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Emotion work: disclosing cancer

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Abstract

Introduction Breast cancer remains one of the leading causes of morbidity and mortality for all women in the US. Current research has focused on the psychological relationship and not the sociological relationship between emotions and the experience of breast cancer survivors. This paper focuses on the emotion work involved in self-disclosing a breast cancer diagnosis in a racially or ethnically diverse population.

Methods The participants (n=176) selected for this study were African American, Asian American, Latina, and Caucasian women who had been diagnosed with stages 0, I, or II breast cancer within the past 4 years. They completed an in-depth qualitative interview on self-disclosure and social support.

Findings The results indicate self-disclosing was done at a time when important decisions about treatment needed to be made. Different strategies for disclosure were used, all of which entailed emotion work. Respondents talked about the various elements of emotion work in the disclosure process including: managing others' worry, protecting and soothing others, and educating and instructing others. For many respondents, disclosure without calculating emotional management meant opening up to others which meant support and an increase in emotional resources.

Conclusions The findings in this paper have implications for women with breast cancer and demonstrate the need for women to be involved in honest disclosure and less emotional management of others' feelings. There is also a need for education about the nature of the cancer experience among people who are not well educated about the treatment and consequences of cancer. This need may be even stronger among racial and ethnic minorities.

Keywords Breast cancer · Self-disclosure · Emotion work · Social support

Introduction

Breast cancer remains one of the leading causes of morbidity and mortality for all women in the US [1]. In 2008, over 182,460 women were diagnosed with breast cancer and 40,480 women died from breast cancer [1]. Breast cancer is the most commonly diagnosed form of cancer for women regardless of ethnic background in this country [1]. A breast cancer diagnosis is often accompanied by fear of death, loss of control, isolation, hopelessness, and depression [13]. Current research has focused on the relationship between emotions and the experience of breast cancer survivors from psychological rather than sociological perspectives. A sociological perspective on these issues is important because it can illuminate how class, gender, age, and ethnicity influence the expression and display of emotion, the potential stress of emotion work, and its implications for physical and psychological well-being [17].

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Emotion work: breast cancer, self-disclosure, and support

In *The Managed Heart*, sociologist Arlie Hochschild states that women are "emotion managers" [23]. Ultimately, the aim of emotion work is to elicit feelings in others and to maintain one's own social roles and memberships by adhering to "feeling" norms and expectations. Women do the majority of the emotion work in their families and are often guided by "feeling" norms of kindness, cheerfulness, and compassion [25]. There is a growing body of literature on how women provide and support the bulk of unpaid emotional work within their intimate relationships and families [12, 24]. They are the glue that holds families together, and they are responsible for bringing family members together and for the emotional caretaking of others [12].

The fears of burdening family and friends with their illness seem to be a major concern among breast cancer patients [2, 3, 26]. The literature indicates that breast cancer patients' primary concern is burdening their families emotionally with their illness [2, 3, 11, 39]. While women do not want to worry their families, at the same time many also feel they would have liked to have disclosed in order to obtain support, and the failure to disclose has meant having less emotional support to get through diagnosis and treatment [2, 3]. Previous research on breast cancer survivors has shown that failure to disclose is associated with less social support, more unsupportive interactions, and decreased levels of emotional well-being [28]. In a study of 299 breast cancer patients conducted by Henderson et al. [22], 7% reported no disclosure other than to a spouse or doctor, and 20–30% reported not disclosing to specific networks of friends and family members. The investigators found that willingness to disclose appeared to be based on attitudes about disclosure [22]. Most participants had no difficulties telling others about their illness. Those who were more optimistic were willing to disclose because they anticipated that with such disclosures they would receive support [22]. Optimism and the perception that cancer would spur personal growth led some women to more disclosure and sharing of their breast cancer diagnosis than others [22]. The findings of these studies have limitation in that 90% of the sample was Caucasian and well educated and, therefore, does not give us information on what disclosure might be like for women from diverse racial or ethnic backgrounds and educational levels.

Disclosure: managing emotions

Self-disclosure involves expressing verbally to others personal information about oneself, such as a breast cancer diagnosis to others [11]. Although emotional expression about one's diagnosis has been shown to reap psychological benefits [6], decisions to disclose can be hampered by stigma and fear around breast cancer. Emotional work and disclosure about illness inherently involves risk and vulnerability [23]; it requires thinking about how individuals will react emotionally to the communication and often results in the discloser feeling a need to anticipate and find ways to manage the emotions of others. Telling others about illness takes emotional resources and opens one up to vulnerability, scrutiny, and possibly rejection.

Paradoxically, disclosure is also required in order to enlist and secure support. Often, this task can be emotionally taxing. According to sociologist Kathy Charmaz [9], the dilemma of disease disclosure is often predicated by what content about the illness the patient wants to have disclosed. Disclosure has emotional consequences such as strained relationships, inability to handle the responses of others, and loss of control and autonomy. According to Charmaz, reluctance about disclosure revolves around the need to maintain control over one's identity, i.e., the need to remain independent and to protect one's self. Charmaz discusses two forms of disclosure, one that is protective and another that is spontaneous. Spontaneous disclosures do not involve controlling what is said but instead involves freely expressing oneself. On the other hand, protective disclosure involves more conscious emotional calculations, providing information without disclosing one's vulnerable emotions, thereby separating the information from the emotion and reducing its threat. In addition, informing can sometimes be used to galvanize attention to an issue or problem, a process that Charmaz calls "strategic announcing." Protective disclosures such as informing and strategic announcing are void of emotions and ultimately "limit the reality of illness to self and others" [9].

Women tend to be more involved in the emotional work of disclosing about illness and health than their male counterparts. Emotional work among women and their families has often been overlooked in the midst of a healthcare crisis because emotional involvement is regularly assumed to be a gendered duty, automatically fulfilled as part of being a daughter, sister, or mother. Recent research among prostate cancer patients has shown that the men with the condition did not choose to do the emotional work of disclosing their illness to family and friends; rather, their female partners take it upon themselves to share with others their partner's illness [21], suggesting a highly gendered division of labor in the emotional work of disclosing illness, even when the illness is someone else's.

Disclosure: managing fear around breast cancer

Even with increasing information about surviving breast cancer, many women still carry beliefs and ideas about cancer, and it is often associated with contagion and death [34]. Attitudes and culturally specific feeling norms around breast cancer, illness, and vulnerability play an important part in the self-disclosure process for women. Among prostate cancer, patients' decisions to limit self-disclosure were constrained by stigma, fear of burdening others, feeling that they did not need help, and minimization of both the illness and the need for support [22]. Previous research on Asian American women and disclosure of HIV status has shown that concerns about disclosing typically include fear of stigma, of being perceived as a burden, and of discrimination [10].

Often, one of the difficulties for those diagnosed with a stigmatic condition is managing the tensions generated through social interaction and subsequently the need to manage the impressions of others. In such social and emotionally charged interactions, there is a potential for avoidance, rejection, and withdrawal by either party. According to Erving Goffman stigma is a condition in which the person is viewed as "culturally unacceptable" and is often associated with shame and marginalization. Goffman associates stigma with difference and disapproving attributes [19]. He categorizes stigma into different three types: (1) physical abnormalities, (2) a character flaw, and (3) a condition can be passed onto future generations. Breast cancer can easily be seen as a stigmatic condition. Because of the treatment side effects associated with breast cancer such as the loss of hair due to chemotherapy and the loss and scarring of the breast due to a lumpectomy or mastectomy a diagnosis of breast cancer can be highly stigmatizing because of the bodily changes involved as a result of treatment. Moreover, the perception that cancer can be prevented through a healthy lifestyle can further add to shaming of those diagnosed. In addition, the perception that cancer is associated with immediate death and that it can be genetically linked to other family members can further make breast cancer a stigmatizing condition.

The degree of stigma regarding breast cancer varies across different ethnic backgrounds, educational backgrounds, age and socioeconomic status. The types of stigma may also differ across different age and racial or ethnic groups. Younger women across all racial or ethnic groups experience more stigma regarding breast cancer, femininity, and sexuality [5, 14]. Younger women are often labeled as "too young" to get breast cancer and, therefore, stigmatized as not normal [14]. On the other hand, many African Americans fear breast cancer as it carries meanings associated with immediate death [31]. Recently arrived Latina and Chinese immigrants may view breast cancer as contagious, terminal, and caused by immoral behavior [3, 4, 38, 41, 42]. Immigrants with limited English ability and those with less education may perceive breast cancer as a death sentence rather than a condition that is treatable [3, 4, 38, 41, 42].

This paper focuses on the emotion work involved in self-disclosing a breast cancer diagnosis among Caucasian, African American, Latina, and Asian American women. This paper is part of a larger study that is examining longitudinally the quality of life and social support of breast cancer survivors from diverse backgrounds. To our knowledge, there are no studies that comparatively and qualitatively examine how breast cancer survivors self-disclose their illness. This paper contributes to the literature on the sociology of emotions and the sociology of health and illness by providing information on when and to whom breast cancer survivors disclose their diagnoses and how those disclosure strategies influence the support they subsequently receive.

Methods

Participants

Procedures

Participants were recruited through the University of California, San Francisco Comprehensive Cancer Center Clinic, San Francisco Bay Area breast cancer organizations and the Northern California Cancer Registry. To be eligible for this study, the participant needed to: (1) have had a diagnosis of breast cancer (Stages 0, I, and II) within the past 4 years, (2) have completed primary treatment, and (3) speak and write English, Cantonese, or Spanish. An initial qualitative in-depth interview was conducted, and quantitative surveys were administered.

Interviews were conducted at the participant's home or in a public place convenient to the respondent. Each tape-recorded interview lasted approximately 1.5 to 2 h. Interviews were conducted in English, Chinese, or Spanish depending on each subject's preference. The open-ended questions were designed by the research investigators to understand the role of supportive networks in helping women get through diagnosis and treatment and survivorship. Participants were asked a series of open-ended questions on the how one told others about their breast cancer diagnosis, reactions of others, definition and types of social support used at diagnosis during treatment and after treatment, and the psychosocial impact of breast cancer. The audiotapes were then transcribed and translated if necessary (Table 1).

Analysis

This paper follows a grounded theory approach with the focus on a core category of self-disclosure. Following the procedures for grounded theory analysis [35, 36], the inves-

Table 1 Background of participants

	N=176 (%)
Race/Ethnicity	
White	54 (30.7)
Latina	25 (14.2)
African American	44 (25.0)
Asian American	52 (29.5)
Mixed	1 (0.6)
Place of birth	
US born	118 (67.0)
Born outside the USA	58 (33.0)
Months since diagnosis (mean)	4–48 (23.3)
Age range (mean)	31–83 (57.0)
Stage of breast cancer	
Stage I	85 (48.3)
Stage II	81 (46.0)
Stage 0	10 (5.7)

tigators first utilized open coding to identify "categories, properties, and dimensional locations" based on the emerging themes found repeatedly throughout the data [35, 36]. The codes that emerged were not forced or fixed. Transcripts were independently reviewed by the research team for commonalities and differences. Next, the transcripts were coded for specific themes within the general category of disclosure that appeared repeatedly in the text. Coding was iterative and refinements were made based on our discussions until we reached a consensus on a final definition of each code. Finally, text within a coding category was evaluated to determine whether it accurately fit the definition of the code. The investigators then used axial coding by ways of making relationships between the major categories and subcategories. This was developed and used to give structure and organization to our emerging analysis, and was compared to the key analytic ideas about self-disclosure and illness found in the sociological literature. Thus, verification of the accuracy of the coding scheme (conceptual categories, their definitions, and observations coded within each category) occurred using both inductive and deductive methods [35, 36].

Findings

Managing emotions of self: utilizing different strategies to tell others

Motivated by not wanting to make others feel vulnerable, managing emotions during a disclosure process meant restraining and controlling one's true feelings. In fact, much thought went into how best to manage one's feelings and disclosure to others. As a result, telling someone, especially a family member, they had breast cancer was an extremely difficult process. Many of the respondents talked about their plans of how they told others, including shielding their own emotions. They were particularly concerned about how others might react to their diagnosis, and they wanted to take care of the sadness, anxiety, fear, and worry which were often the results of the diagnosis. Respondents often told spouses and partners first if they were involved in intimate relationships and then their children. After the initial shock, they then told friends, extended family members, coworkers and employers, and if relevant, members of their religious and spiritual communities. Often, how and when they told others also indicated if and how they would receive social support.

Depending on the quality and character of the relationship, respondents used different strategies such as sitting down with family for a strategy session on what to do or telling coworkers in a humorous way. A 55-year-old white female with Stage II breast cancer talked about the difficulties of telling family:

> My daughter got upset, hysterical, and quit her full-time job with benefits. So at that point I decided I'm fixing this thing anyway. There is no way I am telling anyone else, any of my family members until this thing's fixed. I'm going to tell them, "Guess what, I had cancer. I fixed it." So, there you have it. I did tell—I did talk to my two older boys. They would've been age 13 and 15. And uh I basically told them, "Look mom has cancer. She's going to fix it." And they accepted that and they were a little worried, but not so much.

This respondent illustrated the devastation that followed with her initial disclosure to her family and how she managed the emotional reactions of subsequent disclosures (to her sons) by adopting an instrumental, determined, and focused "fix-it" practical strategy.

Self-disclosure involved managing the emotions of others, which required very different strategies, timing, and language. Women in most societies tend to be the caregivers of others [7, 8]. This includes anticipating and taking care of others' emotional health sometimes to the detriment of their own health. Women are generally caught in the middle of family relationships, and when deciding to tell others their breast cancer diagnosis, they had to spend time anticipating, thinking, and caring about the emotions of those they told. For many of these women, it was enough having to deal with the information of learning one has breast cancer and the need to make important decisions about treatment. Telling others became an added responsibility. A 50-year-old African American woman with Stage II breast cancer discusses the emotional work of telling others:

> It's difficult to just like say it but you know again I didn't want—I felt like I had so much emotional stuff to do myself and this is—this had a lot to do with who I told and when I told to. I had so much to deal with myself and I—I felt like I couldn't do everybody else's emotions. Do you know what I mean?

This participant recognized how much energy disclosure required of her, and she also identified her limitations. She, like many other participants, felt it was important to take care of herself first and then others second. However, like many respondents, she experienced tension in her desire to focus emotionally on herself, when so many cultural and social messages convey to women that the caretaking of others' emotions is a primary responsibility and priority for them.

Disclosure with calculated emotional management

Although managing emotions for most of the participants was a way for them to protect others, several women in this study managed their own vulnerable emotions to protect themselves from disappointment by others. Disappointment by others was often about the fear of being labeled a dependent, the judgment of others who would blame her for having breast cancer, and the terror of others who feared breast cancer (see Table 2). As a result, emotions were limited in disclosures of cancer in several ways, including (1) managing worry of others, (2) protecting and soothing others, and (3) educating and instructing others when telling one had cancer.

Emotion work: managing others' worry

Telling family members was often the most difficult task that survivors faced after learning about their cancer. Many of the respondents did eventually tell aging parents and siblings, but many women also hesitated or deliberately delayed telling specific family members for concerns over worrying particular family members. In order not to worry aging parents and also still appear capable, autonomous, and in control, some participants waited until after initial treatment to disclose. A Chinese immigrant with Stage I disease decided to tell her frail, aging mother after she had recuperated from her surgery:

> Because I know my mom, she will worry about it. Even if I had I told her before the surgery, there is nothing she can do to help. She would just worry. There was no need to tell her. However, I did tell her after one week, because I can walk, I can care for myself. I didn't need to depend on others.

This participant reasoned that disclosure prior to surgery would only cause emotional anguish for her mother, who—importantly—was not in a position to offer help. Moreover, some hesitated to tell specific aspects of their diagnosis or some waited until after their surgery to tell certain family members because they anticipated specific reactions like fear and panic that would further require energy and effort to manage, taking away precious emotional resources from participants who needed to focus on themselves and getting through treatment.

In some cases, when participants anticipated fear or panic or worry, delaying disclosure and not providing information was a way for participants to maintain power and control over the situation. A 54-year-old African American woman with Stage II breast cancer stated that she could not tell her mom:

> I didn't tell her until after my surgery. I just told her I had a little surgery but everything had went very well and after that I had went back to the doctor and they had the pathology report and all areas were free of cancer.

Women were managing others' worry by deliberately delaying telling a cancer diagnosis until they were free of cancer or less dependent on others.

Table 2 Types of emotion work: disclosure of cancer

Types of emotion work	How emotion work is done?
Managing worry of others	Delay or refrain from telling others
Managing shock and terror	Protect and soothe others from cancer
Managing misinformation of others	Educate and instruct others

Emotion work: protecting and soothing others

Younger women across all racial or ethnic backgrounds found themselves doing more of this emotion work of soothing others from their news including spouses or partners, young children, and aging parents than did older women. Because of the anticipated discomfort that others might feel about cancer, the emotional work involved in such a disclosure consisted of trying to minimize the terror and make the diagnosis less threatening to others. A 45-year-old Caucasian woman with stage II breast cancer stated: "What the f**k if I'm not fine? They are going to be crushed. You know so they needed to be fine on all levels and I had to play that role."

Disclosing breast cancer was extremely well planned to ensure that others would not experience the terror of the news. For some women, there was no family history of breast cancer in their family, and they had to prepare for the shock of such a disclosure from others, while others may have a heightened sense of anxiety and doom because of family members who may have died due to breast cancer.

A majority of the respondents discussed that they had to simply inform and limit their emotions so they could be prepared for the emotional devastation of others that followed. Often, older parents were afraid, anxious, and sad, and these women assumed the familial role of emotional caretaker (in addition to simultaneously playing the role of patient in their medical interactions) to comfort and reassure their parents that they would be okay. Women would often work to frame their diagnosis in the most nonthreatening way possible. A 50-year-old Caucasian woman with Stage I breast cancer stated:

> It was so hard to tell my parents. It was hard for them to hear that their child had cancer....I had to calm myself down before I could call my parents....My father said I could tell you were trying to take care of my feelings more than your own. It was so touching and insightful of him because it was true.

A 39-year-old Latina with Stage II breast cancer echoed similar thoughts about her mother:

> She freaked out. She had to be sedated when she found out....I constantly feel I have to protect my mother from this disease and protect her from bad days...she is more freaked out than anyone else is. She's much more freaked out than I am.

Women wanted their families not to fall apart; therefore, many women worked to ensure that how they told their diagnosis was framed in the most positive fashion possible. A 35-year-old South Asian woman with Stage II breast cancer stated how she told her mother:

> I was always on the positive side, I would always tell her, look at these people in Iraq…or stories of people in freak accidents. So I kind of told them these things to make them feel people better. So I ended up having to take care of them more than they were taking care of me.

Although the respondents are the ones diagnosed with breast cancer, many of the respondents felt obligated to provide comfort and reassurance to others, in some cases, to "parent the parents" and to suppress their emotions in telling others. Women engaged in familiar gendered strategies of soothing, reassuring, and consoling others. For many of the respondents, this was difficult and depleting emotion work and came at a time when they were dealing with decisions about treatment and their own fears and uncertainties about the future.

Emotion work: educating and instructing others

Emotions were also limited when women sought to inform and educate others as they disclosed. African Americans, Asian, and Latina immigrants most often discussed the need to manage or minimize the negative association with breast cancer and the consistent need to educate and inform others that cancer was treatable and beatable. A 49-year-old Mexican immigrant with Stage I breast cancer talked about how others viewed cancer as contagious and her need to educate:

> The friend I have, that I told you about, well she sort of couldn't handle it, she was shocked when she heard I had cancer. She thought that she was going to get it from me, it is inexcusable, but I explained it to her that cancer is just not contagious like that.

Although the current mainstream image is that breast cancer is "treatable and beatable" [32, 33], among many African Americans, Asian, and Latina immigrant respondents, there still existed misconceptions, heightened fears, and taboos about openly discussing the breast cancer. A 47-year-old immigrant from El Salvador with Stage II breast cancer stated that those around her viewed cancer as something she would die from immediately:

> They thought I was going to die. Some people tried to avoid me. They don't know. They don't know how to reach you. They don't know what to tell you. So for them, you having breast cancer is a death sentence. So it's considered you poor thing, you are going to die you know. If you don't die now, you will die tomorrow.

She continued saying that many in her social network were not conscious of the fact that women can live and survive breast cancer and die later in life from a different condition.

African American, Asian, and Latina immigrants were most often also in the role of instructing others about how they could best support the respondent. Many found that they had to instruct and inform others that they were not going to die and to remain calm. They felt the need to restrain their emotions and make sure that their families understood that they would survive. A 48-year-old African American female with Stage I breast cancer described her situation:

> They were shocked but then they took it worse than me. Because you know you hear the word cancer and (you found out) huh, it's a death sentence. And I kept trying to explain it to them because my husband cried I don't know how many times. And I kept trying, "Honey, it's Stage I. I'll be ok. It's not going to my lymph node, so I'll be ok."

A 47-year-old African American with Stage II breast cancer stated:

> I didn't want nobody to cry. I didn't want anybody to make a big old scene like I was gonna die. So I was very choosy about who I told and before I said it, I told them do not cry, do not hug me and you know act like they were not going to see me again. A lot of people react that way because I was always taught that cancer is deadly and it's an immediate death.

A 52-year-old Filipina immigrant with Stage I breast cancer discussed how those around her felt her diagnosis meant that she would die soon. She stated, "a lot of people still have that negative thing, when someone says they have breast cancer. Others might respond by saying, 'Oh I'm sorry you have breast cancer.'" She mentioned that when talking about cancer, death is in the back of everyone's mind. She discussed how relatives reacted by embracing her in fear that she would die soon. Her response to other Filipina immigrants was that she was not going to die and that early stage breast cancer was treatable: "I'm not dying, you know I'm going to my treatment."

Several respondents not only wanted their family to know that they would be fine but also strategically felt that they needed to use the diagnosis as an opportunity to discuss with others the importance of caring for their own bodies. Some women used the announcement of their breast cancer diagnosis as a vehicle for emphasizing the importance of self-care and early detection and exhorting loved ones to practice vigilance. Hence, disclosure of their illness became strategic and was a way that they could educate other women family members about the issue of breast cancer. A 68-year-old Filipina immigrant with Stage II breast cancer discussed how difficult it was to tell her family and how she used her disclosure to let female members know the importance of getting screened.

> The hardest part was telling my family. Because usually um I'm sort of like the—the caregiver, and so um I was trying to figure out how to tell them. So what I did is I wrote a letter, I Xeroxed it. I told them what—what it was, Stage I. I told them how supportive the family was—you know how the kids were. That I was going to move along and do all the treatment. But I just wanted them to know because I wanted them to tell their children, especially the females, to make sure that they got mammograms.

Disclosure without calculated emotional management

Breast cancer forced many of the participants to reveal a level of vulnerability and potential dependency in a public and undesirable way. Cancer disrupted all those invisible responsibilities and work that women perform to keep things going in families and relationships. Prior to their diagnosis, many of these women led independent busy lives. Cancer had the potential to make them dependent on others in ways that felt unfamiliar or heightened their sense of vulnerability and anxiety. A 49-year-old African American woman diagnosed with Stage II breast cancer tried to appear strong but stated:

> That was tearing me up. "Oh I'm OK, Oh I'm fine." Even though I wasn't. Then I finally just told them I don't feel good. And I stopped pretending, because that was tearing me apart trying to be physically strong. I couldn't be emotionally strong. I couldn't do both.

Hochschild, in the context of work relationships, discussed how people become actively alienated from themselves when they must project certain emotions publicly but feel entirely different emotions internally [23]. In the case of the participant above, "pretending" to be emotionally strong was her initial and primary strategy but that failed when she could no longer reconcile the external, projected, self of strength at the expense of her integrity and authentic feelings, which differed considerably.

In our sample, we noticed that the situation of breast cancer for many women created an opportunity to increase their emotional capital [29]. When women disclosed honestly about how they felt without calculated strategies to limit or manage the emotions of others, their disclosure allowed them to invest more deeply in themselves and their relationships. In fact, we found that women who did not manage the feelings of others at the expense of their own feelings and who openly disclosed to others were often met with unexpected support. Increased emotional capital often happened when survivors honestly disclosed their vulnerable feelings, which meant that they did not have to be alone during this critical time in their lives.

Those who self-disclosed to others also needed to be willing to receive support—sometimes in surprising ways and from unexpected corners. Often, they were surprised by how others, such as family members, friends, and coworkers, reacted with strength, compassion, and support. Spontaneous self-disclosing to others meant enlisting others for both emotional and tangible forms of support. Spontaneously disclosing to one's personal network often meant that there was a response (sometimes a flood) of support by others. Friends, acquaintances, and family felt compelled to provide some type of support. For many, spontaneous self-disclosures of their breast cancer brought unexpected sources of support, strengthened existing ties with others and created new friendships with others. A Caucasian 45-year-old Stage II breast cancer survivor stated her surprise at the support she received:

> Never—I mean I had never in my life, it brought me to my knees in gratitude, in prayer, in thanks, in the

> human spirit and the generosity and what people did for me and my children for that year. Did I see anything negative? No. I had strangers—I mean I became friends with strangers who are now close friends of mine. People I didn't know—I'm like, "Oh yeah I think I've heard of you,"—who showed up at my door with meals, who drove my children places, who uh sent their housekeepers over to clean my house, who gave me airline tickets to fly where I needed to go to my sister's side. I mean yeah. Nothing negative.

Many respondents talked about the need to just "put it out there" and that once they disclosed, without investing much time in managing the feelings of others, people automatically showed concern and gave back anyway they could. An African American Stage II survivor discussed what it was like to finally talk about her diagnosis:

> When you're closed up or just in a knot and thinking' that you're the only one that has this ugly disease you need to talk about it. Because it'll drive you, it'll drive you to just, when I first heard it, and I, I didn't I didn't think at all. I didn't think. All I wanted to do was take some pills. I just wanted to go to sleep. I wanted to put myself out of my misery. But as the days kept going, you know, it goes behind you. So, it's the initial hearing of the word, the big ugly "C" word, and start doing. Don't stay closed up in the bed in the room. Talk about it. And you know, you would be surprised how many people will call you and let you know, you have our support. What do you want me to do? Blah, blah, blah ya' know? And I had that. I still get it to this day.

As one respondent stated, "99% of people are caring people." Because of their breast cancer, almost all of the respondents reported that they experienced support that they had not expected to receive. The implications of telling someone signaled the opportunity for reciprocity: that help would be enlisted and received. Additionally, the experience of disclosing often allowed these participants to see (sometimes consciously for the first time) how large their social networks actually were. It defied and challenged the American individualist notion of self-reliance at all costs and the assumption that survivors wanted isolation and privacy. A 47-year-old Mexican American woman with Stage II breast cancer talked about how she was surprised that acquaintances she did not know well offered support.

> It was shocking to find out that people care. The lady next door lost a parent to breast cancer and was so sorry to hear about my breast cancer. She would offer food and would just come by. Oh my God, it was just amazing. I've had bad neighbors in the past throughout my adult life, and so it was shocking to see that people can be nice.

Respondents found that most individuals were generally sympathetic and open to hearing about it. For the most part, respondents discussed how their families and friends did not turn away. Rather, many shared their experiences of someone that they knew having breast cancer.

Often, the crisis of a diagnosis brought friendships closer. Survivors realized that there were friends that they had never tapped into that they could rely on in this time of crisis. Often, the support received from friends was overwhelming and unanticipated. A Caucasian 54-year-old woman with Stage II breast cancer talked about the support she received:

> My friends kept telling me, "You have to let us do things for you because that makes us feel better." And so it was like I just made it a rule. Whatever anybody offers, let them do it even—I mean I got some really bizarre looking hats [laughs] but it's OK because—or my mom sent me all this stuff you know. And it was like I just would take everything and smile because I knew that you know it was like really important for them to do something so. I found a use for everything.

When women did not have to worry about managing other people's feelings, they focused on themselves, which sometimes was a revolutionary act for some women. The ability to focus on oneself was a process that defied traditional gendered norms of emotions and caretaking. And for many women, a breast cancer diagnosis meant investing in their emotional resources by interacting with loved ones who "showed up" and provided the support that they needed, which intensified and strengthened intimate relationships with family, spouses, and friends.

Although for the most part, women in this study who spontaneously disclosed received support, there were many who did not face engagement by others. Rather, they experienced a heightened, anxious response that was not always met with support. Several women discussed that there were some in their network that just could not take it and were not emotionally prepared for their disclosure of breast cancer. Due to fear, discomfort, other competing issues, or just being unaware of how to help a friend, partner, or coworker get through breast cancer, a few respondents discussed friends and family who drifted or stayed away. A Caucasian 50-year-old with Stage II breast cancer stated that after her disclosure her friends "they dropped off the face of the earth."

The withdrawal of friends and family meant that there was no support given to them at a critical time in their lives. A 62-year-old African American woman with Stage I breast cancer said that in her network people withdrew: "They didn't understand what I was going through during treatment. Some people called and said they would be there, but they didn't know what to do." Due to fear and the lack of education of the cancer experience, some respondents discussed how others were afraid. A 54-year-old African American with Stage II breast cancer stated that friends were so afraid and unable to provide support: "they stayed away from me like I had the plague My real feelings were that they thought I was going to die and they were detaching themselves." A few respondents discussed how others because of fear or discomfort responded without emotion and minimized their diagnosis.

The purpose of this paper was to qualitatively examine the emotion work involved in self-disclosing a breast cancer diagnosis to family, friends, and acquaintances. As the findings of this paper demonstrate, disclosure of a breast cancer diagnosis to others is a difficult task, but it can also be an opportunity to strengthen and intensify the emotional capital in one's family and wider social network. Women do much of the emotion work in families, and when faced with a breast cancer diagnosis, their role shifts to involve managing the feelings of others at precisely the time when they need support themselves. Previous work on self-disclosure has demonstrated that it may have cultural, historical, and sociological contexts [18]. We argue that the way women disclose may be related to cultural and gendered expectations and reflect changing social conditions in which the disclosure of cancer has become more acceptable. At the same time, the way disclosure is made can subsequently be used as opportunity to enlist and receive social support.

Women are socialized to be responsible for others in families, especially for those that are old and frail and the young [12]. According to feminist scholars [12], women are culturally expected to care for others and to be involved in "attentive love." They are trained to care and to be concerned about the feelings of others over and above their own feelings and concerns. As a result, disclosing to others one's breast cancer has the potential to affect others emotional well-being. Some women perceive disclosure as another responsibility to manage the feelings of others, while other women use disclosure as an opportunity to allow other people to focus on and support them. The disclosure of breast cancer presents women with a series of paradoxical and gendered choices: "how can I ask for help from others when I see myself primarily as an emotional caregiver/manager?" "How can I care for myself during this process, if it comes at the expense of caring for others?"

The findings of this study show that managing others' emotions was a part of their own managed disclosure. Disclosures to close family members such as mothers, sons, and daughters are often thoroughly thought out and anticipated in detail – including the timing of when and how to tell. These disclosures are protective and not necessarily told spontaneously, but are often strategically managed so others will not feel overwhelmed by their condition. Self-disclosure was also heavily influenced by varying perceptions of stigma including breast cancer being a death sentence. As a result, women expressed a strong need to not appear vulnerable and dependent and to educate others through the process. Managing emotions meant a way of managing their own emotions and feelings of vulnerability. Even when they must deal with their own breast cancer diagnosis, women are still the glue holding everything together and having to appear like they have everything under control especially to members in their families.

Past research has shown that when cancer strikes families, women manage the emotions of their entire family [30]. Prostate cancer patients have their female spouses available to do the emotions work of letting others know of their diagnosis [21]. Mothers of children with cancer not only do more physical labor in their care-work but they also do more emotional work than their male spouses [30]. At the same time, women involved in managing emotions for the benefit of others also experience high levels of emotional exhaustion, potential alienation from their own emotional selves, and emotional burn out [40]. Although women are socialized to care for others even during the face of breast cancer, a balance between caring for oneself and others is of often a tension that women must negotiate in order to get through diagnosis and treatment [37]. How a woman disclosed was often their first step towards taking care of themselves.

Paradoxically, spontaneous disclosures were sometimes met with unexpected help that followed. These disclosures were not managed to protect others from stigma or terror—but were free from holding back. With these spontaneous disclosures, respondents were surprised by the width and breadth of their social networks when such honest disclosure happened. They were surprised that others wanted to offer support. In the USA, there is an assumption that even during illness autonomy, privacy, individualism, and independence are valued [15, 16]. Even though the "American ideal" is about maintaining one's independence even in the face of illness, this study shows the benefits and opportunities of authenticity in disclosures and the interdependency, emotional strength, and support that followed these women who spontaneously disclosed. These spontaneous disclosures increased social networks and ultimately social support.

Involving and including others in one's illness may increase intimacy among friends and family. The sharing of emotional experiences made the illness experience accessible to others. By spontaneously disclosing to others, others were made more aware of a need and responded with social support. Several studies examining social networks, support, and breast cancer has shown that this having support is associated with better survival outcomes among women diagnosed with breast cancer [20, 27]. For a woman encountering a breast cancer diagnosis, an antecedent to being able to receive support is to tell others. However, there were a few women in this study, who after honestly disclosing, also encountered a dropping off of support and friendship. For these women disclosure can be viewed as a negative experience, however it can also be seen as "weeding out" the unsupportive people in their network. It can be viewed as "when you have cancer (or another serious illness) you find out who your friends really are". However, lack of support and/or withdrawal can result in anger, depression, and other negative emotions for the women who disclosed.

Some women were afraid of the reactions of others in their support system and, therefore, did not disclose their illness. Oftentimes, those who withdrew were uncomfortable and unaware of how they could engage and support a loved one through a breast cancer diagnosis and treatment. For these women, especially those in racial or ethnic minority communities, there might be a need for increased information on how others can support women through their cancer experience. This reflects the need among some people, especially those in racial/ethnic minority communities for information on cancer in general including survival rates and the issue of shame and stigma as well as how others can be supportive.

This study has some limitations. The women were interviewed up to 4 years after diagnosis (although the mean was 2 years) and the experience of support and disclosure may have changed throughout their cancer experience. Despite these limitations, the findings in this paper have sociological implications for women with breast cancer and demonstrate the need for women to be involved in honest disclosure and less emotional management of others' feelings. There is also a need for education about the nature of the cancer experience among people who are not well educated about the treatment and consequences of cancer. This need may be even stronger among racial and ethnic minorities. Future studies could examine the role of cancer knowledge among others and their reactions to disclosure of a cancer diagnosis.

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