HHS Public Access

Author manuscript

Health Psychol. Author manuscript; available in PMC 2017 October 01.

Published in final edited form as:

Health Psychol. 2016 October ; 35(10): 1085–1096. doi:10.1037/hea0000413.

Adapting a Couple-based Intimacy Enhancement Intervention to Breast Cancer: A Developmental Study

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Abstract

Objective—Sexual concerns continue to be poorly addressed for women treated for breast cancer and evidence-based interventions that adequately address these concerns are scarce. The objective of this study was to adapt a telephone-based Intimacy Enhancement intervention, previously tested in couples facing colorectal cancer, to the needs of women with breast cancer through qualitative focus groups, cognitive interviews, and expert review.

Methods—Three semi-structured qualitative focus groups in partnered post-treatment breast cancer survivors (n=15) reporting sexual concerns were conducted to investigate experiences of breast cancer-related sexual concerns and intervention preferences. Focus group data were coded using the framework approach to qualitative analysis; 8 key themes were identified and used to

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The authors have no conflicts of interest to report.

develop the content and format of the intervention. Feedback from cognitive interviews with study-naïve breast cancer survivors (n=4) and expert review of materials were also incorporated in finalizing the intervention materials.

Results—Qualitative findings centered on the impact of breast cancer and its treatment on women's sexuality and on the intimate relationship, experiences of helpful and unhelpful coping methods, and explicit intervention preferences. Focus group data were particularly helpful in identifying the scope of educational topics and in determining how to structure intervention skills practice (e.g., intimacy-related communication) to be optimally relevant and helpful for both women and their partners. Cognitive interview feedback helped refine intervention materials.

Conclusions—An Intimacy Enhancement intervention was adapted for women with breast cancer and their partners. This intervention offers a promising, potentially disseminable approach to addressing breast cancer-related sexual concerns.

Keywords

Breast Cancer; Couples Therapy; Interventions; Qualitative Research; Sexuality

Over 90% of women with breast cancer are expected to survive at least five years post-diagnosis (Siegel, Miller, & Jemal, 2015). Sexual concerns for breast cancer survivors are distressing and extremely common (Panjari, Bell, & Davis, 2011; Safarinejad, Shafiei, & Safarinejad, 2013), affecting 30-100% of breast cancer survivors (Sadovsky et al., 2010). In contrast to other aspects of quality of life that improve over time after completion of active cancer treatment, sexual problems or inactivity can persist for years post-treatment or even worsen over time if not treated (Frechette et al., 2013; Ganz et al., 1996; Ganz et al., 2002); further, sexual concerns are related to poorer overall quality of life and higher disease interference (Reese, Shelby, Keefe, Porter, & Abernethy, 2010). Sexual concerns are common across various types of surgeries or medical treatments, although chemotherapy and anti-estrogen hormonal therapy are associated with particularly distressing sexual consequences (Baumgart et al., 2011; Ochsenkuhn et al., 2011; Safarinejad et al., 2013). Despite such evidence, sexual concerns tend to be poorly addressed, with the majority of breast cancer survivors reporting that they do not receive help or information about sexual issues in the context of their cancer care (Cox, Jenkins, Catt, Langridge, & Fallowfield, 2006; Flynn et al., 2012; Scanlon et al., 2012; Taylor, Harley, Takeuchi, Brown, & Velikova, 2013). Thus, there is a significant gap between the frequency and distress associated with sexual concerns of breast cancer survivors and the availability of evidence-based interventions addressing such concerns.

Current Interventions Addressing Sexual Concerns in Breast Cancer

Although empirically supported interventions that address the sexual concerns of female cancer survivors are growing in number (Hummel et al., 2015; Schover et al., 2013; Taylor, Harley, Ziegler, Brown, & Velikova, 2011) issues remain with regard to their uptake (Schover et al., 2013) and no interventions have enough support that they have been recommended for routine practice (Taylor et al., 2011). The sexual changes that breast cancer survivors undergo are often complex, involving physical, psychological and

interpersonal factors and varying emotional reactions to these changes (Loaring, Larkin, Shaw, & Flowers, 2015). Thus, minimal interventions, such as those that consist of self-help information alone, (Perz, Ussher, Cancer, & Team, 2015) or medical interventions alone, may not be sufficient in addressing cancer-related sexual concerns. Furthermore, with few exceptions (Goetsch, Lim, & Caughey, 2015), effective medical treatments to treat female sexual dysfunctions are either not approved for women with a breast cancer history (e.g., flibanserin for low libido), or their use is controversial because of medical contraindications for women with estrogen-receptor positive breast cancer (e.g., topical estrogen therapy (Biglia et al., 2010b; Kendall, Dowsett, Folkerd, & Smith, 2006; Melisko, Goldman, & Rugo, 2010). For these reasons, it is imperative to explore the potential impact of behavioral interventions that address sexual concerns in this population. Recently, researchers have called for increasing efforts to develop an evidence base of interventions addressing the sexual concerns of women treated for breast cancer; interventions that are targeted to women reporting sexual concerns and that address the full range of sexual concerns, including body image and the relationship with the partner, are particularly needed (Taylor et al., 2011).

In two prior pilot studies, a telephone-based Intimacy Enhancement (IE) intervention was evaluated in 32 couples facing colorectal cancer (Barsky Reese et al., 2014; Reese, Porter, Somers, & Keefe, 2012). Grounded in principles of cognitive therapy, behavioral couple therapy, and sex therapy, the IE intervention included content relevant to both physical and emotional aspects of intimacy, defined as an interpersonal process involving mutual sharing and understanding, feelings of closeness, warmth, and affection (Reese et al., 2012). While physical intimacy includes sexual behaviors such as intercourse and genital touching, it can also include non-sexual behaviors (e.g., cuddling, hand-holding), both of which were IE intervention targets. The IE intervention was telephone-based to reduce participant burden and consisted of four sessions (Session 1: goal-setting; Session 2: intimacy-related communication; Session 3: cognitive restructuring and behavioral engagement in intimacy-building activities; Session 4: planning ahead); home practice exercises strengthened skill acquisition (for detailed information on the IE protocol, see Barsky Reese et al., 2014; Reese et al., 2012). Overall, the intervention was found to have positive effects on patient and partner sexual outcomes (e.g., sexual function, sexual distress) and intimacy outcomes (e.g., emotional intimacy, communication) across these studies, with particularly strong effects on sexual function and distress.

Considering the need for evidence-based behavioral interventions addressing sexual concerns for women with breast cancer, the initial IE intervention with colorectal cancer patients and partners seemed ideal to meet the needs of women treated for breast cancer. The basic design of the IE intervention is well-suited to addressing sexual concerns in this populations because (a) the telephone format is convenient for reaching longer term breast cancer survivors, who report the greatest interest in receiving help for sexual concerns (Hill et al., 2011), (b) it includes a focus on communication and sex therapy-type skills, which have been shown to be among the most effective tools for addressing sexual concerns in breast cancer patients (Taylor et al., 2011), and (c) it was developed to be delivered to couples, making it highly relevant to women treated for breast cancer (Loaring et al., 2015). However, breast cancer patients differ from colorectal cancer patients in the range and types of sexual problems they experience (e.g., menopausal symptoms and breast changes; Carter,

Goldfrank, & Schover, 2011; Fobair & Spiegel, 2009), the risk factors for sexual impairment and duration of use of treatments with sexual side effects (i.e., hormonal therapy; Fobair et al., 2006; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Milbury, Cohen, Jenkins, Skibber, & Schover, 2012; Traa, De Vries, Roukema, & Den Oudsten, 2012), and the availability of effective management options (Biglia et al., 2010b). Therefore, additional information was deemed necessary to adapt the IE intervention to meet the needs of breast cancer survivors before it could be evaluated for efficacy in a randomized controlled trial.

Rationale

The overall objective was to adapt the promising IE intervention to meet the needs of women treated for breast cancer using qualitative research and cognitive interview data. The following research questions guided the qualitative investigation in the current study, assessed through focus groups with breast cancer survivors: 1) What are the needs of breast cancer survivors regarding the content of an Intimacy Enhancement intervention? 2) What are the preferences of breast cancer survivors for the format of an IE intervention? The qualitative investigation was purposive, with the aim of achieving the breadth and quality of information needed to adapt the IE intervention to breast cancer survivors. An additional objective was to ensure comprehensibility and appropriateness of the resulting IE materials through cognitive interviews with study-naïve breast cancer survivors. This investigation represents the first phase in a research study focusing on developing an evidence-based intervention addressing sexual and intimacy concerns for breast cancer survivors; once developed, the IE intervention will be evaluated for feasibility, acceptability and efficacy at improving sexual and relationship outcomes in a pilot study with women treated for breast cancer who report sexual concerns.

Methods

Approach and Design

The qualitative investigation was guided by two primary theoretical influences: (1) the intimacy-based model of women's sexual response (i.e., the Basson model) which emphasizes the contributions of physical pleasure, the absence of pain/discomfort, and emotional intimacy as key motivators driving sexual activity for women, as well as the cyclical nature of women's sexual response (Basson, 2001), and (2) a cognitive-behavioral therapy model for couples which considers the dual role of both partners in achieving or maintaining relationship adjustment, particularly in relation to coping with medical problems (Baucom, Porter, Kirby, & Hudepohl, 2012). The aim of the qualitative focus groups was to examine patient experiences that would inform the adaptation of the IE intervention to the needs of breast cancer survivors. The framework approach to qualitative analysis was selected because it is a rigorous and pragmatic approach well-suited to meet the objectives of the current qualitative investigation (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Specifically, the analysis was purposive and targeted towards breadth and quality of information with the goal of informing the intervention for breast cancer survivors. Using the qualitative focus groups data, regular meetings, and discussions with the experts on the study team, the PI drafted an interventionist manual and set of participant

materials, using the most recent IE study (Barsky Reese et al., 2014) intervention materials as a starting template. Changes or issues suggested by the cognitive interviews were incorporated into the final intervention materials by the PI. The objective of the individual cognitive interviews was to obtain breast cancer survivors' feedback on draft IE materials.

Setting and Recruitment

The study protocol and procedures were reviewed and approved by the Institutional Review Board at Fox Chase Cancer Center. Participants completed written consent immediately before the focus group or interview. Adult females with a breast cancer diagnosis were eligible if they met the following criteria: a) had non-metastatic breast cancer; b) completed active treatment (e.g., chemotherapy, radiation, surgery) 6 months-5 years ago (current use of endocrine therapy is acceptable); c) were living with a romantic partner ≥ 6 months; and d) were willing to have their participation in the focus group audio recorded. Additionally, to ensure that the data would yield relevant intervention content for women participating in an IE intervention study, women in this study had to score ≥ 3 on a sexual concerns screening item adapted from one used in several prior studies with cancer samples that assesses problems with reduced sexual interest, enjoyment, or performance (Reese, Shelby, & Abernethy, 2011; Reese et al., 2010); body image changes were added to the core item and examples were given during recruitment (e.g., discomfort during intercourse, loss of physical affection) in order to screen for a broad range of common physical intimacy concerns. Using a convenience sampling approach, recruitment efforts for the focus groups and cognitive interviews concentrated on mailings of pre-screened patients identified using the Fox Chase Tumor Registry and supplementary in-clinic recruitment and advertisements located in the education and resource center. The sample composition was structured by the pragmatics and resource constraints of the development phase of an exploratory intervention study. Most of the 19 participants (n = 13) were recruited through the Fox Chase Tumor Registry; four were recruited directly in-clinic and two participants had responded to study advertisements. After consenting, participants completed very brief socio-demographic surveys. Upon scanning of the data, it was determined that three focus groups had offered adequate data with which to adapt the IE intervention, and recruitment efforts were terminated. Survey data were supplemented by clinical data points obtained during the screening process through medical records abstraction, once approved by participants, including breast cancer diagnosis and stage. Participants were reimbursed $75 for participation in focus groups or cognitive interviews.

Sample Characteristics

Sample socio-demographic and clinical characteristics are shown in Table 1. The sample was largely White, employed either full or part-time, and well-educated, with a mean age of 53 years. Most had early stage disease; almost all had had chemotherapy and most were currently on endocrine therapy. The average score on the sexual concerns screening item was in the moderate range based on prior published research in breast and gastrointestinal cancer patients (Reese et al., 2010). Of the five eligible women who did not participate, two did not provide reasons for refusal, one cited distance and one cited lack of relevance of the topic as reasons for refusal, and one was lost to contact. Participants did not differ significantly from study-eligible candidates who chose not to participate on age at diagnosis or current age,

race, stage of disease, current use of hormonal therapy, or sexual concerns score (p values > .26).

Data Collection

Three 90-minute focus groups were conducted in a semi-structured format following a pre-specified guide aimed at answering the research questions (See Table 2 for examples of questions). Because younger women are at risk for worse sexual impairment (Biglia et al., 2010a; Fobair et al., 2006) and may therefore feel more comfortable in a group with other young participants, one focus group was limited to women diagnosed at ≤45 years old; the remaining groups included women > 45. The PI (JBR) and a co-author (EB) co-led all three groups with EB also acting as note taker. In cognitive interviews (60-90 minutes), participants were first asked to share their thoughts and reactions to the material aloud as they read the materials. Then, the interviewer (either the PI or a trained interviewer) solicited feedback from participants on the readability and appropriateness of the material using pre-specified structured questions. The interviewer took notes on participant responses and the actual materials with participants' notes and comments were collected.

Data Analysis

Focus group discussions were professionally transcribed and analyzed for content using the framework approach to qualitative analysis (Gale et al., 2013) and through supervised meetings with a qualitative research expert on the study team (KCS). The qualitative analysis involved two coders (JBR, KC) who first independently open coded the first transcript in hard copy (not using software), and through discussion, arrived at a list of possible codes. Through in-depth discussion and review of codes and concepts, the coders aimed to both uncover additional codes and parsimoniously revise the list of codes and organize them into theoretically meaningful categories. The goal of this analytic process was to inform the development of the intervention and thematic saturation and breadth were explored through the use of an analytic matrix as described in the framework approach. Using the framework approach, codes were then applied to the transcripts using N Vivo software, which helped organize the qualitative data. Using the defining feature of the framework approach, the coders developed a matrix output, which summarized the data and allowed for analysis by case (individual focus group) and code. The coding manual was applied to the three focus group transcripts by two independent, trained coders who were both involved in the development of the tool. The coders worked autonomously and then discussed any emergent differences in coding application until consensus was reached (consistent with an approach described in Bradley, Curry, & Devers, 2007). In the few instances where issues or questions as to appropriate coding remained, a third member of the team was consulted to round out the consensus process.

Results

Results of Qualitative Analyses

Overview of Qualitative Findings—Main themes, illustrative quotes for those themes, and details on how these themes influenced the modification and revision of the IE intervention are shown in Tables 3 and 4. Table 3 includes themes that focus on participants'

experiences with regard to the impact of breast cancer on sexuality and intimacy and reactions to these changes. Table 4 includes themes describing the methods used to cope with breast cancer-related sexual changes, contextual factors, experiences of patient-provider communication about sexual concerns, and explicit intervention preferences or needs. All themes emerged in every focus group offering support for thematic saturation. Themes and codes were selected for inclusion based on relevance and importance to focus group participants, novelty from a research perspective, and relevance with regard to the modification of the IE intervention.

Change and Loss: Women's Perceptions of Sexual and Intimacy Changes after Treatment (Theme 1)—As shown in Table 3, several key themes emerged pertaining to the range and type of sexual concerns experienced by women, the frequent co-occurrence and cyclical nature of sexual problems (e.g., sexual discomfort contributing to low libido), the nearly ubiquitous and multifactorial experience of low libido, and changes in breast sensation and body image. Women also frequently described other general physical symptoms such as hot flashes and post-surgical pain interfering with their interest in sex or ability to engage comfortably in sexual activity. The nature of the sexual changes was a critical factor in determining the overall scope of content in the IE intervention. Given the complexity of sexual concerns described and the potential causes of these concerns, education was included in the IE intervention on the intimacy-based model of women's sexual response described earlier (Basson, 2001), in the hope that improved knowledge can facilitate making changes in one domain that could lead to improvements in other areas (e.g., reducing discomfort can improve sexual desire).

Reacting to Sexual and Intimacy Changes: Feelings, Thoughts, and Beliefs (Theme 2)—Key issues to emerge in this theme pertained to the range of *emotional reactions* to sexual changes and the level of distress that was associated with these changes. The level of distress seemed most tangible for the younger women in Focus Group 3, who felt that the possibility of living decades more with their spouses in a relationship without sexual activity, was particularly daunting. Generally, older women tended to be less bothered by loss of libido, but noted that their lack of distress about loss of libido was often not shared by their partners. As one woman from Focus Group 1 commented: "I really don't care, actually, I really don't care about myself, I just want to satisfy him because I can be for the rest of my life be without [sex] and be fine. Honestly, that is how I feel, but that is not the case with my husband." Negative thoughts and feelings (e.g., thinking that sexual problems may be intractable) further reduced women's sexual interest and impeded their ability to become aroused. These examples of negative/inflexible thoughts were used to shape the cognitive restructuring exercises in the IE intervention.

Worries, Fears, and Feelings: Perceptions of their Partners' Experiences and Reactions to Sexual Changes (Theme 3)—This theme refers to study participants' perceptions of experiences and reactions that *their partners* have had in relation to the women's sexual changes as well as occasional partner-specific sexual changes. One particularly interesting idea to emerge from within this theme pertains to feelings of uncertainty in women's partners with regard to engaging in touching of the women's breasts

during sexual activity; a number of women commented that their partners often seemed to be afraid of hurting them. In some instances, this worry was reportedly so intense that the partners could not achieve an erection, presumably because they could not relax sufficiently. To address this important concern, content pertaining to this issue was added to the intervention material across several sessions. First, to normalize partners' worries and mixed feelings with regard to breast touching during sex, educational material was developed that explains changes in breast sensation and common reactions to this such as partner fears or worries. Second, to reduce partners' fears, the instructions for the sensate focus exercises were modified to offer explicit guidance in this area. Finally, to ensure relevance of the cognitive restructuring session to partners, partner-specific thoughts for these exercises were developed, such as: "I am not sure I know how to please my partner now."

Communication and Other "Us" Effects: Perceptions of the Effects of Sexual and Intimacy Changes on their Relationships (Theme 4)—Some breast cancer-related sexual changes, such as communication about intimacy, were best described as experienced by or within the relationship, rather than by either the woman or her partner individually. While a few women described positive communication with their partners about sex and intimacy, others described more negative patterns of communication about this topic, suggesting the need for intervention on this content domain. For instance, several women noted that their partners sometimes remarked that they "looked fine" or still found them attractive. Although partners may have been trying to be reassuring through such comments, women noted that such comments were not helpful and actually invalidated their feelings. Thus, to guide effective communication about the sensitive topic of body image, an example of a negatively phrased comment was added to a communication exercise ("You look fine. What are you worried about?"); after learning guidelines for effective communication, participants are instructed to change this statement to a more supportive one such as "It seems like it's been really hard for you to deal with changes in how your body looks after your surgery."

Adaptation and Innovation: Adopting Strategies to Cope with Sexual and Intimacy Changes (Theme 5)—This theme describes ways that the woman and couple attempt to cope with sexual and intimacy changes, and includes both behavioral and couple-based strategies and methods that involve aids, devices or treatments (e.g., vibrators, vaginal lubricants, estrogen creams). Some women had adopted quite effective coping mechanisms, often involving focusing on moment-to-moment sensations. One woman who had a very positive marital relationship described engaging in exercises with her husband reminiscent of sensate focus within a Masters and Johnson-type sex therapy approach (Masters & Johnson, 1970), saying that this allows her husband to "re-visualize what my new body feels like." (Focus Group 1). However, quite a few women had difficulty focusing on momentary sensations, reporting that negative intrusive thoughts intruded and made it difficult for them to relax and enjoy sex (Table 4, quote b). The fact that sensate focus-type exercises were effective yet often difficult to implement suggested the value of these exercises, but also the need for explicit guidance and ongoing support with their use during the intervention. At least one intrepid woman in each focus group described experimenting with a vibrator, which they sometimes used outside of sex as a means of improving their desire. This led us

to add vibrator use as a possible strategy to enhance sexual interest in the educational content in Session 1 and as an intimacy-building activity in Session 3.

Age, Stage, and History: Contextual Factors Influencing Sexual Concerns and Intervention Preferences (Theme 6)—This theme refers to factors that impact the sexual and intimacy of study participants and their partners as well as preferences for coping or interventions. The stage within the woman's treatment trajectory influenced perspectives on motivation for a sexual relationship and, relatedly, interest in receiving help for sexual concerns. As shown in Table 4, women frequently noted that during treatment and even for months after completing active treatment, they had little interest in working on addressing their sexual concerns because sex was of a lower priority at that time. These remarks confirmed our initial hypothesis that the intervention would be most appropriate, relevant, and feasible if it included women who were at least several months out of active treatment. Being ready to deal with sexual concerns and wanting to resume a sex life seemed to hinge on the convergence of improvements in both physical and emotional health that came after completing treatment (see Table 4, theme b), highlighting the multifaceted nature of women's sexuality.

Discussions in the Clinic: Experiences with Patient-Provider Communication about Sexual Concerns (Theme 7)—This theme included a range of experiences with patient-provider communication around sex and intimacy and help-seeking. By and large, women in this study noted that discussions about sexual concerns with their providers were scant and a few women who had discussed this issue with providers commented on negative reactions by providers or described their providers as lacking knowledge on available options or treatments. Discussions with providers about sex were more frequent in the young women's focus group (Focus Group 3). Importantly, women in this group were also generally more distressed about their sexual concerns, which seemed to drive their help-seeking. Some women described the importance of having partners involved in discussions with oncologists about potential sexual side effects and treatments. For example, women remarked that their partners would be more supportive if they understood that certain sexual side effects, such as low libido, were expected and related to their medical treatments. Comments such as these reinforced the value of establishing the treatment-related nature of many sexual concerns for partners and, therefore, for educating partners through including them in the IE intervention.

Addressing Sexual Concerns: Preferences for an Intimacy-Focused Intervention (Theme 8)—While women's experiences in many areas reflected needs for intervention (e.g., describing vaginal dryness as an impediment to sexual activity reflects a need for education on this topic), this theme yielded explicit preferences on intervention content and format. Comments within this theme shed light on two key aspects of the intervention format, namely, the couple-based nature of the intervention and its telephone format. Specifically, women commented on the importance of including their partners in an effort to improve their sexual relationship, citing the benefit of normalizing sexual issues for partners. Additionally, a number of women commented that a format that was not face-to-

face had advantages such as appealing to privacy preferences and logistical concerns (work schedules, distance from facility, and childcare).

Results of Cognitive Interviews

In general, cognitive interview participants reported that they found the IE handouts to be appropriate, relevant, and easy to understand. Some clarification was suggested on certain sections including the educational content pertaining to estrogen changes due to endocrine therapy, and these changes were made. In addition, participants expressed negative reactions to a few specific words used in the material, including the word “patient” (which was not a preferred term) and the word “work”, as in “working on addressing sexual concerns,” which was felt to be overly serious. In response, revisions were made such as changing a header entitled “Patient Concerns,” to “Her Concerns,” which elicited a more positive reaction, and considered phrases like “home practice exercises” as opposed to “homework.”

Discussion

The objective of this study was to adapt an Intimacy Enhancement (IE) intervention to the needs of breast cancer survivors in order to be maximally relevant, appropriate, and comprehensible. Although prior qualitative studies have investigated the experiences of women with breast cancer concerning sexuality and intimacy (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012; Loaring et al., 2015; Ussher, Perz, & Gilbert, 2012), this study is unique because it focused on detailing the process by which women’s experiences with breast cancer-related sexual concerns were directly translated into the content and format of an IE intervention suited to this population. The information obtained from this study confirmed some beliefs about the intervention content and format, such as the benefit of including the partner, and the potential benefit of a telephone-based format at reaching and also provided critical information guiding the incorporation of partners into the intervention. Particularly novel aspects of the newly adapted IE intervention are that it could be used to target a wide range of breast cancer-related sexual concerns and that it unites telephone and couple-based approaches in its delivery.

One of the most striking ways in which the qualitative data influenced the content of the intervention was with regard to dealing with breast changes and touching of the breasts as a part of women’s sexual practices, which have clinical implications. Changes in women’s breast sensation, including loss of sensation, and concern about breast appearance were among the most commonly shared concerns and altered whether and how many women wanted to be touched on their breasts during sexual activity; moreover, partners’ fears and worries of hurting them by touching their breasts further hindered their sexual interest and enjoyment. Clinically, these findings suggest the importance of understanding and addressing both the woman’s challenges in adjusting to breast changes and her partner’s reactions when helping a woman cope with sexual concerns post-breast cancer. Because of this, considerable information about breast touching was added to the IE intervention, including explicit guidance in the sensate focus exercises with regard to how both women and their partners should deal with thoughts or feelings about breast touching during these exercises. Thus, the IE intervention is well-suited to address issues related to breast

touching, while other issues limiting engagement in physical intimacy (e.g., low desire) could also benefit. It is notable that breast changes are not assessed in commonly administered sexual function scales, such as the Female Sexual Function Index (FSFI; Rosen et al., 2000), making it potentially more likely such issues may be missed both in research and clinically.

The varied experiences of communication, both between the breast cancer survivors and their partners, and between the survivors and their providers, emerged as critical to women's sexual adjustment in this study. For instance, while some women described helpful patterns of communication with their partners concerning intimacy, others described a lack of communication about the subject or frankly unsupportive comments by their partners. These findings are in line with prior conceptual models of couples' psychosocial adaptation to cancer (e.g., the Relationship Intimacy Model; Manne & Badr, 2008). The IE intervention can enhance communication for many couples, although couples with extremely poor communication might require additional therapy in order to make use of such skills. In addition, although women's discussions with cancer providers about sexual concerns was not a primary question in these focus groups women nonetheless frequently brought up such experiences. Some women noted that their providers often either reacted passively to their expression of concerns, such as by not offering suggestions and encouraging them repeatedly to "wait and see" if the concerns subside, or negatively, as when one participant noted that her provider mentioned that there were other ways of "pleasing your husband." The importance of clear and effective communication between patients and their providers and patients and their partners about the nature of the effects of breast cancer surgery and treatment on women's sexuality and bodies has been noted in prior studies (Loaring et al., 2015). This study underscores the notion that communication is central to women's effective coping with sexual concerns and therefore supports the development of interventions that can enhance communication for both breast cancer survivors and providers.

This study has several strengths including the use of a rigorous qualitative methodology and a stepped process in the development of the IE intervention involving qualitative analysis, cognitive interviews, and expert reviews. This study also has limitations. First, although the sample was not restricted to heterosexual women, women who identified as lesbian, gay, bisexual did not end up enrolling into the study and therefore, these findings may not apply to women in same-sex relationships. Recent research suggests that interventions adapted to the specific preferences and sexual practices of sexual minority women may be most appropriate (Boehmer, Timm, Ozonoff, & Potter, 2012). Unpartnered women may also require separate interventions meeting their needs. Second, it is possible that a larger sample size could have increased the breadth of the information obtained. However, there were consistent and overlapping reactions among participants in all three focus groups on the major themes, and with this sample size, the data analysis achieved the breadth and depth necessary to inform the IE intervention. Importantly, all themes presented here emerged across all of the focus groups, supporting the notion that thematic saturation was achieved. Third, although one fifth of the sample was of minority race or ethnicity, it is possible that a sample more heavily weighted to minority women could yield different perspectives. The breakdown of the sample is reflective of that in the clinical population at the enrolling institution, and perhaps more importantly, these data suggested that the IE intervention

would be relevant to the needs of women irrespective of minority status. Finally, because the participants in the current study agreed to participate in a group discussion with other survivors about sexuality, it is possible that they may not represent the broader population of breast cancer survivors with sexual concerns. Evidence from other successful focus group research in cancer populations on sexuality, however, suggests that the modality is feasible and appropriate (Flynn et al., 2010; Traa, De Vries, Roukema, Rutten, & Den Oudsten, 2014). Those who refused the study did not differ from participants on key demographic or medical factors, further supporting the representativeness of the study sample.

The next phase of this research involves a pilot test of the IE intervention in a randomized controlled trial. It is anticipated that the use of a telephone format to administer the intervention to couples and the use of web-based data collection could aid recruitment efforts, while incorporating women's perspectives into the IE development could enhance retention because of the heightened relevance of the intervention materials. Yet even with these methods in place, recruitment for couple-based interventions in cancer populations can be challenging (Christie, Meyerowitz, Stanton, Rowland, & Ganz, 2013; Fredman et al., 2009); these difficulties can be intensified by sensitive subject matter. Therefore, for a larger definitive trial, a multi-site approach will likely be necessary to achieve an adequate sample size. Once evaluated for efficacy, an intriguing possibility for dissemination of the IE intervention is through community organizations offering telephone counseling, such as the Cancer Support Community.

Conclusions

Evidence-based interventions addressing sexual concerns for women with breast cancer are needed. This study described the process of adapting the IE intervention to women with breast cancer and their partners. The IE intervention offers a promising, potentially disseminable approach to addressing breast cancer-related sexual concerns.

Acknowledgments

This study was supported by a grant from the National Cancer Institute of the National Institutes of Health (R21CA191354) awarded to Jennifer Barsky Reese. Dr. Reese was also supported by P30CA006927 from the National Cancer Institute of the National Institutes of Health.

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Table 1

Participant Characteristics

Characteristic	Sample (N=19) M (SD)
Age	52.8 (9.8)
Sexual concerns [0-10]	6.4 (2.0)
	n (%)
Race/ethnicity	
White/Caucasian	15 (78.9%)
Black/African American	2 (10.5%)
American Indian or Alaskan native	1 (5.3%)
Hispanic/Latina	1 (5.3%)
Education	
High School or GED	3 (15.8%)
Some college	3 (15.8%)
Completed college/Graduate school	13 (68.5%)
Employment Status	
Full/Part Time	13 (68.4%)
Retired	3 (15.8%)
Unemployed/on disability/other	3 (15.8%)
Menopausal Status	
Perimenopausal	2 (10.5%)
Post-menopausal	13 (68.4%)
Unsure	4 (21.1%)
Disease stage (data missing on 3 participants)	
Stage I	3 (15.8%)
Stage IA	4 (21.1%)
Stage IB	1 (5.3%)
Stage II	1 (5.3%)
Stage IIA	4 (21.1%)
Stage IIIA	2 (10.5%)
Stage IIIC	1 (5.3%)
Surgery	
Lumpectomy	9 (47.4%)
Mastectomy with reconstruction	10 (52.6%)
Chemotherapy	
Finished chemotherapy between 6 months and 1 year ago	4 (21.1%)
Finished chemotherapy between 1 and 2 years ago	6 (31.6%)
Finished chemotherapy between 2 and 5 years ago	8 (42.1%)
Radiation Therapy	
Completed radiation therapy	15 (78.9%)
Hormonal Medication Use	

Characteristic	Sample (N=19) M (SD)
Currently taking tamoxifen	8 (42.1%)
Currently taking an aromatase inhibitor	12 (47.4%)

Table 2

Sample Focus Group Question

Desired Content of Intervention
1. What are some of the ways your sexuality, sex life, or sexual satisfaction have been impacted by your breast cancer surgeries and treatments?
2. At what point in your cancer journey did your sexuality, sex life, or sexual satisfaction begin to change as a result of your breast cancer surgery or treatment?
3. What are some of the physical changes that you experienced related to your sexual function? What about other ways, like sexual desire or interest?
4. What has been the hardest or most bothersome of these changes?
5. How did these changes impact your partner? How about your relationship with your partner?
6. How have you and your partner talked about these concerns?
7. How have you dealt with these changes?
8. What kinds of treatments or aids have you used to try to resolve these problems?
9. If we told you there was a brief program that you could participate in that would help you cope with these challenges, what are the three most important issues or problems you'd hope this program would address?
Desired Format of Intervention
10. Some women have discussed wanting a program that would include their partners. What are your thoughts about this? How important would it be to include your partner? How likely do you think your partner would be to participate?
11. We have been considering a telephone-based format to this intervention. What benefits do you see from this format? What drawbacks do you see from this format?
12. At what point in the course of your cancer journey would this be most helpful?
13. What kinds of resources would you like to see included in this program?

Table 3

Qualitative Themes Used to Adapt the IE Intervention (Part 1: Participant Experiences of Sexual Issues)

Main Themes (A)		Sample Experiences (Verbatim Quotes; B)	Modifications to the Intervention (C)
Theme 1 – Change and Loss: Perceptions of Sexual and Intimacy Changes after Treatment			
a)	Physical sexual changes such as vaginal dryness, loss of breast sensation, and orgasmic difficulties co-occurred, made sexual activity difficult, and lowered libido	…it hurt like mad…every time we tried to do anything and so I would pass [on sex]. You know, "let's just work on you, forget me." (FG 2)[a,b]	• Revised educational materials to enhance relevance (e.g., Vaginal Health handout; body image exercises)[a,b,c]
b)	Loss of libido had multifactorial causes such as pain during sex, hot flashes, and general physical problems (e.g., post-surgical pain)	--	• Addressed the multifactorial nature of low libido through education on women's sexual response[a,b]
c)	Body image changes, often related to changes in breast appearance, were common and interfered with women's sexual interest	I have had a lot of issues since starting this whole thing. Number one is no sex drive. It takes a lot to want to [have sex] and I really have to put my head into it. (FG 2)[a,b]	• Modified sensate focus exercises to deal with women's loss of breast sensation in the context of sensual touching[a] • Expanded and revised the list of potential sexual challenges for study activities such as goal-setting[a,b,c] • Added specific examples of women's concerns to communication exercises[a,b,c]
		--	• Classified intimacy-building activities into sexual vs. non- sexual in nature to help couples target their specific concerns[a,b]
		…I had the lumpectomy… and my breasts are so misshapen, and very deformed and ugly… (FG 3)[c]	
Theme 2 – Reacting to Sexual and Intimacy Changes: Feelings, Thoughts, and Beliefs			
a)	Women noted that sex had lowered in priority for them, especially while under treatment, with a shift toward intimacy; some women in FG 3 remarked that they wanted to have sex while in active treatment in order to maintain intimacy	…[when] I lost my hair I still wanted to be intimate… because I didn't want us to lose that - even though you feel like crap and you don't want to do it, but I wanted to do it for him, I wanted there to be some kind of normalcy between us and some sort of closeness. (FG 3)[a]	• Addressed the range of motivations for sex by including content on women's sexual response[a] • Reinforced the inclusion of women who are post-treatment who may be willing to focus on sexual intimacy[a] • Emphasized the value of sensate focus in reducing pressure for sexual performance and focus on relaxation[c]
b)	Several women reacted to changes in sexual arousal/ pain by avoiding sex, noting that attempting sex was not worth the effort	--	• Included information about women's emotional reactions in educational material to normalize their experiences[a,b,c] • Revised cognitive restructuring exercises to reflect common problematic thoughts expressed by women[a,b]
c)	Negative emotional reactions or inflexible thoughts in response to sexual changes detracted from sexual enjoyment and contributed to low libido	I didn't even want to try; this is just like, let's not even…because it is so much work and pressure on you to enjoy sex when it's painful… (FG 2)[b]	• Focused communication practice exercise on discussion about women's and partners' feelings/reactions to sexual changes[a,b]

Main Themes (A)		Sample Experiences (Verbatim Quotes; B)	Modifications to the Intervention (C)
		--	
		…you are scared and you are wondering, is it going to be like this forever? Then before you know it you are out of it and you are never going to have pleasure. (FG 3)[c]	
Theme 3 – Worries, Fears, and Feelings: Perceptions of their Partners' Experiences and Reactions to Sexual Changes			
a)	Women described emotional reactions by their partners which often affected the sexual relationship and their own feelings	They are very judicious in making any move towards you. He would go to hold me. I was like a little doll. (FG 3)[a]	• Included common partner reactions (e.g., partner fear of hurting the patient through touch) in intervention content[a]
b)	Some women described a friction between how they and their partners adjusted to sexual changes; whereas several women adjusted by accepting a "new normal," they felt their partners wished for their old sex life again	--	• Revised explanation of sensate focus exercises to include discussion of partner feelings about breast touching[a]
c)	Occasionally partners' worries affected their own ability to obtain erections during sex	My life will never be the same. It's a new normal which – I understand it - but it gets him pissed off. [He says] 'we should have more sex.' I mean, great for you, I just have to be in the mood. It's just not the same." (FG 1)[b]	• Included specific examples of thoughts related to partner negative thoughts in cognitive restructuring exercises (e.g., "I wish we could go back to how things were")[b] • Focused communication activity on positive expression of women's and partners' sexual wants and needs[b] • Included information in educational material regarding changes in relationship dynamics and partner sexual issues[c]
		--	
		He doesn't want to hurt me either and the other thing is it's hard for him and now when we do it sometimes he can't [have an erection] because he is so worried about me. (FG 2)[c]	
Theme 4 – Communication and Other "Us" Effects: Women's Perceptions of the Effects of Sexual and Intimacy Changes on their Relationships			
a)	Women described complex ways that breast cancer had changed their sexual scripts and relationships (e.g., foreplay activities altered due to changes in breast sensation)	It's just not the same and he, like I said, is very affectionate, and he may think it is good, like, he will go to rub my boobs and I have to turn around and laugh because I can't feel them. Go for it, go right ahead, but there is no sensation and he just doesn't get it. (FG 1)[a]	• Included information about breast changes and breast touching in educational materials to promote discussion, normalize the experience, and educate the couple about these changes[a] • Included an example of communication about breast touching to model a positive exchange about this topic[a] • Modified the sensate focus exercise to be sensitive to changes in breast touching and related concerns[a] • Included a range of intimacy-building activities designed to improve interest in sex by fostering closeness and mutual
b)	Low libido often caused friction for the relationship; some women adjusted by focusing on pleasing their partner while others attempted to return to former levels of sexual activity[b]		
c)	Communication challenges created difficulties for intimacy, as when a partner invalidated his wife's		

Main Themes (A)		Sample Experiences (Verbatim Quotes; B)	Modifications to the Intervention (C)
	feelings of body image distress by saying "You look fine.	--	enjoyment (e.g., engaging in deep kissing, reliving intimate memories together)[b]
d)	Women noted that non-verbal means of communication were often used, even unintentionally, to express feelings about sexual intimacy	I just don't get those urges anymore and sometimes days, a week will go by, and you know, your husband gently reminds you, "hey let's have sex," and you are like, oh yeah… I almost have to have a schedule…I just don't get those urges anymore. (FG 3)[b]	• Added examples of communication regarding lack of interest in sex and women's body image in communication exercises[b,c] • Added non-verbal communication as an area to both understand and enhance during the communication module[d]
		--	
		And he will say to me "You are beautiful, your body is fine." But… he can tell me ten times a day and I am still not going to feel comfortable with it [body image changes]. (FG 1)[c]	
		--	
		…it's a physical way they can see that we are not aware of… like when they touch us and we make that little jerk, or…they touch us a certain way…the way that they always did it before but we are just not responding exactly the same way. They pick up all the cues, they know. (FG 1)[d]	

Note: Superscripts in Columns B and C indicate that the specific quotes or modifications made to the intervention, respectively, refer to particular themes as listed in Column A.

Table 4

Qualitative Themes Used to Adapt the IE Intervention (Part 2: Coping Experiences and Intervention Preferences)

Main Themes (A)		Sample Experiences (Verbatim Quotes; B)	Modifications to the Intervention (C)	
Theme 5 – Adaptation and Innovation: Adopting Strategies to Cope with Sexual and Intimacy Changes				
a)	The most helpful coping methods tended to involve focusing on moment-to-moment experiences during sex; some women even practiced sensate focus-like exercises with their partners to help both them and their partners to adjust to changes in their bodies	I just visually have to put my head in the game. When he starts touching my first reaction is, "Ok, no thanks," and then it is like, ok, ok… and then…it starts to feel ok and it slowly starts to feel good, but you have to get past that first stop sign. (FG 2)[a]	•	Offered hope toward improving sexual problems offering education on women's sexual response (e.g., intervening anywhere in the cycle can help)[a]
b)	Although some women were able to successfully relax and focus on sensations, others had difficulty with this strategy because they continued thinking negative thoughts	--	•	Targeted difficulties in achieving moment-to-moment awareness through providing detailed instructions regarding sensate focus exercises[a,b]
c)	Some women had introduced vibrators into their sexual repertoire, using them either alone or with their partners during sexual activity, and noted that this improved their interest in sex, while others attempted or wished to use lubricants, estrogen therapy, and local testosterone cream	I find myself often in the act of having sex with my husband trying to meditate to get all of those thoughts out of my mind so that maybe I can orgasm, maybe I can get pleasure…(FG 3)[b]	•	Included up to date information on the status of available medical and physical aids or medications as solutions in educational materials in educational readings[c]
		--	•	Included vibrator use as a potential method for improving libido and arousal in educational readings and as a potential intimacy-building activity in behavioral home practice[c]
		I'll say it- vibrator- to get me in the mood…With my partner, and alone sometimes too. Gets me thinking about it [sex] because for a long time I didn't and I wasn't even interested, then I started thinking well maybe I can get interested on my own because there is no pressure to have an orgasm with my husband, and that made me more interested in sex, just being by myself and enjoying it without penetration... (FG 2)[c]		
Theme 6 – Age, Stage, and History: Contextual Factors Influencing Sexual Concerns and Intervention Preferences				
a)	The status in the treatment trajectory influenced interest in seeking help for sexual concerns; while women may have had sexual concerns during acute treatment, they did not feel interested in seeking assistance for sexual concerns at that time	…at the beginning you just want to know if you are going to live or die and you will do anything, and sex	•	Met women's preferences for when to address sexual concerns by focusing the inclusion criteria on women who were at least 6 months post-treatment[a,b]

Main Themes (A)		Sample Experiences (Verbatim Quotes; B)	Modifications to the Intervention (C)	
b)	Moving into the survivorship stage meant feeling better physically (e.g., less fatigue) and emotionally (e.g., hair growing back), both of which helped some women regain motivation for a sexual relationship	seems to be a little bit more on the periphery at least initially. (FG 3)[a,b]	•	Included information in educational readings explaining common experiences with regard to motivation for sex during and after completing treatment[a]
c)	Several women noted having had premorbid sexual concerns that worsened due to treatment such as vaginal dryness that turned into vaginal bleeding with sexual intercourse, resulting in avoidance of sexual activity	--	•	Described pre-cancer sexual concerns or relationship issues as potential contributors to sexual problems in intervention educational content[c]
		I would have to say the first year was, I don't give a crap. I don't care. I don't feel like it…when you lose your hair, when my hair started coming back I started to feel more myself. (FG 2)[a,b]		
		--		
		Even before the cancer, I also had a lot of problems with vaginal dryness. It got so bad that I would bleed with intercourse and that is with using some different products, so I just started, well it became more and more infrequent that we would have sex. (FG 1)[c]		
Theme 7 – Discussions in the Clinic: Experiences with Patient-Provider Communication about Sexual Concerns				
a)	A number of women commented that because their partners had not heard any information about likely sexual side effects of treatments, they were surprised about sexual problems when they occurred, causing relationship friction	Not once in front of my husband did anybody say sexuality is going to be a difficulty through this whole process. (FG 1)[a]	•	Targeted improving partner knowledge and awareness through active involvement by the partner as a key component of the intervention (e.g., providing a set of materials to both members of the couple)[a]
b)	Younger women were particularly distressed by a perceived inaction on the part of their providers in not offering options for treating severe vaginal dryness, discomfort, and difficulty with orgasm	--	•	Included information on severity of sexual concerns for many breast cancer survivors in the educational materials in order to normalize these concerns[b]
c)	Some women expressed the belief that counselors would have more time to address their concerns compared to oncologists and that some providers did not value sexuality as a topic	….I asked about the vaginal dryness…and it is like, "Well, let's wait and see." Meanwhile, years of my life are going by We are waiting and seeing. (FG 3)[b]	•	Included vaginal health handout(Carter et al., 2011) with specific treatment suggestions for addressing vaginal dryness and discomfort in educational materials[b]
		--	•	Insecurities in raising sexual concerns with providers reinforced the decision to develop a counselor-administered intervention[c]
		You feel like you don't have a lot of time with them, you know, they are here to treat your cancer, and a counselor would be there to hear what else is going on with you… (FG 2)[c]		

Main Themes (A)		Sample Experiences (Verbatim Quotes; B)	Modifications to the Intervention (C)
Theme 8 – Addressing Sexual Concerns: Preferences for an Intimacy-Focused Intervention			
a)	Women almost unanimously felt it would be helpful and important to include their partners in an intervention addressing sexual concerns	I think it is like a family disease and I think that counseling or support should be provided for the spouse as to the outcomes and what to look for…(FG 1)[a]	• Reinforced our decision to utilize a couple-based format for the IE intervention [a]
b)	Given the sensitivity of the subject, some women noted that they and/or their partners would prefer greater anonymity in discussions about sexual concerns than is offered in a medical visit	-- Quite frankly, I probably would have had a better time discussing it with somebody who I didn't feel I had a connection with. (FG 2)[b]	• Opinions about preferred anonymity within the intervention format provided reassurance that a telephone-based format could be appreciated by many women and partners[b]
c)	In terms of explicit preferences for the intervention, a number of women stated that they wanted information about advances in treatment options addressing sexual concerns	-- And I think then the other piece that I would hope is getting the latest information when there is new medication, when there is new creams to help especially the dryness, there is new…I don't even know if I have the new and latest. (FG 3)[c]	• Revised and expanded information on treatments and solutions for addressing a range of sexual concerns, including the detailed vaginal health handout[c] (Carter et al., 2011)

Note: Superscripts in Columns B and C indicate that the quotes or modifications made to the intervention, respectively, refer to particular themes as listed in Column A.