



Recruitment of breast cancer survivors and their caregivers: implications for dyad research and practice

Angela Robertson Bazzi, PhD, MPH,¹ Melissa A Clark, PhD,² Michael Winter, MPH,³ Yorghos Tripodis, PhD,⁴ Ulrike Boehmer, PhD¹

¹Department of Community Health Sciences, Boston University School of Public Health, 801 Massachusetts Avenue, Crosstown Center, Boston, MA 02118, USA

²Warren Alpert School of Medicine and School of Public Health, Brown University, Providence, RI, USA

³Data Coordinating Center, Boston University School of Public Health, Boston, MA, USA

⁴Department of Biostatistics, Boston University School of Public Health, Boston, MA, USA

Correspondence to: U Boehmer boehmer@bu.edu

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Abstract

Breast cancer survivors' informal caregivers experience adverse health outcomes and could benefit from interventions. Studies of caregivers' participation in research, to date, have assumed heterosexuality. The aim of this study is to identify factors associated with caregiver participation among survivors with diversity in sexual orientation. We recruited breast cancer survivors into a telephone survey and asked them to invite a caregiver. Logistic regression identified factors associated with caregivers' participation. Among 297 survivors, 12 (4 %) had no caregivers, 82 (28 %) refused to provide caregiver information, 203 (68 %) provided caregiver contact, and 167 (56 %) had caregivers participate. Caregiver participation was more likely among sexual minority than heterosexual survivors (aOR: 1.89; 95 % CI: 1.08, 3.32), dyads with higher cohesion, and among caregivers who were partners. Caregiver participation was less likely among survivors with lower education and higher comorbidity. Findings provide insight into recruitment of diverse dyads into cancer survivorship research that will ultimately inform intervention design.

Keywords

Breast cancer, Caregiving, Dyads, Recruitment, Generalizability, Interventions

INTRODUCTION

Among the estimated 3.1 million breast cancer survivors living in the USA, the majority have partners, family members, or friends serving as unpaid, informal caregivers who help them with the activities of daily living [1]. Increasing research and programmatic attention has focused on the physical and psychological well-being of these caregivers [2], who may experience adverse psychological distress at similar levels as cancer survivors themselves due to the range of emotional and instrumental support that they provide. For example, both cancer survivors and their caregivers frequently report elevated stress and fear of cancer recurrence, which have been associated with poor mental and physical health outcomes, decreased quality of life [3], and reduced adherence to follow-up care [4]. Research has also documented the

Implications

• **Practice:** Innovative and targeted outreach strategies are needed to engage diverse groups of breast cancer survivor-caregiver dyads in health promotion interventions.

• **Policy:** Funding is needed for developing evidence-based models to recruit and retain breast cancer survivor-caregiver dyads in research and interventions.

• **Research:** To increase generalizability and relevance of research findings for intervention development, studies must recruit socio-demographically diverse breast cancer survivor-caregiver dyads.

interdependence of mental and physical health within survivor-caregiver dyads [5–7] and shown that dyad-focused approaches to reducing breast cancer patients' depressive symptoms may be more efficacious than individual-oriented approaches [8]. Thus, there is increasing interest in developing dyad-focused research studies and interventions that involve both breast cancer survivors and their caregivers [9].

A central question underlying the development and implementation of dyadic research and interventions involves how to recruit and retain survivors' caregivers, which can be particularly challenging [10]. A recent review of 83 couple-focused cancer research studies revealed large variation in the successful recruitment of caregivers, with the average couples' response rate (i.e., successful engagement of both members of dyads) estimated at 58 % and ranging from 25 to 90 % [11]. However, information necessary for calculating the couples' response rate was only reported in 38 % of studies, raising serious questions about the ability to understand potential participation bias [11]. Historically, epidemiological studies have varied greatly in their ability to recruit representative samples of specific populations, with important concerns regarding the underrepresentation of men, racial/ethnic minorities, and individuals of lower socio-economic and health status [12].

Representativeness may also be limited in couples-focused research, with higher levels of participation being observed among caregivers who were younger and had better physical functioning and mental health, and among dyads with higher relationship satisfaction [13, 14].

Other gaps remain in the breast cancer survivorship and caregiving literature that also raise important questions regarding studies' representativeness. Significantly, the emerging literature on breast cancer survivor-caregiver dyads has focused almost exclusively on heterosexual dyads of female survivors and male caregivers, typically in the context of marriage. Eligibility criteria for most existing dyadic studies have required female survivors to nominate a male spouse or cohabitating partner [14], and some studies have had to exclude women with female partners due to sample size constraints [15]. However, researchers are increasingly recognizing that breast cancer affects all women, regardless of sexual orientation or marital or partnership status. Compared to heterosexual women, sexual minority women, defined as self-identified lesbian and bisexual women and those who prefer female partners [16], may have greater breast cancer risk factors [17–31], incidence [32], and mortality [33]. Thus, the exclusive focus of most breast cancer survivorship and caregiving research on heterosexual women and dyads carries important implications for the generalizability and translational utility of research findings.

Assuming heterosexuality or focusing exclusively on heterosexual women is particularly problematic for research on survivor-caregiver dyads because caregiving can be drastically different and potentially more challenging for sexual minority populations. Compared to heterosexuals, sexual minority cancer survivors and their caregivers experience (and anticipate) sexual and gender prejudice, microaggressions (i.e., commonplace social exchanges that carry disparaging messages), and discriminatory and heteronormative policies within healthcare settings [34]. With the exception of a focused line of research by one team showing that sexual minority breast cancer survivors and their caregivers had similar levels of distress [35] and interdependent fear of cancer recurrence [35, 36], studies, to date, have not explicitly assessed differences in dyads' participation in breast cancer research by sexual orientation. Given the high translational significance of understanding dyad participation in breast cancer survivorship research, the overall objective of this study was to identify factors associated with successful dyad enrollment (i.e., caregiver participation) into a telephone-based study with particular attention to differences in caregiver recruitment between heterosexual and sexual minority breast cancer survivors. After identifying these factors, we discuss considerations for dyad studies needed to ultimately inform evidence-based interventions.

METHODS

Study design and population

From May to July 2012, this dyad study recruited sexual minority and heterosexual women with breast cancer and asked each of these survivors to refer their informal caregiver, which we defined as their spouse or partner (if partnered) or most important support person (if unpartnered). In line with the literature on dyads of cancer survivors and their caregivers [13], we first recruited sexual minority and heterosexual women with breast cancer by re-contacting women enrolled in a previous study [37] and those who were ineligible for a separate study of advanced breast cancer. Eligible women, who had a diagnosis of non-metastatic (stage in situ to III) and non-recurrent breast cancer after age 21, were invited to participate in a telephone interview. After the interview, participating women were asked to put us in contact with their spouse/partner (if currently partnered) or their most important current support person (if unpartnered) so we could invite them to participate in a similarly structured telephone interview. Any caregiver whose contact information was provided was contacted up to 10 times and invited to participate in a telephone interview involving similar questions asked of breast cancer survivors (see measures described below). The Institutional Review Board of Boston University approved all study procedures and participants provided verbal informed consent.

Data collection and measures

We compared women with breast cancer whose caregivers were successfully enrolled to those whose caregivers did not participate using data collected from women with breast cancer only (i.e., this analysis does not include data collected from caregivers themselves). Telephone interviews lasting approximately 45 min assessed socio-demographics, medical information, and other characteristics of described below. The primary dependent variable for this study was caregiver participation (yes/no).

Socio-demographic measures for the breast cancer survivors included age, race, education, employment, health insurance, income, marital status, having a partner, and duration of relationship with spouses/partners or current support persons. We also assessed sexual orientation as a primary independent variable of interest for this study. This measure distinguished between self-reported heterosexual and sexual minority women, who included those who self-reported being lesbian, gay, homosexual or bisexual or reported preferring same-sex partners. Medical and clinical measures included years since breast cancer diagnosis (calculated from the date of diagnosis to the interview date), stage of cancer at time of diagnosis, cancer treatments including type of surgery (e.g., lumpectomy, mastectomy only, mastectomy, and reconstruction), radiation, chemotherapy, and hormone therapy (e.g., Tamoxifen or aromatase inhibitors), and number of other comorbidities [38]. Caregiver and survivor-caregiver dyad

measures included caregiver gender, type of relationship with caregiver (spouse/partner or other support person), duration of relationship (from which we also determined the proportion of life involved in the relationship), perception of how breast cancer treatment affected the closeness of the relationship [39], and dyadic cohesion derived from the dyadic assessment scale [40] modified for unpartnered women to refer to her nominated caregiver instead of her “partner.”

Data analysis

Descriptive statistics first summarized characteristics of women who reported that they did ($n=285$) and did not ($n=12$) have a caregiver. Then, to compare characteristics of women with breast cancer whose caregivers were successfully enrolled ($n=118$) to those whose caregivers did not participate ($n=167$), bivariate analyses were conducted using t tests and chi-square tests. Variables with significance of $p<0.10$ in the bivariate analyses were considered for inclusion as independent variables in a stepwise logistic regression model. Before regression analyses were performed, Spearman correlation coefficients among the pool of potential independent variables were examined, and when any pair of variables had a correlation coefficient of 0.50 or greater, one variable was eliminated in an attempt to prevent multicollinearity. The resulting final set of independent variables were entered into a stepwise logistic regression model to identify factors independently associated with caregiver participation using significance of $p<0.10$ for variables to enter and stay in the model. All analyses were performed using SAS v9.3.

RESULTS

Characteristics of breast cancer survivors and caregivers

Of the 297 breast cancer survivors who enrolled in the study, 203 (68 %) provided caregiver contact information, 82 (28 %) refused to provide caregiver contact information, and 12 (4 %) reported they did not have a caregiver. Among the 203 caregivers for whom contact information was provided, 167 (82 %) agreed to participate, 25 (12 %) exceeded the number of contact attempts (i.e., passive refusals), 7 (3 %) responded but were unable to participate before the end of the study period, and 4 (2 %) refused to participate. Of the 203 caregivers for whom we had contact information, 167 (82.3 %) participated. The caregiver response rate was slightly higher among caregivers of sexual minority than heterosexual women (86 vs. 74 %, $p=.0552$) and among caregivers who were spouses/partners compared to other support persons (85 vs. 69 %, $p=.0264$).

Among the 12 women who reported not having a caregiver, characteristics were similar to those of the 285 women who reported having a caregiver except that more were sexual minority women (92 vs. 67 %), had never been married (73 vs. 33 %), and had more comorbidities (mean 4.0 vs. 2.8; data not shown in

tables). The remaining results refer to the 285 breast cancer survivors who reported having a caregiver.

Table 1 compares characteristics of women who self-reported having a caregiver by their caregiver’s participation in this study. Caregiver participation did not differ by age or race/ethnicity. Overall, women with breast cancer were 58 years old on average (mean: 9.7 years) and most were white (91 %). Women with lower levels of education (i.e., some college or less) were less likely to have a caregiver participate, although our sample was highly educated with the majority graduating from college or completing graduate school. Compared to women whose caregivers did not participate, more women with caregiver participation were married or partnered, reported sexual minority status, were currently employed, and had higher income. Women with and without caregiver participation were similar with respect to medical and clinical measures except that women with caregiver participation had less comorbidity than those without caregiver participation.

Several caregiver and dyad measures differed between women with and without caregivers participating. Compared to non-participating caregivers, participating caregivers were more likely to be female (74 vs. 61 %, $p=.023$) and spouses/partners than other support persons (85 vs. 73 %, $p=.011$). Women with breast cancer reported shorter relationships with participating caregivers than non-participating caregivers (mean 14 vs. 19 years, $p=.004$) but higher dyadic cohesion (mean 18 vs. 17 points, $p<.001$). More women with participating caregivers also reported that breast cancer brought their relationship closer (72 vs. 53 %, $p=.005$).

We then further examined women’s relationships with caregivers (results not shown tables). Overall, women reported that their caregivers were legal spouses (44 %), unmarried cohabitating partners (25 %), friends (8 %), siblings (5 %), children (3 %), or other support persons (15 %). There were several notable differences in caregiver relationship type by survivor sexual orientation, with more heterosexual than sexual minority women reporting that their caregivers were legal spouses (78 vs. 27 %) and more sexual minority than heterosexual women reporting that their caregivers were unmarried cohabitating partners (35 vs. 3 %, $p<.0001$) for overall differences in caregiver type by sexual orientation.

Factors associated with caregiver participation

The final set of variables entered into the stepwise logistic regression included sexual orientation, education, number of comorbidities, dyadic cohesion, whether the caregiver was a spouse/partner or other support person, employment, proportion of life in relationship/known caregiver, and how breast cancer diagnoses affected dyads’ relationships. Table 2 presents the final model of five factors independently associated with caregiver participation. Sexual minority women had 1.89 times the odds of having

Table 1 | Characteristics of breast cancer survivors without and with caregiver participation (n = 285 survivors)

Variable	Overall sample (n = 285)	Survivor without caregiver participation (n = 118)	Survivor with caregiver participation (n = 167)	p value
SOCIO-DEMOGRAPHICS				
Age at interview (in years)	N	118	167	0.2152
	Mean (SD)	58.1 (9.7)	59.0 (10.8)	57.5 (8.8)
	Median (IQR)	58.0 (51.0, 65.0)	59.0 (51.0, 66.0)	58.0 (51.0, 64.0)
Race: White vs. other	N (%)	27 (9.5)	12 (10.2)	15 (9.0)
	White	258 (90.5)	106 (89.8)	152 (91.0)
Sexual orientation	N (%)	93 (32.6)	50 (42.4)	43 (25.7)
	Heterosexual/straight	192 (67.4)	68 (57.6)	124 (74.3)
	Lesbian/gay/homosexual/bisexual	1	1	0
	Missing	1	1	0
Highest level of education completed	N (%)	14 (4.9)	8 (6.8)	6 (3.6)
	< High school/high school/technical training	37 (13.0)	24 (20.5)	13 (7.8)
	Some college	113 (39.8)	48 (41.0)	65 (38.9)
	Graduated college	120 (42.3)	37 (31.6)	83 (49.7)
	Completed grad school	1	1	0
Currently employed for salary or wages	N (%)	113 (39.8)	55 (47.0)	58 (34.7)
	No	171 (60.2)	62 (53.0)	109 (65.3)
	Yes or self-employed	1	1	0
Currently has health insurance	N (%)	3 (1.1)	1 (0.9)	2 (1.2)
	Missing	281 (98.9)	116 (99.1)	165 (98.8)
	No	18	12	6
	Yes	72 (27.0)	37 (34.9)	35 (21.7)
Individual income before taxes	N (%)	91 (34.1)	32 (30.2)	59 (36.6)
	Less than \$30 K	104 (39.0)	37 (34.9)	67 (41.6)
	\$30 K ≤ \$70 K	3	2	1
	\$70 K or more	93 (33.0)	40 (34.5)	53 (31.9)
Current (legal) marital status	N (%)	141 (50.0)	51 (44.0)	90 (54.2)
	Never married	48 (17.0)	25 (21.6)	23 (13.9)
	Married	57 (20.0)	32 (27.1)	25 (15.0)
	Separated, divorced, widowed	228 (80.0)	86 (72.9)	142 (85.0)
Currently has a spouse or partner	N (%)	57	32	25
Currently lives with spouse or partner	N (%)	57	32	25

	No	15 (6.6)	7 (8.1)	8 (5.6)
	Yes	213 (93.4)	79 (91.9)	134 (94.4)
MEDICAL AND CLINICAL MEASURES				
Time since diagnosis (in years)	N	284	118	166
	Mean (SD)	6.9 (3.7)	6.9 (3.7)	6.9 (3.7)
	Median (IQR)	7.2 (3.5, 9.7)	7.3 (3.7, 9.8)	7.2 (3.4, 9.4)
Stage of cancer at time of diagnosis	N (%)	3	2	1
	Missing	62 (22.0)	28 (24.1)	34 (20.5)
	In situ (same as DCIS: ductal carcinoma)			
	Stage I	97 (34.4)	33 (28.4)	64 (38.6)
	Stage II	95 (33.7)	43 (37.1)	52 (31.3)
	Stage III	28 (9.9)	12 (10.3)	16 (9.6)
Breast cancer treatment	N (%)	246 (86.3)	100 (84.7)	146 (87.4)
	Lumpectomy	21 (7.4)	11 (9.3)	10 (6.0)
	Mastectomy only	18 (6.3)	7 (5.9)	11 (6.6)
	Mastectomy and reconstruction	92 (32.3)	37 (31.4)	55 (32.9)
Radiation	N (%)	193 (67.7)	81 (68.6)	112 (67.1)
	No	133 (46.7)	51 (43.2)	82 (49.1)
	Yes	152 (53.3)	67 (56.8)	85 (50.9)
Chemotherapy	N (%)	1	1	0
	Missing	76 (26.8)	28 (23.9)	48 (28.7)
	No	208 (73.2)	89 (76.1)	119 (71.3)
Hormone therapy / aromatase inhibitors	N (%)	278	116	162
	Yes	2.8 (1.8)	3.3 (1.9)	2.5 (1.6)
Number of comorbidities	Mean (SD)	3.0 (2.0, 4.0)	3.0 (2.0, 4.0)	2.0 (1.0, 3.0)
	Median (IQR)			
CAREGIVER AND SURVIVOR-CAREGIVER DYAD MEASURES				
Gender of caregiver	N (%)	90 (31.6)	46 (39.0)	44 (26.3)
	Male	195 (68.4)	72 (61.0)	123 (73.7)
	Female	228 (80.0)	86 (72.9)	142 (85.0)
Spouse/partner or other caregiver	N (%)	57 (20.0)	32 (27.1)	25 (15.0)
	Spouse/partner	284	117	167
	Other	284	117	167
Duration of relationship (years known) caregiver	N	284	117	167
	Mean (SD)	24.4 (16.4)	27.8 (18.9)	22.0 (14.0)
	Median (IQR)	21.0 (12.0, 32.5)	25.0 (14.0, 40.0)	20.0 (12.0, 30.0)
Proportion of life in relationship with (or known) caregiver	N	284	117	167
	Mean (SD)	0.4 (0.2)	0.5 (0.3)	0.4 (0.2)
	Median (IQR)	0.4 (0.2, 0.6)	0.4 (0.2, 0.6)	0.4 (0.2, 0.5)
How has breast cancer and treatment affected the relationship with the caregiver?	N (%)	5	1	4
	Missing	179 (63.9)	62 (53.0)	117 (71.8)
	Brought you closer			

Table 1 (continued)

Distanced you Had no effect	21 (7.5)	12 (10.3)	9 (5.5)
	80 (28.6)	43 (36.8)	37 (22.7)
<i>N</i>	283	117	166
Dyadic cohesion with caregiver	17.4 (3.2)	16.6 (3.4)	17.9 (2.9)
	18.0 (16.0, 20.0)	17.0 (15.0, 20.0)	18.0 (16.0, 20.0)
Mean (SD)			
Median (IQR)			

caregivers participate compared to heterosexual women (95 % confidence interval [CI]: 1.08, 3.32). Women who completed some college only were less likely to have caregivers participate than women who completed graduate school (adjusted odds ratio [aOR]: 0.27; 95 % CI: 0.11, 0.63). Women with higher comorbidity were less likely to have caregivers participate (aOR: 0.84 per 1-unit increase in comorbidities; 95 % CI: 0.72, 0.97). Women who reported higher dyadic cohesion had higher odds of caregiver participation (aOR: 1.11 per 1-point increase in dyadic cohesion; 95 % CI: 1.01, 1.21). Finally, women whose caregivers were spouses/partners had 1.86 times higher odds of having their caregivers participate compared to women whose caregivers were other support providers (95 % CI: 0.89, 3.86).

DISCUSSION

We explored caregiver participation in a sample of breast cancer survivors and assessed differences between survivors whose caregivers (spouses/partners or other support persons) did and did not participate in a telephone-based research study. Existing cancer survivorship research with dyads of survivors and caregivers [13, 14], which has identified some potential biases in dyad participation [11], have assumed heterosexuality. However, caregiving experiences and potential barriers to dyad participation in research studies and interventions likely differ between sexual minority and heterosexual populations due to the experience, perception, and anticipation of social stigma and discriminatory policies [34]. To date, this study is the first to our knowledge to assess caregiver availability and participation in a cancer survivorship research study that specifically targeted sexual minority women. Our findings pertaining to caregiver participation carry important implications for dyad-focused study design, recruitment, and retention, all of which may ultimately improve the quality of dyad-focused interventions that may be more efficacious than individual approaches to improving mental and physical health among individuals with chronic illness and their caregivers [9].

Among the women with breast cancer in our sample who had spouses/partners or other support persons, the majority (58 %) of these informal caregivers were successfully recruited and enrolled into our study. Despite the high level of sexual minority participation in our sample, which differs dramatically from other study populations, this proportion of dyad participation falls within the range of 25–90 % identified in other couple-focused cancer studies [11]. This demonstrates the feasibility of recruiting breast cancer survivor-caregiver dyads with diversity in sexual orientation into a telephone-based research study.

In our sample of survivors, sexual minority women were more likely to report that they did not have a caregiver available to them, possibly reflecting social isolation and vulnerability [34]. However, among survivors who did have caregivers available, the odds of

Table 2 | Factors associated with breast cancer survivors' caregiver participation ($n = 274$ survivors)

Variable	Adjusted odds ratio ^a (95 % CI)	<i>p</i> value
Sexual orientation: Sexual minority woman Heterosexual/straight	1.89 (1.08, 3.32) 1.00 (REF)	0.0259
Education:	0.61 (0.17, 2.16)	0.0202
High school/technical school or less	0.27 (0.11, 0.63)	
Some college	0.58 (0.32, 1.03)	
Completed college	1.00 (REF)	
Completed graduate school		
Number of comorbidities (per 1-unit increase)	0.84 (0.72, 0.97)	0.0211
Dyadic cohesion (per 1-point increase)	1.11 (1.01, 1.21)	0.0356
Caregiver is:	1.86 (0.89, 3.86)	0.0976
Spouse/partner	1.00 (REF)	
Other		

^a Note: Stepwise selection used significance level criteria, significance level for entry and stay set at $p = 0.10$

The following variables were included in the stepwise model but did not meet the criteria for entry into the model: employment, proportion of life in relationship/known caregiver, how has breast cancer diagnosis affected relationship

participation were twice as high for caregivers of sexual minority women than for caregivers of heterosexual women. With most caregivers of sexual minority women in our sample being female, and sexual orientation and caregiver gender thus being highly correlated, we are unable to separate the effects of sexual orientation and caregiver gender. As described in the caregiving literature, caregivers who participate in dyad studies are more likely to be female [13]. Nevertheless, this study implies that once sexual minority women are enrolled and given the option of providing contact information for a spouse/partner or other support person, they are likely to have informal caregivers participate. Our other findings, including individual and dyad characteristics related to caregiver participation, are also consistent with previous research in predominantly heterosexual study populations or assuming heterosexuality [11, 13, 14].

First, variables pertaining to the socio-economic and health status of breast cancer survivors were associated with the likelihood that caregivers would participate in our study. Although the vast majority of our sample had high levels of education (e.g., completing college and graduate school), survivors with lower education were less likely to have caregivers participate. This finding extends research on recruitment and retention of individual breast cancer survivors [41] and may reflect response biases that have been consistently observed throughout epidemiologic [12] and breast cancer literature [15, 41, 42]. Similarly consistent with previous research, we found that survivors with higher numbers of comorbidities were less likely to have caregivers participate, which may reflect time constraints or lower quality of life among caregivers [14, 15]. In addition to the study design and recruitment considerations discussed below, these individual characteristics of survivors that relate to their caregivers' participation should be carefully assessed as potential sources of participation bias in future dyad-focused research and practice.

Second, other characteristics of survivor-caregiver dyads were also associated with the likelihood of caregiver participation in our study. It should be noted that, based on our findings, relationship duration may not be predictive of caregiver participation. However, dyadic cohesion, an indicator of relationship quality, was positively associated with caregiver participation in our sample, suggesting that dyads with better relationship functioning or support may be better represented in studies and programs. These associations have been identified in studies with heterosexual couples [13, 15] and are significant because relationships with worse cohesion likely experience different needs for, and possibly benefits from, dyad-focused interventions. Finally, while controlling for dyadic cohesion and all other variables in our final model, being married or partnered was independently and positively associated with caregiver participation, highlighting another factor that should be assessed as a potential source of participation bias in dyad-focused studies. Assessing and adjusting for these factors, while also enhancing efforts to obtain more representative study samples, will be critical for understanding and addressing cancer-related and other health disparities.

Taken together, our findings suggest several avenues for investigating methods to improve recruitment and possibly retention of caregivers and dyads with particular characteristics. For example, more targeted outreach could be directed toward the caregivers of breast cancer survivors with lower socio-economic and health status. Particularly for caregivers of survivors with multiple comorbidities, economic and time constraints may reduce the appeal of participating in intensive in-person research or intervention sessions. Web-based and other alternative approaches to increasing the convenience of participation for these dyads should be explored [43]. Research is also needed to better understand how to reach dyads with poor relationship functioning and caregivers who are non-partnered support persons. These particular dyads may represent a population with the potential to gain

significant benefit from dyad interventions [9]. Promoting dyadic cohesion and intimacy has been shown to improve psychological adaptation to cancer and improved well-being [44]. More personal or individual recruitment and administration of research and intervention activities could be explored for dyads with less cohesion or intimacy.

These recommendations should be considered in light of several limitations to our study. First, due to our innovative study design in which breast cancer survivors of different sexual orientations were sampled and invited to provide their caregivers' contact information, there was high correlation between several variables that prevented us from disentangling the effects of caregiver gender and sexual orientation. To better understand the effects of caregiver gender and role, future research should allow enrollment of informal caregivers irrespective of marital/partnership status or relationship type. Second, our sample lacked diversity in other domains (e.g., race/ethnicity), and unlike other studies, we did not identify significant effects of age on caregiver participation [45]. Research with larger samples and more diverse dyads with different types of health conditions is needed to increase generalizability and explore the role of intersectionality in caregivers' and dyads' experiences [46]. We used telephone-based methods; future research should thus explore participation levels with different methods of recruitment, enrollment, and study or program implementation. In particular, studies are needed to identify factors associated with participation in intervention studies in which the levels of required commitment and perceived benefit may differ. Third, we identified factors associated with dyads' initial enrollment into a cross-sectional research study; longitudinal research is needed to understand predictors of retention over time. Finally, with only 12 women reporting that they did not have a caregiver available to them, we were unable to identify statistically significant differences between women with and without caregivers, which will also be important to consider for the development and implementation of dyad- and individual-focused interventions.

Despite these limitations, as an early investigation of breast cancer survivor-caregiver dyad participation in a telephone-based research study, our findings provide important insight into the recruitment of diverse dyads into cancer survivorship research that will ultimately inform interventions. Not only did we demonstrate the feasibility of recruiting a sample of breast cancer survivors and caregivers of different sexual orientations, but we also identified several factors (e.g., survivor socioeconomic and health status, relationship quality and type) that may be related to successful caregiver enrollment and should be considered as potential sources of response bias. Our findings support the conclusions of other investigators that more intensive, targeted, and

innovative recruitment efforts are needed for dyads and caregivers who may be harder to reach yet stand to benefit the most from interventions.

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Compliance with ethical standards

Conflict of Interest: Authors Bazzi, Clark, Winter, Tripodis, and Boehmer declare that they have no conflict of interest.

Human and animal rights and informed consent: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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