

On the Receiving End: Women, Caring, and Breast Cancer

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Abstract Gendered definitions of care influence breast cancer survivors' coping strategies, sense of entitlement to care, and ultimately their capacity to receive care. Using qualitative data from 60 intensive interviews, this study examines how gendered definitions of care influence women's experiences as care-receivers. Findings indicate that negotiating gender boundaries to care for the self is both empowering and stigmatizing. Women with breast cancer are required to break gender norms that stress compliance, nurturing, and putting the needs of others first to prioritize their own needs for care. Concurrently, they take on additional nurturing roles to provide support to other women with breast cancer, relinquishing to some degree the individualistic approach to life they found necessary to cope with their illness in the first place.

Keywords Breast cancer · Chronic illness · Care work · Gender identity · Gender norms

The Pink Ribbon

A letter came today from a name I did not know. The words I read inside I'll not forget I know.

So sorry to inform you your friend has died today. The cancer took her slowly, what more am I to say?

She fought the beast like a marine a battle I'll say she won.

This war she fought with valor with more strength than anyone.

Through all her pain and anger she sailed the roughest seas. She fought for friends and family. She fought the beast for you and me

This pink ribbon I've enclosed is a symbol worn with pride to honor all the women who have fought the beast inside.

~ *Author Unknown*

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Introduction

Breast cancer has increased in the last thirty years, is the most commonly diagnosed invasive cancer in women, and 40 percent of all women diagnosed with invasive breast cancer die within 20 years of diagnosis (ACS, 2006). Despite increased public attention to breast cancer, there is a significant gap between what is portrayed as the breast cancer experience and the real life experiences of women diagnosed with this disease (Gray, Sinding, & Fitch, 2001; Kasper & Ferguson, 2000). As women respond to illness and learn to focus on their needs, they also contend with social expectations about what it means to be a woman and what it means to be a breast cancer survivor (Fosket, Karran, & LaFia, 2000). Such gendered identity is embedded deeply within social positions such as caregivers. For example, in their roles as caregivers, contemporary American women are largely responsible for attending to others' emotional and physical needs and providing care work that is essential for social reproduction (England & Folbre, 1999; Kemp 1994). Assumptions regarding women's gendered caretaking behavior (made both by women themselves and by others) are often taken for granted, and a diagnosis of invasive breast cancer can call them into question. When faced with breast cancer, the women in this study negotiate, challenge, and reify their gendered identities within the societal constraints of a gendered division of labor, in which caring takes on both gendered and feminized meanings.

In this manuscript, I explore three major gendered processes that breast cancer survivors undergo following a breast cancer diagnosis. First, women facing breast cancer put themselves first, breaking gender norms that stress traditional femininity, e.g., self sacrifice and caring for others. Second, they negotiate their gendered identity, as they reflect upon their new identity as a breast cancer survivor and new role as a care recipient. Third, breast cancer survivors reinscribe gender norms as they begin to balance their needs with the needs of others and help other women with breast cancer. Together, these three processes demonstrate the power of gender as an institution, which not only influences breast cancer survivors' attitudes and behaviors, but also affects those around them.

Gender identity is socially constructed through interaction, negotiation, and interpretation of one's actions in terms of broader gendered social expectations (West & Zimmerman, 1987). When a person is ill or in crisis, women frequently extend, or are expected to extend, their social roles as family caregivers to provide care and social support. Because women typically do care work for others and regularly exhibit emotional attachment and recognition of others' needs, they are viewed as intrinsically skilled at giving care, and especially at giving *good* care. Good care is equated with normative feminine attributes—empathy, emotional sensitivity, and genuine concern for others. If good caregiving is assumed to be dependent upon women doing what comes *naturally* to them as mothers, wives, and daughters (Abel & Nelson, 1990; Cancian & Oliker, 2000; Graham, 1983), then women will be held accountable to these expectations both socially and culturally. In framing care as nurturance, scholars define care in terms of the nature of the activity rather than the population to which it is directed (Duffy, 2005).

Care work literature examines how women's unequal participation in caregiving within the family and in the care work market contributes to gender identity, decreases women's social status, and is detrimental to women's mental and physical health (Abel & Nelson, 1990; Cancian & Oliker, 2000; Gerson, 2002; Harrington, 1999). While there are instances when women are able to combine their care work for others with care for the self within the domain of leisure (Johnson & Wilson, 2005; Stalp, 2006), the extent to which women feel entitled to care for themselves and to get care for themselves when they are ill has been overshadowed by evidence that women use health services more than men, are more

accepting of illness in general due to their caring roles, and are typically more protective of their health than are men (Lorber & Moore, 2002). To manage breast cancer, for example, it is vital for women to be protective of themselves and to prioritize their individual needs. Yet, to do so requires that women break with normative gendered assumptions and expectations that define women as *natural* nurturers, placing them in service to others. This frequently contributes to stigmatization, identity crisis, and role confusion. Rather than improving wellbeing, these processes create stress and actually limit women's capacity to get needed care. To reduce stress and protect their identities, women form ties with breast cancer survivors, which enables them to again help others, recast themselves as nurturers, and reconstruct their gendered (although negotiated) identities with the support of their peers.

In this paper, my purpose is to examine how women with breast cancer define and manage their care needs when facing this illness. I address how women negotiate care seeking and being cared for, and what it is like to be on the receiving end of care work rather than the more typical giving end of care work. By examining women's experiences as care receivers, I make two contributions to the care work literature. First, I highlight the status of women within a particular health context to reveal how they are both empowered and constrained by the experience of illness as well as the society more generally. Second, I demonstrate how current definitions of women's health vis-à-vis breast cancer correspond to women's actual experiences and concerns when facing this chronic illness.

This research is based upon interviews with 60 women who were diagnosed with breast cancer. I focus on women's access to care work—in other words, do women possess a sense of entitlement to get care from their families and others during illness (e.g., diagnosis, treatment, and aftercare)? When facing breast cancer study participants found themselves negotiating gender in terms of what it means to be a breast cancer survivor. They also faced social expectations about being nurturers while they were seeking care for themselves. Women found these negotiations empowering and constraining as they made decisions about their health care and wellbeing. Women also re-conceptualized their identities as women, for gender expectations constrained their abilities to *not care* for others, as they asked for care for themselves.

In the sections that follow, I explore women's experiences when facing breast cancer. First, I discuss literature related to women's health and illness, establishing the social context of breast cancer and its construction as a gendered illness. I then discuss the data and methods of the study. In the findings, I present how women's experiences and coping strategies reflect broader social norms about gender, and how these expectations in turn shape women's sense of entitlement to access care for themselves. I conclude with a discussion of how this research illuminates the role of identity and social context in shaping women's responses to illness.

Care work and the gendering of illness

While the physical and emotional demands of caregiving contribute to role strain (Herd & Meyer, 2002), one of the major theoretical directions in the care work literature has been to reframe care work in terms of relationality and interdependence (Duffy, 2005). As it has been largely defined, care work is a process that involves emotionality and responsiveness, thereby situating care within the context of a two-way relationship that requires paying attention to the needs of others and responding to those needs (Cancian & Olicker, 2000; Tronto & Fisher, 1990). As the caregiving relationship is defined here, caregivers do not just disseminate care services, and care receivers are not simply dependents without agency. Instead, both caregivers and care receivers are active participants in the care work process. However,

care work relationships function within a dynamic gender system, and thus within gendered relationships and collective social arrangements that impact the potential for agency on both sides of the caring relationship.

Whereas care work has been defined in terms of feminine gender norms that emphasize selflessness, emotionality, morality, and nurturing; “real” work has been defined as rational and impersonal—qualities associated with masculinity and requiring specialized knowledge or skills to advance (Kemp, 1994). Women are encouraged to use their “innate” feminine qualities to put the needs of others first, maintain the household, care for children, and provide caring and nurturance to family members (Abel & Nelson, 1990; Cancian & Oliker, 2000; Graham, 1983; Kemp, 1994). In this context women are the principle providers of care for families and communities (England & Folbre, 1999; Herd & Meyer, 2002), and the social organization of care work removes the burden of care from the State, and shifts it back to families, (i.e., women caregivers). Western medicine has institutionalized this gendered system of care work by producing a hierarchical structure in which doctors dominate the transmission of health care, and men are disproportionately in specialist positions whereas women overwhelmingly hold caregiving positions (Lorber & Moore, 2002).

Women practice a range of activities within the home and service sector that provide reproductive labor (DeVault, 1991; Romero, 1992). Because of women’s social responsibilities to provide relational and non-relational care for family members and others, women’s identities are specified in terms of caregiving, and not care receiving. Thus, individuals who are ill face deeply embedded beliefs about differences between men and women, how illness reshapes their lives, and how they should feel about it (Charmaz, 1991). Gender shapes the interactions women engage in before they are sick, and magnifies the influence of gender when facing chronic illness. This process is especially prominent when the illness itself has been gendered.

Breast cancer is an illness steeped in gendered meanings, in terms of both breast cancer support and survivorship. Most obvious is the coupling of breast cancer support with the color pink, which is typically associated with passivity, compliance, and sacrifice. Breast cancer supporters often don pink ribbons, wear pink t-shirts, or purchase pink ribbon postage stamps. Because the pink ribbon is regarded as the representative symbol of breast cancer and the breast cancer movement in public awareness campaigns, it marks breast cancer as a public issue (Mills, 1961). But what does it *mean* to display pink in these ways? Resulting from normative expectations about women’s sacrifice, empathy, emotional sensitivity, and a genuine concern for others, displays of pink foster these feminine qualities in the name of awareness and social support. Conflating “pink” with notions of social support obscures the needs and realities of women with breast cancer in two major ways. First, the collective pink response gives the illusion that something is being done, and therefore progress is being made (Ehrenreich, 2001; Fernandez, 1998). Second, it genders breast cancer as an illness, tightly securing notions of feminine sacrifice, empathy, and emotional sensitivity to an idealized model of survivorship imbued with differently gendered meanings, specifically hegemonic masculinity (Connell, 1987).

“Survivor” is a label and a status imposed on women diagnosed with breast cancer, which constructs a gendered illness identity (Charmaz, 1991). The “survivor” ideal is presented widely throughout the media and is also prevalent within cultural artifacts such as poetry, prose, art, music, and items of conspicuous consumption (e.g., plastic bracelets, pins, etc.). Such cultural artifacts can provide a vehicle for self-determination and representation, enabling people to make meaning of their illness and even to resist external representations (see Lorde, 1980; The Breast Cancer Fund, 1998). Numerous breast cancer survivors have used these mechanisms to learn from their experiences and to transform their illness. Yet, these

cultural representations use controlling imagery to guide public perceptions about how to be an exemplary breast cancer survivor. War language and imagery are especially powerful because they define the situation as an emergency in which no sacrifice is excessive (Best, 1999; Sontag, 1978).

In the poem “The Pink Ribbon,” the model breast cancer survivor follows this pattern, exhibiting masculine characteristics, cast as a Marine in the war against breast cancer. For the ideal breast cancer survivor, survivorship is surely a badge of honor, as the sacrifice of women’s lives is obscured in the battle itself, and by gendered social expectations that make sacrifice a normal part of being a woman. Women’s coping strategies reflect their attempts to negotiate these competing gendered expectations within their everyday lives and relationships. The final message of the poem crystallizes the general societal response to breast cancer. In honoring the heroine warrior (e.g., the she-ro), all women (and supportive men) are encouraged to gird themselves in pink, the quintessential cultural icon of breast cancer survivorship. In doing so gender expectations are at work both in shaping respondents’ identities as women, and in constructing their identities as breast cancer survivors. As women with breast cancer account for their decisions and actions after diagnosis, they evaluate, negotiate, resist, and renew their identities as women.

Methods

Over a three year period, I gathered data using observation and intensive interview techniques, and a grounded theory approach to qualitative analysis (Glaser & Strauss, 1967; Gubrium & Holstein, 2002; Lofland & Lofland, 1995; Maxwell, 1996). First, I worked for six months with one community-based breast cancer organization committed to breast cancer education and advocacy. Following this, I tape-recorded and transcribed 60 interviews with women in New York and Pennsylvania, primarily in urban areas, who were diagnosed with breast cancer. In-depth interviews ranging from one to four hours occurred in a location of the participant’s choice, usually their homes or offices. Participation was voluntary and unpaid, as interviewees answered a call for interviews about “how breast cancer survivors find care for themselves.” Participants were recruited from several sources, including community-based breast cancer organizations, support groups, the Komen Race for the Cure and other breast cancer community events, public bulletin boards, and through referrals.

Sample characteristics

Consistent with a grounded theory approach, I used a theoretical sampling strategy (Glaser & Strauss, 1967). In theoretical sampling, the initial sample is largely defined by the research situation. As categories emerge from the data, the researcher seeks to add to the sample in ways that strengthen the emerging theory. This is accomplished by defining the properties of the categories, and understanding the relationships within and among the categories. Using comparison groups that maximize differences on relevant dimensions can verify, challenge, and/or refine core categories and themes as they are developed (Glaser & Strauss, 1967).

After gathering data from an initial sample of 14 women from the community organization where I did my participant observation and defining preliminary theoretical categories and their properties, I defined three comparative groups based on organizational affiliation. These are: (1) Members of a breast cancer education/advocacy organization that stresses social, behavioral, and environmental causes of breast cancer; (2) Members of breast cancer support groups focusing on empowerment, social support, fundraising toward cure, and the

normalization of breast cancer; and (3) Women who are unaffiliated with any formal breast cancer-related organization. Then, I recruited respondents from five support groups, two treatment centers, two breast-cancer related community events, numerous public bulletin boards, and through snowball sampling. Over the course of data collection, the sample expanded to include 18 members of education/advocacy, 22 support group members and 20 women who were unaffiliated formal breast cancer organizations, totaling 60 participants. Characteristics for the whole sample are illustrated in Table 1 in the Appendix.

Data collection and analysis

While involved in the education/advocacy organization, I observed meetings and discussions, attended educational workshops, and met breast cancer survivors at community events. Through observation and informal conversations, and after reading several breast cancer biographies (Lorde, 1980; Mayer, 1993), I constructed an interview schedule which had a loose, chronological order (Reinharz, 1992), open-ended questions and clustered themes. My goal was to understand the holistic worldview of the participants (Oakley, 1982) and generate theory using a constant comparative method in the tradition of Glaser and Strauss (1967).

The respondent initially played a key role in determining what was most relevant and the order of the questioning, and I provided participants with a copy of their transcripts and a copy of the finished work, upon request. Generally, I asked each woman how breast cancer had influenced her daily life, her relationships, and her perspectives. I inquired about reactions from family, friends, co-workers, medical professionals and even strangers to gain insight into personal experiences of social support or stigma. When I asked what kept them going day to day during the most difficult times, I learned of coping strategies used to deal with role strain and feelings of personal responsibility for their health. Women's narratives show that dealing with breast cancer can change people in profound ways, and these women wanted to share their experiences. Telling one's story is not uncommon for people living with chronic illness. As Arthur Frank (1995) argues, illness narratives are a pathway for expressing one's attempt to reclaim the body from modern medicine and to incorporate illness into one's life and sense of self. While many of the women I interviewed clearly wanted to tell their story, they did not generally believe that just anyone could hear it. In that way, I was also a privileged listener.

Consistent with a grounded theoretical approach, I simultaneously collected data and developed analyses over the course of the research, including coding data, formulating concepts, and constructing theoretical models. As conceptual categories and properties emerged, I developed a substantive model of the processes that influence breast cancer survivors' coping strategies and experiences as care receivers. To allow for emergent themes, I revised the interview schedule periodically to incorporate relevant categories and evaluate their properties and the conditions under which they were valid. The model discussed in this paper presents the themes that pertain to women's sense of empowerment and/or constraint when coping with breast cancer. By comparing the phenomena within the contexts of women's lives, I demonstrate how current definitions of survivorship work (or not) for women with breast cancer.

In the next section, I discuss three core themes that explain the relationship between gendered definitions of care and breast cancer survivors' experiences as care receivers. First, "breaking gender norms," relates to social norms that emphasize compliance, nurturance, and empathy, defining women as caregivers and placing them in service to others. Second, "negotiating identity," illustrates the conflict women feel in relation to their identities as women

and as breast cancer survivors. Third, “reinscribing gender norms,” shows how women recast themselves as nurturers by giving back and helping other breast cancer survivors. I show how these processes shape breast cancer survivors’ coping strategies and feelings of entitlement about getting care for themselves. To protect confidentiality, I gave pseudonyms to all respondents.

Findings

Women with breast cancer are frequently not accustomed to the self-interestedness required to cope with a major illness. Even when focusing on their individual needs, taking care of themselves, or receiving care from others, they adjust their gendered understandings of themselves in regard to care in order to accommodate deeply felt imperatives to care about and for others. Gender negotiation is reflected in their ambivalence about accepting help from others; the desire to take care of themselves, instead of asking for help; and the tendency to engage in supportive relationships with other breast cancer survivors, who are typically thought to be the only people who can truly understand their experience. When disrupted by illness, the women I interviewed negotiated their gender identities throughout their experiences with breast cancer.

Breaking gender norms: “I’ve become more of a ‘me, me’ person”

Women’s responses to breast cancer can be understood as a reflection of dominant cultural scripts that define women as “natural” nurturers. As respondents speak about their experiences with breast cancer both within and outside of the medical realm, their narratives illustrate the salience of gender, particularly as it relates to compliance to others’ needs and desires, rather than a prioritization of their own. Respondents demonstrate a level of awareness that these expectations are at work in their everyday lives, understanding themselves in relation to illness (Charmaz, 1991). Repeatedly, women describe their efforts to break from feminine norms to cope with breast cancer—becoming self-interested, assertive, and self-reliant. When successful, these efforts have the potential to promote agency and empowerment. However, such attributes also conflict with the nurturing, other-focused traits typically associated with being female, and many women characterize them as desirable as well as selfish and guilt-inducing. To negotiate this tension, women rely on two interrelated processes: justifying their needs to themselves and others, and being self-reliant to avoid being burdensome to others.

One of the most critical issues participants face after breast cancer diagnosis is “the need to become more individualistic.” This shift of perspective from thinking about others to thinking about oneself is a necessary coping strategy for managing the life-changing aspects of breast cancer treatments, side effects, interruptions to daily routines, strains on relationships, and existential fears. Throughout this process, many women reach an increased sense of personal awareness, seeing themselves for the first time as agents who can give meaning to their experiences and act on their own behalf. All respondents told me that breast cancer changed them in a number of ways: doing things differently, being assertive, setting priorities, and establishing boundaries. While the majority of women would not call breast cancer a “blessing,” many women thought of themselves as transformed and truer to themselves after they learned to break from the constraining attitudes and behaviors that were typical of them prior to their diagnosis. Essentially, what women developed was a gender consciousness.

The sudden thrust into the medical system to procure care for themselves was a primary catalyst for self transformation and gender awareness. The following quote illustrates the role that doctor-patient interactions can have on women's standpoint and personal philosophies. After describing a situation in which her doctor refused to answer her questions, Barbara said: "I think that this is not a position a man with testicular cancer would find himself in. In general, a man would be expected to ask questions and be knowledgeable, where a woman is expected to be the opposite." Many participants felt this way, and believed that the authoritarian nature of doctor-patient relationships evoked gendered responses. When describing her treatment options, Mary said, "I think every woman has a choice. But, we get overwhelmed because of the doctors. We don't question them. Doctors, mostly male, are arrogant. If they can't do a particular procedure, they won't say they can't do it. They'll just recommend something else, saying they think it is best." Although many women also had female doctors, respondents frequently reacted to what is theorized to be a masculine power structure (Lorber & Moore, 2002). In response, they learned to prioritize their needs and become assertive to manage their doctors.

In addition to wanting agency in medical interactions, respondents described a new sense of assertiveness in other areas of social life. After her diagnosis Elizabeth said, "I don't do the same amount of work and I'm not too worried about it . . . I don't want to go back to my normal life because I am enjoying all of the things I'm doing, the people I've met since I got breast cancer. I am not interested in going back to the 60-hour work-week and the boring life." Similarly, Linda said,

It's not as important for me to be the best worker, the best mother, best housekeeper, best wife. If someone is critical of something I do at work, for example, I let it slide more easily than I used to . . . Now, I feel more at ease, more comfortable with life.

Women like Elizabeth and Linda were empowered by a new set of dispositions, and the sense of agency that accompanied them. It is important to note, however, that the women who more easily maintained these dispositions were also those who established social networks with other breast cancer survivors. Recognizing this, Elizabeth said later, "Other people are likely to look at me and say, 'what is wrong with you, and when are you going to get normal again?' I'm not." For Elizabeth, breast cancer was an impetus for breaking some of the constraints of gender.

For some women, the self-determined aspects of life that resulted from breast cancer were less considerable. Barbara was happily married and explained that she did not need a breast cancer diagnosis to examine her life. She said, "I liked my life the way it was before I got sick. I was not working at some horrible job and wanting to quit. I did not have a terrible mate, or make some great discovery when I really looked into my life . . . no, no, no!" Essentially, Barbara's words are a response to the narrowly defined model of survivorship that requires courage, strength, and triumph. Her experience does not fit neatly into this model, and she rejects the cultural expectation that women wear the pink badge of survivorship. Despite her reprimand, she did speak at length about having a new sense of confidence in pursuing what is important to her, and resisting things that might undermine her priorities. She said, "I decided that there was one volunteer activity that I don't want to do any longer . . . They assumed that I would take it back as soon as I was better. I told them . . . my priorities have changed and I'm going to want to spend my time differently."

Feelings of self-confidence, empowerment, or even a new sense of individual identity as women would often conflict with others' expectations. When this occurs, the individuation that was at one time a viable coping mechanism becomes tainted with feelings of selfishness

or guilt. Vivien is a two-year survivor whose words illustrate this:

I've always made [my step-kids] cookies . . . They are in their thirties . . . and they still want those cookies. [My step-son] hadn't been home for a few years . . . I still wasn't really into my good mode . . . and he went to the cookie jar. It was empty . . . He was trying to be understanding, but he really wanted those cookies . . . I felt so guilty. I said [to myself], "Why am I feeling guilty? I couldn't do them. I didn't do them. That was that . . . When I see him, I'll bring him some cookies . . ." Normally I would have just gotten out of bed if I was sick and made [them]. But, I just don't do those things anymore.

Prioritizing her own needs requires Vivien to feel that she is disappointing her step-son by not baking him cookies. When she explains that she "still wasn't really into her good mode," Vivien is referring first to her ability to move and function following her treatment. She believes that this physical difficulty should have validated her decision not to bake cookies. However, in the context of fulfilling her step-son's expectations, it is clear that Vivien is also judging her ability to meet her families' needs. Even though she believes on some level that she is justified in putting herself first, her feelings of guilt cause her to question her actions. With an apologetic tone, she says "I just don't do those things anymore." While the specifics of situation may be different, Vivien's cookie story illustrates a common theme across the interviews of assertiveness followed by guilt.

Becoming self-interested requires time, focus, and support from others. If women are taking care of others and do not have support in prioritizing their needs, they are less likely to maintain this disposition. For instance, Alice is a married, 59-year-old mother of three grown children who fully recognizes the commitment and energy needed to cope with her illness:

I'm glad I got breast cancer after my children were grown. When you get breast cancer you have to think more about yourself. I thought more of myself than the family, the husband, or the kids. I thought, "No, there's just me now." You have to become selfish in many respects . . . Before, I couldn't think about myself at all, because I had to take care of . . . my family. If they needed something, they came first. After breast cancer, I had to turn to myself.

The relief that Alice feels speaks to a gendered dimension of social relationships, which structures her focus and her expectations. Alice feels strongly that she would have been unable to deal with breast cancer when her children were young because it would have been impossible for her to be "selfish" then. Alice believes that family care is her responsibility, not her husband's. Even though it often carries with it the negative connotation of selfishness, participants view self-interestedness as necessary for coping with breast cancer. Many seek the support of friends, often other breast cancer survivors, to stay focused on their own needs. However, the sentiment Alice articulates, "There's just me now," can be internalized as a form of self-reliance.

The goal of self-reliance often contains the desire to shield others from the burden of caring. Leslie was diagnosed with breast cancer when her domestic partner was working outside the country. While her partner offered to return to the US during the treatment, Leslie insisted that Sandy continue her work abroad. She said, "I didn't want her to come back, because it wasn't like I was going to drop dead or anything. I didn't want to alarm her . . . I felt I would be a lot healthier if I did this on my own—with support from her and my friends here. But, it wasn't like I needed someone here watching over me." Leslie's statement illustrates the final dimension of "breaking gender norms." To protect their relationships, many held

the viewpoint that they were on their own. Assessing the severity of their illness in terms of life or death, participants spent enormous personal resources helping others to cope with their illness with as little burden as possible. As a result, they were highly selective in the care they sought from others, men as well as women.

Negotiating identity: “I’m very gray now about who I really am”

This section elucidates the processes that women engage in when managing their identities. When coping with breast cancer, respondents evaluate, negotiate, resist, and renew their identities. This process begins the first time a woman breaks from what has been a repeated gender performance of doing care work for others. If gender expectations that stress sacrifice, empathy, and emotional sensitivity sit squarely within a respondent’s repertoire then the self-interestedness necessary to cope with breast cancer would undoubtedly conflict with it. Living from an individualistic standpoint and prioritizing one’s own needs, for example, was difficult for women who typically sacrificed and put the needs of others first in their relationships, families, communities, and jobs. In addition to self-imposed constraints, women work out power differentials within their relationships, and strains can occur when women who typically care for others need care from others. If these situations reverse “normal” gender relations so that women need care from men, added stresses can arise.

To understand women’s sense of self in relation to gender identity, I asked respondents if they “felt like the same person” after dealing with breast cancer. With consistency, the women I interviewed discussed the need to develop a new sense of normality, and a new sense of self. The ease with which women redefine what they consider to be normal is closely tied to others’ expectations. Justine said, for example, “Things got back to normal, but not really normal. What’s normal for me now is not what was normal three years ago . . . You should ask my husband.” Justine’s understanding of herself is connected to her husband’s perception of her in the sense that she is not confident in her own opinion. When John came home in the middle of our interview, I asked if he could join the conversation briefly to discuss it. What transpired was a dialogue between the two partners that revealed a difference in perspective about how Justine had changed and why. What the conversation revealed was John’s reconstruction of Justine as an exemplary survivor. John remembered Justine’s strength, stoicism, and positive attitude as she faced breast cancer, and he felt that she was a “better person” because of her experience. He said,

I just think you’re better because you went through all this stuff. You always had a positive . . . I mean . . . I really . . . I’m not just saying this. I’m not saying it for your benefit. I don’t remember you complaining very much at all. She didn’t complain much. It was always, “Somebody gets it. I got it. We’ll deal with it.”

Justine seemed annoyed at John’s commentary and explained that the qualities he admired were not developed by choice: “It’s not like I can give it back and say, ‘I’m not ready for it.’” Several times during the somewhat contentious conversation, Justine and John acknowledged the sharp contrast in their respective attitudes about how Justine handled the difficulties of her illness, and who she was as a person. For John, there is a clear distinction between the pitiful person who complains and feels sorry for herself and the strong person who takes control of the situation. He wanted to remember Justine as the latter. He said,

I’m sure there are some people . . . I don’t know who they are personally . . . but I’m sure there’s some people who say, “Why me?” You did say that, but that wasn’t the crux

of your focus. Your focus wasn't, "Why me?" It may have been that in the beginning at one time. But after that it was, "Okay, I got it, let's deal with it."

The strength, courage, and determination of the model survivor shaped John's understanding of what had occurred. Even though Justine did say, "why me," John stresses the transience of this question and the persistence of Justine's matter-of-fact determination. Justine kept interjecting throughout the dialogue, "I didn't have any choice," and John kept reiterating his point. Like most respondents, Justine does not fully incorporate the survivor model into her identity even though elements of the model shape her feelings and interactions. Instead, Justine relies on her own perceptions about the severity of her illness to explain her motives and her actions. And, three years after her diagnosis, she continues to explain them to her husband.

All couples negotiate issues of power and equality within constraints from the larger society. When "normal" gender relations are reversed and women need care from men, difficulties can arise. For example, respondents had a clear understanding that caring for others required extensive mental work to anticipate and assess others' emotional and physical needs, to make appropriate decisions to meet those needs, and to provide care. Knowing this contributed to what Katie called "a painful awareness that [her] needs were not going to be met." Katie is 39 years old, married, and has no children. She said, "If my husband gets a cold, he needs me to baby him. I make him special soup, rub his temples, and do everything to make him feel better. And, I'm the one with cancer!" Whereas Katie responds to her husband's needs without his asking for it, she feels that she cannot expect the same attention and care from her husband. What's more, she does not feel that she is in a position to ask for it.

Joanna is a 60-year-old woman who developed lymphedema following her mastectomy. Lymphedema is a chronic disorder that causes lymphatic fluid to accumulate in the tissues. While it cannot be cured, Joanna learned manual massage techniques to reduce the swelling in her affected arm. She needed assistance from her husband to do the massage, and any chores that would require the use of her arm. She said, "There was no question that he would help me. But, I was feeling bad because I thought I was using him." When I asked if her husband felt used, she said she didn't know. She later added, "When you have lymphedema, you have to keep up the maintenance or it can revert right back to the way it was. My husband doesn't do the massage anymore now, because it gets to be too much. He was very good about it . . . don't get me wrong. But, it just gets to be a chore." While it is widely known that men provide less caregiving than do women (Gerstel & Gallagher, 2001), Katie and Joanna understand the work involved in caring, and lowered their expectations for their husbands. Whereas Katie resented her husband's inattention, Joanna equated her needs for care as exploitation and felt guilty.

Women's guilt about burdening their families and others with their illness contributes to distress, even if the source of burden is clearly outside of their control. Furthermore, institutional barriers can and do hinder men's and women's aspirations and capacity to balance individual needs and desires with caring for others. Patricia said, "There wasn't an appointment that my husband didn't go to, or a decision we didn't make together . . . At work, he was highly criticized for this." She told me that colleagues disapproved of her husband taking time from work to attend her surgeries and doctor visits, saying, "Can't she take somebody else?" She explained,

[My husband] was compared to . . . guys . . . not so involved in their family's lives. People asked, "Why does she need you?" like I was going out to buy a dress or something. Nobody understood it. Nobody discussed it with him. Nobody discussed

me [her emphasis] with him. Nobody wanted to know. To them, he just took too much time off.

Patricia's husband wanted to provide support and care for his wife, and he did so at the risk of losing status with his job and co-workers. While recounting her husband's experience, Patricia was clearly agitated and blamed herself for putting her husband in this position.

Worrying for other family members and taking on blame for situations outside of their control was common. Barbara told me that her husband was very worried about the possibility of losing her to breast cancer. She said, "I felt so guilty for the misery I brought into the marriage. I didn't want to burden him. Then, I started seeing a psychologist. With her help, I came to the conclusion that I was entitled to unburden myself to him, even if it's hurtful to him. So, I started unburdening myself, not all the time . . . but every few days." Barbara had difficulty sharing the burden of her diagnosis because she felt personally responsible for the disruption it caused. At the same time, it was difficult for women to maintain the courage, positive attitude, and strong self image that being an ideal breast cancer survivor required. Karen said,

I often tried to continue to be happy, which is very hard to do when you don't feel that way. I couldn't get back to being myself. At some point I realized that for two months I didn't smile . . . I hadn't felt any joy . . . it's like you are in a movie. I was just walking through life . . . everybody moving along, and you are just stuck, watching everything.

Such disconnectedness can certainly be understood in psychological terms as a typical response to trauma or grief. However, the origin of Karen's response is not unlike that of other women I interviewed, stemming from deeply held feelings about their identities as women. She said later, "I felt like sometimes I was doing my best to stay upbeat to get my family through it . . . I felt so bad, because my mom and dad had to have this going on."

When women care for and about others, they behave in ways that are consistent with gender role expectations and a normative feminine identity. Yet, the non-feminine qualities of assertiveness, self-reliance and deliberate living were echoed across the interviews when breast cancer was the motivating force for women to put themselves first and to take action to keep their needs in focus. For these women, changes in personal perspectives and priorities were as much about negotiating a space for themselves as women as about finding new meaning in their lives in the face of life-threatening illness. While this action was empowering to some women some of the time, it also caused tension in their lives and ambivalence about their identities as women. This was especially visible in work and family situations in which women held significantly less power within their relationships, had responsibilities that required habitually gendered performances, had less freedom to define their individual sense of self, or felt accountable for breaching others' expectations.

Reinscribing gender norms: "Giving back"

Feeling the pressures of pink ribbon survivorship along with normative expectations about gender, the narratives express a conflict between women's needs and expectations for themselves and the internalized scripts that define women in terms of their ability to yield to the needs and expectations of others. On the one hand, participants did feel entitled to prioritize their needs and get care, but they felt uneasy about how much, who should provide it, and the conditions under which it was appropriate. These tensions were felt within women's primary relationships. Yet, they were largely resolved within a secondary sphere of relationships built from women's ties to other breast cancer survivors. The phrase, "giving back" was spoken

repeatedly when I asked women why, for example, they attended support group meetings, participated in breast cancer advocacy, walked in a 5-Kilometer “Race for the Cure,” offered guidance to women who were newly diagnosed with breast cancer, or even why they participated in this research study. I was struck by this phrase because “giving back” suggests that first something was given to them, and second that they were returning it to the person(s) who gave it. What exactly had they received, what were they giving back, and to whom? The answers to these questions reveal that women’s engagement in formal and informal support to other breast cancer survivors stems from an attempt to gain understanding, and to balance the self-interestedness that becomes necessary when responding to their illness.

Women “give back” to a community of women with breast cancer to build ties with the only people who, they believe, can truly understand their experience, women who have “been through it.” This level of understanding was not present within women’s other relationships, and participants regularly distinguished between those who could “sympathize” but not “empathize.” In the search for empathy, women sought understanding from other women, thereby reinforcing the gendered dimension of social interaction in everyday relationships as well as within the context of breast cancer itself. Relationships among breast cancer survivors formed in varied places, from a formal setting like a support group or treatment facility to a serendipitous meeting at work or as women traversed the medical landscape searching for information about diagnosis and treatment. These relationships enabled women with breast cancer to access informational, instrumental, and emotional support that was not readily available to them in other settings. A decade after her diagnosis, Alice still stresses the importance of having “real peers” to deal with breast cancer and its aftermath. She said,

These friends are a different kind of a sounding board than family. Having just a husband and family is fine, but it’s nice to have friends when you go through something like this. It’s very difficult. My girlfriend . . . said “I don’t know what I’d do if I didn’t have you, somebody to support me outside the family. You talk about things differently.”

Peer groups are usually comprised of people of the same age, status, or ability. However, the “real peers” Alice refers to are a new category of peer group in which breast cancer is the genuine equalizer that unites women beyond the usual status characteristics. Everyone agreed that other “survivors” were the only people who could truly understand their experiences.

Social support has been shown to improve health outcomes for people with cancer (Hurdle, 2001; Neuling & Winefield, 1998; Sheinfeld, 1993). Having “been there” allows a person to understand and feel what another person is feeling, not in a physical sense, but in an emotional sense. To empathize means to “put yourself in someone else’s shoes.” As women are socialized into their gender identities, they are trained in empathy in order to have a greater appreciation for what others, particularly loved ones, are experiencing. This helps them to better understand another person’s situation, perspective, and problems, i.e., to be better caregivers. It is not surprising then, that women with breast cancer seek empathy from other women (with breast cancer). As women, they are supposed to be empathetic and self-sacrificing, but to cope with breast cancer they need to break with these gender norms to focus on their own needs. By giving back empathy to other survivors, women with breast cancer are able to get empathy for themselves. Thus, giving back serves to reinforce and reconstruct their identities as women.

As women expand their social networks following a breast cancer diagnosis, “real peers” comprise the bulk of these new relationships. Darlene explained that she “would never have had a chance to meet these kinds of people during her everyday life . . . living out in the country and working in a cafeteria . . . But, they would call me, or I would call them when I was upset.” Breast cancer gave Darlene a reason develop ties with people she would not

have otherwise. Similarly, Roslyn said, “I talk to people now. I did not talk to people before I was diagnosed and I’ve been working in [the same place] for 23 years . . . People every day . . . come to talk to me about it.” In talking to a new group of people, whether it is through loose affiliations or through a formalized support group setting, participants identify with a collective identity or a shared sense of “we” anchored in what is perceived to be shared attributes and experiences (Castells, 1997; Jasper & Polletta, 2001). Patricia said: “A woman [who was recently diagnosed] came up to me yesterday, and she just sobbed and sobbed and sobbed, saying ‘I don’t think I can do this. You’re the only person who even has a rough idea of what I’m thinking.’”

The shared perceptions and feelings of a common experience motivated participants to interact with each other in the name of breast cancer survivorship and offered opportunities to transform their identities as a collectivity. Kathleen is a six-year survivor who said, “There’s a comfort in knowing that you’re not alone. You can be brave in a group of people. You . . . support each other through trials and celebrate . . . the good things. You might also learn . . . from people who have been there . . . if you have to face some of those things, it is not alien territory.” When discussing the support group she went to during chemotherapy, she went on to say,

Sharing experiences [and] feelings helped me. One woman . . . had a really good handle on things. She had cancer three times—three different kinds of cancer . . . I gained so much from listening to her, and being able to converse. At the group, we use each other as a sounding board.

With regularity, respondents described a different quality of relationships with other breast cancer survivors. Although interconnected with their identities as women, mothers, workers, neighbors, family members, and so on, the emergence of the collective identity - breast cancer survivor - was reinforced within the “sounding board” dimension of these new friendships, as women received constant feedback and reassurance.

As social ties among real peers strengthen so does the survivor identity, and those once regarded with affection and trust may not be considered peers after diagnosis. Kathleen described how some of her friends simply “dropped out of [her] life” a few years after her diagnosis. She said, “They weren’t really a lot of support . . . they really didn’t know how to deal with the cancer.” Likewise, Justine said, “Some friends have kind of pulled back. They don’t ask. They don’t want to hear any more . . . and you have to try and gauge their needs so you don’t say things that are offensive.” Participants had a hard time sharing their experiences with those who were not real peers, and they set boundaries on their relationships to manage their needs. Due in part to the strong societal beliefs about empathy as women’s domain and collective notions about the role that breast cancer should have in their lives, many women were compelled to forge relationships with other female survivors.

Conclusion

Gendered identities shape breast cancer survivors’ perceptions of their care needs, how these women reconstruct their identities and self-presentation to manage their needs, and ultimately how they make use of the illness to recast themselves as nurturers within the broader collectivity of breast cancer survivors. These findings are consistent with prior research on the gendered organization of care work and the association between gender and caring identities. However, this research demonstrates that the internalization of gender norms extends beyond the organization of care work to constrain women’s health protective

behaviors and feelings of entitlement to access care. Additionally, focusing on breast cancer as a case makes visible how illness itself can be gendered, further intensifying the impact of gendered social scripts on women and influencing their perceptions and coping strategies.

This research highlights the importance of the specificity of health contexts in shaping women's sense of empowerment and constraint when negotiating their identities as women to cope with illness. While I expected there to be significant differences among the three groups of women I interviewed, I did not find them with respect to the focus of this paper. Even women who were unaffiliated with breast cancer organizations had similar experiences stemming from their identities as women and the meaning of survivorship in their lives. Women with breast cancer as a group are faced with the contradictory cultural meanings of the pink ribbon and idealized representations of survivorship, the role of social support in improving their health and quality of life, and their identities as women. Through their experiences with breast cancer women confront these incongruities on a regular basis, requiring them routinely to re-conceptualize themselves both as authentic women and as breast cancer survivors. To do so, women forge relationships with other breast cancer survivors, provide information and practical support, share "their stories," and empathize with those who, they believe, understand their experiences. Much of this support is loosely defined and loosely constructed, sometimes taking place within formal settings such as support groups, but more often within the informal contexts of women's lives.

In this research I address the complexity of women's experiences when dealing with chronic illness and the impact of gender in shaping women's responses to it. While a full discourse analysis was beyond the scope of this paper, the findings also suggest that gender plays an important role in the narration of illness. Additional research is needed into the language women and men use to speak about illness and assign it meaning. Secondly, to more fully understand how social context and normative expectations like caring and gender contribute to a person's power to make the most of social and personal characteristics when they are ill, it is crucial for in-depth examination of women's and men's experiences within the contexts of their lives and the specific illnesses they face. For example, more research is needed about how women with chronic illness balance their needs with the needs of others to maintain a focus on themselves. Finally, more research is needed into the comparative responses to illness between men and women. Would masculinity play as vital role in men's responses to prostate cancer, for example, as it does for women with breast cancer? Certainly there are major differences in the progression and outcomes of these two types of cancer. Prostate cancer has a significantly higher survival rate, fewer instances of recurrence,¹ and includes deferred treatment or "watchful waiting" as a viable treatment option for many men over age 50 (Scholz, 2003). More importantly, it would be difficult to find a parallel to breast cancer in terms of its public attention, community position, and its particular history - despite the fact that in 2004 September was declared "National Prostate Awareness Month" and research funding for prostate cancer has increased in the past five years but remains at 54% of the funding allocated for breast cancer.

I suspect that there is no illness among men that occupies a similar position to the clearly gendered cultural context of breast cancer, which has provided a sense of collective identity that is politically and personally critical. Draped in the pink ribbon as the primary symbol

¹ One in six men will get prostate cancer. Approximately 90% of all prostate cancers are detected in the local and regional stages, and nearly 100% of men diagnosed at this stage will be disease-free after five years. By comparison, 1 in 8 women will get breast cancer, and only 23% of breast cancers are non-invasive. Of the 77% of women with invasive breast cancer, 88% are alive at five years; 80% are alive at 10 years, and 60% are alive at 20 years (ACS, 2006).

of breast cancer and the breast cancer movement, the collective survivor identity has been crucial in bolstering public awareness campaigns and marking breast cancer as a public issue. Many of the successes of the breast cancer movement are largely driven by this representative publicity. As an anchor for women diagnosed with breast cancer, this identity can offer comfort, support, and personal transformation. In this way the pinking (gendering) of breast cancer solidifies the social categories of “woman” and “breast cancer survivor” while simultaneously limiting the range of personal and social characteristics that should be available to women who are facing breast cancer, the disease. As women attempt to negotiate the competing gendered expectations within their everyday lives and relationships in the face of chronic illness, more and more women are resisting the cultural models given them to behold (or resist) the power of pink.

Appendix

Table 1 Sample characteristics

<i>Marital status</i>		<i>Age</i>	
Married	76.7% (n = 46)	Mean age (in years)	53.6
Divorced	11.7% (n = 7)	Age range	31–79
Widowed	5.0% (n = 3)		
Never married	6.7% (n = 4)		
<i>Race/Ethnicity</i>		<i># Children</i>	
White	90.0% (n = 54)	3 or more children	15.0% (n = 9)
African American	5.0% (n = 3)	1–2 Children	56.7% (n = 34)
Other	5.0% (n = 3)	0 Children	35.0% (n = 17)
<i>Educational attainment</i>		<i>Organizational affiliation</i>	
High school degree	16.6% (n = 10)	Education/Advocacy	30.0% (n = 18)
Some college	15.0% (n = 9)	Support groups	36.7% (n = 22)
Bachelor's degree	31.7% (n = 19)	Unaffiliated	33.3% (n = 20)
Beyond bachelor's	36.7% (n = 22)		
<i>Occupation</i>		<i># Years of survivorship</i>	
Service	11.7% (n = 7)	1 year	21.7% (n = 13)
Administrative	35.0% (n = 21)	2–4 years	41.7% (n = 25)
Education	35.0% (n = 17)	5 years	3.3% (n = 2)
Professional – Health	11.7% (n = 7)	6–9 years	20.0% (n = 12)
Professional – Other	13.3% (n = 8)	10 or more years	13.3% (n = 8)

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