



# “I wish I’d known”: patients’ suggestions for supporting sexual quality of life after diagnosis with metastatic breast cancer

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## ABSTRACT

Research has found that breast cancer and its treatments can have severe consequences for patients’ sexual quality of life (SQoL); however, patients often report not knowing about possible impacts of treatment on their sexual well-being. This gap in information provision has been especially prominent for those diagnosed with metastatic breast cancer (MBC). To address the development of resources for patients diagnosed with MBC, the current study examined patients’ descriptions of resources needed to support their SQoL in palliative care. Semi-structured interviews were conducted with 32 women diagnosed with MBC, aged 35–77 in a US breast cancer practice. Patients were asked to describe those issues that were most pressing and the supports they would find most valuable to improving their SQoL. Thematic analysis focused on what was missing in their care and what they wished they knew (or wish they had been told) about cancer and their SQoL. Four themes were developed from the interviews: (1) unexpected embodied loss and mourning; (2) silences; (3) desires for others’ expertise, and (4) worries about normalcy. Findings across these themes highlighted how patients’ psychosexual needs included both pressing instrumental needs as well as desires for support from oncological medical providers concerning the subjective experience of breast cancer.

## ARTICLE HISTORY

Received 23 March 2015  
Accepted 1 September 2015

## KEYWORDS

Breast cancer; metastatic disease; sexuality; palliative care; qualitative research; information needs

## Introduction

Research has found that breast cancer and its treatments can often have severe consequences for patients’ sexual quality of life (SQoL); however, patients consistently report being uninformed about how cancer treatment would alter their sexual well-being (Emile, Ussher, & Perz, 2010). This gap in information provision has been especially prominent for those diagnosed with metastatic breast cancer (MBC) who are often assumed to be more concerned with their poor prognosis than their sexual well-being (Bensing, Rimondini, & Visser, 2013; Gaston & Mitchell, 2005; Olsson, Athlin, Sandin-Bojö, & Larsson, 2013; Vilhauer, 2011). As studies have found that sexuality remains a central concern for women diagnosed with MBC (McClelland, Holland, & Griggs, 2015a; Milbury & Badr, 2013; Vilhauer, 2008), this patient population may not be provided with the

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information they require or wish for. The current study aimed to address this gap by turning to patients' unique expertise in what they wished they had known about the possible impacts of cancer and its treatments on their SQoL.

## Literature review

### *Impact of MBC on SQoL*

MBC starts in the breast and spreads to one or more distant sites, and as a result, the disease often cannot be completely eliminated. Due to the advanced progression of the disease, MBC is marked by shorter survival intervals: approximately 25% of patients diagnosed with MBC survive for 5 years and of these patients, approximately 10% remain alive at 10 years (American Cancer Society, 2013; Jolly, Williams, Jones, & Muss, 2012). Common treatments for MBC (i.e. mastectomy, lumpectomy, chemotherapy, endocrine, and hormonal treatments) have been found to decrease women's sexual desire, increase vaginal dryness, and increase dyspareunia (Mercadante, Vitrano, & Catania, 2010). In addition to genital changes, treatments often result in increased pain and dulled sensitivity to touch throughout the person's body (Vilhauer, 2008). Common treatments such as tamoxifen have been found to induce menopausal symptoms, sometimes leading to vulvar, vaginal, and clitoral atrophy, coupled with vaginal thinning and decreased elasticity (Carter, Goldfrank & Schover, 2011). Research has also shown that in addition to genital and breast changes, other changes such as hair loss, puffiness, weight gain, or loss have been shown to have considerable impact on a woman's self-identity as a sexual being (Flynn et al., 2012). In addition, chronic pain (McClelland et al., 2015a), depression (Mosher et al., 2013), and fatigue (Vilhauer, 2008) have been found to have deleterious effects on women's sexual well-being.

### *Communication about SQoL*

The bulk of research when addressing patients' sexual health needs has focused on aspects of physician communication (Hordern & Street, 2007a, 2007b; Ussher, Perz, Gilbert, Wong et al., 2013), satisfaction with care (Halkett et al., 2012), and unmet information needs (Morrison et al., 2012; Ussher, Perz, & Gilbert, 2013). Findings across these studies suggest tremendous silence surrounding oncological care when it comes to talking with patients about sex, sexuality, and sexual health. For example, in a study of women diagnosed with primarily early-stage breast cancer, Ussher, Perz, and Gilbert (2013) found that two-thirds ( $n = 1287$ ) of their sample reported that they would like to receive information about sexual well-being; however, less than half of the sample ( $n = 790$ ) had obtained information about the topic.

Studies of patients with early-stage cancers have found that when sex is discussed in health care settings, physicians primarily focus on sexual function (Flynn et al., 2012; Janz, Mujahid, Griggs, Hamilton, & Katz, 2008; Ussher, Perz, & Gilbert, 2013). Studies concerning the dynamics between physician and patient have consistently found that feelings of awkwardness and embarrassment often play a role in how physicians talk to their patients about sex (Hordern & Street, 2007c; Ussher, Perz, Gilbert, Wong, et al., 2013). In a study that combined interviews with patients in palliative care, interviews with health

professionals, and textual analysis of cancer and palliative care clinical practice guidelines, researchers found that talking about sexuality in medical settings was considered personally confronting and ultimately “too risky” for medical professionals; as a result, the majority of this group chose to ignore or avoid intimate and sexual aspects of the patient’s life (Hordern & Street, 2007c). These findings stand out as especially important when compared to studies that have found the benefits that supportive communication between patient and medical professional about sexuality and intimacy can have for breast cancer patients’ well-being (Perz, Ussher, & Gilbert, 2013).

Lastly, patients describe experiencing “fundamental disconnects” as a result of the inconsistencies between their own experiences of sexual side effects following breast cancer treatment and how sexual health was addressed by cancer care providers (Halley et al., 2014). For example, contemporary standards of care regarding sexual function (e.g. asking patients “does it hurt when you have sex?”) limit SQoL support to women having (or wanting to have) intercourse and excludes women who are not interested or not capable of responding to this type of question. Increasing numbers of researchers have argued that these assumptions about women’s sexual health severely limit who receives care and overlooks women who need support for their changing SQoL, regardless of their level, type, or frequency of sexual activity (Halley et al., 2014; McClelland, 2012; McClelland et al., 2015a; Perz et al., 2013; Ussher, Perz, & Gilbert, 2013, Ussher, Perz, Gilbert, Wong, et al., 2013).

When compared to early-stage cancer, there is considerably less research on MBC and SQoL (Johnston, 2010; Reed, Simmonds, Hons, Haviland, & Corner, 2012; Warren, 2010). As a result, the provision of SQoL support in palliative care services is often ill-defined and frequently *ad hoc* (Hui et al., 2010; Smith et al., 2012). McClelland and colleagues (2015a) found that women diagnosed with MBC reported specific concerns regarding sexual positions that could accommodate surgeries and treatments such as chest tubes, and a desire for support to learn more about non-penetrative sexual activities with partners. Participants in this study reported that medical providers relied too heavily on vaginal lubricants as the only solution to SQoL issues without fully understanding patients’ sexual health concerns, which included but were not limited to vaginal dryness. Importantly, this study also found that sexual health questions were neither limited to those who were young nor only those in long-term relationships; patients of all ages and those who were single and/or dating also reported desiring information about SQoL.

The current study builds on research with other ill populations that have turned to patients for their insights on what they wish they were told about psychosexual supports (Faithfull & White, 2008; Moore et al., 2013; O’Brien et al., 2011). For example, in their study with men with prostate cancer, O’Brien and colleagues (2011) found that a lack of rapport with practitioners made it hard for men to discuss and ask questions about their sexual health, specifically the psychosexual side effects of cancer treatments. O’Brien’s and colleagues’ study (2011) focused on what patients wished they had shared with their medical providers (“I wish I’d told them”), while the current study focused on what patients wanted to know more about (“I wish I’d known”). Both sides of this story serve as ways to understand how patients’ perspectives on SQoL provide necessary insight into this important, but often difficult, subject.

## Methods

### *Study design*

This study was part of larger study concerning quality of life of women diagnosed with MBC (McClelland, Holland & Griggs, 2015b). Patients were recruited from the Breast Oncology Program at the University of Michigan Comprehensive Cancer Center. All women attending the breast cancer practice were screened for a confirmed diagnosis of MBC prior to a scheduled appointment with their oncologist. Women over 21 years old, who were able to read and speak English, with no major psychiatric illness diagnosis, and a life expectancy of at least 3 weeks were eligible to participate in the study.

The study included a take-home survey and the possibility of a face-to-face interview for those patients who expressed interest. Thirty-two patients volunteered to participate in the interview portion of the study. Women who participated in the survey and interview portion of the study received \$20 for their time in the form of a gift card mailed to their homes. Institutional Review Board (IRB) approval was obtained, patients provided written informed consent, and study procedures were carried out in accordance with the IRB guidelines.

All interviews were conducted face to face in a private room in the Breast Cancer Center and were completed by a female interviewer (McClelland). Interviews were guided by a semi-structured interview protocol of open-ended questions regarding patients' experiences of their sexual health, well-being, and feelings (see McClelland et al., 2015a, for interview protocol). Throughout the interview, participants were asked how they defined their own sexual health, whether they thought their sexual health had been impacted by cancer diagnosis and/or treatment, what they wished they had learned about, and what resources they imagined would have been useful at various points throughout their diagnosis and treatment. Interviews lasted approximately one hour and were audiotaped and transcribed verbatim for analysis.

### *Sample*

Patients in the interview portion of the study ranged from 35 to 77 years old ( $M = 56.8$ ;  $SD = 9.6$ ). Two-thirds of participants in the sample ( $n = 21$ ) were currently partnered, either married or with long-term dating partners, and all were in heterosexual relationships. Of those in relationships, 16 participants had been in these relationships for more than two decades ( $M = 26.5$  years;  $SD = 16.1$ ), 3 were in relationships shorter than five years, and two participants were actively dating. Time since initial breast cancer diagnosis was approximately nine years ( $M = 8.7$  years;  $SD = 8.6$ ) and time since diagnosis of metastatic disease was just under three years ( $M = 2.9$  years;  $SD = 3.6$ ). Two-thirds ( $n = 20$ ) of the sample had treatments that included mastectomy and nearly all ( $n = 29$ ) had treatments that included chemotherapy.

### *Interview analysis*

To address the development of resources for patients diagnosed with MBC, the current study examined the needs and suggestions of patients in order to provide a set of best practices for supporting SQoL in palliative care. The term SQoL was used to extend the

analysis beyond the more limited definition of “sexual function” which focuses almost exclusively on genital response rather than the larger set of dimensions that an individual may associate with a healthy and pleasurable sexual life. These include sexual responses, cognitions, and attitudes, as well as dimensions related to intimate relationships and a sense of one’s physical body as capable and entitled to experiencing sexual sensations (McClelland, 2012). SQoL, unlike sexual function, includes individuals’ experiences of their body, body image, gender norms, and relational dynamics. As a result, these dimensions were theorized not only as predictors and outcomes of sexuality, but as integral to the experience of sexuality itself (McClelland, 2012; McClelland et al., 2015a).

Interviews were analyzed using thematic analysis, a method for identifying and interpreting patterns in qualitative data (Braun & Clarke, 2006). A team of three researchers read a subsample of the interviews several times and a codebook was developed and refined over several iterations, which was then applied to the entire set of interviews. Two trained research assistants coded interview transcripts using the coding software Dedoose (2013) and inter-rater reliability was very good (Cohen’s kappa = .85), indicating that coders regularly recognized similar patterns in the data and code application procedures. Disagreements in coding were resolved through discussion by the coding team. Thematic analysis of the interviews focused on patients’ descriptions of what was missing in their care and what they wished they knew (or wish they had been told) about cancer and their SQoL. Four themes were developed from the interview material: (1) unexpected embodied loss and mourning, (2) silences, (3) desires for others’ expertise, and (4) worries about normalcy.

## Findings

### *Unexpected embodied loss and mourning*

Throughout the interviews, women spoke about physical and emotional changes that took them by surprise – both after their initial cancer diagnosis and years later after reoccurrence and/or disease progression. Participants described wishing they knew more about how treatments and surgeries would affect their bodies, and importantly, how they felt about their bodies. Women described knowing there would be changes, of course, and that surgery would be difficult. As one woman stated, “when you know you’re going to lose a breast, I guess you know that things are going to change” (56 years old, MBC <1 year). There were, however, aspects of the experience that took them by surprise and they felt unprepared to face.

Patients consistently reported that they had not been prepared for the psychological aspects of breast loss. One participant summed up this loss: “I didn’t know what it would be like to not have a chest. And I miss my boobs big time” (55 years old, MBC 2 years). Breast loss continued to linger for many women long after primary treatment. One woman explained how she was surprised by the way her body appeared post-reconstruction, especially during sex:

The one thing that I would’ve liked to have known before my mastectomy was how muscles would look. And the only reason I say that is, when we were having sex, if I was on top it looks very weird, because the implant is under the muscle, so one breast is down here and one is up there. And it’s like [laughter], you know, I saw that the first time like, “Oh my

God!” You know, you have to look at a freak! I probably would have been happier having a double mastectomy, rather than trying to match (the original breast). (46 years old, MBC 2 years)

These two aspects of breast loss were central for women in this study: the subjective experience of missing one’s breasts paired with instrumental informational needs, such as wanting to know how one’s body and breasts might appear post-surgery.

As seen in this last excerpt, participants’ narratives about embodied loss were often narrated from their own perspective, as well as imagining how their sexual partners saw their (reconstructed) bodies. Descriptions of self and partner perceptions were often interwoven to such a degree that the impact on one or the other was sometimes hard to discern:

The biggest thing is, I immediately had double mastectomy. And so that...was... huge. I just lost—like I didn’t feel feminine at all anymore. You know, to look at me. I guess I felt it, but if I looked in the mirror or, you know, 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. (35 years old, MBC 1 year)

This excerpt details difficulties after a double mastectomy, but also highlights how this participant’s difficulties moved between not being able to look at herself and not letting anyone else see her. This fusion of self and other appeared in many participants’ descriptions of how embodied loss both affected them personally and how they worried about how others saw them.

In fact, the unexpected aspect of embodied loss may have been amplified by the way that some women experienced unexpected levels of worry about the changes they saw in themselves. This can be seen in how the following participant’s feelings about her hair loss after treatment became paired with new fears about the loss of her marriage:

But you know, you lose your hair, you get a cute piece, hairpiece or two and, you know, and then it comes back. So it’s not the end of the world. But emotionally, this emotional thing is difficult. 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. 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. (68 years old, MBC 3 years)

In addition to women in long-term relationships, other women in the sample were single and dating while diagnosed with MBC. One woman described the impact of breast loss and hair loss on how she felt becoming intimate with new partners. Her story is a reminder that hair loss (and treatment more broadly) may not be a one-time issue. For women with MBC, it was a sense of ongoing loss that had the biggest emotional impact on her sexual well-being:

During remission I had no problem with intimacy, however, after I relapsed the thought of being intimate with someone, and the wig was the big thing, for me. It was the wig. Because I would tell people ahead of time, you know, I’ve had a mastectomy, I’ve had reconstruction, and I was not ashamed of that. To me I look normal and I think that’s half the battle. If you believe it others will believe it too. But not having hair off and on for about ten years has, has really done a number on me. (63 years old, MBC 10 years)

In addition to the durational aspects of loss highlighted by this participant (“not having hair off and on for about ten years”), the cross-cutting theme of “normal” appears here and throughout the interviews, as a benchmark of success. Women’s desires to both feel

and appear “normal” were central to many descriptions, as well as the declining ability to maintain “normal” as time passed, as treatments increased, and as cancer diagnoses shifted (i.e. from Stage I to Stage IV).

These examples of psychological loss, mourning, and fear characterized the emotional landscape that participants described both after initial diagnosis of breast cancer and with subsequent diagnoses and treatments. In addition to these psychological elements, participants described requiring specific types of support regarding SQoL that would have helped them deal with these physical changes, but often faced silences instead.

### **Silences**

Women in the study described consistent needs for more information about SQoL and largely agreed, as one patient described, “there wasn’t anything much available” (59 years old, MBC 7 years). Another woman echoed this point: “I’ve had all kinds of questions about sex. And like I said, there’s not really anybody that you can talk to” (56 years old, MBC < 1 year). After breast surgery, women reported not having information about how to deal with a post-surgical body. For example, several participants reported they had not learned about prosthetic breasts, where to find them, that they existed, or the ways that they could be incorporated into daily activities (i.e. in bathing suits). Without this kind of information, one participant described the lengths she went to make her own homemade prostheses and the psychosocial costs of this information gap:

I mean forever I was like stuffing my bra with like stuffing you’d find in a toy. And that would be so light that the bra would ride up. So then I went out and bought fishing weights to weigh down my bras with the stuffing. Just, I was wearing normal bras, so then you had to worry if it would fall out... I just happened to run into a drug store once [and] they had these bras and prosthetic breasts, I guess you call them, and I was like, “Oh my gosh, I wish” – I wish someone had told me those types of things. (35 years old, MBC 1 year)

Participants also noted additional silences surrounding the issue of vaginal dryness. Women consistently noted that they had either received no information from physicians or that the information they received did not sufficiently address the severity of the sexual outcomes they experienced. As one woman reported, the way she learned about dryness was through the regular patient survey she filled out each time she came to the breast cancer clinic:

I hadn’t been forewarned that this could happen, you know. It’s not one of those things you just talk about [laughter], you know...I just think maybe being forewarned of the dryness, you know, and my only thing that triggered me that this may happen is because of one of the questions that I answer every time I come in to cancer center is one [about] “vaginal dryness.” So that’s the only thing that made me think, “Oh I wonder if that’s a possible side effect”. (40 years old, MBC < 1 year)

This highlights the ways that silences about SQoL are a result of several factors, including patients’ discomforts talking about issues related to sexuality. In addition, it highlights the central role that inadvertent communications, such as forms and flyers, can have for patients who do not know what to ask for help with. Lastly, this highlights how silences about SQoL set up patients for unexpected loss since they often reported now knowing what to expect.

In addition to desiring more information for themselves, patients described their male partners as needing more extensive information about how to understand the sexual changes that patients were experiencing. Both patients and partners were described as “in the dark” and this presented a unique challenge as female patients were expected to educate their male partners about changes to their SQoL. As one woman said, “I don’t know what I can and can’t do, and my husband probably doesn’t know what I can or can’t do” (60 years old, MBC 4 years). Other women reported wanting more focused interventions that targeted men who needed to be more aware of and sensitive to their partners’ physical changes and needs:

It would have been very helpful for him to understand...that there may be changes, a kind of a pre-education almost, that, you know, sometimes things in that area change, and why and what might he be able to do to make it an easier experience for me as well. That would have been very helpful, and I think he would’ve liked to have known that stuff because you’re, you’re kind of left in the dark about it. They just don’t talk about sex, you know? (59 years old, MBC 7 years)

In addition to providing male partners with information in order to help maintain or enhance sexual interactions, participants also described ways that they worked to discourage or end sexual interactions with their partner. Some women described the lengths they went to in order to decrease their partner’s sexual demands, which were present both before and after their cancer diagnosis. For example, one woman noted, “I do not want sex. That’s all there is to it. And my cancer...the only thing that made different is that I felt like I could tell him no. Even though we’re married, I’m not doing it. Before I, you know, submitted to it occasionally, but I just don’t feel like I have to” (46 years old, MBC 1 year). These patient experiences reinforce that ways that SQoL is tied to gender norms concerning women’s sexual availability and the role that sexual inactivity may also play in a person’s SQoL (see McClelland, 2012, *in press*).

### ***Desire for others’ expertise***

In order to contend with the unexpected loss they experienced and the silences they often faced in medical settings, many women spoke about wanting to have someone to speak with about sexual issues. This most often included the desire for a specialist or a peer with shared experiences. Participants explicitly expressed a desire to obtain information from other women with MBC rather than women who were undergoing treatment with curative intent or who had completed treatment and were living with no evidence of disease. Others spoke about the desire for individual consultation with sexual health experts:

There’s just so many elements to it, but having the resources, wherever you are in that stage, it could be, you know, very helpful, even if it’s just “it’s okay to be intimate,” or “it’s okay to accept your body,” or “here’s some resources on sexuality for men and women.” (48 years old, MBC 2 years)

The ability to speak to a professional about sexuality issues and hear their reassurance about the normalcy of their sexuality (in whatever form) was important for many women in the study. However, as much as women talked about wanting to get help from experts, this was often accompanied by worries about privacy and difficulty talking about sexual issues. Navigating worries about their own and their partner’s privacy and managing

social norms about sexuality was difficult for some to imagine. As one woman remarked, she was not sure if she would have the “guts” to talk to anyone, but a more anonymous place to call and talk to someone about sexuality issues would have provided her with needed support:

That’s not something I’m going to ask [my doctor]. It’s not something I would have asked anybody... I don’t know that I would ever have the guts to actually call and ask somebody, but as soon as I say that, then I think, if there was just a, like a lifeline, if there was just somebody that you could talk to if you felt like you needed to, that would be wonderful. (54 years old, MBC <1 year)

While the idea of speaking to others, particularly her physician, was intimidating, this patient clearly desired connections to help support her sexual well-being. These examples point to the wide range of SQoL needs that may go unexpressed in clinical settings.

In addition to sexual health experts, patients expressed the desire to talk with other women diagnosed with MBC. This support was imagined in a variety of forms (e.g. pen pals, support groups), but no matter the form, the need to talk with other patients about SQoL concerns was central. Major issues raised were ones of trust, being matched with someone similar in age and cancer stage. Examples of this kind of support included a “buddy system” that would offer an emotionally supportive relationship with another woman diagnosed with cancer:

[If] they had some program where you like buddy up with someone, you know, and you become like maybe even like pen pal types where you can bounce ideas off each other and grow to trust each other, you know, and then maybe those things could be discussed...like a little motivator, like a teammate I guess. (35 years old, MBC 1 year)

These suggestions reflected a need to be in communication with peers who could be candid and facing similar issues as the patient. This emphasis on a shared disease and life stage was evident when another patient described wanting to have people she could ask about sex: “You know, ‘What have you tried?’” She, like others in the study, went on to worry about how this kind of personal information would be shared and how to manage her privacy needs with her own interests in finding out more information:

I want to meet some people like me face-to-face and say, “So how do you deal with not being able to have sex?” and not embarrass somebody, you know, and not have it be 85 year old person who can barely stand up to begin with. (50 years old, MBC 2 years)

Several suggestions made by participants were delicately balanced between the need for informational support and the need for privacy. This included support group meetings where information about intimacy and sexual health would be provided, but would not be the sole focus:

I think it’s just like you’d just have a general meeting and not make it too personal but general like, “Your intimacy will change, and this is suggestions we have to help you get through it, or, or to make your life maybe feel fulfilled in that area.”... I think it’s [important] when you hit Stage IV. (60 years old, MBC 4 years)

The desire for someone’s expertise was central; women consistently wished they had access to information and support for their sexual well-being, but for many women, these topics were sensitive and required discretion. Across the interviews, patients described both craving the support of others but worried about discussing their sexuality in a

“support-group” format. Overall, the possibility of having shared spaces for talking about SQoL was appealing, but required finesse in terms of how sensitive and “private” information would be shared.

### **Normalcy**

One of the most important aspects that emerged in the interviews was women’s desire to know what was “normal,” whether what they were feeling was normal, within the bounds of normalcy, and if other women felt similarly and also struggled with sexual issues. Some women spoke of wanting information about the “normal” spectrum of women’s sexual responses and experiences after cancer diagnosis and treatment.

This desire to understand what intimacy looked like for others often accompanied a more anxious feeling that they were out of step with their peers – not only those peers without cancer, but also their peers with cancer: “I think I’d like to know how on a spectrum people are. Like cancer people—like when do they feel sexual and when do they not?” (65 years old, MBC <1 year). This same participant went on to explain that some of this drive for normalcy, at least for her, was related to how cancer took her away from normal in so many other ways that it left her unsure how to imagine where she fitted in with regards to human pleasures more generally:

Well, having cancer, I’m off the continuum. I’m removed a lot from the normal of stuff. I have to see a doctor once a month. I have to take pills or infusion. I get tired and fatigued. I’m just not the person that I used to be, but I’m still human. I’m still having pleasure in life. I’m still glad to be here, very much so. I would just like to know that I’m within the humanity range of personal intimacy and stuff like that. (65 years old, MBC <1 year)

This desire for a feeling of normalcy extended to wanting to know about what women like themselves were experiencing and the importance of having peers who were not feeling sexually attractive and not engaged in sexual activities:

I’m hoping it’s normal to not feel as sexually desirable when you have a mastectomy or whatever, you know, I think, I would think that that’s normal. But maybe other women feel fine about that, I don’t know...Or maybe might have been more towards the beginning, I guess. Or I guess what people do to maybe feel, like is there like tricks, you know, or something that they do to make themselves feel sexier or, you know, I don’t know. That might be helpful. (35 years old, MBC 1 year)

Desires to feel normal, look normal, and act normal threaded throughout the interviews – and throughout all of the themes in this study. Women described worries about normalcy in relationship to sex, feelings of desire, as well as types and regularity of affection. They wondered about how they measured up compared to their peers in terms of sex, not necessarily to match them, but to know just how far away from “normal” they had moved.

### **Discussion**

The breadth of information and resource needs discussed by women in the study highlights the need to make resources available to support the SQoL of patients diagnosed with MBC. Women in this study spoke about psychological needs related to physical loss

and relational dynamics, as well as more instrumental supports such as learning about breast prostheses, specialized lubricants, and meeting people like themselves who could give them advice. Findings provide insight into what patients *needed* to know, but also what they *wanted* to know. Instrumental needs and psychological well-being are often conceptualized separately, but findings from this study indicate that patients experienced them as intertwined; informational needs were woven through with psychological needs, often without much distinction. While informational issues are easiest to address in medical settings, it is important to underscore the wider range of patients' needs and how the emotional and informational intersect.

### **Loss**

Findings indicated that patients desired information about how cancer treatments and surgery would affect their breasts and genitals – and importantly – that this information was not limited to immediately before or after surgery. As mastectomy is most frequently a treatment for early-stage disease, this finding demonstrates how, even years after primary treatment, patients still described information and support needs related to breast loss. While some wished they knew how hard the loss would be and wished there was more support, others desired more practical information about solutions to address physical changes after treatments (e.g. breast prostheses, vaginal lubricants). The lack of information around SQoL made it challenging for some to navigate changes to their sexuality over the course of their diagnosis, from primary treatment, through the transition to palliative care.

When women in the study talked about “missing their boobs” and feeling unexpected loss about their breasts, it became difficult to know where the speaker ended and where cultural norms and partners' expectations of femininity began. This extends research by Gurevich and colleagues (2004) about the role of embodied experiences in a sample of men diagnosed with testicular cancer, in which they found that discursive constructions of sex, gender, and illness played a central role in men's sense of themselves as sexual beings. Findings from the current study echo research in breast cancer about perceptions of femininity and appearance (see Emilee et al., 2010), but extend this work through a closer look at the role of sex and gender norms in MBC. First, femininity norms remain central in patients with advanced disease. Second, there is not a clear divide between a woman's sense of loss and her partner's reactions to her altered body, but instead, these are complexly woven together and may need to be addressed in ways that do not pretend these are distinct from one another. Feelings of embodied loss remain important, even long after the loss, when many practitioners may assume the sting of loss has passed and these feelings of loss may be more dyadically experienced than current support systems recognize.

### **Silences and expertise**

Women in the sample reported experiencing tremendous silences around their sexual bodies. In response to these silences, participants described wanting structured and formal avenues to learn about issues related to SQoL. Unfortunately, the silences they experienced in medical settings had too often meant they learned about SQoL in ways that were

unintended, informal, or worse yet, incorrect. Information needs most frequently discussed were about treatment effects on sexual desire, surgical options, and additional information about how to cope with changes after surgery and treatments. Although participants frequently expressed insufficient support around their sexual concerns, they identified a variety of solutions that would help them cope with the physical, emotional, and social barriers that hinder SQoL. These interview findings extend Ussher and colleagues' (2013) survey study that found that patients expressed a range of needs, including "information on physical changes, sexual response, relationship issues, psychological consequences, and body image or identity" (p. 330). Collectively, these results indicate that connecting with others – practitioners, sexual health experts, peers, and partners – is central for addressing SQoL among women with MBC. Participants provided a range of suggestions, including wanting access to an expert in women's sexual health, having a pen pal to check in with, information for their male partners, as well as access to support groups. Across this range of recommendations was a desire to connect with others about sexual well-being, sexual problems, and questions about sexuality and cancer.

### **Normalcy**

Feelings of "normalcy" have been found to play a central role in the lives of people diagnosed with cancer, including feelings about breast reconstruction and a desire to appear normal or "return to normal," as in prior to or following surgery (Denford, Harcourt, Rubin & Pusic, 2011; Rubin & Ranenbaum, 2011; Rubin, Chavez, Alderman, & Pusic, 2013). The current study adds to this previous literature by elaborating patients' desires for normalcy in terms of sexual well-being. Women described their SQoL as a social process, one that involved the self, real or imagined partners, as well as peers with and without cancer – all of whom were imagined as important when considering whether the patient herself was going to be able to feel normal while living and experiencing changes in her sexual well-being (see also Tiefer, 1995). Patients did not describe a desired return to baseline (as in before cancer), but instead, normal was a form of "passing" (as in looking normal) or as a social comparison made in order to determine whether they had lost something fundamental along the way, the ability to be within the range of normal human experience (as in, am I still human?).

### **SQoL support recommendations**

This study suggests that women with MBC would benefit from the opportunity to discuss SQoL issues with other women, and more specifically, women of their own age and similar cancer stage. Research suggests that the opportunity to discuss sexual issues with others in a supportive group setting can be beneficial for sexual function and arousal (Caldwell et al., 2003). Group settings have been shown to help women with breast cancer in a variety of ways, for example, through decreasing social isolation, distracting women from their cancer and treatments, learning coping skills, helping others, and obtaining information (Nekhlyudov & Yaker, 2002; Vilhauer, 2009). The current study extends prior research (e.g. Vilhauer, 2011) that women diagnosed with MBC may not be served by mixed-stage support groups. Groups for women with advanced breast cancer may be key to serving the general needs of women with MBC as well as their more specific needs

surrounding SQoL. Women in this study expressed interest in knowing more about the experiences of others “like them,” which suggests that for some women, more peer-led and organized group support would be helpful to some women, while others may want a more medical and professional form of support regarding SQoL.

### ***Partner education***

In addition to needing information and support for themselves, the women in this study emphasized the importance of having their partners educated about possible sexual changes that may result from cancer treatments. Studies with early-stage cancer patients have found that making support and resources available to both patients and partners has been associated with positive sexual health outcomes (Northouse, Kershaw, Mood, & Schafenacker, 2005; Northouse et al., 2013; Taylor et al., 2011). Research has found partner responsiveness to have enormous impact on patients’ experiences of pain (Badr & Milbury, 2011) and psychological well-being (Fletcher, Lewis, & Haberman, 2010).

Extending SQoL education and support to partners is key for several reasons: research has found that partners are concerned about sexual changes, but they also sometimes exact emotional and physical demands from their female partners in illness contexts (Fletcher et al., 2010). The findings from the current study extend Fletcher and colleagues’ (2010) argument that medical providers can help to mitigate partners’ demands on patients during primary treatment, but can also be useful beyond this initial phase of treatment. Partner education would also be important to support what Ussher, Perz, Gilbert, Wong, and Hobbs (2012) have described as the necessity of “renegotiating sex outside of the coital imperative.” Couple-focused interventions (Scott & Kayser, 2009) are certainly a useful step; however, the findings from this study suggest that female patients would benefit from their partners receiving education focused on men’s informational needs and may not need to include the patient herself. Partner-focused educational interventions (Cochrane & Lewis, 2005; Kinsinger, Laurenceau, Carver, & Antoni, 2011) may offer the information that patients need, without putting additional time and energy drains on patients.

### ***Patient communication and education***

Findings from this study suggest that it would be beneficial for medical practitioners to check-in regularly about SQoL. Including a “built-in” assessment or inquiry about SQoL issues, including physical and psychosocial aspects of sexuality, every few visits would help normalize the discussion of SQoL. This would also allow women to bring up issues at different time points in their treatment. Regular assessments of SQoL can also help to normalize the discussion of sexuality in an oncological context, which was a major concern for the women in our study. This may also help combat provider assumptions (e.g. biases about older patients) and ease patients’ feelings of shame and guilt for having sexual needs and questions (see also Perz et al., 2013). Finally, building assessments into regular care may help women access information and supports that they may not be aware of otherwise.

For many women within this study, the clinic was imagined as the primary place for learning. The silence and lack of information about SQoL in oncology care led women in

this study to wonder if they were the only person experiencing troubles with their body and sexuality after cancer treatment, which may have only worsened as “sexy cancer” narratives have increased in contemporary cultural narratives (Segal, 2012). Clinic-based social support options may help lessen feelings of doubt and isolation, as well as provide patients with peer supports to help navigate social and partner pressures to live up to a sexual ideal, even at the end of life.

Because sex is challenging for some women to discuss with medical providers, information about SQoL should be provided to patients in a variety of formats. For example, written materials can be saved and referred to when the information is needed. Comprehensive pamphlets, which explicitly discuss potential SQoL issues associated with various treatments, provide information about breast prosthetics, lubrications, and other tools to facilitate sexual activity and health (e.g. a variety of sexual positions and sexual activities including oral sex), as well as normalize sexual abstinence, would help patients discuss these issues with both practitioners and partners. Written materials can help alleviate patients’ concerns, and may be particularly helpful for those who are uncomfortable discussing sexuality with medical providers.

Lastly, it is essential to expand providers’ assumptions about SQoL and to broaden SQoL discussions with patients beyond penetrative sex. While women in this study expressed concerns and questions about issues related to intercourse, they also had many questions about what other types of non-penetrative sex would include, how to talk to their male partners about this, and how to manage dramatic changes to their genitals and sensations (McClelland et al., 2015a). Expanding discussions in medical settings – as well as definitions within research settings – to include not just functionality, but SQoL (in whatever form is appropriate) is an important next step to support the wide range of issues that women need to support their SQoL, regardless of their level or interest in sexual activity. Future studies are encouraged to include more explicit discussion of sexual practices – including, but not limited to vaginal intercourse – to better understand the role of intimate touch as it relates to patients’ sexual health for those with and without partners (see McClelland, 2012; McClelland et al., 2015a). With this in mind, researchers are also strongly encouraged to design studies that inquire about a wide range of sexual practices, beliefs, and expectations that allow participants to respond and discuss their own image of what sexual health means to them and avoid making assumptions about what counts as “healthy,” “normal,” and “sexual.”

### ***Study limitations and future directions***

The current study contributes to the literature on SQoL after cancer diagnosis, and in particular, after diagnosis of MBC. Its findings are descriptive and due to the small sample size, may not be generalizable to all women diagnosed with advanced breast cancer. Because these data were collected at one university hospital, future studies would be served by examining other hospital and clinic settings across rural, suburban, and urban settings, to assess whether the findings extend to other clinical care settings. In addition, these findings may not describe the experiences of women of color and/or women in a variety of social or geographical locations (Barsotti Santos, Ford, dos Santos, & Vieira, 2014; Janz et al., 2008). It is also worth noting that this research was carried out in the USA. The practices and supports available to patients and their families may be very

different than those in Europe and elsewhere (Barsotti Santos et al., 2014). In addition to international differences, there are important domestic differences that would vary widely depending on the quality of the available health care system, access and availability of insurance, as well as many other factors that consistently impact health care delivery in the USA (CDC, 2012; Wang, McLafferty, Escamilla, & Luo, 2008).

## Conclusion

It is widely recognized that sexual changes are one of the longest lasting negative effects of breast cancer treatment (Emilee et al., 2010; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010). The focus on women with MBC in the current study is important as this group may have specific needs that are overlooked in more general studies that often exclude women diagnosed with advanced breast cancer. The current study identified several issues central to women with MBC regarding their SQoL. The women in this study described several possible solutions, including the expertise of other women and sexual health experts who can normalize women's experiences of their bodies, desires, and intimate relationships. Collectively, these results indicate that connecting with others – practitioners, sexual health experts, peers, and partners – is central for addressing SQoL among women diagnosed with MBC. This discussion offers an opportunity to understand more fully what the likely impacts of advanced breast cancer are on SQoL and to highlight these impacts to health care professionals who may not realize that these are not minor issues for the women and partners concerned.

## Acknowledgements

The authors wish to thank Susie Robinson, Harley Dutcher, Eleanor Stewart, Maya Massing-Schaffer, and all of the research assistants who have been a part of this study. And my sincerest thanks to the participants in the study who were brave and kind enough to give us their time and energy.

## Disclosure statement

No potential conflict of interest was reported by the author.

## Funding

This work was supported by the Comprehensive Cancer Center, Cancer Research Committee, University of Michigan; and the Institute for Research on Women and Gender, University of Michigan.

## Notes on contributor

Sara McClelland is an assistant professor of Women's Studies and Psychology at the University of Michigan. Her research focuses on entitlement, expectation, and how much people believe they deserve in their sexual lives as a result of stigmas around sex, sexuality, and identity. She examines these questions in research with adolescents and women near the end of life.

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