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Gender and Sexual Labor Near the End of Life: Advanced Breast Cancer and Femininity Norms

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ABSTRACT

Feminist researchers have highlighted the increased hyper- and heterosexualization of breast cancer by drawing attention to the gendered dimensions of disease. In a set of interviews with women diagnosed with metastatic disease, I examined how participants labored to fulfill feminine gender and sexual ideals. Two themes were explored: *gender labor*, which included feeling fat and unattractive, and *sexual labor*, which included managing partners' sexual demands and sexual pain. This study builds on emergent feminist critiques that challenge expectations for a woman to be a "sexy cancer patient" and highlights how gender and sexual ideals continue to affect women negatively, even when they are extremely ill.

KEYWORDS

health; gender norms; body weight; sexuality; stage IV cancer

Advocates, researchers, and women with breast cancer have long argued that breast cancer and its treatments have amplified how femininity norms police women's bodies (Ehrenreich, 2001; Lorde, 1980; Rubin, Margolies, & Kaschak, 2014; Ussher, Perz, Gilbert, Wong, & Hobbs, 2012). Some have argued that breast cancer has, in fact, become a context in which "gender is both produced and policed, with the hyper- and heterosexualization of breast cancer now ubiquitous" (Rubin & Tanenbaum, 2011, p. 403). This critical perspective involves more than simply an argument about the sexualization of women's bodies; it also includes a critique of how breast cancer has become a site where women are expected to reclaim their femininity and their sexiness at the same time as they reclaim their health (Segal, 2012; Waples, 2014). These and other critiques of how women are expected to look and behave in illness contexts dovetail with broader feminist critiques of how femininity is policed for all women, both healthy and ill. Breast cancer, in this way, has become an important focal point for highlighting how gender norms and expectations for women's sexuality actively discipline women's bodies. Perhaps it is here—when women are extremely ill—that we can learn the most about the demands of femininity and (perhaps) be surprised anew about the costs of these demands.

Feminist researchers have highlighted several themes of contemporary cancer narratives that include, among other things, the imperative to be sexy, the imperative to have penetrative intercourse, and the conflation of feeling healthy and being sexually active (Perz, Ussher, & Gilbert, 2013; Segal, 2012; Ussher et al., 2012). Segal (2007, 2012), in particular, has highlighted how popular examples found in cancer memoirs, such as advice to wear lipstick to

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one's own mastectomy (Lucas, 2004) or images of a "crazy, sexy cancer patient" (Carr, 2007, p. 1), have fed on femininity narratives that demand women to be sexy at all times and under all conditions. This genre of self-help narrative has successfully redefined wearing lipstick in these cases, not as a capitulation to social demands but as evidence of women's empowerment and as an essential way to make oneself feel "better" and "healthier" because one is living and appearing successfully as a woman rather than as a sick person (see also Gibson, Lee, & Crabb, 2014). In this way, sex and sexiness (i.e., having sex and appearing that one wants to have sex) have become indicators of "good health" and, as a result, a necessary form of labor if one is to be legible as a patient who "fights for her health." Together, these insights have begun to foreground critical questions about the term *sexual health* and have encouraged researchers and patients alike to look more closely at when *good sex* is equated with *good health* (see also Diamond & Huebner, 2012; Tiefer, 1995; Waples, 2014).

The current study builds on these critical questions regarding femininity norms and breast cancer. Drawing on interviews with women diagnosed with metastatic breast cancer who were asked about their intimate lives, I explored how women spoke about their sexuality, their bodies, and their desires to be and not be sexually active. In the current analysis, I turned to women's descriptions of their sexual lives, both felt and enacted, as a way to understand further the thorny relationship between breast cancer and sex. To explore these issues, three areas of research are relevant: body image and breast cancer, sexual activity and cancer, and sexual pain. Within each of these areas, researchers have defined and used specific terms in exploring the impact of cancer on female sexuality. In addition, within each of these areas feminist researchers have encouraged a shift away from simply studying whether or not sexual activity has resumed and instead have argued for focused attention on questions of how, why, and under what conditions sexual contact, feelings, or activities do or do not occur.

Body image and cancer

Body image concerns have been documented in women diagnosed with cancer; indeed, hundreds of studies have shown significant relationships between body image and other indicators of overall well-being after diagnosis (e.g., Dahl, Reinertsen, Nesvold, Fosså, & Dahl, 2010). More specifically, femininity, body image, and body size have been found to be associated with aspects of sexual well-being for female cancer survivors, including their sexual functioning, sexual satisfaction, and sexual relationships (Boquiren et al., 2015; Vilhauer, 2008). Researchers have also found that several aspects of cancer and its treatments, including mastectomy (Fallbjörk, Rasmussen, Karlsson, & Salander, 2013), hair loss (Lemieux, Maunsell, & Provencher, 2008), and weight gain (Biglia et al., 2010) negatively affect women's sense of "feeling feminine."

This wide range of findings regarding femininity, body image, and well-being create a productive and somewhat troubling set of challenges for feminist researchers in the field. Namely, what is the relationship between documenting the importance of gender norms to women (e.g., the impact of hair loss) and the critical assessment of these same gendered norms, which continue to create imbalanced and punishing demands on women? How can feminist researchers both document the impact of these changes on women's sense of femininity and simultaneously work to criticize the very social systems that prioritize women's appearance as central to their well-being? These difficult questions animated the current study, as well as many feminist studies in the field of psycho-oncology (e.g., Parton, Ussher, & Perz, 2016; Rubin & Tanenbaum, 2011; Ussher et al., 2012).

It is important to note that women's body image has been traditionally assessed on a specific set of factors. For example, one of the most commonly used measures in breast cancer

research, the Breast Cancer–Specific Quality of Life Supplement (BR23; Sprangers et al., 1996) includes items such as "Have you been dissatisfied with your body?" and "Have you been feeling less feminine as a result of your disease or treatment?" Items such as these prioritize a particular form of femininity (one that is concerned with appearance), as well as create an implicit link between an individual's quality of life and her implied heterosexuality (see Rubin & Tanenbaum, 2011). With these critical perspectives in mind, it becomes clear that there is more to be understood about the range of ways that women struggle with feelings about their bodies and sexual experiences after cancer diagnosis and treatment. It remains to be seen, for example, what other dimensions might be important regarding body dissatisfaction and the impact of feeling less feminine on women.

Sexual activity and cancer

Cancer treatments, including surgery, radiation, and chemotherapy, often result in dramatic changes to patients' genitals and, as a result, their genital and sexual response (e.g., Cella & Fallowfield, 2008). Research on sexual outcomes related to these genital changes has often shown that sexual activities are negatively affected (see Gilbert, Ussher, & Perz, 2010, for a review). However, researchers often rely on frequency of intercourse and orgasm as primary indicators of post-treatment sexual function and satisfaction (e.g., Baser, Li, & Carter, 2012; see McClelland, 2012, for a discussion). In contrast, other researchers have argued that engaging in sexual intercourse may not be a woman's primary focus of sexual adjustment after diagnosis or treatment. For example, Flynn et al. (2011) found that individuals diagnosed with cancer viewed affectionate behavior (e.g., holding hands, kissing) on the same continuum as sexual activities involving genital contact.

Feminist scholars have increasingly critiqued the social pressure to participate in heterosexual coitus and have demanded models of sexual health that do not rely on intercourse as the indicator of sexual "success" (Ayling & Ussher, 2008; Fahs, 2014; Fahs & McClelland, 2016; Farrell & Cacchioni, 2012; McClelland, 2012; Vares, Potts, Gavey, & Grace, 2007). Ussher and colleagues (2012), for example, described how cancer patients and their partners made efforts to resist and renegotiate the "coital imperative," defined as those discourses that consistently describe penetrative intercourse as the primary form of sexual activity for heterosexual couples. In their study of men and women diagnosed with a range of cancer types and stages, Ussher et al. (2012) found that patients and their partners adopted a wide range of sexual interactions and were often able to resist "progressive" narratives of penetrative intercourse (i.e., that sex culminates in penetration) and to experience closeness and feelings of sexual satisfaction from a wide range of activities. In contrast, McClelland, Holland, and Griggs (2015a) found that, although a few women described resisting the coital imperative, many spoke about prioritizing vaginal intercourse and how they struggled to find and to support their own vaginal lubrication in an effort to maintain this type of sexual behavior after diagnosis and treatment for breast cancer.

The imperative of sex after cancer may drive women to what Cacchioni (2007) called "sex work," a term that describes the (largely invisible) effort and monitoring that women are expected to devote to managing their own and their partners' sexual desires and activities. This set of labors, she argued, sits within a larger matrix of "successful heterosexuality" in which women must continuously manage their sexual difficulties to be a successful heterosexual woman. A framework that acknowledges "sex work" as both pervasive and difficult to see necessitates that researchers examine both the micro-politics of sexual relationships and the institutionalized gender inequalities of power in which these relationships are embedded (Cacchioni, 2007).

Sexual pain and cancer

An additional aspect to consider is the role of sexual pain. Researchers have found that women's reports of painful penetrative intercourse are often associated with vaginal dryness and other genital changes that result from cancer and its treatments (Jensen et al., 2004; Ussher et al., 2012). However, the fact that pain during intercourse continues to be an issue for women may be because it reflects sexual practices that do not sufficiently address women's bodies and sexual needs. For example, in a study of women diagnosed with vulvodynia, Marriott and Thompson (2008) found that women prioritized their male partner's sexual enjoyment to the extent that they often participated in activities they found extremely painful. As one woman stated, "He used to say, am I hurting you? And I used to say no, and clench my teeth and think, actually I'm in agony here" (p. 251). More research is needed to understand patients' and their partners' investment in penetrative sex, even when this activity is experienced as extremely painful (Ayling & Ussher, 2008; Farrell & Cacchioni, 2012).

Much like the research regarding body image and sexual activity discussed above, research on sexual pain faces a set of challenges. Researchers and women themselves are faced with several competing interpretations of sexual pain: pain as a normal part of penetrative sex, pain as a normally problematic part of sex, pain as pathological, and pain as an indicator of a deeply embodied adaptation to patriarchal norms. These competing interpretations should be discussed because they are often central within sexuality research; researchers must decide (and critically assess) which sexual outcomes are, have been, and should be prioritized by individuals. Although some researchers and patients have assumed that pain-free intercourse is a sufficient outcome for "sexual success" (e.g., Engman, Wijma, & Wijma, 2010), others (e.g., Farrell & Cacchioni, 2012) have argued that researchers must not prioritize specific sexual activities (i.e., intercourse) above women's sexual enjoyment or other potential indicators of sexual success. This call for attention to the ways that sexual pain can be normalized in some research and clinical settings serves as a reminder to attend to the ways that women's bodies are always paired with various imperatives to be feminine and sexual. These imperatives may result in determinations that pain is simply part of one's life, especially if sex has been coded as "health work" (Segal, 2012). In this incredibly complicated space, it is important to weigh patients' desires for intercourse along with critical perspectives on how "normal" and "healthy" sex is culturally imagined and subsequently defined in research and clinical settings.

Current study

With these questions in mind, the current study was designed to examine the types of labors women engage in as a way to manage the demands on a woman diagnosed with metastatic breast cancer. About 5% of women diagnosed with breast cancer develop metastatic breast cancer, a specific form of cancer that spreads to the brain, liver, lymph, lungs, and bones (Silber et al., 2013). The median survival rate of those diagnosed with metastatic disease since 2007 is approximately 26 months (Thomas, Khan, Chrischilles, & Schroeder, 2015). Treatment goals in late-stage breast cancer often include prolonged survival and reduced symptom burden. Although researchers have studied sexual issues associated with metastatic disease (Mercadante, Vitrano, & Catania, 2010; Vilhauer, 2008), less is understood about how women living with this diagnosis think about their bodies, gender, appearance, and functionality, as well as how these aspects of gender and sexuality sit within the larger matrix of heterosexuality.

The current study contributes to the growing body of work on sexuality and cancer through a sustained focus on women's descriptions of how and why they are sexually active (or not

active). This focus aims to provide greater insight into the phenomenon of sexuality after cancer diagnosis, as well as greater understanding of how femininity and sexuality norms are woven into the fabric of this experience. Indeed, these are very difficult to see (as all norms are), but increasingly important if researchers want to document women's concerns as well as critically examine the larger set of expectations that women live with and that determine, in some part, the way they feel about themselves and their bodies.

Method

Participants and procedure

The current study is part of a larger multi-method study concerning the quality-of-life concerns of women with metastatic breast cancer (McClelland, 2015; McClelland, Holland, & Griggs, 2015a, 2015b). Patients were recruited from the breast oncology program at a comprehensive cancer center in the Midwestern United States (for details on recruitment and screening, see McClelland et al., 2015a). To be eligible to participate in the study, female patients had to be over 21 years old, be able to read and speak English, have no major psychiatric illness diagnosis, and have a life expectancy of at least 3 weeks. Potential participants were approached during a routine clinic visit and asked whether they would be interested in participating in a study concerning quality of life. The study involved a take-home survey and the possibility of a face-to-face interview of those patients who expressed interest. Consent and study procedures were carried out in accordance with the University of Michigan Institutional Review Board (IRB) guidelines. Thirty-two women were interviewed face to face in a private room in the breast cancer clinic by a female interviewer (the author). Prior to the interview, participants completed a card-sorting procedure and a survey. They were paid $20 for completing all three parts of the study. Interviews were audiotaped and transcribed for analysis.

During the interview, women were asked about how they defined "sexual health," what kinds of intimacy they experienced or wished they could experience (if any), and how this might have changed for them as a result of aging, illness, or something else. Participants were not asked about weight or "body image" during the interview; however, they were asked about whether they had experienced any changes to their body as a result of the cancer treatments. Similarly, they were not asked questions about gender norms, hair loss, or sexual accommodation but were asked about relationships with their partners and, if applicable, what forms intimacy or sexuality took in their lives (for the full interview protocol, see McClelland et al., 2015a).

Patients who were interviewed ranged from 35 to 77 years old ($M = 56.8$; $SD = 9.6$). Two thirds of them ($n = 21$) were currently partnered, either married or with long-term dating partners, and all of them were in heterosexual relationships. Sixteen participants had been in relationships for more than two decades ($M = 26.5$ years; $SD = 16.1$). Five women were dating and had entered their relationships more recently. Average time since initial breast cancer diagnosis was approximately 9 years ($M = 8.7$ years; $SD = 8.6$), and time since diagnosis of metastatic disease was just under 3 years ($M = 2.9$ years; $SD = 3.6$). Approximately two thirds (69%) of the participants had bone metastases, and 41% had metastases in the liver; 29 participants (91%) had received chemotherapy, and eight of the 32 participants (25%) had received two or more regimens of chemotherapy. Participants are identified below using pseudonyms, along with details concerning their age, partner status, and years they had been diagnosed with metastatic disease (i.e., mets).

Data analysis

Thematic analysis strategies (Braun & Clarke, 2006) were used to analyze the interview material. Themes were developed by the author through a process of reading the transcripts over several iterations and noting the evolving connections among the parts of the interview where participants discussed issues related to their body and how they felt about their body and their intimate life. The analysis was driven by the data (i.e., the interview data guided the development of themes and subsequent analysis). During the analysis phase, interviews were read and codes developed pertaining to weight/body size, sexual relationships, and physical pain. These codes were then further analyzed for the range of ways participants spoke about their bodies, their sexual experiences with partners, and the kinds of pain associated with sexual activity. Last, two themes were developed that identified patterns within the data and made the analysis possible at two levels: the manifest content of participants' comments and the subtle articulations of sociocultural norms that were woven throughout the interview material.

In the analysis, I highlighted two types of labor developed from participants' narratives: *gender labor*, including the work it took to feel feminine, feelings of unattractiveness, and feeling fat; and *sexual labor*, including the partner's sexual demands, sexual accommodation, and descriptions of sexual pain. An analysis of gender and sexual labor after diagnosis with breast cancer can highlight unseen and often unacknowledged aspects of women's "sexual health" that remain out of sight if we inquire only about frequency of sexual activity or assess only sexual function.

Results

Gender labor

The *gender labor* theme includes discussion of the work it took to feel feminine. Expectations about femininity were rooted in several connected areas, including women's feelings about their body (e.g., feeling fat, feeling unattractive) and broader requirements of femininity (e.g., caretaking, general accommodation to men). Gender labor enabled an analysis that linked together how women's bodies, women's time and attention, and women's emotional labor were part of a shared femininity imperative to be nice, to be thin, and to take care of others besides themselves (Brownmiller, 1984; Hochschild, 1983).

Laboring to be feminine

Participants described several ways that "feeling feminine" was important to their sense of feeling good. For example, when asked what her advice would be for other women like herself who had been diagnosed with metastatic disease, Alice (46, divorced, mets 1 year) suggested using lipstick to feel better: "You know, put on lipstick, you know, throw on a little eyeliner on your bottom lid or, you know, put on your earrings, and, you know, just try to, you know, beautify yourself where you feel comfortable." This idea of making oneself feel beautiful throughout cancer treatment is increasingly common and, of course, not a problem in and of itself. The advice to wear lipstick, however, becomes more troubling when femininity feels out of reach (and produces feelings of failing to enact one's gender) or when the damaging characteristics of femininity become amplified (i.e., expectations for weight loss and other beauty standards). Donna (35, partnered, mets 1 year) described the impact her double mastectomy had had on

her sense of feeling feminine and feeling pretty and how this impact had affected how she interacted with others:

> I didn't feel feminine at all anymore. You know, to look at me … I would never allow anybody to see, like scars are really ugly, you know. And then losing my hair, that was really tough. That made me feel even less pretty or, you know, that kind of stuff.

Similarly, Debra (63, single, mets 10 years) described the emotional impact chemotherapy had had on her sense of femininity and whether she still "fit in" the category of "woman" when she did not have hair: "When I lost my hair for the first time I just was a basket case because I felt that it so defined who I was …It just made me feel like I was pretending …to be, you know, a female. To fit in …with society's answer to, you know, womanhood, which is to have some sort of hair."

Alice, Donna, and Debra each highlighted how issues of feminine beauty standards played a role in their lives, either by offering a strategy to "feel comfortable" in Alice's case by beautifying oneself or in the feelings of gender failure that emerged for Donna and Debra. Hair loss for Debra did not offer another version of female possibility (woman without hair) but instead made her feel no longer female. This is where gender is revealed as labor. These narratives of breast and hair loss are common to cancer narratives (Lemieux et al., 2008; Moreira, Silva, & Canavarro, 2010; Piot-Ziegler, Sassi, Raffoul, & Delaloye, 2010). However, these narratives are not simply about returning to the category of "woman" after the illness, but rather about the labors that women imagined were necessary to maintain themselves as female and to achieve the precarious aspects of femininity (Chrisler, 2013).

Because the demands of femininity stretch across several domains, examples of gender norms could also be seen in how women prioritized aspects of their lives that included taking care of others. As Jane (66, divorced, mets less than 1 year) described her efforts to "wrap up her life" as her illness progressed to Stage IV, she described efforts to clean out closets so she would "not leave a mess for [her family]."

> Well I have 1,600 books at home to read and I have a closet full of yarn to knit. I have to get my room in order. Yesterday I started working on pictures, putting names on the back of everything so that my daughter, when I am gone—because they told me I have about 3 years. When I am gone, she'll know who all these people are.

Gender labor, as seen in this excerpt, is not limited to one's body image but stretches to include women's labor as caregivers and homemakers, including the responsibility Jane described to keep the house in order for her family, even after she died. For Jane, the desire not to leave a mess was joined with feelings of failure she had about her body weight and feeling unattractive. Jane described herself as "a perfectionist" and explained how that meant that she had to be "hard on [her]self," which extended to her feelings about her body:

> Right now I'm trying to wrap up my life as neat as I possibly can, before I die, you know. So, I'm very hard on myself, you know … I'm hard on every aspect of my life. I'm hard [on myself] because I'm not thin, you know, attractive … I don't want anybody to see me. I'm fat, you know. I used to be pretty, but I'm not anymore.

Jane's attention to cleaning up messes so as not to be a burden on her family and feeling worried about the shape and attractiveness of her body exemplify gender labor near the end of life. Laboring to be feminine includes aspects of being a good woman, such as the interconnected demands of physical beauty and expectations to be tidy, to take care of others, and not to leave "a mess." Femininity takes work (Bordo, 1993; Butler, 1990). The labor that is necessary to maintain femininity often appears across the domains of a woman's life and results in

efforts to be pretty, happy, good, nice, and accommodating in a wide range of situations; there is no rest from femininity norms, not even at the end of life.

Feeling fat

In addition to Jane and Nancy, many women in the study spoke about "feeling fat." In fact, nearly every woman in the study mentioned feeling fat at some point during the interview. Discourses of weight and fatness were woven in and out of participants' descriptions of themselves as sexual (or not), discussions of partners, and feelings about their overall worth. Many women said that various cancer treatments affected their weight (resulting loss of taste and/or lymphedema), and some spoke of their body weight and their worries about weight as lifelong and not related to their illness. For example, Nancy explained that she had "actually gained weight a number years ago when I was on an anti-depressant, and I haven't really been able to get rid of it." In this way, cancer merely amplified feelings of gender failure that women had lived with for years. Regardless of the timing, feelings about their weight occupied many participants' minds as they discussed their intimate lives, including why they did not feel sexual or why they would not pursue any sexual contact for fear of being seen naked and considered fat. In fact, for some women, feeling fat was worse than having cancer: "I don't like to look at the extra weight. But no, as far as the cancer stuff, that doesn't bother me at all" (Laura, 48, divorced, mets 4 years). Jane echoed these same sentiments: "Oh, I hate [my body], but it's not because of my mastectomies. It's because I'm fat. That's why." Feeling fat was not only a long-term form of gender labor that many women in the study lived with, but, in fact, fatness was experienced by many women as more traumatic than metastatic breast cancer.

When they reflected on their feelings about sexuality and their intimate lives more generally, participants consistently referred to feelings of sexual inadequacy, which were tied to their body size. Feeling fat was linked with feeling unattractive, undesirable, and out of commission. Several women explicitly said that feeling fat was the main reason why they felt sexually unavailable: "no one" would want them, and they did not feel desirable. Nancy, for example, narrated how she linked together her desire to lose weight and her feelings of inadequate femininity, and she discussed how these together made her undesirable to men:

> I would like to like exercise more, and losing weight would definitely make me feel better about my body … more attractive sexually and feminine, as a feminine person—a female … I mean people will say it doesn't matter, but it does matter if you're heavy. It does matter to men—they are visual beings and that's one of their ways they get attracted to somebody or turned on. I think it's, it's a primitive response that they have, and so I haven't attracted men in the last however many years because I'm heavy, and even when I have dates from the internet or whatever it rarely amounts to more than one because they're just, I think it's because they're not attracted to me physically.

Nancy makes clear how she sees her body size as linked to feeling feminine and, more important, to her own sense of femininity as related to how men perceive her and her body size. This set of implicit linkages (i.e., her weight, lack of femininity, men's sexual rejections) is noteworthy for the ways that she makes her sexual rejection her own fault (for being heavy) and natural (since men are visual beings). Gender labor, then, not only stretches across several domains in women's lives, but also it is labor that creates women's bodies as sites of failure due to weight gain, which naturally results in rejection.

When participants spoke about feeling fat, they often described this as a familiar feeling, one that had been with them for years. When asked to elaborate a prior response about sex being important to her, Esther (56, partnered, mets less than 1 year) said that sex "had always

been important … since I was a very, very young age," but it had become much less important since her cancer diagnosis. She explained:

> … cancer was not the whole problem, but it just compounded it so much so, you know? Because I have always had self-esteem issues, so that I gained weight so that made it worse, and then I had to have my breasts removed, so that made it worse. And then I had to go in and have some ovaries removed and now I have a scar running from here to there. So I mean I am just way out there, you know, it's just like lots of self-esteem issues now.

Esther touched on several important aspects of gender labor: the role of time, the role of weight gain, and the role of surgery and scars. Esther's description of being "way out there" is a useful way to understand how women in the current study spoke of their bodies—specifically, their female bodies. They often spoke of no longer being women or, at least, being so far away from the idea of "woman" that they were consistently wondering how to regain their footing in the gender category. Women's descriptions of hating how their bodies looked, and their specific shame about feeling fat, offer an important background for the larger category of "body image" that is often discussed in cancer research. Throughout the interviews, women's feelings about their bodies were connected to their histories as women, as well as to their experience of cancer, and the meanings that they attached to their bodies were consistently related to the work it took to remain recognizable as female. In this way, femaleness was revealed to be incredibly precarious, a category that was all too easy to fall out of.

The theme of gender labor highlights how participants' narratives of body shame and "feeling fat" impacted them over a lifetime, linked with side effects of cancer treatment, and became a way not only to feel bad but also to feel less of a woman. Participants not only described the labor of worrying about their bodies but also imagined that they should be doing more physical labor to lose weight. Gender labor usefully focuses our gaze on the ways that women's gender was threatened by cancer treatment, by body size and by feeling less sexually desirable to men. It also reminds us that this labor is more than simply experiencing gender norms but, instead, highlights the ways that aspiring to femininity ideals (and the failure that can often result) takes work and is, in fact, a form of ongoing and consistent labor.

Sexual labor

Sexual labor highlights participants' feelings about their sex lives and how they have worked to become, remain, or refuse to be sexually active. Throughout the interviews, women spoke about sexual demands partners made of them and how they negotiated these demands. These descriptions included experiences of sexual coercion, accommodating extreme sexual pain, and managing feelings of sexual inadequacy. Sexual labor directs researchers' attention to the psychological processes that often invisibly surround the outcome of being "sexually active" or regaining "sexual function."

Negotiating male partners' sexual demands

One of the key pieces of the sexual labor theme was the fear that women described that their partner or husband would leave them when they were ill. Throughout the interviews, women reported stories they had heard (from other patients, both friends and strangers) about men who walked away when a woman was unable to care for herself. Mary (68, partnered, mets 3 years) described how she worried on a regular basis about her husband of 46 years leaving her:

> Is he still going to love, how long is he going to love me, how long is he going to stay with me even though, you know, even though it's been 43 years or whatever. [laughs] We've been together a long time, and it's been a good marriage. So, you know, but still, but still, men move on when they think they need to.

Worries about men leaving often centered on questions of women's sexual availability. Rachel (49, partnered, mets less than 1 year) shared these same worries when she spoke about managing her boyfriend's disappointments about infrequent intercourse: "I think my boyfriend has a hard time accepting why I don't want to have sex as much. It's not that I'm not interested, I just don't have it in me." She described his "big sex drive" in comparison to her absent sex drive and worried that he would "find it somewhere else" if she were not as sexually active as he desired.

This set of fears offers an important background for understanding the ways that participants spoke about wanting to make sure their partners were happy and wanting to make them feel good, even when they themselves felt no sexual desire. Joanne (54, partnered, mets less than 1 year), for example, explained how she worked hard to manage her own pain and lack of arousal, all with the very keen desire to maintain her 9-year marriage or, as she says, "keeping him smooth":

> When we do anything [sexual], it's mostly for his pleasure as part of me keeping him smooth … If we're going to be honest, I could really care less. I just want him to be happy …and I'm not gonna say no to anything. So I don't. I just try to maneuver around so it doesn't hurt. And it doesn't, so we're happy … You know, I just don't want to drive a wedge.

Joanne's descriptions of wanting to keep her male partner happy were paired not only with her own lack of interest in sex but with the additional layer of her work to avoid pain during sex. This offers an excellent example of Cacchioni's (2007) notion of how "sex work" includes a set of invisible labors aimed at managing partners' desires. When paired with worries about being ill and being alone, these labors to please a partner, to avoid "driv[ing] a wedge," are especially poignant in how they position women's sexual labor as not only natural but also necessary for survival.

The interplay between various roles in women's lives (wife, mother, partner, lover) were at times woven together and resulted in a complicated interplay; being "less than" in one category sometimes meant needing to make up for that deficiency in other areas. This dynamic can be seen in Joanne's description of how she felt that she had disappointed her children with her cancer diagnosis, which, in turn, meant that she could not bear disappointing her husband with less sex than before her diagnosis:

> Even though there's changes about me and we have far less sex—and my interest is just about zero. I love my husband, I love my family, I don't want to create more ripples by having someone feel, you know, neglected, or … you know, I just, I think that whether it's sex or anything else, when you have this diagnosis your main job is to make sure that none of your children feel like this is the end of the world or that everything's gonna change, even though it does … I want my husband to feel like I'm still interested in being the best person, best partner, best wife that I can be because he is so good to me, and my children are so good to me.

Joanne's excerpt elaborates how gender and sexual labor intersect: her "main job" is to take care of others, and one of the ways that she is able to do this is through attending to her husband sexually. In this way, sexual labor effectively keeps balance among the various role demands that the women experienced (as mother, partner, person). Sex, regardless of her own desires, was a way to ensure that her male partner would not feel neglected and was seen in the context of other women's worries about men leaving, Joanne worried about creating "ripples," which could, in fact, be very threatening to her well-being. Narratives of negotiating different

sexual desire levels within couples are not specific to women with cancer and are commonly found in sexuality research with healthy couples (Mark, 2012; Willoughby & Vitas, 2012). What is noteworthy is that these negotiations do not, in fact, change when women are ill; they may even become heightened and have higher stakes for women who are increasingly dependent on partners as their illness progresses.

Joanne went on to describe the ways that she managed her sexual labor, including how she dealt with chest tubes during sex, tried different sexual positions, experienced issues of vaginal lubrication, and negotiated wanting to make sure she was still sexually available to her husband, including how she managed her husband's feelings of loss of her breasts, which before her mastectomy had been "huge." Participants who had had surgical treatments for their breast cancer worried about what their husbands were missing out on as a result of their mastectomies.

> Men that fall in love with women that have huge boobs are usually honing in on that area, so it's, that's the kind of thing that I try to protect and … I don't get on top anymore. I try to lay the other way so if he's going to grab something. It's almost like spooning, only in reverse, you know, like he's behind … I have to prop a pillow up there so I'm not rubbing my chest tubes on the bed, and if he's gonna grab something, it's gonna be this [other breast] … Oh he loves 'em [breasts] … He would face plant if ever he had a chance, and …when he was on top was, you know, there was a lot of action going on with my breasts. If I was on top, they were in his mouth, you know, so—and we just don't do that anymore.

Joanne's description highlights the physical labor that is part of sexual labor: how to lay down, what will be grabbed, and what parts, actions, and feelings should and must now be avoided. Her description also highlights the keen sense of what has been lost and how this loss persists as she imagines what her husband wishes were still there; it is his sexual loss that trumps her own bodily loss. Breast loss, in this way, prompts a set of sexual labors in an effort to make up for their absence.

Accommodating and managing sexual pain

In addition to a lack of sexual desire that echoed throughout the interviews, sexual pain also played a major role in women's descriptions of their sexual lives. This pain came from a variety of sources, including bodies that could not move in certain ways or pain felt during intercourse. In the analysis of the theme of sexual labor, sexual pain became another way that women described the lengths they went to in order to accommodate or manage this pain psychologically and physically.

Betty (50, partnered, mets 2 years), for example, described the thought process she went through as she moved from not wanting to be intimate with her husband to feeling guilty about her feelings, and then to feeling angry about her willingness to accommodate the sexual pain she experienced. "If he wants to initiate being intimate …I don't feel right about it but then at the same point I feel, why should I? And then I feel kind of guilty about that." In order to have intercourse with her husband, she described mentally "checking out" to manage the pain that accompanied sex and the anger she felt about this kind of accommodation:

> I mean we've tried with different techniques and vibrators or whatever and it's just—I'm just like not there. Mentally I go somewhere else to try to avoid the pain so that at least I can satisfy my husband, which then I start feeling, I don't know, a bit angry over it.

Similarly, Dawn (61, partnered, mets 17 years) talked about the pain she experienced during intercourse and how she pursued medical intervention, in this case using lidocaine to reduce the pain, and the potential relational problems she avoided as a result.

> I mean that was the main thing was that [it] really hurts when you have [intercourse]. So the lidocaine solves the problem …You don't wanna lose your relationship, you don't want your husband to go someplace else. So you're prepared to put up with some pain, but that's not fun, and he knows it's not fun, so it's a problem, it can be a real serious problem. Oral sex is fine, but, and it's great, but you need also intercourse.

Several points are noteworthy in Dawn's description, including how pain is seen as normal and to be expected ("you're prepared to put up with some pain"), that penetrative intercourse is a priority ("you need also intercourse"), and that lack of intercourse can introduce a real threat to one's relationship. Like other excerpts included in the sexual labor theme, Dawn linked her sexual problems with fears of losing her relationship and her husband going "someplace else." Managing her sexual pain, then, became a necessary way to ensure that her relationship would not suffer. When asked how intercourse felt with the lidocaine, Dawn's replied, "Oh, it's great. I mean, you know, it has to take its, its effect. And initial penetration can be a little bit tricky, but once it's finished, it's fine. It's as if it was before all my, you know, cancer." Her reply is noteworthy because her desire to be sexual, as she was before cancer, justified whatever sexual labor was required, including putting up with some pain and a numbing gel.

Sexual refusals

Sexual refusals were also an important part of sexual labor. This includes women who began refusing sex when they were diagnosed with metastatic disease or who, as a result of cancer treatments, said that they did not have the energy for sex and described how they communicated this to their partners. Alice described the moment when she got the diagnosis: "They were saying I had 12 weeks to live! And when somebody tells you have 12 weeks to live, I don't like having sex, I'm not having it." Betty described her experience with refusals as less abrupt and, instead, rooted in a desire to please her husband.

> I want to be able to please my husband, but at what cost physically? So I'm willing to try once in a while and sometimes I think to myself, "I feel pretty good today, maybe I'll be nice." As soon as I hit the bed at the end of the day it's like, "Don't touch me."

Betty referred here to her own process of balancing the desire to please her husband and her own physical well-being. In contrast to the other women who spoke about accommodating sexual demands and sexual pain, Betty's example is a sexual refusal, a decision to opt out of sex ("don't touch me"), even if only for the night.

Sexual refusals are an important aspect of sexual labor because the moment of refusal may itself be a form of labor. Descriptions of refusals often came with reflections about the past. For example, Alice reflected on the way she had never liked sex, but it was her cancer diagnosis that had finally allowed her to refuse: "I do not want sex. That's all there is to it. And my cancer …the only thing that made it different is that I felt like I could tell him no. Even though we're married, I'm not doing it." She reflected on her prior decisions to have sex even when she did not like sex: "Before I, you know, submitted to it occasionally, but I just don't feel like I have to. I know probably people continue to have sex, but I'm sure lots of people like that, you know." Sexual refusals came with useful insight into the phenomenon of what sexual labor involves; at times, it may involve submitting to sex that is not wanted and, at other times, it may involve drawing a line in the sand when sex is no longer on the table.

The theme of sexual labor highlights how participants worked to remain sexual at times, as well as the stakes of remaining sexually available to male partners. Labor is evident in several ways; there is the physical labor involved in arranging one's body during sexual activity, the labor of worrying about one's duties as sexual partner (and making up for losses), the labor

of managing sexual pain, and the labor involved in making refusals. Sexual labor focuses our gaze on the reasons women offered for being sexual with their partners; these motives often included being sexually active as a necessary part of keeping a male partner "happy," "smooth," and not leaving. The stakes of this sexual labor were often talked about in terms of relationship maintenance, but, for extremely ill women, the potential costs of losing one's relationship are extremely high. This context is important in order to frame the sexual labors women described, such as "putting up with" sexual pain and remaining sexually active even when they had "zero" desire. Sexual labor, like gender labor, encompasses psychological as well as physical elements, and, seen together, they illustrate the range of ways that women spoke about how they managed being extremely ill and, for some, nearing the end of life.

Discussion

The current study focused on aspects of labor woven throughout women's descriptions of their sex lives after having been diagnosed with advanced breast cancer. This study extended previous feminist research on sexuality and breast cancer by exploring how women labor to remain feminine and sexually active. As sexuality research continues to develop in the field of breast cancer, additional insight is needed into the reasons why women do and do not engage in sexual activity that push beyond the mere presence or absence of specific activities. For example, this study revealed that women's shame about their body size created a complex set of motives that kept them from being sexual because weight gain was linked with sexual rejection from men. In addition, women in this study described a complex set of reasons for engaging in intercourse with male partners, even when they had no desire or the sex was painful for them. Without this kind of attention to sexual motives (i.e., why and how individuals engage in various forms of sexual activities), sexuality research may simply reproduce sexist and heterosexist assumptions about how women's bodies can and should perform (e.g., as simply sexually functional or dysfunctional). In addition, sexual refusals offer insight into the ways that women felt obliged to have penetrative sex and felt able and unable to say "no" to sex. Cancer, in this way, may be serving a positive function by increasing women's sexual agency.

The two themes regarding gender and sexual labor offered distinct types of insight: gender labor offers insight into the ways that women make efforts to feel and appear feminine, and sexual labor offers insight into the work that women are willing to do to remain sexually available within their relationship. The focus on labor in both themes highlights both the sheer effort involved in each, as well as the ongoing nature of this labor; one does not stop laboring to be gendered appropriately or to be sexually available. Breast cancer offers a way to see these dynamics in an extreme moment of life (near its end); however, these dynamics are also utterly normal. In fact, they have long been critically cited as the expected labors of being a woman more generally (Bay-Cheng, Zucker, Stewart, & Pomerleau, 2002; Bordo, 1993; Brownmiller, 1984; Chrisler, 2013; de Beauvoir, 1953; Willis, 1982). Through this examination of gender and sexual labor, it is possible to observe the range of efforts needed to maintain one's sense of femininity, including time, energy, emotion, and physical work.

Analysis of women's labor has a long history as an important feminist project. For example, Hochschild's (1983) articulation of emotional labor highlighted how labor, when performed by women, is consistently read as normal, not effortful, and, paradoxically, as a sign that she is less worthy of respect. Much like Cacchioni's (2007) "sex work," the invisible sexual work that women with breast cancer perform to keep partners happy is difficult to track, in part because it is a form of feminine care work. Femininity labor is often invisible because it has

become "natural" and, as a result, difficult to observe and difficult to interrupt. The women in the current study described a set of priorities that highlight just some of the ways that their own survival is backgrounded to accommodate other demands in their lives, including husbands' sexual demands and sociocultural demands to be thin and attractive. Yet such issues are routinely ignored in most models of quality of life after cancer diagnosis. In the current study, women's worries about how they looked and concerns about their weight represent more than simply the "body image disturbances" that are often reported in the breast cancer literature (e.g., Brunet, Sabiston, & Burke, 2013). I argue, instead, that highlighting the role of gender and sexual labor demands a set of theories and methods that enable researchers and women to recognize more clearly how demands associated with femininity become interwoven with the demands to be a good patient and, of course, a "sexy" survivor.

The results of the current study demonstrate how women speak about themselves as largely failing to live up to beauty ideals and expectations for women's sexual availability, including how these pair with the pressure to be a "crazy, sexy" cancer patient. Through an analysis of their narratives, it is possible to hear how women described their own failures, not because they were dying, but because they felt fat, because they felt unattractive, and because they did not feel sufficiently sexual. Within the context of breast cancer, it is possible to see how women's "failures" to be sufficiently feminine come at a tremendous cost to them. These failures not only punish them as women but additionally push them outside the category of "good" cancer survivors who prioritize looking and feeling good and feeling sexy.

Conclusion

The context of breast cancer enables new insights into the ways that "woman" is a category that one can easily lose or be pushed outside of and, perhaps most important, requires endless labor to maintain its upkeep yet appear to occur "naturally." In studies of the impact of breast cancer on women's sexuality, researchers have commonly focused on when and if women experience decrements to their sexual function. Largely missing from that research is critical analysis of how women's sexual relationships are always already imbued with social norms regarding femininity and sexual availability that do not necessarily diminish with a cancer diagnosis. A focus on an extreme moment of life (e.g., when a person is very ill) makes it possible to see with fresh perspective how women across the lifespan contend with demands to remain feminine within very limited boundaries. Ill and aging women are shaped by expectations others have of them, and sexuality remains an object of negotiation and sacrifice, even late into life. The types of labor documented in the current study—both gender and sexual—remind us of the sheer normalcy of femininity labor. Because these descriptions come from women who are so ill, with little time remaining in life, it is possible to see these experiences in fact as laborious and unfair. Rather than assume that femininity is a state that should be necessarily be sustained or restored, it is essential to document the labor, costs, and investments that femininity requires for all women across the lifespan and to see these, too, as laborious and unfair.

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