BRIEF REPORT

Characteristics of Breast Cancer Survivors That Predict Partners' Participation in Research

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Abstract

Background Psycho-oncology couples' research frequently includes fewer than 50 % of those eligible.
Purpose This research examined individual and relationship characteristics associated with recruitment and retention of breast cancer survivors' partners.
Methods Investigators asked survivors from the Moving Beyond Cancer trial for permission to invite their partners to a parallel, longitudinal study.
Results Of 384 survivors with male partners, 280 survivors provided consent to contact partners, and 164 partners completed both assessments. Backward stepwise regression indicated that greater family income and support from a partner and helpful other increased the likelihood of survivor consent to contact her partner. Greater family income, better survivor physical and emotional quality of life, and white ethnicity increased the likelihood of partner participation.
Conclusions Breast cancer patients who are ethnic minorities, have lower socioeconomic status, or have poorer physical and mental quality of life appear less likely to participate in psycho-oncology couples' research, whereas women with supportive partners might be overrepresented.

Keywords Couple/partner · Recruitment · Retention · Breast cancer · Socioeconomic status · Quality of life

Introduction

Breast cancer is increasingly recognized as a disease that affects both the woman diagnosed and her partner [1]. As more studies examine psychosocial adjustment among couples facing cancer, the challenges of recruiting and retaining patients and partners are becoming apparent. Recruitment rates of less than 50 % for couples' research are not uncommon [2]. It is possible that participation is related to nonrandom factors, including demographic and illness characteristics, cancer treatment, as well as emotional and physical well-being. In addition, patients who are interested in participating in research with their partners, and are able to convince their partners to participate, are unlikely to fully represent the population of breast cancer patients [3].

Demographic and emotional factors have been associated with non-participation in research on psychosocial adjustment following cancer. Ethnic minority patients appear less likely to participate than non-Hispanic white cancer patients [2, 4, 5]. Fewer years of education [5] and greater emotional distress have been associated with non-participation [3, 6], and younger age has been associated with both participation [5] and non-participation [7]. In addition, patients and partners who participate as a couple may have stronger relationships or report greater levels of support than couples who do not participate. However, it has been difficult to identify individual and relationship factors associated with individuals who prefer not to be involved in a study with their partners.

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In this paper, we investigated characteristics associated with the recruitment and retention of partners of breast cancer survivors participating in a longitudinal, randomized controlled trial of a psychoeducational intervention. This analysis was possible because the parent study [8, 9] used a stepped approach to survivor and partner recruitment. Survivors were recruited initially (see [5] for a full description), and then, following the intervention, survivors were asked for permission to invite their partners into a parallel study. Thus, partners could be excluded because the survivor refused to provide consent for her partner to be contacted, or if the survivor gave consent, the partner could refuse to participate or to complete the study. We sought to determine if demographic, cancer treatment, relationship, or quality of life characteristics were associated with partner participation or study completion.

Method

Participants and Procedure

Data for this study come from the Moving Beyond Cancer intervention study and a parallel study of the partners of Moving Beyond Cancer participants. Moving Beyond Cancer was a multisite (Kansas, Los Angeles, and Washington, D.C.), randomized, controlled psychoeducational intervention study for women following completion of treatment for nonmetastatic breast cancer. Women were recruited to the study with a letter from their physicians, followed by a telephone call from project staff. A detailed description of the Moving Beyond Cancer study methodology and recruitment procedures has been published previously [8, 10]. Institutional review boards at each of the participating universities approved the studies, and all participants provided informed consent. During informed consent, survivors with partners were told that investigators would like to contact partners at a later date, to request their participation in a separate study. Survivors' participation in the Moving Beyond Cancer intervention study was not contingent on providing consent to contact their partners. Participation of survivors and partners was voluntary and not compensated.

Within 4 weeks of completing cancer treatment, Moving Beyond Cancer participants completed a mailed baseline questionnaire and were randomized to one of three intervention arms: pamphlet only (arm A) (1994 National Cancer Institute booklet, "Facing Forward"), pamphlet plus a video describing challenges and coping strategies associated with transition from active treatment (arm B), or pamphlet plus video plus two counseling sessions and a specially developed workbook designed for breast cancer patients at the end of treatment (arm C). After completion of the baseline survey and intervention, investigators invited partners to participate in a study examining partners' perspectives following treatment. Partners did not participate in the psychoeducational intervention. Data were collected via mailed questionnaires approximately 2 months (T1) and 6 months (T2) following survivors' participation in the intervention. Partners were asked to complete study questionnaires without discussing them with the survivors.

Measures

This study focused on three dichotomous outcomes: (1) survivor consent to contact the partner (no/yes), (2) partner completed T1 (no/yes), and (3) partner completed T1 and T2 (no/yes). Survivor data from the baseline questionnaire were used to predict the first two outcomes. Partner data from the T1 questionnaire were used to predict the third outcome.

Demographic Characteristics

Survivor demographics included age, ethnicity (non-Hispanic white or other), family income, level of education, employment status (part or full time/unemployed), Moving Beyond Cancer intervention arm (two dummy-coded variables), and study site (two dummy-coded variables). Partner demographics included age, ethnicity, and employment status.

Cancer Treatment

Survivors reported which treatment(s) they received (i.e., mastectomy versus breast-conserving surgery, chemotherapy, radiation, or endocrine therapy (four dichotomous variables).

Relationship Characteristics

Survivors and partners independently rated their Relationship Satisfaction with the Revised Dyadic Adjustment Scale [11]. This scale contains 14 self-report items that measure agreement on relationship issues and the frequency with which couples engaged in specific behaviors. Items were rated on a variety of Likert-type scales, with a possible score from 0 to 69. Cronbach's alphas were ≥0.89. Length of the relationship in years was provided by the survivor.

Partner support was rated by the survivor on a 1 (not at all) to 5 (extremely) scale with the item, "How supportive has your partner been with respect to your breast cancer experience?" Support from a helpful other was rated by the survivor with the Bolger et al. [4] scale. Survivors were asked an open-ended question, "Think about all the people who know about your diagnosis and treatment. Who currently is the most helpful to you (e.g., spouse/partner, daughter, friend)?" Survivors then answered eight questions about support received from this person. Items included "Provide you with encouragement and reassurance when

you need it" and "Listen to you when you need to talk about things that are important to you." Items were rated on Likert-type scales ranging from 1 (not at all) to 5 (a great deal). Cronbach's alpha was 0.95. Partner-provided support was rated by the partner using the Bolger et al. [4] scale, as a self-rating of the support he provided to the survivor. Cronbach's alpha was .91.

Quality of Life

Survivors and partners rated their own quality of life with the physical component summary and mental component summary of the RAND SF-36 [12]. The physical component summary measured general health, pain, physical functioning, and impairment. The mental component summary measured energy, emotional well-being, degree of social activity, and impairment. Summary scales ranged from 0 to 100. Cronbach's alpha for the scales was ≥0.87.

To complement the broader construct of the mental component summary, we used the Positive and Negative Affect Schedule [13], which contains 10 adjectives that assess positive affect and 10 that assess negative affect. Survivors and partners rated the extent to which they had experienced these emotions in the past 4 weeks on a Likert-type scale ranging from 1 (very slightly/not at all) to 5 (extremely). Cronbach's alphas were ≥0.90 for positive affect and ≥0.86 for negative affect.

Statistical Analyses

Predictors were examined for multicollinearity. Receipt of radiation was collinear with mastectomy versus breast-conserving surgery ($r_s=-0.72$); thus, radiation was not included as a possible predictor. In the analysis that predicted partner completion of the T2 questionnaire, partner T1 mental component summary and partner T1 negative affect were collinear ($r=-0.76$). Because the mental component summary is a broader measure of emotional well-being than negative affect, negative affect was not included as a predictor of T2 questionnaire completion.
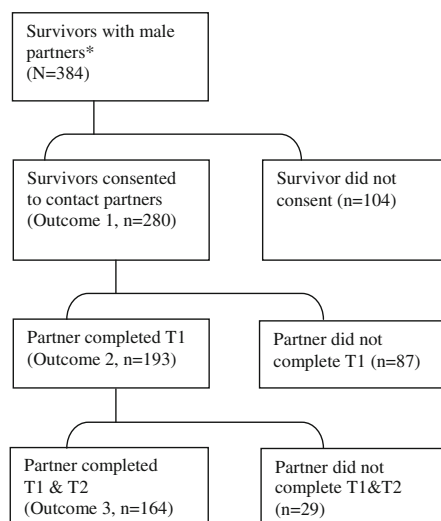
Analyses were conducted with backward stepwise logistic regression as it allowed for a parsimonious final model and was consistent with our aim to determine which demographic, cancer treatment, relationship, or quality of life characteristics were associated with partner participation or study completion. Predicting consent to contact the partner was based on survivors with male partners. Nine survivors had female partners but were excluded because the group was too small to allow for reliable analysis. Sample sizes varied for each outcome (see Fig. 1 flow chart). Partner completion of the T1 questionnaire was predicted for the survivors who provided consent, and completion of the T2 questionnaire was predicted with the partners who the completed T1 questionnaire. Because a less stringent inclusion criterion is recommended for stepwise regression [14], any predictor was removed from the model if $p>0.10$. To control for the effect of the Moving Beyond Cancer study, intervention arms B and C and study site were forced to remain in the equation.

Results

Description of Sample Characteristics and Participation

Of the 384 breast cancer survivors with male partners, 280 (73 %) provided consent for investigators to contact their partner. Of those 280, 193 partners (69 %) completed the T1

Fig. 1 Flow chart of partner recruitment

Note: * Nine survivors had female partners and were not included in the current study because the group was too small for reliable analysis.

questionnaire, and of those 193, 164 (85 %) partners completed both T1 and T2 questionnaires. Table 1 displays descriptive statistics for survivors as well as partners who completed the T1 questionnaire. Survivors and partners reported relationship satisfaction scores similar to norms from nondistressed couples [11]. Survivors reported receiving strong support from their partners, as well as from their primary support person. Survivor and partner mental component summary scores were similar to the general population norms for US women and men (i.e., standardized M= 50, SD=10 [15]), though the survivor physical component summary fell ½ SD below the norm. Both survivors and partners had mean negative affect in the lower quartile of the scale and positive affect above the scale midpoint.

Predictors of Consent and Participation

Table 2 displays results of the logistic regression equations. Backward stepwise logistic regression analysis indicated that only greater income, feeling more supported by her partner, and feeling more supported by a helpful other significantly increased the likelihood that a survivor provided consent to contact her partner.

The backward stepwise logistic regression analysis predicting partner decision to participate with survivor characteristics revealed that greater income and non-Hispanic white ethnicity increased the likelihood of T1 partner participation. Additionally, higher survivor mental component summary and physical component summary were associated

Table 1 Sample characteristics for survivors and partners

Variable (possible range)	Survivors at baseline (n=384) Mean (SD) or frequency	Partners completed T1 (n=193) Mean (SD) or frequency
Demographics		
Age (29–88)	55.85 (10.52)	57.93 (11.39)
Ethnicity	87 % non-Hispanic white	94 % non-Hispanic white
Current employment		
Retired/unemployed/volunteer	44 %	30 %
Part/full time	56 %	70 %
Family income		
Under $30,000	5 %	2 %
$30,001–60,000	21 %	16 %
$60,001–100,000	33 %	36 %
Over $100,000	41 %	46 %
Education		
Less than college	13 %	–
Some college/2-year degree	24 %	–
College degree	35 %	–
Masters/doctoral degree	28 %	–
Cancer treatment		
Breast-conserving surgery	65 %	
Mastectomy	35 %	–
Radiation	68 %	–
Chemotherapy	54 %	–
Endocrine blockade	56 %	–
Relationship variables		
Length of relationship (1–58 years)	26.16 (13.35)	26.34 (13.02)
Relationship satisfaction (0–69)	49.82 (8.78)	50.64 (7.72)
Support from partner (1–5)	4.66 (0.79)	–
Support from helpful other (1–5)	4.02 (0.96)	–
Partner-provided support (1–5)	–	4.03 (0.70)
Quality of life		
Physical component summary (0–100)	45.43 (9.43)	52.67 (7.97)
Mental component summary (0–100)	49.10 (9.81)	50.74 (9.47)
Positive affect (10–50)	33.90 (7.59)	34.81 (7.08)
Negative affect (10–50)	16.73 (5.99)	17.31 (6.96)

Table 2 Backward stepwise regression predicting consent to contact partner and partner participation

Predictor[a]	Consent to contact partner OR (95 % CI)	Partner completed T1 OR (95 % CI)
Income	1.43 (1.09, 1.87)	1.46 (1.06, 1.99)
Ethnicity	–	3.32 (1.40, 7.87)
Partner support	1.78 (1.20, 2.65)	–
Support from helpful other	1.40 (1.78, 2.65)	–
Mental component summary	–	1.07 (1.03, 1.11)
Physical component summary	–	1.04 (1.01, 1.07)
Positive affect	–	0.94 (0.89, 0.99)
Likelihood ratio test	χ^2 (7, N=384)= 56.93, p<0.001	χ^2 (9, N=280)= 30.30, p<0.001

Variables entered in model that did not reach significance: age, employment, education, mastectomy, endocrine blockade, chemotherapy, MBC intervention and site, years in relationship, relationship satisfaction, negative affect

[a] To account for variables inherent to the MBC intervention study, arms B and C, as well as study site dummy variables were forced to appear in the equation; these variables were not associated with study outcomes (p's≥0.11).

with a greater likelihood of partner participation, although higher survivor positive affect was related to a lower likelihood of partner participation.

Partner retention through T2 was predicted with partner T1 data. The overall backward stepwise regression model failed to reach significance, χ^2(6, N=193)=7.55, p=0.27. A chi-square difference test comparing the overall model to the intercept-only model also indicated a nonsignificant result, χ^2(5, N=193)=7.35, p=0.20.

Discussion

This study began with 384 male partners of breast cancer survivors and ended with data from 164 partners, representing 43 % of those eligible. Substantial declines in participation occurred at two time points: when investigators requested the survivor's permission to invite the partner to participate and when partners decided whether to participate. This participation rate is modest but consistent with much of the psycho-oncology literature [16]. Greater income, greater partner support (as perceived by the patient), and greater support from a helpful other (as perceived by the patient) increased the likelihood that a breast cancer survivor would provide consent for investigators to contact her partner. Although partner support may seem to be an obvious predictor, this study provided empirical support that has been lacking in light of the fact that couples are usually

recruited as a dyad. Support from a helpful other also increased the likelihood of consent. Although women were asked to identify who was most helpful during their cancer experience, only 25 % provided an answer, with friends and nonpartner family members (e.g., daughter, sibling) cited most often. Ambiguity remains about the most supportive person for the 75 % of women who did not name someone, and it is possible that many of these women viewed their partners as the most supportive person. Although partner support and support from a helpful other were significantly correlated (r=0.65), they were independently associated with greater likelihood of the survivor's willingness to contact her partner.

With partner support as a face valid predictor of consent, it is notable that relationship satisfaction was not a significant predictor. Relationship satisfaction was significantly associated with partner support (r=0.53) and with support from a helpful other (r=0.69), indicating overlapping, but also unique variance. The measure of relationship satisfaction (Revised Dyadic Adjustment Scale) does not specifically query about feeling cared for or supported in the relationship and is not specific to the breast cancer experience. In two post hoc analyses, we removed partner support and support from helpful other as predictors, but neither relationship satisfaction nor any other predictors gained or lost significance. Our results suggest that feeling supported specifically regarding breast cancer was a more important predictor of survivor willingness for the partner to participate than was general relationship satisfaction.

Higher income was the only characteristic associated with a greater likelihood of both consent and partner participation. SES has been associated with lower participation in cancer trials [17]. Possible explanations for SES discrepancies in the breast cancer literature have been offered, including the negative correlation between SES and disease severity, as well as greater logistical barriers to participation (e.g., inflexible work schedule, inconvenient travel) [17]. However, these reasons are not as relevant to the current study in that all survivors had localized cancer, participation required a minimal amount of time, and questionnaires could be completed at home. Although the reasons for the disparity are unclear, it is apparent that each step of partner recruitment restricted the range of income represented in the final sample.

In addition to income, partners of non-Hispanic white survivors were more likely to complete the first questionnaire than partners of ethnic minorities. Of the 193 partners who completed the T1 questionnaire, 94 % were non-Hispanic white, 3 % African–Americans, 2 % Asian–American, and 1 % Hispanic–American. The underrepresentation of ethnic minorities in cancer research is not a new finding [18], and in order to increase research participation among

ethnic minorities, it must be a designated priority during study design since population-based sampling is unlikely to yield sufficient representation [19]. While more deliberate and extensive recruitment of ethnic minorities is necessary, once ethnic minorities are recruited, additional barriers to participation appear to persist. Further research is needed to identify these barriers and implement strategies for retaining ethnic minority participants.

Finally, survivors with higher physical and mental component summary scores were more likely to have partners who completed the first questionnaire. Better quality of life following treatment may reflect a mindset that the cancer is behind them, which may have helped partners be more willing to participate in a study about the cancer experience. The finding that greater survivor positive affect was associated with decreased likelihood that partners would participate could suggest that a middle ground of emotional well-being is optimal for research participation. That is, after accounting for quality of life, perhaps partners who saw greater positive affect in the survivor did not see a need to participate or may not have wanted to spend time on activities related to the cancer experience.

It is important to consider if the stepped recruitment strategy, which made this study possible, could also limit how well our findings apply to studies in which couples are recruited as a unit or are facing different cancers. In a recent review of psychosocial interventions for couples in which either the husband or wife was affected by cancer [20], the majority of samples were similar to our participants in terms of rate of participation, racial identity, and socioeconomic status. And as noted in that review, authors have suggested differences in participants versus non-participants such as emotional warmth between partners, but lacked data to test this hypothesis. Thus, the current recruitment strategy yielded a participant group that appears reflective of the current literature and allowed for empirical identification of participation factors that are frequently speculated about but unable to be examined.

Although our findings offer empirical support that psycho-oncology research with couples is likely skewed, they require replication. Replication is particularly important when findings are based on stepwise regression analyses. A barrier to replication is that data cannot be collected from individuals who do not consent to participate, suggesting the need for more efficient screening measures prior to recruitment. Given the predictive value found for partner support, researchers might consider using a single item to assess support when screening couples for study inclusion. It would also be beneficial to screen each member of a couple separately for inclusion in a study, in order to examine factors associated with gender or role as patient/survivor or partner. Indeed, it is possible that some partners whose survivors refused consent may have been interested in participating, if given the invitation. Until further research is available, researchers and clinicians should consider the possibility that the current literature perpetuates the underrepresentation of lower income and ethnic minorities in couples' research and fails to include individuals with greater levels of suffering.

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