

Living With Metastatic Breast Cancer: Sexual Dysfunction, Relationship Changes, and Supportive Care Needs

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Abstract

Background

As survival continues to improve for women with metastatic breast cancer (mBC), understanding sexual health concerns in this population is increasingly important.

Methods

We conducted a cross-sectional mixed-methods study among women with mBC treated at the University of Alabama at Birmingham. Participants completed quantitative surveys, including the PROMIS Sexual Function and Satisfaction (SexFS) measures and PROMIS Global Health Scale. Semi-structured qualitative interviews were conducted with a purposively selected subgroup.

Results

Of the 107 participants, 67 (63%) were sexually inactive and 40 (37%) were sexually active within the prior 30 days. The most common reasons for sexual inactivity were lack of interest (54%), health-related conditions (33%), and lack of a partner (30%). Among sexually active women, 28 (70%) met criteria for sexual dysfunction. Sexual dysfunction was associated with poorer PROMIS Global Physical and Mental Health scores, whereas sexual activity status alone was not associated with significant differences. Regardless of sexual activity status, 70% considered sexual life important, and 57% reported distress related to cancer-associated sexual changes. Qualitative interviews identified five themes: sexual problems following mBC diagnosis, factors contributing to sexual problems, psychological and relationship impacts, unmet communication needs, and preferences for low-burden supportive interventions.

Conclusions

Sexual dysfunction and sexual inactivity are common, clinically meaningful concerns in women with mBC that remain underrecognized and undertreated. These findings underscore the need for proactive sexual health discussions and patient education about low-burden supportive interventions in clinical practice.

Background

Approximately 168,000 women in the US were living with metastatic breast cancer (mBC) in 2020^{1,2}. This population is projected to grow to over 246,000 by 2030 as advances in therapy have significantly improved survival³. A satisfactory sexual life is an important component of quality of life (QOL) for

women, including women with cancer, regardless of age or relationship status^{4,5}. Breast cancer and its treatments can profoundly affect sexuality through both physical and psychological mechanisms, including premature menopause, vulvovaginal symptoms, impaired body image, and reduced sexual desire^{6–17}. These changes can cause significant distress and adversely affect intimate relationships. Sexual health problems among women, particularly those with early-stage breast cancer, have been well documented^{8,10–12,15,16,18–24}. However, most of the previous studies included only small numbers of women with mBC and rarely reported findings specific to this population, limiting our understanding of their unique experiences.

Sexual changes may be more profound among women with mBC than among those with early-stage breast cancer^{25,26}. Women with mBC usually remain on systemic therapy indefinitely, with functional status often declining over time^{27,28}. Continuous treatment can progressively impair sexual function through decreased libido, vulvovaginal changes, cancer related-fatigue, and other symptoms²⁵. In addition, the psychological burden of an incurable diagnosis and the financial and time-related demands of ongoing care, may further compromise sexual and relationship well-being²⁹.

In this mixed-methods study, we evaluated the prevalence, characteristics, and QOL impact of sexual problems in women with mBC, explored strategies to improve clinical communication about sexual health, and assessed interest in interventions to address these concerns.

Methods

Study design

This convergent, observational, cross-sectional mixed-methods study was conducted at the University of Alabama at Birmingham (UAB) between October 2024 and October 2025 and was approved by the UAB Institutional Review Board.

Participants

Participants were adults (≥ 18 years) with mBC who self-identified as female and were able to speak, read, and provide informed consent in English. Men with mBC, patients receiving hospice care or with an estimated life expectancy ≤ 6 months, and non-English-speaking individuals were excluded. Participants were recruited from the UAB medical oncology clinic after providing informed consent. From the quantitative survey cohort, 20 interested participants were purposively selected for qualitative interviews and provided separate informed consent.

Data collection

Quantitative data

All participants completed a quantitative survey hosted on REDCap^{30,31}. Sexual function and satisfaction were assessed using the PROMIS® Sexual Function and Satisfaction Measure (SexFS) version (v) 2.0 Brief Profile (Female)^{32–35}. Sexual activity was defined as partnered sexual activity (vaginal or anal intercourse, oral sex, or foreplay) or solo sexual activity (masturbation) within the past 30 days³². A screening item determined sexual activity within the prior 30 days. Sexually active participants completed domain-specific items assessing vaginal lubrication, vaginal discomfort, labial discomfort and clitoral discomfort, orgasm function, and satisfaction with sex life. Sexually inactive participants selected reasons for inactivity from a predefined list³². Sexual interest and desire to engage in sexual activity were assessed using two items in both sexually active and sexually inactive participants³².

Additionally, participants completed 32 items from the PROMIS® Item Pool v2.0: Factors Interfering with Sexual Satisfaction, 10 items from the PROMIS Global Health Scale v1.2, self-reported demographic information, and 16 additional items assessing perceptions of sexuality, communication preferences, and interest in interventions^{36,37}.

Qualitative data

Twenty interested survey participants were purposively selected to ensure diversity in age, race, socioeconomic background, tumor subtype, and treatment status. Interviews were conducted one-on-one by a trained clinical research coordinator (TP) using a semi-structured interview guide developed in collaboration with medical oncologists (NJ, GR), with input from a qualitative researcher (NH). Interviews were conducted via HIPAA-compliant Zoom or telephone, audio-recorded, and professionally transcribed verbatim using Rev.com.

Sample size

For quantitative analyses, a convenience sample was captured for a 1-year period³⁸. As the purpose of the study was exploratory in nature, there was no formal power calculation. Twenty interviews were considered sufficient to achieve thematic saturation for qualitative component³⁹.

Data analysis

Quantitative analysis: For PROMIS SexFS, calibrated item scores were converted to PROMIS T-scores, where a score of 50 represents the mean of the sexually active US adult population⁴⁰. Dysfunction was defined as one standard deviation (10 points on the T-scale) below 50 for domains including lubrication, orgasm ability, orgasm satisfaction, satisfaction with sex life, and pleasure of sex life, or above 50 for domains including vaginal pain, vaginal discomfort, labial discomfort, and clitoral discomfort⁴⁰. These criteria were adopted from the PROMIS SexFS scoring manual and prior studies using PROMIS SexFS instruments^{11,40–42}. Women reporting dysfunction in one or more sexual domains were classified as

having sexual dysfunction¹¹. Differences in patient characteristics between sexually active and sexually inactive women, as well as between women with and without sexual dysfunction, were quantified using effect size measures (Cohen's d for continuous variables and Cramér's V for categorical variables). Effect sizes were interpreted according to Cohen's conventional thresholds: Cohen's d values of 0.2, 0.5, and 0.8 and Cramér's V values of 0.1, 0.3, and 0.5 were considered small, medium, and large, respectively^{43,44}. Quantitative analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC, USA).

Qualitative analysis

Qualitative data were managed and analyzed using NVivo (version 15; Lumivero, Denver, CO, USA) utilizing a theoretical thematic analysis approach informed by the study objectives, interview guide, and quantitative survey domains^{45,46}. Initial coding was performed by the principal investigator (NJ), followed by iterative review and refinement of codes by other authors to identify recurring themes and representative quotations.

Integration of qualitative and quantitative data

Quantitative and qualitative findings were integrated to provide a comprehensive understanding of sexual problems and receptivity to supportive interventions. Quantitative analyses characterized prevalence and patterns, while qualitative findings provided contextual understanding of participants' experiences.

Results

Quantitative analysis

Between October 2024 and October 2025, 153 women with mBC were approached; 110 (72%) consented and 43 (28%) declined participation. The most common reasons for declining were lack of interest (67%), perceived inapplicability because of sexual inactivity (9%), nonresponse (14%), and discomfort with the study topic (5%). Three participants did not complete key survey items, leaving 107 women for analysis. The median age at survey completion was 61 years (interquartile range, IQR, 48–68). Most participants were heterosexual (94%), White (66%), postmenopausal (91%), and partnered (64%) (Table 1).

Among the 107 women included in the analysis, 67 (63%) reported being sexually inactive, while 40 (37%) reported being sexually active within the past 30 days. Among sexually inactive women, the most common reasons for inactivity were lack of interest (54%), health-related conditions (33%), lack of a partner (30%), and pain (15%) (Fig. 1A). Twenty-nine (43%) reported multiple reasons for sexual inactivity.

Among the 40 sexually active women included in the analysis, 28 (70%) met criteria for sexual dysfunction. Among women with sexual dysfunction, vaginal lubrication difficulties were reported by 16

(40%), vaginal discomfort by 16 (40%), clitoral discomfort by 15 (38%), labial discomfort by 13 (33%), reduced satisfaction with sex life by 11 (28%), and decreased orgasmic pleasure by 9 (23%) (Fig. 1B). Notably, 20 women (50%) reported dysfunction across more than one sexual domain.

Compared with sexually active women ($n = 40$), sexually inactive women ($n = 67$) reported lower sexual interest and desire. Among sexually inactive women, 67% ($n = 45$) reported no sexual interest compared with 5% ($n = 2$) of sexually active women. Similarly, 40% ($n = 27$) of sexually inactive women reported never experiencing sexual desire, whereas all sexually active women reported experiencing desire at least rarely. Sexually active women were younger at both survey completion (median age, 52 vs 64 years; Cohen's $d = 0.69$) and metastatic diagnosis (median age, 49 vs 61 years; Cohen's $d = 0.72$) and were more likely to be partnered (85% vs 51%; Cramér's $V = 0.34$). Other demographic and clinical characteristics, including tumor subtype, metastatic presentation (de novo vs recurrent), number of prior lines of therapy, prior chemotherapy exposure, and PROMIS Global Physical and Mental Health T-scores, were similar between groups, with small effect sizes (Table 1).

Among sexually active women, those with sexual dysfunction had poorer global physical health (mean PROMIS Global Physical T-score, 42.2 vs 50.4; Cohen's $d = 0.83$) and global mental health (mean PROMIS Global Mental T-score, 43.2 vs 50.7; Cohen's $d = 0.77$) than those without sexual dysfunction, representing the largest observed effect sizes (Table 2). Women with sexual dysfunction were also more likely to have received two or more prior lines of therapy (79% vs 42%; Cramér's $V = 0.36$) and prior chemotherapy (79% vs 42%; Cramér's $V = 0.36$). Differences in age, race, income, marital status, tumor subtype, and metastatic presentation were otherwise modest, with small to medium effect sizes across most variables (Table 2).

Following an mBC diagnosis, 70% of participants considered their sexual life important, 57% reported sexual changes are bothersome or distressing, and 32% reported negative effects on their relationship with their partner. Using the PROMIS SexFS Factors Interfering with Sexual Satisfaction item pool, the most commonly reported contributors to reduced sexual satisfaction were fatigue/lack of energy (63%), tiredness (61%), pain (55%), stress (51%), feeling unattractive (49%), impaired mobility (42%), depression (42%), anxiety (42%), sadness (41%), and worry about satisfying a partner (39%). Less common contributors included surgical scars (33%), hot flashes (32%), hair loss (21%), organ loss (21%), weight gain (17%), and medical devices (13%).

Only 14% had received prior cancer-related sexual health information and 14% reported clinician-initiated discussions about sexual problems. However, 36% desired interventions for sexual concerns, 43% wanted more information on available treatments, and 90% were comfortable discussing sexual concerns with healthcare providers. Oncologists were the preferred healthcare professionals for these discussions (59%), followed by nurse practitioners (35%), primary care providers (34%), and nurses (30%) at cancer clinics.

Regarding interest in interventions for sexual problems, 58 participants (54%) reported no interest in any intervention. Among those interested, the most commonly selected interventions were non-hormonal

vaginal creams for dryness (34, 32%), medications to increase sexual desire (19, 18%), counseling with a sexual health provider (19, 18%), counseling with a sexologist (15, 14%), and estrogen- or testosterone-containing vaginal creams (10, 9%). Figure 2 presents participant preferences for three intervention categories: low-barrier interventions (lubricants, moisturizers, educational materials, and behavioral strategies), prescribed interventions (vaginal estrogen, vaginal testosterone, desire-enhancing medications, and couples or sex counseling), and both.

Qualitative Analysis

Twenty participants aged 30–77 years completed the semi-structured interviews. Eleven (55%) were White and nine (45%) were African American; 19 (95%) identified as heterosexual and one (5%) as bisexual. Ten (50%) were married or partnered and Ten (50%) were widowed, single, or divorced. Most participants (90%) were postmenopausal.

Theme 1: Sexual Problems Following Metastatic Breast Cancer Diagnosis

Participants described several sexual problems that emerged following cancer diagnosis and treatment.

Subtheme 1.1. Reduced sexual desire or interest

All 20 participants reported that sexual interest declined after diagnosis of mBC. One participant described this change, *“I still have those difficulties with just having interest in sex, whether that be because of medications.”* [P77] Another reported, *“It’s like I’m not interested versus before.”* [P62]

Subtheme 1.2. Vulvovaginal symptoms

Vaginal dryness and discomfort during intercourse were also frequently reported, often resulting in reduced sexual pleasure and enjoyment. As one participant explained, *“It was not just the pain and the bleeding; it was more like somebody was doing something down there, but it didn’t feel sexual. The sexual acts didn’t feel sexual.”* [P32] These symptoms often led women to avoid penetrative intercourse. Another participant shared, *“And even then, I’m like, oh man, forget it. I’m not even going to try this because the last time I tried it, it was painful.”* [P29]

Subtheme 1.3. Reduced sexual frequency: Reduced sexual frequency was a commonly reported consequence of decreased sexual desire and vulvovaginal symptoms. One participant described this change succinctly: *“Nope. It is just utterly declined!”* [P51]

Subtheme 1.4. Reduced satisfaction with sex life

Changes in sex life related to mBC diagnosis often led to lowered satisfaction with sex life. *“No, I’m not satisfied. I mean, I wish I had the libido that I had when I was 40 years old.”* [P36]

Theme 2: Factors Contributing to Sexual Problems

Participants identified several physical and emotional factors that contributed to sexual difficulties following mBC diagnosis.

Subtheme 2.1. Body image changes after cancer

Body image changes related to breast surgery and systemic therapy, including breast loss, asymmetry, scars, hair loss, nail changes, skin toxicities, and medical devices, contributed to sexual problems. Breast changes were among the most commonly reported concerns. As one participant shared, *"I've never been super model material but walking around with the one boob just way up in the air and the other one not, was kind of, like I said, body image is not something I normally worry about, but when it's something that's so overtly obvious, you still kind of are like, wait."* [P64] These changes also affected participants' confidence and comfort with intimacy. Another participant expressed, *"I saying, God, please give me my hair back. Do something. Don't let me go into a relationship."* [P45]

Subtheme 2.2. Cancer therapy-related sexual symptoms

Participants reported that cancer therapy-related side effects, including chemotherapy and endocrine-based therapy, contributed to sexual problems. One participant described the impact of chemotherapy – *"When I started going through chemotherapy, it gives you a burning sensation where it makes your whole body hot. Like I say, it knocked my menstruation off. It threw me into early menopause where I'm having hot flashes all the time. And once you start going through that, it throws your sex drive off as well."* [P29] Another participant described the effects of endocrine therapy – *"Well, since the initial diagnosis, because some of the drugs I was putting on decreased the estrogen, definitely difference in ability to achieve an orgasm, libido dropped, and then all the more so with the metastatic."* [P36]

Subtheme 2.3. Non-sexual physical Symptoms

Participants also reported that physical symptoms related to mBC and its treatment reduced their ability or desire to engage in sexual activity. Fatigue was one of the most frequently described barriers. One participant shared, *"I was tired too, and after one treatment that I was getting had me feeling just really weak and out of it, and I just was really tired. I was sleeping all day."* [P51] In addition, several women described joint stiffness, pain, and general physical discomfort associated with cancer treatments that made sexual activity physically difficult or less appealing. One participant described, *"Uh, caused fatigue and there were some early one that also caused a significant amount of pain. I'm not in, that's not true now, but, um, lots of joint pain."* [P02]

Theme 3: Psychological and Relationship Impacts of Sexual Changes

Sexual changes following mBC diagnosis often had important psychological and relational consequences.

Subtheme 3.1. Emotional distress related to sexual changes

Participants frequently described negative emotional reactions, including distress, frustration, sadness, and disappointment, related to diminished sexual functioning. Several participants described feeling that an important aspect of their lives had unexpectedly changed following diagnosis and treatment. One participant shared, *“And my lack of sexual desire has even put masturbation off the table, and I want to want it more, and I want him to want it more. And it's just not happening. And I don't know that it ever will.”* [P32]

Subtheme 3.2. Feelings of inadequacy and guilt toward partners

Some participants expressed concern about disappointing their partners due to decreased libido or reduced sex frequency. These concerns sometimes led women to feel guilty or inadequate within their relationships. *“Yeah, I am frustrated. I think I said mainly because I'm disappointing him.”* [P36] In some cases, participants reported engaging in sexual activity despite discomfort or lack of desire to avoid disappointing their partners. *“He kept asking me, and then I told him that I really haven't been wanting to, and then a few times that we did it wasn't comfortable. And I said, it actually might've hurt just a little bit too.”* [P21]

Subtheme 3.3. Relationship strain versus increased closeness

The impact of sexual changes on relationships varied across participants. Some women described tension, misunderstandings, or even relationship dissolution related to these changes, as one participant shared, *“It really upset me when my boyfriend decided to break up with me because we couldn't do the things that we used to do.”* [P29]

In contrast, others reported that their relationships became stronger and more supportive during the cancer experience. As one participant noted, *“Just because I feel like it's something that you go through. It's not only me going through it, I feel like it's him too, just being there for me. And I just feel like it brings you closer as a couple just because he sees what you're going through.”* [P44]

Theme 4: Improving Clinical Communication About Sexual Health

Participants offered several recommendations for how clinicians could better address sexual health concerns in oncology care.

Subtheme 4.1. Normalization of sexual health discussions

Participants emphasized the importance of normalizing sexual health discussions in cancer care to reduce isolation and the perception that these challenges are unique. As one participant shared, *“Being*

comfortable with the conversation and making it not seem like it's something that's taboo... can help patients feel more comfortable talking about something they may otherwise avoid." [P77] Participants also recommended incorporating sexual health as a routine component of treatment planning, particularly for those who are sexually active or in relationships. One participant noted, *"I think it should be a part of the treatment plan—something you talk about before treatment, especially for people who are in relationships, marriages, or otherwise sexually active."* [P51]

Subtheme 4.2. Educational materials for independent learning

Participants also expressed interest in self-review educational resources, such as pamphlets, flyers, or online materials. These resources could help patients understand potential sexual side effects of treatment and prepare them to discuss these issues with healthcare providers. *"Yeah, and patients with breast cancer would be much more comfortable just reading about it rather than asking about it. And then once they read about it and knew that yes, there was a lot of people had this problem, I think that then they could be more open to talking about it to the doctor [P14]."*

Theme 5: Perceptions of Potential Interventions

Subtheme 5.1. Preference for low-burden, non-prescription approaches

Participants generally favored low-burden, non-pharmacologic strategies to manage sexual symptoms, particularly over-the-counter lubricants, sex toys, and behavioral approaches to maintain intimacy. One participant shared, *"And I have a rose, if you ever heard of those. Those are pretty good."* [P21] Another noted, *"My number one go-to—I always use *** gel... most of the time it worked for me."* [P33]

Subtheme 5.2. Reservations toward prescription and formal therapeutic interventions: Participants were more hesitant about prescription-based therapies, citing concerns about side effects, long-term safety, uncertainty about effectiveness, and the burden of additional medications or interventions. Regarding vaginal estrogen, one participant stated, *"I'd probably prefer not to use hormones if I could."* [P77] Another expressed uncertainty about medications for low desire, saying, *"I would need to understand the side effects and how it would affect other things."* [P64] Treatment burden was also a concern: *"There are already so many pills to take."* [P77] Similarly, participants expressed skepticism toward couples or marital counseling, with one remarking, *"To a therapist? No, I've done that."* [P36]

Discussion

This mixed-methods study highlights that sexual inactivity and dysfunction among women with mBC are common, multifactorial, and clinically meaningful. Despite metastatic disease, most participants valued sexual health, and many described sexual changes as bothersome. However, sexual health concerns remain underrecognized and insufficiently addressed in oncology practice, underscoring a critical gap in comprehensive cancer care.

A key strength is inclusion of women regardless of sexual activity status, demonstrating that nearly two-thirds were sexually inactive—higher than prior reports in general and cancer population^{5,19}. This finding highlights a major limitation of commonly used sexual function instruments, such as the Female Sexual Function Index (FSFI) and the Brief Index of Sexual Functioning for Women (BISF-W), which primarily assess sexually active individuals and may underestimate sexual health concerns in mBC^{47–49}. These findings suggest that sexual inactivity and sexual dysfunction should be conceptualized as overlapping constructs rather than distinct entities in women with mBC⁵⁰. Sexual inactivity and reduced sexual frequency among women with mBC are multifactorial. Lack of sexual interest emerged as a central driver of inactivity, with markedly lower interest among sexually inactive women, consistent with prior literature⁵¹. Additional contributors included treatment-related adverse effects, such as vulvovaginal symptoms, fatigue, poor body image, and prioritization of cancer treatment over sexual health.

Observed sexual dysfunction patterns—including reduced desire, vaginal dryness, dyspareunia, and decreased satisfaction—are consistent with early-stage breast cancer literature^{6,17}. Approximately 70% of sexually active participants reported dysfunction in at least one domain, and 50% reported dysfunction in multiple domains (excluding interest). Greater therapeutic exposure and prior chemotherapy use were moderately associated with a higher burden of sexual dysfunction consistent with early-stage breast cancer data⁵².

Sexual dysfunction, rather than sexual activity status, was associated with clinically meaningful physical and mental health impairments. While the association between sexual dysfunction and poorer QOL is consistent with findings from early-stage breast cancer populations,⁵¹ the lack of a significant association between sexual inactivity and QOL was somewhat unexpected. Nonetheless, sexual function represents an important component of QOL among women with mBC. Younger participants were more likely to be sexually active, suggesting that younger women living with mBC may be particularly vulnerable to the impact of unaddressed sexual concerns. This is increasingly relevant given the rising mBC incidence among younger women and highlights the need for greater attention to sexual health in this population⁵³.

Sexual changes had variable but clinically meaningful relational impacts. Although most participants did not report worsening relationships, nearly one-third described negative effects on their relationships. Qualitative findings demonstrated diverse emotional and relational experiences, including distress, guilt, relationship strain, and adaptive responses characterized by closeness, communication, and non-sexual intimacy.

Despite this burden, only 14% received sexual health information, consistent with prior literature showing limited discussion in oncology settings. Notably, interest in interventions was lower than that reported in early-stage populations: 36% expressed interest in interventions and 43% in receiving additional information, while the majority reported no interest in either⁵⁴. This pattern may reflect competing priorities, overall symptom burden, or limited awareness of available options.

Qualitative findings suggest that normalizing discussions of sexual health may be an important first step in addressing sexual concerns. Both qualitative and quantitative findings demonstrated a preference for non-prescription approaches, including lubricants, sex toys, and greater emphasis on non-sexual intimacy, consistent with a previous study⁵⁵. Sex toys emerged as a novel qualitative finding but were not included in the quantitative survey because their use was not anticipated during study design. In contrast, both quantitative and qualitative analyses suggested that prescription-based interventions, such as vaginal estrogen, desire-enhancing medications, formal sex therapy, and couples therapy, were infrequently used and often approached with hesitation.

Several limitations of this study should be acknowledged. This was a single-center, cross-sectional study, limiting generalizability and preventing assessment of changes over time. The cohort was restricted to English-speaking cisgender women, limiting generalizability to more diverse populations. Self-reported measures may be subject to recall or reporting bias⁵⁶. In addition, participation bias is possible, as women who chose to enroll may have differed from those who declined participation, particularly in their interest in or willingness to discuss sexual health.

Our findings address a gap in literature largely focused on early-stage breast cancer and survivorship populations^{57–60}. Sexual dysfunction and sexual inactivity are common, overlapping, and clinically meaningful concerns in women with mBC that remain under-recognized in oncology practice. These findings support routine, normalized discussions of sexual health using inclusive assessments that capture both sexually active and sexually inactive patients. Given preference for low-barrier strategies, education on accessible non-prescription interventions may serve as an effective entry point. Future studies should evaluate whether similar patterns exist among people living with other advanced cancers and determine the most effective interventions for this growing population.

Declarations

Conflicts of interest

Erica Stringer-Reasor: Advisory boards—Lilly, Novartis, Pfizer, Seagen, Tesaro, AstraZeneca, Daiichi Sankyo, and Gilead; research funding—Lilly, Novartis, Pfizer, Seagen, Tesaro, and Corcept Therapeutics Inc.

Competing Interests

Erica Stringer-Reasor: Advisory boards—Lilly, Novartis, Pfizer, Seagen, Tesaro, AstraZeneca, Daiichi Sankyo, and Gilead; research funding—Lilly, Novartis, Pfizer, Seagen, Tesaro, and Corcept Therapeutics Inc. Gaurav Goyal: Advisory boards—Opna Bio, Seagen, Sobi, and Electra; research funding—Electra; consulting—Recordati and PharmaEssentia. Nusrat Jahan: Advisory boards—AstraZeneca, Daiichi Sankyo, and Stemline Therapeutics. Gabrielle B. Rocque: Research funding—Pfizer, Genentech, and

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Author Contribution

Author ContributionsConceptualization: NJ;Methodology: NJ, CPW, GBR, AA, GG, EHS;Analysis: NJ, JAF, CPW, SCO, AA, EHS;Manuscript—original draft: NJ;Manuscript—review and editing: All authors.

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Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Tables

Table 1

Demographic, clinical, and quality of life characteristics of participants stratified by sexual activity status

	Overall N = 107	Not Sexually Active N = 67	Sexually Active N = 40	Effect Size†
Demographics				
Age at survey, median (IQR)	61 (48–68)	64 (54–70)	52 (42–64)	0.69
Age at metastatic diagnosis, median (IQR)	57 (46–65)	61 (52–68)	49 (40–62)	0.72
Sexual orientation				0.02
Heterosexual	101 (94)	63 (94)	38 (95)	
Homosexual/bisexual/other	6 (6)	4 (6)	2 (5)	
Race				0.15
White	71 (66)	48 (72)	23 (56)	
Black	29 (27)	15 (22)	14 (37)	
Other	7 (7)	4 (6)	3 (7)	
Education				0.04
High school or less	21 (20)	14 (21)	7 (18)	
Some college or higher	86 (80)	53 (79)	33 (82)	
Household income				0.07
Less than \$50,000	54 (50)	32 (48)	22 (55)	
\$50,000 or more	53 (50)	35 (52)	18 (45)	
Employment status				0.13
Employed	32 (30)	17 (25)	15 (38)	
Unemployed/retired/on disability	75 (70)	50 (75)	25 (62)	
Partnership status				0.34

Data are presented as n (%) unless otherwise indicated. Continuous variables are presented as median (interquartile range [IQR]) or mean (standard deviation [SD]), as appropriate. †Effect sizes were calculated using Cohen's d for continuous variables and Cramér's V for categorical variables. Cohen's d values of 0.2, 0.5, and 0.8 and Cramér's V values of 0.1, 0.3, and 0.5 indicate small, medium, and large effect sizes, respectively. Abbreviations: HER2, human epidermal growth factor receptor 2; HR, hormone receptor; IQR, interquartile range; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation.

	Overall N = 107	Not Sexually Active N = 67	Sexually Active N = 40	Effect Size†
Demographics				
Married or partnered	68 (64)	34 (51)	34 (85)	
Single/divorced/widowed	39 (36)	33 (49)	6 (15)	
Disease Characteristics				
Menstrual status				0.02
Postmenopausal	97 (91)	61 (91)	36 (90)	
Premenopausal/perimenopausal	10 (9)	6 (9)	4 (10)	
Tumor subtype				0.04
HER2+	21 (20)	14 (21)	7 (17)	
HR+/HER2-	71 (66)	44 (66)	27 (68)	
HR-/HER2- (triple-negative)	15 (14)	9 (13)	6 (15)	
Metastatic presentation				0.003
De novo metastatic	43 (40)	27 (40)	16 (40)	
Recurrent metastatic	64 (60)	40 (60)	24 (60)	
Time from breast cancer diagnosis to survey (months), median (IQR)	62.5 (32–125)	63.0 (32–130)	59.0 (27–111)	0.08
Time from metastatic diagnosis to survey (months), median (IQR)	25 (11–52)	26.0 (12–54)	24.0 (9–52)	0.05
Treatment History				
Prior breast surgery				0.15
Lumpectomy	30 (28)	22 (33)	8 (20)	
Mastectomy	43 (40)	24 (36)	19 (48)	
No breast surgery	34 (32)	21 (31)	13 (33)	
Data are presented as n (%) unless otherwise indicated. Continuous variables are presented as median (interquartile range [IQR]) or mean (standard deviation [SD]), as appropriate. †Effect sizes were calculated using Cohen's d for continuous variables and Cramér's V for categorical variables. Cohen's d values of 0.2, 0.5, and 0.8 and Cramér's V values of 0.1, 0.3, and 0.5 indicate small, medium, and large effect sizes, respectively. Abbreviations: HER2, human epidermal growth factor receptor 2; HR, hormone receptor; IQR, interquartile range; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation.				

	Overall N = 107	Not Sexually Active N = 67	Sexually Active N = 40	Effect Size†
Demographics				
Prior radiation therapy				0.06
Yes	68 (64)	41 (61)	27 (68)	
Number of prior lines of therapy				0.004
0–1	35 (33)	22 (33)	13 (33)	
≥ 2	72 (67)	45 (67)	27 (68)	
Prior chemotherapy				0.06
Yes	68 (64)	41 (61)	27 (68)	
No	39 (36)	26 (39)	13 (33)	
Patient-Reported Outcomes				
PROMIS Global Physical Health T-score, mean (SD)	44.7 (8.7)	44.7 (8.2)	44.6 (9.5)	0.01
PROMIS Global Mental Health T-score, mean (SD)	45.8 (8.4)	45.8 (7.6)	45.4 (9.7)	0.05
Data are presented as n (%) unless otherwise indicated. Continuous variables are presented as median (interquartile range [IQR]) or mean (standard deviation [SD]), as appropriate. †Effect sizes were calculated using Cohen's d for continuous variables and Cramér's V for categorical variables. Cohen's d values of 0.2, 0.5, and 0.8 and Cramér's V values of 0.1, 0.3, and 0.5 indicate small, medium, and large effect sizes, respectively. Abbreviations: HER2, human epidermal growth factor receptor 2; HR, hormone receptor; IQR, interquartile range; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation.				

Table 2

Demographic, clinical, and quality of life characteristics of sexually active participants by sexual dysfunction status

	Overall N = 40	No Sexual Dysfunction N = 12	Sexual Dysfunction N = 28	Effect Size†
Demographics				
Age at survey, median (IQR)	52 (43–64)	51 (43–62)	52 (44–66)	0.31
Age at metastatic diagnosis, median (IQR)	49 (40–62)	47 (41–53)	49 (40–64)	0.39
Sexual orientation				0.10
Heterosexual	38 (95)	11 (92)	27 (93)	
Homosexual/bisexual/other	2 (5)	1 (8)	1 (4)	
Race				0.10
White	23 (58)	6 (50)	17 (59)	
Black	14 (35)	5 (42)	9 (32)	
Other	3 (8)	1 (8)	2 (7)	
Education				0.16
High school or less	7 (18)	1 (8)	6 (21)	
Some college or higher	33 (83)	11 (92)	22 (79)	
Household income				0.25
Less than \$50,000	22 (55)	9 (75)	13 (46)	
\$50,000 or more	18 (45)	3 (25)	15 (52)	
Employment status				0.28
Employed	15 (38)	7 (58)	8 (29)	
Unemployed/retired/on disability	25 (62)	5 (42)	20 (71)	
Partnership status				0.19
Data are presented as n (%) unless otherwise indicated. Continuous variables are presented as median (interquartile range [IQR]) or mean (standard deviation [SD]), as appropriate. †Effect sizes were calculated using Cohen's d for continuous variables and Cramér's V for categorical variables. Cohen's d values of 0.2, 0.5, and 0.8 and Cramér's V values of 0.1, 0.3, and 0.5 indicate small, medium, and large effect sizes, respectively. Abbreviations: HER2, human epidermal growth factor receptor 2; HR, hormone receptor; IQR, interquartile range; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation.				

	Overall N = 40	No Sexual Dysfunction N = 12	Sexual Dysfunction N = 28	Effect Size†
Demographics				
Married or partnered	34 (85)	9 (75)	25 (89)	
Single/divorced/widowed	6 (15)	3 (25)	3 (11)	
Disease Characteristics				
Menstrual status				0.18
Postmenopausal	36 (90)	10 (83)	26 (93)	
Premenopausal/perimenopausal	4 (10)	2 (17)	2 (7)	
Tumor subtype				0.15
HER2+	7 (18)	1 (8)	6 (21)	
HR+/HER2-	27 (68)	9 (75)	18 (64)	
HR-/HER2- (triple-negative)	6 (15)	2 (17)	4 (14)	
Metastatic presentation				0.13
De novo metastatic	16 (40)	6 (50)	10 (35)	
Recurrent metastatic	24 (60)	6 (50)	18 (64)	
Time from breast cancer diagnosis to survey (months), median (IQR)	59.0 (27–111)	69.0 (36–94)	53.5 (27–122)	0.21
Time from metastatic diagnosis to survey (months), median (IQR)	24.0 (9–52)	41.0 (7–70)	22.5 (9.5–43.5)	0.25
Treatment History				
Prior breast surgery				0.27
Lumpectomy	8 (20)	1 (8)	7 (25)	
Mastectomy	19 (48)	5 (42)	14 (50)	
No breast surgery	13 (33)	6 (50)	7 (25)	
Data are presented as n (%) unless otherwise indicated. Continuous variables are presented as median (interquartile range [IQR]) or mean (standard deviation [SD]), as appropriate. †Effect sizes were calculated using Cohen's d for continuous variables and Cramér's V for categorical variables. Cohen's d values of 0.2, 0.5, and 0.8 and Cramér's V values of 0.1, 0.3, and 0.5 indicate small, medium, and large effect sizes, respectively. Abbreviations: HER2, human epidermal growth factor receptor 2; HR, hormone receptor; IQR, interquartile range; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation.				

	Overall N = 40	No Sexual Dysfunction N = 12	Sexual Dysfunction N = 28	Effect Size†
Demographics				
Prior radiation therapy				0.13
Yes	27 (68)	7 (58)	20 (71)	
Number of prior lines of therapy				0.36
0–1	13 (33)	7 (58)	6 (21)	
≥ 2	27 (68)	5 (42)	22 (79)	
Prior chemotherapy				0.36
Yes	27 (68)	5 (42)	22 (79)	
No	13 (33)	7 (58)	6 (21)	
Patient-Reported Outcomes				
PROMIS Global Physical Health T-score, mean (SD)	44.8 (9.6)	50.4 (11.7)	42.2 (7.5)	0.83
PROMIS Global Mental Health T-score, mean (SD)	45.7 (9.6)	50.7 (11.1)	43.2 (8.3)	0.77
Data are presented as n (%) unless otherwise indicated. Continuous variables are presented as median (interquartile range [IQR]) or mean (standard deviation [SD]), as appropriate. †Effect sizes were calculated using Cohen's d for continuous variables and Cramér's V for categorical variables. Cohen's d values of 0.2, 0.5, and 0.8 and Cramér's V values of 0.1, 0.3, and 0.5 indicate small, medium, and large effect sizes, respectively. Abbreviations: HER2, human epidermal growth factor receptor 2; HR, hormone receptor; IQR, interquartile range; PROMIS, Patient-Reported Outcomes Measurement Information System; SD, standard deviation.				

Figures

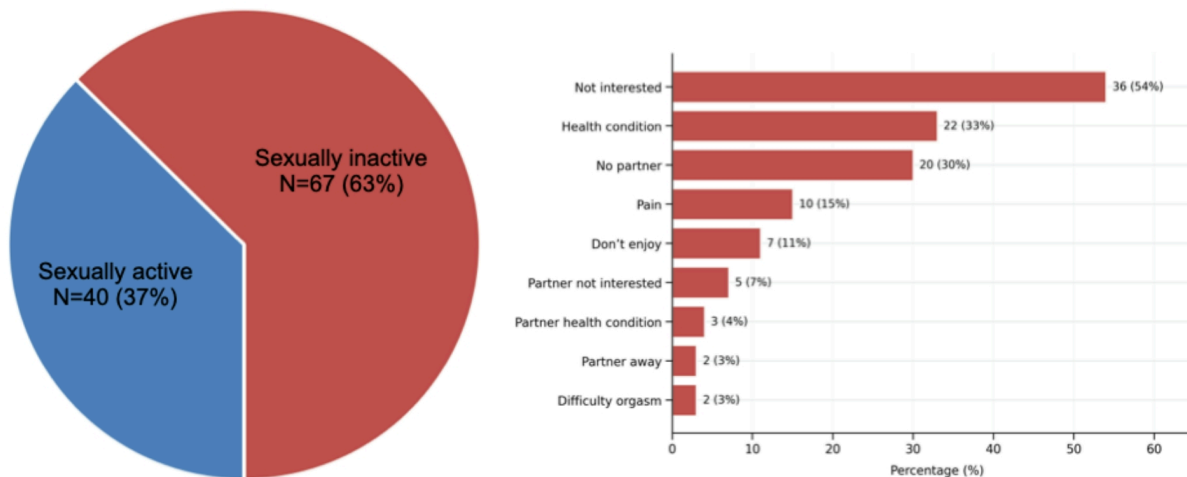


Figure 1A. Sexual activity status and reasons for sexual inactivity.

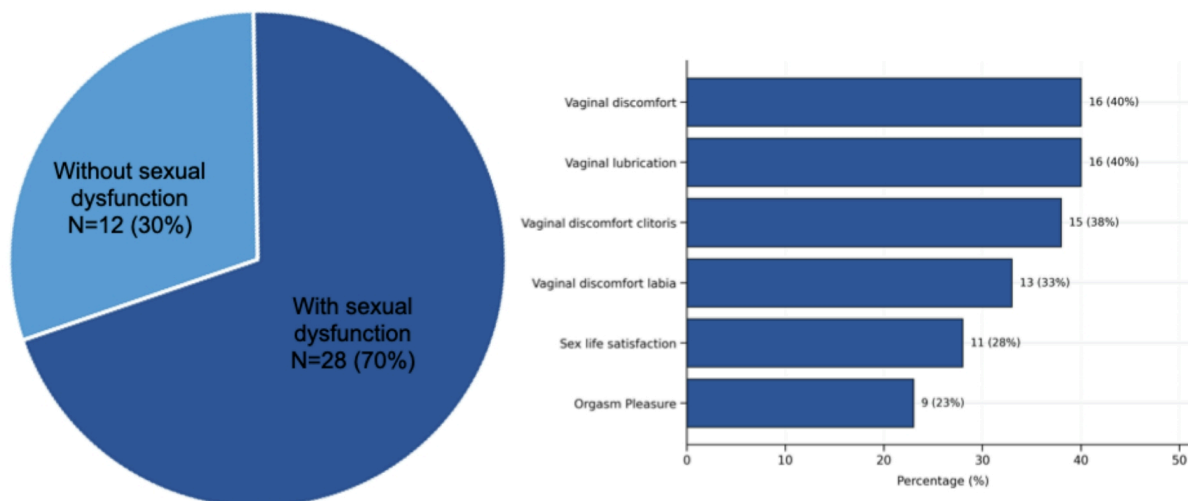


Figure 1B. Sexual dysfunction domains among sexually active participants.

Figure 1

Sexual activity (1A) and sexual dysfunction (1B) among women with metastatic breast cancer.

(A) Sexual activity status among study participants and reported reasons for sexual inactivity during the preceding 30 days.

(B) Prevalence and types of sexual dysfunction among sexually active women with metastatic breast cancer. Sexual dysfunction was defined according to the PROMIS Sexual Function and Satisfaction Measures (SexFS) scoring criteria. The figure displays the overall prevalence of sexual dysfunction, and the frequency of specific domains affected, including lubrication difficulties, vaginal discomfort, clitoral discomfort, labial discomfort, reduced sexual satisfaction, and decreased orgasmic pleasure.

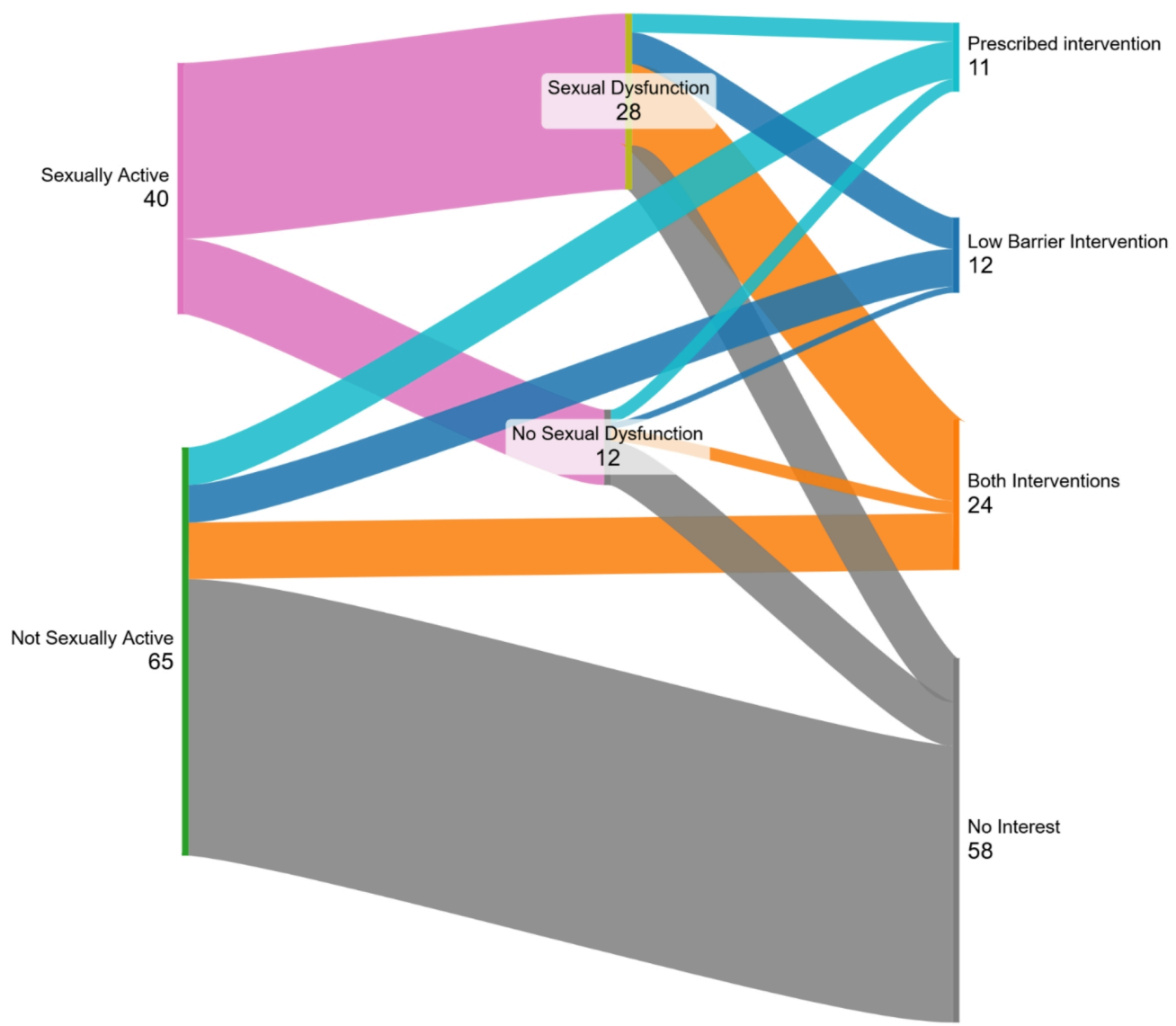


Figure 2

Participant preferences for sexual health interventions. Sankey diagram illustrating participant interest in receiving different types of interventions to address sexual health concerns. Interventions were

categorized as prescribed interventions (e.g., vaginal estrogen, vaginal testosterone, desire-enhancing medications, and couples or sex counseling), low-barrier interventions (e.g., lubricants, moisturizers, educational materials, and behavioral strategies to improve intimacy), or both prescribed and low-barrier interventions. Flow widths are proportional to the number of participants selecting each category. Overall, the majority of participants expressed no interest in receiving any intervention.