause of her cancer, her own feelings about the origin of the disease were affirmed. Sarah felt discredited by the label of unhealthy which was attributed to her: "they only knew me as weak and sick and needy. They no longer knew me as healthy and alive and relevant. People would sometimes treat me like I didn't have the experience to talk to them about their life - they just had a hard time thinking of me in that way." Goffman holds that this stigmatization creates discredited individuals (Goffman: 1986).

As a result of this stigmatization, Adam, a survivor of Chronic Myeloid Leukemia, felt he had to downplay or all together hide his identity as a cancer survivor: "I don't tell people about my cancer at first until they get to know me...I find that people treat you differently when they find out you beat cancer. I give them a chance to know me first, then I decide whether or not they need to know." Not only did survivors fear that cancer would overwhelm their identity, they worried that others would view them primarily as someone who battled cancer and treat them accordingly.

Along with this stigmatization came an increasing demand to act and look the way a cancer patient should. After enduring 2 years of treatment including surgery and radiation, Lindsay remembers how

rumor flew that I was dying...I was stared at. People would ask whether I was going to lose my hair...such petty questions. I realized there is such a stereotype

that goes along with cancer. Just because you have cancer doesn't mean you are bald and sickly...I was not... You have an enormous amount of pressure from the day of diagnosis to beat this disease.

This pressure to act in accordance with societal standards of illness grew out of misconceptions about treatment and cancer in general.

Some people in the lives of the interviewees were unable to support or understand what the experience of cancer was for that individual, or even how it now to fit into his or her life. Friends or family members filled the lack of knowledge with expectations of normalcy which ultimately only alienated the survivors. The stigmatization of these individuals as unhealthy rendered them isolated. Adam continues to find that

People who have never had a near-death experience of any kind have no clue what they're talking about. They simply can't relate. It's not their fault, but I've found that people will try to compare their 'near death' experiences with mine and they usually come off sounding like morons. How can you even compare a week long flu with what I went through? But, I guess it's human nature to try and relate to someone else, and when the worst thing you've been through in life is a week long flu, it's what you work with I guess.

In other instances, survivors were actively alienated by their friends: "a couple of friends because they could not deal with what I was going through so they distanced themselves. I saw this as them rejecting me when I needed them the most and so I have cut some of them out of my life completely." The response of the social world offered either feelings of empowerment or disempowerment. Survivors were apt to describe their experiences as negative and themselves as sick or weak if those around them responded to them in that way.

Self-identification and Self-categorization: "You beat cancer, you can handle this!"

Social space links individuals together in patterns and forms by which individuals interact and associate with one another. Simmel argues that this acts as a process of self-identification and definition. Individuals play an active role in internalizing their interactions: "if men define

situations as real, they are real in their consequences” (Wallace and Wolf: 2006: 202). Self-identification and self-categorization occur through the act of adopting the survivor title. As a result, individuals take on a new role as survivors, gain empowerment, and reintegrate themselves into society. Before advances in oncology, the term cancer survivor was often used to describe those loved ones left behind after a patient succumbed to cancer. As rates of survival of diagnosed cancer patients increased, the term came to be defined as “those who lived beyond 5 years with no evidence of disease” (Ganz: 2007: 9). Now the term is even more broadly applied by cancer patients; many agreed that everyone diagnosed is a survivor: “Once you’ve been diagnosed, if you’re still alive, remission or not, I think you are a survivor.” The term survivor is one of empowerment, as it implies having survived the disease. Amy describes feelings of victory and strength from having beaten cancer; “I identify myself as a survivor because cancer is the most difficult thing that I have ever been through. I sometimes refer to it as a “battle.” I feel that I lived through the battle therefore I am a survivor.” 21-year old McKenzie depicts her survival differently, separating the physical fight from the emotional one and subsequently disentangling her body from her self:

to me, in a way, I didn’t do anything, just let doctors inject me with chemo. My body survived it. What I did myself was to survive and get through it mentally and emotionally. I survived it just because the days went on and I couldn’t stop them, I didn’t have a choice. The choice I did have was to accept the positives of it and let it affect myself for the better.

Taking on the survivor title also encapsulated the meaning of pride and empowerment:

“It is a title I have earned and deserve to wear proudly.” Danielle exclaimed, “survivorship is empowering, I often tell myself, ‘you beat cancer, you can handle this!’” Similarly, Sandra described the nature of the role of being a survivor, even equating it with her other major roles: “cancer shapes your life whether you wanted it to or not. I am alive today as a cancer survivor

and a lot of undeniable baggage comes along with it. As much as I identify myself as a new wife, daughter, sister, homeowner, I am also a survivor.” Rachel, a breast cancer survivor who had bilateral mastectomy and didn’t require chemotherapy, described feeling as though she had not ‘earned’ the title cancer survivor: “At times I feel I ‘cheated’ by not going through chemo.” This emphasizes the idea that survivorship is an accomplishment highly valued by our society.

Calling oneself a survivor didn’t mean the experience of cancer was over: Aaron explained that although he is cancer free, he lives with the physical effects of his treatment everyday: “I am consistently feeling as if I have to explain myself to friends and family that even though I am a 'survivor' of cancer I am still a fighter of the side effects.” A minority of my interviewees rejected cancer as a part of their identity entirely as they transitioned into survivorship; they wanted to move past this “phase” in their lives.

Transitioning From Patient to Survivor: “Just like anyone, finding my place in the world is a constant learning process.”

Adopting the title and role of survivor and transitioning into a survivorship mode proved to be a lengthy and difficult process for many. Difficulty in resuming regular life after their treatment ended was experienced by all interviewees. Part of that obstacle in transitioning was losing the identity of a patient and the social network that comes with that title: “For the first few months I was scared and I panicked. I no longer had my best buds, my nurses, to talk with, give me support, tell me everything was alright. That my pains in my legs were side-effects, and not cancer again. That my chemo-brain was gonna be a challenge. I had to find a new source to help me get through it now.” As a result, many of my interviewees joined support groups or contacted fellow cancer survivors to replace their hospital social networks. Kelly B, a survivor of Acute Myelogenous Leukemia, found the transition from patient to survivor more difficult than the

cancer itself: “No one prepares you for the transition. When you are diagnosed, the doctors and nurses prepare you for all the things you will experience – hair loss, pain, nausea, depression, etc. But on the day you are released for good, no one tells you what to expect. Then you get home and think “Now what?” For many, this transition is still a work in process. Tia anticipated that her transition to be swift and transformational, however, she found that the process was slow especially in terms of returning to work:

I expected that on the last day of treatment, or at least on the day I received my clean bill of health, that I would be elated and things would be different. But actually I think the change back to normal was much more gradual. I think other people actually needed to remind me of how important those milestones were. Getting back to work after being off for about 8 months has been extremely difficult and I am still not back to my full time work load. I had to take leave in the middle of working on a promotion and as a result that has been put on hold for an extremely long time.

For Beth and Amy, six months of treatment and three years off treatment respectively, they are both still working to assume survivorship. “I don’t think I have [transitioned from a patient to a survivor] – people expect you to resume life where you broke off,” Beth described. This evokes symbolic interactionist theory; individuals internalize societal expectations about their roles. Amy struggles to find the balance between her role as a survivor and a regular young adult: “I feel that I am still working on that. I call it ‘my balance’ of being a cancer survivor and also being a 22-year old young woman who is trying to move on in life and make decisions that will impact the rest of it. It’s hard.”

Returning to the life before cancer while balancing and internalizing their experiences with cancer proved to be an arduous task for many. Danielle expressed her struggle: “I had to relearn how to live a normal life. The biggest challenge is learning how to balance living for the moment and planning for the future.” The transition back into workforce proved difficult for

many. Adam described how going back to work was “100 times worse than just coming back from vacation and forgetting how to do your job. I actually doubted that I could do my job.”

Her inability to return to her normal, pre-cancer routine was and still is increasingly frustrating for college student, McKenzie.

It was a very long transition, in fact, it is still going on. I lost my entire body muscle, so I had to relearn how to walk, which was one of the first and most basic step. I had to readjust myself to everyday life and school. I hadn't been in school for over four years when I decided to go to college so I started out with three classes and am working my way up. For everything, like, amount of time each day that I sleep, exercise and schooling I started small and didn't set my expectations too high and eventually became more and more “normal” with a regular routine. Although I am two years done with chemo, I am still on some pain medications, which make me tired a lot with not a lot of energy. It limits my activities, like the amount of classes I can take because I don't have enough energy. It is frustrating that my physical health is still what is holding me back, because it has been for so long. I am ready to be fully healthy and not have it be holding me back. Most 21 year olds don't have their physical health holding them back, in fact, they usually don't even have to think about their health, they just assume they'll always have it.

Michelle echoed the notion that her health continued to play a large role in her life post-treatment, making it extremely difficult to resume her pre-cancer life.

It was like, ‘OK...so this is what I'm left with.’ It's hard to see the end of the road sometimes. Everything feels permanent until it changes. It was a big deal to go through so much physical therapy. Everyone thought that since the cancer was behind me that I would be good-to-go. This has been such a long road. I feel like the journey is never really over once you've been put on this road. This is something I need to deal with for the rest of my life. I still have to go to Houston once every three months for scans etc. even though I've been off-treatment for a year. I will be going to Houston, meeting with my doctors and surgeons, for the rest of my life. Every time I go to the doctor's, get my teeth cleaned, take a medication, I have to detail my entire health history yet again.

The existence of the experience of cancer, and the psychological and health effects that come along with it, within the identity of survivors is thus permanent. The ways in which individuals choose to express this portion of their identity varies.

Support Groups: “You share such a special bond knowing that you had both survived this dreaded disease.”

Most of the interviewees participated in support groups both during and after treatment. Sharing and relating to each others stories helped solidify their identities as survivors: “the people with whom they relate form a primary means of identity” (Wuthnow, 26). This suggests the importance of a structured support for both patients and survivors of cancer. In addition, educational resources for family and friends are necessary in order to anticipate and understand the survivor’s experience and offer guidance or support. In order to ease the transition from patient to survivor as well as find help in negotiating a new identity and lifestyle, many interviewees noted that attending support groups aided in this process. Kelly B explained that she “found the process of returning to normal life daunting, and sought guidance from others who had already been there might help.” Attending support groups or finding online cancer survivor networks helped the interviewees come to terms with their experience and with the challenges of reintegrating into their social world. Lisa was comforted by finding others who could relate to her experience both as a patient and a survivor:

Someone that knew exactly what I was going through and could tell you that it is ok, that is was normal to feel the way I did and to reassure me that I would get through it. Your family and friends can only say so much, but not going through the treatment themselves they have no idea what it is that you are going through so talking to someone that had been there before was a great help... You share such a special bond knowing that you had both survived this dreaded disease.

Tom found that participating in a support group made the transition easier: “It was a very emotional time and I found it comforting to be in a situation where I could just ‘be’ and speak without having to explain all the terminology that I had picked up at the hospital.” Even 12 years later, Sara still finds it easiest to relate to friends from her

support groups: “My cancer survivor friends know what I am going through more than anyone can.”

Conversely, a minority of my interviewees did not engage in support groups as they felt it prevented them from moving on with their lives. Adam asserted that, “When cancer survivors get together, cancer seems to be all we talk about. I’m tired of sharing war stories with other survivors because it puts me right back to where I was mentally 4 years ago.” As I only had a small sample of male respondents, this could also be attributed to gender differences in seeking social support networks.

Meaning: “How do I go back to doing an unimportant office job when there are so many more important things to life?”

The survivor identity was described as being characterized by a renewed appreciation for life and sense of purpose. Those who embrace this identity often consider cancer a gift and found greater meaning in life. Most, if not all, found meaning in both having had cancer and the transition from patient to survivor: “how individuals begin to understand the meaning of cancer, understand cancer’s effects on the self, begin to integrate illness-related changes in the self or formulate a new self” (Carpenter et al.:1999: 1403). The question of how to live ones life after cancer involved shifts in priorities, change in values, new orientation to life, as well as a new worldview or sense of purpose. Aaron’s transformation and sense of meaning in his experience was most apparent:

I took it to mean that I had no purpose in my life and I needed something in my life that was more meaningful. Something that made me put the brakes on and evaluate myself. Learn who I was and what my purpose was for...pre-cancer, I was a soul with no purpose. I now have a drive and a purpose in my life. My eyes are wide open... Cancer made me stop and go 'WAIT!' Life doesn't just come to you. You have to provide your motivation. You have to set goals, you have to plan ahead, you have to want to be part of what’s going on around you!

Individuals made meaning of their experiences in such a way to inform understanding of self (McAdams, 1993). For Aaron, finding such meaning in his experience transformed his identity: “I feel as if I have been given an opportunity to do something special. To no longer be Aaron in Akron. To be a voice to other survivors, for other survivors. It's my passion to give others strength now.” They found lessons and new strength “because of” or “in spite of” the traumatic event or illness. McKenzie communicated that, “I learned such a great amount of important things while going through chemo. I wish everyone could have learned the lessons I've learned but not have to have cancer to learn them. Maybe a purpose of me having cancer was to help others understand and spread my knowledge to other people, to help them to learn and appreciate life.” Meaning was also found through establishing a connection to religion. Sandra described forging a stronger bond to God: I believe more in the higher power of God and that there are reasons for why I am a survivor. I believe there is a path for me already laid out and I just need help in heading the directions I need to go.”

Many interviewees grappled with the question of how to lead their lives after having gone through the experience of cancer. Adam struggled to return to his old life and job, asking himself, “how do I go back to doing an unimportant office job when there are so many more important things to life?” Sophia found that after cancer, any other trials in her life seemed inconsequential: “I mean if I can beat cancer, it makes other challenges I face seem pretty trivial.” For Kelly B, integrating her experiences with cancer into a new way of living proved to be a balancing act:

Cancer can be both a blessing and a curse when it comes to your outlook on life. Now, when something comes along that might have upset me before, I can think “well, at least I don't have cancer.” To steal a phrase, it helps me not sweat some of the small stuff in life. But on the other hand, I sometimes feel as if I can't really get upset about anything. Who am I to complain about an annoying co-worker or someone cutting me off in traffic – I'm alive and well and cancer-free.

I've had to learn the balance. No, some problems in life seem so insignificant now, but I'm not Gandhi. If I have a bad day, I'm allowed to be whiny or irritable or overwhelmed sometimes. Having overcome such a big obstacle doesn't permanently erase all the small problems.

Taking meaning from an experience and applying it to one's view of the world proved to be a challenge for the survivors.

In addition to seeking meaning in their lives post-cancer, a number of survivors described a pressure to live "life right" and with meaning. Kelly B characterized this pressure both as a "call to responsibility and leadership" and a "burden." In beating cancer she felt that it was her duty to "do everything in my power to help someone else" and to "do something great with [her] life." Sophia described her battle with cancer as

a force of empowerment in my life, but also a source of pressure. I see how much I can accomplish in the world around me and yet feel the pressure of living up to my own expectations. I want to use this second chance to make a difference in the world but often times feel that no matter what I do it is not enough. That somehow I will never be able to give back enough.

This pressure to live right and find meaning in their experiences was difficult in the context of construction of their identities.

Making Sense of Cancer: "Cancer remains a mystery to me"

Making sense of the experience and how to incorporate it into their personal identity was a challenge cancer survivors faced. Although many of the interviewees found some sort of meaning in their experiences, they expressed a struggle in making sense of their cancer and their experience with it. Respondents react in various ways to cancer inexplicability. Amy said, "to be honest, I don't think I really have wrapped my head around that fact of how huge cancer really is and that I lived through it. It hasn't really hit me yet and I am a bit nervous for that day." Tia did not assign any meaning to the experience: "Maybe someday we will find out the cause and be

able to avoid getting it, but until then, it is just a random thing that hits some people. I don't think there's any meaning or sense to it." McKenzie expressed that perhaps she may never be able to make sense of cancer:

I think I will be facing that question for the rest of my life. I have lots of ideas, it doesn't have one answer. I am grateful that I went through what I did because it made me who I am and gave me the outlook I have. Some people will never learn the things that I have, and I learned it at a young age. I do not know why I got cancer, I had no control over it but since I got it, I'll do my best with it.

Much as identity is never static, making sense of cancer is an ongoing process. For Danielle, the concept is still perplexing:

cancer remains a mystery to me, I don't know if it's a cell gone wrong or a path to a higher spiritual role in my next life...I have not made sense of cancer; I've seen such sadness and things that seem unfair, so I am waiting for my explanation after my own death. I imagine myself standing at the heavenly gates tapping my foot with my arms crossed waiting for God to show up and do some explaining!

Similarly, Tom exclaimed: "I'm looking forward to some answers. Life, it's bonkers!"

Many linked cancer's inexplicability to bad luck. Adam described this as:

Cancer is an anti-lottery. Sometimes you hit the jackpot and get a disease that 1 in a million have. You can do things like smoke to get a higher chance of winning the anti-lottery, or you can just have dumb luck and hit the jackpot like I did. It boils down to probability and dumb luck (or unluck as the case may be).

Rationalizing cancer in this way allowed survivors to accept that this happened to them. In accepting this as part of the fabric of their life, cancer survivors were able negotiate a new, balanced identity of their former self and their experiences with cancer.

Summary of Analysis: Challenges and Aids to Identity Reintegration

As noted, individuals felt that their identities were threatened by the role of cancer survivors. Yet, they also faced risk of not being able to integrate this experience into their identity at all. Social ties, people's lack of knowledge about the disease, and the late-effects of

treatment reinforced this risk. Many of my interviewees were successful at finding methods to balance their experiences with cancer and the rest of their identity. Even those who felt as though this was still a process were at the very least conscious of its importance. For those who were succeeding or consciously addressing this problem of reintegration, they were doing this by acknowledging that cancer was a defining feature of their lives, but that it did not define them. Sara eloquently described this conciliation: “I’m not a cancer survivor named Sara, but I am Sara who is a cancer survivor. It doesn’t own me, but I own it. It is part of who I am, not all of who I am. It is part of who and what I’ll become. It will always be a part of me.” Norman echoed this notion: “there is much more to me than just surviving cancer.” For some, like Kelly B, moving away from the small, supportive hometown allowed her to find her true self in relation to her cancer: “Once I felt able physically, financially, emotionally and spiritually, I chose to move from Alabama to Georgia. It helped me re-establish myself as just Kelly, instead of the young Bearden girl with cancer. And I think it also helped my hometown see how I had moved past the cancer.” Removing herself from a community who defined her as the “girl with cancer” allowed Kelly B to restore her identity, incorporating cancer as she saw fit.

Finding where, how, and to what extent cancer fits into their lives was and continuous to be a slow process of balancing experiences. For some, the role of cancer survivors fades in and out of their lives:

my identity as a cancer survivor has recently re-entered my life...I am only now taking charge of my identity as a cancer survivor...I am coming to realize where my experience with cancer fits into my life. That while it may not be the happiest memory I have, it played a huge role in making me the person I love today...Reclaiming my identity has not only meant thinking about the past, but also looking forward to the future: researching the latent affects of my treatment and trying to keep myself cancer free for another 15 years. At times it has been a reality that is difficult to reconcile, but I wouldn’t trade the person I am today to erase my cancer story.

My interviews suggest that a strong social network, support groups, and accepting survivorship were most helpful in this identity transition. Emily expresses the way in which support groups helped her integrate her experiences with cancer into her life and thus negotiate a new identity:

I make sense out of the cancer experience (treatment, recovery) by talking about it. I am very open about my experience. Some people don't understand why I talk about it or how I could talk about it, but I find that if I talk about it I am in control of it. I "own it." It doesn't own me. Cancer isn't the only thing that defines me, but it is a big contributor to who I am today. To not talk about it is like denying the person I have become and want to continue to become.

In lacking such an avenue for expression, Sophia recognized its importance: "sometimes I really wish I had a friend who had gone through a similar experience. When I bring it up to others, they find it hard if impossible to relate." Adopting new roles aided in identity reintegration. These roles included participating in new activities, organizations, careers, majors, or social networks. Engaging in new roles and activities was key to survivors' identity integration.

The analysis of my interviews has assessed identity conflict as a result of cancer. Most viewed cancer as a disruption or interruption to their life and identity, a threat to their identity, and an experience which changed their social roles. Physical changes, lifestyles changes, and fear of relapse threatened the former self leading some to feel as though cancer was beginning taking over their identity. Negotiating the extent the role the cancer played into their identity proved to be a difficult task. Many individuals took on new roles in terms of career, relationships, volunteering, and social participation all as a result of adopting the title of survivor. Through the restoration of their identity, survivors found that the cancer experience gave new meaning, renewed appreciation, and a sense of purpose for life.

Suggestions for Further Study

Research on survivors is not only important for that specific population itself, but also for newly diagnosed individuals who may want to know what they might experience in terms of identity. Education for family and friends is also a vital aid in the negotiation of elements of identity for survivors. Further research is needed to create resources and supportive environments for those surviving cancer. Research on gender differences in terms of coping, dealing, and processing issues of survivorship is also needed.

Conclusion: “I do believe that everything happens for a reason. You may not know the reason why something has occurred until months, or even years later, but everything happens for a reason.”

In this paper, I have analyzed excerpts from my interviews with cancer survivors in order to discuss the implications of the cancer experience on social identity and sense of self. I argued that the cancer experience is (1) a disruption to the identity, (2) a threat to identity, (3) a means to develop and take on new roles of identity, and (4) an agent to create new meaning in the lives of cancer survivors. Foundational ideas from symbolic interactionists were essential in explaining both the social construction of cancer survivorship and the formation of the cancer survivor identity. Cancer survivors engaged and coped with survivorship through social interaction: defining themselves in relation to others. Ultimately, individuals make sense of experiences, such as cancer, and use them as identity construction. In doing so, they find not only new meaning but a new sense of themselves. Thus, at the very core of the cancer survivor experience is a renegotiation of identity that exists not only as a permanent result but also as a coping strategy.

Bibliography

- Bridges, William. 2004. *Transition: Making Sense of Life's Changes*. 2nd Edition. Perseus Book Group.
- Carpenter, Janet S., Brockopp, Dorothy Y., and Andrykowski, Michael, A. 1999, "Self-Transformation as a Factor in the Self-esteem and Well-being of Breast Cancer Survivors." *Journal of Advanced Nursing* 29: 1402-1411.
- Charmaz, Kathy and Paterniti, Debora A. 1999. *Health, Illness, and Healing: Societal, Social Context, and Self*. Los Angeles: Roxbury Publishing Company.
- Charmaz, Kathy. 1983. "Loss of self: A fundamental form of suffering in the chronically ill." *Sociology of Health and Illness* 5: 168-195.
- Charmaz, Kathy. 1987. "Struggling for a self: identity levels of the chronically ill." *Research in the Sociology of Health Care* 6: 283- 321.
- Charmaz, Kathy. 1993. *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Cooley, Charles Horton. 1902. "The Looking Glass Self." Pp. 184-186 in *Social Theory: The Multicultural and Classical Readings*, Third Edition, edit by Charles Lemert. Boulder, CO: Westview Press.
- Corbin, J. & Strauss, A. 1988. *Unending work and care: Managing chronic illness at home*. San Francisco: Jossey-Bass.
- Deimling, Gary, Bowman, Karen, Wagner, Louis J. 2007. "Cancer Survivorship and Identity Among Long-Term Survivors." *Cancer Investigation* 25: 758-765.
- English, Jennifer, Wilson, Kathi, and Keller-Olaman, Sue. 2008. "Health, Healing, and Recovery: The Therapeutic Landscapes and the Everyday Lives of Breast Cancer Survivors." *Social Science & Medicine* 67: 68-78.
- Ganz, Patricia A. 2007. *Cancer Survivorship: Today and Tomorrow*. Los Angeles: Springer Publishing.
- Goffman, Erving. 1955. "On Face-Work." Pp. 332-336 in *Social Theory: The Multicultural and Classical Readings*, Third Edition, edit by Charles Lemert. Boulder, CO: Westview Press.
- Goffman, Erving. 1986. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.

- Kaiser, Karen. 2008. "The Meaning of Survivor Identity for Women with Breast Cancer." *Social Science and & Medicine* 67: 78-79.
- Mathieson, Cynthia M. and Stam, Henderikus J. 1995. "Renegotiating Identity: Cancer Narratives." *Sociology of Health and Illness*. 17: 283-306.
- McAdams, D. P. 1993. *The Stories We Live By*. New York: William Morrow & Company, Inc.
- Mead, George Herbert. 1934. *Mind, Self, & Society: from the Standpoint of a Social Behaviorist*. Chicago: University of Chicago Press.
- Neimeyer, R. 2006. "Re-storying the loss: Fostering growth in the posttraumatic narrative." Pp. 68-80 in *Handbook of posttraumatic growth* edited by L. G. Calhoun & R. G. Tedeschi. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Price, Bob. 1996. "Illness Careers: The Chronic Illness Experience." *Journal of Advanced Nursing* 24: 275-279.
- Radley, Alan and Green, Ruth. 1987. "Illness as Adjustment: A Methodology and Conceptual Framework." *Sociology of Health and Illness* 9: 179-207.
- Thoits, Patricia. 2003. "Personal agency in the accumulation of multiple role-identities." Pp. 179-194 in *Advances in identity theory and research* edited by P. J. Burke, T. J. Owens, R. T. Serpe, & P. A. Thoits. New York: Kluwer Academic/Plenum Publishers.
- Ucok, Ozum. 2005. "The Meaning of Appearance in Surviving Breast Cancer." *Human Studies* 28: 291-316.
- Wallace, Ruth A. and Wolf, Allison. 2006. *Contemporary Sociological Theory: Expanding the Classical Tradition*. Sixth Edition. New Jersey: Pearson Prentice Hall.
- Weigert, Andrew J. 1986. *Society and Identity*. London: Cambridge University Press.
- Wuthnow, Robert. 1994. *Sharing the Journey: Support Groups and America's New Quest for Community*. London: The Free Press.

Appendix I: Interview Questions

Age:

Type of Cancer:

Age at Diagnosis:

At what stage were you diagnosed: (ex: Early, Midrange (no metastases), Advanced (metastases)

Type of treatment (ex: surgery/radiation, chemo, other):

Length of treatment:

How long have you been in remission?

Where you in the first in your family or within your group of close friends to have cancer?

Did you feel as if there was any stigma attached to the type of cancer you had?

Did you attend support groups during treatment?

If yes

How often?

Where?

How big of a group?

Why did you choose to attend?

What was most helpful about the support group?

What was least helpful about the support group?

Did you attend support groups after your treatment was completed?

If yes

How often?

Where?

How big of a group?

Why did you choose to attend?

Was it helpful?

Are you in contact with other survivors? Why or why not?

If you are in contact with other survivors, how do you communicate with them? (by email, telephone, in person)

Are you involved in any volunteer work which is related to cancer?

Do you identify yourself as a survivor? Why or why not?

What does survivorship mean to you?

What changes, if any, have you made in your lifestyle post-treatment?

What things are different about your life now and before you had cancer?

What has changed, if anything, about your outlook on life?

What has changed, if anything, about your self-perception? How so?

How have your experiences with cancer impact your self-hood or sense of self?
What is different about yourself?

How have your experiences with cancer impact your perceptions of the world and your relation to it?

How have people responded to your cancer? What have they said, or done which has been helpful or not helpful? Did any of these things change the way you thought about yourself or about having cancer, or about beating cancer?

How have your goals changed after facing cancer? Why or why not?

Do you find it difficult to relate to non-cancer survivors due to your experiences? Why or why not?

How have your experiences with cancer shaped your relationships with your family and friends?

How, if at all, has your perception of your body changed?

How, if at all, have your perceptions about the health care system changed?

What was it like to transition from a cancer patient to a cancer survivor?

What were some the challenges specifically?

Are you afraid the cancer may come back? How does this affect the way you live your life?

Have you developed new relationships as a result of your experiences with cancer? If yes, with whom?

How are these different from other relationships you had before cancer?

How do you make sense of cancer?

How do you make sense of your experiences with cancer?

How does the cancer experience fit into your life?

What does cancer mean to you?

How does having had cancer impact your perceptions of the future?

Have you found a greater meaning to your life as a result of beating cancer?

What is the most significant change in your life that has taken place as a result of the diagnosis?