
EMPIRICAL ARTICLES

Vaginal Dryness and Beyond: The Sexual Health Needs of Women Diagnosed With Metastatic Breast Cancer

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While research on the sexual health of women with early stage cancer has grown extensively over the past decade, markedly less information is available to support the sexual health needs of women diagnosed with advanced breast cancer. Semistructured interviews were conducted with 32 women diagnosed with metastatic breast cancer (ages 35 to 77) about questions they had concerning their sexual health and intimate relationships. All participants were recruited from a comprehensive cancer center at a large Midwestern university. Three themes were examined: the role of sexual activity and intimate touch in participants' lives, unmet information needs about sexual health, and communication with medical providers about sexual concerns. Findings indicated that sexual activities with partners were important; however, participants worried about their own physical limitations and reported frequent physical (e.g., bone pains) and vaginal pain associated with intercourse. When women raised concerns about these issues in clinical settings, medical providers often focused exclusively on vaginal lubricants, which did not address the entirety of women's problems or concerns. In addition, women diagnosed with metastatic breast cancer reported needing additional resources about specialized vaginal lubricants, nonpenetrative and nongenitally focused sex, and sexual positions that did not compromise their physical health yet still provided pleasure.

Research on sexual well-being after breast cancer diagnosis has gained considerable momentum in the past decade (Goldfarb et al., 2013). The bulk of this work, however, has focused on those with early-stage breast cancers and has often excluded those with Stage IV diagnoses (Pauwels, Charlier, De Bourdeaudhuij, Lechner, & Van Hoof, 2013; Schmid-Büchi, Halfens, Dassen, & van den Borne, 2011; Sharpley, Bitsika, & Christie, 2011). Reasons for this exclusion vary. Some studies have focused on issues of survivorship and, as a result, have highlighted how patients regain sexual function after diagnosis and treatment (e.g., Pauwels et al.,

2013; Schmid-Büchi et al., 2011). Others have focused on the long-term implications of interventions and treatments, which require patients to have longer life expectancies than typically found in patients with advanced cancer diagnosis (e.g., Sharpley et al., 2011).

While these studies have offered important information for patients with early-stage breast cancer, considerably less attention has been paid to the sexual health needs of women living with later-stage breast cancer. As a result, this group of women may not receive the support needed as they transition from curative to palliative care (Aranda et al., 2005; Mosher et al., 2013; Reed, Simmonds, Haviland, & Corner, 2012). To better address this gap, the current study examined the sexual health concerns of women diagnosed with metastatic breast cancer (MBC). Previous research has shown that sexuality concerns are important to individuals with advanced cancers (Lemieux, Kaiser, Pereira, & Meadows, 2004; Vitrano, Catania, & Mercadante, 2011), and those in palliative care may have distinctive

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sexual health concerns, including issues related to physical impairments, ill and aging partners, and distinct psychosocial needs related to the end of life (Stausmire, 2004; Vilhauer, 2008).

Breast cancer treatments have been shown to have a substantial negative impact on women's sexual health (Emilee, Ussher, & Perz, 2010). Treatments for breast cancer—including surgery, radiation, hormone therapy, and chemotherapy—often result in dramatic changes to patients' genitals and, as a result, their genital and sexual response. For example, treatments such as tamoxifen have been found to frequently induce menopausal symptoms in women, sometimes leading to vulval, vaginal, and clitoral atrophy, coupled with vaginal thinning and decreased elasticity (Carter, Goldfrank, & Schover, 2011; DeSimone et al., 2014). Changes in vaginal secretions contribute to symptoms of genital dryness, irritation, and burning as vaginal pH levels shift from acidic to alkaline during treatment (see Nappi, Albany, Strada, & Jannini, 2011). Women who undergo chemotherapy have been found to be at higher risk for sexual dysfunction than those who are not treated using chemotherapy (Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999); chemotherapy has consistently been associated with reports of decreased sexual desire, dyspareunia, difficulty with arousal, lubrication, and orgasm (for reviews, see Emilee et al., 2010; Hughes, 2008).

While frequency of intercourse and pain during intercourse are often primary indicators of posttreatment sexual health (e.g., Rosen et al., 2000; Vitrano et al., 2011), these indicators may, in fact, correlate poorly with female sexual satisfaction or sexual quality of life (McClelland, 2012). One area of emergent research has examined other, perhaps more relevant, indicators of sexual quality of life for women diagnosed with cancer (Flynn et al., 2010; Ussher, Perz, Gilbert, Wong, & Hobbs, 2012). Research in this area has found a wide range of important factors to consider when evaluating sexual health in this population, including the presence and frequency of intimate touch (Flynn et al., 2010); development of new definitions of sex and sexuality that extend beyond intercourse (Cleary & Hegarty, 2011; Lemieux et al., 2004; Ussher, Perz, Gilbert, Wong, et al., 2012); the presence of couple support, intimacy, and communication (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Lindau, Surawska, Paice, & Baron, 2011; Milbury & Badr, 2013); changing gender expectations in heterosexual relationships (Gilbert, Ussher, & Perz, 2013; Oliffe, 2005); as well as developing new sexual practices that attend to physical and/or psychological changes as a result of breast cancer (Manderson, 2005; Ramirez et al., 2010; Wilmoth, 2001). These findings highlight that practitioners in clinical settings may need to support women's sexual health by offering a broader set of information sources and providing support that extends beyond intercourse-related sexual activities and helps patients, both with and without partners, to

develop strategies for feeling and sharing sexual intimacy and pleasure.

In the context of cancer treatment, this need for information and emotional support about intimate and sexual changes is unfortunately not often met in medical settings (Carter et al., 2011; Flynn et al., 2012). Flynn and colleagues (2012) recently found that sexual problems were a widespread concern among patients; however, many did not receive the information they needed from their oncology providers. In particular, only 33% of breast cancer patients in their sample ($N=252$) had received information from an oncology doctor or nurse about how cancer or cancer treatments may affect their sex life (Flynn et al., 2012, p. 598). Other studies have found that doctors overlook sexual health issues altogether with this population, sometimes due to assumptions about its lack of importance to patients (Stausmire, 2004) or discomfort with the subject of sexuality (Ussher, Perz, Gilbert, Wong, et al., 2013). Researchers have also found that practitioners often limit their understanding of patient sexuality to fertility, contraception, menopause, and erectile function (Hordern & Street, 2007). This information is likely useful to some but not all patients. Questions therefore remain about what information and educational support for patients is overlooked as important or ignored altogether. Given these concerns about sexual health needs and information gaps, as well as the scant information available about the specific and unique information needs of patients diagnosed with metastatic disease, the current study used qualitative interview methods to examine the sexual health concerns of women diagnosed with MBC to help guide clinical practice and intervention design.

Method

Procedures and Participants

The current study was part of a larger study concerning quality of life of women diagnosed with MBC (McClelland, Holland, & Griggs, *under review*). Patients were recruited from the breast oncology program at a Midwestern comprehensive cancer center. All women attending the breast cancer clinic were screened for a confirmed diagnosis of MBC prior to a scheduled appointment with their oncologist. To be eligible to participate in the study, female patients were required to be over 21 years old, able to read and speak English, have no major psychiatric illness diagnosis, and a life expectancy of at least three weeks. Before approaching patients, medical providers were consulted about whether each patient met these inclusion criteria. If inclusion criteria were confirmed, patients 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 for those patients who expressed interest. Institutional review board (IRB) approval was

obtained, and patient consent and study procedures were carried out in accordance with IRB guidelines. Part of the informed consent procedure included permission to extract relevant information from medical charts concerning participants' disease and treatment details.

Of the 192 patients who agreed to be in the larger study, 108 (56%) consented to be contacted separately for an interview. We sought to interview 37 women (approximately one-third of the survey sample). In the four months allotted to conduct interviews in the breast cancer practice, we were able to interview 32 women. This sample size was decided to be sufficient as we were able to maximize data saturation while minimizing participant burden. Data saturation is considered the point in the data collection process when interviewing additional participants would not yield additional theoretical insights (Charmaz, 2006). For many researchers, 25 to 30 interviews is considered the minimum sample size required to reach this saturation point when working with in-depth interviews (Dworkin, 2012). In addition to these concerns, we had to weigh the unique ethics involved in research with participants near the end of life; lessening participant burden was an essential aspect of our sample size decision.

Because sexual health has been found to differ across the life span (DeLamater, 2012), we were attentive to participants' ages when creating the interview sample. When contacting participants for the interview portion of the study, a purposive sample of women from three age groups (30 to 49; 50 to 65; 66 to 85) was created to ensure that a wide range of ages were represented in the interview sample. Patients were selected to be in the purposive sample relative to the number of participants in each age group who had participated in the survey portion of the study. The number of participants in the three age groups was not evenly distributed; the largest group was the middle (50 to 65 years old) group. In total, 73 patients were contacted by phone to schedule an interview that occurred in conjunction with a scheduled visit to their oncologist. Of these 73 women, 32 (44%) agreed to be interviewed; 14 women declined when reached by phone; seven could not be reached after three attempts by phone and were considered a passive decline; two participants were deceased; two were ineligible due to hospice stays; and 16 were not scheduled to be in the clinic in the four months when interviews were scheduled.

Of the 32 women who participated in the interviews, eight women were in the younger age group (30 to 49), 18 women were in the middle age group (50 to 65), and six women were in the older age group (66 to 85). (Refer to Table 1 for additional sample details.) Results from chi-square and *t*-tests were examined to determine whether participants who were interviewed differed from those who were not interviewed. No differences were found related to participants' demographics (age, socioeconomic status, race/ethnicity, sexual orientation, partner status, menopause stage), diagnosis (time since initial cancer diagnosis, time since metastatic diagnosis),

Table 1. *Sample Demographics (N = 32)*

Variable	Mean	SD	n	%
Age at interview	56.8	9.6		
Years since initial breast cancer diagnosis	8.7	8.6		
Years since metastatic breast cancer diagnosis	2.9	3.6		
Relationship status				
Partnered			21	66
Not currently partnered			11	34
Sites of metastatic disease*				
Visceral				
Brain			2	6
Liver			13	41
Lungs			6	19
Pericardial effusion			1	3
Mediastinum			1	3
Pleura			2	6
Bowel			2	6
Peritoneum			1	3
Ovaries			1	3
Nonvisceral				
Bone			22	69
Lymph nodes			7	22
Skin			4	13
Chest wall			1	3
Treatment and visceral disease (at time of interview)				
Endocrine/nonvisceral disease			12	38
Endocrine/visceral disease			15	47
Chemotherapy/nonvisceral disease			2	6
Chemotherapy/visceral disease			3	9
Chemotherapy history				
No chemotherapy/unknown			3	9
Chemotherapy received			29	91
Adjuvant setting only			10	31
Metastatic setting only			8	25
Both			11	34

Note. All reported time in years. *SD* = standard deviation; *Sites may be represented more than once, exceeds 100%.

or treatment characteristics (chemotherapy, mastectomy, Herceptin, radiation, hormone therapy, endocrine therapy). Women who participated in the interview portion of the study received \$20 for their time in the form of a gift card mailed to their homes. To ensure confidentiality, cards were mailed from the university and did not contain any details concerning the study or the research team.

All interviews were conducted face-to-face in a private room in the breast cancer clinic and were completed by a female interviewer (the first author) with extensive experience in conducting in-depth interviews. Prior to the interview, participants completed a card-sorting task that involved sorting 63 cards about aspects of sexual health into piles according to how much they agreed or disagreed with the statement on the card (McClelland, 2014; Perz, Ussher, & Gilbert, 2013). This procedure allowed participants to gather their thoughts before beginning the interview; the findings from the card-sorting procedure are presented elsewhere (McClelland, under review). During the semistructured 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 these changes were (if any), what they had learned about any sexual health changes to expect from their medical providers (doctors and/or nurse practitioners), what they wished they had learned about, and what advice they had for others going through something similar (see appendix for interview topic guide). Interviews lasted approximately one hour and were audiotaped and transcribed for analysis.

Analysis

Participants' descriptions of their sexual health, sexual activities, and concerns related to sexual health were examined, as well as their descriptions of ease and ability to communicate with medical providers. Last, patients' recommendations for best practices were examined. This included their ideas about what information and support would have been helpful to them from their initial breast cancer diagnosis through the present. 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.

In alignment with previous research that identified gaps in sexual information provided to patients (Ussher, Perz, Gilbert, Wong, et al., 2013) and patient/provider communication issues (Hordern & Street, 2007), four categories of coded data were analyzed. These included what kinds of information patients reported receiving about their sexual health ("Info I Got"); the types and timing of information they wished they had received ("Wished I Knew"); what they would tell another woman going through a similar situation ("Advice"); and the nature of interactions with medical providers, including oncologists and nurse practitioners, concerning sexual health ("Docs & NPs"). Within these larger codes, several subcodes were developed to represent the patterns found within each of these larger categories; themes within these codes are described in the following sections. Two trained research assistants coded interview transcripts using the coding software Dedoose, version 4.5 (2013, SocioCultural Research Consultants, Los Angeles, CA); interrater reliability was very good (Cohen's kappa = .85; Cohen, 1960), indicating that coders regularly recognized similar patterns in the data and code application procedures.

Results

Sample Demographics

Patients who were interviewed 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 of these were in heterosexual relationships. Of those in relationships, 16 participants had been in these relationships for more than two decades ($M = 26.5$ years; $SD = 16.1$). Five women were dating and had entered relationships more recently; of these five, three 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; $SD = 3.6$). Approximately two-thirds (69%) of the sample had bone metastases and 41% had metastases in the liver (see Table 1 for details); 29 participants (91%) had received chemotherapy, and eight of the 32 participants in the sample (25%) had received two or more regimens of chemotherapy.

To examine the range of disease severity in the sample, an index variable was created which distinguished patients' current treatment regimen (endocrine therapy, chemotherapy) and the presence of visceral/nonvisceral disease at the time of participation. Visceral disease was defined as having metastases in one or more of the following: brain, liver, lungs, pericardium, pleura or mediastinum, bowel or peritoneum, or ovaries. In this sample, 18 (56%) had visceral disease, most ($n = 27$, 85%) were on endocrine therapy, and five (15%) were on chemotherapy at the time of participation (see Table 1).

Thematic Findings

Three themes emerged in the analysis related to patients' sexual health needs: the role of sexual activity and intimate touch in participants' lives, patients' unmet information needs about sexual health, and communication with medical providers about sexual concerns. Findings are described in the sections that follow. When patients are quoted, their age, partner status, and time since MBC diagnosis are included with each interview excerpt to give a sense of the range of experiences represented in the findings.

Role of sexual activity and intimate touch. The women in our study expressed that sexual experiences and intimacy were an important component of their lives. For instance, some patients described sexual activity as a way to bond with a partner and relieve stress. This finding is consistent with research done with healthy women on sexual motives (Brotto, Heiman, & Tolman, 2009; Meston, Hamilton, & Harte, 2009). Women in our study also described how navigating their sexual lives while dealing with MBC presented unique challenges. These challenges were often related to experiences of physical frailty and painful intercourse. Overall, women reported feeling frustrated and worried about how to maintain sexual activity both alone and with their partners, as well as concerns about how to work within the limits of what their body

could handle. This is seen in two participants' descriptions of sex as both potentially healthy and as a form of abuse:

A sexual life is a healthy life, so they always say—which I understand because there's so many things that you get from it. . . . But physically the thought of it is almost like abuse to my body. So if we could figure out a way—without having to play Twister, which I can't do—to be able to be comfortably intimate, you know, well we've tried everything possible we can think of. (50, partnered, MBC 2 years)

And when we tried to have sex initially it was very difficult. It was so painful, and we actually were hurting, both of us, because it was real important to both of us, and big stress relief. (61, partnered, MBC 17 years)

These women benefit, or benefited, from sexual activity with their partner; however, they consistently reported that their sexuality became a source of stress and frustration within the context of their illness. Participants regularly expressed that sexual relationships were important, yet physical limitations prevented some sexual activities that were once enjoyable. For example, the following participant described how she experienced her body being affected by the presence of cancer in her hip joints:

Now, with the bone metastases, being that it's in my hips, it makes it really difficult because physically that whole region is affected, and sometimes just the thought of being touched sends me into pain. The lesions being right on the hip bone and in the ball of the femur joint, movement that typically would be used with intimacy is out of the question on most days. Though in your mind you think you can, and physically you look like you can, internally your body is saying, "Don't even think about it." (50, partnered, MBC 2 years)

Diagnosis and treatment of MBC can limit women's sexuality in unique ways. One of the ways that sexuality can become limited is due to the physical stress that sexual activity can require. For example, some women expressed that their physical pain was a significant barrier to their initiation of sexual activity. Bodily limitations associated with cancer treatments presented significant barriers to sexual activity, both physically and emotionally. The physical toll that treatments take is an important part of this puzzle; as this participant described, these issues are not often talked about:

I mean of course you always hear about the hair. You never hear about the skin. You never hear about your fingerprints falling off. You don't hear about your nails turning black, your teeth breaking off, your thyroid going black. That stuff you don't hear about. Because a lot of people don't live that long for that kind of effects to show up, or they just don't talk about it, never put the pieces together. (53, divorced, MBC 2 years)

Participants frequently stated that they were uncertain about what their bodies could and could not handle, and ultimately that the physical limitations and fears associated with these limitations had a negative impact on their sexual well-being. Patients reported not knowing how to navigate these physical changes without help from their medical providers.

I'd probably, I would say [my sexual health] is not as good is because of the fear, but in reality, too, is 'cause I have cancer all through, down my spine and on my ribs, even on my hips, so it's pretty hard to say. And I guess it's mainly because—I don't know, because the fear of the unknown is—the doctors don't tell you how far you can and can't go. They don't even discuss what you can and can't do. (60, partnered, MBC 4 years)

Overall, the context of MBC created specific problems and concerns for women's sexual well-being. Pain prevented some women from engaging in sexual activity. Other women expressed concern about their body's physical capacity to be sexual. Ultimately, these fears of physical limitations affected their sexual decisions and actions.

Patients who were not currently partnered also discussed changes in their sexual health and physical sexual response as a result of their breast cancer. Patients who were actively dating and looking for partners talked about the stress of not knowing how and when to talk to dating partners about their illness or what sexual relationships would be like now that their bodies had changed as a result of surgery and/or chemotherapy. In addition, women who described dating men struggled with how they imagined male partners would emotionally and physically respond to them once they knew about their cancer. Most pressing for many was the issue of changing sexual norms in relationships to include nonpenetrative sex:

That doesn't mean that a man's going to understand my shifting thinking about the fact that intercourse doesn't have to be the gold standard. Again, you know, it's touchy. At what point do you talk about that? Certainly wouldn't be the first coffee date [laughs]. (63, single, MBC 10 years)

These experiences highlight the fact that women in this sample, regardless of their diagnosis, were interested in seeking out satisfying relationships and engaging in new intimate relationships—an image that is not often enough portrayed when considering advanced-stage cancer and sexuality.

Unmet information needs about sexual health. Throughout the interviews, participants described questions and concerns they had about their sexual health. The two most salient themes described were issues related to vaginal lubrication during intercourse and finding sexual positions and activities that would not injure them or cause them additional pain.

Vaginal lubrication. Participants consistently reported wishing they had more information about vaginal lubrication and ways to deal with vaginal pain during intercourse but either felt embarrassed to ask or unable to get sufficient information from their doctors. In particular, participants reported feeling that they were not sufficiently warned about vaginal pain and how to cope with these changes.

Intercourse was very painful, yeah. But I think that we just took it easy. I hadn't been forewarned that this could happen, you know. It's not one of those things you just talk about [laughs]. (40, partnered, MBC less than 1 year)

In addition, patients reported needing much more detailed information about vaginal lubricants, given that doctors frequently recommended vaginal lubrication but did not often elaborate on this recommendation further.

What's the best type of lubricant to use? Because I tried all kinds of things, and some of them are just nasty. And you have to go through all that to find out, [and] maybe some different ways to work around the fact that I'm in pain. Those kinds of questions, it would be good to have somebody to talk to about that. (56, partnered, MBC less than 1 year)

A lot of people talk about K-Y Jelly, so that's what I tried right away, and it might have helped for a little bit, but it seemed as time went on it got more painful for some reason. I don't know. We still don't know why. (60, partnered, MBC less than 1 year)

Patients often reported that lubricants alone were not sufficient to solve the pain associated with sexual intercourse. Women were confused about which lubricant to try and why some vaginal lubricants seemed to result in irritation. In addition, vaginal dryness may have been problematic for other reasons, including pain from contact with the vulva or clitoris with manual sexual stimulation. Overall, patients described needing more detailed information not only on what types of lubricants worked best for women posttreatment but also where to find lubricants more generally and, if specialty lubricants were needed, how to locate and purchase these as well.

If patients reported that a medical provider had discussed sexual health issues with them, the information had come at a time when they were not able to understand the information or did not understand the information as relevant to them. The pressing issue for participants, as highlighted in the following quote, was that these conversations were often one-shot deals and did not provide sufficient information for patients:

You know, I've never really discussed my sexual health with [Doctor 1], and the last time I think I had any conversation about sex was my return visit after I had my ovaries removed with [Doctor 2]. He just said,

"You know, now that your ovaries have been removed you're going to notice that, you know, some sexual difficulty, like your vaginal walls will get thinner and there will be some pain and you might not get lubricated as much." But it was like, you know, a few weeks after I had my surgery so I didn't really pay that much attention to it. I thought, "There's no way." So I haven't had a discussion about sexual health with anyone. (44, single, MBC 4 years)

This example demonstrates that sexual health information should be regularly discussed, as patients may not think of themselves as anticipating sexual activity or may not remember early conversations about cancer treatments and potential outcomes. As timing of sexual health information may differ across women, this points to the need to regularly address issues related to sexual health rather than only intermittently or early in the treatment timeline.

Sexual positions and activities. In addition to vaginal lubricants, patients expressed information needs surrounding ways to engage in sexual activities beyond penetrative intercourse. Nonpenetrative sexual activity and intimacy were regularly described as important in the interviews, although women reported a variety of feelings about the lack of intercourse in their lives. For example, the following participant described this shift as adaptive ("maximize other things that are available") but also expressed that this was not necessarily her first choice:

I guess the main thing is—is you have to find a way to still be sexual, you have to find a way to still give love and feel loved . . . Even if you aren't able to or don't feel up to frequent intercourse the way things were, you know, it would be to really maximize the other things that are available to you. (59, partnered, MBC 7 years)

Participants described engaging in a range of sexual activities, including oral sex, while others emphasized the importance of intimate touch. For example, one participant commented that touching and holding hands with her partner was most important to her:

More of just touching, feeling, holding hands, putting your arm around each other, things like that—not necessarily sex. Just the touching and like that. Yeah. (40, partnered, MBC less than 1 year)

Several women expressed the desire to have more information about sexual positions and activities that would be safe, not exert stress on their bodies, and still be pleasurable. For example, one woman stated:

I have the chest tube on this side, that's also the side that I have the breast cancer . . . If one position is gonna advance something or hurt you or whatever, that would be really helpful, because who knows? You know, you feel great and walk in here one day and you find out you're not . . . It wouldn't occur to me to think that

maybe I shouldn't be doing that while I've got this, or laying in that position could make this [cancer] spread. We don't know anything like that. (54, partnered, MBC less than 1 year)

Patients described wanting more information about how to engage in sexual activities that would not put them in further danger or hurt their bodies more.

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, so I guess it's an education issue that's dawned on me while I'm doing this, that we don't know what we can or can't do. (60, partnered, MBC 4 years)

In addition to questions concerning vaginal lubrication and comfortable sexual positions, participants described several other types of questions they had about their sexual health. For example, one woman expressed her uncertainty and concern about giving a sexual partner cancer:

What if I was in a relationship—I don't even mean about pain or dryness or anything like that, I just mean about is there any risk? I know it's a crazy thing, but is there any risk, cancer cell, you know, is there any risk to transfer a cancer cell? (56, divorced, MBC less than 1 year)

This kind of question about the role of intimate contact in women's lives highlights the way that women lacked both basic information about how vaginal contact would impact a partner, as well as information about how best to engage in desired vaginal intercourse with a partner. These findings demonstrate that women with MBC have specific questions and concerns about their sexual health and well-being and a desire to have their questions answered by medical professionals. Patients consistently described the importance of practitioners recognizing and validating ways of being sexual beyond penetrative intercourse. Women expressed the desire for medical providers to help them maximize their sexual health and activities, even if intercourse was not desired and/or not possible. Unfortunately, these aspects of sexuality were not regularly discussed with patients.

Communication with medical providers about sexual concerns. Although patients in our study frequently had questions about their sexual health, they experienced difficulty finding appropriate support to address these questions. For instance, some women were unsure of how to ask questions or even what to ask for. Other participants reported that they felt their doctors were uncomfortable with talking about sexual health topics, so they did not want to broach the subject as a result. Still others reported feeling rebuffed by providers who offered limited or unhelpful support:

I've been told, "Oh, they're men, they'll deal with it," and from that to, "Talk to a sex therapist," you know,

and everything in between...I'm dealing with mets [metastases] in my bones till the day I'm gone...and I sure can't figure it out on my own, so if we could have somebody that could help us with that. (50, partnered, MBC 2 years)

Participants in the study reported that their medical providers were reluctant to bring up the discussion of sexual health, and as a result it made it difficult for patients to bring up their questions. As one participant said, "[If] you're not gonna bring it up, I'm not gonna bring it up" (60, partnered, MBC less than 1 year). Another participant echoed this sentiment: "Our doctors don't feel that comfortable talking to us about it" (50, partnered, MBC 2 years). This discomfort created a consistent set of interactions in which women's desire for information about sexual health was frequently ignored or even sometimes disparaged when meeting with their oncologists. For example, one participant related her experience of feeling this lack of information provision: "[The doctor] said, 'You're just not wet!' You know, 'Go get some lube!' You know, there was a lot of insensitivity from physicians" (77, partnered, MBC 2 years).

In addition to feeling uncomfortable talking about sex and sexual health, participants reported that the information they received from doctors was often limited both in terms of specificity and in terms of the consistent focus on penetrative sex. For example, one participant described this as follows: "Doctors would just say, 'Well, just use more lubricant.' Yeah, like that will fix it all, and just doesn't" (59, partnered, MBC 7 years). Medical providers almost exclusively focused on improving vaginal penetration, which some patients did want to know more about, but this did not address the needs of all women in the study. For example, this participant highlighted that focusing on penetrative sex actually overlooked the way that she experienced sexual pleasure:

I don't know where any sex shops are or anything like that. And it seems like most of those are focusing on [pause] penile replacement. And that isn't where most of my pleasure center comes from. So actually the more—the vibrators for the muscle massage seem to work better. (53, single, MBC less than 1 year)

While patients reported that vaginal dryness was important, it was not the extent of their sexual health issues. Patients described a wide range of sexual health information needs, such as needing information about nonpenetrative sexual behaviors and more details about vaginal lubricants, and nearly all felt that the overall topic of sexual health was underdiscussed. For example, this participant described wanting to have a resource center available to help answer her questions:

It would—it would be nice if even the [hospital] resource center would have something. And I looked for books and I went to the library, and there's absolutely nothing

on there on what women who have no hormones should do about sex. Or how to get it back other than you can use lube. (44, single, MBC 4 years)

Of note, the hospital in which the breast cancer clinic operated had a center that served the sexual health needs of patients, although very few patients reported that they knew of this resource and most stated that they would not feel comfortable using such a resource. It was either described as “not for them” or, most important, if patients were not engaging in intercourse, they felt this information resource was not warranted.

This finding speaks to the need for medical providers to be one of the main sources of information on issues related to sexual health. Having specialized centers or designated staff to provide sexual health information is certainly an essential resource for those who consider themselves as needing sexual health information. However, not all patients think of themselves as needing sexual help, and as a result specialized resources may be overlooked, ignored, or seen as irrelevant. This may be especially true for those patients who are in the process of developing or learning about sexual practices that they may not see as “sexual” because they do not include intercourse activities. Patients experiencing a wide range of needs—from mundane needs to much more serious issues—may be too easily overlooked in current support systems.

Discussion

Women with MBC experience unique sexual health challenges that are not well addressed in standard patient communication with medical providers. In line with previous research, women with metastatic diagnoses endorsed the importance of sexual desire, activity, and relationships (Mercadante, Vitrano, & Catania, 2010; Vitrano et al., 2011). Findings from the current study provide additional details about what patients need to know more about, including specific concerns regarding vaginal lubricants, sexual positions that can accommodate unique surgeries and treatments (including chest tubes), and sexual support in clinical settings which encourages and educates patients about nonpenetrative sexual activities with partners.

Previous research has consistently found a strong relationship between cancer, its treatments, and negative sexual health outcomes (DeSimone et al., 2014). Findings from our study extend this prior research and help us understand several important insights: (1) women require information and support to navigate their own (changing) sexual health; (2) this may require supporting women in imagining sexuality beyond vaginal dryness and penetrative intercourse, which may not be desired and/or available to them; (3) support is needed from medical providers, including physicians, to navigate patients’ and their partners’ investment in penetrative

sex, even when this activity is experienced as extremely painful (Ayling & Ussher, 2008; Farrell & Cacchioni, 2012); (4) having sexual health information as part of the hospital system may not be sufficient; participants consistently reported physician communication as highly influential in their self-assessment of normalcy; (5) sexual health questions were not limited to those who were in long-term relationships; participants who were single and/or dating also reported needing information about sexual health; and (6) interest and investment in sexual health was not limited to only the younger women in the study; it was found to be important to women of varying ages.

The Role of Medical Providers

Recent studies have found that medical providers recognize the importance of sexual information for their patients but may avoid conversations about sexuality because they prioritize competing clinical interests, perceive sex as inappropriate or irrelevant for some patients, and in addition lack knowledge, confidence, and comfort in discussing sexuality (Flynn et al., 2012; Lindau et al., 2011; Ussher, Perz, Gilbert, Wong, et al., 2013). Our results suggest that medical providers may rely too heavily on certain solutions (e.g., vaginal lubricants) without fully understanding patients’ sexual health concerns. In tandem with providers’ discomfort, research also suggests that patients’ embarrassment may prevent them from initiating conversations about sexuality with their doctors (Sharpley et al., 2011; Ussher, Perz, Gilbert, Wong, et al., 2013). The current study emphasizes the importance of recognizing how practitioners who do not inquire about sexual well-being may inadvertently communicate that patients should also keep quiet about this issue. As a result, patients may suffer in silence about physical pain, relationship strains, and concerns about whether they can experience sexual pleasure alone and/or with partners.

Unfortunately, medical providers are often ill-equipped to discuss sexual health with their patients. In their study of health exams with older adults aged 50 to 80 years old, Ports, Barnack-Tavlaris, Syme, Perera, and Lafata (2014) found that physicians inquired about patients’ sexual health in only 4% ($n = 17$) of the exams. The researchers found that physicians relied on vague references such as, “Is everything ok down there?” and “Are you having any vagina problems?” (p. 5), which highlights the limits of how sexual health care is sometimes provided. Similarly, in a study with health care professionals, Ussher, Perz, Gilbert, Wong, and colleagues (2013) found that providers made assumptions about which patients would (and would not) want to know about information related to sexuality. As a result, individuals in the palliative stages of cancer were positioned as outside the boundaries of sexuality, as well as “[p]atients who were of older age, had a non-reproductive

cancer, and were not in an intimate relationship” (Ussher, Perz, Gilbert, Wong, et al., 2013, p. 1381). Clearly, more physician education and support is needed, as many have argued persuasively elsewhere (Flynn et al., 2012; Hordern & Street, 2007; Lindau et al., 2011). Ussher, Perz, Gilbert, Wong, and colleagues (2013) proposed several useful recommendations for increasing the medical provision of sexual health support, such as including sexuality on routine clinical checklists, ensuring privacy during clinical consultations, and providing specific training in discussing sexuality as part of basic communication training and ongoing professional development.

A larger and more complicated issue is how and when to make information available to patients about their sexual health. The current study highlights two important points: (1) the need for information about sexual health to be integrated with the rest of oncological care and (2) current definitions of and assumptions about “sexual health” limit the kind of care that women receive. This raises two separate but related issues: one of timing and one of definition.

In terms of timing. Our findings demonstrate that if sexual health information was received, it often arrived at a time when women were not yet aware of what they would need and could not yet anticipate their support needs until their bodies had begun to change from effects of cancer or treatment. This finding demonstrates that sexual health assistance needs to be integrated with the rest of treatment. Providers asking patients about sexual health concerns, including genital and relational well-being, is one step; listening to patients’ desires and suggestions for how they would like to learn about sexual health is another (McClelland, Holland, & Griggs, *under review*).

In terms of definition. Our findings highlight several key limitations in defining optimal sexual health solely in terms of vaginal intercourse. While intercourse was important to some, it was consistently held up as the only way to have sex, even when this activity caused tremendous pain for women. This was echoed in the ways that physicians limited their support for women to “get some lube” even when this did not address the larger issues of how to feel sexual pleasure alone or with a partner. The persistent definition of sexual health as marked by the presence of penetrative intercourse resulted in some women feeling they were outside of the scope of “sex” and “sexual health,” and as a result they often did not seek care or supports that may have been beneficial for them.

Not every participant indicated that they had unmet sexual health needs in the current study. However, most participants discussed having support needs related to relationships, body image, and desire for intimate touch. In our analysis, and following previous research (McClelland, 2012), we defined these concerns as dimensions of sexual health, although participants themselves may not have considered these comments as necessarily relevant to their

sexual health. This speaks to the complicated definition of sexual health in terms of research studies, medical care settings, and in patients’ experiences of their intimate lives (Cacchioni, 2007; Segal, 2012). With this in mind, providers and researchers alike are encouraged to widen the definition of sexual health to include nonpenetrative sexual activity (McClelland, 2012; Ussher, Perz, Gilbert, Wong, & Hobbs, 2012), pair discussions of mastectomy and body image with discussions of sexual health (Fobair et al., 2006), and find ways to support patients regardless of their age, marital status, or disease progression (Carter et al., 2011). In addition, and perhaps more importantly, medical providers may also need to be provided with the resources to be able to imagine their patients as sexual beings at the same time as they are also helping them prepare for the end of life (Granek, Krzyzanowska, Tozer, & Mazzotta, 2013).

Beyond Vaginal Dryness

While participants consistently described the issue of vaginal dryness as important, the information they received about lubricants was either insufficient or not timed well in their care trajectory, resulting in mismatched needs and information provision. This focus on dryness also did not allow for conversations about what their bodies could handle in terms of exertion or weight, alternative forms of sexual interaction, and candid discussions of sexual positions. This finding does not diminish the importance of vaginal dryness, but it does press for an expanded definition of sexual health concerns and needs. Information is needed on several levels: specialized lubricants and their use posttreatment; where to purchase and why these might be important; what kinds of intimate and sexual interactions might be available or possible; ways to treat vaginal atrophy; and where to seek out information about genital health, intimate touch, and sexual pleasure. Hence, the needs described by patients in this study included—but extended beyond—information about increasing vaginal lubrication.

Previous studies have regularly found women reporting painful intercourse, both in women without cancer (Ayling & Ussher, 2008; Hyde, 2007; Vares, Potts, Gavey, & Grace, 2007) and women with early-stage cancers (Jensen et al., 2004; Ussher, Perz, & Gilbert, 2012). Building from this research, it is increasingly clear that a wider range of sexual information and support is needed—and that support for sexual and intimate practices which do not focus only on achieving penetrative intercourse are warranted (Ussher, Perz, Gilbert, Wong, & Hobbs, 2012). The presence of pain during intercourse is a complex issue to be sure; one important response to this set of findings has been a feminist intervention to examine the underlying social pressures to participate in heterosexual activities—even when these activities are painful (Ayling & Ussher, 2008; Fahs, 2014; Farrell &

Cacchioni, 2012; Vares et al., 2007). While these feminist critiques were not developed within a cancer context, these perspectives and insights are very relevant to those diagnosed with cancer as well. In particular, the argument for articulating and valuing a wider set of sexual behavior norms seems especially relevant to women in the current study. As Farrell and Cacchioni (2012) argued, “We support the revision of [research designs] . . . that assume pain-free intercourse is the ultimate goal or primary sign of recovery from sexual pain” (p. 334). It is important to weigh patients’ desires for intercourse with critical perspectives on how “normal” and “healthy” sex is consistently defined in clinical settings, and within this complicated space, provide information for patients and their partners on ways of being intimate that will be pleasurable, not harm patients or put their bodies under duress, and also provide comfort that they are still sexual.

Findings from this study, while most relevant to patients diagnosed with MBC, may extend to those with early-stage cancers as well. While the sample in this study was comprised entirely of heterosexually identified women, findings regarding nonpenetrative and nongenitally focused sexuality would be relevant, and perhaps more so, to lesbian and bisexual women, as well as nonpartnered women, for whom penetrative intercourse may not be desired. In addition, a wide range of ages was represented in this study. While studies have often found that sexual concerns are most frequently reported by younger women with a diagnosis of breast cancer (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998), we found these concerns not limited by age but instead relevant across the life span. Finally, in regard to thinking more carefully about the types of disease that women with MBC face, participants in this study had a range of disease severity, including both visceral and nonvisceral disease. As newly developed cancer treatments emerge and life expectancies extend, these issues should gain further attention as research on MBC continues to grow.

Study Limitations and Future Directions

The current study contributes to the literature on sexual health and well-being after cancer diagnosis, and in particular, after diagnosis of MBC. Its findings are descriptive and due to the small size, may not be generalizable to all women diagnosed with Stage IV breast cancer. One limitation of the study relates to the fact that the majority (85%) of our sample was on endocrine therapy rather than chemotherapy; our findings may not generalize to women on chemotherapy, given that women on chemotherapy are, in general, living with more severe disease and more severe adverse effects of treatment. Because the study was conducted in a clinical setting, our sample did not include those patients who were too ill or physically unable to come to the clinic. This aspect of our design may have decreased the number of patients

in the sample who were uninterested in sexuality or unwilling to express sexual health concerns. Future studies with this population would be served by sampling participants who are not able to come to the hospital regularly and/or travel to participants’ homes to better include their experiences. In addition, because the 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. Lastly, like many studies on breast cancer and sexual health, the current study was severely limited by its lack of racial/ethnic diversity; as a result, the findings may not describe the experiences of women of color and/or women in a variety of social or geographical locations (for relevant research in this area, see Ashing-Giwa et al., 2004; Janz et al., 2011).

When designing studies about sexual health, researchers often face questions concerning selection bias in their samples; there are concerns that those participants with more or fewer sexual health needs are more or less likely to participate in a study about sexual health. We made several decisions in order to address these concerns. Participants were recruited into a study about “quality of life concerns of women with metastatic breast cancer.” During study recruitment, potential participants were not told that the study was about sexual quality of life to diminish selection bias and to increase the likelihood that patients who did not consider themselves as “having sex” (often assumed to be intercourse) were included in the sample. This helped ensure diversity of sexual and intimate practices in the sample. Prior to being interviewed, participants had taken a paper-and-pencil survey that contained eight scales, four of which were sexual health or sexual function scales. Because patients had been exposed to these survey questions prior to being contacted about the interview, this may have impacted who was willing to be interviewed.

In addition, group differences may, of course, be important to consider more fully. We did not find patterns of difference related to the three age groups we sampled for or patients’ partner status; however, both of these have been found to be important dimensions of sexual health for women diagnosed with cancer in previous research (e.g., Avis, Crawford, & Manuel, 2004). Future researchers are encouraged to examine potential group differences, while also keeping in mind that the social norms for various groups (e.g., single, older, not having sexual intercourse or genitally focused sexual activity) may limit what patients feel comfortable sharing, what they imagine for themselves, and/or what they (or others) expect as “normal” when sharing experiences about “sexual health.” 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.” For example, one of the important pieces of the sexual health puzzle is the role of masturbation in patients’ lives. Masturbation was not discussed often by participants in the current study; this may be due to several reasons, including participant age or because discussion of specific sexual activities was not included in the interview guide. Future studies are encouraged to include more explicit discussion of sexual practices to better understand the role of intimate touch as it relates to patients’ sexual health for those with and without partners.

Conclusion

Patients who want to remain sexually active and/or intimate, but who do not desire or are not capable of sexual intercourse, are nevertheless deserving of—and desirous of—information about sexual health. Findings from this study can guide the types of information offered by medical providers to patients and their partners, help direct the development of clinical interventions, and help support the sexual and relational adjustment of women diagnosed with MBC (Badr et al., 2010; Flynn et al., 2010; Stausmire, 2004). This study provides necessary patient-based data for those treating women diagnosed with MBC to sufficiently address the unique conditions that this population faces and to include women’s sexuality near the end of life as an essential component of the evolving discussion of sexuality and cancer.

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Appendix: Interview Topic Guide

Please note that partner questions were asked only if participants identified themselves as partnered during their interviews.

Cancer-Related Changes

1. What are some of the ways that cancer and its treatment have affected your sexual health (physical intimacy)?
2. Has this illness changed the way you feel about your sexuality?
3. How important is sex (activities and intimacy) to you?
 - a. Has this changed over time? If so, when did it change?
 - b. Was it important to you before becoming ill?
4. Were you in a relationship with a partner when you were diagnosed with breast cancer (primary and/or metastatic diagnosis)?
 - a. Was sexual activity (not limited to intercourse) an important aspect to this relationship?
 - b. How did you deal with the physical changes?
5. Are you in a relationship now?
 - a. If so, has anything changed about what you imagine and/or experience in terms of your sexual relationship?
 - b. How has breast cancer affected your sexual relationship with your partner?
 - c. How important is sexuality to your partner?

Sexual Attitudes and Definitions

6. When you think about your sexual well-being, what aspects are the most important to you?
7. What's your relationship to sex like now?
8. What does "sexually active" mean to you?

- a. Would you say that you are sexually active?
9. How would you define intimacy?
 - a. What role (if any) does intimacy play in your life?
 - b. Recently, how satisfied have you been with your ability to share warmth and intimacy with another person?
10. If you are not currently sexual, is this something that you wish were a part of your life?
 - a. If so, when do you think that will be? What needs to happen before then?
 - b. If not, why not?

Medical Professionals and Information

11. Has any doctor, nurse, or other medical professional asked about your sexual health since you were diagnosed with breast cancer (primary and/or metastatic diagnosis)?
 - a. If yes, what kinds of information did you receive?
 - b. If no, would you have liked to have someone bring up the subject?
12. Were you told anything about how the surgery or treatment would affect your sexual life? Do you wish you were told anything?
13. Would there have been an ideal time to bring up the subject?
14. What types of information, if any, regarding sexual activity were you told? By whom?
15. What would you tell someone going through this type of surgery now?
16. If you could go back and tell yourself something that you know now, but didn't know then, what might that be?
17. Is there anything that you think would be helpful for doctors to know about how cancer changes physical intimacy or sexuality?