




## No One-Size-Fits-All: Sexual Health Education Preferences in Patients with Breast Cancer

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### ABSTRACT

**Background.** Using explanatory mixed methods, we characterize the education that patients with breast cancer received about potential sexual health effects of treatment and explore preferences in format, content, and timing of education.

**Patients and Methods.** Adult patients with stage 0–IV breast cancer seen at an academic breast center during December 2020 were emailed questionnaires assessing sexual health symptoms experienced during treatment. Patients interested in further study involvement were invited to participate in semistructured interviews. These interviews explored sexual health education provided by the oncology team and patient preferences in content, format, and timing of education delivery.

**Results.** Eighty-seven (32%) patients completed the questionnaire. Most patients reported decreased sexual

desire (69%), vaginal dryness (63%), and less energy for sexual activity (62%) during/after treatment. Sixteen patients participated in interviews. Few women reported receiving information about potential sexual effects of breast cancer treatment; patients who did reported a focus on menopausal symptoms or fertility rather than sexual function. Regarding preferences in format, patients were in favor of multiple options being offered rather than a one-size-fits-all approach, with particular emphasis on in-person options and support groups. Patients desired education early and often throughout breast cancer treatment, not only about sexual side effects but also on mitigation strategies, sexual function, dating and partner intimacy, and body image changes.

**Conclusion.** Few patients received information about the sexual health effects of breast cancer treatment, though many experienced symptoms. Potential adverse effects should be discussed early and addressed often throughout treatment, with attention to strategies to prevent and alleviate symptoms and improve overall sexual health.

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Improved survivorship due to advances in breast cancer screening, detection, and therapy demands an emphasis on improving quality of life. An estimated 3.8 million survivors of breast cancer are living with the temporary and permanent physical and psychosocial consequences of treatment, many of which impact sexual health.<sup>1</sup> More than

70% of breast cancer patients have reported changes in sexual health and function during treatment and beyond, ranging from issues with vaginal health and low sexual desire to body image dissatisfaction and concerns about intimacy.<sup>2-7</sup> Given the high prevalence of post-cancer sexual health concerns, the National Comprehensive Cancer Network has published clinical practice guidelines for addressing adverse sexual symptoms in patients with cancer.<sup>8</sup>

Despite these established national guidelines, sexual health remains an unmet need for many women living with breast cancer. Healthcare providers infrequently discuss the sexual health implications of cancer treatment with patients for a variety of reasons, such as limited availability or time, discomfort with the topic, or lack of training in the diagnosis and treatment of sexual sequelae.<sup>9-11</sup> Yet, multiple studies have demonstrated that patients actually prefer their healthcare providers initiate sexual health discussions, offering an opportunity for improvement in the value and quality of care.<sup>10-13</sup>

While several studies have assessed the type of sexual health information patients of breast cancer desire, there are limited data to advise providers on the preferred format or most appropriate timing of sexual health education. Both patients and providers agree on the importance of addressing sexual health, yet how and when best to do so remain unclear.<sup>10,11</sup> Using a mixed methods approach, this study aims to: (1) characterize the sexual health symptoms experienced during and after breast cancer treatment, (2) evaluate the sexual health education received from the oncology team as well as resources used by the patient, and (3) determine the preferred format, content, and timing of sexual health education.

## PATIENTS AND METHODS

### *Design*

After obtaining exemption from the overseeing Institutional Review Board (COMIRB number 20-1789), we performed an explanatory mixed methods study involving survey questionnaires followed by semistructured interviews or focus group discussion.

We identified our cohort by performing a retrospective review of all adult female patients seen by breast surgical or medical oncologists at a single academic institution during the month of December 2020. Those who were diagnosed with stage 0-IV breast cancer within the last 5 years were included, incorporating a spectrum of patients ranging from the newly diagnosed to survivors who had completed adjuvant therapy. Patients seen for recurrent disease were excluded. We electronically delivered web-

based surveys to those meeting criteria via Research Electronic Data Capture (REDCap 10.6.5); initial surveys and four weekly reminders were distributed throughout January of 2021. Additionally, we posted flyers with study criteria and Quick Response (QR) codes linked to the REDCap questionnaire in outpatient clinics within our breast center. Those who completed the survey and indicated interest in further study engagement were invited to participate in semistructured individual interviews or focus group discussions, which took place between February and April of 2021.

### *Questionnaires and Semistructured Interviews*

Survey questions and interview/focus group guides (“Appendices 1 and 2”) were developed through an iterative process with multidisciplinary input from breast surgeons, medical oncologists, gynecologists, health psychologists, and sexual health consultants who routinely work with women with early and advanced breast cancer. Surveys first assessed general demographic information as well as gender identity, sexual orientation, relationship status, and sexual relationship status. Additional sections focused on breast cancer treatment received, sexual health symptoms experienced during and after treatment, and the effect of these symptoms on patients’ sexual well-being and mental health. Lastly, patients indicated preferred timing of sexual health education.

The semistructured focus groups/interviews further explored patients’ sexual health experience and appraised the education provided by the oncology team about the possible adverse sexual health effects of breast cancer treatment. Our team inquired as to patients’ preferred content, format, and timing of potential discussions on this topic. Focus groups/interviews were conducted virtually via Zoom (Zoom Video Communications Inc., 2016) in the setting of the Coronavirus disease 2019 (COVID-19) pandemic and led by one to three research personnel (K.H., J.P., M.F., H.C.) trained in best practices in qualitative methods. Focus groups were limited to no more than six patients to ensure that each participant had the opportunity to express her viewpoints and to facilitate interactive discussion. Individual interviews were conducted if interested patients were unavailable to attend the scheduled focus groups.

### *Data Analyses*

Questionnaire data were summarized using descriptive statistics. All interviews were audio-recorded, transcribed verbatim, and deidentified. Two independent researchers (V.H., S.T.) performed data coding and interpretation with iterative, methodical reviews of individual transcriptions to

create a summary code book of the key thematic elements identified. Jointly, the investigators then reviewed these summaries along with the original transcripts to produce consensus documents. This process involved comparing findings, discussing divergent coding, and resolving differences of interpretation where appropriate. On the basis of these discussions, we developed a summary of recurrent themes applicable to the entire sample.

## RESULTS

### Survey Questionnaire

Eighty-seven out of 271 patients (32%) completed the questionnaire. Table 1 summarizes the characteristics of the study population. The vast majority of patients were less than 65 years of age (85%), white (83%), and heterosexual (98%). Most were married (67%) and in a sexual relationship (69%). Many (58%) patients were within the first 2 years of diagnosis, though a considerable proportion of participants (28%) were greater than 4 years from diagnosis. A majority of patients had breast surgery (86%), chemotherapy (71%), and/or endocrine therapy (66%). Sixty-four percent were actively in treatment at the time of survey completion.

Figure 1 illustrates the frequency with which sexual health symptoms were experienced during and/or after treatment. Almost all participants (93%) reported at least one symptom affecting their sexual health. A majority of patients endorsed decreased sexual desire (69%), vaginal dryness (63%), or less energy for sexual activity (62%). Half of patients reported issues with hair loss, weight changes, and dissatisfaction with their bodies. Many also noted difficulty achieving orgasm (44%), pain during intercourse (38%), and breast pain (38%). Only six (7%) patients did not experience adverse sexual side effects from their breast cancer treatment.

Sexual health symptoms affected patients' desires to participate in sexual intimacy/activity (82%) and ability to enjoy sexual activity (80%) somewhat or to a great extent (Fig. 2). Similarly, patients reported these symptoms taking a toll on their mental health (75%). For those in relationships, 75% noted that their sexual relationships with their partners had been affected somewhat or to a great extent. Emotional relationships with significant others were impacted to a lesser degree (50%).

When asked about preferred timing of discussions about the potential adverse sexual health effects of breast cancer treatment, only 6% of patients did not want this information provided by the oncology team (Fig. 3). Most patients wanted discussion of sexual health changes around the time of diagnosis or early after diagnosis (73%) as well as multiple times throughout treatment (34%). Fewer patients

**TABLE 1** Study population characteristics

Patient characteristic	N = 87	
	N	%
<i>Age</i>		
< 45 years	35	40.2
45–65 years	39	44.8
> 65 years	11	12.6
Not reported	2	2.3
<i>Race</i>		
White/Caucasian	72	82.8
Asian	5	5.7
Black/African American	4	4.6
Latina	1	1.1
American Indian or Alaskan	1	1.1
Other/prefer not to answer	4	4.6
<i>Sexual orientation</i>		
Heterosexual/straight	85	97.7
Prefer not to answer	2	2.3
<i>Relationship status*</i>		
Single/not dating	14	16.1
Dating/boyfriend/girlfriend	5	5.7
Partnered	5	5.7
Married	58	66.7
Divorced	7	8.0
Widowed	2	2.3
<i>Are you in a sexual relationship?</i>		
Yes	60	69.0
No	25	28.7
Prefer not to answer	2	2.3
<i>Clinical stage</i>		
0	4	4.6
I	30	34.5
II	22	25.3
III	5	5.7
IV	4	4.6
Unknown	22	25.3
<i>Cancer treatment received*</i>		
Surgery	75	86.2
Chemotherapy	62	71.3
Radiation	48	55.2
Hormonal therapy	57	65.5
<i>Are you currently in treatment?</i>		
Yes	56	64.4
No	30	34.5
<i>Interval since diagnosis (months)</i>		
0–12	36	41.9
13–24	14	16.3
25–36	7	8.1
37–48	5	5.8

**Table 1** (continued)

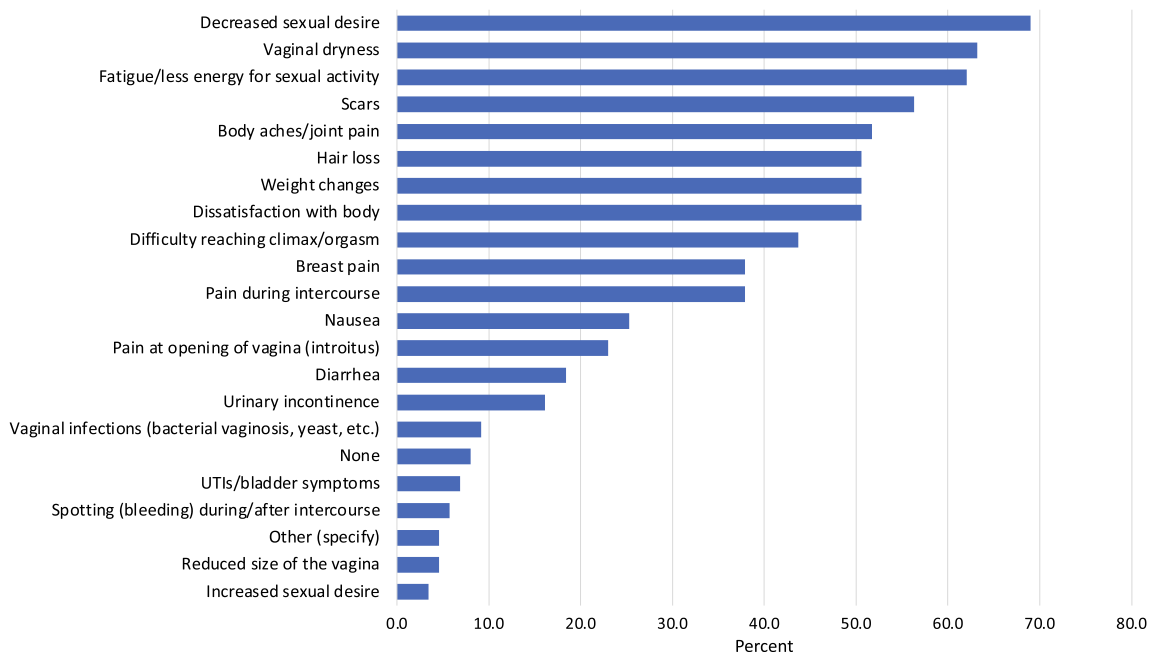
Patient characteristic	N = 87	
	N	%
> 48	24	27.9

\*Surveys asked participants to select all that apply

wanted these discussions to take place while undergoing surgery or chemotherapy (21%) or after all treatment had been completed (21%).

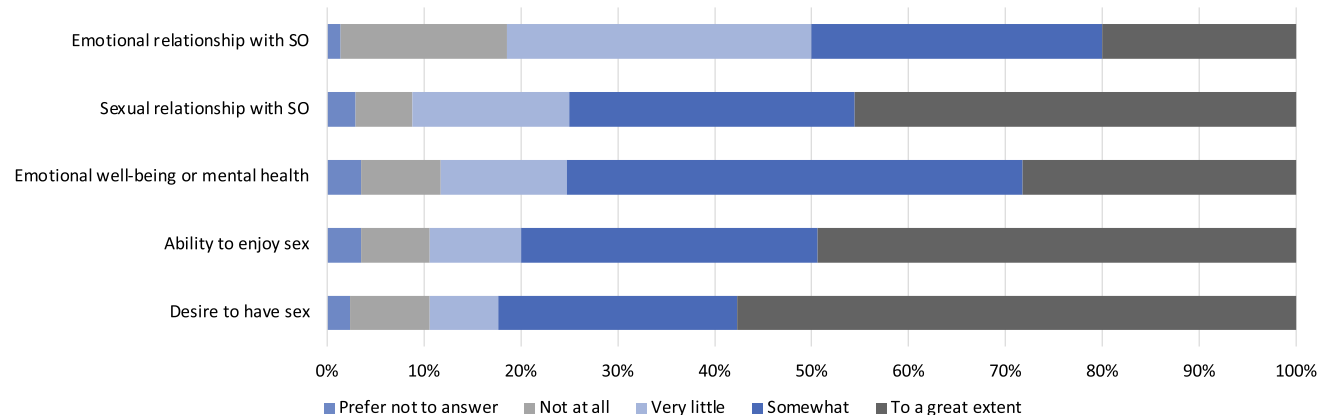
*Thematic Qualitative Findings*

Sixteen patients participated in focus group discussions (n = 13) or individual interviews (n = 3). Focus group discussions and individual interviews explored: (1) sexual health



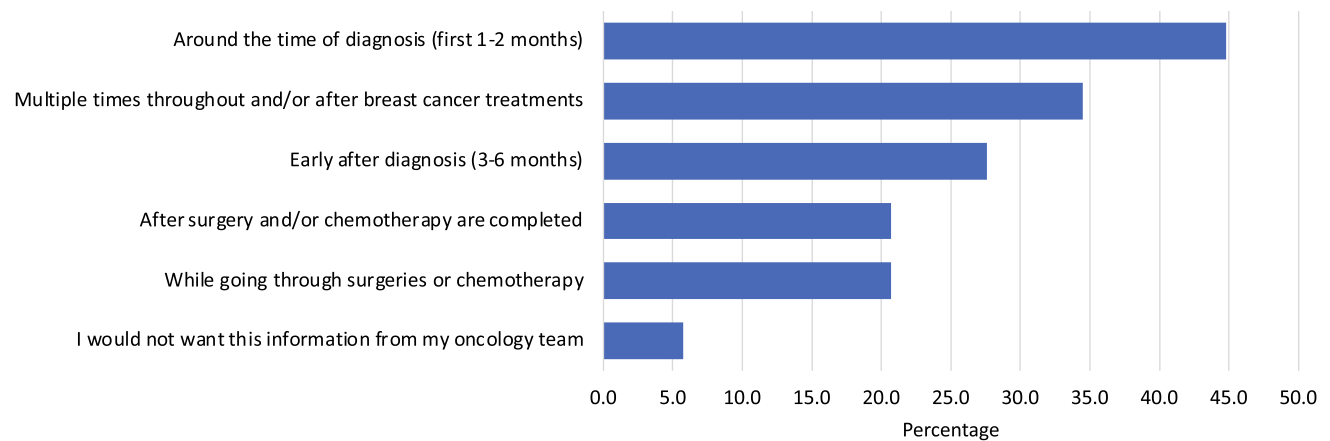
**FIG. 1** Frequency of symptoms affecting sexual health in breast cancer patients: 87 patients completed the questionnaire assessing sexual health-related symptoms experienced during and after treatment; almost all (93%) patients reported at least one symptom

affecting their sexual health; patients endorsed decreased sexual desire (69%), vaginal dryness (63%), and less energy for sexual activity (62%)



**FIG. 2** Impact of symptoms on sex and relationships: sexual health-related symptoms experienced impacted a majority of patients' desires to have sex and ability to enjoy sex somewhat or to a great

extent; similarly, these symptoms took a toll on patients' emotional well-being; for those in relationships, sexual relationships were more affected than emotional relationships with significant others



**FIG. 3** Preferred timing of sexual health discussions with the oncology team: most patients desired discussions about the possible sexual health effects of breast cancer treatment at the time of diagnosis or early after diagnosis (73%) as well as multiple times

throughout treatment (34%); fewer patients wanted these discussions to take place while actively undergoing therapies (21%) or after they had been completed (21%)

**TABLE 2** Themes: patient experience and education received

*Patient experience*

Body image	“I am shocked. I wouldn’t have considered myself a terribly vain person, but man, you lose half your hair and ... it takes a toll on you ... I feel like the most asexual person at this moment in time, you know? Just because of my own self-image.”
	“I hate my body. I hate my breast.”
Libido/sexual desire	“Will I ever want to have sex again?!”
Dyspareunia	“It was hard on him when he found out that sex was uncomfortable. He’s like oh, I don’t want to make you feel bad, and I’m like, let’s just keep trying.”
Nipples	“They said it’d be an easier transition from having your breasts removed if you have your nipples. And I absolutely hate them. They are perpetually hard ... it’s painful to be touched. They are never symmetrical. And that is the one thing that has affected my sexual relationship with my husband the most. My nipples were ... involved a lot before breast cancer. Those outcomes were never mentioned by my plastic surgeon or oncologists or anyone on my team ... if I had known that, I would never would have kept them.”
Intimacy	“I feel very scared that ... I’m not going to be successful dating. I know there’s more to dating than sex, but ... that’s a big part of it for me. So I feel very scared for that.”
Induced menopause/ chemotherapy	“I get [hot flashes] at night. And because they affect your sleep ... it affects everything...sometimes you are too tired to engage in sex ... not just the lack of libido and all the things that you have, but ... because you are not sleeping as well as before.”

*Sexual health education received*

No discussion	“I did not realize any of this was because of chemo or...what I went through. I thought it was all age. I don’t remember [sexual side effects] ever being brought up to even know about it, that this was even a thing.”
Menopause/fertility versus sexual function	“I think there was a really interesting distinction with sexual reproduction...we’re going to address...all the things we can do to help you conceive. But there was no conversation about how the physical pleasure of having sex might be affected. It wasn’t the relationship piece. It was just the reproduction.”

symptoms experienced, (2) sexual health education received from the oncology team, and (3) preferred sexual health educational content, format, and timing. Tables 2 and 3 includes key themes identified with select, representative quotes.

*Patient Experience*

While discussion of sexual health symptoms and experiences ranged from fear of intimacy and dating to the

immense fatigue felt throughout treatment, most patients reported concerns with decreased sexual desire, pain with intercourse, and difficulty with body image changes, echoing findings from the survey questionnaire.

“I don’t even want to kiss a guy right now. I was single, ready to mingle, and I don’t want any part of it. Zero. Like don’t touch me. Don’t kiss me. Don’t look at me funny. I want nothing.” Another patient

**TABLE 3** Themes: preferred educational content, format, and timing

<i>Preferred educational content</i>	
Dating and partner intimacy, support systems	<p>“How do I disclose when I find a new person or I want to go on a date?”</p> <p>“It would have been helpful for [the medical team] to talk to [my husband] about ... what to expect. He’s just completely oblivious and so trying to explain things to him, he doesn’t get it. And with my brain fog, trying to articulate this is very difficult and frustrating.”</p>
Adverse effects and mitigation strategies	“Getting some real experiences and then also hearing...some of the things that worked for some people ... things you could think about if/when you experience them, and things you can tell your doctor.”
Sexual function	<p>“Arousal, satisfaction. You know, orgasms ... does it all work the same, or will it work differently?”</p> <p>“Relationships, and not just fertility preservation, but actual...libido and enjoyment of sex and these types of things.”</p>
Body Image	“I wish that there was more importance placed on how a woman feels in her breasts versus just how they look.”
<i>Preferred educational format</i>	
Support groups or in-person options	<p>“I would volunteer myself to be ... part of an online forum or something where women can post their questions or ... talk about their experience. I mean this [focus group] alone feels ... very cathartic. I’ve been in tears the whole time. But that’s something that I know I personally would be open to participating in and would have really appreciated years ago.”</p> <p>“It would be helpful to have different information or different support groups ... for women that are partnered versus those that are interested in dating.”</p>
Medical team-initiated discussion	“I know that at every visit, I was...asked the question, have you thought about hurting yourself? Or have you felt down since the last time we saw you? Maybe if [sexual health] was asked about more often, I would have been prepared to have an answer the next time.”
Handout/pamphlet	“When you do the initial multidisciplinary meeting...they give you this massive packet. Some people go through it, and some people don’t, but maybe just having something in there that touches on [sexual health], so it’s not a surprise.”
Videos	“I’m happy reading, but I think videos [can be effective]. Done right, I think it’s a really good tool and sometimes makes it more interactive.”
Multiple options	“Somebody might want to really have some literature to read, and somebody else might want to just talk to someone, and somebody else might want to...watch a video on it, and somebody might want to do everything. So I think it’s important to have several options available so that you can choose what’s most comfortable for you and not what’s the most comfortable for the majority.”
<i>Preferred educational timing</i>	
Multiple times during treatment	<p>“I think they give you too much information in the beginning and not enough information throughout.”</p> <p>“With respect to when to ... bring that up. I know everybody’s different. And everybody’s course of treatment is different ... maybe it’s not just at one point, maybe it’s along the spectrum.”</p>
Early around diagnosis (not at diagnosis)	<p>“I’m someone who likes to get all my information at once and then take some time to digest it ... and then come back and be ready with my questions.”</p> <p>“At diagnosis, there’s just so much information that everything’s overwhelming. But what I did appreciate is that at diagnosis, when we had our consent meeting for chemotherapy, they made me aware that there would be implications, and that we would discuss these at a later time.”</p>

describes her sexual desire as “[falling] off the face of the earth.” Patients almost universally expressed a lack of desire for sexual intimacy, and some noted surprise that this desire did not return even after completion of treatment. Further, several patients endorsed discomfort with sex, describing pain “like I’m a virgin.”

Of particular emphasis amongst focus group/interview participants were changes to body image. “I didn’t give enough weight to how ... my self-image would change. I

don’t really know how to describe that, other than not feeling prepared ... to look like somebody different as I go through [treatment].” Many reported an inability to accept their “new” breasts—“I never felt it was part of my body at all.” Patients expressed discomfort in their bodies, noting a disconnect between how their reconstructed breasts may look versus how they actually felt as women, and highlighted the interdependence of body image and sexuality.

### *Sexual Health Education Received*

Most patients received no information from the oncology team or any other medical providers about the possible sexual side effects of breast cancer treatment. Those that did noted a focus on fertility and menopausal symptoms rather than on sexual function or pleasure. In those few instances, patients heard about the possibilities of vaginal dryness and pain, hot flashes, and potential reproductive consequences. Patients overall described sexual health education as “more reactionary than preventative”—the burden was placed on the patient to present symptoms to the oncology team after they arose, at which point sexual health would be addressed, rather than being counseled of these possibilities beforehand.

### *Sexual Health Education Preferences*

**Content** Patients not only desired information about the adverse sexual health effects of treatment but also emphasized the need for potential strategies to mitigate them. “I don’t want to talk to somebody who is just going to educate me. I want someone who is going to give me the solution as well.” Additionally, patients wanted information about changes in sexual function and body image, highlighting the difficulty of addressing sexuality without also addressing body image as it relates to sexual health. Lastly, patients requested more resources on navigating dating and partner intimacy with a breast cancer diagnosis, including partner education.

**Format** The women in this study advocated for use of handouts and pamphlets, online videos, and support groups targeted toward different breast cancer populations and life stages (e.g., younger vs. older, single vs. partnered, childbearing vs. not). Ideas for medical team-initiated discussions were also offered, such as routine incorporation of sexual health questions into providers’ review of systems during clinical visits. Focus group/interview participants supported a multimodal approach to sexual health education, understanding differences in patient preferences and learning styles, with an emphasis on in-person options. “I feel that it would be best to have several avenues available. Then you could choose what you feel most comfortable with.”

**Timing** Participants preferred sexual health education early around diagnosis, but not necessarily at diagnosis, and recommended that the topic be addressed multiple times during treatment, echoing results of our surveyed population. At diagnosis, patients were fixated on treatment and survival, and were already overwhelmed by the volume of information given. However, they felt it was appropriate

to have the information presented early so that they could anticipate changes and address it later during the course of treatment. “It is important that everything is presented to you. I know you can’t process it perhaps at the time, and you will need to focus on survival first ... but I didn’t want surprises. I think knowledge is power.”

## **DISCUSSION**

We found that few patients received information about the potential sexual health implications of breast cancer treatment, even though almost all experienced adverse sexual symptoms both during and after treatment, and the education that was received was suboptimal. Further, we found that patients desired sexual health education early and often throughout treatment, not only about the possible sexual side effects but also mitigation strategies, as well as anticipating and coping with body image changes, and navigating dating and partner intimacy. Lastly, patients favored a multimodal strategy to education rather than a one-size-fits-all approach, preferring multiple options targeted toward different breast cancer populations to align with their stage of life and sexual needs.

Patient experience within our cohort largely mirrored that of prior literature with 93% of patients enduring sexual health symptoms during and after breast cancer treatment. A majority of patients experienced decreased sexual desire, vaginal dryness, and sexual activity-limiting fatigue, and more than half of patients reported issues with body image. In a prospective cohort study of 1600 newly diagnosed patients with breast cancer, Panjari et al. reported that women with body image issues were 2.5 times more likely to report sexual problems, a key theme that arose during our focus group discussions.<sup>4</sup> Similarly, Ljungman et al. found that negative body image was closely related to poor sexual health and satisfaction, with young breast cancer patients reporting that “feeling unattractive” and being “too tired” were the most common reasons they had not had sex in the last 30 days.<sup>2</sup> In a cross-sectional patient-reported outcomes comparison of women with and without breast cancer, high depressive symptoms predicted poor sexual health.<sup>3</sup> A similar relationship was noted in our cohort, with 75% of patients reporting that sexual health symptoms affected their mental health. Shaffer et al. in a study of breast cancer survivors and their partners, found that patients want not only information about the sexual side effects of treatment but also relationship support.<sup>14</sup> Altogether, these findings highlight the need for counseling beyond fertility and menopausal symptoms and suggest that comprehensive sexual health education incorporates discussions of the physical and psychosocial ramifications of treatment.

Not only did our patients desired more comprehensive education but focus groups revealed that they also preferred multiple formats targeted toward multiple populations, recognizing that different patients may have distinct sexual health needs and differing educational preferences. For example, a comparison of patients with and without breast cancer demonstrated that premenopausal and perimenopausal breast cancer survivors were less sexually active than their normative controls, while there were no differences in sexual activity among postmenopausal patients.<sup>6</sup> Further, a study of sexual health education preferences in patients with breast and gynecologic malignancies found that older women were less interested in online interventions despite almost all having access to a computer.<sup>12</sup> This study also found that younger women preferred in-person discussions, while older women preferred to read written material on their own.<sup>12</sup> Other studies have suggested that cancer patients differ in whom they would like to raise the topic of sexual health, with some favoring their primary care provider but others preferring the oncology team.<sup>10</sup> In a qualitative study of premenopausal breast cancer survivors, young patients specifically wanted reproductive health information and realistic expectations of conceiving post treatment.<sup>15</sup> Cultural differences in sexual health education needs are also apparent, as studies of Chinese patients with breast cancer have shown that they avoid sexual activity owing to perceptions that it may affect treatment outcomes and recurrence risk.<sup>16,17</sup> A multipronged approach to sexual health education may offer options suitable for a variety of needs.

Several studies have evaluated the feasibility and acceptability of various interventions addressing sexual health. Reese et al., for instance, developed a podcast-based learning intervention aimed at enhancing breast cancer clinicians' knowledge and comfort in discussing patients' sexual health concerns and found that it was overall viewed positively and assisted clinicians in normalizing the topic and taking a proactive approach to discussing sexual health.<sup>18–20</sup> A newly implemented sexual health program at a Canadian cancer center also proved

useful to healthcare providers and was deemed valuable in addressing gaps in care.<sup>21</sup> Evaluating the patient perspective, Tracy et al. introduced a nurse-led sexual health clinic and found that patients experienced improvements in sexual well-being after participation.<sup>13</sup> Studies suggest that clinicians are open to instruction, and that patients are eager for education—it normalizes treatment-related sexual health changes and reduces anxiety, provides an opportunity for further questions, and helps improve communication with partners.<sup>11</sup> Our own institution is working toward developing educational sexual health videos through an iterative process with valuable input from breast cancer patients and other key stakeholders.

There are limitations to the study. Inherent with surveys is the possibility of selection bias. Those who have experienced adverse sexual health symptoms may be more inclined to participate in the study, and the proportion of patients endorsing sexual health issues may be overrepresented. Additionally, our study cohort represents a relatively homogeneous population. There may be different educational preferences and needs among those of differing relationship statuses, gender identities, socioeconomic groups, varied education levels, and ethnicities. This is the first study, to the authors' knowledge, however, that broadly evaluates preferences in sexual health educational format and timing.

In summary, the potential adverse sexual health effects of treatment should be addressed early in diagnosis, and counseling should be provided throughout treatment, with attention to strategies to prevent and alleviate symptoms, improve sexual health, reduce emotional distress, and improve quality of life. Greater emphasis on measures beyond traditional cancer outcomes, such as sexual health, will continue to be a priority to patients and critical to ensuring high-quality, patient-centered care.

## APPENDIX 1

### *Survey Questionnaire*



1. How old are you? \_\_\_\_\_ years
  
2. Are you Hispanic/Latina or of Spanish origin?
  - a. Not Hispanic/Latina or of Spanish origin
  - b. Hispanic/Latina/Spanish origin
  - c. Prefer not to answer
  
3. How would you describe your race?
  - a. Black/African American
  - b. Latina
  - c. Native Hawaiian/Pacific Islander
  - d. American Indian or Alaska
  - e. Caucasian/White
  - f. East Asian
  - g. South Asian
  - h. Other (specify)
  - i. Prefer not to answer
  
4. At this time, what is your sexual orientation?
  - a. Heterosexual or straight
  - b. Lesbian, gay, homosexual, or same-gender loving
  - c. Bisexual
  - d. Pansexual
  - e. Other (specify)
  - f. Prefer not to answer
  
5. At this time, what is your gender identity?
  - a. Female
  - b. Male
  - c. Trans male/trans man
  - d. Trans female/trans woman
  - e. Gender non-conforming/non-binary
  - f. Other (specify)
  - g. Prefer not to answer
  
6. What is your current relationship status (select all that apply)?
  - Single/not dating
  - Dating/boyfriend/girlfriend
  - Partnered
  - Married
  - Divorced

- Widowed
  - Other (specify)
  - Prefer not to answer
7. At this time, are you in a sexual relationship?
- a. Yes
  - b. No
  - c. Prefer not to answer
8. When were you first diagnosed with breast cancer (approximate month and year)? MM/YYYY
9. What type of cancer treatment you have ever received (check all that apply)?
- Surgery
  - Radiation
  - Chemotherapy including targeting therapy
  - Hormonal therapy (tamoxifen, aromatase inhibitors)
  - Other (specify)
  - Prefer not to answer
10. When was your first treatment for breast cancer (which may have been surgery, chemotherapy or hormonal therapy) (approximate month and year)? MM/YYYY
11. Are you currently on treatment?
- Yes
  - No
12. Have you experienced any of the following during or after your cancer treatment that affected your sexual health or sexuality, including your interest in having sex or enjoyment of sex (check all that apply):
- Vaginal dryness
  - Pain at opening of vagina (introitus)
  - Pain during intercourse
  - Decreased sexual desire
  - Increased sexual desire
  - Dissatisfaction with body
  - Weight changes
  - Scars
  - Hair loss
  - Breast pain
  - Body aches/joint pain
  - Fatigue/less energy for sexual activity
  - Nausea
  - Diarrhea
  - Difficulty reaching climax/orgasm

- Reduced size of the vagina
- UTIs/bladder infections
- Vaginal infections (bacterial vaginosis, yeast, etc.)
- Spotting (bleeding) during/after intercourse
- Urinary incontinence
- Other (specify)
- None

13. To what extent have these symptoms impacted your desire to have sex?
- a. Not at all
  - b. Very little
  - c. Somewhat
  - d. To a great extent
  - e. Prefer not to answer
14. To what extent have these symptoms impacted your ability to enjoy sex?
- a. Not at all
  - b. Very little
  - c. Somewhat
  - d. To a great extent
  - e. Prefer not to answer
15. To what extent have these symptoms impacted your emotional well-being or mental health?
- a. Not at all
  - b. Very little
  - c. Somewhat
  - d. To a great extent
  - e. Prefer not to answer
16. To what extent have these symptoms impacted your sexual relationship with your significant other?
- a. N/A – I don't have a partner at this time.
  - b. Not at all
  - c. Very little
  - d. Somewhat
  - e. To a great extent
  - f. Prefer not to answer
17. To what extent have these symptoms impacted your emotional relationship with your significant other?
- a. N/A – I don't have a partner at this time.
  - b. Not at all
  - c. Very little
  - d. Somewhat
  - e. To a great extent

f. Prefer not to answer

18. When would you recommend that your oncology team introduce the possibility that your breast cancer treatments may impact your sexual health and sexuality (select all that apply)?

- Around the time of diagnosis (first 1-2 months)
- Early after diagnosis (3-6 months after diagnosis)
- While going through surgeries or chemo
- After surgery and/or chemotherapy are completed
- Multiple times throughout and/or after breast cancer treatments
- I would not want this information from my oncology team

19. If you would like to provide any additional details about your response to the above, please write-in here: \_\_\_\_\_

20. Would you be interested in learning more about participation in a virtual focus group discussion regarding changes in your sexual health during cancer?

a. Yes.

i. Please provide an email and/or phone number:

email: \_\_\_\_\_ phone: \_\_\_\_\_. You will be contacted by one of our study staff with information about when the focus group will be held and what to expect.

b. No

## APPENDIX 2

### *Focus Group Semistructured Interview Guide*

Welcome everyone. Before we get started, I would like to review some ground rules. This is a safe space. We need to honor each other's experiences and reactions, and respect diversity of perspectives, backgrounds, and experiences. Please do not use derogatory language. Anything that is said in this group should remain confidential and stay only within the group. We also need to protect the privacy of participants in the group so that everyone feels safe sharing experiences with breast cancer and opinions. We will be recording these sessions, but all data will be deidentified and no names will be used when we analyze, present, publish, or otherwise disseminate findings from this project.

The goal of this focus group is to help us develop a better understanding of the sexual side effects and needs of women going through different forms of breast cancer treatment, including surgery, radiation, chemotherapy, or hormonal therapy, in an effort to develop helpful educational tools to better prepare patients for common sexual side effects during and after their treatments.

1. *Introductions* To get us started, we'd like to get to know each other a bit before jumping into the discussion.

- Tell us a little about your breast cancer experience, such as when you were diagnosed and where you are in your treatment journey.

2. *Education received* We would now like to discuss the education/information you may have received regarding how your sexual health would be affected by your breast cancer treatment from your healthcare team as well as any outside resources you may have used.

- Would you please tell us if you received any type of education from your healthcare team on how your sexual health would be affected by your cancer treatment?
  - Who gave you the information?
  - What format was the education?
    - A brochure or pamphlet from your providers during an appointment or exam?
    - Directed to an online resource?
    - Any other format?
- What type of information was provided about the impact of breast cancer treatment on your sexual health? Were prevention or treatment options offered?
- Have you used any resources outside of the healthcare team to find information on sexual side effects from cancer treatment?

- What sources of information did you use?
    - Other women with breast cancer or other types of cancer?
    - Attended a workshop on sexual health in women with cancer
    - The internet/online sources? For example, LBBC, Breastcancer.org, ACS, etc.
    - Podcasts?
    - Social media platforms?
    - Social support from friends, family, or colleagues?
    - Cancer support groups?
    - Other?
  - When in your treatment experience/journey did you get education/information or seek out information on sexual health?
    - Why did you begin looking at this time?
    - Was the information you received or found helpful?
    - Why or why not?
    - Were you satisfied with the information?
3. *Perceptions of education* What made the information more or less satisfying?
- Based on your experience with breast cancer and treatment so far, when do you think would be the best time to deliver education on sexual side effects to women diagnosed with breast cancer? Was there a time that you feel you would have been most open or interested in getting this type of information?
    - Early—around the time of diagnosis?
    - During a specific phase of your treatment (before or after breast surgery, before or after radiation, before or after chemo, before or after starting endocrine therapy)
    - At completion of all acute cancer treatment (if applicable, like 1–2 years after diagnosis)?
  - What do you wish you had known about sexual health and side effects prior to starting any treatment?
  - What type of information would have been the most helpful while you were going through treatment?
  - What format would you have liked to received education on sexual health during cancer treatment?
    - Online?
    - Written?
    - In-person during a follow-up visit?
  - Do you have a preference for telehealth or in-person sexual health consultation?
    - Why would you prefer this format?
  - Would you be open to online education around sexual health?
    - Why? Why not?
    - What type of online education would you be interested?
      - A website with educational handouts you could read when you are ready?
      - A website with educational videos you could watch when you are ready
      - A website with information on sexual health topics or survivorship topics including sexual health?

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