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Karen Kaiser

University of Illinois at Chicago Cancer Center Chicago, IL, UNITED STATES, kkaiser1@uic.edu

Abstract

“Survivor” has become a ubiquitous and largely unquestioned term in culture and cancer discourse. While anecdotal evidence suggests women with breast cancer find fault with survivor images and discourse, the extent to which women identify with or reject the survivor identity has not been empirically studied. This paper examines whether women treated for breast cancer embrace survivorship. Data come from 39 in-depth interviews with women in the United States who completed treatment for breast cancer 3 to 18 months prior to the interview. Despite the positive meanings attached to survivorship, many women altered the meaning of survivorship or rejected survivorship. In particular, the survivor discourse alienated women who struggle with the threat of recurrence, who feel their cancer experience was not severe enough to merit this title, or who desire a private disease experience. These findings illustrate the failure of our cultural conceptions of cancer to adequately reflect lived experience and highlight how individuals actively “craft” illness meanings.

“I woke up, still alive. Does that mean ‘cured’?”

Marilyn Hacker, 1994 (cited in Bahar, 2003)

Keywords

USA; breast cancer; survivor; meaning; identity; culture; illness experience

Introduction

In recent decades breast cancer has become a highly visible and well-funded disease in the United States. Pink ribbons symbolizing breast cancer and events to raise money for breast cancer research are a ubiquitous part of the cultural landscape and represent a dramatic departure from the stigma, secrecy, and blame previously attached to breast cancer (King, 2006; Leopold, 1999; Plotkin, 1996; Sontag, 1979). Instead of succumbing to a secret and shameful disease, women with breast cancer today are openly honored as “survivors”. Intuitively, it makes sense that the cultural images of breast cancer will shape the experiences of women with the disease. In fact, the breast cancer culture implies that women with the disease readily embrace the identity of survivor. However, while studies have examined the changing cultural representations of breast cancer (Block, 1995; Brown, Zavestoski, McCormick,

Correspondence to: Karen Kaiser.

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Mandelbaum, & Luebke, 2001; Fosket, Karran & LaFia, 2000; King, 2006; Klawiter, 1999; Leopold, 1999; Patterson, 1987; Sontag, 1979; Thorne & Murray, 2000), researchers have not empirically considered how the new survivor identity shapes the disease experiences of women with breast cancer.

In this article, I consider the extent to which women embrace the survivor identity following breast cancer treatment. I begin with an overview of the dominant representations of breast cancer survivors and the criticisms of these representations. I then summarize two complementary approaches for understanding how constructions of breast cancer affect women. The first approach posits that survivorship is a tool that women can use to frame their disease experience (Swidler, 1986, 2001). According to the second approach, survivorship is “craftwork” (Frank, 1995), whereby women consciously construct their lives and the meaning of cancer. After describing my research methods, I provide data from in-depth interviews with 39 women in the United States who recently completed treatment for breast cancer. In the data presented here, a number of women did embrace the survivor identity. Other women crafted new meanings of survivorship. Additionally, some women explicitly rejected the label for failing to account for the possibility of recurrence, for being overly heroic, or for being too public of an identity. I discuss the implications of these findings for women with breast cancer and for the sociology of health and illness.

The Breast Cancer Survivor

The Dominant Image of the Survivor

The term “survivor” entered cancer discourse in 1985 when Dr. Fitzhugh Mullan described his cancer experience in a New England Journal of Medicine article, “Seasons of Survival” (Kolata, 2004; Mullan, 1985). Dr. Mullan later established the National Coalition for Cancer Survivorship (NCCS), which worked to shift the perception of cancer patients from victims to survivors and formally defined a survivor “from the time of diagnosis and for the balance of life” (NCCS, 2007).

The word survivor is arguably most often associated with breast cancer. The breast cancer survivor is most often represented as triumphant, happy, healthy, and feminine (Batt, 1994; King, 2006). She triumphed over breast cancer through medical treatment and now holds a place of honor in the cancer world (Ehrenreich, 2001; Klawiter, 1999). This image is consistent with the positive tone characteristic of early anti-cancer campaigns in the United States (Batt, 1994; Patterson, 1987). It also reflects the history of the breast cancer movement and subsequent corporate interest in breast cancer. During the 1980s and 1990s, the burgeoning breast cancer movement consisted of a large and diverse group of women, including feminists seeking radical change and women who simply wanted greater medical investment in a disease that devastated so many. The movement ultimately secured widespread support by portraying breast cancer patients and survivors as deserving mothers, wives, and citizens, and by working within medicine to demand greater research on cancer treatments and a medical cure for breast cancer (Kaufert, 1998; King, 2006). In short, the goal was reform, not revolution (Kaufert, 1998) and the movement became pro-woman, but not pro-feminism (Ehrenreich, 2001; King, 2006). Within this framework, the breast cancer survivor represented the power of medicine to beat breast cancer and return women to fulfilling lives (Ehrenreich, 2001). Federal funding for breast cancer research jumped from 155 million dollars in 1991 to 400 million by 1993, an influx of money not seen by any other cancer (King, 2006; Stabiner, 1997). Breast cancer continues to be portrayed as a medicalized disease that is approached with both fear and optimism (Clarke, 1999).

Breast Cancer as the Darling Cause: Survivors Take Center Stage

The image of the breast cancer patient as feminine, deserving and devoted to a medical cure made breast cancer the perfect charity. By associating their products with breast cancer fundraising ("cause related marketing"), companies could build the reputation of a brand, secure brand loyalty, and differentiate the brand without having to cut price or be innovative (King 2006). Companies such as Yoplait, Ford, and countless others adopted breast cancer as their cause, which led to an influx of symbols of breast cancer into the market (Ehrenreich, 2001; King 2006). The number of products and corporations pledging contributions to breast cancer grew so large that the grassroots organization Breast Cancer Action launched the Think Before You Pink campaign in 2002. Think Before You Pink urges consumers to learn how much (or how little) money from a purchase goes to breast cancer causes (Breast Cancer Action, 2007; King, 2006).

While breast cancer gained corporate and federal support, breast cancer survivors took center stage (literally and figuratively) at breast cancer runs and walks around the country (King, 2006). At the forefront of physical activity fundraisers is the Susan G. Komen Race for the Cure. The Race for the Cure, which is a five kilometer run/walk to raise funds and awareness of breast cancer, first took place in Dallas, Texas in 1983. By 2002, the Race had expanded to over 100 locations in the United States and abroad, with well over one million participants each year (Komen, 2007). At each race, survivors don pink hats and are honored in special ceremonies such as the survivor parade (Kaiser, 2006; King, 2006; Klawiter, 1999). The Race's message is that advances in treatment ensure that a cancer detected early will be cured (Klawiter, 1999). According to Klawiter (1999, p. 111), survivors at the Race were "honored for their courage in fighting breast cancer and for their willingness to demonstrate to other women through their rejection of the cultural code of silence and invisibility, that breast cancer is not shameful, that is it survivable, and that it is neither disfiguring nor defeminizing." Notably, mastectomy scars and disfigured bodies are hidden at the Race. Prostheses makers and cosmetic companies at the Race and at other breast cancer walks encourage women to project an image of wholeness and femininity (King, 2006).

Alternative Images and Criticisms of Survivorship

Alternative constructions of life after breast cancer co-exist with the dominant image of survivorship. For example, some women have rejected the title of survivor in favor of "thrivers" or "breast cancer warriors".¹ Others have chosen not to conceal the effects of cancer. The artist and model Matuschka bared her mastectomy scar on a 1993 cover of the New York Times Magazine next to the caption, "You can't look away anymore." According to Matuschka (1993, p.162), "If we keep quiet about what cancer does to women's bodies, if we refuse to accept women's bodies in whatever condition they are in, we are doing a disservice to womankind." Audre Lorde (1980) chose not to wear a prosthesis following her mastectomy and battled for her right to define and present her body in her own way (Batt, 1994; Lorde, 1980). First-hand accounts of breast cancer such as those by Lorde (1980), Butler and Rosenblum (1991), and Williams (1993) serve as a place for women to express pain and fear and to disclose the reality of breast cancer (Kaufert, 1998; Leopold, 1999; Potts, 2000).

Alternatives to the dominate survivor image exist on an organizational level as well. The Bay Area Women and Cancer Walk shows women's bodies following mastectomy (without prostheses), uses the color black (instead of pink), and welcomes discussions of death and displays of anger (Klawiter, 1999). The Toxic Tour of the Cancer Industry attacks the industries that produce carcinogens and embraces the term "cancer victim" to emphasize that women get

¹I am thankful to a reviewer of this manuscript for informing me of the use of the term "thrivers" by women with breast cancer at the Second World Conference on Breast Cancer.

cancer because of larger social forces (Klawiter, 1999). These organizations, like their mainstream counterparts, want to inform women and raise awareness of breast cancer (Anglin, 1997). However, on the one hand, being informed and empowered means questioning the status quo and showing the dark side of cancer. On the other hand, being informed and raising awareness means educating women about screening, encouraging fundraising for research, being joyful, and displaying a highly feminized, intact body (Batt, 1994; King, 2006).

The dominant breast cancer images have also been directly criticized. Hozman (2005, p. 39), herself a breast cancer survivor, criticized the upbeat, grateful image of breast cancer survivors and the failure to mention the “indigestible images of cancer” such as “nonanesthetized injections at the tumor site, nipples inflamed from radiation.” Barbara Ehrenreich (2001) railed against the breast cancer culture of survivorship and “pink kitsch” after her own bout with the disease. She criticized the breast cancer culture for the abundance of childlike products (e.g., Teddy Bears) marketed for breast cancer, the absence of feminism in the mainstream breast cancer culture, and its relentless emphasis on “cheerful” representations of breast cancer that effectively silence other emotions such as anger and grief.

Survivorship has also been criticized for encouraging women to conceal the physical effects of cancer. While stigmatized persons have long worked to “pass” unnoticed in society (Goffman, 1963), survivors are simultaneously encouraged to proclaim their status via pink t-shirts and ribbons and disguise the true nature of their bodies following treatment via clothing, reconstruction, and prostheses (Batt, 1994; Thomas-MacLean 2005). By enacting this “reverse passing”, survivors become the “mirroring body”, attempting to recreate themselves in the image of healthier bodies (Frank, 1995). Moreover, by disguising their suffering, survivors experience what Frank (1995) calls the “monadic body”—aspects of their experience are solitary and separate from a sisterhood of other survivors. Women who work to project an image of perfect health following cancer pay an emotional (and monetary) price for pretending to be well and whole (Batt, 1994).

Critics also contend that survivorship fails to capture the uncertainty inherent in the cancer experience. The language of survivorship—“beat”, “conquer”, “win the battle”—is consistent with an acute model of illness. However, cancer is typically not experienced as an acute episode of disease (Fosket, 2000; Frank, 2001; Little, Paul, Jordens, & Sayers, 2002; Sontag, 1979). Rather, following treatment, patients often struggle with an inability to define themselves as healthy or as ill (Frank, 2001; Rosenbaum & Roos, 2002), endure ongoing screening and medication, and struggle with fears of recurrence (Quigley, 1989). In her breast cancer memoir, Williams (1993) wants to avoid being yet another cancer patient who publicly declares herself a survivor, only to later die of the disease. Rather than befall that irony, she chooses to see cancer as with her “in one form or another for forever” (230).

Survivorship’s story of diagnosis, treatment, and recovery makes it a “restitution narrative” (Frank, 1995). The restitution narrative is powerful because it celebrates the heroism of medicine and the individual and supports the optimism of oncology (Clarke, 1999; Goode, 1990). Like persons with disabilities who are lauded for exceptional accomplishments (i.e., the “super-crip”, Couser, 1997), the image of breast cancer survivors is one of *exceptional* health and strength in the face of adversity. While success stories may be inspiring, they may also be alienating (Mayer, 1993; Potts, 2000), particularly to those who experience ongoing effects of cancer, have a poor prognosis, or ultimately die from the disease (Batt, 1994; Ehrenreich, 2001; Frank, 1995). In her analysis of the narrative content and form of breast cancer survivors’ stories of cancer, Thomas-MacLean (2004) found elements of the restitution narrative as well as elements of Frank’s chaos narrative (i.e., a story of never ending problems) and quest narrative (i.e., a story of change). Her results indicate the story of survivorship may not work for many people.

In short, the meanings of survivorship have been harshly criticized, particularly within firsthand accounts of breast cancer. Despite these critiques, researchers have not considered how the typical breast cancer patient views survivorship. Such research would contribute to our understandings of the process of adjustment following cancer and would augment the sociology of health and illness in two key ways. First, although the sociology of health and illness has examined the impact of cultural meanings of disease for the illness experience (Bury, 2000; Charmaz, 1991, 1999; Conrad, 1987; Corbin & Strauss, 1987; Karp, 1992, 1996; Kleinman, 1988), this research has overwhelmingly focused on the effects of stigmatizing, negative disease meanings (e.g., Alonzo & Reynolds, 1995; Fife & Wright, 2000; Goffman, 1963; Link & Phelan, 1999, 2001). Thus, we know little about the illness experience under overtly positive cultural meanings. Intuitively, positive meanings should facilitate healthy adjustment by producing feelings of pride and social worth. However, the criticisms of survivorship shed doubt on the benefits of the survivor identity. Thus, prior to considering possible psychological benefits of the survivor identity, qualitative research is needed to establish whether women embrace this identity. Second, following the tradition of Parsons (1951), we have learned a great deal about entry into the sick role but have paid less attention to recovery from illness. In particular, cancer patients who live with the possibility of recurrence represent a blurring of the boundaries between sickness, recovery, and health (Conrad, 1987; Frank, 2001). This work attempts to clarify women's relationship to the survivor identity. Next, I discuss two theoretical frameworks for conceptualizing women's relationships to survivorship.

Survivorship as a Cultural Tool and Survivorship as Craftwork

The cultural sociology of Swidler (1986, 2001) provides a framework for conceptualizing how the meanings of survivorship impact women with breast cancer. According to Swidler (2001), individuals possess knowledge of a variety of cultural meanings. In *Talk of Love* (2001), Swidler is interested in how people use some cultural materials while rejecting others, especially as they attempt to "retool" their lives following a major life event or transition. The identity of breast cancer survivor can be conceived of as a "tool" (Swidler, 1986) that women use to become a certain kind of person. Given the disfigurement, disruption, and ontological insecurity brought by cancer (Mathieson and Stam, 1995; Nelson, 1996), it makes sense that women would use survivorship to organize the self and life. Furthermore, according to Swidler (2001, p. 73), "Becoming a certain kind of person is learned, practiced, and sustained through culture." For the woman with breast cancer, culture provides clear guidelines for what it means to be a survivor, as well as opportunities (e.g., breast cancer walks) to practice being a survivor.

However, if women question or reject survivorship, it is unclear what alternative meanings they embrace, given that other images of breast cancer are largely negative (Schover, 2004) or less available. If survivorship is deemed an inadequate cultural tool, women may work to construct alternative meanings; in other words, they may enact survivorship as "craftwork". According to Frank (2003, p. 251), survivorship as craftwork is the "embodied, exacting skill (of) building something or making something work in a precise way." Most importantly, craftwork requires practice and the self-conscious construction of one's life. Frank is primarily interested in how individuals construct the role of service for others following cancer. I extend his notion of craftwork to include the self-conscious crafting of the meanings of survivorship.

Together, Swidler's and Frank's conceptions of cultural tools and craftwork provide a conceptual framework for understanding how individuals may embrace or reject survivorship or actively construct meanings following cancer. Thus, in this article, I consider two questions. First, do women embrace the survivor identity as a way to make sense of their lives following cancer? And second, to what extent do women craft new meanings for their experiences?

Methods

Data come from in-depth interviews conducted between 2003 and 2006 with 39 women who completed treatment for breast cancer 3 to 18 months prior to the interview. Treatment is defined as surgery, chemotherapy, or radiation. The sample includes individuals undergoing adjuvant treatment, such as those taking Tamoxifen. One advantage of this sample is that the women were interviewed within 18 months of treatment, whereas samples used in much of the survivorship literature includes individuals of many different survival durations (e.g., weeks and years).

Respondents were referred to the study by a cancer support center in a small city and through personal referrals. The mean age of the sample is 52 and ranges from 28 to 87 years of age. Twenty-eight of the women received chemotherapy. Sixteen women had a lumpectomy to remove their cancer. The remaining 23 women underwent either a unilateral or bilateral mastectomy. Of the 39 women interviewed, 36 were Caucasian; all had at least a high school degree or General Education Diploma (high school equivalent) and 16 had at least a Bachelor's degree. Twenty-three of the women in the sample were currently employed. Two women were homemakers and eight women were retired. The remaining six women in the sample were unemployed but hoped to return to work in the future. The sample was largely middle-class. Class determinations are based upon education, occupation, and the author's observations of many of their homes during the interviews. Three women were unusual in that they were employed in blue collar jobs (e.g., assembly line worker). Because the sample is largely white and middle class, it represents women most likely to identify with the survivor culture.

A flexible interview guide allowed respondents to talk freely about their cancer experiences, including diagnosis, treatment, and life after treatment. Two questions assessed respondents' views towards survivorship. First, each woman was asked if she referred to herself as a "survivor". Each woman was also asked what the word "survivor" meant to her. Questions about survivorship were posed near the end of the interview so women could talk about survivorship prior to direct questions about survivorship. Interviews lasted, on average, 90 minutes. Each woman was paid \$25.00 for participating in the interview. Interviews were audio-recorded, transcribed and entered into ATLAS.ti (Scientific Software Development, 1997). Each woman was assigned a pseudonym by the author.

Analysis combined both deductive and inductive strategies. First, each transcript and corresponding field notes were read in their entirety to gain a sense of the respondent's experience as a whole. Preliminary workings with the data utilized grounded theory methods, which consist of a set of flexible principles for constructing theories from an analysis of rich data (Charmaz, 2006; Glaser and Strauss, 1965, 1967). After becoming familiar with the data, a more deductive strategy was adopted. First, data related to the identity of a cancer survivor was coded by applying the code "survivor" to any text in which the respondent used the word survivor as well as to her response to the questions, "Do you refer to yourself as a cancer survivor?" and "What does the term survivor mean to you?" Coded data were extracted from each interview to create a complete picture of each woman's views of survivorship and to examine patterns across women. Initially, transcript was coded into one of two categories—those who identified as survivors and those who did not. Among those who rejected survivorship, three distinct reasons for rejecting the identity quickly emerged in the data. Additional work with the data revealed that among the women who identified as survivors, some enthusiastically embraced the dominant meanings of survivorship and others expressed ambivalence towards survivorship. Deeper analysis of the latter group revealed that they often modified the meaning of survivorship. Thus, in my discussion of women who accept survivorship, I distinguish women who embrace survivorship and those who identify as survivors but alter the meaning of survivorship.

Results

Accepting the Survivor Identity

Rarely did women spontaneously refer to themselves as survivors. Instead, the title of survivor was typically used to describe others. For example, a woman might say, “My aunt is a five-year survivor.” When asked, “Do you refer to yourself as a survivor?” 20 women said yes. Even among the women who identified as survivors, the meaning of the survivor identity varied. Some women clearly embraced the dominant meanings of survivorship. Mary (age 57) was one such woman. When asked if she referred to herself as a cancer survivor, Mary replied with confidence and without hesitation, “I’m a survivor.” She explained that being a survivor “means you’ve beat it. You were stronger; you won the battle.” It’s not hard to imagine Mary at a breast cancer fundraising event, donning a pink survivor hat to “proudly, voluntarily, and publicly mark herself as a breast cancer survivor, visually embodying an identity not otherwise apparent” (Klawiter, 1999, p. 111). Consistent with Swidler’s (2001) contention that our use of culture is more obvious during “unsettled” periods of life, Mary’s new cultural skills are exaggerated. Not only did she proudly declare herself a survivor but she also described the breast cancer pins and ribbons she owns. She exhibited a careful use of culture by referencing the definition of survivorship created by the National Cancer Survivor Coalition—“you are a survivor from the day you are diagnosed”.

Other women in the sample drew more selectively from the survivor discourse. Yolanda (age 37) she sees herself as a survivor because she was strong enough to make it through the experience. She said, “It’s a test really of how strong you are and for me how strong my faith was.” A respondent named Kim (age 56) felt proud to be a survivor during the breast cancer walk she attended each year. According to Kim, “I think I am proud that I survived it. I didn’t fall apart. I found an inner strength.” She explained, “There is part of me that is gone, but there is something else that came in. (The surgeon) might have taken a boob, but he gave me a different personality... something has happened to quiet little Kim.” By saying she “found” an inner strength, Kim’s story fits the quest narrative—cancer brought out new aspects of her self, making her a better person than she was before (Frank, 1995; Thomas-MacLean, 2004).

Lisa, age 55, said that she “absolutely” identified herself as a survivor. Like the women quoted above, she felt pride for having the strength to make it through treatment and proudly wore pink symbols of breast cancer. However, Lisa poignantly described her ongoing fears of cancer:

Every ache and pain I have I think, hmm ... wonder what this is. ... I feel like an unattached buoy in a large body of water because... when you’re in chemo you feel like something is killing it, but now I’m on my own. I’m out there and I can’t take Tamoxifen because it will be no good for me, so I feel a little bit like a buoy in rough waters. I feel like I get thrown around a little bit by the waves of life, you know and it’s scary for me that way.

The notions of beating cancer and fearing that cancer lingers are contradictory. How is Lisa able to identify as a survivor while believing that cancer may be lurking behind “every ache and pain”? One possibility is that Lisa has not thoroughly examined her use of culture and contradictions in her views go unnoticed (Swidler, 2001). Rather, Lisa uses a very specific definition of survivorship that allows for her lingering fears. Lisa’s definition entails seeing cancer as an *ongoing* war. “(Survivorship) means I have won a huge battle in a war that will last the rest of my life.” Lisa has adopted a definition of survivorship that acknowledges her successful treatment *and* her fears of recurrence.

Brooke’s construction of survivorship is further removed from the dominant meanings. Brooke (age 53) initially saw survivorship as “empowering” and felt “part of a great sorority of people”. Her feelings developed in part from watching the character Samantha from *Sex in the City*

successfully undergo treatment for breast cancer. However, Brooke's identification with survivorship faded as she allowed herself to notice breast cancer deaths around her, such as an obituary she read on the morning of her interview. Brooke's confidence in her ability to survive cancer had been shaken.

However, she crafted new meanings around survivorship that enabled her to retain the survivor identity. She explained what being a survivor meant to her now:

I came from a really tough family and I've been a survivor long before I became a cancer survivor. I had a really screwed up mother ... I'm estranged from her. I did reconnect with her while I had my treatment and it was awful, so I'm no longer communicating with her. *But one of the things I've thought about, it's not so much being a cancer survivor, it's being a survivor in general. I mean cancer is just one more thing I added to the list...* so I don't dwell on the term cancer survivor. I did more before, but now this is just one more notch on the survival bedpost.

(Emphasis added)

Because Brooke altered the meaning of survivorship to fit her personal biography and self-conceptions as someone who has overcome difficulties, survivorship retains significance for her. Like Brooke, a 39 year old named Lauren also feared a recurrence of breast cancer:

I mean the one thing I just can't stand is when people say, 'Oh, so you're cured now?' Like people don't get it; there is no cure. If I die of a heart attack at 75, I'll know I was cured of breast cancer. But the rest of my life is a question mark. You never know if it will come back.

Koocher and O'Malley (1981) labeled the threat of cancer recurrence the Damocles Syndrome after the character from Greek mythology who was seated beneath a sword suspended by a single hair. Lauren lives with cancer as an ever-present feature of her life. Nonetheless, she saw herself as a survivor. Her definition of survivorship centers on having done her best to fight cancer:

I think it just means I did all the treatment I could do and I've done everything I can to keep it from coming back and I'm going to live my life like normal.... whatever happens is going to happen, but I don't walk around saying it's not going to come back. I'm afraid if I let my guard down too much, that if it does come back, I'll be totally thrown for a loop. So I always leave like a little thing in my mind that it could come back someday.

(Emphasis added)

These data demonstrate that the group of women who identify as survivors includes women who feel they have beaten the disease, as well as others who view cancer as a permanent feature of their lives. For the later group, dominant notions of survival are incongruent with their belief that medicine cannot guarantee the permanent removal of cancerous cells from the body. Thus, they alter the meaning of survivorship to account for the possibility of recurrence.

Next, I turn to the women who did not identify as survivors. The fear of recurrence also weighs heavily on these women. However, rather than accept the survivor title and modify it to fit their fears, the women below do not accept the survivor identity. In addition, I present data for two additional reasons for rejecting survivorship—not being sick enough, and not wanting to be part of the survivor group.

Distancing Self from Survivorship

Rejecting Due to the Fear of Recurrence

I struggle with (my feelings about survivorship), you know. And that's always a question I think with other women I've spoken to. It's like well wait a minute, what I am? Do I have cancer? Have I had cancer? Am I survivor? Am I warrior? What am I? I don't have a really good answer for that technically. Supposedly the day you're diagnosed you can call yourself a survivor. It feels really awkward somehow, because I guess I still feel like I'm in the battle.

Sophia (age 43, quoted above) is aware of the available cultural and metaphoric definitions. However, Sophia was among the 19 women in this sample who did not identify as a survivor. Many of these women believed the survivor identity was too incongruent with the uncertainty they keenly felt. Whereas the first group of women kept the survivor title but tailored its meaning to their views, these women could not accept the identity. For example, Kathleen (age 45) poignantly described how the possibility of recurrence makes the term survivor flawed:

I don't like that term because I don't know if I have beaten it... I'm not sure, have I really survived? What, I survived for a whole few months? I don't know. I guess I don't think of it that way because...if you're in a plane crash and you survive, you survived the plane crash. You're not gonna get back in the plane and crash again. But, I had cancer, I made it through treatment, it is gone for now. But that doesn't mean it's not gonna come back.

Because of the possibility that she could “crash again”, Kathleen instead refers to herself as “cancer free for now”, a phrase which better captures the tentative nature of her health. Ann (age 45) also views cancer as lingering. When asked if she identified herself as a survivor, Ann replied, “No, I don't like that word at all.” She explained, “Surviving means you're never going to have a problem again and I think that's not maybe practical. I think surviving cancer means you're dying at 90 of something else.” Ultimately, Ann chose to classify herself in accordance with the reality of her experience. She said, “I phrase it as I was treated for breast cancer. I figure, that's really fact; that's what I know to be true.”

In the quote below, Tara (age 36) explains her reluctance to identify as a survivor by highlighting the contrast between the exacting, medicalized periods of diagnosis and treatment and the uncertain, vague period following treatment:

I want to be positive at the end of this and say, yes I'm gonna beat it and I'm gonna be a survivor for life. But there are times that you just wonder. You know I get online and check and there is not any conclusive evidence out there on what your risks are for recurrence... and I want somebody to tell me you are a great candidate for not recurring and nobody has told me that. I'm looking for that and my oncologist, he's like, I'm not going there with you, you know? *There was so much definition to the cancer, you know the cancer is this grade, and it's estrogen receptor positive, and you're this age and all these factors and this is what we can do. Everything was so precise and now it's like you're back to the unknown again like I was before, and I don't like that.*

(Emphasis added)

Sophia, whose earlier quote expressed her difficulty with the term survivor, explains how she sees herself:

So while technically I can call myself a survivor, I kind of guess I think of myself as a warrior, as a breast cancer warrior, which symbolizes that at some point I've had

this, but that I recognize that the struggle may be still, it's still ongoing to some degree...because you just don't know what's coming down the pike.

Not Close Enough to Death to be a Survivor—Given the longstanding cultural fears associated with cancer and medicine's inability to prevent breast cancer or cure metastatic breast cancer (Leopold, 1999; Patterson, 1987), it is not altogether surprising that women face difficulties reconciling their fears of recurrence with the message that they have beaten cancer. More unexpected is that several of the women in this sample rejected survivorship because they believed they were not sick enough to be a survivor. A 42 year old respondent by the name of Olivia explained, "I don't see me as being close to death, you know. So in terms of going to the relay event, they say I'm a survivor. I may look at it like this one lady said, she's a conqueror instead of a survivor. I probably tend more to believe on that end." Like other women, Olivia crafted her own definition of survivorship but did so because she did not come close enough to dying. Likewise, Martha (age 66) rejected survivorship because to her being a survivor means that "they were just deathly ill and I don't feel like I was deathly ill, but I would have been, probably within six months." What is interesting is that neither of these women had an easy bout with cancer. Each underwent surgery, chemotherapy and radiation. Women like Olivia and Martha suggest that the breast cancer culture has emphasized the heroic battle against cancer to an extent that has alienated some women from the breast cancer culture.

Rejecting the Social Identity of Survivor—The final set of cases contains women who explicitly refuse to be part of the social identity that is breast cancer. Individuals facing chronic, stigmatized, severe, or debilitating illness risk being socially identified by their disease (Bury, 1988; Charmaz, 1995; Goffman, 1963; Locker, 1983; MacDonald, 1988). In response, the ill person may work to define herself as more than just an illness (Charmaz 1991, 1995). In the case of survivorship, this desire to not be identified by one's illness extends even when the identity has positive overtones. Gwen (age 32) explained that she did not need "those symbols" around her to remind her of what she had been through. She said she was not the kind of person to wear the "badge of honor" and she likes to think of herself in more complex terms. Kate (age 44) describes how she sometimes hates to be reminded of her cancer by the pink ribbons and license plates she sees around her. She perhaps best articulated the discomfort with the public nature of breast cancer:

I don't like being part of groups, you know what I mean, like I don't like being part of clichés, I don't like being a part of a society. I like being an individual, so I don't like being linked in with a label and that's the uncomfortable piece to me. I don't mind telling you that I've had breast cancer, but I don't want to commit myself to marches across the US and I don't want to commit myself to this cause, you know what I mean?

A 53 year old woman named Joanna takes the reluctance to identify as a survivor further, refusing to be labeled and refusing to ignore larger factors she beliefs cause cancer:

I just don't feel like I see myself (as a survivor) and I don't like to buy into. . . it's like when the soldiers come home from Iraq and they're told you can have this prosthesis and you won't mind not having an arm and you're a war veteran now, that's who you are. And I don't like the government or the medical establishment labeling me something.

Interviewer: And what do you think that label means or implies?

Cancer survivor is somebody who's been screwed by the government once again. The reason we get cancer is due to pollution and lack of care of human beings in our culture and cancer survivor just means you've been convinced to look at yourself as somebody who can't think of the reasons but you survived. You don't know anything about globally where this event stands, you just survived and that's your label.

Joanna was the only woman in the sample to politicize the cultural definitions of survivors and consider how those definitions preclude a consideration of structural factors. Joanna drew upon a tradition within her Native American culture to craft her own conception of breast cancer:

I only got through this because I'm part Native American and I have certain things to think about during such times, like the Sundance where you put piercings in your chest and you pull them out to prove your love of your fellow man and to show you can suffer and love. So I viewed it like that...but it really came in handy for me because it gave me a reframing device, a way to look at this that made me not a cancer victim or cancer survivor. I'm someone who went to a Sundance and I lived and I'm stronger now.

As Joanna so beautifully articulates, the Sundance represents the meanings she wants to associate with breast cancer—the mutilation of her chest, suffering, and the continuation of her life.

Survivor as a Non-Salient Framework

For a final group of women, survivorship was not a salient part of their cancer experience. When asked if she considered herself a survivor, Betty (age 68) replied, “You know, I’ve never really thought about it! But I guess I am.” The women for whom survivorship lacked salience were all over the age of 65. For them, survivorship was unavailable or undesirable. Instead, they relied on the discourse of the aging body. As Martha (age 66) explained, “I wasn’t really shattered by it or anything, I mean after you live 65 years, you know you’re bound to have something like that.”

Discussion

For medical sociologists, these findings suggest that dominant representations of disease can pose challenges for individual attempting to make sense of illness even when disease meanings are positive. Truthful, or what Frank (1995) refers to as “good” stories, are more desired than positive, cheerful stories. For breast cancer, a good story would acknowledge the long-term role of cancer in women’s lives and their fears of recurrence. Such a framework would reduce the separation of the private and public experiences of cancer (Batt, 1994) and draw women closer to the communicative body (Frank 1995), which accepts the contingency of life, exhibits suffering openly and can share with others in their pain. Such a framework would also entail a shift in terminology from “survivor” to “living with cancer” or “co-existing with cancer” (Clarke 1999). There have been recent calls to recognize cancer as a chronic disease such as the 2005 Institute of Medicine report, “From Cancer Patient to Cancer Survivor: Lost in Transition”, which detailed the long-term needs of cancer patients. However, the data presented here demonstrate that women with breast cancer still face a conflict between cultural definitions of survivorship and their own ongoing battles with cancer.

A good cancer story would also acknowledge the variation in responses to breast cancer (Langellier and Sullivan, 1998). Women’s responses to survivorship varied even among a relatively homogenous sample captured at similar points post-treatment. The diversity of women’s responses to survivorship presents a challenge to clinicians and others responsible for addressing the needs of cancer patients. Clearly, labeling women as survivors will assist some in their adjustment and leave others feeling uncomfortable.

Moreover, these findings add to our understandings of the use of culture. Because these women are in the process of retooling their lives, the agentic process of building meanings around illness is evident. A set of cultural meanings was salient to them; however, meanings were always not simply rejected or accepted. Rather, individuals worked to modify cultural meanings to fit their lives. By crafting meanings, women reclaim agency after a medical event

that can be highly impersonal, abstract, and technical (Batt, 1994) Women's meanings post-cancer are important because frameworks attached to experience shape subsequent action (Swidler, 1986). Women sought meanings that supported their ongoing efforts to prevent a recurrence or quickly detect a new cancer.

How can we explain why some women and not others adopted the survivor identity? Neither disease stage nor treatment modality predicted views of survivorship in this sample. Future work should further examine the influence of disease and person characteristics on women's ability to identify as survivors. Women of color and women of lower socioeconomic status may view survivorship differently or may draw upon other salient cultural frameworks (Mathews, Lannin and Mitchell, 1994). Future work should also examine women's relationship to the survivor identity at other points in the illness experience. Perspectives on survivorship may shift over time as women work through the effects of treatment, feel greater distance from the disease, or face a recurrence. In addition, this study did not systematically examine how the survivor culture shapes women's physical selves. However, prior work suggests that the breast cancer culture sends clear messages to women that they must conceal the effects of cancer. Therefore, future work should further pursue connections between survivorship and women's bodies.

Political and feminist responses to breast cancer were largely absent from these data. This may reflect the sample and future work should consider whether other samples articulate these perspectives. However, even if women do not identify with the breast cancer culture or draw upon it in limited way, the dominant model may affect them by limiting their ways of thinking about the disease. In other words, cultural construction of breast cancer may mute feminist or political responses to the disease (Batt, 1994; Leopold, 1999).

Why does the current image of the survivor persist if it does not work for many women? On a social level, contemporary constructions of breast cancer succeeded in securing funding, sympathy, and respect for the disease. The narrative of survivorship supports the medical model wherein illness is diagnosed, treated, and cured (Batt, 1994; Frank, 1995). On an individual level, women have opportunities to join in the dominant culture via consumerism, pink ribbons and symbols. Fewer opportunities exist to act in alternative ways. What would it mean to embrace a new construction of survivorship that recognizes the lasting effects of breast cancer and the diversity of responses to breast cancer? First, it would mean acknowledging physical sensations, management of appearance, and effects of treatment (Fosket, 2000; Thomas-MacLean, 2005). Second, it would mean acknowledging the limits of medicine in controlling cancer. According to Batt (1994, p. 237),

If each woman with breast cancer understood medicine's limited ability to control the disease, our reliance on physicians, tests and medical interventions would be enormously reduced. The power of these institutions over us would dwindle accordingly. Without the Rosy Filter (of the breast cancer culture), women with breast cancer would gain the right to map our own futures, within the very real constraints imposed by a life-threatening disease.

Conclusion

Views of breast cancer have changed dramatically in recent decades. Women with breast cancer today will face less shame, have access to greater information about their disease, and openly receive the support of others. This is an overwhelming positive change for breast cancer patients. However, in constructing a positive, cure-oriented definition of survivorship, the breast cancer culture has left many women searching for representations which acknowledge their fears and the *ongoing* presence of cancer in their lives. Moreover, women's responses to

breast cancer are varied. Thus, a better model of life after cancer would acknowledge the variety of responses to the disease and the ongoing significance of the disease in women's lives.

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