



The meaning of the survivor identity for women with breast cancer

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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 3–18 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.

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“I woke up, still alive. Does that mean ‘cured’?”
Marilyn Hacker, 1994 (cited in Bahar, 2003)

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 (Black, 1995; Brown, Zavestoski, McCormick, 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

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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, 1995).

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 5 km 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 are “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 it is 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

¹ I 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.

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