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ORIGINAL PAPER

Evaluation of approaches to recruitment of racially and ethnically diverse breast cancer patients from an integrated health care setting for collection of observational social network data

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Abstract

Purpose We compared approaches to recruitment of diverse women with breast cancer in a study designed to collect complex social network data.

Methods We recruited 440 women from the Kaiser Permanente Northern California population newly diagnosed with breast cancer, either in person at a clinic, by email, or by mailed letter. In clinic and mail recruitment, women completed a brief 3-page paper survey (epidemiologic data only), and women had the option to complete a separate, longer (30–40 min) personal social network survey online. In email recruitment, we administered epidemiologic and personal social network measures together in a single online survey. In email and mail recruitment, we limited the sample of non-Hispanic white (NHW) women to 30% of their total. We used descriptive analysis and multinomial logistic regression to examine odds of recruitment vs. mailed letter.

Results Women responded to the social network surveys on average 3.7 months post-diagnosis. Mean age was 59.3 (median = 61.0). In-person clinic recruitment was superior with a 52.1% success rate of recruitment compared with 35.6% by mail or 17.3% by email ($\chi^2 = 65.9$, $p < 0.001$). Email recruitment produced the highest completion rate (82.1%) of personal network data compared with clinic (36.5%) or mail (28.7%), ($\chi^2 = 114.6$, $p < 0.001$). Despite intentional undersampling of NHW patients, response rates for Asian, Hispanic, and Black women by email were lower. However, we found no significant differences in recruitment rates by race and ethnicity for face-to-face clinic recruitment vs. by letter. Letter recruitment produced the highest overall response.

Conclusion Mailed letter was the best approach to representative recruitment of diverse women with breast cancer and collection of social network data, and further yielded the highest absolute response.

Keywords Race · Ethnicity · Recruitment · Breast cancer · Social networks

Introduction

Critical to the promotion of health equity is the recruitment of persons from racial and ethnic minority groups in health research. However, representative recruitment is challenging due in part to socioeconomic barriers and mistrust in healthcare settings. In breast cancer, recruitment is made further challenging by the lower proportions of Black, Asian, and Hispanic women in the population, lower incidence of breast cancer relative to non-Hispanic White (NHW) women, and greater disease severity (later stage disease and a higher likelihood of comorbidity).

Recent discussion has centered on augmenting recruitment of persons from racial and ethnic minority groups, who

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are underrepresented in research, into cancer clinical trials [1]. Representative recruitment into observational cancer studies is also needed. Strategies to augment recruitment in research have included oversampling [2, 3], monetary incentives [4], face-to-face (‘warm handoffs’) methods [5, 6], passive but targeted methods of recruitment [7, 8], race- and cultural-concordant recruiters [5, 9, 10], personalization and targeting of messages [11], community-based recruitment (e.g., religious settings, local newsletters and businesses, community organizations) [12, 13], follow-up phone calls [14], and timed incentives [15], among strategies considered.

Understanding more about the impact of social relationships on management of treatment and outcomes is important to understanding how to design social network interventions in cancer survivors. However, there have been no published studies about recruitment of participants in breast cancer research for the collection of complex social network data. The current study addresses this gap in the literature.

We began recruitment of women diagnosed with breast cancer as a part of a pilot study to collect epidemiologic and personal social network data in breast cancer patients diagnosed in a health care setting. Additional funding to examine how structural differences in the social networks of Black and White women influenced differences in breast cancer treatment and outcomes, prompted us to evaluate different approaches to augment recruitment in terms of the largest rates and numbers recruited, representative recruitment, and completion of both epidemiological and personal social network data. Our overall goal was to achieve population-representative recruitment and maximize the collection of social network data whether epidemiologic or egocentric though we further wanted to test strategies to augment the collection of personal social network data since it affords more in-depth information on social networks. Methods we tested included oversampling, face-to-face clinic recruitment, email, and mail recruitment.

Methods

INSIGHT-BC study

The Investigating Network Support in Gaps in Health and Treatment-Breast Cancer (INSIGHT-BC) Study began as a pilot study funded by the National Cancer Institute (PI: Kroenke, K07CA187403) which was designed to collect personal social network and epidemiologic social network data in women diagnosed with invasive breast cancer. The American Cancer Society provided additional funding to do mixed methods work on social networks and breast cancer treatment in Black and White women. This enabled us to extend recruitment (PI: Kroenke, RSG-16–167-01-CPPB) for the quantitative portion of the study; the result of these efforts is reported here.

Study protocols and training

We generated study protocols in accordance with practices associated with the collection of personal social network data. One of us (DK) assisted with access to the EgoWeb 2.0 software and trained KPNC staff in the generation of questions and collection of data using this method. The KPNC Division of Research implemented EgoWeb 2.0 using a Linux stack application server with MySQL Enterprise serving as the database. EgoWeb 2.0 is software designed to support in-depth collection of data on personal (egocentric) social networks. MySQL is an open-source relational database management system that supports EgoWeb 2.0. Customized security protocols were implemented to supplement native authentication as required by the parent KPIT Technology Risk Office to ensure HIPAA compliance. We developed two versions of an online survey described below – one to collect personal social network data and a second to collect both epidemiologic and personal social network data. One of us (EK) tested the online survey to ensure the technology was working according to specification.

Participants and recruitment

Participants for the study were recruited from Kaiser Permanente Northern California (KPNC) oncology clinics within 100 miles of Oakland, CA between November 2017 and May, 2021.

We identified eligible participants through electronic health records and through the KPNC Breast Cancer Tracking System (BCTS). BCTS is a specialty care tracking program designed to ensure timely follow-up and improve the quality of breast and other hereditary high-risk cancer care for our members. Tracking ensures completion of abnormal breast imaging and biopsy work-ups, breast cancer treatment, and surveillance for members with breast cancer and those at increased risk. Eligible participants included women diagnosed with stages I–IV invasive breast cancer within the year prior to recruitment who were 21–80 years of age and English speaking. As indicated, recruitment was conducted in two phases: (1) a pilot phase (11/2017–2/2019) funded by a career development award in which a research assistant recruited all women face to face who attended clinic at the Oakland Medical Center, and (2) a second phase (6/2019–5/2021), funded by the American Cancer Society, in which we shifted our goals to augment recruitment and ensure racial and ethnic representation.

Methods designed to augment recruitment of racial and ethnic minority women

Because of the success of the Pathways Study, an observational cohort of women diagnosed with invasive breast cancer recruited in the Kaiser Permanente Northern California setting, in recruiting racial and ethnic minority women with breast cancer [2], we similarly oversampled these women by recruiting all racial and ethnic minority and 30% NHW women. We evaluated, in succession, face-to-face recruitment in the clinic, email recruitment, and then recruitment by letter. Recruitment methods are described below and summarized in Table 1.

Clinical recruitment

In the clinical setting during the surgeon visit following diagnosis, a breast care coordinator at the Oakland Medical Center, informed of the goals of the study, asked patients if they would like to participate in a ‘study about how women’s social supports affect their treatment after a diagnosis of breast cancer’ and introduced interested participants in a “warm hand-off” to the study team’s research assistant who was waiting in a conference room to obtain informed consent and administer the 3-page paper epidemiologic survey with questions on demographics and epidemiologic measures of social ties, social support, and social strain. Approximately two to three women attended clinic per week. After completing the short survey, participants were provided the option to participate in an additional, longer, online personal network survey at a later time using the EgoWeb 2.0 platform in which they could obtain a $25 gift card for completion of the survey. A link was sent by email approximately two months after the paper survey to participants who indicated they were willing to take the online portion of the survey; instructions for completing the survey were provided online. The time to complete the epidemiologic survey was ~ 2–3 min; time to completion for the personal social network survey (described below under Personal social network assessment) was ~ 30–45 min.

We noted good representation of Black, Hispanic, and Asian women among those recruited in the clinic. However, we discontinued face-to-face recruitment because we were unable to recruit sufficiently high numbers of women given the limited number of newly diagnosed women attending clinic each week in Oakland and limited resources to expand recruitment to other KPNC sites. We also noted early in the study a significantly higher proportion of women who were socially integrated (vs. isolated) than expected among those recruited in person, based on a brief social network index [16]. Finally, moving away from face-to-face recruitment was eventually made further necessary by COVID-19 pandemic restrictions against in-person contact in observational research.

Email recruitment

We subsequently conducted recruitment by email of women diagnosed with breast cancer from all of KPNC within 100 miles of Oakland. We identified patients through electronic health records and through the KPNC BCTS. We initially sent an email to potentially eligible patients’ doctors requesting that they should let us know if the patients should not be asked to participate. If the doctors did not respond within two weeks, a research assistant sent eligible patients a recruitment email with a link to the EgoWeb 2.0 survey and then followed up one week later with a phone call if the patient did not respond. A research assistant called

Table 1 Recruitment methodology

Sequence	Description	Oversampling	Three-page epidemiological survey	Monetary incentive for epi survey*	30 min personal social network survey	RA** follow-up by phone
Clinic (Face-to-face)	Warm hand-off from BCC** to RA**; could decline with BCC	No	Paper	No	EgoWeb 2.0 online	No
Email	Letter sent by email, link to online EgoWeb 2.0 survey sent to participants who replied	Yes	Online; could end administration after the epi survey	No	EgoWeb 2.0 online, paired with epi survey	Yes
Letter	Mailed letter, postage paid for return of paper survey link sent by email	Yes	Paper	Part 1: No Part 2: $10 gift card	EgoWeb 2.0 online	No

[*] All participants received a $25 incentive (gift card) for completing the personal social network assessment

[**] Breast care coordinator (BCC); research assistant (RA)

participants up to three times who did not respond to recruitment attempts.

In recruitment by email, the epidemiologic survey was included with and preceded the personal social network survey in the online administration. Participants were given the option to complete just the epidemiologic survey or to complete both the epidemiologic and personal social network surveys.

Recruitment by mail

We identified eligible participants through BCTS. After identifying potential participants, we asked clinicians to indicate any reservations about their inclusion. After waiting two weeks, we sent women a recruitment letter by mail along with the 3-page paper epidemiologic survey. As part of the mailing, which included a consent form and the paper survey, women were asked whether they were interested in completing the longer, online personal social network assessment. Those who replied to the mailing and indicated interest in the online survey were provided a link by email. We discontinued follow-up calls among nonparticipants given the large who received mailed letters and staff attrition. We started recruitment by mail in June of 2020. Originally, women were not offered compensation for the short survey. To augment recruitment, in January 2021, we began offering women a $10 monetary incentive (gift card) for completing the short survey regardless of completion of the EgoWeb 2.0 personal social network assessment. After June 2021, we stopped recruitment and the personal social network survey was taken offline.

The study protocol and multiple modifications were approved by the KPNC institutional review board. Recruitment methods are summarized in Table 1.

Data collection

Demographic and clinical characteristics.

Data on age, race (to facilitate recruitment), AJCC cancer stage, and hormone receptor status were gathered from the KPNC electronic health record (EHR). Participants reported their race and ethnicity and educational level by survey.

Epidemiologic social network variables

Social network index

Participants provided information on marital status, number and frequency of contact with close friends and relatives, religious service attendance, and participation in volunteer work. We combined these using a previously published *epidemiologic* social network index [16] to measure level of social integration.

Social support

We used a modified, six-item version of the Medical Outcomes Study Social Support (MOS-SS) survey [17] to assess perceived social support, including an additional item to assess ‘positive social interaction’ [18]. Participants were asked how often they had someone to provide different types of social support including, for example, “someone you can count on to listen to you when you need to talk” or “someone who shows you love and affection.” Responses ranged from “none of the time” to “all of the time,” with values from one to five points, respectively. The level of social support was computed as the sum of these values and ranged from 7 to 35 points.

Social strain

We measured social strain with the four items used in the Women’s Health Initiative Study [19] of the original Antonucci scale [20], which asked how many people who are important to them get on their nerves, ask too much of them, do not include them, and try to get them to do things they do not want to do. Responses included five response options ranging from none to all, and the score ranged from 4 to 20 points.

Loneliness

Starting with recruitment by email, we asked women the 3-item UCLA loneliness survey [21, 22] which asked women how often they feel they lack companionship, feel left out, or feel isolated from others. Response included three response options ranging from hardly ever to often, and the score ranged from three to nine points.

Personal social network assessment

Using the EgoWeb 2.0 software which was integrated within the online KP environment, we asked participants to list 15 people in their personal network with whom they had contact in the past year (i.e., their “alters”), focusing on time since diagnosis. Participants provided information about alters including demographic characteristics (age, gender, race/ethnicity), characteristics of the relationship (e.g., nature of relationship, length of acquaintance, closeness, frequency of contact, whether caregiving was provided, types of social support provided by the alter, and relationship strain or burden). Participants provided further information about alters’ involvement in their breast cancer treatment (whether they accompanied them to a doctor’s appointment, talked about cancer treatment, influenced decisions about treatment, made it easier (or harder) to start or continue treatment, or provided support in a way that made things more difficult and if so, how). The survey asked patients about other alter characteristics (extent of healthy lifestyle, highest level of education). Finally, they reported how well each unique pair of alters knew each other (not at all, a little, well). The EgoWeb 2.0 software produced visualizations of the participant's social networks and participants could provide further detail about their relationships and support upon seeing the diagram. The software generated values for multiple structural and alter-level personal network variables.

Statistical analysis

We evaluated numbers and proportions who completed surveys by method of recruitment. We conducted analysis of covariance with age adjustment to evaluate characteristics of participants by race and ethnicity. We used multinomial logistic regression (SAS PROC LOGISTIC) to evaluate odds of recruitment relative to mailed letter in post hoc analysis.

Results

Recruitment

Of 1751 women who were invited to participate, we successfully recruited 440 patients who completed the 3-page epidemiologic survey. Of those participants, 236 (53.6%) also completed the personal social network assessment using EgoWeb 2.0. Clinical recruitment was superior overall with 52.1% success rate of recruitment compared with 35.6% by mail or 17.3% by email ($\chi^2 = 65.9$, $p < 0.001$) for an overall response rate of 25.1%. Of the recruited women, email recruitment resulted in the highest response to the epidemiologic survey (44.3% of all responses vs. 38.9% by letter and 16.8% in the clinic) and the highest completion rate (82.1%) of personal network data compared with clinic (36.5%) or mail (28.7%), ($\chi^2 = 115.6$, $p < 0.001$) (Table 2). Our recruitment rate did not change with the addition of the $10 gift card incentive (data not shown).

Recruitment by race and ethnicity

By oversampling, we successfully recruited a higher percent of Black women (14% vs. 7%) compared with their representation in the KPNC breast cancer population. However, Hispanic (6% vs. 12%) and Asian women (10% vs. 14%) were underrepresented [23].

We were not able to assess success of clinical recruitment by race against those invited into the study since the research assistant was not provided information about those who declined participation. However, among those recruited, we were equally likely to recruit Black, Asian, and Hispanic women face to face in the clinic and by letter though we were less successful in recruiting Black (OR = 0.53, 95% CI: 0.28–0.998), Asian (OR = 0.35, 95% CI: 0.15–0.79), or Hispanic (OR = 0.28, 95% CI: 0.10–0.78) women by email vs. letter. We were also less successful in recruiting older women (OR = 0.97, 95% CI: 0.96–0.99, continuous age) by email vs. letter (Table 3).

Black, Asian, and Hispanic women were more highly represented among those who completed the epidemiologic survey vs. the personal social network assessment and the general population (Table 4).

Study population characteristics

Women responded to the epidemiologic and/or personal social network measures on average 3.7 months following diagnosis. Mean age was 59.3 (median = 61.0) though NHW

Table 2 Recruitment for INSIGHT-BC

	Approached	Completed personal social network (PSN) surveys	Completed PSN within strategy*	Completed PSN by strategy	Completed epidemiologic survey only	Percent of total enrolled	Completed epi only surveys	Total enrolled**	Completed surveys, all
		N, % of approached	%	%	N, % of approached	%	%	N, % of approached	%
Total	1751	236 (13.5)	53.6	100	204 (11.9)	46.4	100	440 (25.1)	100
Strategy									
Clinic	142	27 (19.0)	36.5	11.4	47 (33.1)	63.5	23.0	74 (52.1)	16.8
Email	1128	160 (14.2)	82.1	67.8	35 (3.1)	17.9	17.2	195 (17.3)	44.3
Mail	481	49 (10.2)	28.7	20.8	122 (25.4)	71.3	59.8	171 (35.6)	38.9

* $\chi^2 = 114.6$, $p < 0.001$, differences in response to personal social network data by method

** $\chi^2 = 65.9$, $p < 0.001$, differences in recruitment by method

Table 3 Multinominal logistic regression of patient characteristics and method of recruitment* (N = 440)

	Clinic			Email			Letter	
	N	OR	95% CI	N	OR	95% CI	N	OR
Age								
	74	0.99	(0.96-1.01)	**195**	**0.97**	(0.95-0.99)	171	Ref
Race								
White	35	Ref		136	Ref		97	Ref
Black	11	1.06	(0.47–2.42)	23	0.53	(0.27–1.01)	28	Ref
Asian	12	1.43	(0.60–3.43)	12	**0.35**	**(0.15–0.78)**	18	Ref
Hispanic	7	1.49	(0.53–4.17)	7	**0.3**	**(0.11–0.88)**	13	Ref
Other	9	1.41	(0.54–3.70)	17	0.55	(0.24–1.24)	15	Ref
Stage								
Stages 0, I (%)	57	Ref		159	Ref		147	Ref
Stages II, III, IV (%)	17	1.63	(0.78–3.37)	36	1.47	(0.80–2.71)	24	Ref
Social strain	74	1.87	(1.06-3.29)	186	1.57	(1.01-2.44)	163	Ref

*Models simultaneously adjusted for variables in the table. Other covariates examined were unrelated to recruitment method and dropped from models

Table 4 Baseline characteristics by race and ethnicity in women from the INSIGHT-BC study

N	Overall 440	White 268	Black 62	Asian 42	Hispanic 27	Other 41	*p**
Age at diagnosis, mean (SD)	59.2 (12.0)	61.3 (11.3)	59.1 (11.3)	53.9 (11.2)	58.6 (13.7)	51.8 (12.7)	< 0.001
Months between dx and study baseline, mean (SD)	3.6 (1.9)	3.7 (1.8)	3.6 (1.7)	3.2 (2.0)	3.4 (2.1)	3.5 (2.1)	0.537
Education, N (%)							
HS or less	34 (7.7)	18 (6.7)	5 (8.1)	3 (7.1)	3 (11.1)	5 (12.2)	0.624
Vocational/Some college	131 (29.8)	79 (29.5)	17 (27.4)	10 (23.8)	11 (40.7)	14 (34.2)	
College degree or higher	274 (62.4)	171 (63.8)	40 (64.5)	29 (69.1)	12 (44.4)	22 (53.7)	
Missing	1 (0.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (3.7)	0 (0.0)	
Comorbidity, mean (SD)							
Weighted Elixhauser score (no cancer)	1.3 (1.7)	1.2 (1.5)	2.0 (2.0)	0.6 (1.0)	1.6 (2.4)	1.1 (1.9)	0.796
Stage, N (%)							
Stage 0	13 (3.0)	5 (1.9)	6 (9.7)	1 (2.4)	0 (0.0)	1 (2.4)	0.006
Stage I	350 (79.6)	228 (85.1)	44 (71.0)	27 (64.3)	22 (81.5)	29 (70.7)	
Stage II	62 (14.1)	27 (10.1)	10 (16.1)	13 (31.0)	3 (11.1)	9 (22.0)	
Stage III	11 (2.5)	5 (1.9)	2 (3.2)	1 (2.4)	1 (3.7)	2 (4.9)	
Stage IV	4 (0.91)	3 (1.1)	0 (0.0)	0 (0.0)	1 (3.7)	0 (0.0)	
HR +, N (%)	404 (91.8)	248 (92.5)	56 (90.3)	41 (97.6)	23 (85.2)	36 (87.8)	0.318
Her2 status, N (%)							
Positive	47(10.7)	27 (10.1)	9 (14.5)	4 (9.5)	4 (14.8)	3 (7.3)	0.171
Negative	378 (85.9)	234 (87.3)	47 (75.8)	37 (88.1)	23 (85.2)	37 (90.2)	
Equivocal/Not done	15 (3.4)	7 (2.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Method of recruitment, N (%)							
Clinic	74 (16.8)	35 (13.1)	11 (17.7)	12 (28.6)	7 (25.9)	9 (22.0)	0.027
Email	195 (44.3)	136 (50.8)	23 (37.1)	12 (28.6)	7 (25.9)	17 (41.5)	
Letter	171 (38.9)	97 (36.2)	28 (45.2)	18 (42.9)	13 (48.2)	15 (36.6)	
Survey Completion, N (%)							
Epi only	206 (46.8)	107 (39.9)	37 (59.7)	23 (54.8)	19 (70.4)	20 (48.8)	0.003
Epi + Ego	234 (53.2)	161 (60.1)	25 (40.3)	19 (45.2)	8 (29.6)	21 (51.2)	

$^*p$ value, χ^2

women were older on average than women from other racial and ethnic groups; Asian and 'other' women were youngest. Most women in the study had stage I breast cancer; Black and Asian women were more likely to have stage II cancer than NHW or Hispanic women. Race and ethnicity were unrelated to education; participants were generally highly educated with over 62.4% having a college degree or higher and fewer than 7.7% had a HS degree or less. Women also did not differ with regard to HR + status, Her2 status, or comorbidity (Table 4).

Discussion

In the INSIGHT-BC study, we recruited 440 participants, 236 of whom completed personal social network assessments. Success in recruitment varied by method; in-person clinic recruitment was superior to mail or email recruitment in terms of recruitment rate, but we were able to recruit larger numbers of women overall by letter and email. Because the online-only survey reduced the number of survey administrations, email recruitment produced the highest overall response to the personal social network assessment. However, although recruitment rates by race and ethnicity were similar for clinic and letter recruitment, email recruitment of Black, Asian, and Hispanic women was considerably lower. Given the main goal of the study, recruitment by mail appeared the best approach to collection of complex social network data and still ensuring representation of diverse women. This research provides novel information about recruitment of racial and ethnic minority women with cancer in studies collecting personal social network data.

Many articles have called for the need to recruit racially and ethnically diverse participants in health research. Successful strategies have included community-based recruitment [12, 13], targeted recruitment [11], oversampling [2, 3], "high-touch, warm handoffs" [5, 6], race- and cultural-concordant recruiters [5, 9, 10], phone calls[14], and monetary incentives [4, 11]. Modifications that have been less successful at further encouraging participation have included timed incentives [15] and personalization of messages [11]. Depending on the population, active, in-person methods [24] have been shown to be more effective though some work has shown better results with targeted, but passive methods [7].

Although we did not test all of these strategies, our work was consistent with prior work showing higher rates of recruitment with face-to-face, "warm hand-offs." Unsurprisingly, email produced the lowest rates of recruitment compared with other methods [25] reducing our overall recruitment rate. Low rates by email may be due to lower rates of internet connection among older persons of color, those of low socioeconomic status as well as issues specific to email – emails going to spam folders, mistrust of email from unrecognized sources, the sheer number of emails that make it difficult to gain attention, and the challenge in distinguishing an email as sent from a legitimate source.

Because we were able to reach large numbers of women by both email and mail, recruitment by these methods led to higher recruitment efficiency and higher absolute numbers recruited despite lower recruitment rates than in-person recruitment. Furthermore, because of the way we designed data collection for those recruited by email, with epidemiological and personal social network survey data collected together online, email recruitment led to the highest rates of personal social network data. The higher rate of personal social network data from email recruitment suggested the potential power of behavioral approaches in research; women were far more likely to complete both epidemiologic and personal social network surveys administered together online than they were to respond to separate administrations. When administrations were separate, women had to indicate their interest in completing the online personal social network survey on the paper survey, send the survey via mail to the study team, then wait for the study team to email a link to the personal social network survey, perhaps reducing interest and motivation to complete it. Thus, multiple administrations may have created physical and psychological hurdles to completing the online personal social network survey since participants had already achieved the benefit of having contributed to research. The tradeoff of email recruitment was, of course, lower representation of Black, Asian, and Hispanic women.

Given the primary study goal to maximize the number of participants, collect (either epidemiologic or personal) social network data, and ensure representative recruitment, recruitment by mail, therefore, appeared to be the best approach, increasing recruitment rates over email recruitment, maximizing absolute numbers recruited, and increasing the numbers of women who provided personal social network data. Furthermore, recruitment by mail, in combination with oversampling of Black, Hispanic, and Asian women, augmented representation of racially and ethnically diverse women compared with recruitment by email.

Study strengths included the novel personal social network approach with the ability to examine social networks in depth and the ability to examine these in racially and ethnically diverse women. Among study limitations, our pilot study was not originally designed to evaluate multiple methods of recruitment and analyses were post hoc. A precise comparison of methods was further compromised by the multiple changes that often occurred with each major change to our approach. For example, women who we recruited in clinic (warm handoffs) were there because they were meeting the surgeon shortly (< 1 month) after diagnosis to learn about recommendations for treatment; those recruited in the clinic were thus recruited closer in time to diagnosis than those recruited by email or mail and may have been experiencing higher levels of distress, potentially leading to biases in recruitment. Finally, the addition of a $10 gift card incentive occurred in conjunction with a reduction in staff time available for follow-up, complicating comparisons.

Recruitment and successful collection of data were inhibited by multiple survey administrations, complicated processes due to IRB requirements, and limited resources. Although face-to-face clinic recruitment was the best overall, we were substantially limited in our ability to recruit due to the low numbers of women attending clinic each week and we did not have sufficient resources to hire multiple RAs to attend clinics KPNC-wide. Of additional concern, personal social network assessment may be somewhat burdensome for participants. Only 65% of participants who started the survey provided information on ties between alters which fell at the end of the survey though race/ethnicity was not significantly related to completion rates ($\chi^2 = 2.1, p = 0.71$). Alternate survey approaches exist to personal social network data collection which may facilitate data collection though they may provide less structural data. Future methods should nonetheless attempt to simplify data collection for participants to the degree possible.

In summary, recruitment rates by email for the collection of complex social network data were higher since the online-only administration, though time consuming, minimized the number of administrations. However, given lower response rates in racial and ethnic minority women, mail recruitment was the best approach overall to representative recruitment of diverse women with breast cancer and collection of social network data, and further yielded the highest absolute response.

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Author contributions CHK, EK, VCS, AA, and DPK contributed to the conceptualization and study design. CHK, EK, VCS, TDC, LMB, and JB-T contributed to data collection. CHK, EK, and RA contributed to data analysis and interpretation. CHK, EK, and RA drafted the article. All authors contributed to critical revision and provided final approval of the article.

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Data availability Data are available from Kaiser Permanente Northern California (contact via Candyce Kroenke candyce.h.kroenke@kp.org) for researchers and institutions who meet the criteria for access to confidential data. Investigators will be able to contact the Principal Investigator for access to the data. Each request will be evaluated on a case-by-case basis and access granted to approved investigators with a signed data use agreement.

Declarations

Competing interest The authors report no conflicts of interest.

Ethical approval The Kaiser Permanente Northern California institutional review board approved the study. The study team obtained informed consent from patients in-person, online, or by mail depending on method of recruitment.

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