

“WE’VE DONE DRUGS KEITH RICHARDS NEVER HEARD OF”:

A QUALITATIVE STUDY OF YOUNG ADULT

CANCER NARRATIVES ONLINE

by

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The purpose of this thesis is to explore the communication young adult cancer survivors develop to cope with the cancer experience. This qualitative study incorporates interviews with 16 young adult cancer patients. Working within the framework of Charland's (1987) theory of constitutive rhetoric, the data reveal that young adult cancer patients do not believe that they are a part of the dominant cancer narrative. However, through the use of Web-based communication resources, young adult cancer survivors are developing and validating alternative cancer narratives that better encompass their experiences with the disease. The results of this study expose the marginalization of this segment of the cancer community and show how the participatory nature of the virtual world empowers the young adult cancer population to reconstitute cancer by developing and validating more inclusive cancer narratives.

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CHAPTER I

INTRODUCTION

Preface: The Diagnosis

My best friend sat across the small, sterile room and looked at me, her eyes filling with tears as my oncologist described common side effects of chemotherapy and radiation treatment. My body may be shocked into premature menopause. I might lose my fertility. I could experience extreme nausea. My hair would almost certainly fall out and I would face exhaustion so extreme that one patient had described it as a “full body meltdown.”

Karen and I met in college when we lived in the same dorm freshman year. We had seen each other through numerous boyfriends, difficult classes, the launch of our respective careers, and countless nights out reveling in the endless opportunities available to healthy, young 24-year-olds living alone in Boston. As we walked out of the cancer center that day Karen broke down sobbing and I hugged her crooning, “it’s okay, it’s going to be okay.” As I comforted the friend who had attended this appointment intending to provide a shoulder should I feel the need to cry, I realized this experience was going to change my life irrevocably.

I was diagnosed with Hodgkin’s disease, a form of lymphatic cancer more common in young adults, in February 2005. A cancer diagnosis was one of the first things that Karen and I could not share. She would hang out with me in the chemo room

watching “Sex in the City” DVDs while the caustic drugs dripped into my veins. When I brought home my \$500 prescription wig Karen laughed with me at the unnatural, 50s housewife style I had chosen in a moment of nausea-induced desperation. But as much as Karen supported me during treatment, there was a break in our relationship. While Karen was still a young, successful career woman enjoying the single life, I had been assigned a new identity. I was still young, still employed in the professional world, still living on my own in a major city, but now I was also a cancer patient. My new identity was one that came fraught with centuries of cultural baggage in the form of fear, misconceptions, and pity. This new identity made me distinctly “other” to Karen’s norm.

Diversity of Cancer Experiences

The term “cancer” is a broad label that actually refers to a multitude of unique diseases. Over 100 types of cancer are recognized by the U.S. medical system. While all types of cancer are characterized by the abnormal and uncontrolled reproduction of cells, the causes, symptoms, treatments, and cure rates for the varieties of the disease vary widely. In Susan Sontag’s seminal 1978 work, *Illness as Metaphor*, she described cancer as the “leprosy of modern times.” Similar to that notorious skin disease, cancer is feared, reviled, and the subject of many common misconceptions.

In the early fall of 2005, I underwent five-and-a-half months of grueling chemotherapy and radiation as part of my treatment for Hodgkin’s disease. During the final month of treatment I participated in a support group for young adult cancer patients whose diagnoses included colon cancer, bone cancer, leukemia, and brain cancer. Some

of my support group peers had gone through major surgery, some had experienced chemotherapy or massive dosages of radiation, and some took medication to manage, not cure, their disease.

We all had cancer, but my experience with the disease was vastly different than those of these other cancer survivors. My treatment was time consuming and resulted in such typical side effects as vomiting, hair loss, and radiation burns. While the course of my treatment was what many would consider typical for “cancer,” the treatment process, and subsequent side effects, was unique for each of the persons in my cancer support group. As one support group participant commented, “The only thing that’s the same about our diseases is that we all had cancer.” Our medical diagnoses tied the members of my support group together because of the cultural and social importance of cancer and because of our unique position within the larger cancer community. Young adults make up only a small minority of the individuals diagnosed with cancer each year, and according to young adult cancer advocate Heidi Adams (2007), our presence in chemo rooms and radiation suites is a lonely, isolating experience.

According to the American Cancer Society (2007), about 1.4 million cases of cancer are diagnosed in the United States each year. Only about 70,000, or roughly 5% of those diagnosed, are between the ages of 20 and 45. As someone who was diagnosed with cancer just before I turned 24, I can sympathize with young adult cancer patients who lament the feelings of isolation that arise during the treatment and post-treatment process. I went through many changes while I was fighting cancer. I felt disconnected from my body, and for the first time, my physical appearance did not reflect who I felt

myself to be. Although I certainly was a cancer patient as defined by the medical community, I did not feel like I fit into the mold of how a cancer patient is supposed to look, feel, and act.

Several cancer organizations have attempted to change the prevailing feelings associated with cancer and educate the public about early detection, modern treatments, and funding needs, among other cancer issues. Prominent celebrities have spoken publicly about their cancer experiences, many in conjunction with major cancer awareness campaigns, to combat powerful stigmas associated with cancer. Perhaps most well known of these cancer celebrities is Lance Armstrong, a championship athlete whose very public battle with testicular cancer is often held up as a shining example of survivorship (Armstrong & Jenkins, 2000). Armstrong battled late-stage testicular cancer at the height of his competitive cycling career, then returned to the sport after treatment and went on to win the Tour de France. Cancer advocacy campaigns that focus on promoting inspirational stories like Armstrong's, while effective in achieving fundraising goals and promoting cancer screenings, may contribute to a singular mainstream narrative that artificially narrows the extremely diverse group of diseases recognized as forms of cancer. The language, images, and tone used in cancer advocacy publications may create expectations of a cancer experience that do not match many cancer patients' and survivors' realities.

Theoretical Grounding

All of the cultural baggage that cancer has accumulated, both historically and through modern cancer communication campaigns, may position cancer in a singular or limited way in U.S. society. This study presents an analysis of dominant and alternative cancer narratives based on the theoretical framework proposed by Maurice Charland (1987) regarding the rhetorical constitution of a particular public, in this case cancer patients and survivors, which is ideologically grounded in the greater culture. Audiences do not exist outside rhetoric. They are not the target of rhetoric but rather “live inside” the rhetoric that constructs them (Charland, 1987). Rhetoric is composed of narratives, which build and define major concepts. This study clarifies the existing dominant cancer cultural narratives by examining literature addressing this topic and analyzing interview data provided by young adult cancer survivors. Furthermore, this study discusses the ways young adult cancer survivors develop alternative cancer narratives and what resources they use to reinforce their personal views of the cancer experience.

The Internet has provided young adults with a set of tools they can use to share and validate their personal cancer experiences. Many young adults are comfortable with using new technologies, and the Web provides a wealth of information on coping with cancer and cancer survivorship. The online world has provided space to explore new ideas and collaborate with like-minded peers on such varied issues as software, music, literature, and architectural development. The participatory nature of the Web may play a role in the development of new ways for young adults to think and talk about cancer.

Major communication campaigns may find they are more successful if publics have the opportunity to challenge, subvert, or even rewrite the messages produced and reinforced by organizations. By understanding how cancer is presented by cancer communications campaigns, examining the current status of cancer in U.S. society, and revealing how young adults produce cancer narratives, cancer organizations could better shape their messaging and potentially adopt alternative cancer narratives to provide improved communication resources to this group. In addition, examining the alternative narratives that young adult cancer patients produce may encourage organizations that produce and distribute cancer literature to rethink their approach to describing cancer and the cancer experience.

Cancer in America: A Historical Review

To understand the role cancer plays in U.S. society, it helps to review the cultural history of disease in this country. Cancer is the bogeyman of the disease world, and its reputation is laced with imagery of painful treatments, extensive periods of illness, and death. Cancer is hardly a recent phenomenon; accounts of the disease date back to the Egyptian Pyramid Age or roughly 3000-2500 B.C. Hippocrates, the Greek “Father of Medicine,” referred to “hard tumors within the breast” in his early writings (Lerner, 2000). Cancer was brought to the forefront of the country’s collective consciousness in 1885 when newspapers printed lurid stories describing former president Ulysses S. Grant’s death from aggressive cancer of the throat. Confusion and fear surrounded cancer, a disease associated with an inevitable, painful, and wasting death. Surgery, the

only viable treatment offered by the 19th century medical community, was dangerous, rarely successful at fully removing the cancer, and fraught with the risk of death from a secondary infection (Patterson, 1987).

However, cancer has inherited many of its associated fears from a long history of Western disease lore. Leprosy was once common in every part of Europe and inspired volumes of medical works, detailed works of art, and reams of literature. Fear of the disease led to social and geographical isolation of the afflicted and the dread illness inspired horror by its ability to steal life from both child and adult, rich and poor, servant and king (Dormandy, 2000). Although millions are still affected by leprosy, the disease has all but disappeared in Europe and the Americas.

The wane of leprosy in the 16th and 17th centuries shifted public concern to another prolific killer: tuberculosis. While cancer held a place in the public conscience even at the turn of the century, it was overshadowed by the scores of deaths caused by tuberculosis. Tuberculosis was a prolific killer during the 1900s and, like leprosy before it, was marked by mysterious origins and almost certain death. While at the time cancer was seen largely as a disease of the elderly, tuberculosis, or “the white death,” struck young and old alike, draining the life out of its victims and leading to a lengthy, painful death. The attention of the Western medical community was focused on finding a cure for this disease, which struck down prominent poet John Keats and writer Franz Kafka among scores of others. In 1945 the first successful drug to treat all strains of human and bovine tuberculosis, streptomycin, was discovered (Dormandy, 2000).

As tuberculosis treatment and prevention have become more effective, cancer has inherited the aura of fear that distinguished these other early fatal diseases (Sontag, 1978). Like tuberculosis and leprosy before it, the causes of cancer are murky and the prognosis for many cancers, until only recently, has been grim. But why are these diseases held on a pedestal as particularly deserving of our dread? Why is the word “cancer” still whispered by many as if afraid of drawing the wrath of the monstrous plague? Why does the idea of cancer strike such fear in modern Americans when medical conditions like heart disease and diabetes affect far more of us? The answer may lie more in how Western culture has responded to the diseases than in the nature of the disease itself.

Until the mid-20th century, cancer research was under-funded and largely rudimentary (Patterson, 1987). There was no obvious cause of cancer, treatments were difficult and rarely effective, and the number of people who were dying of the disease was growing (Sontag, 1978). American culture was primed to enter a state of cancerphobia, and although fear gripped much of the population, several of the educated elite in the emerging upper-middleclass began to organize to fight back against the deadly illness (Patterson, 1987).

When the American Society for the Control of Cancer (ASCC), the original name of the now ubiquitous American Cancer Society, was founded in 1913, cancer was still largely considered an incurable disease (Ross, 1987). In 1925 the United States Public Health Service published a special examination of cancer mortality rates, which showed that longer life expectancies were leading to “an ever-darkening shadow of increased

liability to what seems, though slow-moving, the grimmest and most inexorable malady of all” (as quoted in Patterson, 1987, p. 82). These studies primarily presented “cancer” as a singular disease. This early practice of compiling the variety of different diseases that fall under the category of cancers into a singular disease led to the distribution of large and frightening numbers of cancer cases (Patterson, 1987). Cancer was reviled. Considered a private affair, the word was not mentioned in polite society. It was shameful to have cancer or be associated with an individual who had the disease (Ross, 1987).

While cancer advocacy work during the early part of the 19th century was primarily the domain of private citizens and the ASCC, by the mid-1900s the government began to show support for the cause in the form of limited public funds to support cancer research. The National Cancer Institute (NCI) Act was passed in 1937 and established an independent research institute to study causes and treatment options. However, NCI was not adequately funded, and the institution made limited progress during the first several decades of existence (Patterson, 1987).

Starting in the early 1950s, cancer survivors, mostly women, began speaking publicly about their experiences with the disease, effectively attacking the taboo against public cancer speak and resulting in a heated public discourse (Patterson, 1987). In September 1974, just three weeks after her husband Gerald Ford was sworn in as President of the United States, First Lady Betty Ford was diagnosed with breast cancer. Ford went through an extremely public battle with breast cancer, leveraging her public position and using the media to promote breast cancer awareness issues. In a speech to the American Cancer Society presented in 1975, Betty Ford said,

[I] decide[d] to discuss my breast cancer operation openly, because I thought of all the lives in jeopardy. My experience and frank discussion of breast cancer did prompt many women to learn about self-examination, regular checkups, and such detection techniques as mammography. These are so important. I just cannot stress enough how necessary it is for women to take an active interest in their own health and body.

Too many women are so afraid of breast cancer that they endanger their lives. These fears of being "less" of a woman are very real, and it is very important to talk about the emotional side effects honestly. They must come out into the open.... Cancer also produces fear -- and much of that fear comes from ignorance about the progress already made and ignorance of the need for preventive medicine for men and women alike (Ford, 1975).

The U.S. government publicly expanded its financial support of cancer research during President Nixon's second inaugural address when he called for an extra \$100 million to fund a campaign to find a cure for cancer (Chubin & Studer, 1978). This influx of funding to a struggling research effort was supported by a public facing rising cancer rates and increasing fear of an early death. The goal of cancer eradication found universal support among Washington politicians, and on December 31, 1971, Nixon signed the National Cancer Act to officially declare the "War on Cancer." The act significantly increased funding for cancer research and treatment in the United States and raised the profile of the disease both in the political arena and among the larger population (DeVita, 2002).

Uncertainty of Cancer

Great strides have been made in the treatment of many types of cancer, and recent cancer history shows progression in the efforts to eradicate the disease. But many questions remain. While research in the 1970s and 1980s showed evidence that

environmental factors like pollutants and proximity to radiation may cause certain types of cancer (Patterson, 1987), there is still no single entity that doctors can point to as the cause of cancer. Treatment processes are not exact, and what works for one patient may fail miserably for another. Like a many-headed hydra, killing one cancer occurrence does not guarantee the disease will not appear again, more virulent than ever.

The uncertainty of cancer has uniquely positioned the illness in U.S. culture (Sontag, 1978). Citizens of the United States are both fascinated and repelled by the disease (Sontag, 1978). Because of its exceptional history, cancer poses specific challenges to communication professionals producing cancer communications campaigns.

The next chapter examines the literature on cancer communications and the position of cancer in U.S. culture.

CHAPTER II

LITERATURE REVIEW

This chapter examines the existing body of cancer communications research, starting with a review of tactics used in health-related public information campaigns. This section is followed by a review of the research done on the importance of empowering cancer patients to take an active role in their medical experience and an overview of influential writings on the cultural position of cancer. This leads into a discussion on the language used to develop and reinforce cancer's cultural position, which is then examined using Charland's (1975) theory of constitutive rhetoric. The chapter concludes with a discussion of the use of participatory media to adjust cultural understandings of a subject.

Defining Disease: Health-Oriented Public Information Communication

To understand cancer communication practices, it is helpful to examine general trends in disease-focused public information campaigns. The health care industry is unique in that the product of medicine is intensely personal. Instead of selling a product or service, the health care industry is concerned with the maintenance of life, avoidance of death, and promotion of healing (Starr, 1982). This personal nature of disease makes sickness both difficult to experience and difficult to define (Harrison, 2005). Simply by addressing disease publicly, organizations weigh in on this personal and private

experience. Advocacy communications campaigns take private experiences and transform them into public issues. When health advocacy organizations produce materials designed to educate the public or spurn people to action, they define a disease within the constructs of the campaign and comment on that private disease experience.

Health communication campaigns were created with the goal of providing people with accurate and valuable information about their health (Wallack & Dorfman, 2001). Mass-mediated health campaigns have used numerous strategies to educate, inform, and persuade the public and have achieved varying levels of success. Although much of the literature on health-related public information campaigns are directed toward practitioners looking to become more effective health communicators (Atkin, 2001; Brown, Waszak, & Childers, 1989; Hetherington, Ekachai, & Parkinson, 2001), several pieces discuss, at least tangentially, the ways that mass communication campaigns position disease.

Fear-based messaging. Many health and disease public advocacy campaigns use fear to convey risk and modify behavior (Stephenson & Witte, 2001). Although this strategy can be successful when targeting a message to a specific group engaging in risky behaviors, fear mongering can also backfire when potential danger is stressed but the audience is given little direction regarding ways to avoid the threat (Stephenson & Witte, 2001). As a disease characterized by a long history of fear-based communications campaigns (Patterson, 1987), fear has been a frequent tool used by health advocacy groups hoping to encourage early behaviors that can lead to early cancer detection (Stephenson & White, 2001).

However, without appropriate calls to action, the fear-based cancer messaging can have limited success at modifying behavior (Stephenson & Witte, 2001). There is a general consensus in the medical community that cancer is a serious problem, which has led to a wealth of information about causes, treatments, and early detection, but the disease and the causes of it are still surrounded by vague claims and conflicting information. In a study conducted by the Department of Public Health at the University of Wisconsin in 2007, 71% of people surveyed agreed with the following statement: “There are so many recommendations about preventing cancer, it’s hard to know which ones to follow.” In addition, the research showed that, in general, people do not think they have much control over their personal chances of getting the disease (Niederdeppe & Gurmankin, 2007). The Wisconsin study shows that the fear aspects of cancer communications may be powerful and prevalent enough to encourage action. However, there is no solid efficacy message, or attainable call-to-action, providing those at risk of developing cancer a roadmap they can follow to avoid the feared disease.

Positive appeals. The inverse of the fear appeal model of healthcare communication is the positive appeal strategy. Positive appeal strategies are well suited to campaigns such as drug use (i.e., avoiding drugs is cool, a drug-free lifestyle is enjoyable), where the health issue at hand represents a conscious choice on the part of the individual (Atkin, 2001). The recent television and print advertisement for the drug Neulasta[®], which uses the slogan “are you ready to start chemotherapy? Support your natural defenses to help protect against infection right from the start,” uses positive appeal strategies. While this example references a for-profit organization intending to

influence cancer patient's buying habits, the example was included because it is one of the few instances of positive appeal techniques used in cancer communications campaigns this researcher could find.

Patient empowerment. The research on the mixed effectiveness of fear-based health communication campaigns has led to a fairly recent trend in healthcare communications: patient-centered care. Public relations efforts related to the promotion or communication efforts of the health care system are most successful when they focus on patient-centered care (Hetherington et al., 2001). There is evidence that cancer patients in particular benefit from directives that empower the individual (Butow, Harrison, Choy, Young, Spillane, & Evans, 2007). Patient-centered communication has caused friction between patients who desire inclusion in the decision-making process and medical professionals who value their autonomy in patient treatment decisions (Butow et al., 2007). Poor communication between doctors and patients is a universal complaint that frequently appears on patient satisfaction surveys (Buller & Buller, 1987). However, studies show that patients who take an active role in their treatment decisions feel positive about their experience (Butow et al. 2007). Advances in communication technology have led to greater access to health care related information, as illustrated by the following quote:

I can see [technology] empowering patients who can now access medical information for themselves. I have twice been a cancer patient, once in the late seventies and now again. The difference between how much patients know about their cancers is night and day. ... In the late seventies, when I had cancer for the

first time, I was very curious and read medical books and asked a lot of questions, to the great annoyance of some of my physicians.

And I remember sitting day after day, month after month, getting chemotherapy. There were five, ten, fifteen people in the room and day after day I was with them. I'm talkative, curious, and I would ask what drugs they were taking ... Nobody knew the names of their drugs. I knew the names of my drugs. They were polysyllabic words, but it's not rocket science. "Chemotherapy," they'd say. But what particular chemotherapy? It's always a cocktail; it's always more than two drugs.

Cut to twenty-two years later, I have a new cancer, I'm back in the hospital in the chemo room, and every single person knows the names of their drugs. Not only that, but they are chatting away about having read a protocol from the University of Indiana, or research from somewhere else, and they give you the Web site. And that's wonderful. (Sontag, 2000)

The positive aspects of control during a cancer experience may be expanded when patients are able to direct not only their course of treatment, but also the way cancer is communicated.

Fear-based messaging, a common tool used in healthcare communications campaigns, is most effective when the target audience is granted a degree of control over their health situation. Healthcare communication research has trended toward advocating for empowered patients, despite reluctance in the medical community to embrace the concept and practice. When patients are granted a degree of self-efficacy in medical situations, they are better able to handle the treatment experience. The next section examines Susan Sontag's influential writings in the area of the language of disease and explores the possibility that the benefits of self-efficacy may extend beyond the medical experience. If cancer patients are also empowered to influence the language and cultural

position of cancer and the cancer experience, might the same benefits of self-efficacy apply?

Susan Sontag: Illness as Metaphor

One of the most influential scholars who commented on the language of cancer was breast cancer survivor Susan Sontag. A noted intellectual, filmmaker, novelist and essayist, Sontag somewhat ironically begins one of her most famous polemics, *Illness as Metaphor* (1978), with a metaphor:

I want to describe not what it is really like to emigrate to the kingdom of the ill and live there, but the punitive or sentimental fantasies concocted about that situation: not real geography but stereotypes of national character.

Sontag wrote *Illness as Metaphor* while going through treatment for breast cancer. She died at the age of 71 from acute myelogenous leukemia, which was likely a result of the aggressive chemotherapy and radiation treatments she went through in the 1970s. The treatments Sontag underwent to battle breast cancer – a radical mastectomy, four subsequent operations for secondary lesions, and 30 months of intensive chemotherapy – were successful but left her profoundly shaken (Crow, 2001). Although she spoke about cancer only in the abstract, never publishing pieces detailing her own struggles with the disease, Sontag's writing influenced a generation of scholars examining disease culture (Clow, 2001).

Sontag (1978) first pointed out the importance of examining the language used to discuss cancer. She claimed that the common use of cancer as a metaphor for anything horrible, insidious, and damaging, such as the Nazi's common

comparison of Jews as a cancer on the Germany people, causes patients to feel ashamed of their illness and makes cancer patients and survivors reluctant to share their diagnosis. While there is evidence that the use of cancer metaphors may not lead to either shame or silence (Clow, 2001), Sontag made a major contribution to the field of health communications by insisting that individuals recognize the importance of examining the language of disease.

Metaphors of Cancer

The convoluted nature of language traditionally used to discuss major illnesses in the United States makes the examination of that language important in the area of healthcare communication research. The literary theorist Kenneth Burke (1966) argued that our being is inextricably tied to our use of symbols because it is through language that individuals make sense of the world around them. Language is a collection of symbols that constitutes our reality. The world around us makes sense and we understand our place in it only through the symbols we use to describe our existence (Burke, 1966). Without the symbolism of language we cannot communicate, but we also cannot understand our environment. Burke identified metaphor as one of the “four master tropes,” which he addressed as follows: I refer to metaphor, metonymy, synecdoche, and irony. And my primary concern with them here will be not with their purely figurative usage, but with their role in the discovery and description of “the truth” (Burke, 1969, p. 503).

“Metaphor,” Burke wrote, “is a device for seeing something in terms of something else” (Burke, 1969, p. 503). To better understand the language of cancer, and therefore the culturally constituted nature of the disease, this section examines the metaphors used to present cancer “in terms of something else.”

Although metaphor is one of the primary ways that people make sense of difficult, complicated, or confusing topics, the field of communication has produced few studies specifically examining the meaning of cancer through metaphor (see Bowker, 1996; Gibbs & Franks, 2002). Metaphors not only clarify difficult concepts like cancer, but they also build issue identity by creating shared human understandings (Lakoff & Johnson, 1980). In fact, there is evidence that metaphors are more effective at conveying complex health topics than are definitional approaches (Sopory, 2005). Public relations practitioners have often used metaphors as a tool to convey confusing or difficult messages simply and effectively (Zhang, 2007).

Metaphors both contribute to and stem from the stigma of cancer, which was born out of stereotypes surrounding the disease and leads to widespread dread of diagnosis. Cancer is an internal disease, associated with images of a body turning against itself (Hunt, 1998). While traditional imagery of the disease illustrated cancer patients as condemned, hopeless, and victims, this image is changing to one of empowerment (Weiss, 1997). The evolution of the cancer patient metaphor has resulted in the evolution of metaphors relating to the disease itself.

A recent study of cancer coverage in women’s magazines showed that metaphors of war were frequently used when discussing breast cancer (Gill & Babrow, 2007). This

graphic and combative imagery is occasionally challenged by the less common imagery of breast cancer as an odyssey or journey (Gill & Babrow, 2007). These contrasting images show the beginnings of a diverging approach to dealing with the cancer experience. However, additional research shows a still varied cultural understanding of cancer.

The most extensive study I found to date on the types of metaphors used to describe and define cancer was published by Teucher (2003), who surveyed 126 participants, including 60 cancer patients in cancer hospitals and/or support groups and 66 people without cancer who were enrolled at universities. Using standardized questionnaires, Teucher asked participants to provide descriptors of cancer and cancer treatment. He received over 1,600 descriptors, which he then condensed into 184 cancer metaphors and 145 cancer treatment metaphors. The responses were organized into four groups of metaphors for cancer as a disease: invasion, intrusion, oppressive surroundings, and growth inside. The responses for cancer treatment metaphors were organized into six groups: contingency, battle, race, work, task, and hope (Teucher, 2003).

By far, the most common metaphor used to describe both cancer and cancer treatments was that of a war. The dominance of the war metaphor is evidenced by the responses Teucher received illustrating invasion, intrusion, and battle metaphors. Given the horrendous effects of many cancer treatments, the use of a strong metaphor signaling catastrophic destruction, pain, and loss may be apt. However, when any single cluster of metaphors (e.g. battle, survivor, fight) dominate the discourse for a variety of experiences, the meaning becomes limiting. Experiences that fall outside of the situation

a metaphor suggests, such a cancer patient who is able to live with the disease but will never be cured and therefore never complete a “battle” or win the “war,” become excluded from the accepted cancer narrative. Metaphor informs language, and as Burke (1966) posited, language constitutes reality. Burke’s writings led to Charland’s (1987) work on constitutive rhetoric.

The next section expands this examination of the accepted cancer narrative using Charland’s (1987) theory to describe the development of cultural narratives and explain how they define major societal constructs.

Cancer’s Cultural Narrative: Charland’s Theory of Constitutive Rhetoric

Charland’s (1987) concept of constitutive rhetoric describes the importance of narrative context in the development of a sense of being. Charland builds on Burke’s (1950) argument that the rhetorical process is dependent on identification rather than persuasion. “The very moment of recognition of an address constitutes an entry into a subject position to which inheres a set of motives that render a rhetorical discourse intelligible” (Charland, 1987, p. 147). People become subjects when they acquire language skills, allowing them to fit symbols to their existence and position themselves within larger cultural systems.

Our first subject positions are modest, linked to our name, our family, and our sex. As we enter the adult world, they become more complex, as different constitutive rhetorics reposition us with respect to such formal and informal institutions as the state, the economy, the church, and the school. (Charland, 1987, p. 147)

When people are diagnosed with cancer they are assigned a medical identity that comes packaged with the baggage from the disease's cultural identity. Beyond the complexities of state, economy, religion, and education, a medical diagnosis is an unexpected shift in cultural position. Sontag (1978) wrote that we all hold dual passports, one to the land of the sick and one to the land of the healthy. While most of us spend the bulk of our time among the healthy, diagnosis of a major medical condition leads to a mandatory journey to the land of sickness.

Upon diagnosis, cancer patients are thrust into new social and cultural positions. Initial subject positions, such as race, gender, and age, and secondary positions, such as behavioral habits like "smoker" or "healthy eater," will influence the reaction patients may have to their diagnosis and could affect their treatment experience (Harwood & Sparks, 2003). The tertiary identity of a person diagnosed with cancer refers to the way individuals identify with their positions in relation to the disease. Survivor, fighter, patient, victim, advocate, role model – the personal identification of individuals with cancer stem from the existing cultural narrative defining the disease and may well affect their experiences with the disease and their success dealing with the physical, mental, and emotional toll it will take on their lives (Harwood & Sparks, 2003).

Charland's (1987) theory of constitutive rhetoric posits three distinct statements. The first involves the constituting of a subject through narratives, which provide a field of identification that is stronger than economic, gender, race, or other social identities. The second involves the posit of a transhistorical subject, and the third refers to the allusion of freedom and agency of a narrative's protagonist (Stein, 2007). This project

focuses on the first of these aspects of the theory, the constituting of a subject through narrative. The current cancer narratives, established through the cultural history of cancer and the current metaphors that inform the language used to discuss the disease, tell cancer patients who they, as embodiments of the disease, are expected to be.

Participatory Media

The online environment provides individuals with a forum to produce and publish their own thoughts, ideas, and concepts. Cancer narratives develop as a way for individuals experiencing the disease to renegotiate their identities in relation to cancer. Although the process of narrative creation has proven vital to the identity shifting that occurs as part of the experience of being diagnosed and treated for a major illness (Mathieson & Stam, 1995), I have been unable to locate any studies that address how personal narratives may grow into acceptable cultural narratives, particularly in regard to major diseases, and the use of participatory media.

The Web has opened up a world of self-publishing possibilities. Young adults are not only a highly wired segment of the population, they are more likely than older adults to use the Web for “fun” communication and socialization (Wellman & Haythornthwaite, 2002). Young adults have several years of experience using the Internet and are comfortable with online resources (Fox, 2004). With a minimal amount of technical proficiency, any individual with regular Internet access and a computer can start a blog. Those same common requirements are needed to comment on message boards, join social networking sites like MySpace and Facebook, and jump into e-mail Listservs. The

availability of creating and publishing narratives through outlets that can easily be distributed and shared makes it possible to build a dialog with others who share similar interests or beliefs. Online networks transcend geographic boundaries. Just as a real life community is not made through interactions at a single location, online communities can be created through a variety of sites that allow people to promote shared traits and interests. This paradigm shift is evident in Castells' (1996) classic study of shifting community structures, *The Rise of the Network Society*. The primary concept explored in this book, which has been largely supported by media scholars since publication, is that the Internet has provided the technological capability to organize by interest-based networks. But online networks may go beyond just organization and lead as well to the development of common language and understandings.

It is clear that young adults are comfortable with the integration of new technologies into social interactions (McMillan & Morrison, 2006). Research has shown that young adults are the most wired age group in the United States (Fox, 2004). Although scholars have primarily studied the ability of new media to create and maintain a new social space, unique from real-world community practices (Slater, 2001), often times virtual interactions serve to bolster existing social relations, practices, and offline community membership (McMillan & Morrison, 2006). The McMillan and Morrison study documented Internet use among college students born between 1975 and 1980 – roughly the midrange of ages considered “young adult” for the purposes of this study. This generation is wired, comfortable with exploring new technologies, and likely to use the Web for socializing as well as information gathering.

Young adults are a minority within the larger cancer community, accounting for only a small percentage of new cancer cases diagnosed each year. A January 2007 *U.S. News and World Report* article dubbed young adult cancer patients “Cancer’s Orphan Generation.” A smattering of researchers have published pieces lamenting the fact that survival rates for young adults with cancer have plateaued (Thomas, Seymour, O’Brien, Sawyer & Ashley, 2006). There have also been studies addressing the psychological needs of adult cancer patients (Zebrack & Walsh-Burke, 2004) and their parents (Grinyer, 2006), but my search has revealed no relevant research on issues of communication, identity formation, or coping techniques used by young adult cancer patients. Beyond simply giving voice to young adult cancer patients who have been ignored in healthcare communication research, the perspective of young adults are uniquely suited to the questions asked in this study. The participatory nature of the Web may provide a gatekeeper-free venue for individuals to connect with other cancer patients and survivors and publish accounts of their cancer experience.

The Web, particularly for the younger, tech-savvy generation, can bolster ties within communities that exist offline (Johnson, 2001). For a disparate community, such as young adult cancer survivors in the United States, who tend not to be clustered in distinct locations but instead are scattered across the country, Internet technology can be used as a tool to build a shared community. Participation in online cancer communities correlates to some benefit in terms of reduced stress during cancer treatment and survivorship adjustment process (Wright, 2002). However, that benefit is only realized if participants have at least some degree of cultural similarity (Orgad, 2006). This study

expands on the idea of needing a shared culture to participate successfully in online communities and examines how shared cultures are being built through the conversations, commerce, and collaboration happening in the online world.

Summary

The history of cancer in the United States has built the disease into a powerful, menacing creature to be feared and reviled. This fear-based cultural history of cancer has led to communications campaigns that play on common fears, which have fueled dominant images of cancer. While campaigns that focus on fear can be successful at changing behavior, that success comes from providing the audience with an efficacy message combined with the fear-based appeal. The efficacy message must be stronger than the fear exhibited through the campaign. The positive effects of empowering cancer patients to take an active role in their treatment process are well documented; if cancer patients and survivors react positively to taking control throughout the course of treatment for their disease, it may also prove helpful if cancer patients are able to take an active role in directing cultural understandings of the disease.

Cancer has a strong image in U. S. culture, and to best understand how the dominant cancer narrative can be challenged, it is necessary to examine the language used to discuss the disease. An examination of cancer metaphors, the majority of which use violent, competitive imagery to convey cancer and the cancer experience, provides insight into the language that constitutes the current dominant cancer narrative. Charland's (1987) theory of constitutive rhetoric posits that a subject, in this case cancer,

is constituted through narrative, which is developed in large part through metaphor and language. If cancer patients and survivors are able to modify the dominant existing narrative, perhaps through the recent advances in Web-based participatory technology, this group may play an active role in writing and validating an alternative acceptable cancer subject position.

The next section presents the research questions addressed in this study. These questions grew out of the literature presented in this chapter.

Research Questions

The literature suggests that historically cancer has been viewed as a fearful, reviled disease harkening tragic disfigurement or death. A new generation of cancer patients and survivors, however, may not have adopted this dominant cancer messaging. This study examines what young adult cancer survivors identify as the dominant cancer narrative they observed throughout their cancer experiences.

Research Question 1: What do young adult cancer patients identify as the dominant cancer narrative?

While an understanding of how young adults interact with current cancer narratives is enlightening, this study focuses primarily on the ways young adults experience cancer and how they share those experiences. A cancer narrative consists of the cultural expectations and understandings of what cancer is and how cancer should be experienced. The dominant cancer narrative exists as part of the larger culture and is

difficult to adjust. However, research shows that there are benefits to empowering cancer patients; therefore, interest lies in the area of new narrative creation as well as existing narrative identification. This study seeks to identify ways that young adults may be changing the cancer narrative or perhaps developing a counter-narrative to better inform their subject positions.

Research Question 2: How are young adult cancer patients challenging existing cancer narratives and what alternative cancer narratives are these survivors developing?

Participatory media have the potential to be powerful tools to create and validate alternative narratives. Because young adults are among the most wired segments of the population, this project also looks at the ways young adult cancer patients use the Web to interact with the expected cancer narrative, modify the expected cancer narrative, and/or build and validate a counter cancer narrative.

Research Question 3: How do young adult cancer survivors use participatory media to formulate, expand, and validate alternative cancer narratives?

CHAPTER III

METHOD

Qualitative Research

According to research, disease is an intensely personal experience. To tease out the nuances of the cancer experience and answer the research questions I employ one-on-one interviews with individuals who have been diagnosed and successfully treated for cancer.

Participant Sampling. Selecting interview participants from the spectrum of cancer patients and survivors seemed a daunting task. Unlike quantitative research, which necessitates random sampling to ensure statistically verifiable results, this study could best be served through gathering data from a purposeful sample of cancer patients and survivors who could provide rich information and emotion-rich data. For this study the purposeful sample consists of young adults who had gone through treatment for cancer. For the purpose of this study, I use Erik Erikson's (1950) definition of the stages of human development and consider the category of "young adult" to include persons between the ages of 19 and 40. When interview participants offered particularly data-rich commentary on the cancer experience, these standards were stretched to include slightly older or younger participants. This age range is also the generally accepted medical definition of a young adult.

Interview participants were originally recruited through Planet Cancer, an online community for young adults with cancer. While there are limits to utilizing a community sample, because of the disparate nature of the young adult cancer population and the sensitivity of the topic, this sampling technique was the only feasible option given the time and funding restrictions. In an attempt to mitigate the risk of interviewing only individuals in a specific social group within Planet Cancer, I recruited participants in three ways: by e-mailing interview requests to individuals I had met while attending a Planet Cancer sponsored retreat, by contacting frequent posters to the site to request an interview, and by asking interview participants to recommend contacts who might be interested in participating in the project (i.e., snowball sampling).

To diversify the pool of interview participants, snowball sampling was used. The result was 11 interview participants contacted through Planet Cancer and five participants contacted through the snowball technique. This study utilized snowball sampling primarily to build a diverse sample of participants. About a third of participants agreed to pass on my contact information to other young adult cancer patients. This step was completely voluntary and at no times were participants pressured or coerced into providing additional participant recommendations.

Interviews

I conducted semi-structured interviews with young adults cancer survivors who were diagnosed and received treatment when they were between the ages of 18 and 40.

The interview sample consisted of 16 participants. While there is no universally recognized formula to determine the exact number of participants needed for a qualitative study, the goal of the interview process was to reach data saturation. Data saturation was considered achieved when the interviews revealed no new information. A valid study may include as few as eight interview participants (McCracken, 1988); however, it was necessary in this case to perform significantly more than that to achieve saturation. Five of the interview participants were male and 11 were female. The interview pool included people with a variety of cancer diagnoses, including breast cancer, Hodgkin's disease, brain cancer, lymphatic cancer, and leukemia. While the majority of interview participants were in their early to mid-20s when they were first diagnosed, there were also several participants who were in their 30s. The youngest interview participant at the time the interviews were conducted was 18 years old and the oldest was 38.

Due to time and financial constraints and the geographically scattered nature of the young adult cancer community, interviews were conducted over the phone with participants throughout the country. Each participant verbally agreed to a consent form dictated to the participant at the start of the interview. All participants agreed to the use of their comments in academic papers and this thesis. This project was reviewed and approved by the University of Oregon's Institutional Review Board.

The interviews lasted between 45 minutes and an hour and 15 minutes, with most sessions lasting about an hour. Interviews, which were conducted in September 2007, were audio taped to ensure an accurate representation of the participants' remarks. I both conducted and transcribed all 16 interviews to provide consistency in the interview

experience and data collection process. An interview guide consisting of open-ended questions was used in each interview to ensure that all areas were covered in roughly the same sequence in each interview. Each interview started with a request for the participant's "cancer story." When I asked for a cancer story, each participant provided a synopsis of his or her diagnosis, treatment, and, if applicable, relapses, without further prompting. This universal understanding among the participants of what a "cancer story" is may stem from repeated requests to explain their cancer experience to medical professionals, friends, colleagues, and new acquaintances. The remainder of the questions listed on the interview guide were worked into the interview as the conversation developed (See Appendix A).

Data Analysis

Data analysis began with interview transcriptions. Interviews were transcribed verbatim from audiotapes, and interpretation of the data began only after transcriptions were completed. Interview data were analyzed using the three-step coding methods developed by Glaser and Strauss (1967). This process begins with the researcher scanning the full body of text to identify similarities and differences across the interviews and forming broad categories from these first impressions (Strauss & Corbin, 1998).

This initial open coding process exposes the major thoughts, ideas, meanings and themes running through the conversations. The goal of this process is to identify a range of possible meanings present in the text (Strauss & Corbin, 1998). Although I expected to be able to examine each paragraph as a unit of analysis, when transcribing the interviews

it became clear that paragraphs often covered several separated and distinct thoughts. Therefore, each sentence served as the unit of analysis. At this stage of the coding every attempt was made to use *in vivo* codes, words and phrases that originated from the interview text, to label the emerging categories culled from the text during this early stage of analysis.

The second stage of the coding process, axial coding, combined these individual codes into mutually exclusive codes (Strauss & Corbin, 1967). The data are examined to find relationships between the categories identified in the first stage of coding. I organized the categories to illustrate the processes interview participants used when describing the experience of having cancer. Particular attention was paid to comments relating to what they felt was expected of them as cancer patients and survivors. This sorting process links categories at the level of category properties and leads to the emergence of cohesive messages within the data set (Strauss & Corbin, 1967). During axial coding, instances that appear to contradict the primary messages were also identified and noted to ensure depth of analysis.

The third and final step of the coding process is selective coding, in which the previously identified categories are refined into a logical concept that encompasses and describes the relationships in the interview data (Strauss & Corbin, 1967). The selective coding process made it possible to distinguish a distinct causal story describing the ways young adults deal with the expected cancer narrative and strategies for challenging that expected narrative.

To maintain a record of the interview and coding process, memos were created during each major stage of the study. The coding memos in particular illustrate the generative process of the three-step coding method. False starts, changes in direction, and abandoned narratives were recorded, documented, and eventually analyzed to advance the final analysis.

Reactivity and Reflexivity

Although there was a risk of emotional or mental distress during the interview, most cancer patients said they found it cathartic to discuss their experiences. To mitigate the possibility of unnecessary mental anguish, interviews were conducted only with willing and eager participants. The choice to use responsive interviewing and personal narrative techniques was also made, in part, to ensure that interviews were largely participant driven. There are no “right” ways to experience cancer and, as the researcher, I worked to avoid leading participants toward canned answers and focused on encouraging participants to tell their personal stories.

All the participants involved in the interviews had been through at least one full course of treatment for a cancer diagnosis. Several individuals had been through more than one cancer diagnosis, and many were facing ongoing treatment for issues related to the disease. Cancer was not something that existed solely in the past for the young adult cancer patients I spoke with, and many brought up current health, financial, and emotional concerns related to their cancer experience. Also, a few of the interview

participants were in the process of dealing with a cancer relapse or a secondary cancer diagnosis.

As a young adult cancer patient, I understand that discussing the cancer experience can be difficult and emotional. My own experience with the disease earned me an “in” with the young adult cancer community and made it possible to commiserate with survivors during the interview process. However, because I have strong associations with the disease, it has been difficult at times not to project my own thoughts and ideas on the study participants. While I believe that my cancer experience led to a rich collection of data and an insightful outcome from coding, I had to be self-reflexive throughout both the interview and coding process to prevent my personal thoughts and biases from influencing the participants’ replies or my reading of the data.

Transcribing the data and coding it was frustrating, exhausting, and emotionally wrenching. Many of the interviewees detailed stories of incredible physical suffering and mental trauma. Recollections of chemotherapy-induced nausea brought memories of my own miserable hours spent curled up on worn couch cushions waiting for the waves of stomach-turning sickness to end. The interviews brought up many issues, particularly the possibility of a relapse, that I did not want to deal with, and immersing myself in the data was a struggle. However, cancer is a part of my life, and by turning the experience into a research project, I have been able to distance myself from the more emotional aspects of the disease to present the stories of my research participants, who each lived his or her own experience.

The next chapter presents the results of the open and axial coding processes.

CHAPTER IV

RESULTS

This chapter describes the results of the open and axial coding of the interview data collected from the 16 young adult cancer survivors who participated in this project. As discussed in Chapter 3, the transcriptions were coded using the methodology outlined by Strauss and Corbin (1998), which provides a way for researchers to pull meaningful points from data, assemble these points into categories and subcategories, and show how relationships between categories leads to recognizable observations and conclusions.

This analysis presents the perspectives and viewpoints of the participants, and quotations taken directly from the interviews are used as much as possible to articulate the key concepts that emerged from the data. *In vivo* (emic) codes, which are codes created using the verbiage provided by interview subjects, are frequently used to maintain the integrity of participants' remarks. On occasion, etic codes, which are codes assigned by the researcher to attribute meaning and patterns to the text, are used when no appropriate *in vivo* code is possible. The emic and etic codes are reinforced through the use of supporting quotations from participants.

The first section of this chapter is an overview of the interview participants, which provides a basic description of the group from which the conclusions presented in this study were drawn. This initial discussion is followed by an analysis of the main categories that emerged: the recognition and description of a dominant cancer narrative,

steps taken to develop alternative cancer narratives, and community development around alternative cancer narratives. The chapter ends with the description of a model that reflects the process young adult cancer patients go through as they react to the expectations they face as cancer patients and challenge those expectations through developing alternative explanations of cancer and the cancer experience.

Participants

Sixteen young adult cancer survivors at various points in their recovery and treatment were interviewed over a one-month period. Each participant was assigned a pseudonym to protect his or her privacy (Appendix B). The pseudonyms are used throughout this chapter and the discussion when attributing beliefs, statements, and quotations to individual interview participants.

Of the 16 participants interviewed, about two-thirds are women. Because the interviews were conducted by phone, it is unclear if any participants are members of a racial or ethnic minority. The topic of race and ethnicity did not come up in any of the interviews. One interview participant (John) is openly gay, and several interview participants referenced heterosexual relationships, although sexual preference was also not a topic specifically discussed in the interviews.

Three of the interview participants had been out of active treatment for less than a year at the time of the interviews, 12 participants had been out of treatment for between one and five years, and one participant (Hilary) had been out of treatment and in remission for 12 years. Although the original intent had been to interview only

individuals who had been out of treatment fewer than five years, the interview with Hilary, who completed treatment for Ewing's sarcoma in 1995, was included because she had been particularly active in young adult cancer advocacy work and she was able to provide insight into the online and real world young adult advocacy community, making her a data-rich source.

Half of the interview participants were between the ages of 17 and 24 when they were first diagnosed with cancer. A quarter of the participants were between 25 and 30, and the last four were between 31 and 35 years old. The range of diagnoses represented in the pool of interview participants is broad, consisting of two individuals with brain cancer, two with breast cancer, four with Hodgkin's lymphoma, four with acute myelogenous leukemia (AML), one with non-Hodgkin's lymphoma, one with Ewing's sarcoma (bone cancer), one with thyroid cancer, and one individual with multiple myeloma (cancer of the plasma cell).

Participants came from all areas of the country; however, because snowball sampling was used, starting with frequent posters on Planet Cancer, a couple of locations are particularly well represented in the interview sample. Four individuals, which constitute a quarter of the sample, are from Michigan. Five individuals are from locations in Texas, which is also the state in which Planet Cancer is headquartered. Two interview participants live in Ohio, two in the Washington, D.C. area, one in Boston, one in Seattle, and one in Manhattan.

The variety of participants involved in this study adds to the richness of data collected. While some interviews were more fruitful than others, all participants had

insightful comments to contribute regarding their thoughts about the cancer experience. Although these results cannot be generalized across the entire young adult cancer population, the commonalities and differences represented in this group may lead to a better understanding of how young adults in general undergo this trying medical experience. Overall, open coding resulted in 19 categories, which during axial coding were collapsed into eight categories. The following section describes the open and axial categories that emerged from interview participants' discussions of a dominant cancer narrative (Table 4.1).

But, You're too Young for Cancer: Healing on the Margins of the Cancer Community

A frequent concern discussed by participants during the interview process was the idea that young adult cancer patients were consistently going against what was expected of them. The expectations of friends, family, medical professionals, even their own pre-cancer expectations, were often at odds with the young adult cancer patients' experiences with the disease.

The following table lists the codes used in this section to build a description of what young adults see as the current dominant cancer narrative, which they believe fuels cultural expectations of cancer and the cancer experience.

Table 4.1: Codes Related To Dominant Cancer Narrative

Classification	Category	Description
<i>Open code</i>	Out of place (in cancer community)	Feeling unwelcome, surprised to be seen in cancer situations
Property	Isolation	Feeling alone, out of place
Property	Too young	Not old enough to have cancer
Property	Mistaken identity	Mistaken for caregiver, medical personal
Property	Insufficient resources	No support groups, no survivorship resources, support not convenient/accessible for young adults
<i>Open code</i>	Unexpected by peers	Friends and family are shocked by cancer diagnosis
Property	Friends/Family shocked	Shock at diagnosis
Property	Difficult to accept	Refused to talk about cancer, difficult to recognize illness, avoidance of patient, anger directed at patient
Property	Avoidance of peers/family	Developing strategies (writing over phone, not going out, leaving school) to avoid family, friends, and colleagues
<i>Axial code</i>	Young adults are not supposed to get cancer	Unexpected nature of diagnosis with being out of place in the cancer community
<i>Open code</i>	Cancer kills	Cancer leads directly to death
Property	Death	Cancer as cause of death
Property	Tragic	Cancer is horrible, sad, tragic
Property	Removes characters	Convenient way to kill off characters
<i>Open coding</i>	Cancer only happens to “high risk” people	Cancer happens to children, old people, middle-age women
Property	Nobody looks like me	Young adult cancer patients are not portrayed
Property	Middle-aged women	Middle-age women with breast cancer
Property	Children	Bald little kids in commercials and sad television shows and movies
<i>Open coding</i>	Cancer is easily recognizable	People with cancer are obviously sick
Property	Sick	Looking sick
Property	Bald	Bald children (primarily)
Property	Weak	Pale, thin, ill
<i>Axial coding</i>	Cancer is so horrible it uniquely defines those affected	Recognizability and deadlines of cancer, and limited mainstream media portrayals
<i>Open coding</i>	“Beating” cancer	Cancer can be destroyed with the application of enough strength

Classification	Category	Description
Property	Empowering	Storyies of cancer survival inspire others
Property	Powerful	Cancer patients are powerful
Property	Good example	Armstrong is a good role model for cancer survivors
Property	Public	Cancer is not private
Open coding	Can't live up	Expectation of cancer survivors set too high
Property	Winner	Cancer as a fight
Property	Out of reach	Example set by public cancer figures unattainable
Property	Superman	Inhuman abilities of public survivors
Axial coding	Cancer can be beaten through strength	Power is the key to beating cancer
Open coding	Finishing cancer	Cancer has a set end point
Property	Survived	Finishing cancer to become a survivor
Property	Beat cancer/won the battle	Metaphor for ending the cancer experience
Property	Done/Finished	The moment of "finishing" cancer
Open coding	Effects of cancer continue after treatment	Ongoing effects of treatment
Property	Side-effects	Nausea, reduced use of limbs, weakness, menopause
Property	Relapse	Secondary recurrence of cancer
Property	Fatigue	Super tired, most common side effect
Property	Follow-ups	Doctor visits continue long after remission
Axial coding	Cancer has a definite end.	Survivors stop being sick at remission or "cure."

During the interviews, without exception, participants discussed the awkward position they entered when they were diagnosed with cancer. During open coding, evidence emerged that young adult cancer patients are not readily accepted in the cancer community. Participants frequently used the word "isolation" to describe the experience of being diagnosed with cancer. The interview participants reported being isolated in chemotherapy and radiation treatment centers, oncologist offices, cancer support groups,

and other situations where cancer is the norm, as well as in their personal and professional lives. As Kim said:

I didn't find any support groups until more than halfway through my treatment because I just didn't know where to go ... I wasn't a fan of The Wellness Community [a cancer support community with locations throughout the United States]. It was all people older than 50. They used to do a young adults group but they said no one would go so they stopped doing it. It was really frustrating. They didn't really know what to do [with young adults].

Resource Deprivation in the Cancer Community

Table 4.2 outlines the coding process that led to the analysis presented in this section.

Table 4.2: Resource Deprivation In The Cancer Community

Properties	Open	Axial
Isolation	Out of place (in cancer community)	Young adults are not supposed to get cancer
Too young		
Mistaken identity		
Insufficient resources		
Friends/family shocked	Unexpected by peers	
Difficult to accept		
Avoidance of peers/family		
Isolation		

The young adult cancer survivors interviewed felt “out of place” and “totally alone” after being diagnosed. Receptionists, nurses, and other patients were “surprised” to see them in cancer wards, and two of the interview participants reported being mistaken for caregivers rather than patients. Cynthia told this story:

My grandfather took me in for chemo one time and he saw someone he knew and they said, “Lenny, I didn't know you had cancer.” He said, “I don't, my granddaughter does.” I'd go in for treatment or follow-up and people give you

crazy looks because you're the one getting blood drawn or you're the one going back to the infusion room.

The medical system divides cancer care into two categories, pediatric and adult oncology. The particular needs of the young adult cancer patient are easily overlooked in this binary system. Young adults are, according to Hilary, "too young to fit in with the older crowd and too old for the children's ward." Prior to diagnosis, the young adults I spoke with admitted that they had rarely associated cancer with anyone their age.

Apparently the medical community does not typically expect cancer to appear in young adults either. Nine of the 16 interview participants mentioned being misdiagnosed early in their cancer experience, forcing the patients into a position where they had to act as advocates for their own treatment. As Tim said, "There are pediatric oncology wards because children have whole different needs than adults. But with the 20s and 30s group, you're too old for pediatric but still too young for cancer." Only four of the interview participants knew anyone in the young adult age range who had gone through cancer.

Bonnie described her expectations as follows:

I think this age is probably one of the more difficult ages to have this experience. When you hear cancer at that age you think oh, grandma and grandpa or great aunt so and so had cancer or you think of the little kids on the telethons you see with the commercials with bald-headed kids. You never really see the young adults.

Open coding revealed that the interview participants believed their needs were not met by the cancer resources available to them at the time of diagnosis and during their treatment. Furthermore, this lack of information was expressed as a function of age rather than any other cultural identity such as gender, race, sexual preference, or ethnicity.

According to Hilary, a woman who has devoted much of her adulthood to bringing attention to the needs of young adult cancer patients, the group is concerned with issues related to “dating,” “self image,” “health insurance,” “long-term effects of treatment,” “occurrence of secondary cancers,” “loss of fertility” and “physical ramifications of treatment,” among other things. In addition to dealing with the diagnosis of a potentially life-threatening illness, young adults often find that they lose their newfound independence. Kim described the challenges she faced dealing with both a cancer diagnosis and a radically altered position in life in the following way:

For the first time I was officially living on my own so trying to be away from my family. I'd lived alone before, but I usually had roommates, so for the first time I was trying to do this thing on my own. I had an amazing job so I was planning on saving money. Trying to become an adult, you know? A month later I was diagnosed and it just didn't really happen ... I kept my apartment because I did treatments in Boston anyway and my apartment is so nice. And I don't think I could have broke my lease anyways so I kept my apartment and I worked until about February, mid-February, I would go in for some days some days, I would email everyone saying I'm not coming in or I would try to do some work from home and then it just got to be too much.

Kim, who prior to her diagnosis had recently moved into her first apartment in Boston, was forced to moved back in to her parent's house in Western Massachusetts shortly after starting treatment for Hodgkin's disease. The young cancer patient not only had to adopt her new cancer identity, but the disease also forced her to largely vacate the identity she had been building as a social, independent young adult. About half the interview participants referred to major lifestyle changes as a result of their diagnosis that resulted in the survivors reverting back to positions more reminiscent of their childhood. This is just one example of a social issue common in the young adult cancer community

that interview participants said was not expected and not addressed by the support services offered to them through their medical facilities.

Changes in social position are only part of the frustrations young adults discussed facing. The young adults also complained of little support in the area of long-term medical support. Likely because the bulk of the cancer community is over the age of 65, survivorship issues are not always a top priority for medical professionals and support group facilitators. While many adult cancer patients are looking at 15 or 20 more years of life after cancer treatments, young adult cancer patients may expect to live another 60 years. Quality of life after treatment is one of the major complaints that came up several times in the interviews. Carol's treatment for breast cancer has thrust her into premature menopause twice since she was diagnosed in 2005. "It's possible that when I stop this current drug I'll come back out of it again so I may need to go through [menopause] three times. These are the things nobody talks to you about when you are doing cancer treatments," Carol said. These universal complaints from young adult cancer survivors regarding the ill-fitting nature of standard cancer resources indicate that whatever the dominant cancer narrative is, they do not believe it includes their age group.

Cancer is powerful. "Pulling the cancer card" can stop a conversation short, said Tim when discussing the issues he has talking to other people about his diagnosis. The next section examines how young adults deal with the expectations of friends and family who do not see young adults as playing into the accepted cancer narrative.

Managing Expectations: Convincing Peers and Family that Cancer is for Real

The interview participants reported experiencing ongoing negotiations with family and friends regarding their cancer status. Relationships changed as caretakers became dependent on parents and colleagues, and friendships lagged as treatment took its toll on participants' physical and mental states. Open coding revealed that these changing relationships were dominated by a degree of discomfort. Families at times just "didn't want to deal with it" and friends were "totally freaked out," or "just didn't understand." Two of the interview participants reported family directing anger at them because of their diagnosis. For example, Carol's relationship with her mother was complicated while she went through cancer treatment.

My mother was completely horrid [laughing]. She could not handle the fact that I had cancer. She didn't want to acknowledge that it was a big deal. She wanted to be as little a part of it as she could be and now she continually finds reasons why it must be my fault ... that I got sick in the first place.

This example is not meant to imply that all families and friends do not play an important and often instrumental role in the treatment and recovery process of young adult cancer patients. Six of the interview participants described specific ways that their family members helped them through their treatment. For example, Kevin's mother spent hours online searching out and archiving Web sites on cancer and cancer support systems, which she then provided to Kevin for his perusal. Just over a third of the cancer survivors interviewed mentioned either moving back in with their parents for support during treatment or appreciation of family members who accompanied the survivors on hospital visits or provided rides to treatment appointments.

Feeling isolated from friends was a common issue raised during the interviews. Interview participants gave examples of friends being reluctant or “refusing to accept” that sometimes cancer can happen to young adults. One acquaintance of Kim’s blamed her smoking for her diagnosis of Hodgkin’s disease. While it has been shown that smoking leads to certain kinds of cancer, there is no evidence that smoking has any influence on the development of Hodgkin’s disease. “It was ridiculous. It was easier to blame me than think that cancer could happen to them too,” said Kim.

Not only were roles changing, but they were changing because of a disease that young adults were not expected to have. “Friends don’t want to have to deal with your mortality. People don’t want to accept the idea that even in your 20s you can get something that either can kill you or can have a lasting impact on the rest of your life or longevity,” Tim said.

Several of the patients I spoke with developed avoidance strategies to mitigate some of the more uncomfortable interactions with peers regarding cancer. Kim found that it was easier to minimize her physical symptoms by limiting the methods of communication she used during treatment.

I found I’d rather write it than talk to people. I’d never answer my phone if people called. I would answer emails and things like that. That way I didn’t have to be “on” all the time. I could feel like shit and that would be okay because no one knew.

When other people’s expectations of who gets cancer conflicted with reality, it led to cognitive dissonance that was evident in the shifting relationships young adult cancer patients experienced. Parents and friends sometimes had difficulty “dealing” with the

unexpected diagnosis. If even the medical community does not expect and welcome young adult cancer patients, it is not surprising that young adult cancer patients face abject surprise and confusion from friends and relatives. What emerged from these interviews is that the mainstream cancer narrative does not include young adults.

The next section examines interview participants' perceptions of cultural representations of cancer in mainstream media to build on this construction of what young adults see as the dominant cancer narrative.

Media Representations of the Cancer Experience

Young adult cancer patients described numerous conflicts with the experience they felt that others expected them to have as cancer patients and their actual experience with the disease. While only two of the cancer survivors who participated in this project knew another young adult cancer patient prior to being diagnosed, several participants had been exposed to cancer portrayals through mainstream media.

All participants were asked if they could think of any notable representations of cancer in mainstream media. If people had a difficult time coming up with any instances of cancer in general media they were prompted to consider television, movies, or books that may have featured cancer patients or survivors. When pressed to list any cancer representations they had seen on television or in the movies, a quarter of the young adults still had an extremely difficult time naming any characters with cancer. When prompted, several interview subjects responded with something similar to "oh yeah, she/he had

cancer?” As Denise said, “I’m sure there are cancer patients on shows that I’ve seen, like soap operas and stuff, but nothing that really sticks out.”

Individuals who were able to list media representations said that instances of what they felt were “accurate” or “realistic” representations of cancer were largely absent from mainstream media. Interview participants lamented that media representations of cancer either showed tragic images of people dying of cancer, a type of entertainment roundly rejected by the cancer survivors I spoke with, or white, affluent women facing breast cancer diagnoses such as Samantha in the popular HBO show “Sex in the City” and Celia Hodes in the Showtime series “Weeds.” Interview participants expressed frustration that their experience of cancer did not adhere to the representations of cancer they saw in the mainstream mass media.

Cancer Portrayals

Table 4.3 represents the open and axial coding that led to the results presented in this section regarding media coverage of cancer leading to what young adult cancer patients perceive to be the dominant cancer narrative.

Table 4.3: Cancer Portrayals

Properties	Open	Axial
Death	Cancer kills	Cancer is so horrible that it uniquely defines those affected.
Tragic		
Removes characters		
“Nobody looks like me”	Cancer only happens to certain “high risk” people	
Middle-aged women		
Children		
Sick (in hospital)	Cancer is easily recognizable (different)	
Bald		
Weak		

Brian’s Song, Stepmom, Sweet November, The Family Stone, A Walk to

Remember, Terms of Endearment: these popular movies all feature cancer as a lead character. In every movie, cancer plays the villain. Said Hilary,

Other than Lance [Armstrong], most people die if it’s portrayed in the general media and it’s always this very sad, heart-wrenching experience. Not to say that that doesn’t happen. It certainly does. But there’s a lot of kick ass cancer survivors who are doing amazing things.

Interview participants bemoaned the use of cancer as a “tragic” plot twist or a convenient way to remove a character from a story line. Kyle described this phenomenon as follows:

There was a stage when I was pretty sick of cancer being used as a plot device to get rid of a minor character. It seemed like whenever there was a TV show or a movie that had a character they wanted to get sick and die it was like, “Oh, just give him cancer and he’ll be gone.”

Several participants said they actively avoided watching television shows or movies that used cancer as a central plot line. Carol shared a story of receiving a book of

short stories about cancer from a friend. While the tales were meant to be inspirational, Carol said she could not read more than a couple of the pieces before putting the book down for good. “Too depressing” she said. “I was living cancer. I didn’t want to read what someone else was saying about it.”

Interview participants who were able to give examples of cancer patients or survivors in entertainment media often took issue with inaccuracies in media portrayals of cancer and the cancer experience. Like many complicated issues, cancer is often cleaned up and simplified in mainstream mass media. Several interview participants pointed out aspects of the cancer experience that they saw as frequently misrepresented on television and in movies. Molly told this story of a particularly frustrating instance of cancer in the mainstream media:

There’s this episode of *Gray’s Anatomy* where Izzy had to donate bone marrow to her daughter. First of all, it’s very, very, very unlikely that Izzy would have matched her daughter enough to be a bone marrow match. It’s genetic so you get half from your mother and half from your father, so it’s very unlikely you’re going to have a whole match and if you have a half match it’s really, really dangerous to do a bone marrow transplant and the doctors probably would have refused to do it. And of course her daughter looked just gorgeous and had her eyebrows. In real life her daughter would have looked like crap and would have been throwing up and wouldn’t have had eyebrows or eyelashes or anything. Oh and the fact that it happened so quickly. It takes weeks to get the results back and they would have had to do more testing on Izzy and you can’t just go into a room and take bone marrow then send it to another room and put it in her daughter. It’s just, the whole thing is ridiculous.

The point that Molly brought up regarding the physical appearance of cancer patients in mainstream media was echoed by Hodgkin’s survivor Kim, who said “I saw this article in the paper about lymphoma and they had this weird little bald girl sitting on

a couch and she had a blanket pulled up to her neck and, you know, I still have my hair and I didn't look like that at all. It just confused people.”

The major exception to the portrayal of cancer as a tragic, disfiguring condition harkening the arrival of a swift death was the media coverage of testicular cancer survivor Lance Armstrong. In the case of Armstrong, the cancer patient is anything but weak. However, this more empowering portrayal of cancer comes with its own set of complications.

Armstrong: Empowering, But a Lot to Live Up To

Several interview participants tied misconceptions and unrealistic expectations of cancer survivors in part to the prominence of major cancer spokespeople. By far the most common cancer spokesperson recognized by the young adult interview subjects was world-renowned cyclist and testicular cancer survivor Lance Armstrong.

Table 4.4 shows the open and axial codes that led to the results presented in this section on the effect of Lance Armstrong on young adult cancer patients' experiences.

Table 4.4: Armstrong: Empowering, But a Lot To Live Up To

Properties	Open	Axial
Empowering	“beating” cancer	Cancer can be beaten if you are strong enough
Powerful		
Good example		
Public		
Winner	Can't live up	
Out of reach		
Superman		

The Lance Armstrong Foundation (LAF) started a national craze in 2004 when it released its yellow LIVESTRONG wristbands. By the end of 2005 more than 55 million LIVESTRONG wristbands had been sold through the foundation. The use of the cancer awareness wristbands, first developed by LAF in its “LIVESTRONG” campaign, was also deemed too mainstream by participants. As one interviewee said “there’s a wristband for everything now,” which detracts from the original cancer awareness message. Several individuals shared that they wore the yellow “LIVESTRONG” bracelet but explained that they emphasized to those who inquired that they wore the bracelet because they had actually had cancer. According to John:

I’m proud to wear the bracelet. People are like that’s so over the bracelet thing, why are you still wearing that? I’m like, I have a reason to wear this. ... I had cancer. I really do carry this around. I like, look down at my wrist and usually it’s like part of my body. It’s almost like a tattoo but to me it really does mean something. It’s not just like a trendy thing to wear.

When discussing Lance Armstrong and LAF directly, interview participants expressed mixed feelings. Everyone interviewed was familiar with Lance Armstrong, his cancer experience, and LAF. A few interview subjects were largely ambivalent, explaining that they were not really interested in the Lance Armstrong stuff, but a majority of interview subjects shared sharply conflicting views regarding the influence Armstrong has had on cancer advocacy. When Kim was asked about her thoughts on Lance Armstrong she replied:

Umm I think it’s great but I also think it makes people feel like shit when they’re not awesome like him. Because, I’m not going to ride my bike 100 miles. You’ll be lucky if I walk a mile now. I mean, great. I know they give a lot of money to stuff and people were telling me they have these binders to help you be organized and everything and that’s stuff’s great. You need something sort of strive toward being, but I don’t know ... it seems a little unrealistic for most people.

The mixed feelings expressed in this quote illustrate the major conflict expressed by the cancer survivors interviewed. While LAF was overwhelmingly commended by the interview subjects for the work that it does to raise awareness about cancer and survivorship issues, the interview participants also expressed concern that Lance Armstrong's exceptional story was viewed as the norm. Because they were "never going to win the Tour De France," several interview participants said they felt frustrated because of the expectations they faced after treatment. Said Carol:

I think it's great to have him at the forefront of the young cancer alliance because he's such a public figure and I think that people like that bring a lot of attention to something that's happening to a whole lot of a hell more people than anyone realizes. He's the cancer patient that then went on to win the Tour De France seven times. But I'm not going to do that, and a lot of people who go through cancer treatment aren't gonna do that. It makes you feel like you're not doing enough just by getting through the damn thing.

In addition to the blatant expressions of mixed admiration and frustration in regards to the prominence of the Lance Armstrong story and LAF, some interview subjects also stated that Lance Armstrong had been a source of inspiration during treatment. The more complicated feelings of mixed appreciation and frustration over unattainable expectations arose only after treatment was completed.

Lance Armstrong's presence as an extremely public figure in the young adult cancer community has led to both admiration and frustration on the part of the young adult cancer patients I interviewed. While his work was frequently called "important" and "inspiring," about two thirds of the young adults interviewed expressed concern that they could not live up to the expectations his prominence created. Armstrong's successful

battle with testicular cancer caused some of the cancer patients interviewed to feel excluded when their cancer experience did not end in a definite “win.”

Cancer Cure

As touched upon in the discussion of Lance Armstrong, the young adults I interviewed identified the perception that cancer is finite as one of the major misconceptions regarding cancer. The Susan B. Komen Foundation pledges to “find a cure for breast cancer,” and the Lance Armstrong Foundation encourages cancer patients to “fight to win.” For many of the interview participants, there literally is no cure for their cancer and the fight is never going to end. During the interviews several of the cancer survivors described their discontent with common terminology that implies cancer is finite. Table 4.5 lists the open and axial codes that led to the results presented in this section.

Table 4.5: Cancer Cure

Properties	Open	Axial
Survived	Finishing cancer	Cancer has a definite end. Survivors stop being sick at remission.
Beat cancer		
Done/Finished		
Relapse	Effects of cancer continue after treatment	
Fatigue		
Follow-ups		
Side-effects		

A few of the cancer survivors interviewed held particularly strong views on the idea that cancer is finite because even the medical community does not see their disease as ever reaching a “cured” state. As Carol, a breast cancer survivor, said:

They don't talk about it as remission when you're a breast cancer patient. They won't use words like remission, which is actually really frustrating because people ask these questions and say “you're cured now.” Well no, I'm a cancer patient for the rest of my life.

Several interview subjects discussed their experience with cancer as a “fight,” but rarely did interview subjects speak of “beating” the disease. When they did use words like “beat” or “won” it was typically in reference to how others wanted them to experience cancer. Several interview participants took great pains to explain that going into remission did not, in fact, mean they were finished with cancer. According to the interview data, this idea of being a cancer patient for life is difficult for young adults trying to deal with worried friends and concerned family members. In the following paragraph Tim described the challenges he faced speaking with his friends about cancer shortly after he went into remission.

People, maybe specifically at this age, want you to be done. They want to be able to say “Hey, Ted beat cancer. Ted's done.” Like it's finished. You know, “cancer is his bitch,” and it's not like that. Survivor is such a loaded word, and I've had so many conversations about this. All that means is that you're not dead of cancer right now ... I mean the things you go through [in treatment], they may kill the first cancer but the things that you do – the risk you take – is that you'll get another cancer so I'll never be cured. Hopefully I'll die at age 99 in my sleep from heart failure. Hopefully my old age death will have nothing to do with cancer but until that day .. Until I don't die of cancer I'll never be cured. The moment I'm cured is the moment I die from something else.

Of the 16 young adult cancer patients interviewed, five had experienced at least one relapse. John relapsed for the second time three months after the interview, and at the time that we spoke, Kim was preparing to go into the hospital for a biopsy to check for a secondary recurrence of Hodgkin's disease. As evidenced by the experiences of the young adult cancer patients interviewed, the possibility of a secondary occurrence weighs heavily on these survivors' minds. Kevin explained his reluctance to see an "end" to cancer this way:

I don't necessarily think that there is an end and maybe that's ... because I was in remission and then been told I wasn't anymore so I have less of a concept of there being a finite beginning and end to the whole process. I can pick out dates that indicate important landmarks in my treatment, but I can't pinpoint a date and say this is when my cancer experience was over. When I think of the word survivor I don't think of an ending in that way. The psychosocial issues and the physical issues continue. It seems to me that once you're diagnosed there's something that's changed that's never going to switch back.

The young adult cancer patients interviewed do not see cancer as having a defined end and therefore expressed difficulty coming to terms with the expectation that after they reached the end of active treatment or were declared in remission, they were done. Even interview participants diagnosed with "curable" cancers, or those which the medical profession will consider cured after patients are in remission for a certain number of years, did not claim their cancer experience was finite. However, interview participants did express frustration at the expectation that they could "finish" cancer, "win the battle," "kick cancer's ass" and be done.

Summary

The results produced through the open and axial coding process show an emergent dominant cancer narrative. Young adults do not get cancer; it is a disease of the very young, the very old, and middle-aged women. The young adult cancer patients interviewed described several aspects of their personal cancer experience that they said did not fit within what they saw as expected of them as cancer patients. The interview data showed that that young adults are not supposed to be members of the cancer community, at least not as patients. The young adults interviewed said that their age group was extremely underrepresented in mainstream media, where cancer is portrayed as deadly, horrible, and enough to completely define a character. Discussion of prominent cancer patients, such as testicular cancer survivor Lance Armstrong, led to the revelation that cancer is seen as conquerable if the cancer patient is strong enough to take it on. Also, there is a prevailing belief, recognized but roundly criticized by the interview participants, that once cancer has been beaten the disease experience is over.

The next section presents the results, developed through Strauss and Corbin's three-step coding method, to show how young adult cancer patients are challenging the dominant cancer narrative and developing and distributing their own alternative cancer narratives.

Taking Control: Building Alternative Cancer Narratives

Table 4.6 describes the open and axial categories that emerged from interview participants' discussions of their alternative descriptions of the cancer experience.

Table 4.6: Codes Related To Development Of Alternative Cancer Narratives

Classification	Category	Description
<i>Open code</i>	Combative cancer metaphors	Language used that compare cancer to combative situations
Property	Battle/fight/war	Cancer is a war
Property	Win	When you beat cancer, you “win” the battle/war/fight
Property	Survivor	Person who has or did have cancer
<i>Open code</i>	Active cancer metaphors	Language that puts the cancer patient in an active position in relation to cancer
Property	Thrifer	Not a survivor, but a thrifer
Property	Conquerer	Conquerer of cancer
Property	Journey	Embarking on a cancer “journey”
Property	Experience	Cancer is an experience
Property	Veteran	Not a survivor, but a cancer veteran
<i>Axial code</i>	Combative metaphors are challenged by active cancer metaphors	Young adults take issue with traditional combative cancer metaphors
<i>Open code</i>	Cancer humor can be useful, uncomfortable	Young adult cancer survivors enjoy cancer humor, it can make people uncomfortable
Property	Providing information	Using humor to provide unpleasant answers to questions/avoid pity
Property	Softening blow	Joking about difficult things makes them easier to share
Property	Creating discomfort	People upset by cancer humor
<i>Open coding</i>	Cancer humor is fulfilling	Humor plays an important role in the recovery process
Property	A relief	Humor to ease tension
Property	Coping	Humor to cope with difficult parts of treatment or survivorship
Property	Comfortable	Humor to make cancer survivor feel comfortable
Property	Powerful	Laughing at cancer takes away power from the disease
<i>Axial coding</i>	Young adult cancer patients want to use humor, but it can make people uncomfortable	Humor is often not acceptable in regards to cancer.
<i>Open coding</i>	Experience built expertise	Cancer survivors are experts on the disease
Property	Advice	Cancer survivors as sources of advice
Property	Experience	Passing on experience to others

Classification	Category	Description
Property	Mistakes	Helping others by sharing common mistakes
Property	Tips	Providing snippets of information
Property	Support	Giving and receiving support from cancer patients and survivors
Open coding	Improve experience for others	Make the treatment and recovery process easier for other cancer patients
Property	Donate	Donate time, money, expertise
Property	Advocate	Speak out publicly on needs of cancer patients
Property	Return the favor	Current survivors who received help want to pass the favor along
Open coding	Cancer gives person value	Cancer experience makes a personal a valuable resource
Property	Tell my story	Share cancer experiences
Property	Something to say	Cancer story is important enough to be shared
Axial coding	Cancer survivors have valuable expertise that should be shared	A cancer experience infuses survivors with knowledge and expertise that they feel obligated to share
Open coding	Communication tools	Ways of publishing and building networks online
Property	Blogging	Online personal journals
Property	Bulletin boards	Areas to post information online
Property	Social networking	Interconnected network of personal Web pages
Property	List serves	Email conversations for groups of like-minded individuals
Open coding	Web-based relationships	Relationships built and/or maintained through Internet-based resources
Property	Role model	Looking up to someone based on online publications
Property	Friends	Social relationships developed online
Property	Teacher	Provider of information, answers questions
Property	Mentor	Teacher-like relationship formed with someone who went through a similar experience
Open coding	Can be yourself online	Online world is unconstrained by dominant cultural norms
Property	Freeing	Unconstrained conversation/comments
Property	Supportive	Finding like-minded individuals to reinforce experiences and ideas

Classification	Category	Description
Property	Comfortable	Description of feeling like one “fits in”
Property	Organized	Creating change through interconnected network
Property	Validation	Reinforcing individual ideas through group buy-in
<i>Axial coding</i>	Online tools make it possible to build relationships and validate the cancer experience	The Web is a place where alternative narratives can be developed and validated

The Language of Disease: Changing the Cancer Dialog

Interview participants repeatedly referred to issues with the language used to discuss cancer and the cancer experience. Table 4.7 shows the coding process that led to the analysis presented in this section.

Table 4.7: The Language Of Disease

Properties	Open	Axial
Win	Combative cancer metaphors	Combative metaphors are challenged by active cancer metaphors
Battle/fight/war		
Survivor		
Thriver	Active cancer metaphors	
Conquerer		
Journey		
Experience		
Veteran		

Combative cancer metaphors

The prevalence of war metaphors became immediately apparent during the interview sessions. Interview participants spoke of “fighting” cancer, having to “battle”

cancer, “beating” the disease, and “winning the battle.” These references to cancer as a battle between patient and disease were peppered throughout conversations and mirrored the language used culturally to describe cancer.

During the interviews the participants repeatedly referred to themselves, and other people affected by cancer, as “survivors.” Metaphor is a common language technique used when describing cancer and cancer patients; however, the use of metaphor limits the acceptable identity of the disease and those who experience it. Although the word “survivor” was used frequently throughout the interviews, many of the young adult participants expressed concern regarding the omnipresent nature of the survivor metaphor. Several interview subjects complained of the word being “watered-down” and “overused.” However, they were unable to provide an alternative word that would better describe their position as post-cancer patients. While the word was criticized for being inaccurate and too common, it was still the word of choice used by the young adults interviewed to describe their position in relation to cancer. The following excerpt from Brian’s interview shows the prevalence of the survivor metaphor.

B: I hate the word “survivor.”

K: Well, what do you call yourself?

B: I don’t know, destroyer of cancer? Cancer killer? I guess ‘survivor’ but only because that’s what everyone calls it.

As evidenced by the above quote, metaphors for cancer have become entrenched in U.S. vernacular to such an extent that individual attempts to modify or adjust these metaphors are unsuccessful on a large scale. Despite my personal frustration with the term “survivor,” I have used it several times in this paper. There is simply no other word

as universally recognized in describing individuals who are undergoing or have completed cancer treatments.

Alternative cancer metaphors

The young adult interview participants did mention several words to describe individuals who are post-cancer treatment. These include “conquerer,” “destroyer,” “cancer veteran,” and “killer.” A common theme running through these alternative descriptions is their active nature. However, a desire to modify existing cancer metaphors does not easily translate to actual change. Kevin elaborates on this point in the following quote:

I tend to use, well survivor actually is the only word I’ve used much lately, partly because it’s become so commonplace. I don’t even think of all the implications of it when I say it. It’s tough because so many people’s experiences are so different that I know everybody carries along slightly different meanings of the word. For me, it means almost more a veteran than anything else. I went there and I did these things and I was a part of it. It didn’t just happen to me. I think if anything maybe a little bit more active word would fit the way I feel about that experience [cancer] a little better, but until someone comes up with a different word I’m sticking with survivor.

The use of common cancer metaphors has sparked discussion on a number of online cancer discussion boards, and numerous bloggers have touched on this topic. While Web-based cancer communities are providing a forum where individuals who have or have had cancer can openly discuss frustration with the current language used to describe cancer patients, there does not yet appear to be a unifying movement to change the way the larger, non-cancer community discusses the disease. The young adult cancer

survivors interviewed expressed preference for active wording when describing cancer, but recognized that combative wording still dominates the language of cancer.

Laughing in the Face of Cancer

According to the interview participants, the use of humor in healthcare communications resonates with the young adult cancer population and helps them cope with the diagnosis and subsequent treatment regimes. Kim describes how she used humor during her cancer experience as follows:

Kim: Yeah, it's no fun but you know you've got to be funny.

K: 'You've got to be funny to deal with it.' Tell me about that philosophy.

Kim: For me I think that's the only way you're going to get through things. I threw myself a party when I found out I had cancer because I wanted to be able to have fun and be normal while I still looked the same and still pretty much was the same. We had a lot of fun; it was hilarious. Somebody bought me funny wigs. I still have three wigs and they're sitting on top of my fridge in my apartment right now and they come out whenever I have people over.

Table 4.8 shows the codes that led to the analysis presented in this section on the use of humor in healthcare communication.

Table 4.8: Laughing In The Face Of Cancer

Properties	Open	Axial
Providing information	Cancer humor can be useful, but uncomfortable	Young adult cancer patients want to use humor, but it can make people uncomfortable
Softening blow		
Creating discomfort		
A relief	Cancer humor is fulfilling	
Coping		
Comfortable		
Powerful		

However, the taboo of joking about serious illness appears to have stifled cancer humor in many situations. Within this larger topic of laughing at/with/about cancer, there are two primary themes that emerged from the data: humor in the cancer community and cross cancer community humor. While young adult cancer patients describe cancer humor as “a relief,” they also said that cancer humor made peers and family members uncomfortable, making it difficult to express themselves through humor outside of groups of cancer survivors. Said Cynthia,

When I was going through treatment you know I’d make jokes here or there and my friends wouldn’t know how to react. They were like “do I laugh with her?” So that was pretty different, but laughter was the best medicine a lot of time.

Many interviewees discussed the “discomfort” and “shock” experienced by non-cancer community members when cancer survivors discussed cancer in a humorous or only semi-serious manner. Feeling “out of place” or “offensive” when joking about cancer was common among respondents. Molly told this story about using humor around her healthy friends while she was going through cancer treatments:

I went back to visit my college friends and it happened to be over Halloween so they were dressing up. I said, “I have the perfect costume. I’m going to be a cancer patient.” I was bald. I looked sick. Why not? And they said, “this is horrible. Don’t say that again. It’s not funny.” It was really frustrating for me that they had that attitude because you know, I was trying to deal with it and I felt like they were impeding my self expression and that was very stifling to me.

While the young adults interviewed stated without exception that they joked about their cancer and cancer treatment, interview participants were mixed regarding whether it was acceptable for non-cancer survivors to joke about cancer. As Tim said, “not to say

that my friends didn't joke about it because they did and some of them were hilarious. But I think it's kind of like Jewish jokes. If you're not Jewish it's not funny." Among several of the interview participants there was an attitude of entitlement that lent legitimacy to the young adult cancer survivors' humorous take on the illness. Apparently, as an insider, they had the privilege of joking about the disease, whereas those outside the community were barred from this irreverent behavior.

When discussing the cancer community, particularly the online cancer community, several participants indicated that they felt they fit in because "people got my jokes." The young adults interviewed said that traditional cancer advocacy groups use campaign strategies that speak about cancer as a serious, almost reverent issue. While there is no question that cancer is a serious illness, when actually going through treatment the young adults interviewed said they found it difficult to focus solely on the unpleasant aspects of the disease experience. According to Hilary,

There was a lot of really bizarre stuff that was in a very twisted way funny. You didn't have permission to laugh anymore. You had to be so deadly serious about everything and that gave cancer way too much power. I laughed at things before, why should I not laugh at things now? It's a great coping mechanism because humor takes away the power. If you can laugh at cancer it doesn't have the power, you have the power.

Groups like the American Cancer Society and the Leukemia/Lymphoma Foundation produced literature that, according to several interview participants, was "informative" but also "dry" or "depressing." The primary online young adult cancer community, Planet Cancer, takes a particularly irreverent stance on cancer issues and features humorous articles and joke items poking fun at everything from chemo-brain to

getting used to a prosthetic limb. Young adult cancer community members who found Planet Cancer expressed relief and support of the Web site's attitude saying that "it totally spoke to me" and "finally someplace I feel comfortable." John said,

When I first went to Planet Cancer I just kind of was all over the place. I was so excited to find something where it was all young adults and I felt like I fit right in. It was it was really interesting and they talked about cancer the way I did and nobody got upset or weird because of it. I love the joking and have like, a bunch of shirts and stuff from them. It always freaks people out when I wear them.

Although the interview participants recognized that making jokes and laughing about cancer made people outside of the cancer community uncomfortable, humor was still seen as a highly effective coping mechanism. The young adults I spoke with often felt frustrated when their attempts at humor were shot down by friends and family, It was, as Hilary said, like they "didn't have permission" to laugh. But at the same time, the young adults I spoke with needed to laugh both to cope and to become empowered patients and survivors. While the interview participants used traditional cancer advocacy groups for information on disease and survivorship resources, online resources provided opportunities for humorous discussions of the cancer experience.

Giving Back: Survivor as Cancer Resource

Of the 16 interview participants, 14 specifically mentioned some way they had tried to make the cancer experience easier for other young adult cancer patients. This trend is made even more significant because, as the interview guide shows, no single question specifically addressed this idea of giving back to the cancer community. The point was deemed important enough by interview participants that, in nearly every

conversation, they mentioned their attempts to be a resource to the larger cancer community (Table 4.9).

Table 4.9: Giving Back

Properties	Open	Axial
Advice	Experience built expertise	Cancer survivors have valuable expertise that should be shared
Experience		
Mistakes		
Tips		
Support		
Donate	Improve experience for others	
Advocate		
Return the favor		
Tell my story		
Something to say	Cancer gives a person value	
	Gives a valid voice	

The interview data indicated that young adults believe the experience of having cancer changes them. Finishing treatment did not mean that these young survivors' experiences were over. In fact, two of the interview participants said that the hardest part of the cancer experience was actually readjusting to their life after treatment. Molly shared the difficulties she had readjusting to her life in the following passage:

It was a really hard transition from treatment back to normal life. Literally I got the clear from my doctor and I was at school five days later. I had just had chemo a month before. I was just so happy to not be in treatment and be alive, but I think I was pretty lonely that semester. A lot of friends were studying abroad so a lot of people weren't around, and the friends who were around didn't necessarily know what to say or how to talk about it and I was trying to figure out how to fit back into a life that didn't center around going to the hospital every day ... It was hard to be in that environment which was in some ways very superficial when I didn't feel like I belonged there anymore. It was hard working out a balance between the "cancer world" and the "normal world."

The experience of having had cancer not only left the young adults “changed,” but also made many of the cancer survivors interviewed feel like they owed something to cancer patients who would come after them.

Taking action. Several of the interview participants took part in events held by traditional cancer advocacy groups to raise funds and awareness of cancer. Four of the interview participants had walked in Light the Night programs sponsored by the Leukemia & Lymphoma Society. Two of the interview participants had taken part in the Avon Walk for Breast Cancer, and at the time of the interview Cary was training to run a half-marathon with Team in Training, a Leukemia & Lymphoma Society program.

Bonnie went into great detail explaining to what use the money she raised was put. After completing treatment for Hodgkin’s disease, Bonnie participated in several Light the Night Walks to raise money for the Leukemia & Lymphoma Society. According to Bonnie, the most rewarding part of doing the walks was knowing where exactly the money she raised was going. During the interview Bonnie discussed the co-pay assistance program the Leukemia & Lymphoma Society was implementing and she gave examples of researchers funded by the group. “It’s amazing what the Leukemia & Lymphoma Society does with their funds and how they distribute them to research and patient services. I think it’s really great that they talk about where their money goes.”

The interview data showed that fulfillment for the young adult cancer survivors came both from working to give back to the larger cancer community and from knowing how those funds would be used. The young adults interviewed appreciated seeing

tangible results from their advocacy activities. Participants were eager to donate their time, energy, and expertise, but they wanted to be kept informed and stay involved in the charitable giving process.

Being a cancer expert. Beyond time and money, the cancer survivors interviewed saw value in the expertise gained through their cancer experiences. The role of “expert” in the cancer world is not relegated just to medical professionals. As David put it:

Unless the doctors have had cancer they’re not going to really know. They’ve treated cancer patients, but they can’t know because they’ve never been there. It would be like me offering advice to an AIDS patient. I don’t really know what it’s like to be an AIDS patient so I can only empathize. I think that that’s what a doctor can do, empathize.

When the young adult cancer patients I spoke with found it difficult to find cancer “experts,” they took matters into their own hands and became the expert they sought. John, who was unable to find any support groups or networking programs for young adults with cancer in the Washington D.C. area, worked with a friend to start a local support group. Several of the interview participants mentioned starting Web-based journals, commonly known as blogs, to pass along information and expertise to current cancer patients.

Denise is a frequent participant in online bulletin boards, where she answers questions and shares her experience with individuals currently going through cancer treatment. She describes her reason for participating in online forums as follows:

There’s a lot of people that I’ve met through this process that are a lot worse off than I am, so I kind of feel like it’s my responsibility. You know, I did survive this, and I did do well, so I need to give back to other people.

This “giving back” process takes several forms. Several interview participants mentioned passing information, or wanting to pass information, on to those who are new to the cancer experience. Basic information on various kinds of cancer are available through online resources, informational material from groups like the American Cancer Society and the Lance Armstrong Foundation and medical professionals. However, many questions arise during the cancer process that are difficult to find answers to. What will a bone marrow transplant feel like? What should I eat before a chemo session? How do I find a bathing suit that covers up the port scar on my chest? These more obscure questions are difficult to find in traditional cancer communication material. According to Molly:

I e-mail with a number of people from Planet Cancer. And that I really enjoy and some people have contacted me and said “oh, I love this post and I’m about to get a transplant. What can you tell me about it.” I really like that because I know how scared I was before my transplant so anything I can do to help them or reassure them is an important thing to do. I think it’s an important way to give back.

The young adult cancer patients interviewed saw their cancer experiences extending long beyond active treatment ended. They found themselves in a position to provide time, energy, and expertise to cancer patients going through treatment. While the interview data indicated that the young adults were eager to give back to the larger cancer community, they gravitated toward charitable activities that allowed them to maintain a degree of control over their donations of time, money and information. The most common method the young adults interviewed used to help the larger cancer community

was to provide emotional and informational support for other young adult cancer patients. This was accomplished primarily through Web-based publishing.

Interconnectedness Online: Validating Alternative Cancer Experiences

All of the young adult cancer survivors interviewed were regular Internet users. The entire participant group used Web-based resources for informational purposes and, to varying degrees, all participants took part in social interactions online. Table 4.10 shows the open and axial coding process that led to the results presented in this section.

Table 4.10: Interconnectedness Online

Properties	Open	Axial
Blogging	Communication tools	Online tools make it possible to build relationships and validate the cancer experience
Bulletin boards		
Social networking		
List serves		
Role model	Web-based relationships	
Friends		
Teacher		
Mentor		
Freeing	Can be yourself online	
Supportive		
Comfortable		
Organized		
Validation		

The Web has played a pivotal role in building a young adult cancer community. As mentioned in Chapter 3, participant recruitment for this project began at the Web site PlanetCancer.com. This online environment includes sections listing cancer resources, a

chat room, a MySpace-like social networking feature, and a series of bulletin boards.

These bulletin boards provide space for young adult cancer patients and survivors to ask questions or post thoughts regarding the cancer experience and survivorship issues.

“There were so many nights where I was up so late and I couldn’t sleep and that [Planetcancer.com] was the one place I could go at any time of day. That was kind of nice,” said Denise when discussing her participation in online cancer forums.

During the interview process several additional methods of sharing information about cancer were discussed. Nine of the interview participants mentioned keeping blogs while they went through treatment, and several maintained those blogs into survivorship. Several of the young adults interviewed discussed their participation in various disease-specific list serves targeted to patients dealing with cancers such as Hodgkin’s disease, AML, and breast cancer. One participant, David, is working on developing a book consisting of life-stories provided by young adult cancer patients from across the country.

Becoming an online cancer celebrity

Although young adult cancer survivors did not identify with traditional mass media cancer patients, nearly all interview participants mentioned a connection to cancer experiences that they read about online. Furthermore, the production and distribution of personal cancer stories through the use of online journals, more commonly known as “blogs,” was common practice among young adults. John described his motivations for blogging as follows:

I’ve never really been a big journal person, I was just kind of a wanna be. Like I’d start a journal and then I’d just like you know fall off the wagon. It felt really good for me. You know, it was validating for me. I had something to journal about and it was something that people were interested in reading. People checked

the site, they commented, they offered support, and other people that found my blog when they were going through these experiences, or somebody else, you know one of their loved ones was, and I connected with people that way. It was rewarding and a little bit depressing because some of them died, but I guess that's the reality of the situation that we're in.

Through the creation of blogs, young adult cancer survivors are able to publish their own stories and share what they believe is the "real" cancer experience. Through blog links and Web communities, bloggers can form relationships that can translate into real-world friendships. Interview participants also said they utilized online support groups to share what they viewed as accurate versions of the young adult cancer experience. Several participants posted on forums such as Yahoo Health and Planet Cancer, which offer discussion boards where individuals can publish their stories and experiences in real time. The young adult cancer patients interviewed also said they found these sites "helpful" because they could read about the cancer experiences of other young adults. While the data indicate that non-cancer peers of the interview participants often had a difficult time adjusting to a cancer diagnosis, through young adult cancer support groups cancer patients and survivors said they found a ready audience for personal experience pieces and an entire library of real-life young adult cancer stories. Not only were the young adult cancer survivors in this study able to solidify their alternative take on what a cancer story is supposed to look like, by publishing their personal story online, they could compare their personal story with similar stories written by other young adult cancer patients. According to Tim:

Blogging helped me a lot. I ended up saying a lot of things on there that I probably would never have said if I hadn't said it on the blog. It was really helpful for me to just bitch or be sad and just talk to everybody and nobody at the same time. ... It was not only writing but my own but reading other people's blogs and

finding connections. All these people [online] they are writing about not just the greater lessons but little things that you can pick up on.

Web-based tools bring together members of the young adult cancer population to an extent that a brick and mortar organization could never achieve. Of the 16 young adults interviewed, 15 said that they spend more time on the computer than they did using any other form of media. Young adult cancer patients use the Web to build relationships with other members of the young adult cancer community. These relationships serve several purposes. They facilitate the exchange of information, advice, and tips to deal with cancer treatment and survivorship, they can provide support, and they can build friendships. The interconnected web of online relationships that constitute the young adult cancer community create a powerful network to address issues of importance to the young adult cancer population.

Summary

The young adult cancer population is challenging the existing dominant cancer narrative by resisting traditional cancer metaphors, using humor when discussing cancer and the cancer experience, and sharing personal cancer experiences rather than relying on cancer-celebrities or media representations to dictate what is and how a cancer survivor looks and acts. Online tools have made it possible to challenge dominant cancer narratives by providing a place for young adult cancer patients to publish their own thoughts and experiences. Also, despite being a geographically disparate population, young adults are able to connect with the larger young adult cancer community by using Internet-based tools. As a group, young adult cancer survivors are able to organize,

validate alternative cancer narratives and address advocacy issues of importance to this particular population.

The next chapter pulls these themes together through the selective coding process.

CHAPTER V

DISCUSSION OF RESULTS

This chapter discusses the results of the research presented in relation to the existing literature, outlines the selective codes developed from the open and axial codes discussed in Chapter 4, and addresses directions for practical application and future study of this topic. But first, limitations of the study should be noted.

Limitations

In choosing to use qualitative research, I was able to gain extensive information regarding the young adult cancer survivors interviewed. However, given the method choice, the conclusions drawn in this study are not generalizable to the entire young adult cancer population. Although not generalizable, the issues discussed bring to light clear concerns regarding the support needs of young adult cancer patients.

As discussed in Chapter 3, I first recruited interview participants through the Web-based young adult cancer community, Planet Cancer, using my own cancer experience as an “in.” I then utilized snowball sampling techniques to expand on this original group of participants. Using directive rather than random sampling was the only feasible option given the geographically diverse nature of the subject population. While this sampling process resulted in a diverse group of research participants in terms of their diagnoses, treatments, and ages, it likely biased the sample in regards to level of group

participation. The primary way that young adult cancer patients meet other young adult cancer patients is through either online or real-world support groups. By starting with a sample culled from an online support group and relying on snowball sampling recommendations from individuals who primarily know cancer peers through support groups, I built a research pool of individuals who are involved in cancer communities. This sampling technique did not allow me to attract participants who do not participate in either real-world or online support groups, and who thus may have had different experiences and perspectives.

While this study is by no means a complete exploration of the young adult cancer experience, the interviews did provide information on the position of young adult cancer patients in mainstream and alternative cancer communities. The next section applies the results presented in Chapter 4 to the three original research questions asked in this study.

Research Question 1: What do Young Adult Cancer Patients Identify as the Dominant Cancer Expectations?

Young adult cancer patients first and foremost see the dominant cancer narrative as restrictive. According to the young adults interviewed, people their age are not “supposed” to get cancer. If young adults do get cancer, they are expected to withdraw from their active lives so they can grow weak, pale, skinny, and lose their hair in private. When young adults have cancer they are supposed to look like they have cancer. Young adult cancer patients are also supposed to discard their sense of humor and treat the disease with a degree of seriousness befitting a deadly illness. During cancer treatment, a

young adult cancer patient's energy must be directed toward "fighting" the disease. If young adults are positive enough and strong enough, they can "win" the "battle" against cancer and move into survivorship. Once cancer treatment is over the young adult cancer patient is supposed to be done. They have moved from the land of the sick back to the land of the well, and their cancer experience is supposed to be over.

These expectations of what cancer is supposed to look like and how it is supposed to be experienced, which were identified by the study participants, combine to form an overarching dominant cultural cancer narrative. Charland's (1987) theory of constitutive rhetoric states that a subject is constituted through narratives, which provide a domain of identifications that shape the personal and cultural understandings of that subject. Cancer is therefore constituted by the cultural narratives surrounding the disease.

The overwhelming message culled from the interview data is that young adult cancer patients do not believe they are included in the dominant cancer narrative. The institutions that have been developed to address cancer – both in the medical and in the advocacy fields of cancer work – do not come close to fully addressing the needs of young adult cancer patients. Previous researchers have indicated that cancer is a personal disease (Harrison, 2005). The interview participants confirmed this finding, but rather than identifying cancer as "personal," the young adults described cancer as "isolating." Cancer distanced young adults from their peers, most of whom had never had to deal with any kind of major illness. Most of the cancer patients interviewed were in the process of moving away from the support and supervision provided through their families when they were diagnosed. Several of the interview participants were in college at the time of

diagnosis, a few were living on their own, and a couple had recently been married.

Relationships with peers were important to the young adults interviewed, but the cancer diagnosis made the young adults I spoke with feel “different” and “separate” from their friends.

The isolation from non-cancer peers is perhaps understandable given the history of dread and mystery that has surrounded the disease; young adult cancer patients shared that they also felt unwelcome in places where a cancer diagnosis is the norm. The institution of medicine as it relates to cancer care is binary, dividing patients into segments for pediatric and adult care. Young adults fall into the middle no-mans-land of cancer care and support. The cancer patients interviewed were consistently the only young people in oncology waiting rooms and treatment facilities, and they had trouble finding support groups where they felt comfortable and where their needs were addressed. The young adults interviewed believed they were not experiencing cancer in the way that they were “supposed” to experience it. They do not adhere to the expectations established through the dominant cancer narrative.

Despite their marginalization from the larger cancer community, the young adults interviewed still identified more as young adult cancer patients and survivors than any other common social group identification. Existing research shows that tertiary identities play a role in how a cancer patient experiences the disease and reacts to treatment and survivorship issues (Harwood & Sparks, 2003). This research supports these findings regarding tertiary identities, but indicates that, at least for the young adult population, the age at the time of diagnosis plays a large role in the cancer experience, even when

compared to other common societal identifications such as race, gender, sexuality, education, or economic position. Despite the salience of racial issues in U.S. culture, race was not mentioned at any point as a factor contributing to the feelings of inclusion or isolation of the young adult cancer patients interviewed. Gender was also not addressed in the interviews, even though same-sex support groups are common for adult cancer patients and survivors. Support groups are often organized by diagnosis so breast cancer groups, for example, tend to be primarily women and testicular cancer groups all men. Several interview participants had the opportunity to join single-sex support groups, but gravitated toward situations with other young adults, either forming small subgroups within the larger support group, or seeking out young adult support groups.

All the young adult support groups, both online and real-world, that participants mentioned during the interview process included both male and female participants. The young adults interviewed indicated that they felt the most comfortable and “got the most out of” support groups and networking situations where the population was other young adult cancer survivors. Being of similar age was more important to the study participants than having the same diagnosis or coming from the same geographic or economic background. Common cultural identity characteristics rarely came up in the interviews, and participants took part in support groups with a diverse array of individuals. Other tertiary identities, such as gender and race, may have been expressed as more salient factors in the cancer experience if the interview participants had been chosen based on those characteristics. However, the concerns expressed by the young adult cancer patients

interviewed focused primarily on aspects of the treatment and post-treatment process that related directly to age and point in life.

Young adult cancer patients said they felt most “out of place” when they were significantly outnumbered by much older or much younger cancer patients and when they were in situations where they were the only cancer survivors. When young adults are diagnosed with cancer the experience isolates them from their existing social networks; however, their status as non-entities in the dominant cancer narrative prevents them from gaining acceptance into the cancer community.

Research Question 2: How are Young Adult Cancer Patients Challenging Existing Cancer Narratives and What Alternative Cancer Narratives are These Survivors Developing?

Young adult cancer patients are challenging existing cancer narratives by publicly challenging the expectations of what cancer is “supposed” to look like and how they as cancer patients are “supposed” to act. Young adult cancer patients are not barricading themselves from the outside world during treatment and survivorship. They are talking about cancer, advocating for better care for themselves and others, infusing humor into the disease experience, and challenging traditional binary notions of sickness and health.

Much of the cancer conversations that take place in the young adult cancer community are infused with a raw humor that stands in sharp contrast to the expected nature of cancer conversations. Using humor as a means to discuss cancer and the cancer experience can be isolating in that most of the people the young adult interview

participants communicated with outside the young adult cancer community found cancer humor “offensive” or “didn’t get it.” However, within the young adult cancer community humor was used as a tool of inclusion and empowerment.

The prominence of major cancer spokespersons, Lance Armstrong in particular, is an aspect of the modern cancer experience that has led to polarization in the cancer community. Lance Armstrong has probably done more to bring attention to the issue of cancer in young adults than any other person in modern cancer movements. However, some of the young adults interviewed expressed concern that his almost superman-like recovery from testicular cancer had created unrealistic expectations for normal cancer survivors. The LAF is spearheading young adult cancer advocacy. They sponsor medical research with the goal of raising survival rates for young adult cancer patients and they are founding members of the Young Adult Alliance, a recently created coalition of organizations doing advocacy work for young adult cancer patients. While the good work has increased medical resources to the young adult cancer community, it reinforces major aspects of the dominant cancer narrative.

In addition to bringing attention to major cancer issues, the LAF’s frequent use of the word “survivor” in reference to cancer patients has led to widespread use of the word. This topic is yet another issue that occupies a grey zone of influencing both the dominant cancer narrative and the creation of alternative cancer narratives. The term has become the primary descriptor for cancer patients. While the young adult cancer patients interviewed agree that survivor is far preferable to older cancer terms like “cancer victim,” the word “survivor” is not without its critics. “Survivor” is an improvement over

“victim,” but it still implies a lack of personal empowerment. This term has become so common when discussing cancer that attempts to replace the word on an individual level are largely unsuccessful.

The Web has provided a space for young adult cancer patients to build and develop a community, albeit a largely virtual one. Because the process of alternative cancer narrative creation and validation is inextricably linked with online communications, the next section goes into much greater detail into the development of alternative cancer narratives.

Research Question 3: How do Young Adult Cancer Survivors Use Participatory Media to Formulate, Expand and Validate Alternative Cancer Narratives?

Young adult cancer patients cut across geographic, racial, ethnic, and economic boundaries to seek out other young adult cancer patients. The advent of Web-based communication tools has made it possible to organize communities around shared interests or experiences and decreased the dependence of geographic location (Castells, 1996). This study confirms Castells’ (1996) work, showing a group that has not only organized through shared communication, it has used the features of the Web to challenge the dominant cultural understandings of the experience the group formed around. Using such tools as social networking sites, blogs, bulletin boards, and list serves, young adults are reaching out to build a virtual community of young adult cancer patients and survivors.

By creating an Internet-based cancer community outside of the bounds of the mainstream cancer community, young adult cancer patients are able to challenge the dominant cancer narrative. The participatory nature of the Web gives young adult cancer patients the opportunity to draft their own version of what cancer is supposed to look like and publish their own interpretation of the cancer experience.

While numerous studies have examined how cancer patients use the Web for informational purposes, the emerging alternative social aspects of the online cancer community are largely unexplored. The cancer patients interviewed confirmed that the first place they turned to for information on their particular cancer diagnosis was the Web. Often times the young adult cancer patients interviewed were symptomatic long before they were actually diagnosed. These individuals said they surfed the Web for information on their symptoms and possible disease diagnoses even before they even knew they had cancer. But the time spent online did not stop at the point of medical data saturation. The Web provided the young adult cancer patients with an outlet for the alternative, at times irreverent, approaches to dealing with cancer that spoke to the interview participants.

Adjusting the Language and Tone of Cancer Communications

Using online communications, young adults can control cancer messaging. While the interview participants recognized the dominance of traditional combative cancer metaphors referencing wars, battles, fights, and survivorship (Teucher, 2003), the participatory nature of online media provides young adult cancer patients a venue to

submit alternative cancer language. Conversations on cancer bulletin boards dissect the word “survivor,” bloggers write about their “cancer journey,” and personal Web pages are dedicated to cancer “thrivers.” With no gatekeepers controlling what gets published, new ideas and ways of speaking are able to find an outlet.

Susan Sontag (1975) decried the shame and silence that typified the cancer experience toward the end of the 20th century. The publicity of prominent cancer stories has removed much of the stigma associated with speaking about the disease, but the fear remains. Young adults are using the Web to attack the domination of fear-based messaging that surrounds the disease.

Perhaps the most flagrant attempts to rewrite “appropriate” cancer speak is the use of humor in online cancer messaging. Laughter has long been a coping mechanism, and the ability to laugh at something removes some of the power of that event or object. Social biases against humor surrounding major atrocities, such as the Holocaust, speak to the power of laughter to redefine an event or experience. The ability to laugh at cancer within the cancer community, and the difficulty using humor to deal with the effects of the disease when in contact with the external community, may lead to some of the issues involved in poor interactions between young adult cancer patients and the non-cancer young adult community. This disconnect may also point to additional reasons why young adult cancer patients seek out Web-based communities of like-minded individuals.

The title of this study, “We’ve Done Drugs Keith Richards Never Heard Of,” is printed on t-shirts and buttons sold through the online cancer community, PlanetCancer.com, which also publishes a section full of cancer “Top Ten” lists including

“Top 10 Pick-up Lines for Cancer Patients,” “Top 10 Ways to Get a Taste of the Chemo Experience,” “Top 10 Reasons to Date A Cancer Chick,” and “Top 10 Reasons Being Bald Rocks.” The Web-based cancer retailer GotCancer.com sells a full line of “CCKMA” (Cancer Can Kiss My Ass) merchandise, and buttons, t-shirts, hats, bumper stickers, coffee cups, and water bottles with the phrases “Fuck Cancer” and “Cancer Sucks” are easy to order online.

The irreverent discussions of cancer that dominate the virtual young adult cancer community are in direct contrast to the historically acceptable way of talking about the disease. The interview participants recognized that cancer has customarily been spoken of in hushed tones befitting what many people traditionally believe is its stature as a feared and vile illness. However, when actually going through the treatment and survivorship process the interview participants found that humor was a valuable tool for dealing with the physical and emotional challenges that came along with a cancer diagnosis. Their need to use cancer as a way to address and cope with their experience was in direct contrast to the dominant acceptable cancer narratives.

The adjustments to the language and tone used to discuss cancer, made possible through online communication, are important because, as Burke (1950) noted, the way a subject is discussed constitutes the subject itself. By changing the acceptable cancer metaphors and modifying the tone used when talking about cancer, the young adult cancer community is drafting the beginning of an alternative cancer narrative. This alternative narrative, although still primarily Web-based, not only accepts young adults as

welcome members of the cancer community, it validates their preferred method of discussing and dealing with the disease.

Changing the Cancer Conversation

In addition to modifying the language and tone used to discuss cancer, forays into the online communication process prove it to be a viable tool to address issues of importance to the young adult cancer population. The interview participants expressed frustration at the common misconception that cancer has an ending. Several interview participants discussed the adjustment period that occurred at the end of treatment when their oncology visits dropped off sharply. After monthly, weekly, or even daily interaction with medical professionals, patients often transitioned to quarterly or bi-yearly follow-ups. Many of the young adult cancer survivors said they often found themselves facing ongoing survivorship issues with few resources.

Survivorship advocacy has flourished online. Young adult cancer patients, who are typically facing more than half their lives as cancer survivors, are using online forums, blogs, and social networking sites to address survivorship issues. The dominant cancer narrative portrays cancer as having a defined beginning and end. By stepping outside the dominant cancer narrative young adults are able to maintain their cancer identity far beyond the date of remission. While survivorship centers are only beginning to appear in the mainstream medical community, a grassroots network of cancer survivors are building a library of survivor information on the Web.

Young adults are using online resources to build alternative cancer narratives. Through the social aspects of the virtual world, alternative ways of talking about and discussing cancer are reinforced by the growing online community. Web-based communication resources allow young adult cancer survivors to introduce alternative cancer metaphors, change the tone of cancer communications, and address issues that are ignored or under-addressed in the mainstream cancer community.

Benefit of Communication Control

The reactions the young adult survivors interviewed faced from friends and family reflected the use of fear-based cancer advocacy campaigns, which provided dire warnings of the dangers of cancer with no relevant call to action. Stephenson and Witte, (2001) argued that fear-based messaging is ineffective when not paired with reasonable calls to action. Niederdeppe and Gurmankin (2007) showed that the general population felt there was no real effective way to avoid cancer, which was confirmed through data presented in this study, which showed that fear-based cancer messaging is an ineffective strategy that led to frustration among the young adult cancer survivors interviewed who had to deal not only with their own fear of the disease, but the fear of their friends, peers, and loved ones.

One thing that emerged during the interview data was repeated reference to control of the cancer situation. Locus of control has been applied to healthcare research through the health belief model, which is a psychological system used to explain and predict health-related behaviors (Rosenstock et al., 1988). The model stresses the

importance of efficacy in the disease process. This research confirms the importance of efficacy in the medical process, but expands on the Rosenstock's (1988) work to show the importance of efficacy in disease narrative development process as well. The interview participants spoke frequently of playing an active role in the cancer detection and treatment process. The misdiagnosis experience, common in the young adult cancer community, may contribute to the importance the community places on maintaining some degree of personal control throughout the medical process. This advocating for control has extended beyond the scope of simply being empowered patients and led to the quest for control over not only how cancer is treated, but also how cancer is viewed in U.S. culture. The variety of online publishing tools available and the scope of the virtual world has created an environment where empowered cancer survivors can take an active role in building alternative cancer narratives to contradict dominant cultural expectations of the disease experience.

Selective Coding

Examining the open and axial codes that emerged in response to the research questions leads to the selective coding process. Selective coding is the process through which open and axial codes are examined to determine the core variable illustrating the behavior and experiences of the interview participants. By examining the axial codes developed from the research presented in this study it is clear that the experience of young adult cancer survivors centers around issues of isolation.

Sontag's (1978) metaphor of the contrasting "land of the sick" and "land of the well" is helpful in illustrating this issue of isolation. When young adults are diagnosed with cancer they become exiles from the land of the well, but they also find that the land of the sick does not provide adequate resources to meet their needs as young adult cancer patients. To cope with the isolation of being an anomaly in the land of the sick, young adults try to use a tool that has severed them well in their previous life to dissipate uncomfortable issues, humor. Because the cultural history of cancer has positioned the disease as sacred in our society, attempts at humor only further distance the young adult patients and survivors from their old social networks in the land of the well. Humor also falls flat in the mainstream cancer community, which is populated by adult patients, earnest caregivers and advocates, a standoffish medical community, and dry, informative cancer resource groups.

Young adults often look to major players in the cancer game to help them navigate this shift from well to sick. Prominent cancer figures like Lance Armstrong, who appears to be able to traverse easily between the land of the sick and land of the well, are inspirational, but may also contribute to isolation by setting up potentially unrealistic expectations. When young adults find the transition between well and sick difficult, Armstrong's story becomes evidence of personal shortcomings in the young adult patient.

A cancer diagnosis results in the wrenching away of a person's identity as a healthy person, but many young adults find the identity of a cancer patient a poor fit. They are left in a medical no man's land where they are caught between their lives in the land of the well and their membership in the cancer community. Rather than conform to

the expectations in either of these unwelcoming lands, this study shows that young adult cancer survivors are building their own land with bridges to both the mainstream cancer community and the land of the well.

Young adult cancer patients have primarily built this land through virtual communications, transcending boundaries of time and space. In this new land, the distinguishing identities are cancer and age. Secondary identities, such as race, gender, class, and geographic ties, are of minor concern in this land. In this space young adult cancer survivors are empowered to create their own definitions of what cancer should look like and how it should be experienced. Humor is used as a coping mechanism and a communication tool. Through interconnecting and interrelated conversations, young adults are modifying the language used to talk about cancer and the metaphors used in relation to cancer and people who are post-cancer treatment.

Many young adults find this new land, built from input from various members of the young adult cancer community, empowering. Through the validation of their cancer experience and views, young adults are able to make forays into adjusting even the dominant cancer narrative. The popularity of irreverent cancer bumper stickers, t-shirts, coffee mugs, and other merchandise indicates that young adults are taking this cancer attitude into both the mainstream cancer world and the land of the well. While the creation of a validated alternative cancer existence empowers many young adults to maintain ties with the land of the well and participate to a degree in the mainstream cancer community, the virtual nature of the young adult cancer community may also lead to individuals withdrawing into the online space where acceptance is easy to achieve

Interview participants referenced attempts to limit communication with the land of the well, using techniques like avoiding phone calls and withdrawing from family activities.

Upon completion of active cancer treatments, young adult cancer survivors gradually assimilate back into the land of the well, but according to the interview participants, they never completely leave the young adult cancer community. Young adult cancer patients may be able to segue back into the social aspects of the well-world but they carry with them their cancer history. Interview participants described “dropping the ‘C’ bomb” or “playing the cancer card,” as the moment when their dual passport in the land of the sick and the land of the well is revealed. In telling others about a history of cancer, a young adult survivor admits that their passport in the land of the well has not always been valid and could be easily revoked at any time. Young adults never completely leave the cancer community. Follow-up visits, concerns of secondary diagnoses, relapses, and ongoing health issues ensure that young adult survivors must make regular trips to the cancer community they built. They also do not stop caring about their peers in the young adult community. Young adults feel responsible for the world they helped create and look for ways to “give back” and make the experience easier for cancer patients who come after them by improving the developing young adult cancer network.

This study contributes to Charland’s theoretical framework by building on his posit of narrative composing the rhetoric that constitutes reality. While dominant cancer narratives compose one societal definition of cancer, this study shows that narratives can be adjusted, potentially leading to alternative definitions that are also socially acceptable.

Through community-based efforts to change the language of a subject, the societal understandings of that subject can be adjusted. The online environment provides a public space, unencumbered by traditional media gatekeepers, in which individuals can publish information on and discuss subjects in a way that challenges dominant understandings of the subject.

Future Opportunities for Research and the Profession

To better understand the emerging cultural narratives discussed in this study, the dominant cancer narrative could be further examined and defined. A historical exploration of the language that constitutes the cancer experience may provide insight into current combative descriptions of cancer. This study addressed the nature of dominant cancer metaphors, most of which incorporate war imagery, but further research could examine in greater detail how these war metaphors developed and were applied to the disease experience. This potential project could further define how the dominant cancer narrative systematically excludes certain marginalized groups.

This study illustrates the need for additional research in the area of young adult cancer advocacy and communication practices. Further research could determine if results discussed in this study could also be applied to young adults facing other major health issues. Young adulthood is a time of shifting familial and friend relationships, high mobility, and tenuous social ties, making this a difficult population to target for researchers. However, the marginalized status of young adults facing unexpected diagnoses, like cancer, is evidence of the need for further research into this group. This

study could be expanded by conducting a survey with a representative sample of young adult cancer patients to determine how to empower young adult cancer survivors and determine exactly what resources would make the population feel included in the larger cancer community. This work could also be extended beyond the realm of cancer to address young adults' experiences with other major diseases.

The development of alternative narratives through online communication practices could also be addressed in greater depth in future research. A comparative textual analysis of traditional cancer advocacy communications and Web-based non-traditional advocacy communications would better illustrate an emerging virtual alternative cancer narrative. Also, this phenomenon of creating alternative, Web-based narratives could be expanded beyond the realm of healthcare communications to see how other marginalized groups are challenging dominant cultural narratives online. While some researchers are currently examining the use of online communication tools by marginalized groups (Mehra, Merkel, & Bishop, 2004), the rapid increase of access to participatory media resources makes this topic ripe for further study.

In terms of contributions to the profession of health communication, this study offers insight into the motivations and potential contributions of young adults who have experienced a major illness. The young adults interviewed were eager to give back to the larger cancer community, but they want to do that in ways that were comfortable and convenient. Young adults see their age as a major influence on their cancer experience and view their demographic as underrepresented and underserved in the cancer community. Young adult cancer patients are geographically dispersed and there is

no single treatment center that acts as a hub for their care. Given the scattered nature of this group, Web-based channels serve as the best way to access and organize this population.

The young adult cancer survivors interviewed identified most with cancer communications that presented raw, realistic information about cancer. The young adults did not want their cancer information sugarcoated, but they also believed that much of the cancer information was presented in overly grim terms. Every interview participant mentioned referred to the use of humor during their cancer experience. The overwhelming commendation of cancer-related humor indicates the potential need for a shift in traditional cancer communication techniques. Further research into the use of humor in health-related communication campaigns could flesh out the potential for using a variety of tones when discussing major illnesses. While the use of humor can be inflammatory when dealing with serious situations like major diseases, interview data suggests that it is a necessary part of the young adult disease experience. Further study is needed to determine how humor can be successfully integrated into health communication campaigns without offending key audiences.

The young adults in this study were hungry for the advice and experience of others in the population, suggesting that the best spokespersons may come from within the population itself. A program pairing up new young adult cancer patients with more experienced members of the young adult cancer community using online communication channels could prove therapeutic for both participants. Cancer advocacy organizations also may find that by providing a sounding board for young adult cancer patients they are

able to fulfill the information and support needs of the group conveniently and effectively. Given the highly wired nature of the community, virtual space to communicate and pool resources is key to pulling in young adult content contributors.

The 20s and 30s are a busy time in young adults lives. When a cancer diagnosis is thrown into the mix, this population faces increased demands for their time on energy. However, the eagerness of the young adult cancer population to reach out to others facing this difficult diagnosis makes many willing to take on advisory capacities regardless of their other commitments. Virtual communications and opportunities for online advocacy work minimize the challenges in coordinating schedules and travel arrangements. By providing opportunities for young adults to take on projects that have clear, transparent benefit for the young adult cancer population health advocacy groups can tap into an energetic resource. Young adult cancer survivors attempting to navigate the assimilatory process back into the land of the well from the land of the sick may benefit particularly from programs that allow them to reach out to their geographic community. For example, cancer advocacy organizations could provide resources that young adults could use to produce customizable events or projects in their own community. This project could help ease the transition back into the “real world” and solidify young adults’ dual citizenship in both the land of the well and the young adult cancer community.

Summary

While this study suggests many areas for further research, it also provides insight into the changeable nature of subject position through the development of alternative narratives. Web-based communication resources have led to greater flexibility of generally accepted understandings of major concepts. Dominant cultural narratives may no longer be the only cultural narratives. Participatory media does more than just build interest based communities; the communication tools used by these communities allow users to build alternative narratives that can reconstitute subjects.

This study also adds to our understanding of the isolation faced by young adult cancer patients and their use Web-based resources to collaborate within their isolated group. Young adult cancer patients recognize the existence of a dominant cancer narrative. The most distinguishing feature of this dominant narrative is that it does not include young adult cancer patients or survivors. However, once young adults are diagnosed with cancer their existing social relationships are irrevocably changed, leaving this population searching for alternative communities for acceptance of validation. The Web has created an empowering space for the young adult cancer community to organize and grow. In utilizing the Web to publish their own thoughts regarding cancer and write their own disease story, young adult cancer patients are building alternative cancer narratives, which contradict, modify, and build on the existing dominant cancer narrative. But this alternative “land of the sick” is still a work in progress.

Challenges to the existing dominant cancer narrative and the creation a fully formed constitutive rhetoric are still in their formative stages, but the initial development

of alternative cancer narratives are starting to expand the definitions of what cancer is “supposed” to look like and how it “should” be experienced. Perhaps by broadening the acceptable cancer narratives, young adult cancer patients will be able to influence medical and support providers to better fulfill the needs of all cancer patients.

APPENDIX A

INTERVIEW GUIDE

1. Tell me about your cancer experience. Please start with your date of diagnosis and continue through today.
 - Current age, time since diagnosis, and geographic location
 - In what ways do you think your age affected your cancer experience?
2. Who, if anyone, would you consider your “cancer role model?”
 - Do any cancer messages or campaigns stand out in your mind? Is there a particular group or message that you particularly do or do not support? Which one and why?
 - What do you think about the Lance Armstrong/Livestrong campaigns?
3. When and how did you first find out about Planet Cancer?
 - How have you been involved with the group?
 - What do you think of Planet Cancer’s approach to the disease? Is it unique? How so?
 - What are the primary forms of media you use (newspaper, books, magazines, television, internet)?
 - Do you participate in other online cancer groups?
 - Do you participate in online groups not related to cancer?
4. Where/who do you turn to for information about cancer?
 - Where/who have you turned to for support and socializing during your cancer experience?
5. Have you noticed any cancer patients in movies, on television, or in books?
 - What do you think about those portrayals?

- Do you identify with any of those portrayals?

6. If you could change one thing about how the general public views cancer, what would it be?
7. Would you like to recommend any other young adult cancer survivors that may be interested in speaking with me?

APPENDIX B
PARTICIPANT INFORMATION AND PSEUDONYMS

Name	Age at Diagnosis	Age at time of interview	Location	Cancer Type	Diagnosis Date	Remission	Date of Interview
Bonnie	23	28	Michigan	Hodgkin's	2002	5 years	9/7/07
Brian	23	24	Ohio	AML	2006	1 year	9/26/07
Carol	35	37	Texas	Breast	2005	1.5 years	9/6/07
Cary	28	30	Texas	AML	2005	1.5 years	9/21/07
Cynthia	17	20	Texas	Hodgkin's	2005	2 years	9/13/07
Danielle	33	38	New York	Myeloma	2002	3 years	9/19/07
David	23	27	Ohio	Non-Hodgkin's Lymphoma	2003	2.5 years	9/28/07
Denise	32	35	Virginia	Thyroid cancer	2005	2 years	9/25/07
Erin	26	30	Michigan	Brain Tumor	2004	3 years	9/19/07
Hilary	26	39	Texas	Ewing Sarcoma	1995	12 years	9/19/07
John	22	25	Washington DC	Brain	2004	16 months	9/9/07
Kevin	20	26	Seattle	AML	2002	5 years	9/21/07
Kim	24	25	Boston	Hodgkin's	2006	2 months	9/13/07
Lauren	32	37	Michigan	Breast	2004	3 years	9/18/07
Molly	20	23	Michigan	AML	2004	3 years	9/20/07
Tim	25	26	Texas	Hodgkin's	2006	3 months	9/12/07

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