

Breast cancer survivors' perceptions of their partners' interest in cancer-focused psychosocial interventions

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Abstract

Background: Despite that partners of breast cancer survivors (BCS) often experience long-term consequences from the cancer experience, including fear of recurrence and depression, there are rarely psychosocial interventions aimed at mitigating these consequences. Because partners are usually recruited to research studies through BCS, it is important to understand the views of BCS regarding their partners' involvement in interventions. The aim of this study was to explore perceptions of BCS regarding the advisability of offering a psychosocial intervention to their partners. **Methods:** BCS (N=22) enrolled in 1 of 3 interventions (acceptance and commitment therapy [ACT], survivorship education [SE], or enhanced usual care [EUC]) were queried about whether they believed their partner would be interested in a psychosocial intervention similar to what they had just completed and asked to provide their opinions about how a partner intervention should be structured and what it should address. Twenty-two BCS (ACT group [n=5], SE [n=11], and EUC [n=6]) completed the interviews. **Results:** The participants identified 3 unmet partner needs that they thought could be addressed by a psychosocial intervention: problems with coping, communication breakdowns, and lack of information. They also provided 3 recommendations regarding the development of a partner intervention: the use of a group format, the provision of separate sessions for partners and BCS, and the inclusion of intervention components that provide practical or factual information related to breast cancer. **Conclusions:** BCS can provide valuable insights that can inform the development of psychosocial interventions for partners of survivors. The development of such partner interventions is critical to address the negative and often hidden health and social effects experienced by partners of BCS.

Keywords: acceptance and commitment therapy, breast cancer survivors, intervention, partners, psychosocial, spouses, survivorship education

Introduction

Approximately 3.8 million women in the United States are living with breast cancer.^[1] Breast cancer survivors (BCS) are living longer, cancer-free lives, with approximately 90% surviving 5 years or longer in the United States.^[2] However, BCS remain at risk for long-term physical, psychological, social, and spiritual challenges, even while in remission.

BCS are not alone in facing the effects of cancer. Partners or spouses caring for a loved one with breast cancer are also affected by and report long-term consequences from the cancer experience, including higher anxiety and depression,^[3] more hospitalizations due to affective disorders,^[4] and greater use of antidepressants compared to partners of healthy women.^[5] Partners are also more likely than survivors to report fear of cancer

Research reported in this publication was supported by IU Health Values Grant (0952; S.A. Johns, PI). Its content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, including the National Cancer Institute.

AAC is supported by National Cancer Institute under award number K05CA175048 (VL Champion, PI) and by the Indiana Clinical and Translational Sciences Institute (KL2 Program), UL1TR002529 (A Shekhar, PI), 05/18/2018-04/30/2023. EFK is supported by National Cancer Institute of the National Institutes of Health under T32CA117865 (VL Champion, PI). EAV is supported by National Cancer Institute of the National Institutes of Health under T32CA117865 (VL Champion, PI). SAJ is supported by National Cancer Institute under award number K05CA175048 (VL Champion, PI).

Authors' contributions: AAC drafted all sections except the introduction; led data analysis; made all tables; EFK drafted the introduction, analyzed data for 2 interviews, and provided edits; EAV analyzed data for 2 interviews, participated in team discussions, and provided edits; AHC analyzed data for 2 interviews, participated in team discussions, provided analytic guidance, and provided edits; PVS analyzed data for 2 interviews, participated in team discussions, and provided extensive edits; JSA analyzed data for 2 interviews, participated in team discussions, managed citations, and provided edits; SAJ was the parent study PI, analyzed data for 2 interviews, participated in team discussions, and provided edits.

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J of Psychosocial Oncology Research and Practice (2021) 3:1(e042)

Received: 9 March 2020 / Accepted: 10 December 2020

<http://dx.doi.org/10.1097/OR9.000000000000042>

recurrence.^[6] In fact, they are more likely than survivors to report fear of recurrence even 4 years after diagnosis.^[7] Furthermore, higher levels of distress and lower levels of relationship satisfaction predict greater unmet needs in partners.^[8] Partners report fear of recurrence, desires to reduce stress in survivors' lives, case management concerns, and need for information about family risk of cancer.^[8,9]

Although partners often report similar or increased levels of distress as BCS,^[10] they are rarely the focus of psychosocial interventions in cancer. A recent systematic review reported that previous psychosocial intervention studies in breast cancer are largely couple-based, focusing on dyadic outcomes.^[11] Only 1 intervention was solely partner-focused, in which partners were recruited through BCS. The main reason partners did not enroll in the study was that the BCS believed her partner would not be interested in participating (48% of refusals).^[12] Because BCS traditionally have strongly influenced their partners involvement in cancer-related studies,^[12] understanding BCS views on their partners' engagement in psychosocial interventions aimed at improving their health outcomes is critical.

The aim of this study was to explore perceptions of BCS regarding the advisability of offering a psychosocial intervention to their partners. Data were drawn from post-intervention interviews conducted with BCS who had completed an intervention trial aimed at decreasing their fear of cancer occurrence (FCR). The intervention trial and the interviews are briefly described below to provide context for the results of the current study.

Methods

Intervention trial

Breast cancer survivors (N=91) participated in a 3-arm pilot randomized controlled trial. Eligible BCS were identified through a large academic health care system in Indiana. They had been diagnosed with stage I-III breast cancer, had completed curative treatment (ongoing endocrine therapy was allowed), had not experienced a cancer recurrence, and had reported clinically significant FCR (Fear of Cancer Recurrence Inventory-Short Form score ≥ 13).^[13] BCS with severe depression (Patient Health Questionnaire-8 [PHQ-8] score ≥ 20)^[14] were excluded.

Participants were randomly assigned to 1 of 3 group-based, psychosocial interventions: acceptance and commitment therapy (ACT; n=33), survivorship education (SE; n=32), or enhanced usual care (EUC; n=26). ACT and SE groups met 2 hours per week for 6 weeks, whereas EUC participants received a single 30-minute coaching session and self-administered survivorship readings. ACT is a behavioral intervention that incorporates mindfulness- and acceptance-based processes to reduce interference of difficult internal experiences (eg, fear) with meaningful activities aligned with personally held values.^[15,16] The SE intervention provided evidence-based information relevant to BCS with FCR, such as managing symptoms, managing weight through healthy eating and physical activity, and managing the costs of cancer care. This study was approved by the Indiana University Institutional Review Board (#1507511085). Additional details about the intervention trial and the results have been presented elsewhere.^[17]

Post-intervention interviews

To obtain rich data regarding participant reactions to each intervention, approximately half of participants in each inter-

vention group were selected for post-intervention semi-structured interviews. The interviews were conducted on the phone by trained interviewers. Fifty-three participants were interviewed: 18 from the ACT and SE groups each and 17 from the EUC group. The interviews lasted between 20 and 45 minutes. Questions were focused on how the participants experienced their fear of cancer recurrence before and following the intervention, how they used the study materials to manage their fear of recurrence, and what components of the intervention they found to be most helpful. Of the 53 participants who completed the interviews, 22 were partnered: 5 from the ACT group, 11 from the SE group, and 6 from EUC. In total, 65 of 91 BCS (71.43%) were married or partnered.

These participants were asked questions about their partners' likely interest in an intervention similar to the one they received, aspects of the intervention that may be helpful to partners, intervention components that should be added for partners, and how the intervention may help couples. All interviews were audio-recorded and transcribed for analysis. The first author checked all transcripts for accuracy.

Analysis of partner data

To address the aim of the study reported here, all data related to partners were highlighted and analyzed using a standard content analysis as described by Miles et al.^[18] Analysis of these data occurred in 6 steps. First, the team constructed a data display table in which the 4 questions that guided the interviews were used as column headers. Second, all participant remarks related to their partners were highlighted, and 2 team members independently coded these remarks. The codes were brief labels that captured the essence of the participants' remarks. The team members met to discuss their codes and final codes were determined by consensus between the 2 team members. Because the codes were at a low level of interpretation and remained close to the data, there were few disagreements on the final codes. Third, all of the final codes were placed on the data display table in the relevant columns. Fourth, 2 team members were assigned to each column of the data display table and met to group similar codes into categories that answered each question. Fifth, the research team met to discuss the categories and determined they were best organized into 2 broad topics (discussed below). The first author wrote a narrative summary of the categories and the 2 topics. Sixth, the narrative summaries were presented to the team, discussed, and finalized (Table 1).

Results

Most of the participants supported the idea of developing a psychosocial intervention similar to what they had experienced during the trial, and many indicated that they believed their partners would participate in such an intervention. The 2 main topics they discussed in this regard were their perceptions of the unmet cancer-related needs of their partners that could be addressed in an intervention and their recommendations for developing a psychosocial intervention for partners.

Unmet cancer-related needs of partners

The 3 unmet needs that the participants had observed in their partners included problems with coping, communication breakdowns, and lack of information. A summary of the participants' perceptions of these three unmet needs and their beliefs about

Table 1**Themes and subthemes with descriptions and direct quotes.**

Themes	Subthemes	Description	Quotes
Maladaptive Coping		Specific ways their significant others dealt with cancer-related stress that survivors believed were problematic and could be improved by the intervention	
	<i>Avoidance</i>	Not discussing or thinking about cancer	"I think it would be helpful for him to understand that shutting feelings down doesn't take them away and that there is value in allowing yourself to feel the feelings and the thoughts and to take time every day to pray. I wish he would understand the value of that." (ACT-001)
	<i>Hypervigilance</i>	Partners anxiously observing their survivors' wellbeing	"To help him not hover over me . . . to know that I'm okay as far as we know." (SE-008)
	<i>Denial</i>	Refusing to believe the cancer happened	"He was like, 'no, it isn't true, it isn't there' . . . It's like he tried not to think about it or talk about it." (EUC-005)
	<i>Acceptance</i>	Noticing and accepting cancer-related thoughts without judging themselves or the thoughts harshly	"[He] has a tendency to shove it back . . . somewhere and occasionally it pops up . . . He really more needs something along the lines of . . . 'Don't judge the thought.'" (ACT-002)
Relationship	<i>Closeness</i>	Ways that the dyadic relationship might be affected by both individuals participating in the intervention Interpersonal connection between partners and how one's coping will affect the other's coping	"It's not just my values. He's my other half. I mean, I'm not a whole without him, so your values have to kind of correlate . . . It would bring you closer together because you're on the same road . . . They're going through a lot, too." (ACT-003)
	<i>Intimacy</i>	Ways that cancer has changed the physical and emotional intimacy aspects of their relationships	"There is life after cancer . . . your sexual life isn't going to be the same... I've gone through all the body changes, which doesn't bother him. It does bother me . . . I think it's a team effort, and even the physical and sexual—it all goes (together). (ACT-003) "Probably the session we had with the video of sex . . . because I think sometimes men treat you like a china cup that's ready to break." (SE-010) (describing session on the sexual implications of cancer treatment)
Communication	<i>Providing a Conversation Starter</i>	How the intervention might be a resource for starting or enriching cancer-related conversations Ways the intervention could provide an opportunity to discuss cancer-related issues that survivors and partners may not have talked about before	"He may hear something that I had not shared with him . . . you know, he may just say in a really sympathetic manner, 'Do you deal with that? Is that something you're experiencing?' (SE-003)
	<i>Fostering Open Communication to Enhance Partner Understanding</i>	Ways the intervention would be able to help partners learn about the experience of being a breast cancer survivor	"Anything that opens an avenue for discussion improves your relationship." (EUC-001) "It would help our dialog, specifically about cancer or recurrence of cancer, be a little bit better." (ACT-002) "I think it would've been . . . one more thing that we shared [and] make it easier to communicate because we've had the same . . . background information." (SE-007) "Your significant other has to understand where you are with this so that they know how to help you." (SE-001)
Information		How the intervention might improve partners' understanding of what the survivor is experiencing (e.g., illness/treatment, symptom experiences, body image, emotional aspects of the illness)	"Him seeing other survivors and how they are feeling about it would be probably most helpful because he just sees me." (SE-007) "I think understanding the symptoms, especially 'chemo brain.' Because I know my husband sometimes—even as supportive as he is and he is incredibly supportive—thinks I'm losing my mind." (SE-004)

(continued)

Table 1
(continued).

Themes	Subthemes	Description	Quotes
Group		Important considerations for including partners in the intervention	<p>"I could talk to him about the body changes and intimacy thing. I don't think it's really super affecting us, but maybe he does." (EUC-004)</p> <p>"I think enhanced sensitivity to the emotional aspects of the anxiety or the insecurity would be nice, which I think comes from the group discussions." (SE-006)</p>
	<i>Comaraderie/ Safe Space</i>	Partners' need to share their cancer-related experiences with other partners in an environment where they felt comfortable	"I think the camaraderie with the other men or, you know, partners that have gone through it before (would be helpful) because I don't think he's talked to anybody that he knows in dealing with it." (SE-010)
	<i>Separate Sessions</i>	The need to have separate sessions for partners and survivors	"If at least one of the sessions was just for survivors in one room and the partners in another room, they might ask questions that they would not necessarily want their survivor spouse to hear. I think they probably have fears that they don't communicate." (SE-004)
Program Improvement		ways the interventions would need to be changed to appeal to partners including more scientific rationale, reassurances, and contact information	<p>"It would need to be much more logical. More science—you need to talk about numbers." (ACT-002)</p> <p>"If there were some way to reassure a partner that everything's going to be okay. That this is all going to be handled . . . one way or another, it's going to be doable, that your spouse is gonna be alright." (SE-007)</p> <p>"Having maybe a person someone could contact if they need additional support. Maybe it isn't just a person, but an option saying here's the social worker at the hospital with her name and number, here's the chaplain if someone wanted to go that route, here's the number to call." (ACT-001)</p>

how an intervention might address the needs is provided below and accompanied by verbatim quotes from the interviews. Following each summary, findings of previous research related to each of the 3 unmet needs are provided.

Problems with coping

Participants suggested that their partners were coping in some ways that were not helpful. Some participants, for example, were concerned that their partners tried not think or talk about cancer. One participant said, "*He [her partner] was like, 'No, it isn't true. It isn't there.' . . . It's like he tried not to think about it or talk about it.*" (EUC-005) The participants believed that their partners avoided discussing the cancer as a way to deny their feelings and fears. These participants proposed that an intervention developed for partners would provide an opportunity for them to express rather than suppress their emotions. One said, "*I think it would be helpful for him to understand that shutting feelings down doesn't take them away and that there is value in allowing yourself to feel the feelings and the thoughts.*" (ACT-001)

Other participants were concerned that their partners were overly attentive and vigilant and tended to "hover" over the

participants. The participants believed this stemmed from their partners' need to reassure themselves that the participants were okay. The participants felt that although "hovering" was well-intentioned, it was not helpful, and an intervention could provide some reassurance to their partners regarding reoccurrence. One stated, "*It [intervention] would help him not hover over me . . . to know that I'm okay as far as we know.*" (SE-008)

The participants' observations that some partners avoid talking about the cancer, deny its impact, or become overly watchful over the BCS are consistent with studies on maladaptive coping. For example, research has demonstrated that avoidance, hypervigilance, and denial can lead to fear of recurrence and depressive symptoms in BCS and their partners.^[6,19,20] Moreover, research has also shown that some therapeutic approaches such as ACT, an approach that helps persons become mindful of their present-moment experiences, may be useful for addressing avoidance, denial, and hypervigilance among BCS and their partners.^[21]

Communication breakdowns

Participants remarked that their partners at times struggled with discussions about cancer-related issues and did not communicate

in ways that would be beneficial. Some participants, for example, remarked that their partners had difficulty expressing empathy for what the participants were going through. The participants suggested that an intervention that provided insights about the cancer experience could help with this aspect of communication. One participant said, “*He may hear something [in a group] that I had not shared with him He may just say in a really sympathetic manner, ‘Do you deal with that? Is that something you’re experiencing?’*” (SE).

Participants also suggested that communication between partners could be affected by the cancer experience. Some suggested that if partners and BCS were included together in an intervention, they would have an opportunity to express their thoughts and feelings to each other and therefore obtain a better understanding of each other’s experiences related to the cancer. The participants felt a couple’s intervention would provide opportunities for them to discuss relationship issues that were affected by the cancer, including their sexual life. One participant said, “*Your sexual life isn’t going to be the same... I’ve gone through all the body changes, which doesn’t bother him. It does bother me . . . I think it’s a team effort, and even the physical and sexual—it all goes (together).*” (ACT-003). Participants also felt an intervention could bring the couple closer as both partners could both discuss what was really important to them. One participant said, “*It’s not just my values. He’s my other half. I mean, I’m not a whole without him, so your values have to kind of correlate . . . It would bring you closer together because you’re on the same road . . . They’re going through a lot, too.*” (ACT-003)

The participants’ suggestion that communication between partners and BCS might be an important intervention target has been supported by prior research. For example, one study revealed that the nature of daily couple communication played an important role in the relationship between severity of illness representation and fear of cancer recurrence for cancer survivors and their spouses.^[6] Research has also shown that congruent adaptive coping (when couples are able to face their difficult experiences in similar adaptive ways) in couples when one person has cancer is important for each person’s ability to process cancer-related trauma. For example, if one partner uses avoidant coping and imposes social constraints (ie, behaviors that limit discussion of cancer) while the other partner craves social connection and wants to process cancer-related thoughts and feelings, the partner needing to talk about cancer is at greater risk for experiencing fear of recurrence.^[6] Furthermore, one study revealed that adaptive dyadic coping is associated with less depression for each partner when one has cancer.^[22]

Need for information

Participants suggested that their partners had a need for more information about the cancer experience. Some participants indicated that their partners lacked information on cancer treatments, symptoms like “chemo brain,” common survivor concerns related to body image, and emotional consequences of cancer. One survivor stated, “*I think [having husband] understand the symptoms, especially ‘chemo brain.’ Because I know my husband sometimes – even as supportive as he is and he is incredibly supportive – thinks I’m losing my mind.*” (SE-004) Participants also felt it was important that their partners understand the physiological and psychological effects of cancer. Participants thus endorsed interventions that would provide partners with such information.

Previous research has somewhat supported participants’ claims that partners of BCS have a need for information about the illness, treatments, and symptoms. Among partners and caregivers of a diverse sample of cancer survivors, Turner et al^[23] reported information about familial risk, help managing fear of recurrence and coordination of care as among the most cited unmet needs. Partners have identified a critical need for information directed to them that is relevant to their own situation and answers questions throughout the time period following diagnosis.^[24] Exploring these information needs with partners specifically would be beneficial as there has not been much work done in recent years on information needs of partners of BCS.

Intervention recommendations

In addition to identifying the unmet needs of their partners, the participants provided 3 main recommendations for developing partner interventions. Some of the recommendations were based on what they believed would be acceptable and of use to their partners and some were based on their thoughts about how the interventions they had just completed could be modified for their partners. The 3 recommendations are discussed below.

First, participants recommended that a partner intervention should be delivered in a group format so that partners could garner support from other partners. Participants suggested that a group format would instill a sense of camaraderie among partners. One participant said, “*I think the camaraderie with the other . . . partners that have gone through it before (would be helpful) because I don’t think he’s talked to anybody that he knows in dealing with it.*” (SE-010) The participants stressed that having other partners to talk to who had had similar experiences would be beneficial for their own partners.

Second, participants recommended that the intervention should provide an opportunity for partners to have one or more sessions apart from the BCS. These sessions would allow the partners to more fully express fears or concerns that they did not want to discuss with the BCS. One participant stated, “*If at least one of the sessions was just for survivors in one room and the partners in another room, they might ask questions that they would not necessarily want their survivor spouse to hear. I think they probably have fears that they don’t communicate.*” (SE-004)

Third, participants recommended that although the interventions should include opportunities for partners to discuss their emotions and concerns, the interventions should also include a component that provides factual or pragmatic information for partners as well. One participant said, “*It [partner intervention] would need to be much more logical [than the ACT intervention]. More science - you need to talk about numbers - you know, so that’s the thing with him is you will need to focus on, ‘Hey we’re using a science that has some backing behind it and here are some of the statistics.’*” (ACT-002) Some practical information that participants thought should be provided in partner interventions included topics such as financial toxicity (financial problems arising from cancer such as medical bills and losing employment), managing insurance claims, and healthy nutrition/cooking. Participants also recommended that partner interventions provide some connections to health professionals. One participant said, “*Having maybe a person someone could contact who thinks they need additional help and maybe it isn’t just a person but an option saying here’s the social worker at the hospital with her name and number, here’s the chaplain program if someone wanted to go that route, here’s the number to call.*” (ACT-003)

Discussion

Participants of an intervention trial aimed at testing the efficacy of 3 psychosocial interventions to decrease fear of cancer recurrence in BCS endorsed the importance of developing similar interventions for their partners. They identified 3 unmet needs that they had observed in their partners and that the participants felt could be addressed with an intervention. The unmet needs were problems with coping, communication breakdowns, and lack of information. These needs resonated with existing literature on maladaptive coping,^[25] communication patterns, and social constraints among couples in which 1 partner has cancer,^[20,26] and the informational needs of partners of cancer survivors.^[23] In addition, the participants provided 3 recommendations to consider when interventions are developed for partners. The recommendations included providing interventions in a group format, providing sessions in which partners meet separately from BCS, and including intervention components that provide practical information in addition to emotional and communication support.

Study limitations

Although this study provided a unique opportunity to query BCS about their perceptions of partners' intervention needs, there were several limitations. First, the sample interviewed came from 3 diverse intervention arms, and the interview questions did not probe which specific elements of each intervention would be recommended for partners. We can thus make no claims about which of the 3 interventions, or particular components of those interventions, would be preferable for partners. We do believe, however, the group assignment could have well-influenced participants' recommendations. Second, the participants might not have accurately gauged their partner's interest in receiving an intervention. One BCS who originally stated that her partner would not be interested in participating in an intervention called back after speaking with her partner to say that he would indeed be interested. Third, the sample was limited to breast cancer survivors, the majority of whom were in heterosexual relationships, and thus these results may not be generalizable to other cancer populations or LGBTQ relationships.

We recommend that future research includes in-depth interviews with partners of BCS to explore their interest in participating in research trials of interventions that address their unique needs. To do this, researchers should consider recruitment methods that will reach partners directly, such as targeted Facebook advertisements.^[27] The vast majority of Americans use Facebook and subscribe to support and interest groups that would help researchers target their population of interest.^[26] Partners could then be queried about their therapeutic or practical needs and asked to describe what types of interventions they would view as feasible and acceptable.

Practice implications

Despite the study limitations, our findings suggest several practice implications. The 3 unmet needs of partners identified in this study—problems with coping, communication breakdowns, and lack of information—will likely need to be considered when developing partner interventions. Interventions tailored to meet specific partner needs may be especially beneficial.^[8,9] For example, some partners may benefit from interventions that address their practical needs (eg, connections with health professionals, dealing with financial toxicity), whereas others

may benefit from interventions that address their emotional needs (eg, handling fear of recurrence, avoidance of feelings^[27]). The participants' suggestions to offer treatment in a group format, to have some sessions in which partners meet with the BCS, and to include a component of the intervention that focuses on providing practical information should be considered.

Conclusions

Although much work is to be done to develop an effective intervention that can meet the varied needs of partners of BCS, the views of BCS who had themselves participated in a psychosocial intervention provided useful insights into what a partner intervention might entail. Because BCS will often be the first point of contact for engaging partners in psychosocial interventions, their views are useful to inform intervention development. The development of such psychosocial partner interventions is critical to address the negative and often hidden health and social effects experienced by partners of BCS.

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