

Breast Cancer Survivors' Perceptions of Partners' Intervention Needs

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Purpose: Fear of a cancer recurrence (FCR) is one of the most commonly reported and most distressing psychological consequences of breast cancer for survivors (Ferlay et al., 2015; Zdenkowski et al., 2016). FCR is related to poor health outcomes, such as sleep disturbances, fatigue, and poor concentration, which impact overall wellbeing and increase healthcare costs (Brown, Kroenke, Theobald, Wu, & Tu, 2010). Partners report similar levels of FCR as the survivors themselves (Bigatti et al., 2012; Nakaya et al., 2010), effects that can last years after diagnosis and treatment (Cohee et al., 2017; Simard, Savard, & Ivers, 2010). However, partners' psychological and health outcomes are rarely the focus of interventions. Specifically, no interventions designed to reduce FCR in partners currently exist, and there are no published reports of the relationship between partners' FCR and their own health outcomes. A recent RCT (quantitative results not yet published) was designed to compare FCR outcomes in breast cancer survivors between 2 interventions. The team of researchers hypothesized that the intervention may also be effective in reducing FCR in partners, if tailored to meet their unique needs. Knowledge about partners needs immediately following treatment have been assessed only once, with partners reporting needs of information about familial risk, help managing FCR, and coordination of care (Turner et al., 2013). Unknown, though, are the partners' needs, preferences, and willingness to participate in a survivorship education intervention.

Methods: Qualitative descriptive methods were used to analyze narratives from eleven partnered breast cancer survivors who participated in a survivorship education intervention. As a first step to learn about partners' interest in an intervention, survivors were asked about their spouse or partner's interest in a similar hypothetical intervention, potential benefits and barriers to participation, and specific aspects of the intervention that may be especially useful to partners.

Results: All eleven survivors believed the intervention would be beneficial to partners but had mixed responses as to whether their partners would agree to participate. Several barriers to participation were discussed, including lack of time, wanting to move on from cancer, and acting like cancer never happened. Survivors identified personal, partner, and dyadic benefits to participation. Survivors also described wanting their partners to learn about the emotional and physiological impact breast cancer had on them, and their needs as survivors.

Conclusions: Survivorship education interventions designed to reduce FCR for both breast cancer survivors and their partners should consider unique needs and desires of partners. Partners should be interviewed directly to gain better insights about their needs, rather than breast cancer survivors' perceptions of their needs.

Title:

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Keywords:

Breast cancer survivors, Fear of recurrence and Partners

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Abstract Summary:

Breast cancer survivors and their partners report similar levels of fear of recurrence; however, partners are rarely the subject of intervention. Survivors' perceptions for partners' interests and barriers in a survivorship education intervention are discussed.

Content Outline:

1. Fear of cancer recurrence (FCR) is one of the most common and distressing psychological problems for partners resulting from breast cancer
 1. Partners report similar levels of FCR as the survivors
 2. FCR is related to poor health outcomes and increases healthcare costs
2. Partner's needs and preferences for interventions to reduce FCR are unknown
 1. No interventions to date have focused on reducing FCR for partners
 2. Only one published study has even asked partners for their needs after treatment
3. Partners' interest in and barriers to participating in survivorship education interventions are unknown
 1. Qualitative interviews were conducted with partnered survivors enrolled in a survivorship education intervention
 2. Survivors were asked about their partners' interest and potential barriers and benefits to participating in a similar, hypothetical intervention
4. All eleven survivors believed the intervention would be beneficial to partners

1. Several barriers to participation were discussed, including lack of time, wanting to move on from cancer, and acting like cancer never happened
2. Survivors identified personal, partner, and dyadic benefits to participation
3. Survivors wanted partners to learn about their own needs
5. Survivorship education interventions should consider unique needs and desires of partners
 1. Partners should be interviewed directly to gain better insights about their needs

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Problem

Partners of Breast Cancer Survivors have:

1. High levels of distress: depression, anxiety, fear of recurrence¹⁻⁴
2. More unmet needs than their breast cancer survivor spouse⁵
3. Lower general health and quality of life than partners of healthy women⁴



Purpose

To qualitatively assess breast cancer survivors' perceptions of their partners' needs and interest in an intervention to improve their fear of cancer recurrence



Parent Study

1. 3-arm trial to reduce FCR
2. Compared Acceptance and Commitment Therapy, Survivorship Education, and Survivor Pamphlet
3. 30 women in each arm
4. Breast cancer survivors any time post diagnosis and treatment



Methods

- Qualitative study
- 11 women randomly selected from any trial arm
- All questions related to the intervention they received



Interview Questions

1. “Do you think that your partner would be interested in participating in a study like this?”
2. “What parts from this study would be helpful for spouses or partners?”
3. “What do you think a study like this could do for couples?”

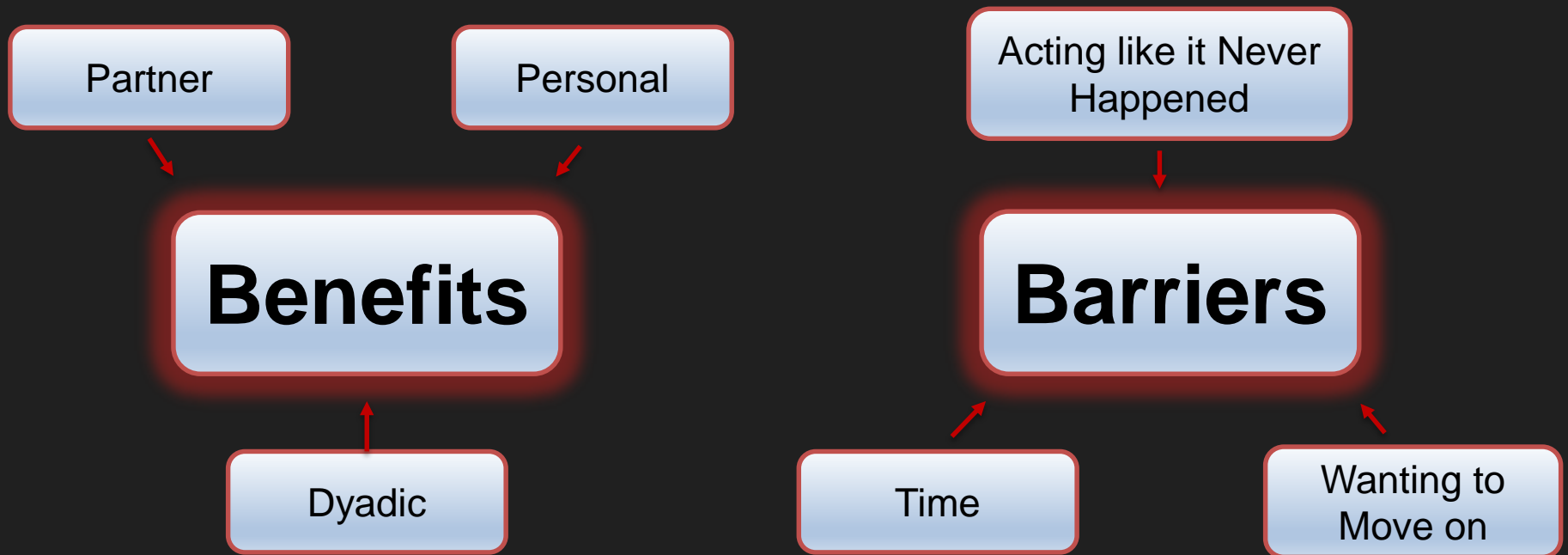


Content Analysis

1. Interviews recorded and transcribed
2. Themes generated by first author
3. Themes confirmed by co-author



Themes



Benefits to participating

Personal: Benefits to the survivors themselves if partners participated

- “He probably would have learned a little bit about... why I go through the depression I go through and unable to sleep and worried about, you know, when it's time for my mammogram because I really get stressed out. And... he just keeps saying, ‘Everything is going to be all alright. Everything is going to be all right. Don't worry.’”

- Pat



Benefits to partners for participating

- “I think that 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.”
 - Addy



Benefits to Dyad if partners participated

- “I think it would help in ways where I think he would feel comfortable talking to me more about it. Like I feel like it would help our dialog, specifically about cancer or recurrence of cancer, be a little bit better. It’s not that it’s bad, it’s just that – and I honestly can’t say- how often does he think about if my cancer’s going to come back. *Does he think about it?*”
 - Bella



Barriers to Partner Participation

Time	Wanting to Move on	Acting like it never happened
<p>Not having the time to attend</p> <p>“My [sessions] were during the daytime and he wouldn’t be able to come to that because he’s working.” - Leann</p>	<p>Not wanting to discuss or think about the cancer any longer, wanting to get back to normal</p> <p>“I think [he] has a tendency to think through stuff but he kind of shoves it back in a place, you know, shoves it back somewhere and never – and occasionally it pops up.” -Ophelia</p>	<p>Avoiding the topic of cancer</p> <p>“I think it would be very helpful. He wouldn’t go. He likes to pretend like it never happened now. When you called and I started talking about it, he got up and walked away.” -Marilyn</p>



Summary

1. Survivors identified benefits and barriers to partners participating
2. All survivors believed partner participation would be helpful to themselves, their partners, and their relationships



Future Directions

1. Determine if partners express the same intervention needs as described by their survivors
2. Develop future survivorship interventions that include partners to reduce FCR

Cohee, A. A., Johns, S. A. (2018). *Breast cancer survivors' perceptions of partners' intervention needs*. Manuscript in preparation.



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