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ORIGINAL ARTICLE

Perpetuating the cycle of silence: the intersection of uncertainty and sexual health communication among couples after breast cancer treatment

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Abstract

Purpose The aims of this study are (1) to identify sources of uncertainty breast cancer survivors and partners of breast cancer survivors (BCS) report as a result of sexual health changes after primary treatment and (2) to investigate the challenges they experience when attempting to communicate about sexual health-related uncertainty.

Methods Forty BCS and 13 partners completed written reflections and participated in semi-structured interviews.

Results Analyses revealed five predominant sources of uncertainty for BCS and partners: *perceptions of post-treatment body*, *worry about effects on relational partners*, *ethical concerns about dissatisfaction with sexual relationship* (partners only), *fears about future of the relationship*, and *apprehension about SH treatment futility.* These concerns are linked to communication challenges for couples: *supporting survivors' body esteem*, *navigating potentially hurtful disclosures*, *responding to partners'* "*obstructive behavior*," and *believing communication is futile.*

Conclusions Findings suggest women and partners find themselves caught in a destructive cycle that reinforces uncertainty and inadvertently perpetuates silence and relational distress. To disrupt the cycle of silence, BCS and partners need to know that their interpretation of the other person's behaviors/needs is not always accurate. Strategies are required to help women and their partners express uncomfortable thoughts and feelings in safe and supportive environments. Practitioners should be conscious of potential SH issues, be familiar with existing support resources for survivors, and be prepared to disseminate information that will empower women and their partners.

Keywords Female sexual dysfunction · Breast cancer survivor · Relational communication · Qualitative analysis

Breast cancer survivors (BCSs) experience a range of physical, psychological, and relational sexual health (SH) issues that affect quality of life. Breast cancer treatments alone or in combination can result in symptoms such as fatigue, nausea, vomiting, hot flashes, sleep disturbances, susceptibility to infection, decreased arousal and sensation, inability to

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orgasm, and pain during intercourse [1–3]. BCSs also experience depression, anxiety, body image concerns, and relational issues with partners stemming from diminished intimacy [4–7]. Although the severity of other quality of life concerns may decrease several years after primary treatment, SH concerns are complications that can persist through long-term survivorship [7, 8]. Survivors list SH concerns among their supportive care needs years after treatment [9, 10].

Uncertainty and sexual health concerns

Sexual health concerns can be a source of uncertainty for patients. Mishel (1981) identified four key factors that typify illness-related uncertainty: ambiguity concerning the state of illness, insufficient information about diagnosis and illness severity, disease course and prognosis unpredictability, and complexity regarding treatment [11]. These factors closely align with the realities of coping with SH distress after primary cancer treatment. Adjuvant hormone therapies, typically given after primary treatment (radiation, surgery, chemotherapy), are associated with the continuation of symptoms experienced during chemotherapy [12]. Previous research suggests that many women are not told or do not understand the impact these treatments can have on their SH [6]. Patients may enter survivorship with insufficient information about the state and severity of potential SH concerns. This is problematic as women can remain on adjuvant treatment regimens anywhere from 5 to10 years [13]; however, 2015 guidelines extended that duration to a full 10 years for many women [14]. The prognosis surrounding SH issues is unpredictable. SH concerns associated with treatment may vary in intensity and longevity. They can last months to years; some may even be permanent [15]. Further, treating SH concerns in BCS is complex. Universal consensus on the safe use of hormone replacement therapy to treat vaginal symptoms in survivors is lacking [6, 16]. Constraints on treatment options may exacerbate this SH-related distress.

The relational nature of sexual health concerns

For women engaging in partnered sex, this uncertainty is not experienced in isolation. One of the most consistent predictors of SH survivorship is relational health [17]. Research suggests women who have more confidence in their partner's sexual commitment and interest report greater feelings of femininity and less psychological distress [18]. SH issues also reduce the partner's quality of life [19, 20]. Both survivors and partners report SH distress causes isolation and sadness and describe difficulty reengaging in sexual life years after primary treatment [4, 21, 22]. In Goldsmith and Miller's (2014) exploration of couples' cancer communication, sex was the second most frequently cited concern (following treatment decision making) and was one of the two most difficult topics to discuss (alongside death) [23]. Couples have reported difficulty talking openly about sexual problems or seeking help from professionals [24]. Couples' perceptions of quality SH communication have been associated with fewer depressive symptoms and greater sexual satisfaction [25].

Uncertainty has been connected to topic avoidance [26] and couples' relational communication during and after primary treatment has been shown to support patient resilience [27]. Despite this, an in-depth examination of uncertainty and SH-related communication for survivors and partners is still needed [28]. Our aim is to explore how couples experience and attempt to navigate this challenging terrain and to uncover what the supportive care community can do to assist them. To achieve these goals, two research questions were posited:

RQ1: What sources of uncertainty do BCS and partners report as a result of the SH changes they experience?

RQ2: What challenges do BCS and partners experience when attempting to communicate about SH-related uncertainty?

Methods

Recruitment and sampling

Following institutional review board approval, researchers distributed recruitment flyers with the first author's contact information to cancer navigators and oncology social workers based in hospitals, medical centers, non-profit organizations, and survivor support groups located in northeastern, northwestern, southeastern, and midwestern USA. To recruit partners, researchers asked survivor participants if they would like to invite their partners to participate. If a survivor decided she was comfortable, she shared the study website and e-mail address with her partner to contact the first author.

Participants

Survivors

Forty women participated in this study. The women varied in age from 24 to 70 years old (mean = 49, *SD* = 12.26). All women underwent some combination of surgery, radiation, and/or chemotherapy, completing primary treatment anywhere from 3 months to 25 years prior to recruitment, and were in heterosexual relationships.

Partners

Thirteen male partners participated. Partners ranged in age from 39 to 73 years old (mean = 55, $SD = 9.82$). Eleven of the 13 survivor-partner pairs were married; 2 were in committed relationships. See Table 1 for survivor and partner sample characteristics.

Procedures

Following consent, survivors and partners completed individual written narrative reflections and private in-depth semi-structured interviews. The Critical Incident Technique (CIT) informed the written reflection prompt as well as the interview scripts [29]. CIT is a flexible set of principles, which help researchers capture behavior, interpretations, and consequences of meaningful events in a non-threatening way [30]. Aligned with CIT, a writing prompt was designed to elicit a narrative surrounding a memorable moment the participant thought was a good example of how sexual lives had changed after breast cancer treatment. Survivors and partners e-mailed/mailed their reflections to the first author prior to the interview. The stories were used as an interview-priming device for the researcher and participants. They were not used in data analysis.

Interviews were conducted via telephone using a semi-structured interview script containing mainly open-ended questions. The interviewer directed participants' attention to elements of their written narrative with subsequent questions focusing on SH experiences, sources of uncertainty, and challenges communicating about those problems. Interviews were audio-recorded and transcribed. Survivor interviews are represented with numerical identification codes (1, 2, etc.). Partners' identification is also numerical; however, a p is placed before the number (p1, p2, etc.)

Analytical process

The constant comparative method (CCM) [31] was used to conduct a separate thematic analysis for each research question. CCM is a procedure for interpreting empirical data that emphasizes the importance of comparing all the data throughout the analytical process [31]. Three analytic steps were employed to analyze the transcript data: (1) assigning codes to text, (2) grouping related codes, and (3) developing and refining themes and their dimensions. The first step involved inspecting the data and assigning words/phrases that epitomize their essence. During second-level coding, descriptive codes and associated data were critically examined for recurring or repetitive ideas and codes were categorized into interpretive themes that made conceptual sense. Finally, as analysis continued, themes and associated dimensions were developed as data associated with each recurring theme was continually compared. Where appropriate, definitions were modified to fit new data or separated to create new codes. Analysis continued until themes and their dimensions were distinguishable and succinct [31, 32]. Findings for each group (survivor and partner) were then systematically compared. Tables were constructed to present overarching themes for survivors and partners, their dimensions, and representative quotations. Secondary analysis attended to two sources of diversity within the sample of BCS. Data associated with women in different age groups and survivorship lengths were contrasted and compared to better understand the nature of women's SH

Table 1 Sample characteristics

		N (%)
Breast cancer survivors		
Age group	Young adulthood (< 40)	12 (30)
	Middle adulthood (41–59)	16 (40)
	Older adulthood (60+)	12 (30)
Race	White	30 (75)
	Black	6 (15)
	Latina	3 (7.5)
	Multiracial/other[a]	1 (2.5)
Relationship status	Committed relationship	6 (15)
	Married/civil union	34 (85)
Education	High school graduate	4 (10)
	Some college/vocational training	7 (17.5)
	College graduate	20 (50)
	Completed graduate school	9 (22.5)
Survivorship length	0–2 years	13 (32.5)
	2–5 years	14 (35)
	5+ years	13 (32.5)
Partners		
Partners to women in survivor	Young adulthood (< 40)	1 (8)
Age groups	Middle adulthood (41–59)	8 (61)
	Older adulthood (60+)	4 (31)
Race	White	10 (80)
	Black	2 (15.3)
	Latino	1 (7.7)
Education	High school graduate	1 (7.7)
	Some college/vocational training	2 (15.3)
	College graduate	8 (61)
	Completed graduate school	2 15.3)
Relationship status	Committed relationship	2 (15.4)
	Married/civil union	11 (84.6)
	Middle adulthood (41–59	8 (61)
	Older adulthood (60+)	4 (31)

Notes: Total = 53 (survivors and partners)

[a] Other includes, Asian, Native American, Native Alaskan, Pacific Islander

experiences and communication challenges. Variations, where uncovered, are reported at the end of the results section.

Results

RQ1: Sources of uncertainty

Analyses revealed five predominant sources of uncertainty for BCS and partners: *perceptions of post-treatment body*, *worry about effects on relational partners*, *ethical concerns about dissatisfaction with sexual relationship* (*partners only*), *fears about future of relationship*, and *apprehension about SH treatment futility.* Each source of uncertainty manifested in different questions for survivors and partners. See Table 2 for themes, dimensions (presented as questions), and example quotes.

Perceptions of post-treatment bodies

Survivors reported asking themselves "Is my partner still attracted to me?" They suggested this stemmed from physical changes created by cancer treatments or the belief the cancer experience medicalized partners' views of women's bodies. These feelings negatively impacted multiple aspects of survivors' biopsychosocial health. Continually questioning how their partners viewed them exacerbated their psychological challenges (e.g., body image concerns, depression, anxiety) as well as their physical problems (e.g., low libido, pain during intercourse), which challenged their ability to engage in sexual activity.

Partners reported they were troubled by survivors' preoccupation with changes to their bodies. Partners suggested women often hide their bodies during sexual activity. They described being deeply disturbed by women's struggles and were uncertain if these issues were part of the "typical process." They wondered if these behaviors would become permanent.

Worry about effects on relational partners

Women reported several concerns about the way SH changes may affect their partners. Survivors discussed concerns their partners may feel rejected or dissatisfied with their current sexual relationship. These feelings were particularly acute when women reported powerlessness to "correct" problems. In these situations, women ruminated about how their perceived inability to "make [him] happy" or provide a "satisfying relationship" was "unfair" to their partners—especially after they supported the women through primary treatment. Regardless of whether their partner expressed concerns about SH changes, many women said they wondered if partners felt like survivors had "failed" them.

Partners discussed fears they may play a role in the presence or severity of survivors' SH problems. Specifically, they worried that a survivor's low libido could be attributed to the partner's appearance or performance. Partners were aware cancer treatments can affect libido; nevertheless, they reported the lingering suspicion they might be in some way responsible for women's loss of sexual interest.

Ethical concerns about dissatisfaction with sexual relationship (partner data only)

Men reported uncertainty regarding how they are "allowed" to feel about the desire to have sex after their partner survived cancer. Partners said they felt guilty for being concerned about sexual gratification after women endured a life-threatening experience. They emphasized their affection for the women and their gratitude for their survival. They reported they were uncertain if it was acceptable to "push for" sexual activity when women were reluctant or unable to reciprocate. Others discussed struggling with anger about changes to their sexual relationships. They reported the sexual activity was absent from their relationships the more frustrated and helpless they became.

Fears about future of the relationship

Survivors and partners expressed concerns that changes in their sexual lives threatened the future of their relationship. Women repeatedly hypothesized the pain they experience during intercourse prevents their partners from initiating other forms of intimacy (such as holding hands, kissing, intimate touching) and suggested they worried their partners would leave them. Men reported grave concern surrounding the decline in sexual activity. Survivors and partners both discussed feeling anxious when they were unable to maintain previous patterns of overall intimacy, as they worried their current situations were "not sustainable."

Apprehension about SH treatment futility

Survivors and partners described uncertainty about the existence of safe and viable treatments for SH concerns**.** These women reported discussing pain during intercourse with their medical providers or consulting the internet for information about SH changes. Some women reported feeling confident there was nothing that could be done to alleviate SH concerns while others were given contradictory information in medical settings or found conflicting information online. Treatment futility exacerbated women's uncertainty about the effect SH changes were having on partners (previous theme). Partners also reported fears about treatment futility. Men discussed conversations they had with survivors or providers in which they were dissuaded from perusing hormone replacement

Table 2 Interview themes, dimensions (questions), and exemplary quotes

Source of Uncertainty	Survivor (S) and partner (P) questions	Example Quotes
Perception of post-treatment bodies	S: Is my partner still attracted to me?	*I used to take my shirt off [during sex] but I after [cancer] I do not think he [my partner] knows what to do with my reconstructed breasts. He was ignoring them. After [noticing] that I keep my top on every time…. I thought reconstruction would help but I'm just not sure he's attracted to me anymore.*(*11*)
	S: Does my partner see me as a woman or a patient?	*I have lost a great deal of weight, so pretty much like a POW and he sees that. He's afraid to touch me because I look like a sick person … like if he touches me I'll break and it really depresses me… that's what I think, or, I'm afraid this is what he thinks.* (*6*)
	P: How worried should I be about her body image concerns?	*There's never a day that goes by that she's not worried about her body image or her chest. That's very troubling…How worried should I be for her?* "*What level of suffering is normal* (*p3*)*?*"
	P: Will she ever feel comfortable letting me see her naked again?	*The weight gain left her more disappointed with her appearance than the mastectomy… I can tell she does not want to show me her body anymore… it really bothers me and I do not know what to do about it.* (*p7*)
Worry about effects on relational partners	S: Does my partner feel rejected?	*He [says],* "*Do you want to make love?*"*… I said,* "*I have enough to deal with*"*…I was so anxious about what he would think if he saw me naked again. I think his feelings were hurt because he felt like,* "*So you are saying sex now is something to deal with?*" *I'm worried he feels rejected.* (*15*)
	S: Does my partner feel dissatisfied?	*I tried to hide how much the pain was bothering me but he knew. I said let's try other things and he said,* "*No, I don't* want it to be all about me. Forget it." *After that there was nothing I could do. [I had to] sit there knowing he's… not satisfied. It's a struggle to maintain a relationship that I can feel good about—feeling like I am pleasing him and am an equal partner when I cannot have sex.* (*32*)
	P: Is her lack of sexual desire my fault?	*Before her diagnosis one of us would start foreplay, but now there is zero coming from her. I know the chemotherapy and tamoxifen messed with her hormones but I still feel like part of it is me. She does not see me the same way anymore. I do not know how to make myself attractive to her anymore.* (*p5*)
Ethical concerns about dissatisfaction with sexual relationship (partners only)	P: Should I feel guilty about being dissatisfied with our sex life?	*Her breasts were a big part of what stimulated me. They were something I really enjoyed and I miss them. Without them she's not the same and I am not the same with her… but I feel bad about that. I married my wife because I love her.* (*p2*)
	P: Is it okay to be angry about the lack of sex in our relationship?	*We have not made love for 10 years… and I don't know what to do… we are still together now but are either of us happy? Sometimes I am really angry but then I think,* "*am I allowed to be angry?*"(*p5*) *I am in my 40s and now I am not going to not have sex for the rest of my life? That is not what I signed up for and eventually that frustration lead to me being involved with other women and now that's another problem between us… I feel like I should be allowed to be upset about this but sometimes I am not sure.* (*p13*)
Fears about future of the relationship	S&P: What does this pattern of decreased intimacy mean for the quality of our relationship?	*I guess he knew [how uncomfortable I was] because he stopped approaching… and then there was nothing, not even making advances. I feel like this old couple that is just together as roommates… that's not what I want.* (*26*) *It's not much of a marriage anymore. I love her but since we stopped having sex we slowly stopped doing other things too. Even holding hands on the couch, we are not doing that… I'm afraid of what this could mean for us.* (*p6*)
	S&P: How can this relationship last if nothing changes?	*Since he knows it's hard to have sex he just does not approach me anymore for anything sexual. Sometimes I still want to try even if it does not work… to be close to him… I wonder what this could mean for us. Can a relationship last if a couple stops doing anything sexual?*" (*1*)

Table 2 (continued)

Source of Uncertainty	Survivor (S) and partner (P) questions	Example Quotes
		I lie awake at night thinking how many more nights like this? We have been together 20 years and I thought we could make it through anything. I thought at the beginning I could handle this too [lack of sexual activity] but I don't think I can. I honestly do not know what's going to happen if this does not change soon. (*p1*)
Apprehension about SH treatment futility	S & P: No existing treatment to alleviate survivors' symptoms	*The oncologist told me there's a treatment available but that it was too dangerous for me. I sometimes think about getting a second opinion on that, but I have done a little reading online. I think he's right. Maybe I don't pursue because I am afraid he's right and I just don't want to hear it again. I cannot believe I'm hurting my husband so much and there's nothing I can do.* (*18*) *She told me her doctor said there's not much they can do and that things should improve but it's been five years. I want to believe him but I am starting to give up hope.* (*p4*)

therapy. Survivors and partners expressed concerns that if BCS were not candidates for this particular kind of therapy, nothing could be done to address SH concerns.

RQ2: Uncertainty and couples' communication efforts

Analyses revealed the uncertainty reported by BCS and partners contributed to four overarching communication challenges: *supporting survivors' body esteem*, *navigating potentially hurtful disclosures*, *responding to partners'* "*obstructive behavior*," and *believing communication is futile.* This data illustrates how uncertainty complicates couples' attempts to discuss changes in their sexual lives. See Table 3 for themes, dimensions, and example quotes.

Supporting survivors' body esteem (partner data only)

Men said they were troubled by survivors' complicated relationships with their bodies and struggled to find ways to show support and be sensitive to their concerns. When partners sensed women were insecure about their breasts, they responded by diverting their eyes from her chest during sexual activity to avoid triggering destructive feelings. Their verbal communication efforts were often aimed at easing women's concerns. These efforts often took the form of general affirmations and assurances. Partners reported they did not feel these "strategies" were successful and continue to look for better ways to support women's body esteem.

Navigating potentially hurtful disclosures

Survivors and partners discussed challenges stemming from disclosure of potentially hurtful thoughts and feelings about survivors' post-treatment bodies and changes to their sexual relationships. The issue of assurances reemerges within this theme. Women reported when they directly asked partners how they feel about their post-treatment bodies, partners primarily responded with brief assurances such as "You look fine," or "You're still beautiful." Women also expressed frustration that partners only answered with general statements about the quality of their sexual relationship such as, "It's okay," or "It doesn't bother me." Women reported they believe these declarations were "not the truth" but did not want to say "you are lying." Women doubted the authenticity of partners' responses, but they reported uncertainty about how to encourage partners to disclose their true feelings without upsetting their partners. In addition, they suggested they were reluctant to pursue the issue because they worried partners' responses might confirm women's worst fears about their appearance.

Partners struggled with disclosure too. They reported feeling reluctant to disclose potentially hurtful thoughts about changes to women's appearance or the lack of sexual activity. They described a tension between using assurances to protect women and feeling frustrated they needed to lie. Moreover, they reported survivors know they are not disclosing "the whole story" and that this causes arguments. Despite this, partners described avoiding disclosure because they did not know how survivors would respond to the truth. Partners also reported difficulty disclosing their frustration about the lack of sexual activity in relationships.

When men in this study were uncertain how to disclose their frustration without upsetting survivors, they eventually stopped trying to talk about it or changed the topic when women initiated SH-related discussions. Partners suggested their inability to express themselves made them feel powerless and in some cases caused resentment to build.

Table 3 Interview themes, dimensions, and exemplary quotes

Overarching communication challenges	Survivor (S) and partner (P) dimensions	Example quotes
Supporting survivors' body esteem (partners only)	P: Deciding how to respond to survivor silences and/or nonverbal cues	*I know she's always thinking about the way her body has changed. I see it on her face all the time. … She doesn't really want me to touch, or even look at her breasts in general. . . so, what I do is work around them. She's less likely to get upset if I don't draw attention to them by focusing on them… She gets too upset so I try to just diffuse the situation without talking… I think this is working? I hope anyway.*(*p4*)
Navigating Potentially Hurtful Disclosures	S:Mistrusting partner assurances regarding appearance/sexual relationship	*If I ask him," Does this bother you? How does this look?" he'll just say "It does not bother me, I love you, do not worry" and that's it. I know it's not the truth, that he probably doesn't love me anymore but he just sticks to the script… How can I say, "you are lying" when he's sitting there being this great guy saying, "you are beautiful." That would make me the one whose hurting feelings. Will that make him feel better about our relationship?*(*27*)
	P: Disclosing their thoughts about changes to women's bodies	*She asks me what I think about her breasts and I say I think they look good but I don't think that… I know she knows I am not telling the truth but what am I supposed to do?… The truth would crush her so I'm like a broken record "They are fine. They are fine" but in all honesty so much has changed—I just do not know what will happen with us.*(*p5*)
	P: Disclosing frustration about their need for sex	*I want to tell her I need sex but she starts crying. I know there is nothing she can do to stop the pain she has. She's joked around that I should just find a girlfriend but it's just a way to diffuse the argument. We are either crying or yelling about this all the time but I've never found a way to tell her how important this is … I know this isn't her fault but honestly sometimes I think I'm getting resentful. What am I supposed to do? Sometimes it feels like the only choice is to separate.* (*p13*)
Responding to partners' "obstructive behavior" (survivors only)	S: Partner avoidance/topic change	*It makes me so angry when he avoids it. He'll pretend he didn't hear me or say something unrelated and I am like, "I know what you are doing… this obstructive behavior. You are doing everything you can to throw me off course and I get mad and storm off"… after I always get this panic, "like what did I just do, is he just gonna walk out now?"* (*37*)
	S: Partner defensiveness	*He gets so angry, so defensive… I don't want to upset him. No matter what I say he's going to blame himself. He's been through enough and if I push it maybe that'll be the straw that breaks the camel's back… It's been so long [since we have been intimate] I feel like there's not enough connecting us anymore. We are just too fragile to move the conversation forward.* (*39*)
	S: Partner unwillingness to seek help	*I was scared thinking about where we were headed… I suggested marriage counseling and we have been talking about having someone come into our house to work on this and he's refused that too.*(*33*)
Believing communication is futile	S and P: No existing treatment to alleviate survivors' symptoms	*There is nothing you could do because I cannot be on estrogen. There is nothing they could do for me… and so I just do not bring it up… We don't need to be reminded of how hopeless it is. It's already so hard to stay together.*(*16*)
	S and P: Prior attempts at communication made things worse	*What's the point in talking about it? There are no treatments out there and nothing can change unless I leave her so nothing comes of these big emotional talks but tears… I do not like even bringing up the topic because then it comes down to [her saying], "Well, you are saying there's no way you can be physically satisfied by me? Maybe I want you to leave"*… when we talked about this in the past it only made things worse. (*p9*)

Responding to partners' "obstructive behavior"

Women in this study discussed difficulty responding to what they perceived to be partners' obstructive behavior. Obstructive behaviors included the avoidance and topic shifts men reported using to prevent upsetting survivors. When partners used avoidance and topic shifts in SH conversations, women reported "giving up" and withdrawing from the conversation or becoming angry with partners for his refusal to have "difficult conversations."

Perceptions of partner defensiveness and unwillingness to seek help created obstacles for women in this study. Women reported when they tried to initiate conversations about SH, partners sometimes reacted as if she is making a "personal attack" on him and implying he is responsible for problems in their sexual lives. In these cases, conversations end abruptly. Partner defensiveness led women to withdraw from the conversation and avoid the topic in the future as they did not know how to allay partners' concerns and wanted to avoid upsetting them further. Often, women struggled with balancing two demands in their communication: absolving her partner from responsibility and trying not to blame herself. Women reported in some ways SH changes after cancer changed their patterns of communicating more so than the cancer diagnosis and treatment.

Believing communication is futile

Survivors' and partners' fears about SH treatment futility were linked to communication behaviors. Two related dimensions contribute to the perception of futility: the belief that there are no existing treatment to alleviate survivors' symptoms and prior attempts at communication made things worse. BCS and partners often said they no longer believed it was a productive conversation. Women reported there was nothing that can be done—particularly when they were told they were not candidates for "hormonal replacement therapies". Partners suggested there is no "magic pill" and so the topic is "not worth talking about." Participants in both groups suggested that previous conversations "made things worse." As a result, they feared future conversations would only further destabilize the relationship. Overall, women reported feeling "stuck" or "trapped" because they knew there are no easy solutions. Many of their concerns remained acutely felt but "left unsaid." Several partners described avoiding the discussion until the frustration became too much to bear, and they verbally "lashed out" at survivors.

Variations by age and survivorship length

Women's perspectives remained largely consistent across developmental stages and survivorship length. However, certain variations were uncovered within the following themes: *perceptions of post-treatment bodies*, *responding to partners'* "*obstructive behavior*," and *believing communication is futile*.

All BCSs in this study reported concerns about their post-treatment bodies. The accounts of women in middle or older adulthood contained a unique features. They reported "surprise" and "disappointment" in themselves stemming from their pre-occupation with their partner's perception of the way they look. Women in these groups reported feeling like they were "too old to indulge" in these worries or believing they should be "above all of this." Differences also emerged according to survivorship length. Women in their first 2 years of survivorship were more likely to report partner defensiveness surrounding SH conversations. While marred by tension, women in this group more often described engaging in ongoing attempts at communication with their partners. However, women in the long-term survivor group (5+ years) most frequently reported avoidance accompanied by an overall feeling that they could not come to a resolution through communication, which often resulted in resignation.

Discussion

Findings suggest there is a tension between a desire for open communication and a desire to protect one's partner. This tension emerged in a number of themes and contributes to two pathways of communication that perpetuate the cycle of silence for both partners: (1) using indirect communication approaches, which can create additional uncertainty, and (2) viewing communication as futile and avoiding talk.

Communication patterns perpetuating the cycle of silence

Talking openly about changes to couples' sexual lives was difficult for women and partners. In an effort to comfort survivors, partners reported diverting their eyes from parts of women's bodies they believed women were concerned about during intercourse. Partners used general assurances (e.g. "you look great," "everything's fine") to respond to women concerns and described their attempts "speed past" certain issues or avoid discussing SH topics altogether. These efforts were intended to protect BCSs (and the relationship); however, this approach can backfire. These communication strategies tended to reinforce survivors' uncertainty. In the face of partners' resistance, survivors reported they were unsure how to initiate conversations and often made fewer attempts to communicate as time went on. Thus, this unhealthy cycle of silence became self-sustaining.

The perception that communication was futile further obstructed dialog, perpetuating uncertainty and contributing to relational stagnation. In accordance with Mishel's uncertainty in illness [11], survivors and partners reported the belief women were not candidates for available treatments or there was a lack of consensus regarding the safety of treatments. When partners felt no viable method could ameliorate SH concerns, it created instability within the relationship. In these instances of powerlessness, communication was viewed as too risky. This often resulted in long periods in which both parties suffered in silence punctuated by destructive arguments. To prevent misunderstandings and breakdown in relationships, there is a critical need for therapeutic interventions to facilitate appropriately open, sensitive dialogue.

Therapeutic/practice recommendations

To disrupt the cycle of silence, practitioners, survivors, and their partners need to understand indirect communication strategies used to protect one another can actually reinforce or increase uncertainty, relational stagnation, and distress. Survivors and partners should be made aware that their interpretation of motivations for the other person's behaviors is not always accurate. Strategies are needed to help women and their partners express their uncomfortable thoughts and feelings. Simply informing women and partners that discrepancies exist may create a platform from which to facilitate more open communication about their sexual experiences. However, direct verbal communication can be challenging so it may be helpful to find less threatening means of communicating sensitive information within partnerships.

Several women and partners in this research reported they shared their narrative reflections with one another after participating in the study. They indicated writing and sharing their thoughts helped them understand each other's point of view and provided time to digest potentially upsetting information before talking with one another. This is important for two reasons. First, it underscores the value of direct verbal communication about this topic. Much of the suffering reported by participants was produced or reinforced by the inability to talk openly. Second, writing could provide a less-threatening medium for couples to make sense of their thoughts and feelings, disclose difficult information, and process what their partners are sharing. Writing has been supported as a therapeutic tool when coping with traumatic experiences and taboo health contexts, including breast cancer [33].

This study uncovered variations in women's experiences according to age and survivorship duration. These findings could inform practitioners' understanding of how to better attend to women's unique needs. For example, women in middle and older adulthood within this sample criticized themselves for worrying about their post-treatment appearance. It is important for practitioners to normalize and validate survivors' concerns. In this study, women in the earlier stages of survivorship were more likely to continue attempts to communicate with their partners about SH issues. These attempts wane as time goes on. Relational distress is tied to decreased intimacy and poor communication [4]. Couples require support to engage in and continue this challenging dialogue before communication ceases.

The women and men in this study reported a desire to see more resources created to help couples cope with SH changes together. While some cancer centers like MD Anderson Cancer Center offer this, these resources are not widely available. As such, it is important for practitioners to be aware of the presence and nature of SH conversations for couples, to locate existing support resources for survivors, and to disseminate information that will empower women and their partners.

Limitations and future research

Future research should explore the use of open and avoidant communication in response to uncertainty and how the modes of discussing SH function for relational health. Prior research indicates the use of open and avoidant communication is highly contextual [33]. Participants suggested avoidant communication was problematic, but this study did not capture the effect of open communication regarding these difficult topics. There is much to be learned about how communication functions for couples in survivorship.

Future studies should explore possible relationships among this kind of SH-related adversity, pathways to supportive communication, and post-traumatic growth. Post-traumatic growth (PTG) is positive psychological change experienced after a life-altering struggle and has been linked with patient outcomes [34]. It could be particularly useful to study PTG and SH, as it is a challenging health context with few effective treatments that are safe for all breast cancer survivors [35].

Uncertainty is not inherently good or bad [36]. In this study, uncertainty functioned in unhelpful ways, but it is important to explore alternative ways uncertainty may function for couples experiencing SH concerns after cancer treatment.

Although saturation of themes was accomplished, a larger sample may be able to draw out further areas of significance. Comparing data within dyads as opposed to across groups (survivors and partners) may yield further insights. In addition, this research reflects the perspectives of a relatively homogeneous sample comprised of educated, mostly white individuals in heterosexual relationships. Therefore, the study does not capture the multiplicity of experiences that may be revealed through inclusion of a more diverse group of BCS and partners. While the current study is not a comprehensive guide to managing relational health in the midst of sexual dysfunction, it provides distinct insights for helping couples understand the concerns that drive each other's behavior and creates a starting point for dialog.

Compliance with ethical standards

We have full control of all primary data and we agree to allow the journal to review our data if requested.

Conflict of interest The authors declare that they have no conflict of interests.

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