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Communication about Sexual Health in Breast Cancer: What Can We Learn from Patients' Self-Report and Clinic Dialogue?

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ABSTRACT

Objective: Research assessing clinical communication about sexual health is limited. We compared clinical communication about sexual health across patients' self-reports and coded dialogue in breast cancer outpatients.
Methods: 134 patients had clinic visits audio-recorded and coded for sexual health communication and completed self-report questionnaires immediately after the visit. Associations between the self-report and dialogue were assessed using Phi coefficient. Agreements (present/absent) and discrepancies (omissions, commissions) about discussed topics were classified and discrepancies analyzed for themes.
Results: Sexual health was discussed in 61 of 134 patient visits (46%). Associations were significant ($p < .01$) but differed by topic ($\varphi = .27$-$.76$). 37 women (23%) had ≥ 1 self-report error. Discrepancies were common (19 omissions, 29 commissions). Patients often omitted communication about sexual concerns when such concerns were not problematic, and interpreted non-specific discussions as including specific topics of concern, even when not explicitly stated. Omissions were more common for women with lower education.
Conclusions: Patients' reports of whether sexual health communication occurs does not always align with observed dialogue, and may vary by personal relevance of the topic.
Practice Implications: There are limitations in determining the prevalence of clinical communication about sexual health through patient self-report. Explaining sexual health terms might enhance shared understanding.

1. Introduction

For women diagnosed with breast cancer, sexual problems are common and include difficulties with sexual interest, excitement, and orgasm, as well as menopausal-type symptoms (e.g., vaginal dryness), and body image concerns [1–3]. Sexual problems are distressing and persistent [4] and have negative consequences both for breast cancer survivors' individual well-being and intimate relationships [5]. Moreover, most women with breast cancer want sexual issues to be discussed as part of their care [6]. Organizations such as the National Comprehensive Cancer Network (NCCN) and the American Society for Clinical Oncology (ASCO) recommend including sexual health in clinical discussions for those with breast and other cancers [7,8]. Yet fewer than half of women with breast cancer report discussing sexual issues with their cancer clinicians [6,9,10], due to multiple factors including patient and clinician discomfort and unhelpful beliefs, perceived time constraints, and inadequate clinician training [11–13]. Without such discussions, many women may not have sexual issues addressed [8,14,15].

As recognition of the importance of clinical communication about sexual health in cancer increases, research efforts to understand [10,15–19] and improve this communication have also grown [20–22]. However, there is little consensus on how best to capture this communication. In a recent systematic review, the majority of studies examining the prevalence of sexual health communication in cancer (62%) employed self-report measures [9], whereas only 10% used observation or recordings of dialogue from actual clinic encounters. Self-report measures are easy to administer and score and are cost-effective, but may be subject to potential recall errors and offer less rich data than time-intensive measures (e.g., observation). In contrast with other areas of quality of life [23], to our knowledge, no studies have

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examined how well aligned patients' self-report and observed clinic dialogue are for clinical communication about sexual health. We surmised that an analysis into discrepancies between patients' self-report and clinic dialogue might offer insight into how patients interpret clinical discussions of sexual health.

Therefore, the objective of the present study was to compare two methods of assessing patient-clinician communication about sexual health in a sample of breast cancer outpatients. We used quantitative and qualitative analyses to answer several key research questions. 1) To what extent do patient self-reported questionnaires assessing clinical discussions of sexual health align with audio-recorded, coded dialogue for the same sexual health topics? 2) Do patients omit reporting discussions of sexual health that occurred during their visit or, alternatively, report discussing sexual health when no such discussion occurred? If so, could particular features of the clinical communication (e.g., certain terminology, non-specific language) be driving these self-report errors? 3) Might certain patient characteristics (e.g., demographic or medical factors) be associated with patients' self-report errors?

2. Methods

2.1. Study Design and Setting

Clinic encounters with female breast cancer patients and their clinicians were audio-recorded and the dialogue was coded for communication about sexual health. Immediately post-clinic encounter, patients completed a questionnaire about the communication during their encounter. Data for the present investigation were obtained as part of a pilot trial of a sexual health communication intervention for breast cancer clinicians [20]. Pre- and post-intervention data were used. We enrolled 134 patients in order to recruit approximately 8-16 patient visits per clinician at pre- and post-intervention. The study setting was a comprehensive cancer center located in an urban setting. Approval was obtained by the Institutional Review Board at Fox Chase Cancer Center (IRB Protocol #14-833).

2.2. Study Sample

Participants in the study consisted of breast cancer patients and clinicians. All participants completed written consent.

2.3. Patient Participants

Patients were identified through clinicians' schedules, pre-screened for eligibility through scanning their medical records, and approached by a study recruiter in the oncology clinic with clinicians' approval to participate in a study about improving breast cancer clinicians' communication about quality of life topics. Women were eligible if they were: diagnosed with any stage breast cancer, patients of participating clinicians, being seen in follow-up (i.e., not a consultation visit, because communication could differ at consult versus follow-up visits), and receiving breast cancer treatment or completed treatment within 10 years. Women were ineligible if they were unable to speak English, had poor physical performance (determined through an Eastern Cooperative Group Score (ECOG) [24] score > 2), or showed significant psychiatric or cognitive concerns. Patients received $10 gift cards for participation. Third parties (e.g., spouse, family member) present during the clinic visit gave consent to be audio recorded but otherwise received no instructions.

2.4. Clinician Participants

All clinicians (oncologists or advanced practice clinicians) treating breast cancer patients in medical oncology clinics at Fox Chase Cancer Center were approached to participate in the communication intervention trial [20], and all but one agreed (N = 7). Clinicians were compensated $500.

2.5. Data collection

2.5.1. Patient self-report data

Immediately post-clinic visit, patients completed a paper-and-pencil questionnaire assessing the communication that occurred during the visit, sociodemographic characteristics, satisfaction with their clinician's care, and breast cancer-related symptoms. The current analysis includes the socio-demographic data and communication self-report data.

2.5.2. Clinician self-report data

Clinicians completed a brief demographic questionnaire.

2.5.3. Additional data

Chart review yielded medical data pertaining to patients' cancer stage and date of diagnosis, menopausal status, and dates and types of treatments received.

2.6. Measures

2.6.1. Self-Reported Communication

Women indicated (yes/no) whether during the clinic encounter communication occurred related to five sexual health topics: vaginal dryness/discomfort, sexual interest/excitement difficulties, orgasm difficulties, body image, and relationship issues. This questionnaire was developed with input from experts on the multidisciplinary team as a potential standalone measure of sexual health communication if established as reliable.

2.6.2. Observed Clinical Communication

2.6.2.1. Overview of Audio Recording and Coding Dialogue. The research assistant placed two audio recorders in different locations in the room immediately prior to the clinic visit to capture all dialogue. Audio recordings of clinic encounters were transcribed and coded for sexual health communication using two levels of analysis. First, two coders determined the presence (yes/no) of any sexual health communication [10]. Second, dialogue relevant to the five patient-reported sexual health topics assessed in the questionnaire was identified and coded using a codebook developed for this study. The codebook included parameters of each sexual health topic code and sample dialogue meeting/not meeting parameters, and coding difficulties were resolved through discussion. A random 20% of transcripts were analyzed for inter-rater reliability. Kappa coefficients indicated perfect agreement for most topics ($\kappa = 1.0$). For orgasmic difficulties and body image, percent agreement was calculated because limited variability in codes applied meant that kappa coefficients could not be generated; percent agreement for these topics was excellent (100% and 88%, respectively).

2.6.2.2. Coded Sexual Health Topics. The following codes were used to indicate presence of clinical communication about sexual health topics and were coded dichotomously as present versus absent (1=Yes; 0=No). *Vaginal dryness/discomfort* was defined as any mention of dryness or discomfort of the vagina or vulva (e.g., " . . . people can have a little bit of vaginal dryness or discomfort . . . "). *Sexual interest or excitement* was defined as any mention of sexual interest, excitement, arousal, libido or sex drive (e.g., "[this medication] could cause decreased libido"). *Body image* was defined as any mention of thoughts and feelings to patients' appearance or body image relevant to sex or relationships (e.g., "It

[the breast] looks very ugly"). Because breast self-image is critical in sexual functioning and relationships for many women with breast cancer [25], mentions of breast appearance were categorically included. *Difficulty with orgasm* was defined as any mention of difficulty with orgasm or climax during sexual activity. Finally, *relationship issues* were defined as any mention of the patient's partnered relationship (e.g., "And otherwise how is your relationship with him?").

2.6.2.3. Characterization of Agreements and Discrepancies (Self-Report Errors). Agreements across self-report and coded dialogue were classified as agreement that a sexual health topic either was or was not discussed. Discrepancies across measures were classified as either self-report omissions (i.e., patient did not report a sexual health topic during the clinic visit yet there was evidence that it did occur in corresponding clinic dialogue; "self-report miss"), or self-report commissions (i.e., patient reported a sexual health topic during the clinic visit yet there was no evidence that this occurred in corresponding clinic dialogue; "self-report false hit").

2.7. Analysis

2.7.1. Quantitative Analysis

Descriptive analyses characterized the study sample. We reported descriptively on the frequencies of discussions of sexual health overall and by topic. Associations between self-reported and coded dialogue for sexual health topics were calculated using Phi coefficients (φ; correlations between dichotomous variables). Frequencies characterized the prevalence of discrepancies (omissions or commissions). Independent t-tests, Chi-square tests, or Fisher's Exact tests compared women with versus without self-report errors (omissions; commissions, separately) on their age, educational level (high school graduate or above versus less than high school) and chemotherapy use (currently on chemotherapy versus not), as appropriate.

2.7.2. Content Analysis of Dialogue

For clinic discussions with discrepancies between the two measures (i.e., either a patient self-report omission or commission), we first read through transcripts for which an omission or commission occurred and extracted potentially relevant dialogue that could be further analyzed. Then we charted the omissions and commissions with the dialogue (when available) for each patient with a discrepancy in an Excel spreadsheet and characterized the communication that occurred (e.g., "clinician assessed sexual concerns but patient did not endorse any"). Finally, we used the descriptions of the observed communication to infer possible reasons behind the omissions and commissions (e.g., "patient may not have reported discussing sexual concerns because it was not relevant to her due to lack of concern"). We then grouped the clinic discussions according to these features by sexual health topic to analyze their frequency.

3. Results

3.1. Patient Characteristics

Characteristics of the patient sample are shown in Table 1. The acceptance rate for this study was 80%. Most patients who refused cited lack of interest or not wanting to have their visit recorded. The patient sample was predominantly white, married/partnered, and over half were college graduates. Clinically, most patients were diagnosed with early stage breast cancer and were post-treatment (M = 35.8 months since diagnosis; SD = 33.5). Most patients had undergone curative surgery as well as radiation therapy, and over half had received chemotherapy. Three quarters of the patient sample had used hormonal therapy and over half was currently on hormonal therapy or Herceptin.

Table 1
Patient Characteristics (N = 134)

Characteristic	M (SD)
Age	58.3 (11.1)
	n (%)
Partnered (married or cohabiting)	96 (71.6)
Sexual Orientation	
Heterosexual/straight	131 (97.8)
Lesbian/homosexual	1 (0.7)
Bisexual	1 (0.7)
Something else	1 (0.7)
Race	
White/Caucasian	114 (85.1)
Black/African American	9 (6.7)
Asian	1 (0.7)
Native Hawaiian or Pacific Islander	1 (0.7)
American Indian/Alaska Native	1 (0.7)
More than one Race	4 (3.0)
Other	3 (2.2)
Unknown or Not Reported	1 (0.7)
Ethnicity	
Hispanic/Latina	6 (4.5)
Education	
Less than High School	2 (1.5)
High School or GED	25 (18.7)
Some College	34 (25.4)
Completed college	39 (29.1)
Graduate school	34 (25.4)
Disease Stage	
Stages I-II	103 (76.9)
Stages III-IIIC	13 (9.7)
Stage IV	18 (13.4)
Current Treatment Status	
On active treatment	30 (22.4)
Completed adjuvant treatment, on hormonal therapy/Herceptin†	86 (64.2)
Off all treatments	18 (13.4)
Treatments Obtained	
Surgery	122 (91.0)
Lumpectomy	82 (60.4)
Mastectomy	40 (29.9)
Chemotherapy	74 (55.2)
Radiation Therapy	89 (66.4)
Hormonal Therapy	101 (75.4)

Note: †One patient included in this group was taking hormonal therapy but had not completed other adjuvant treatments.

3.2. Clinician Characteristics

The sample of 7 clinicians consisted of 5 medical oncologists, 1 nurse practitioner, and 1 physician assistant, who were majority white (5/7) and female (4/7). Four clinicians had fewer than 5 years in practice, 1 had 5-10 years, and 2 had > 15 years.

3.3. Comparison of Self-Report and Coded Dialogue

3.3.1. Agreements

Overall, sexual health topics were observed in the clinic dialogue in 61 (46%) of 134 patient visits. The most frequently discussed topic was vaginal dryness or discomfort (37 visits, 27%), followed by body image (12 visits, 9%), relationship difficulties (11 visits, 8%), and sexual interest/excitement (4 visits, 3%). Orgasmic difficulties were not discussed. As shown in Table 2, there was greatest agreement across measures for the presence of vaginal dryness/discomfort discussion, followed by relationship difficulties, body image, and sexual interest/excitement. There was also strong agreement for the absence of discussion about vaginal

Table 2
Frequencies of Coded Sexual Health Topics, Associations across Measures, and Types of Agreements and Discrepancies by Sexual Health Topic

Topic	Observed in Dialogue	Association	Types of Agreement		Types of Discrepancies	
	–	Phi Coefficient	# Agree across Measures "Present"	# Agree across Measures "Absent"	Omissions (Self-Report Miss)	Commissions (Self-Report False Hit)
Vaginal dryness/ discomfort	37	.75***	29	91	8	5
Sexual interest/ excitement	4	.27**	2	121	2	9
Body image (breast appearance)	12	.30***	5	112	7	10
Orgasmic difficulties	0	N/A	–	–	0	3
Relationship difficulties	11	.80***	9	121	2	2

**$p < .01$; *** $p < .001$.

dryness/discomfort and relationship issues relative to sexual interest/excitement. Associations between the self-reported and coded dialogue were statistically significant for all sexual health topics except orgasmic difficulties (see Table 2). Associations were largest for vaginal dryness/discomfort and relationship issues (.75 - .80) and smallest for sexual interest/excitement and body image (.27 - .30).

3.3.2. Discrepancies (Self-Report Errors)

3.3.2.1. Prevalence of Self-Report Errors (Omissions and Commissions). Table 2 shows the number and types of discrepancies between the self-report and coded dialogue by sexual health topic and overall. Overall, 37 women (27.6%) had discrepancies in their self-report and coded dialogue: 16 women had $\geq$ 1 self-report omission and 21 women had $\geq$ 1 commission. No women had both an omission and a commission. In all, there were 19 self-report omissions and 29 commissions. Of the 16 women with $\geq$ 1 self-report omission, the majority (n = 14, 87.5%) had only 1, whereas 1 patient had 2 omissions and 1 patient had 3 omissions. Of the 21 women with $\geq$ 1 self-report commission, the majority (n = 16; 76.2%) had only 1, whereas 2 patients had 2 commissions (9.5%) and 3 patients had 3 commissions (14.3%). As shown in Table 2, omissions were most common for the topic of vaginal dryness/discomfort, followed by body image, and finally, sexual interest/excitement and relationship issues. There were no omissions for orgasmic difficulties because this topic was not observed in the dialogue. Commissions were most common for body image, followed by sexual interest/excitement, vaginal dryness, orgasmic difficulties, and relationship issues.

3.3.2.2. Content Analysis of Dialogue with Discrepancies (Self-Report Omissions/Commissions). Tables 3 and 4 show the nature of communication occurring for the patient visits with evidence of omissions or commissions and relevant dialogue that could be analyzed, with who raised the topic, our inferred possible reasons for these errors and illustrative quotes, by sexual health topic.

3.3.2.2.1. Content Analysis of Dialogue with Omissions. For vaginal dryness/discomfort, in one visit, there was a clear discussion about vaginal dryness as an identified sexual problem. Because a clear discussion had occurred, we could not infer a reason for the self-report omission other than simple recall error. By contrast, in the other 7 patient visits with omissions for this topic, the clinician raised the topic of vaginal dryness or discomfort, either by asking a question (e.g., "Any vaginal dryness with the medication?") or by counseling on it (e.g., "It [tamoxifen] can cause vaginal dryness and things like that"; "In regard to things like vaginal dryness, there's lubricants and there's moisturizers . . . "), but the patient responded during the discussion by indicating that this was not a problem for her. We inferred that the patient may not have recalled these discussions because the issue was not deemed personally relevant.

A similar pattern was evident for body image in 3 patient visits, in which the clinician raised the topic of breast appearance (e.g., "It looked like from the way the [surgeon's] report was written that you're pretty pleased with the result?"), but the patient did not endorse a problem (e.g., "Mm hmm"). In 4 visits, however, the patient and clinician discussed breast appearance and it seemed personally relevant for the patient (e.g., "I don't have to see him [surgeon] for a while . . . I'm getting nipples"). However, we inferred that patients may not have considered a discussion of breast appearance as falling under the category of "body image," and thus may have omitted discussing this topic.

For sexual interest/excitement, there were 2 omissions, and in both of these patient visits, the clinician mentioned libido as a potential sexual problem in a list of other possible problems. We inferred that patients either did not recall this topic because it was mentioned within a list, or they did not understand that the term "libido" referred to "sexual interest." Finally, for relationship issues, there were 2 omissions, and in both of these visits, a brief discussion of relationship issues occurred, but it did not appear to be a major focus for the patient. We inferred that again, lack of personal relevance of the topic could have been behind the omission.

3.3.2.2.2. Content Analysis of Dialogue with Commissions. For vaginal dryness/discomfort, in 3 patient visits, the clinician used generic or non-specific language to discuss sexual health ("Any sexual concerns . . . ?"). In one visit, the discussion concerned menopausal issues, which we surmised the patient may have interpreted as including a discussion of vaginal dryness even though it was not directly stated. In the other visit, a discussion of general discomfort during sex may have been interpreted as including vaginal discomfort.

In 9 of the 10 visits with a body image commission, the topics of hair loss and/or weight gain were discussed (e.g., "My hair is . . . thinning dramatically within the past . . . six months or so"), yet these topics fell outside of the body image code, because of the focus of that code on breast appearance. Patients likely considered these topics as falling within body image, and thus reported they had discussed this topic on their questionnaire. One visit lacked discernable dialogue to analyze.

In 6 of the 9 patient visits where had been a sexual interest/excitement commission, the sexual health communication was characterized by non-specific clinician language (e.g., "Are you still intimate?"). We inferred that because sexual health was discussed using non-specific language, patients may have interpreted the discussion as including sexual interest or excitement. In one visit, the clinician mentioned specific sexual problems in a list but interest/excitement were not mentioned. We inferred that the patient may have overgeneralized the list as including sexual interest/excitement, even though it was not explicitly stated. Two visits lacked discernable dialogue.

For orgasmic difficulties, two of three commissions had discernable dialogue to analyze. In one visit, the clinician

Table 3
Nature of Communication and Possible Reasons for Self-Report Omissions of Sexual Health Topics

Description of Observed Communication [Who Raised Topic]	Possible Reason for Omission	Frequency	Illustrative Quote from Clinic Dialogue from Visit with Sexual Health Omission
Vaginal Dryness/Discomfort (8 Omissions)			
Clinician raises the topic (either by asking or by counseling on possible future side effects) but patient does not endorse a sexual problem [Clinician raised = 7]	Patients may not have considered it a "discussion" or may not have recalled due to lack of salience of the topic	7	Clinician: Sometimes people can get a little bit of vaginal dryness, can be an issue. Patient: Eh. Clinician: Okay, nothing? Patient: Not really.
Clear discussion occurred for patient about a sexual issue [Clinician raised]	Unclear, likely recall error	1	Clinician: So no more . . . any vaginal dryness with it or no more? Patient: Mmmm . . . Clinician: Yeah? Patient: [Whispered] I use coconut oil. Clinician: Say that again? Patient: [Whispered] Coconut oil. Clinician: Coconut oil. Patient: Yes. Clinician: That's what I've been telling a lot of my patients to do. Patient: I think I heard it from you. No. There was a doctor here, [name]? Clinician: No, I told her to say that. That was from me! Patient: Oh, okay, yeah. I start using it and it's like, a miracle. Clinician: Yeah. That's what I lot of my patients tell me. Patient: Because I couldn't use the Premarin or those other . . . estrogen, you know.
Body Image (7 Omissions)			
Patient and clinician discuss breast appearance issues that are endorsed by patient as a concern [Clinician raised = 1; Patient raised = 2]	Patients may not have considered a discussion of breast appearance to fall under "body image"	3	Clinician: We just examined you recently. Patient: It looks very ugly. Clinician: It looks very ugly? Patient: Yes. Clinician: The skin and everything? Patient: Yeah, just looks abnormal. Clinician: Is it starting to heal up? Patient: Yeah, it's not that ugly. Clinician: The week or two after is sometimes the worst, and then it should start getting better. So you should be at that point now where it should start getting better. Patient: Okay.
Clinician raises topic of breast appearance but patient does not endorse concern [Clinician raised = 4]	Patient may not have considered it a "discussion" or did not remember due to lack of salience of the topic	4	Clinician: You're unbelievably even though. Patient: He [plastic surgeon] did a nice job with that. Clinician: Yeah, I have to say as far as patients go, I've seen some really good jobs and I've seen some ones that I've had patients that had to go back and have things fixed up but- Patient: Yeah. He warned me that that might happen, but I'm fine with it. Clinician: No, you look great!
Sexual Interest/Excitement (2 Omissions)			
Clinician mentions libido as a potential problem in a list with other concerns [Clinician raised = 2]	Patients may not have recalled the topic as it was within a list	2	Clinician: There could be a little bit of vaginal dryness, decreased libido, all these things that were the same for Tamoxifen.
Relationship Issues (2 Omissions)			
A brief discussion of relationship issues occurred but was not a focus of concern for the patient [Clinician raised = 1; Patient raised = 1]	Patients may not have recalled discussion due to lack of salience of the topic	2	Clinician: And how are things at home, good? Patient: Yeah. I'm by myself [laughs]. Clinician: By yourself. Patient: Yeah. Clinician: Not in a relationship right now? Patient: No. Clinician: Okay. Patient: Not for the past five years I guess. He's a good friend. Clinician: Yeah. But you're not intimate or anything like that? Patient: No. Clinician: And it's not because of the medicine or anything? Patient: Nope. Clinician: Okay. Well, good.

Table 4
Nature of Communication and Possible Reasons for Self-Report Commissions of Sexual Health Topics

Description of Observed Communication [Who Raised Topic]	Possible Reason for Commission	Frequency	Sample Relevant Observed Dialogue from Visit with Sexual Health Commission
Vaginal Dryness/Discomfort (5 Commissions)			
Clinician used generic or non-specific language used when discussing sexual health [Clinician raised = 3]	Patient may have interpreted non-specific sexual dialogue as including vaginal dryness/discomfort	3	Clinician: Any sexual concerns or anything since you've been-? Patient: No.
Patient and clinician discussed menopausal issues broadly [Clinician raised]	Patient may have interpreted a broader discussion of menopausal symptoms as including vaginal symptoms specifically	1	Clinician: Okay. Yeah, there's not a good alternative to Tamoxifen when you're pre-menopausal, like we talked about, because basically we're making you live in a menopause body, with a period. Patient: Right.
Patient and clinician discussed general pain during sex [Clinician raised]	Patient may have interpreted non-vaginal pain with sex as including vaginal discomfort	1	Patient: It just hurts when it's touched, you know what I'm saying? It's not like it's a constant hurting. Clinician: Does that make . . . time at night more difficult? Patient: Yes. Partner: oh, yeah. [Laughs] Patient: [Laughs] but you know, it's gonna always be sensitive.
Body Image (10 Commissions)			
Hair loss or weight gain was discussed during the patient visit [Clinician raised = 4; Patient raised = 5]	Patient may have included hair loss and weight gain as within their definition of body image	9	Clinician: So there's some possible benefits and some possible tradeoffs [of switching hormonal therapies] but in general . . . Patient: Weight loss would be fabulous, because if it gains weight, I'm not doing it. I had enough trouble with this one. Clinician: Okay. Patient: I really did, I put on 20 pounds. I am not putting on any more weight. I'm almost 200 pounds. That's not acceptable to me. Clinician: Okay. So- Patient: I'm telling you, I will fight tooth and nail. Clinician: Yeah. We certainly don't have to change.
No discernable dialogue	Unknown	1	–
Sexual Interest/Excitement (9 Commissions)			
Clinician used generic or non-specific language used when discussing sexual health [Clinician raised = 6]	Patient may have interpreted non-specific sexual dialogue as including interest/excitement	6	Clinician: Has the medicine interfered with your intimate life at all? Patient: No. Clinician: Are you guys active, or . . . ? Patient: Yeah. Husband: Yeah. Clinician: Good. Great.
Clinician mentions specific sexual problems in a list (but not interest/excitement) [Clinician raised]	Patient may have remembered a list of sexual concerns to include sexual interest/excitement	1	Clinician: Some people taking these hormone pills will report that they have some sexual troubles, too, would you say that in terms of dryness or discharge or discomfort? Anything going on there? Patient: No, you know I had a little tiny bit of discharge, like not crazy or anything, that I noticed and it's not always present.
No discernable dialogue	Unknown	2	–
Orgasmic Difficulties (3 Commissions)			
Generic or non-specific language used when discussing sexual health [Clinician raised]	Patient may have interpreted non-specific sexual dialogue as including orgasmic difficulties	1	Clinician: And partnering is okay? Patient: Yeah. Clinician: Is the medicine affecting any of your . . . ? Patient: No. Clinician: So you guys are intimate and happy? Patient: Yeah, yeah. Clinician: Good.
Clinician mentions specific sexual problems in a list (but not orgasm) [Clinician raised]	Patient may have remembered a list of sexual concerns to include orgasmic difficulties	1	Clinician: I think one thing I didn't ask you last time was a lot of people taking the Anastrozole as being post-menopausal have more sexual complaints like dryness, discharge, discomfort, low drive, things like that. Patient: No, hasn't bothered me at all. Clinician: Has dryness been a problem? Patient: Not at all, no.
No discernable dialogue	Unknown	1	–

Table 4 (*Continued*)

Description of Observed Communication [Who Raised Topic]	Possible Reason for Commission	Frequency	Sample Relevant Observed Dialogue from Visit with Sexual Health Commission
Relationship Issues (2 Commissions)			
Clinician asked the patient generically about "life at home" [Clinician raised]	Patient may have interpreted the generic question as including relationship issues	1	Clinician: How's life at home? Patient: Life is good.
Patient and clinician had a discussion about dating [Patient raised]	Patient interpreted dating discussion as relationship issues; coders coded this separately	1	Clinician: So what about everything else in your life, what's going on? Patient: I mean, I'm not dating anybody. Clinician: Not dating? Patient: No. I mean I tried dating sites but . . . eh. You know? Clinician: Didn't find the right person? Patient: I don't think that's how I'm gonna find . . . Clinician: Yeah. Patient: I mean they're just, they start out nice and then the crazy comes out, so it's like, yeah. But it'll get there, I was at a football party yesterday and one of the girls said the same thing, you know? You're 55, you're young, you need to . . . it'll happen. Clinician: Yup. It will happen.

mentioned specific sexual concerns within a list but orgasmic difficulties were not mentioned explicitly. We surmised that the patient may have overgeneralized the list as including orgasmic issues, even though it was not explicitly stated. In another visit, non-specific clinician language was used to discuss sexuality more generally, and we surmised that the patient may have understood this general discussion to include orgasmic difficulties.

Finally, for relationship issues, in one visit, home life was discussed very generally, and we surmised that the patient may have interpreted this discussion to include relationship issues. In the other discussion, the patient and clinician had a discussion of dating, which fell outside our relationship issues code.

3.3.2.2.3. Demographic/Medical Factors Influencing Self-Report Omissions/Commissions. We explored whether women with omissions or commissions would differ on age, educational level, or current chemotherapy use within the subgroups of patients who either discussed (n = 61) or did not discuss sexual health in their visits (n = 73), respectively.[1] Educational level was significantly associated with self-report omissions of sexual health communication (i.e., not reporting discussing sexual health despite evidence in the dialogue); more women with lower education (7/13; 53.8%) omitted sexual health communication as compared to women with greater education (9/39; 18.8%; $\chi^2 = 6.5$, $p = .01$). Educational level was not associated with self-report commissions (i.e., reporting discussing sexual health when this was not observed in the dialogue; $p = .35$). Age and chemotherapy were not associated with self-report errors.

4. Discussion and Conclusion

4.1. Discussion

We compared two different methods of assessing sexual health communication – patient self-report vs. coded dialogue from clinic encounters – in a sample of breast cancer outpatients, hoping that the results might offer useful insights into how patients interpret sexual health communication when it occurs. Although we found that the two measures were often in agreement, there were considerable discrepancies. An in-depth analysis of the communication occurring for patients with such discrepancies suggested that patients may miss communication about sexual health when the topic discussed is not problematic to them, and conversely, may interpret non-specific sexual discussions as including specific topics of concern to them, even when not explicitly stated. Although most discussions omitted were raised by the clinician (84%), in fact, sexual health topics were raised by the clinician in 83% of *all* such discussions (data not shown), suggesting that it is the perceived relevance of the discussion rather than who raises it that seems to influence recall. Having a third party present also did not appear to influence recall. Importantly, the patient self-report questionnaire was administered immediately following the visit, decreasing the likelihood that recall errors were caused by decay in memory over time. Nevertheless, clinic visits can be overwhelming for patients, and recall errors are possible.

Interestingly, the agreement and discrepancies across the two measures differed by sexual health topic. The topics with the best agreement and fewest discrepancies were those that were physical (vaginal dryness/discomfort) or social in nature (relationship issues), whereas those with poorer agreement and more discrepancies tended to be those that were emotional or motivational in nature (sexual interest/enjoyment, body image). As one example, we considered body image narrowly as focused on breast appearance, since the breasts and breast appearance can impact partnered sexual activity for women with breast cancer [26,27]. Yet the concept of body image can be complex for cancer survivors [28], and the narrow definition we employed probably increased the commissions found for this topic, given that many of the issues patients reported discussing (e.g., hair loss, weight gain) fall within the term "body image." Consistent with prior research, these findings suggest that patients can have different interpretations of terms used in sexual function measures [24].

As expected, women with lower education were more likely to incorrectly omit (miss) sexual health discussions as compared to women with higher education. Prior research shows that lower education can influence cancer patients' understanding of health terminology [29]. For this reason, we surmised that lower education could adversely affect patients' understanding of certain

[1] We also examined whether discrepancies differed by having a third party present, and found that 7 omissions and 8 commissions of sexual health communication for visits with a third party present, compared to 9 and 13 when a third party was not present; these rates were not significantly different, $p \geq .76$.

technical terms used when discussing sexual health (e.g., "libido") or interfere with how patients encoded and remembered information from the clinical encounter. However, we did not see associations between older age or chemotherapy and patients' self-report errors, despite these being risk factors for cancer-related cognitive impairment [30,31]. It would be useful to examine these discussions in larger, more diverse samples with respect to treatment history and in survivors experiencing chemotherapy or age-related cognitive impairment.

This study offers novel findings with respect to how breast cancer patients interpret and report on sexual health discussions with their clinicians. However, there are several limitations worth noting. First, we used single items to assess communication about the specific sexual health topics, whereas multiple items could increase accuracy. Second, the sample was largely heterosexual and had limited racial/ethnic diversity, and the subsample of women with lower education was small. In addition, relatively few women had metastatic disease. Future research could examine whether these findings hold for specific subgroups of patients characterized by sexual orientation, racial/ethnic minority status, educational attainment, and metastatic disease. Finally, we cannot conclude that our findings would apply to populations with different cancers or other medical populations.

4.2. Practice Implications

This study has several practice implications for researchers and clinicians. For researchers, one implication is that using multiple items to assess the prevalence of clinical communication about sexual health may be preferable to using single items (as we did here), particularly when assessing communication about complex or broad-ranging sexual health concepts (e.g., sexual desire) that are subject to considerable individual interpretation. Another implication is that using patient self-report for this purpose may be more appropriate in subgroups of women characterized by heightened sexual concerns (e.g., those who are seeking treatment for sexual problems), because these concerns are likely to be perceived of as more relevant and thus possibly less prone to recall errors. Findings underscore the importance of checking the accuracy of clinicians' understanding of patients' sexual concerns, particularly given that patients may interpret non-specific discussions of sexual health as including specific topics that were not mentioned explicitly. On the other hand, some clinicians may take comfort in knowing that when they ask their patients about non-specific sexual concerns, their patients understand these expressions to include a number of specific topics that may be of concern. Care should be taken when discussing sexual health with patients of lower educational attainment. However, all women can benefit from clear, direct communication with regard to sexual health, regardless of educational attainment. Finally, our findings highlight the importance of defining and explaining complex and broad sexual health terms – whether during the clinic visit or on a self-report questionnaire.

4.3. Conclusions

Sexual health is of substantial concern for women treated for breast cancer and yet continues to be under-discussed clinically. This study offers insight into how breast cancer patients may interpret clinical discussions of sexual health. This research could inform efforts to promote effective clinical communication about sexual health in cancer.

Declaration of Competing Interest

None

CRediT authorship contribution statement

Jennifer Barsky Reese: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Visualization, Supervision, Project administration, Funding acquisition. **Kristen A. Sorice:** Conceptualization, Methodology, Software, Formal analysis, Investigation, Data curation, Writing - original draft, Writing - review & editing, Visualization, Project administration. **Lauren A. Zimmaro:** Conceptualization, Methodology, Investigation, Writing - original draft, Writing - review & editing, Visualization. **Stephen J. Lepore:** Conceptualization, Methodology, Writing - original draft, Writing - review & editing, Visualization. **Mary Catherine Beach:** Conceptualization, Methodology, Writing - original draft, Writing - review & editing, Visualization.

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References

[1] M. Panjari, R.J. Bell, S.R. Davis, Sexual Function after Breast Cancer, J. Sex. Med. 8 (2011) 294–302.
[2] S.B. Hummel, D.E.E. Hahn, J.J.D.M. van Lankveld, H.S.A. Oldenburg, E. Broomans, N.K. Aaronson, Factors Associated With Specific Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Sexual Dysfunctions in Breast Cancer Survivors: A Study of Patients and Their Partners, J. Sex. Med. 14 (2017) 1248–1259.
[3] S.-Y. Fang, Y.-C. Lin, T.-C. Chen, C.-Y. Lin, Impact of marital coping on the relationship between body image and sexuality among breast cancer survivors, Support. Care Cancer 23 (2015) 2551–2559.
[4] G.A. Raggio, M.L. Butryn, D. Arigo, R. Mikorski, S.C. Palmer, Prevalence and correlates of sexual morbidity in long-term breast cancer survivors, Psychol. Health 29 (2014) 632–650.
[5] D.A. Male, K.D. Fergus, K. Cullen, Sexual identity after breast cancer: Sexuality, body image, and relationship repercussions, Current opinion in supportive and palliative care 10 (2016) 66–74.
[6] K.E. Flynn, J.B. Reese, D.D. Jeffery, A.P. Abernethy, L. Lin, R.A. Shelby, L.S. Porter, C.B. Dombeck, K.P. Weinfurt, Patient experiences with communication about sex during and after treatment for cancer, Psychooncology 21 (2012) 594–601.
[7] C.S. Denlinger, T. Sanft, K.S. Baker, S. Baxi, G. Broderick, W. Demark-Wahnefried, D.L. Friedman, M. Goldman, M. Hudson, N. Khakpour, A. King, D. Koura, E. Kvale, R.M. Lally, T.S. Langbaum, M. Melisko, J.G. Montoya, K. Mooney, J.J. Moslehi, T. O'Connor, L. Overholser, E.D. Paskett, J. Peppercorn, M. A. Rodriguez, K.J. Ruddy, P. Silverman, S. Smith, K.L. Syrjala, A. Tevaarwerk, S.G. Urba, M.T. Wakabayashi, P. Zee, D.A. Freedman-Cass, N.R. McMillian, Survivorship, Version 2.2017, NCCN Clinical Practice Guidelines in Oncology, J. Natl. Compr. Canc. Netw. 15 (2017) 1140–1163.
[8] J. Carter, C. Lacchetti, B.L. Andersen, D.L. Barton, S. Bolte, S. Damast, M.A. Diefenbach, K. DuHamel, J. Florendo, P.A. Ganz, S. Goldfarb, S. Hallmeyer, D.M. Kushner, J.H. Rowland, Interventions to Address Sexual Problems in People With Cancer: American Society of Clinical Oncology Clinical Practice Guideline Adaptation of Cancer Care Ontario Guideline, J. Clin. Oncol. 36 (2017) 492–511.
[9] J.B. Reese, K. Sorice, M.C. Beach, L.S. Porter, J.A. Tulsky, M.B. Daly, S.J. Lepore, Patient-provider communication about sexual concerns in cancer: a systematic review, J. Cancer Surviv. 11 (2017) 175–188.
[10] J.B. Reese, K. Sorice, S.J. Lepore, M.B. Daly, J.A. Tulsky, M.C. Beach, Patient-Clinician Communication about Sexual Health in Breast Cancer: A Mixed-Methods Analysis of Clinic Dialogue, Patient Educ. Couns. 102 (2019) 436–442.
[11] J.B. Reese, M.C. Beach, K.C. Smith, E.T. Bantug, K.E. Casale, L.S. Porter, S.L. Bober, J.A. Tulsky, M.B. Daly, S.J. Lepore, Effective Patient-Provider Communication about Sexual Concerns in Breast Cancer: A Qualitative Study, Support. Care Cancer 25 (2017) 3199–3207.
[12] M.R. Canzona, C.J.W. Ledford, C.L. Fisher, D. Garcia, M. Raleigh, V.B. Kalish, Clinician barriers to initiating sexual health conversations with breast cancer survivors: The influence of assumptions and situational constraints, Fam Syst Health 36 (2018) 20–28.
[13] L.A. Zimmaro, S.J. Lepore, M.C. Beach, J.B. Reese, Patients' Perceived Barriers to Discussing Sexual Health with Breast Cancer Healthcare Providers, Psychooncology (2020) (Manuscript Submitted).

[14] S.M. Seav, S.A. Dominick, B. Stepanyuk, J.R. Gorman, D.T. Chingos, J.L. Ehren, M. L. Krychman, H.I. Su, Management of sexual dysfunction in breast cancer survivors: a systematic review, Womens Midlife Health 1 (2015) 1–27.
[15] J.B. Reese, S.L. Bober, M.B. Daly, Talking about Women's Sexual Health after Cancer: Why Is It So Hard to Move the Needle? Cancer 123 (2017) 4757–4763.
[16] K. Dyer, R. das Nair, Why Don't Healthcare Professionals Talk About Sex? A Systematic Review of Recent Qualitative Studies Conducted in the United Kingdom, J. Sex. Med. 10 (2013) 2658–2670.
[17] M.R. Canzona, D. Garcia, C.L. Fisher, M. Raleigh, V. Kalish, C.J. Ledford, Communication about sexual health with breast cancer survivors: Variation among patient and provider perspectives, Patient Educ. Couns. 99 (2016) 1814–1820.
[18] R. O'Brien, P. Rose, C. Campbell, D. Weller, R.D. Neal, C. Wilkinson, H. McIntosh, E. Watson, "I wish I'd told them": a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment, Patient Educ. Couns. 84 (2011) 200–207.
[19] T. Almont, F. Farsi, I. Krakowski, R. El Osta, P. Bondil, E. Huyghe, Sexual health in cancer: the results of a survey exploring practices, attitudes, knowledge, communication, and professional interactions in oncology healthcare providers, Support. Care Cancer 27 (2019) 887–894.
[20] J.B. Reese, S.J. Lepore, M.B. Daly, E. Handorf, K.A. Sorice, L.S. Porter, J.A. Tulsky, M.C. Beach, A brief intervention to enhance breast cancer clinicians' communication about sexual health: Feasibility, acceptability, and preliminary outcomes, Psychooncology 28 (2019) 872–879.
[21] L.Y. Wang, A. Pierdomenico, A. Lefkowitz, R. Brandt, Female Sexual Health Training for Oncology Providers: New Applications, Sexual medicine 3 (2015) 189–197.
[22] J. Winterling, C. Lampic, L. Wettergren, Fex-Talk: a Short Educational Intervention Intended to Enhance Nurses' Readiness to Discuss Fertility and Sexuality with Cancer Patients, J. Cancer Educ. (2019).
[23] D.L. Hilarius, P.H.A.M. Kloeg, S.B. Detmar, M.J. Muller, N.K. Aaronson, Level of agreement between patient self-report and observer ratings of health-related quality of life communication in oncology, Patient Educ. Couns. 65 (2007) 95–100.
[24] M.M. Oken, R.H. Creech, D.C. Tormey, J. Horton, T.E. Davis, E.T. McFadden, P.P. Carbone, Toxicity and response criteria of the Eastern Cooperative Oncology Group, Am. J. Clin. Oncol. 5 (1982) 649–655.
[25] J.S. Gass, M. Onstad, S. Pesek, K. Rojas, S. Fogarty, A. Stuckey, C. Raker, D.S. Dizon, Breast-Specific Sensuality and Sexual Function in Cancer Survivorship: Does Surgical Modality Matter? Ann. Surg. Oncol. 24 (2017) 3133–3140.
[26] J.M. Loaring, M. Larkin, R. Shaw, P. Flowers, Renegotiating sexual intimacy in the context of altered embodiment: The experiences of women with breast cancer and their male partners following mastectomy and reconstruction, Health Psychol. 34 (2015) 426–436.
[27] J.B. Reese, L.S. Porter, K.E. Casale, E.T. Bantug, S.L. Bober, S.C. Schwartz, K.C. Smith, Adapting a couple-based intimacy enhancement intervention to breast cancer: A developmental study, Health Psychol. 35 (2016) 1085–1096.
[28] M.C. Fingeret, I. Teo, D.E. Epner, Managing body image difficulties of adult cancer patients: Lessons from available research, Cancer 120 (2014) 633–641.
[29] N.D. Berkman, S.L. Sheridan, K.E. Donahue, D.J. Halpern, K. Crotty, Low health literacy and health outcomes: an updated systematic review, Ann. Intern. Med. 155 (2011) 97–107.
[30] J.N. Vega, J. Dumas, P.A. Newhouse, Cognitive Effects of Chemotherapy and Cancer-Related Treatments in Older Adults, Am. J. Geriatr. Psychiatry 25 (2017) 1415–1426.
[31] M. Li, K. Caeyenberghs, Longitudinal assessment of chemotherapy-induced changes in brain and cognitive functioning: A systematic review, Neurosci. Biobehav. Rev. 92 (2018) 304–317.