AD________________

Award Number DAMD17-94-J-4334

TITLE: An Evaluation of a Peer Support Program to Improve Quality of Life with Breast Cancer

PRINCIPAL INVESTIGATOR: Carol P. Somkin, Ph.D.

CONTRACTING ORGANIZATION: Kaiser Foundation Research Institute
Oakland, California 94612-3416

REPORT DATE: July 1999

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1. AGENCY USE ONLY *(Leave blank)*

2. REPORT DATE
July 1999

3. REPORT TYPE AND DATES COVERED
Final (1 Jun 94 - 30 Jun 99)

4. TITLE AND SUBTITLE
An Evaluation of a Peer Support Program to Improve Quality of Life with Breast Cancer

5. FUNDING NUMBERS
DAMD17-94-J-4334

6. AUTHOR(S)
Carol P. Somkin, Ph.D.

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)
Kaiser Foundation Research Institute
Oakland, California 94612-3416

8. PERFORMING ORGANIZATION REPORT NUMBER

9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

10. SPONSORING / MONITORING AGENCY REPORT NUMBER

11. SUPPLEMENTARY NOTES

12a. DISTRIBUTION / AVAILABILITY STATEMENT
Approved for Public Release; Distribution Unlimited

12b. DISTRIBUTION CODE

13. ABSTRACT *(Maximum 200 words)*

The objective of this study was to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augmented and complemented the American Cancer Society's Reach to Recovery Program. Our primary aim was to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. Participants were paired with trained breast cancer survivors who provided them with ongoing peer support, in addition to specific information and skills to help them navigate the Kaiser Permanente Medical Care Program. Study volunteers received the standard Reach to Recovery training, in addition to a two-day skills training which prepared them to become breast cancer peer support volunteers and advocates. Results from this study showed that many variables affect whether or not an expanded peer support program is beneficial to women, including level of participation in the program, social support, and education. Although we did not find statistically significant differences between the two groups in major outcomes of interest, subgroup analysis showed that among women who used either program intensively, women in the intervention group scored better on quality of life measures than women in the control group.

14. SUBJECT TERMS
Breast Cancer , Peer Support,Patient Decision Making, Patient Satisfaction, Sociodemographic Factors, Intervention

15. NUMBER OF PAGES
128

16. PRICE CODE

17. SECURITY CLASSIFICATION OF REPORT
Unclassified

18. SECURITY CLASSIFICATION OF THIS PAGE
Unclassified

19. SECURITY CLASSIFICATION OF ABSTRACT
Unclassified

20. LIMITATION OF ABSTRACT
Unlimited

NSN 7540-01-280-5500

Standard Form 298 (Rev. 2-89)
Prescribed by ANSI Std. Z39-18 298-102

USAPPC V1.00

FOREWORD

Opinions, interpretations, conclusions and recommendations are those of the author and are not necessarily endorsed by the U.S. Army.

____ Where copyrighted material is quoted, permission has been obtained to use such material.

____ Where material from documents designated for limited distribution is quoted, permission has been obtained to use the material.

____ Citations of commercial organizations and trade names in this report do not constitute an official Department of Army endorsement or approval of the products or services of these organizations.

____ In conducting research using animals, the investigator(s) adhered to the "Guide for the Care and Use of Laboratory Animals," prepared by the Committee on Care and use of Laboratory Animals of the Institute of Laboratory Resources, national Research Council (NIH Publication No. 86-23, Revised 1985).

_X_ For the protection of human subjects, the investigator(s) adhered to policies of applicable Federal Law 45 CFR 46.

____ In conducting research utilizing recombinant DNA technology, the investigator(s) adhered to current guidelines promulgated by the National Institutes of Health.

____ In the conduct of research utilizing recombinant DNA, the investigator(s) adhered to the NIH Guidelines for Research Involving Recombinant DNA Molecules.

____ In the conduct of research involving hazardous organisms, the investigator(s) adhered to the CDC-NIH Guide for Biosafety in Microbiological and Biomedical Laboratories.

7/30/99

PI - Signature Date

TABLE OF CONTENTS

Final Report

An Evaluation of the Effect of a Peer Support Program
On Quality of Life with Breast Cancer

Introduction

This report summarizes activities for our study to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augmented and complemented the American Cancer Society's Reach to Recovery Program. Our primary aim was to determine the value of providing a comprehensive, organizationally specific, peer support program to women beginning at diagnosis and continuing for up to one year. This randomized controlled trial asked four research questions:

1. Compared to a standard peer support program, does this expanded program improve (a) quality of life with breast cancer, (b) participation with treatment decisions, and (c) satisfaction with care?
2. How do patient sociodemographic characteristics influence these outcomes?
3. What are the main benefits of this program?
4. Does participation in treatment decisions improve quality of life?

Women recruited into the study from five Kaiser Permanente medical centers were randomly assigned to the intervention or control group. Participants in the intervention group were paired with a trained breast cancer survivor (peer support volunteer or "peer supporter") who provided them, beginning at diagnosis, with ongoing peer support along with specific information and skills to help navigate the Kaiser Permanente Medical Care Program. Participants in the control group received the usual support services offered to women newly diagnosed with breast cancer, which in most cases included a referral to Reach to Recovery.

Body: Summary of Accomplishment of Tasks in Approved Statement of Work

Task 1. Design of Peer Support Intervention: Conduct five focus groups with newly diagnosed breast cancer patients to ascertain their information needs, barriers to participation in treatment decisions, and ways to address these barriers.

We conducted five focus groups with breast cancer survivors to ascertain their information needs barriers to participation in treatment decisions and perceived ways to address these barriers. We held three multi-ethnic focus groups, one group composed entirely of African American women, and another group composed entirely of Latina women. The primary goal of these focus groups was to refine the plans for the intervention and volunteer training and to ensure that the program would meet patient needs. The focus groups were audiotaped, transcribed and analyzed for relevant themes.

Data from the focus groups supported our initial concept of the intervention. Focus group participants provided strong validation for the dual importance of providing both emotional support and information (beginning at diagnosis and continuing throughout the process of treatment and follow-up) to women with breast cancer. They also emphasized the unique value of "peer" support compared to other types of support from family, friends, and health care providers. Participants explained how emotional support — provided by another person who had "been there"— helps to ease the fear that necessarily accompanies a diagnosis of breast cancer. They said that decreasing this fear makes the newly diagnosed woman better able to "hear" the information they needed to make decisions and begin to feel in control. One participant elucidated how the provision of emotional support contributed to her active participation in decision making. She reflected, "My most important thing was the emotional support, because you can't make decisions when you are a physical wreck...And I think once you're emotionally able to handle something, everything else seems to fall into place, because when you're calmer about it you can make decisions (SRF51)." Another participant articulated the relationship between information and support. "I mean people need to be informed. And percentages and numbers always seem to, you know, do that factually. But for some people, they don't 'get' numbers, and they don't 'feel' percentages in the same way. That's why you really have to have somebody that can talk with you, and make you see the importance of something as obviously important as chemotherapy under certain circumstances...and you have to operate from knowledge and somebody has to be able to get you to understand (HAY35)."

Task 2. Design of Measures: (a) Construct and pretest patient decision making scale; (b) develop and pretest baseline, 3-month, and 1-year questionnaires.

While there is increasing interest in the issue of patient preferences for decision making (2-5,8-10,15,16,20-23,29), an extensive review of the literature unearthed no validated self-reported measures of actual patient participation in medical decisions. We found one study that asked patients to respond to the question, "How are medical decisions usually made?". The possible response categories were: the clinician makes the decision, using all that's known about the medicines; the clinician makes the decision but strongly considers the patient's opinion; the clinician and patient make the decision together on an equal basis; the patient makes the decision but strongly considers the clinician's opinion; the patient makes the decision using all the patient knows or learns about the medicines. (28). Using the same response categories (removing the wording about medicines which was not applicable) we adapted this question to ask study participants about how the decisions regarding their breast cancer surgery and their adjuvant therapy were actually made. Questionnaires were pretested with a sample of 45 breast cancer patients and slight modifications were made to improve clarity of newly developed questions. The baseline, 3-month and 12-month follow-up questionnaires are found in Appendix 1.

Task 3. Recruitment of KPMCP Peer Support Buddies: Recruit 80 breast cancer survivors who got their medical care at Kaiser Permanente Medical Care Program (KPMCP) to become KPMCP peer support buddies.

Recruitment of peer support volunteers was conducted on an ongoing basis to keep apace with patient recruitment. Over the course of the project, we held a total of 10 trainings and trained a total of 71 volunteers from 1995-1997. We maintained good volunteer retention.

Twelve volunteers did not renew their commitment after the first year, 5 dropped out because their breast cancer recurred, and 2 women died.

During the first year of this project it became clear that volunteer recruitment and training could most effectively be conducted on an incremental basis. Through incremental recruitment we were able to accomplish a number of objectives. First, we were able to recruit those volunteers who most closely matched the women being recruited into the study, in terms of age, race/ethnicity, and marital status. In addition, since we did not know, at the outset, how many newly diagnosed women a peer support volunteer could optimally work with at any one time, incremental recruitment allowed us to gage as we went along how many peer supporters we would need for both short- and longer-term planning. Finally, incremental recruitment enabled the project staff to be responsive to the volunteers' needs, through making certain that we did not have volunteers with either too little or too much to do. This required determining how many newly diagnosed women to match an individual volunteer with, and varied according to several factors, including the characteristics of the peer supporters themselves (such as time availability, temperament, and experience), and the particular needs of the newly diagnosed women, which tended to fluctuate at different points during the first year following diagnosis. In general, the level of involvement required of the volunteer diminished somewhat as her buddy moved farther from diagnosis, freeing the volunteer to take on an additional buddy if the 'match" was right. Thus, some volunteers were able to work with two or three buddies simultaneously, while others might only work with one.

The intervention matched every woman assigned to the treatment group with a trained volunteer, a woman who was both a breast cancer survivor and Kaiser Permanente member. In general, matches were made as follows: Each newly diagnosed breast cancer patient who was assigned to the treatment group was contacted by project staff. This staff member would spend some time with the new patient on the phone, in order to find out a little about her as a person, including her environmental resources and her attitude to her recent diagnosis. During this phone call it was explained to the new patient that she would be provided a "buddy"— a woman who had been treated for breast cancer at Kaiser Permanente, and who had chosen to join this project because she wanted to help newly diagnosed breast cancer patients in whatever way she could.

This phone conversation generally took between twenty to forty minutes. It was a critical interaction, as it provided important information project staff would use to assign the new patient a volunteer. This phone conversation provided important information about the new patient, including what was most important to her in a potential buddy. For many of the new breast cancer patients we spoke with, the primary concern was that the buddy with whom they were matched have the same diagnosis and treatment they had. However, there were still others who made more specific requests of us. For example, one new patient said that because she didn't drive, the thing she most wanted was a buddy who would be willing to drive to her house for visits. Another new patient told us that because she was a lesbian the thing she most wanted was a lesbian buddy. Another new patient told us she was extremely anxious about how she would manage working during chemotherapy, and wanted to be matched with a volunteer who had been able to work during chemotherapy treatment. Still, another new patient sheepishly warned us that she often swears when she talks, and so she hoped we had a volunteer who didn't mind her occasional "bad mouth."

Because of the diversity of our volunteer pool, it was almost always possible to meet new patients' requests. However, sometimes things didn't go exactly as planned. For example, at our Oakland site, one match was made that ended-up requiring unexpected attention. In this case a new patient was matched with a volunteer who was the same age, the same race, and had the same treatment. In addition, the two women had an amazing amount of similar interests— both women traveled frequently, and both were committed to work with children. However, four months after the match was made the new patient called project staff. She told us that although she adored her volunteer, because this woman was married and she not, the volunteer simply wasn't able to understand a big struggle she was having, that of "wanting to meet a man and having breast cancer." In this case, after talking with all parties, the decision was made to keep the original match but at the same time to put the new patient in contact with one of our single volunteers.

Task 4. Training of Peer Support Buddies: (a) Develop training agenda and manuals. (b) Coordinate with American Cancer Society so that KPMCP peer support buddies receive Reach to Recovery training. (c) Conduct four 1-day trainings (one at each of 4 medical centers) for buddies.

Each volunteer participated in three days of training prior to being matched with a new patient. Volunteers received the standard American Cancer Society Reach to Recovery Training, in addition to a two-day skills training in which we trained them to be breast cancer advocates. (See training agenda and volunteer training manual in Appendix) We developed the training with input from a number of sources, including Kaiser Permanente physicians, nurses, health educators, social workers and the patient support organization, Women's Information Network against Breast Cancer. The objective of the training was to prepare carefully selected volunteers to provide ongoing emotional and informational support to newly diagnosed breast cancer patients. The training provided both information on the medical and psycho/sexual aspects of breast cancer and the skills needed to enable volunteers to help new patients to access the resources of Kaiser Permanente and participate actively in treatment decision making. Learning took place in a variety of ways. For example, volunteers were led through role playing exercises in which they practiced helping their buddies with a variety of problems and issues, such as how to be an informed consumer of medical care, or how to go about making treatment decisions, as well as how to talk with their doctor, how to take better care of themselves or communicate better with family members.

Supporting the volunteers after the initial training took on a variety of forms. In order to be effective in their role as breast cancer peer supporters, volunteers relied on project staff for training, information, and continuous availability for debriefing and troubleshooting. In addition to receiving assistance as needed, each volunteer attended monthly meetings where she was provided with a safe and reliable place to meet with other volunteers and project staff; discuss buddy contacts and raise questions or concerns; exchange information; and receive feedback and reinforcement. At the monthly meetings each volunteer was encouraged to share her feelings, reactions, fears, successes and perceived blunders. This structure enabled the volunteer to approach the woman she was working with — often a woman in extreme distress, uncertain and overwhelmed — from a place of personal strength and flexibility.

The process of going through the training and performing the role of peer supporter, of necessity, affords the volunteer frequent opportunities to confront any personal issues she may have regarding breast cancer. The role of staff (who were licensed clinical social workers or Registered Nurses) was to facilitate the review of these issues to promote healing. Their clinical skills were exceptionally valuable, especially when a peer support volunteer recurred or died. The following are some examples of other types of issues dealt with by staff. A common concern voiced by the peer supporters was a reluctance to be too "pushy" if a buddy said she "didn't need anything." In this situation, we talked about numerous ways one can offer support without being intrusive and also about how to tell when it is time for the volunteer to back off. Another volunteer concern was what to do if she had not undergone the *exact* treatment as her buddy. In order to maximize the resources of the volunteer pool, we would handle this concern in one of two ways. Either we would talk with the volunteer until she felt comfortable directing her buddy to the information or resource she needed or, if preferable, we would ask another volunteer who *did* have the missing experience to work with the buddy on a short-term basis.

In addition to regular volunteer support, we organized three special events to thank the volunteers for their work and to mark special points in the project, such as the end of the recruitment phase. These events provided the opportunity for volunteers to express their feelings about work that for many had proved emotionally meaningful.

We wanted the intervention (i.e. the extent and type of interaction that the volunteer offered to her buddy) to be tailored to needs of each newly diagnosed woman. Therefore we did not require that volunteers follow a specific protocol that described a required set of activities. Volunteers were thus trained in a variety of skills and resources which they could use or offer as appropriate. For example, our volunteers:

- Visited with newly diagnosed patients, at any number of locations, including cafes, homes, and medical facilities;
- Answered countless questions about their experiences with different aspects of the cancer experience, including drug therapies, alternative treatments, and side effects;
- Gave books and pamphlets to newly diagnosed patients' spouses, when requested.
- Spoke with newly diagnosed patients on the phone, to "check in";
- Sent cards to their buddies;
- Went for walks with their buddies;
- Helped with locating information their buddies wanted (eg, how to schedule an appointment with a social worker, or how to how to use the health education department);

- Simply by being themselves, our volunteers provided positive role models of what life "after" breast cancer might be like.

Task 5. Recruitment of Subjects: (a) Recruit 500 subjects (an average of 28 patients per month for 18 months). (b) Randomly assign subjects to intervention and control groups.

Overall, 38% (n=292) of the women who were sent the invitational packet returned the baseline materials and were randomized into either the intervention group or the control group (Table 1). This response rate varied by five factors: (1) age at diagnosis, with the older women being less likely to agree to participate than younger women (Table 2); (2) race/ethnicity, with white and multi-ethnic women being most likely to agree to participate, followed by Black and Latina women, with Asian/Pacific Islander women being the least likely to agree to participate (Table 3); (3) marital status, with divorced and separated women being most likely to agree to participate (Table 6); and (4) Kaiser Permanente facility, with some facilities recruiting a greater percentage of invited participants than others (Table 5). (5) Also a greater percentage of women who were diagnosed with regional stage breast cancer participated than did the percentage of women diagnosed with local or in situ breast cancer (Table 5).

Participant recruitment proved to be a stimulating challenge. It required developing and perfecting effective recruitment procedures at five research sites—each of which has its own personality, culture, and attitudes about care delivery. We added another site early on to help increase enrollment. During the period of recruitment for this study, Kaiser Permanente, like many other health care institutions, underwent a period of organizational restructuring. This created a climate in which all staff, from professional to clerical, were required to do more with reduced resources. Therefore our project sought ways to make as few demands on medical center staff as possible and at the same time accomplish our recruitment goals. This required special efforts to enlist support for our project at all facilities. To accomplish this we attended task force meetings, met with surgeons, nurses and social workers at all facilities. We hired project staff at each facility and attempted to work as insiders from within each facility as much as possible, building study recruitment into the structure of each workday.

The recruitment process involved the following steps: Every week during the recruitment period, study coordinators at each facility identified potentially eligible women from pathology reports and obtained permission to contact these women from their surgeons. The eligibility criteria included having had: (1) a first diagnosis of ductal carcinoma in situ or invasive breast cancer of any stage; and (2) a study contact prior to primary treatment. If the surgeon approved, the patient was sent an invitation letter (signed by her surgeon) along with a baseline questionnaire and informed consent form. If we had not received the questionnaire and consent form seven days after the letter was mailed, we made one follow-up telephone call to answer any questions and/or to send another invitation packet if needed. Inasmuch as the time immediately surrounding the diagnosis of breast cancer is an extremely emotional one in which many decisions have to be made, patients appreciated a gentle reminder about the study and an opportunity to talk about it with project staff. They often reported to us that they placed the invitation packet at the bottom of a pile to be dealt with after the most pressing issues are handled and were glad we called. Upon receipt of baseline questionnaire and informed consent form, each woman was randomly assigned to either the intervention or the control group

The final sample size for this study was below our original estimate of 500 participants. Our original sample size of 250 in each study group was estimated to provide sufficient power (80%) to detect a .25 standard deviation unit difference in the mean of each measure of effectiveness, using a two-sided Z-test and significance level = .05. A reduced sample size of 145 in each study group provided sufficient power to detect a .33 standard deviation unit difference in the mean of each measure of effectiveness. This represented a 32% increase in the minimum detectable difference. While our project biostatistician concluded that our reduced numbers would not produce a dramatic change in the minimum detectable difference for our outcome measures, as we indicate below, the reduced sample size did make subgroup analysis difficult. In some cases when we found no differences between the intervention and control groups we could not determine whether that was because the two groups truly did not differ or because we did not have enough power to detect a difference. This study represents the only randomized controlled trial of a one-on-one peer support intervention for breast cancer that we are aware of and we were able to discern very interesting patterns in the data which merit follow-up with larger samples.

In order to determine whether study enrollment differed from the population of Kaiser Permanente members who were diagnosed with breast cancer by sociodemographic and disease characteristics of the participants, we linked the women who were sent invitation letters to the data in Kaiser Permanente's cancer registry. Using a chi-square test of association, we investigated whether participation in the study differed by various sociodemographic and disease characteristics (age at diagnosis, race/ethnicity, marital status, stage at diagnosis, and treatment facility within Kaiser Permanente).

Task 6. Data Collection: (a) Mail questionnaires to subjects at baseline, 3 months, and 12 months. (b) Assure complete response rate.

The data for this study were collected using three self-administered surveys, completed at entry into the study (baseline), three months, and twelve months after entry into the study (see Appendix for copies of the surveys). Three months after randomization, we mailed each study participant the three-month follow-up survey. If the survey was not returned within one week, the woman was sent a reminder postcard. If the survey was not returned after an additional week, the woman was sent a second copy of the survey. Finally, if the survey was still not returned after an additional two weeks, a research assistant spoke with the woman by phone and offered special assistance. This process was repeated with the twelve-month follow-up surveys.

The response rate for both the three-month and the twelve-month surveys were high. Overall 94.5% of the women enrolled in the study returned the three-month survey. 89% returned the twelve-month survey. Women in the intervention group were more likely to return both the three-month and the twelve-month surveys than women in the control group (Tables 7,8).

Task 7. Data Entry: (a) Edit and enter data from baseline, 3-month and 1-year questionnaires.

All data from questionnaire responses were edited and then entered and verified (double entered) for accuracy.

Task 8. Data Analysis:

We performed an intention-to-treat analysis to determine the effect of the intervention at three months and at twelve months. First we determined whether the randomization to the intervention or the control groups resulted in samples with balanced sociodemographic and disease characteristics. With data from the baseline survey, we used chi-square tests of association to compare various characteristics (treatment facility within Kaiser Permanente, age at intervention, stage at diagnosis, race/ethnicity, education level, marital status, employment status, language, living situation, and social support) (Table 9). We found that the intervention and control group differed on two baseline characteristics (the percentage of women who lived alone and education—when used as a collapsed variable). Thus, we ran all subsequent analyses adjusting for these baseline characteristics.

This study had four main hypotheses:

1. Women in the intervention group will have a better perceived quality of life one year after diagnosis than women in the control group;
2. Women in the intervention group will be more likely to take an active role in their breast cancer treatment decisions than women in the control group;
3. Women in the intervention group will be more satisfied with their health care one year after diagnosis than women in the control group;
4. Less educated and ethnic minority women will benefit most from the intervention given that it is likely that they find it most difficult to navigate the medical care system.

We tested each hypothesis in the following ways: First we compared the means of the outcome scales between the intervention and the control groups, using t-tests. Then we used standard regression techniques to adjust for education and living situation (the two variables that differed at baseline between the intervention and control groups). In addition, we conducted stratified analyses and investigated interaction effects by adding and testing the significance of appropriate cross-product terms to our regression models. It is important to note a limitation inherent in the large numbers of comparisons we make and the small sample size in some of the stratified analyses. In these numerous exploratory analyses, we are able to identify patterns evident and areas for future study.

We measured quality of life using four well validated, reliable, self-report instruments: the Functional Assessment of Cancer Therapy - Breast (FACT-B), the Medical Outcomes Study

Short Form (SF-12), the Center for Epidemiologic Studies Depression (CES-D), and the Illness Intrusiveness Scale. The FACT-B (6,7) is a 44-item instrument comprised of six subcales that measure different dimensions of general quality of life among cancer patients (physical well-being, social well-being, emotional well–being, functional well-being, relationship which doctor). It also includes a subscale designed specifically to capture issues of concern to breast cancer patients, such as body image and genetic risk to family members. The SF-12 is subset of questions from the Medical Outcomes Study 36 Item Short Form Survey (SF-36). The developers of the SF-36 used regression analysis to identify 12 items from the SF-36 that reproduce the Physical Component and Mental Component Summary scores in the general population (30). Numerous studies have shown that the SF-12 is a useful alternative to the SF-36 when a shorter scale is required (14,19,24,30). The CES-D (25,26) is a 20-item scale that has been used to measure symptoms of depression, especially depressed mood, in the general population. The Illness Intrusiveness Scale (11-13) has been used to measure the negative effect (or intrusiveness) of an illness on an individual's involvement in 13 types of activities (health, diet, work, active recreation, passive recreation, financial situation, relationship with spouse or partner, sex life, family relations, other social relations, self expression/ self improvement, religious expression, community and civic involvement).

Hypothesis 1: Quality of Life. We predicted that women in the intervention group would have a higher quality of life one year after diagnosis than women in the control group.

Based on unadjusted analyses, we found no statistically significant differences between the intervention and control groups at 12 months in their scores on the FACT-B, SF-12 Physical Component, Illness Intrusiveness, or CES-D scales (Table 11). The control group did score better than the intervention group on one quality of life measure, the SF-12 Mental Component (p = .01). These results were maintained when we adjusted the analysis for education and living situation, the two variables that differed in the intervention and control groups at baseline (Table 13). In addition, in the adjusted analysis a non statistically significant trend favoring the control group emerged in two of the FACT subscales (Physical Well-Being (p=.08) and Functional Well-Being (p=.06). We found similar results at three months, including an advantage for the control group on the SF-12 Mental Component, however we did not observe a trend favoring the control group in the FACT Physical Well-Being or the Functional Well-Being scales (Tables 10,12).

In order to identify subgroups of the study population who derived greater benefit from the intervention, we performed a number of subgroup analyses. Since we found that social support had a strong impact on quality of life measures (Table 14,15) we tested for intervention effect modification by other sources of social support (Table 16,17). We constructed an index of social support in the following way. We asked women at the three-month and twelve-month follow-up to what extent they experienced eight types of social and instrumental support, such as someone to "listen to you when you need to talk," to "give you good advice about a problem," or to "take you to the doctor if you need it." After making sure that none of the items correlated with each other more than .80 we constructed an index of social support by adding up responses to these questions and then dividing the total score by the number of questions that were answered, to come up with a mean score. To arrive at a measure that had only two categories, we then collapsed the mean scores to create a high and a low category (scores from 1-3.9 represented low and from 4-5 represented high social support).

At twelve months, we found that there was significant interaction between intervention and social support with respect to the overall FACT scale, as well as with several of the FACT subscales, with the SF-12 Physical Component, and with the CES-D (Table 17), while at three months none of the interaction terms were significant (Table 16). In general, at both three months and at twelve months we found that quality of life scores on all scales were consistently better (for women in both groups) who had high social support (Table 14,15). When we controlled for social support a pattern emerged in the data at 12 months (Table 19). When we controlled for social support (along with education and living situation), among women with high social support, women in the control group scored more favorably on the overall FACT scale (p=.01) and two subscales of the FACT scale—physical well-being (p=.01)and functional well-being (p=.01)—, the SF-12 Mental Component (p=.005) and Physical Component (.04) and the CES-D (p=.02). There was also some indication that, for these measures, the intervention worked better than the control group for women with low social support. While only one of the analyses favoring the intervention among women with low social support was statistically significant, the differences in means were all in the direction of positive intervention effect. The lack of significance may likely be due to a power problem. At three months, the patterns are also suggestive of a positive intervention effect.

Women in both the intervention and control groups had the opportunity to interact with a breast cancer survivor, either a Kaiser Permanente peer support volunteer for women in the intervention group or an American Cancer Society Reach to Recovery volunteer for members of the control group. In order to see whether women who used either program more intensely derived more benefit from it than women who used it less, we considered the level of participation in a peer support program. We constructed a measure of participation by combining the number of volunteer contacts (phone calls and visits, with visits counting somewhat more than phone calls) that each study member reported (Table 20).

In general we found that women in the intervention group used the peer support program to a greater extent than women in the control group used the Reach to Recovery Program. Fifty percent of the women in the control group had no contact with a Reach to Recovery volunteer, compared to 13% of women in the intervention group who had no contact with the peer support program (Table 21). On the other hand, 20% of the intervention group were high participators compared to 6% of the intervention group. At 12 months, when we stratified by level of participation in a peer support program, we found consistent evidence at twelve months that the intervention was successful among women with the highest level of participation, while it may not have been better than the control group among women with lower levels of participation (Table 25). Among high program participators, numerous indicators of quality of life were better among the intervention group compared to the control group. Among the *high participators*, women in the intervention group scored significantly better on the FACT overall scale (p=.004), the FACT Physical Well Being scale (p=.05), the FACT Functional Well Being scale(p=.05), and on the FACT breast cancer Additional Concerns scale (p=.008) and marginally better on the SF-12 Physical Component (p=.09) and the SF-12 Mental Component (.15). Among th*e moderate participators*, women in the control group scored marginally better on the FACT

Social and Family Well-Being scale (p=.09), and the CES-D (p=.09) while the intervention group scored better on the SF-12 Mental Component (p=.07). Among the *low participators,* the SF-12 Mental Component was significantly better among women in the control group (.004), however among the medium and high participators there was an non-statistically significant trend in favor of higher quality of life on this measure among the treatment group. Although these results were generally not found at the three-month follow-up, this may indicate that it takes longer for the effects of participating in the program to be felt (Table 24).

Hypothesis 2: Participation in Treatment Decisions. We predicted that women in the intervention group would be more likely to take an active role in their breast cancer treatment decisions than would women in the control group.

Participation in treatment decisions was measured in the three month questionnaire using two questions: "How were the decisions made regarding your surgery for breast cancer, that is whether to have a lumpectomy or mastectomy?" The response categories were: (1) The doctor(s) made the decisions; (2) The doctor(s) made the decisions but considered my opinion; (3) The doctor(s) and I made the decisions together on a equal basis; (4) I made the decisions, but strongly considered the doctor's opinions; (5) I made the decisions using all I knew or learned about the treatments that were available. A similar question was used for adjuvant treatment — "How were the decisions made regarding any additional (adjuvant) therapy you considered, such as chemotherapy or Tamoxifen?" These questions were treated in the analyses as continuous variables, although future analyses will explore more thoroughly the patterns of association across categories.

Based on unadjusted analyses (Table 10) there were no differences in the mean scores for women in the intervention and control groups on either of the two participation in treatment measures. There was no change in these findings when the analysis was adjusted for living situation and education (Table12). Participation in treatment decisions was only measured at three months.

Hypothesis 3: Satisfaction with Care. We predicted that women in the intervention group would be more satisfied with their health care one year after diagnosis than women in the control group

We measured satisfaction with care using two measures. Overall satisfaction with care was measured using the question, "Overall, how would you describe the care you received at Kaiser Permanente to diagnosis and treat your breast cancer?" We also constructed an additive satisfaction scale, summing the scores on the following 5 satisfaction items: "Overall how would you rate the following aspects of breast cancer care at Kaiser Permanente (poor; fair; good; very good; excellent): (a) Your care before surgery; (b) Your care in the hospital for surgery; (c) Your care during chemotherapy or Tamoxifen; (d) Your follow-up care; (e) The amount of information you received; (f) The amount of emotional support you received. We found no differences between the intervention and control group in either of these measures of satisfaction with care in the unadjusted analysis or in the analysis adjusting for differences in baseline education and living situation at either the 3- month or 12-month follow-up (Tables10,11,12,13).

<u>Hypothesis 4: Sociodemographic Factors</u>. We predicted that less educated and ethnic minority women would benefit most from the intervention given that it was likely that they would find it most difficult to navigate the medical care system.

We tested whether the effect of the intervention varied by level of education of the participants. At three months, we found a significant effect modification by education for participation in decisions about adjuvant therapy (Table26); while at twelve months, we found a significant effect modification for the FACT Emotional Well Being scale (Table 27). At twelve months, when we stratified for the education of the participants (as well as controlling for living situation) we found—contrary to our hypothesis— that among women with less than a high school education, those in the control group fared better on the FACT Emotional Well Being Scale, (p=.05) while among women with at least some college, there were no differences between the two groups (Table 29).

We did find support for our hypothesis in the three-month follow-up data. Among women with a high school education or less, women in the intervention group were significantly more likely to report that they participated in the treatment decision for adjuvant therapy than women in the control group (p=.005) (Table 28). This relationship only existed among the less educated women. Among the more highly educated women there was no difference between the two groups.

In addition we investigated the potential for heterogeneity in the intervention effect by race/ethnicity (Tables 30,31). At three months, we found a significant intervention effect modification for the FACT Relationship with Doctor scale (p=.03) and the Overall Satisfaction measure (p=.03) (Table 30) and, and at twelve months, we found a marginally significant effect modification for the FACT Relationship with Doctor scale (p=.06), and the Satisfaction scale (p=.07) (Table 31). When we stratified by race/ethnicity, at three months (Table 32), we saw a non statistically significant trend among African Americans showing higher satisfaction scores in the control group than the intervention group, whereas among women of other racial/ethnic group no differences in satisfaction between the two groups were evident.

At twelve months (though not statistically significant) analyses suggested, among Latinas, satisfaction with care may have been better in the intervention group than in the control group, while among multi-ethnic women satisfaction may have been better in the control group; among women of other race/ethnicities there was no difference (Table 33).

At twelve months (Table 33), analyses suggested (though not statistically significant) that among African Americans, women in the intervention group scored better on the FACT relationship with doctor scale while mulit-ethnic women in the control group scored better, and there seemed to be no differences among women of other racial ethnic groups. On the SF-12 Mental Component, among Asian/Pacific Islanders (.004) and African Americans (.02), women in the control group scored higher than women in the intervention group. While among women in other racial/ethnic groups the differences are in the same direction but much weaker. On the SF-12 Physical Component, among Asian/Pacific Islanders (.05), women in the intervention group scored better than women in the control group, while among multi-ethnic women, those in the control group scored better. Among all others there were no differences between the intervention and control groups.

On the other main outcome of interest in this study, participation in treatment decisions (Table 32), among African Americans, women in the treatment group reported a more active participation in treatment adjuvant decisions at three months than women in the control group, while among multi-ethnic women, those in the control group were more active on this issue. None of these relationships were statistically significant.

It is important to remember that since the numbers of women who participated in the study from each racial/ethnic group were quite small, it is difficult to make strong conclusions from this data. Based on these data, we cannot determine conclusively whether, or to what extent, the impact of the intervention on quality of life, satisfaction and participation in treatment decisions varied by race/ethnicity. Further research is needed to investigate this issue.

We investigated the role of intervention effect modification by disease and treatment factors. Although none of the interaction terms were significant, when we stratified for stage at diagnosis we found some interesting trends (Tables 34,35,36,37). Among women diagnosed with ductal carcinoma insitu, women in the intervention group were marginally more likely (p=.09) to participate in their treatment decisions regarding adjuvant therapy than women in the control group at three months, (Table 36) however women in the control group were marginally more likely (p=.09) to score better on the SF-12 Mental component. At twelve months (Table 37), among women with local disease, those in the control group were more likely to score better on the SF-12 Physical Component (p=.04) and among women with Regional or Distant disease, women in the control group were more likely to score better on the SF-12 Mental component (p=.02).

When we stratified for type of surgery, we found that, at three-months, among women who had a mastectomy, women in the intervention group scored better on the FACT relationship with doctor scale (p=.04) while, among women who had a lumpectomy, those in the control group scored better on this dimension (p=.02) (Table 38). Among women who had a lumpectomy, those in the control group also scored better than women in the intervention group on the SF-12 Mental Component (p=.04) (Table 38).

There were no significant intervention effect modifications by whether or not the woman had chemotherapy or reconstruction (Tables 40-47). We did find evidence of this by whether or not the woman had tamoxifen (Tables 48,49). At three months (Table 50) among women who did not take tamoxifen, women in the control group were more satisfied than women in the intervention group (.01) while there were no differences between the two groups among women who took tamoxifen). At twelve months (Table 51), among women who took tamoxifen, women in the control group scored better than women in the intervention group on the FACT Physical Well Being scale.

Additional Issues

The discussion of the hypotheses above has addressed the study's first two research questions. Below we present data to address the remaining two research questions.

What are the main benefits of the program?

We evaluated the benefit of the expanded peer program in a number of different ways. The first way to ascertain its ability, compared to the standard (Reach to Recovery) approach, to improve quality of life, patient satisfaction and participation in treatment decisions. These findings have been summarized above. We also asked study participants how much their peer support or Reach to Recovery volunteer helped them in a variety of areas. We found significant differences between women in the intervention and control group in a number of areas (Table 52). A greater percentage of women in the treatment than the control group reported that their volunteer was very or somewhat helpful in the following areas: to get the information they needed (61% vs. 43%; p=.007); understand their breast cancer diagnosis (66% vs. 33%; p=.001); know what questions to ask their doctor (35% vs. 25% p=.09); take better care of themselves (39% vs. 25%; p=.04); and find out about and use Kaiser Permanente resources better (22% vs. 36% p=.02). There were no differences between the two groups in the following areas: decide what treatment to have (20% vs. 19%); communicate better with their doctor (29% vs. 24%); deal with job stress (9% vs. 8%); deal with family relationships (19% vs. 16%); and deal with sexual issues (7% vs. 8%).

We conducted stratified analyses to see whether the perceived benefit of the intervention varied by sociodemographic and program participation variables (Tables 53-58). In general, we found that the program was more likely to be perceived as somewhat or very helpful among women in the intervention group than control group among younger than older women (Table 54); among more educated than less educated women (Table55); among white women than women of color (Table 56); among women living with someone rather than living alone (Table 57); and among married women (Table 58). It is interesting to note that while the relative difference in perceived helpfulness between members of the intervention and control group was greatest among white women, the greatest perceived effect of either the program was perceived by women of color in the intervention group (Table 56).

We investigated the issue of how satisfied women were with their level of contact with their volunteer). We found that 81 percent of the women in the intervention group reported that the level of contact was "just right" compared to 72% of women in the control group. 85% of women in the intervention group who had no contact said it was "just right" compared to 60% of women in the control group.

Does participation in treatment decisions improve quality of life?

At three months, there were no statistically significant effects for level of participation in surgery decisions on any of the quality of life scales (Table 60). However, there was some indication that women who reported "I made the decisions" had the least favorable scores on many of the quality of life measures. Similar results were found at twelve months (Table 61).

For participation in the decisions about adjuvant therapy, a somewhat different pattern was found. At three months, statistically significant relationships were found between participation in treatment decisions and quality of life on two measures (Table 62). On the FACT Emotional Well Being subscale, women who reported "the doctor made the decisions" had higher scores than women who reported other decision making approaches to adjuvant treatment decisions (p=.003). On the FACT Relationship with Doctor subscale, women who reported "the doctor made the decisions" shared the highest scoring position with the women who said "we made the decisions on an equal basis" and the women who reported "I made the decisions" had the lowest scores (p=.007). At twelve months, the women who reported that "the doctor made the [adjuvant therapy] decisions" had the most favorable scores on the SF-12 Mental Component compared to women who reported other approaches to making treatment decisions (p=.02) (Table 63). While it is difficult to make too much of these results, there is some indication that active participation in treatment decisions may not improve quality of life.

When we tested the effect of the intervention for interaction effects with participation in treatment decisions none of the interaction terms were significant in either the three month or twelve month data (Table 64). In addition, we found no difference at three months in participation in treatment decisions comparing the intervention and control groups (Table 65) At twelve months, (Table 66) however, there was some indication, that among women who participated more in their treatment decisions, women in the control group scored better on the Overall Fact Scale (p=.03) the FACT physical well-being (p=.03) functional well being (p=.02), emotional well-being (p=.03) and the SF-12 Mental Component (p=.01).

Task 9. Prepare Reports.

All annual reports have been completed in a timely manner and approved. A no cost extension was obtained to complete the analysis and prepare the final report.

Key research accomplishments

- Determined in a randomized controlled trial, that there were no statistically significant differences at the three-month or twelve-month follow-up on various quality of life measures between women who received an expanded, organizationally specific one-on-one peer support program and women who received a standard peer support program.

- Determined that among women who participated intensively in either support program, women in the intervention group scored better on quality of life measures than women in the control group.

- Determined that among women with low social support, an expanded one-on-one peer support program may have worked better than the standard peer support program.

- Determined that among women with less than a high school education, women in the control group scored better at twelve months than women in the intervention group on the FACT Emotional Well Being scale.

- Determined that women in the intervention group were no more likely to report that participated actively in their treatment decisions than women in the control group.

- Determined that among women with less than a high school education, women in the intervention group were more likely to report they participated actively in their adjuvant therapy treatment decisions.

- Determined that for women in both control and intervention groups reported participation in breast cancer surgery decisions was not related to quality of life measures and that there were mixed results for participation in adjuvant therapy decisions.

- Determined that women in the intervention group were no more satisfied with their health care then women in the control group.

- Determined that a greater percentage of women in the intervention group (than the control group) reported that their peer support volunteer was very or somewhat helpful in enabling them to get the information they needed, understand their breast cancer diagnosis, know what questions to ask their doctor, take better care of themselves, and find out about and use Kaiser Permanente resources better.

Reportable outcomes

The principal investigator presented a poster at the Department of Defense, Breast Cancer Research Program, Era of Hope Conference, October, 1997 (Appendix 2)..

We have a manuscript that will be submitted for publication in preparation.

Carolyn Klassen, MPH conducted an extensive literature review for this study on patient participation in treatment decision. This review formed the basis of her master's thesis at the University of California Los Angeles. She did not receive funding from the study.

> Literature Review and Evaluation of Instruments Used to Measure Patient's Participation in Medical Decision-Making, October 1995, Master Thesis, MPH in Epidemiology, University of California Los Angeles

Hannah Wedgley, Research Associate on this study, is writing her PhD dissertation at the Wright Institute in Berkeley California, using survey data and interviewing volunteers from this study.

> The Breast Cancer Peer Support Volunteer: Participation in a One-On-One Peer Support Project From the Volunteer's Perspective

Conclusions

Quality of Life

In the main intention to treat analysis, we found no statistically significant differences between the intervention and control groups (at 3 months or 12 months) on the majority of the quality of life measures. There was even a suggestion that the control group may have done better than the intervention group on a few of the measures.

Social support was found to be a strong determinant of quality of life. Adjusting for education and living situation, we found that, among women with high social support, women in the control group scored more favorably than women in the intervention group on many of the quality of life scales. At the same time there was a suggestion that, among women with low social support, women in the intervention group did better. While we cannot make too much of this because of the small sample size and the large number of comparisons being made, it may indicate that the intervention worked best among women who had fewer support resources and therefore needed it the most.

When we stratified the analysis by level of participation in the program we also found that the intervention worked best among women with the highest participation in the program. While we found that most women in the study participated at a lower level, we also found that 81% of women in the intervention group felt their level of participation in the program was "just right" (compared to 72% of women in the control group). The level of intensity of the intervention, i.e. how often volunteers interacted with newly diagnosed women, was driven by the desires of the newly diagnosed woman. When delivered at lower intensity levels (i.e. fewer contacts) this program was not better than the standard Reach to Recovery program offered in the community. However for a small subset of women—those who took advantage of this program's extensive resources—this tailored approach seemed to be better. It is necessary to develop a way, at the time of diagnosis, to identify those women who are most likely to benefit from an intensive program so we can better target them for peer support interventions.

Participation in treatment decisions.

The hypotheses that women in the intervention group would be more likely to take an active role in treatment decisions than women in the control group and that participation in treatment decisions would be related to higher quality of life were not generally confirmed. We found no differences in the level of participation in treatment decisions between the intervention and control groups. We did find some support for the hypothesis when we stratified by education. Among women with a high school education or less (but not among more educated women), women in the intervention group were significantly more likely to report that they participated in the treatment decision for adjuvant therapy than women in the control group.

We also found that self-reported participation in treatment decisions did not seem to improve quality of life among breast cancer patients three or twelve- months from diagnosis. The advantages and disadvantages of participating in treatment decisions is a subject which has received little empirical research and requires more investigation, especially to determine how these issues vary by women of different racial/ethnic backgrounds and different approaches to medical care.

Satisfaction with Care

The hypothesis that women in the intervention group would have a greater level of satisfaction with their medical care was not confirmed. We found no differences between the intervention and the control groups on the two measures of patient satisfaction used in this study, however, as we discuss below women in the intervention group were more likely to find their volunteer contact useful than women in the control group in a number of areas.

Sociodemographic Factors

We found that on some measures less educated ethnic and minority women benefited more from the expanded peer support program than they did from the standard Reach to Recovery program and on some measures they did not. It is very difficult to know how much to make of these comparisons since the numbers of women in each racial/ethnic group are small and there are many comparisons with conflicting findings. Further study is needed in this area.

Benefits of Peer Support

For women in the intervention group, Kaiser Permanente peer support volunteers were perceived to be more useful than were the Reach to Recovery volunteers in helping newly diagnosed breast cancer patients to get needed information and to understand their breast cancer diagnosis. These two areas were the ones in women in both programs found peer support to be the most useful. Peer support volunteers were also considered more helpful than the Reach to Recovery volunteers in helping women to know what questions to ask their doctor, take better care of themselves and find out and use Kaiser Permanente resources better. They were not perceived to be more useful than the Reach to Recovery Volunteers in helping them to make treatment decisions, communicate with their doctor, deal with job stress, deal with family relationships or deal with sexual issues. It is unclear why the peer support program was not more successful in the area of doctor patient communication and treatment decision making, since this was a specific emphasis of the training. More research is needed to investigate how to better address this issue.

Other Considerations

This study had several limitations that are worth noting. It was hampered by the fact that we did not assess quality of life indicators at baseline. This was not done because we felt it would be too intrusive to do this at a time of crisis. Therefore we cannot tell whether women in the treatment and control groups differed at baseline on this crucial outcome, though the two groups are expected to be balanced with respect to these variables via the randomization procedure. We cannot tell whether there was an intervention effect modification by baseline level of quality of life.

There was also quite of bit of missing data on the quality of life scales. Women who have a life-threatening disease may find it hard to confront —and write down on a questionnaire—the difficult time they may be having, or may have had, and instead leave those questions blank. In addition our questionnaires were relatively long. We recommend that future studies of quality of life among women with breast cancer use interviews, where there is more control over missing data, instead of mailed questionnaires.

This study did not have a placebo group. We thought it unethical not to offer support services to newly diagnosed breast cancer patients. It is standard care to provide a referral to the American Cancer Society's Reach to Recovery program. Our design allows us to compare outcomes in women randomized to a tailored, expanded approach to providing peer support with those randomized to the more standard approach. We learned that, except for women in certain subgroups—notably, women who used the program the most or had the least amount of other social support resources—this expanded program may not have been better than the standard (Reach to Recovery) approach. However, we cannot tell exactly how good either program is, relative to no program.

This study had an important strength. As far as we know it is the only randomized controlled trial of a one-on-one peer support intervention for women with breast cancer (1,17,18,27). Results from this study showed that many variables affect whether or not an expanded peer support program is beneficial to women. The study has collected a large body of rich data on which further analyses are planned

References

1. Ashbury FD, Cameron C, Mercer SL, et al: One-on-one peer support and quality of life for breast cancer patients. Patient Education and Counseling 1998;35:89-100.

2. Beaver K, Luker KA, Owens RG, et al: Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs 1996;19:8-19.

3. Beisecker AE, Beisecker TD: Patient information-seeking behaviors when communicating with doctors. Med Care 1990;28:19-28.

4. Beisecker AF: Aging and the desire for information and input in medical decisions: patient consumerism in medical encounters. The Gerontologist 1988;28:330-335.

5. Bilodeau B, Degner LF: Information needs, sources of information, and decisional roles in women with breast cancer. Onc Nursing Forum 1996;23:691-696.

6. Brady MJ, Cella DF, Mo F, et al: Reliability and validity of the functional assessment of cancer therapy-breast quality-of-life instrument. J Clin Oncol 1997;15:974-986.

7. Cella DF, Tulsky DS, Gray G, et al: The functional assessment of cancer therapy scale: development and validation of the general measure. J Clin Oncol 1993;11:570-579.

8. Degner LF, Kristjanson LJ, Bowman D, et al: Information needs and decisional preferences in women with breast cancer. JAMA 1997;277:1485-1492.

9. Degner LF, Russell CA: Preferences for treatment control among adults with cancer. Research in Nursing and Health 1988;11:376-374.

10. Degner LF, Sloan JA: Decision making during serious illness: what role do patients really want to play? J Clin Oncol 1992;45:941-950.

11. Devins GM: Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. Adv Renal Replace Ther 1994;1:251-263.

12. Devins GM, Edworthy SM, Seland TP, et al: Differences in illness intrusiveness across rheumatoid arthritis, end-stage renal disease, and multiple sclerosis. J Nerv Mental Dis 1993;181:377-381.

13. Devins GM, Stam HJ, Koopmans JP: Psychosocial impact of laryngectomy mediated by perceived stigma and illness intrusiveness. Can J Psychiatry 1994;39:608-616.

14. Gandek B, Ware JE, Aaronson NK, et al: Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. International Quality of Life Assessment. J Clin Epidemiol 1998;51:1171-1178.

15. Greenfield S, Kaplan S, Ware JE: Expanding patient involvement in care. Ann Intern Med 1985;102:520-528.

16. Hack TF, Degner LF, Dyck DG: Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. Soc Sci Med 1994;39:279-289.

17. Helgeson VS, Cohen S: Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. Health Psychol 1996;15:135-148.

18. Helgeson VS, Cohen S, Schulz R, et al: Education and peer discussion group intervention and adjustment to breast cancer. Arch Gen Psychiatry 1999;56:340-347.

19. Jenkinson C, Layte R, Jenkinson D, et al: A shorter form health survey: can the SF-12 replicate results from the SF-36 in longitudinal studies? J Pub Health Med 1999;

20. Lerman C, Daly M, Walsh WP, et al: Communication between patients with breast cancer and health care providers. Cancer 1993;72:2612-2620.

21. Levine MN, Gafni A, et al. A bedside decision instrument to elicit a patient's preference concerning adjuvant chemotherapy for breast cancer. Ann Intern Med 1992;117:53-58.

22. Llewellyn-Thomas HA: Eliciting patient preferences. Ann Intern Med 1993;118:76-77.

23. Pennypacker HS, Criswell EL, Neelakantan P, et al: Toward an effective technology of instruction in breast self-examination. Int J Ment Health 1982;11:98-116.

24. Pickard AS, Johnson JA, Penn A, et al: Replicability of SF-36 summary scores by the SF-12 in stroke patients. Stroke 1999;30:1213-1217.

25. Radloff LS, Locke BZ: The community mental health assessment survey and the CES-D Scale; in Weissman MM, Myers JK, Ross CE (eds): Community surveys of psychiatric disorders. New Brunswick, NJ, Rutgers University Press, 1986, pp 177-190.

26. Radoff LS: The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement 1977;1:385-401.

27. Rogers TF, Bauman LJ, Metzger L: An assessment of the Reach to Recovery program. CA-A Cancer Journal for Clinicians 1985;35:117-124.

28. Strull WM, Lo B, Charles G: Do patients want to participate in medical decision making? JAMA 1984;252:2990-2994.

29. Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, et al: Cancer patients: their desire for information and participation in treatment decisions. J Royal Society Med 1989;82:260-263.

30. Ware J, Kosinski M, Keller SD: A 12-item short-form health survey: construction of scales and preliminary tests of reliability and validity. Med Care 1996;34:220-233.

List of Tables

Table 1: Overall Response Rates

Sent Invitation Letter	768
Enrolled in Study (N)	292
Enrolled in Study (%)	38.0%

Table 2: Response Rate by Age at Diagnosis

Age	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Under 40 years	22	9	40.9
40-49 years	150	71	47.3
50-59 years	233	106	45.5
60-69 years	198	69	34.8
70-79 years	132	30	22.7
80 plus years	21	7	33.3

Table 3: Response Rate by Race/Ethnicity

Race/Ethnicity	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
White, Non Hispanic	580	222	38.3
Black, Non Hispanic	63	21	33.3
Asian/Pacific Islander	59	18	30.5
Hispanic	42	14	33.3
Multi-ethnic/other	20	16	80.0

Table 4: Response Rate by Stage

Stage	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Insitu	112	37	33.0
Local	477	175	36.7
Regional	158	72	45.6
Distant	7	2	28.6
Unknown	10	6	60.0

Table 5: Response Rate by Facility

Facility	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Facility A	157	72	45.9
Facility B	105	26	24.8
Facility C	165	84	50.9
Facility D	83	26	31.3
Facility E	246	84	34.1

Table 6: Response Rate By Marital Status

Marital Status	Sent Invitation Letter	Enrolled in Study (N)	Enrolled in Study (%)
Single	69	25	36.2
Married	398	160	40.2
Separated	4	4	100.0
Divorced	100	51	51.0
Widowed	85	27	31.8
Domestic Partner	102	25	24.5

Table 7: Response Rate for 3 Month Survey

	Control Group N (%)	Treatment Group N (%)	Overall N (%)
Responded	132 (91.7)	144 (97.3)	276 (94.5)
Did Not Respond	12 (8.3)	4 (2.7)	16 (5.5)

Table 8: Response Rate for 12 Month Survey

	Control Group N (%)	Treatment Group N (%)	Overall N (%)
Responded	123 (85.4)	137 (92.6)	260 (89.0)
Did Not Respond	21 (14.6)	11 (7.4)	32 (11.0

Table 9: Baseline Characteristics: Treatment Group Vs. Control Group

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Facility			.99
Facility A	12 (8.3)	14 (9.6)	
Facility B	37 (25.7)	35 (24.0)	
Facility C	13 (9.0)	13 (9.0)	
Facility D	41 (28.5)	43 (29.5)	
Facility E	41 (28.5)	41 (28.1)	
Age at Intervention			.10
Under 50 Years	46 (31.9)	34 (23.3)	
50-64 Years	62 (43.1)	81 (55.5)	
65 Plus Years	36 (25.0)	31 (21.2)	
Stage at Diagnosis			.82
Insitu	15 (10.6)	22 (15.3)	
Local	87 (61.3)	86 (59.7)	
Regional	38 (26.8)	34 (23.6)	
Distant	1 (.7)	1 (.7)	
Race/Ethnicity			.83
White, Non-Hispanic	110	112	

Characteristic	**Control Group** **N** **(%)**	**Treatment Group** **N** **(%)**	**P Value***
	(76.9)	(75.7)	
Black, Non-Hispanic	11 (7.7)	10 (6.8)	
Hispanic	6 (4.2)	8 (5.4)	
Asian/Pacific Islander-Non Hispanic	10 (7.0)	8 (5.4)	
Multi-ethnic	6 (4.2)	10 (6.8)	

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Education			.36
8th Grade or Less	1 (.71)	1 (.70)	
9th-11th Grade	5 (3.6)	4 (2.8)	
High School Graduate/GED	23 (16.4)	12 (8.3)	
Some College	50 (35.7)	62 (42.8)	
4 Year College Degree	40 (28.6)	39 (26.9)	
Completed Graduate Degree	21 (15.0)	27 (18.6)	
Education (collapsed)			.04
HS Grad and Less	29 (20.7)	17 (11.7)	
At least some college	111 (79.3)	88.3 (128)	
Marital Status			.34
Single	11 (7.6)	14 (9.6)	
Married	87 (60.4)	71 (48.6)	
Domestic Partner	13 (9.0)	12 (8.2)	
Divorced	19 (13.2)	32 (21.9)	
Separated	2 (1.4)	2 (1.4)	
Widowed	12	15	

Characteristic	**Control Group** **N** **(%)**	**Treatment Group** **N** **(%)**	**P Value***
	(8.3)	(10.3)	

Characteristic	Control Group N (%)	Treatment Group N (%)	P Value*
Employment Status			.26
Working Full Time	68 (47.6)	56 (38.4)	
Working Part Time	14 (9.8)	21 (14.4)	
Homemaker	8 (5.6)	12 (8.2)	
Student	1 (.7)	0 (0)	
Temporary Medical Leave	9 (6.3)	15 (10.3)	
Permanently Disabled	1 (.7)	1 (.7)	
Retired	34 (23.8)	39 (26.7)	
Not Employed, Looking for Work	7 (4.9)	2 (1.4)	
Speak Language Other Than English in Home			.71
Yes	19 (13.2)	17 (11.7)	
No	125 (86.8)	128 (88.3)	
Comfort Speaking English			.35
Very Comfortable	17 (89.5)	14 (73.7)	
A Little Comfortable	1 (5.3)	4 (21.1)	
Not At All Comfortable	1 (5.3)	1 (5.3)	
Living Situation			.003

Characteristic	**Control Group** **N** **(%)**	**Treatment Group** **N** **(%)**	**P Value***
Live Alone	22 (15.6)	46 (31.5)	
Live with Partner, Family, Friends	118 (83.7)	97 (66.4)	
Other	1 (.7)	3 (2.1)	
How many relatives do you have that you feel close to?			.27
None	6 (4.3)	7 (4.9)	
1-2	34 (24.3)	40 (28.0)	
3-5	64 (45.7)	60 (42.0)	
6-9	15 (10.7)	24 (16.8)	
10+	21 (15.0)	12 (8.4)	
How many friends do you have that you feel close to?			.72
None	4 (2.9)	3 (2.1)	
1-2	21 (15.3)	27 (19.0)	
3-5	51 (37.2)	56 (39.4)	
6-9	28 (20.4)	21 (14.8)	
10+	33 (24.1)	35 (24.7)	

*Chi-Square

Table 10: Effect of Intervention at Three Months—Unadjusted Analyses

Scale	Control Group Mean (SD)	Treatment Group Mean (SD)	P Value*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	111.2 (20.2)	110.7 (18.3)	0.83
Physical Well-Being	21.7 (5.8)	21.8 (5.9)	0.87
Social/Family Well-Being	23.3 (4.5)	22.7 (4.6)	0.28
Functional Well-Being	20.2 (5.6)	20.8 (5.3)	0.33
Emotional Well-Being	16.6 (3.0)	16.7 (2.9)	0.78
Relationship with Doctor	6.7 (1.5)	6.6 (1.6)	0.59
Additional Concerns	25.2 (6.2)	25.1 (5.9)	0.84
Normed-Based SF-12 Mental Component	50.4 (9.7)	47.8 (9.8)	0.03
Normed-Based SF-12 Physical Component	45.0 (9.3)	45.1 (9.3)	0.93
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	10.3 (9.2)	10.9 (8.3)	0.58
Illness Intrusiveness Scale	33.9 (18.7)	34.2 (17.2)	0.92
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2 (0.8)	4.1 (1.0)	0.31
Satisfaction scale	4.0 (0.8)	4.0 (.9)	0.80
Participation in decisions about surgery	3.6 (1.0)	3.5 (0.9)	0.97
Participation in decisions about adjuvant therapy	2.5 (1.3)	2.6 (1.4)	0.60
Should go along with Dr even if disagree	1.8 (0.7)	1.8 (0.7)	.98

*t-test

**comprised of 5 questions on satisfaction (care before surgery, care in hospital, follow-up care, amount of information received, and amount of emotional support received)

Table 11: Effect of Intervention at Twelve Months—Unadjusted Analyses

Scale	Control Group Mean (SD)	Treatment Group Mean (SD)	P Value*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	115.9 (19.0)	113.0 (19.2)	0.22
Physical Well-Being	24.2 (4.8)	23.3 (5.3)	0.14
Social/Family Well-Being	23.2 (4.9)	22.7 (4.8)	0.38
Functional Well-Being	22.4 (5.2)	21.3 (5.3)	0.10
Emotional Well-Being	16.9 (2.6)	16.5 (3.2)	0.31
Relationship with Doctor	6.5 (1.9)	6.6 (1.7)	0.63
Additional Concerns	24.7 (6.3)	25.2 (5.5)	0.48
Normed-Based SF-12 Mental Component	47.0 (17.7)	44.3 (18.2)	0.01
Normed-Based SF-12 Physical Component	48.0 (9.9)	47.3 (10.4)	0.57
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	9.1 (9.2)	10.3 (9.4)	0.31
Illness Intrusiveness Scale	29.9 (17.7)	30.6 (18.2)	0.75
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1 (0.9)	4.0 (0.9)	0.33
Satisfaction scale	3.9 (0.9)	3.9 (0.9)	0.74
Should go along with Dr. even if disagree	2.1 (0.8)	1.9 (0.8)	0.16

Table 12: Effect of Intervention at Three Months, Controlling for Education and Living Status

Scale	Control Group Adjusted Mean	Treatment Group Adjusted Mean	P Value (main effect)*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	110.4	109.1	0.60
Physical Well-Being	21.9	21.7	0.80
Social/Family Well-Being	23.3	22.7	0.25
Functional Well-Being	19.8	20.3	0.49
Emotional Well-Being	16.8	16.6	0.60
Relationship with Doctor	6.8	6.6	0.38
Additional Concerns	25.1	24.6	0.51
Normed-Based SF-12 Mental Component	50.1	47.2	0.02
Normed-Based SF-12 Physical Component	45.0	44.9	0.91
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	10.9	11.8	0.39
Illness Intrusiveness Scale	32.7	33.3	0.82
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2	4.1	0.23
Satisfaction scale	4.0	4.0	0.84
Participation in decisions about surgery	3.4	3.4	0.78
Participation in decisions about adjuvant therapy	2.5	2.6	0.52
Should go along with Dr even if disagree	2.0	2.0	0.80

Table 13: Effect of Intervention at Twelve Months, Controlling for Education and Living Status

Scale	Control Group Adjusted Mean	Treatment Group Adjusted Mean	P Value*
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	116.0	112.6	0.16
Physical Well-Being	24.3	23.2	0.08
Social/Family Well-Being	23.4	22.9	0.41
Functional Well-Being	22.2	21.0	0.06
Emotional Well-Being	17.2	16.6	0.13
Relationship with Doctor	6.6	6.8	0.59
Additional Concerns	24.8	25.1	0.72
Normed-Based SF-12 Mental Component	47.1	44.3	0.01
Normed-Based SF-12 Physical Component	47.9	46.4	0.24
Center for Epidemiologic Studies Depression Scale (CES-D)—Short Form	9.9	11.3	0.34
Illness Intrusiveness Scale	28.4	29.3	0.71
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	4.0	0.44
Satisfaction scale	3.9	3.9	0.99
Should go along with Dr. even if disagree	2.2	2.1	0.19

***Analysis of Variance**

Table 14: The Effect of Social Support on Quality of Life, Satisfaction with Health Care and Participation in Treatment Decisions at 3 Months

Outcome	Social Support		P Value
	Low Support	High Support	
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	99.0	114.7	0.0001
Physical Well-Being	20.9	22.3	0.09
Social/Family Well-Being	20.0	24.4	0.0001
Functional Well-Being	17.4	21.3	0.0001
Emotional Well-Being	15.4	17.4	0.0001
Relationship with Doctor	6.4	6.9	0.01
Additional Concerns	23.1	25.7	0.0007
Normed-Based SF-12 Mental Component	45.1	50.4	0.001
Normed-Based SF-12 Physical Component	43.5	45.4	0.13
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	15.1	9.5	0.0001
Illness Intrusiveness Scale	36.9	30.9	0.01
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	3.8	4.1	0.006
Satisfaction scale	4.1	4.2	0.46
Participation in decisions about surgery	3.2	3.5	0.05
Participation in decisions about adjuvant therapy	2.5	2.6	0.78
Should go along with Dr even if disagree	2.1	1.9	0.04

Table 15: The Effect of Social Support on Quality of Life, Satisfaction with Health Care and Participation in Treatment Decisions at 12 Months

Outcome	Social Support		P Value
	Low Support	High Support	
Functional Assessment of Cancer Therapy Scales (F.A.C.T.)—Overall	104.4	119.0	0.0001
Physical Well-Being	22.8	24.1	0.06
Social/Family Well-Being	20.1	24.7	0.0001
Functional Well-Being	19.0	22.8	0.0001
Emotional Well-Being	16.2	17.2	0.02
Relationship with Doctor	6.1	7.0	0.0001
Additional Concerns	23.4	25.8	0.002
Normed-Based SF-12 Mental Component	42.9	46.9	0.0003
Normed-Based SF-12 Physical Component	44.9	48.2	0.01
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	14.5	8.8	0.0001
Illness Intrusiveness Scale	33.4	26.6	0.004
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	3.8	4.2	0.005
Satisfaction scale	3.7	4.0	0.005
Should go along with Dr even if disagree	2.1	2.2	0.65

Table 16 : Test for Interaction Between Intervention and Social Support, Controlling for Education and Living Status at 3 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Social Support P value	Interaction: Txt vs. Cont by Soc spt P value
F.A.C.T			
Overall	P=0.40	P<0.0001	P=0.76
Physical Well- Being	P=0.77	P=0.08	P=0.73
Social and Family Well-Being	P=0.08	P<0.0001	P=0.96
Functional Well-Being	P=0.49	P<0.0001	P=0.31
Emotional Well-Being	P=0.19	P<0.0001	P=0.37
Relationship with Doctor	P=0.65	P=0.0077	P=0.33
Additional Concerns	P=0.42	P=0.0005	P=0.80
Normed-Based SF-12			
Mental Component	P=0.02	P<0.0001	P=0.74
Physical Component	P=0.80	P=0.11	P=0.25
Center for Epidemiologic Studies Depression Scale (CES-D)—Short Form	P=0.47	P<0.0001	P=0.23
Illness Intrusiveness Scale	P=0.97	P=0.01	P=0.38
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.25	P=0.34	P=0.90
Satisfaction scale	P=0.0.85	P=0.006	P=0.49
Participation in decisions about surgery	P=0.98	P=0.05	P=0.72
Participation in decisions about adjuvant therapy	P=0.83	P=0.81	P=0.40
Should go along with Dr even if disagree	P=0.59	P=0.02	P=0.55

Table 17: Test for Interaction Between Intervention and Social Support, Controlling for Education and Living Status at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Social Support P value	Interaction: Txt vs. Cont by Soc spt P value
F.A.C.T			
Overall	P=0.42	P<0.0001	P=0.03
Physical Well- Being	P=0.36	P=0.03	P=0.01
Social and Family Well-Being	P=0.53	P<0.0001	P=0.42
Functional Well-Being	P=0.16	P<0.0001	P=0.15
Emotional Well-Being	P=0.26	P=0.01	P=0.30
Relationship with Doctor	P=0.34	P<.0001	P=0.17
Additional Concerns	P=0.37	P=0.002	P=0.08
Normed-Based SF-12			
Mental Component	P=0.04	P=0.003	P=0.30
Physical Component	P=0.69	P=0.006	P=0.03
Center for Epidemiologic Studies Depression Scale (CES-D)—Short Form	P=0.64	P<.0001	P=0.02
Illness Intrusiveness Scale	P=0.998	P=0.002	P=0.28
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.42	P=0.006	P=0.86
Satisfaction scale	P=0.83	P=0.003	P=0.45
Should go along with Dr even if disagree	P=0.11	P=0.72	P=0.25

Table 18: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Social Support at 3 Months

	Social Support					
	Low Social Support (N=79)			High Social Support (N=196)		
Outcome	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	99.6	97.5	0.67	115.8	113.0	0.28
Physical Well Being	20.4	20.1	0.87	22.6	22.2	0.59
Social/Family Well Being	20.5	19.5	0.45	24.8	23.8	0.06
Functional Well Being	17.0	18.2	0.40	21.4	21.1	0.66
Emotional Well Being	15.7	14.8	0.27	17.3	17.2	0.78
Relationship with Doctor	6.1	6.2	0.84	7.1	6.8	0.15
Additional Concerns	24.0	22.7	0.39	25.6	25.2	0.69
Norm-based SF-12 Mental Component	46.3	43.5	0.24	51.9	48.7	0.02
Physical Component	42.8	44.9	0.39	46.4	44.9	0.28
CES-D	14.5	14.1	0.89	9.0	11.0	0.08
Illness Intrusiveness	36.0	35.0	0.84	31.3	32.9	0.54
Satisfaction Scale	3.8	3.9	0.70	4.2	4.0	0.40
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	3.9	0.35	4.2	4.2	0.64
Participation in treatment decisions regarding surgery	3.2	3.2	0.81	3.5	3.6	0.71
Participation in treatment decisions regarding adjuvant therapy	2.7	2.6	0.61	2.4	2.6	0.22
Should go along with doctor even if you disagree	2.1	2.1	0.71	1.9	1.9	0.73

Table 19: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Social Support at 12 Months

	Social Support					
	Low Social Support (N=68)			High Social Support (N=188)		
Outcome	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	99.1	102.1	0.47	124.2	117.3	0.01
Physical Well Being	22.2	23.1	0.39	25.1	23.1	0.01
Social/Family Well Being	19.4	19.8	0.74	25.4	24.6	0.17
Functional Well Being	18.1	18.1	0.99	24.4	22.4	0.01
Emotional Well Being	15.4	15.4	0.95	18.0	17.2	0.08
Relationship with Doctor	5.7	6.2	0.29	7.1	7.0	0.85
Additional Concerns	21.5	23.3	0.17	26.5	25.9	0.53
Norm-based SF-12 Mental Component	42.7	41.5	0.53	49.3	45.7	0.005
Physical Component	42.5	44.8	0.34	50.2	47.1	0.04
CES-D	18.5	16.6	0.32	5.7	8.9	0.02
Illness Intrusiveness	35.3	32.9	0.58	26.1	27.5	0.61
Satisfaction Scale	3.5	3.6	0.58	4.0	4.0	0.82
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	3.8	3.7	0.60	4.2	4.2	0.63
Should go along with doctor even if you disagree	2.3	2.0	0.08	2.1	2.1	0.90

Table 20: Level of Participation in Peer Support Program or Reach to Recovery Program as Reported by Participants

	Visits				
Phone Calls	0	1-2	3-5	6-10	11+
0	None	Low	Low	Moderate	High
1-2	Low	Low	Moderate	Moderate	High
3-5	Low	Moderate	Moderate	Moderate	High
6-10	Moderate	Moderate	Moderate	High	High
11+	High	High	High	High	High

Table 21: Level of participation in Reach to Recovery or Kaiser Permanente Peer Support Program

Level of Participation	Reach to Recovery % (n)	Kaiser Permanente Peer Support Program % (n)
None	50.4 (59)	13.3 (17)
Low	35.9 (42)	35.2 (45)
Moderate	7.7 (9)	32.0 (41)
High	6.0 (7)	19.5 (25)

Table 22: Test for Interaction Between the Intervention and Level of Participation in the Peer Support Program, controlling for Education and Living Situation at 3 months

Scale	Main effect: Treatment vs. Control P value	Main effect: Level of Participation Support P value	Interaction: Txt vs. Cont by Level P value
F.A.C.T			
Overall	P=0.66	P=0.49	P=0.94
Physical Well- Being	P=0.56	P=0.29	P=0.89
Social and Family Well-Being	P=0.64	P=0.57	P=0.93
Functional Well-Being	P=0.16	P=0.47	P=0.85
Emotional Well-Being	P=0.76	P=0.23	P=0.37
Relationship with Doctor	P=0.67	P=0.15	P=0.15
Additional Concerns	P=0.97	P=0.64	P=0.89
Normed-Based SF-12			
Mental Component	P=0.80	P=0.22	P=0.14
Physical Component	P=0.60	P=0.98	P=0.66
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.78	P=0.45	P=0.69
Illness Intrusiveness Scale	P=0.41	P=0.07	P=0.96
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.54	P=0.86	P=0.11
Satisfaction scale	P=0.56	P=0.84	P=0.07
Participation in decisions about surgery	P=0.64	P=0.28	P=0.34
Participation in decisions about adjuvant therapy	P=0.51	P=0.34	P=0.62
Should go along with Dr even if disagree	P=0.32	P=0.01	P=0.09

Table 23: The Test for Interaction Between the Intervention and Participation in the Peer Support Program Controlling for Education and Living Situation at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Level of Participation P value	Interaction: Txt vs. Cont by Level P value
F.A.C.T			
Overall	P=0.50	P=0.66	P=0.42
Physical Well- Being	P=0.25	P=0.44	P=0.30
Social and Family Well-Being	P=0.35	P=0.29	P=0.51
Functional Well-Being	P=0.41	P=0.74	P=0.42
Emotional Well-Being	P=0.15	P=0.44	P=0.63
Relationship with Doctor	P=0.98	P=0.49	P=0.21
Additional Concerns	P=0.22	P=0.26	P=0.33
Normed-Based SF-12			
Mental Component	P=0.24	P=0.39	P=0.06
Physical Component	P=0.60	P=0.65	P=0.04
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.50	P=0.15	P=0.23
Illness Intrusiveness Scale	P=0.34	P=0.04	P=0.62
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.62	P=0.53	P=0.20
Satisfaction scale	P=0.63	P=0.66	P=0.18
Should go along with Dr. even if disagree	P=0.33	P=0.95	P=0.32

Table 24: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Participation in the Peer Support Program at 3 Months

	Participation in Peer Support Program or Reach to Recovery								
	Low Participation (N=86)			Moderate Participation (N=49)			High Participation (N=32)		
Outcomes	C Mean	T Mean	P Value	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	115.2	115.8	0.90	106.4	105.1	0.88	105.9	111.1	0.47
Physical Well Being	22.7	23.1	0.71	18.4	20.4	0.41	21.2	22.5	0.67
Social/Family Well Being	25.2	25.0	0.79	23.7	22.0	0.38	23.1	22.5	0.74
Functional Well Being	20.1	21.3	0.31	19.9	19.4	0.80	18.2	21.6	0.21
Emotional Well Being	17.2	17.1	0.84	17.2	16.0	0.30	16.8	17.3	0.77
Relationship with doctor	7.1	6.5	0.06	6.0	6.4	0.60	6.7	6.7	1.0
Additional Concerns	26.5	27.1	0.70	24.8	23.6	0.61	22.9	22.7	0.94
Norm-based SF-12 Mental Component	54.3	49.5	0.03	47.8	46.2	0.70	42.3	45.5	0.50
Physical Component	43.9	44.9	0.69	46.8	45.3	0.66	44.7	44.3	0.92
CES-D	8.7	7.9	0.71	9.1	12.2	0.38	16.2	13.1	0.51
Illness Intrusiveness	28.3	25.0	0.40	35.1	35.4	0.97	41.5	46.0	0.65
Satisfaction Scale	4.2	3.9	0.05	3.9	4.2	0.34	4.0	4.2	0.61
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.3	3.9	0.03	4.2	4.3	0.89	4.3	4.0	0.58
Participation in treatment decisions regarding surgery	3.5	3.6	0.88	4.0	3.5	0.17	3.1	3.4	0.63
Participation in treatment decisions regarding adjuvant therapy	2.5	2.4	0.80	2.3	2.6	0.66	2.0	2.1	0.78
Should go along with doctor even if you disagree	1.9	1.8	0.77	1.9	2.0	0.61	1.7	1.4	0.38

Table 25: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Participation in the Peer Support Program at 12 Months

	Participation in Peer Support Program or Reach to Recovery								
	Low Participation (N=87)			Moderate Participation (N=49)			High Participation (N=32)		
Outcomes	C Mean	T Mean	P Value	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	115.0	111.8	0.50	121.0	110.0	0.15	104.4	122.3	0.004
Physical Well Being	23.4	21.5	0.19	25.4	23.9	0.30	21.1	25.5	0.05
Social/Family Well Being	23.4	24.4	0.42	24.4	20.9	0.09	24.6	25.1	0.77
Functional Well Being	21.6	20.5	0.39	23.0	20.4	0.21	19.7	24.2	0.05
Emotional Well Being	17.5	16.2	0.08	17.9	16.4	0.18	15.1	16.9	0.13
Relationship with doctor	6.9	6.9	0.97	6.6	6.7	0.95	7.4	6.9	0.37
Additional Concerns	24.4	24.7	0.82	25.9	24.7	0.63	20.4	26.3	0.008
Norm-based SF-12 Mental Component	48.1	42.2	0.004	41.7	44.6	0.07	39.1	45.9	0.15
Physical Component	46.9	45.3	0.53	46.7	47.0	0.16	40.4	49.8	0.09
CES-D	8.9	10.7	0.36	5.3	10.7	0.09	17.5	10.1	0.15
Illness Intrusiveness	31.8	30.6	0.80	30.4	34.1	0.62	41.8	27.9	0.15
Satisfaction Scale	4.0	3.7	0.18	3.6	3.9	0.56	4.0	4.1	0.77
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2	3.9	0.15	4.0	4.0	0.93	4.5	4.3	0.55
Should go along with doctor even if you disagree	2.2	2.1	0.36	2.8	2.2	0.04	2.1	1.6	0.30

Table 26: Test for Interaction between Intervention and Education Controlling for Living Status at 3 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Education P value	Interaction: Txt vs. Cont by Education P value
F.A.C.T			
Overall	P=0.53	P=0.17	P=0.72
Physical Well- Being	P=0.66	P=0.43	P=0.71
Social and Family Well-Being	P=0.51	P=0.80	P=0.80
Functional Well-Being	P=0.78	P=0.10	P=0.73
Emotional Well-Being	P=0.48	P=0.27	P=0.64
Relationship with Doctor	P=0.84	P=0.94	P=0.53
Additional Concerns	P=0.34	P=0.12	P=0.49
Normed-Based SF-12			
Mental Component	P=0.15	P=0.51	P=0.68
Physical Component	P=0.26	P=0.41	P=0.12
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.21	P=0.07	P=0.35
Illness Intrusiveness Scale	P=0.33	P=0.57	P=0.24
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.86	P=0.96	P=0.29
Satisfaction scale	P=0.86	P=0.66	P=0.97
Participation in decisions about surgery	P=0.33	P=0.32	P=0.27
Participation in decisions about adjuvant therapy	P=0.04	P=0.97	P=0.02
Should go along with Dr even if disagree	P=0.10	P<0.0001	P=0.03

Table 27: Test for Interaction between Intervention and Education Controlling for Living Status at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Education P value	Interaction: Txt vs. Cont by education P value
F.A.C.T			
Overall	P=0.15	P=0.48	P=0.53
Physical Well- Being	P=0.36	P=0.35	P=0.62
Social and Family Well-Being	P=0.42	P=0.54	P=0.77
Functional Well-Being	P=0.08	P=0.27	P=0.55
Emotional Well-Being	P=0.008	P=0.48	P=0.02
Relationship with Doctor	P=0.34	P=0.21	P=0.41
Additional Concerns	P=0.95	P=0.45	P=0.64
Normed-Based SF-12			
Mental Component	P=0.04	P=0.61	P=0.77
Physical Component	P=0.30	P=0.11	P=0.80
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.16	P=0.02	P=0.44
Illness Intrusiveness Scale	P=0.64	P=0.59	P=0.77
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.52	P=0.88	P=0.91
Satisfaction Scale	P=0.98	P=0.72	P=0.98
Should go along with doctor even if disagree	P=0.93	P=0.005	P=0.21

Table 28: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation Stratified by Education at 3 Months

	Education					
	HS Grad and less (N=43)			At least some college (N=231)		
Outcome	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	108.6	105.6	0.81	112.5	111.2	0.64
Physical Well Being	21.5	20.8	0.73	22.3	22.1	0.81
Social/Family Well Being	23.3	23.0	0.81	23.3	22.6	0.27
Functional Well Being	19.1	19.2	0.97	20.6	21.1	0.49
Emotional Well Being	17.0	16.2	0.48	16.9	16.9	0.87
Relationship with Doctor	6.6	6.8	0.76	6.8	6.6	0.22
Additional Concerns	24.1	22.8	0.52	25.9	25.4	0.54
Norm-based SF-12 Mental Component	49.7	47.6	0.48	50.6	47.7	0.03
Physical Component	46.2	41.9	0.12	45.1	45.6	0.69
CES-D	10.3	14.1	0.19	10.0	10.4	0.72
Illness Intrusiveness	30.0	36.1	0.29	34.3	33.9	0.86
Satisfaction Scale	4.1	4.0	0.87	4.0	4.0	0.91
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2	4.3	0.75	4.2	4.1	0.26
Participation in treatment decisions regarding surgery	3.3	3.6	0.36	3.5	3.5	0.96
Participation in treatment decisions regarding adjuvant therapy	1.8	3.0	0.005	2.7	2.6	0.66
Should go along with doctor even if you disagree	2.1	2.5	0.11	1.8	1.7	0.65

Table 29:The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation Stratified by Education at 12 Months

	Education					
	HS Grad or Less (N=40)			At least some college (N=217)		
Outcome	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	117.3	109.7	0.31	116.6	113.8	0.27
Physical Well Being	24.0	23.3	0.69	24.7	23.5	0.10
Social/Family Well Being	23.9	22.9	0.56	23.1	22.7	0.59
Functional Well Being	22.3	20.1	0.30	22.6	21.5	0.11
Emotional Well Being	17.9	15.4	0.05	17.1	16.9	0.63
Relationship with Doctor	6.7	7.2	0.45	6.5	6.5	0.86
Additional Concerns	23.8	23.9	0.96	25.3	25.6	0.76
Norm-based SF-12 Mental Component	47.8	43.9	0.13	47.2	44.6	0.03
Physical Component	46.8	44.5	0.48	49.2	47.9	0.37
CES-D	11.2	14.5	0.40	8.2	9.4	0.32
Illness Intrusiveness	28.3	29.9	0.78	29.3	29.8	0.85
Satisfaction Scale	3.9	3.9	0.98	3.9	3.9	0.94
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2	4.0	0.62	4.1	4.0	0.51
Should go along with doctor even if you disagree	2.4	2.5	0.68	2.0	1.9	0.11

Table 30: Test for Interaction between Intervention and Race/Ethnicity Controlling for Education and Living Status at 3 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Race/ethnicity P value	Interaction: Txt vs. Cont by Race/ethnicity P value
F.A.C.T			
Overall	P=0.23	P=0.41	P=0.57
Physical Well- Being	P=0.69	P=0.12	P=0.80
Social and Family Well-Being	P=0.30	P=0.63	P=0.66
Functional Well-Being	P=0.70	P=0.87	P=0.78
Emotional Well-Being	P=0.32	P=0.68	P=0.34
Relationship with Doctor	P=0.18	P=0.45	P=0.03
Additional Concerns	P=0.40	P=0.05	P=0.68
Normed-Based SF-12			
Mental Component	P=0.57	P=0.91	P=0.70
Physical Component	P=0.24	P=0.007	P=0.30
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.39	P=0.45	P=0.65
Illness Intrusiveness Scale	P=0.95	P=0.05	P=0.97
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.38	P=0.72	P=0.03
Satisfaction scale	P=0.31	P=0.96	P=0.39
Participation in decisions about surgery	P=0.80	P=0.98	P=0.81
Participation in decisions about adjuvant therapy	P=0.94	P=0.11	P=0.61
Should go along with Dr even if disagree	P=0.69	P=0.11	P=0.89

Table 31: Test for Interaction Between Intervention and Race/Ethnicity Controlling for Education and Living Status at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Race/ethnicity P value	Interaction: Txt vs. Cont race/ethnicity P value
F.A.C.T			
Overall	P=0.02	P=0.07	P=0.22
Physical Well- Being	P=0.05	P=0.006	P=0.66
Social and Family Well-Being	P=0.78	P=0.12	P=0.59
Functional Well-Being	P=0.008	P=0.33	P=0.25
Emotional Well-Being	P=0.03	P=0.57	P=0.35
Relationship with Doctor	P=0.69	P=0.81	P=0.06
Additional Concerns	P=0.37	P=0.18	P=0.58
Normed-Based SF-12			
Mental Component	P=0.001	P=0.88	P=0.11
Physical Component	P=0.77	P=0.03	P=0.38
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.13	P=0.20	P=0.77
Illness Intrusiveness Scale	P=0.62	P=0.0003	P=0.74
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.34	P=0.96	P=0.11
Satisfaction scale	P=0.63	P=0.90	P=0.07
Should go along with Dr. even if disagree	P=0.34	P=0.43	P=0.64

Table 32: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified Race/Ethnicity at 3 Months

	Race/Ethnicity														
	Asian/Pacific Islander N=18			African American N=19			Hispanic N=11			White N=212			Multi-Ethnic N=15		
Outcome	C	T	P Value	C	T	P Value	C	T	P Value	C	T	P Value	C	T	P Value
FACT Scale Overall	109.0	108.7	0.98	107.8	107.3	0.97	103.5	100.0	0.82	110.6	110.8	0.94	111.3	107.7	0.77
Physical Well Being	23.2	22.1	0.69	19.4	23.0	0.28	18.6	16.3	0.67	22.3	22.0	0.72	19.9	22.0	0.58
Social/Family Well Being	23.0	24.7	0.33	23.6	22.7	0.66	22.0	21.9	0.97	23.4	23.1	0.66	22.6	18.6	0.31
Functional Well Being	19.4	20.7	0.63	18.7	18.2	0.87	20.3	18.5	0.62	20.0	21.0	0.21	19.5	21.2	0.60
Emotional Well Being	16.8	17.3	0.79	16.3	18.0	0.24	16.2	14.8	0.65	16.7	16.7	0.92	18.1	17.3	0.64
Relationship with Doctor	5.9	5.8	0.94	7.1	6.9	0.84	6.3	7.0	0.57	6.7	6.7	0.94	7.3	5.3	0.18
Additional Concerns	23.8	22.6	0.79	24.1	23.5	0.87	21.5	23.6	0.71	25.3	24.8	0.51	25.2	25.8	0.89
Norm-based SF-12 Mental Component	52.7	54.0	0.80	50.5	43.9	0.25	44.8	50.2	0.50	50.2	47.2	0.04	49.5	52.8	0.62
Physical Component	42.7	42.6	0.97	39.8	42.2	0.73	46.4	33.7	0.02	45.7	46.1	0.77	44.1	44.6	0.93
CES-D	10.0	3.9	0.31	13.7	17.3	0.53	14.1	14.1	1.0	10.3	11.1	0.52	8.7	9.6	0.81
Illness Intrusiveness	33.4	25.3	0.45	45.4	31.4	0.15	44.4	46.7	0.84	30.1	31.3	0.62	45.5	31.4	0.26
Satisfaction Scale	3.8	3.9	0.88	4.4	3.8	0.10	3.8	4.1	0.71	4.0	4.1	0.50	3.8	3.7	0.88
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	3.9	3.8	0.86	4.4	3.9	0.21	3.8	5.0	0.02	4.2	4.2	0.85	4.2	3.6	0.50
How were decisions made regarding surgery	3.2	3.8	0.25	3.4	3.4	0.99	3.7	3.2	0.25	3.4	3.5	0.66	3.4	3.0	0.52
How were decisions made regarding adjuvant treatment	1.8	1.58	0.71	2.1	3.1	0.17	3.3	3.6	0.80	2.5	2.5	0.96	3.8	2.5	0.21
Should go along with doctor even if you disagree	2.3	1.9	0.34	2.1	2.1	0.93	1.9	1.8	0.90	1.9	2.0	0.77	1.6	1.7	0.81

Table 33:The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Race/Ethnicity at 12 Months

	Race/Ethnicity														
	Asian/Pacific Islander N=16			African American N=16			Hispanic N=11			White N=203			Multi-Ethnic N=13		
Outcome	C	T	P Value	C	T	P Value	C	T	P Value	C	T	P Value	C	T	P Value
FACT Scale Overall	117.2	104.7	0.30	113.2	103.8	0.53	109.2	101.4	0.71	115.2	114.9	0.90	120.8	111.3	0.56
Physical Well Being	23.9	23.1	0.80	22.1	21.2	0.84	21.1	19.3	0.74	24.2	23.7	0.45	24.5	22.1	0.63
Social/Family Well Being	24.9	24.6	0.84	22.7	23.1	0.89	21.1	21.6	0.92	23.4	23.1	0.67	23.5	23.1	0.88
Functional Well Being	21.8	18.4	0.20	21.5	17.3	0.41	22.0	18.5	0.48	22.2	21.7	0.51	24.3	20.3	0.32
Emotional Well Being	16.7	17.2	0.80	18.1	14.8	0.16	16.6	14.4	0.66	16.9	16.9	0.80	18.3	17.1	0.60
Relationship with Doctor	5.8	6.3	0.65	6.0	7.3	0.33	6.5	6.6	0.93	6.7	6.9	0.46	7.0	5.6	0.48
Additional Concerns	23.4	19.5	0.34	25.3	23.7	0.67	22.4	22.4	0.99	24.9	25.6	0.38	25.3	25.3	1.0
Norm-based SF-12 Mental Component	50.0	36.3	0.004	49.9	38.5	0.02	47.1	42.4	0.15	46.3	45.0	0.31	48.5	45.8	0.72
Physical Component	42.3	52.4	0.05	43.0	43.7	0.93	39.6	41.3	0.85	48.3	47.1	0.40	52.2	44.0	0.18
CES-D	9.9	9.9	0.99	12.8	16.0	0.68	11.2	18.6	0.56	9.3	10.2	0.50	8.4	12.1	0.59
Illness Intrusiveness	39.7	28.7	0.39	36.8	36.2	0.42	49.5	50.5	0.96	25.6	26.2	0.83	38.7	46.6	0.70
Satisfaction Scale	3.7	3.6	0.70	4.0	3.8	0.78	3.2	4.2	0.18	3.9	3.9	0.52	4.2	3.6	0.52
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	4.0	0.77	4.1	3.9	0.71	3.7	4.4	0.44	4.0	4.0	0.89	4.5	3.6	0.36
Should go along with doctor even if you disagree	2.8	2.4	0.44	2.1	1.8	0.32	1.9	2.5	0.49	2.2	2.1	0.39	2.4	1.5	0.30

Table 34: Test for Interaction Between Intervention and Stage at Diagnosis Controlling for Education and Living Status at 3 Months

	Stage at Diagnosis		
Outcomes	Main Effect Control vs. Treatment P Value	Main Effect Stage P Value	Interaction Stage By Control/Treatment P Value
FACT Scale Overall	0.40	0.07	0.71
Physical Well Being	0.43	0.001	0.49
Social/Family Well Being	0.10	0.97	0.41
Functional Well Being	0.91	0.12	0.60
Emotional Well Being	0.34	0.19	0.19
Relationship with doctor	0.92	0.85	0.28
Additional Concerns	0.58	0.13	0.99
Norm-based SF-12 Mental Component	0.02	0.45	0.32
Physical Component	0.87	0.09	1.0
CES-D	0.32	0.54	0.35
Illness Intrusiveness	0.89	0.001	0.93
Satisfaction Scale	0.65	0.65	0.66
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	0.44	0.62	0.91
How were treatment decisions made regarding surgery	0.22	0.03	0.20
How were treatment decisions made regarding adjuvant therapy	0.03	0.03	0.04
Should go along with doctor even if you disagree	0.85	0.59	0.03

Table 35: Test for Interaction between Intervention and Stage at Diagnosis Controlling for Education and Living Status at 12 Months

	Stage at Diagnosis		
Outcomes	Main Effect Control vs. Treatment P Value	Main Effect Stage P Value	Interaction Stage By Control/Treatment P Value
FACT Scale Overall	0.28	0.14	0.74
Physical Well Being	0.05	0.01	0.48
Social/Family Well Being	0.26	0.56	0.52
Functional Well Being	0.34	0.70	0.71
Emotional Well Being	0.54	0.16	0.19
Relationship with doctor	0.81	0.69	0.80
Additional Concerns	0.54	0.06	0.52
Norm-based SF-12 Mental Component	0.04	0.86	0.32
Physical Component	0.78	0.20	0.12
CES-D	0.32	0.54	0.35
Illness Intrusiveness	0.86	0.005	0.99
Satisfaction Scale	0.82	0.35	0.95
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	0.27	0.88	0.16
Should go along with doctor even if you disagree	0.41	0.43	0.92

Table 36: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Stage at Diagnosis at 3 Months

	Stage								
	Insitu			Local			Distant/Regional		
Outcomes	C Mean	T Mean	P Value	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	115.2	108.2	0.35	112.2	111.5	0.83	102.8	102.9	0.99
Physical Well Being	23.6	21.6	0.30	22.0	22.3	0.79	20.4	20.4	0.97
Social/Family Well Being	23.5	21.6	0.25	23.4	23.3	0.94	22.9	21.6	0.27
Functional Well Being	23.5	21.6	0.36	20.3	20.8	0.52	17.5	18.5	0.49
Emotional Well Being	16.9	15.0	0.19	16.9	17.1	0.70	16.1	16.5	0.61
Relationship with doctor	7.5	7.4	0.88	7.0	6.6	0.07	6.1	6.3	0.66
Additional Concerns	24.0	23.5	0.80	25.8	25.1	0.50	23.3	23.1	0.92
Norm-based SF-12 Mental Component	51.5	44.0	0.09	49.9	49.2	0.64	48.1	44.3	0.16
Physical Component	49.0	48.1	0.83	45.4	45.0	0.80	43.1	42.9	0.91
CES-D	11.9	15.3	0.36	10.9	10.0	0.50	12.7	14.2	0.53
Illness Intrusiveness	35.7	37.3	0.82	30.1	29.2	0.75	42.3	42.6	0.96
Satisfaction Scale	4.4	4.1	0.41	4.1	4.1	0.73	3.7	3.7	0.76
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.9	4.5	0.35	4.3	4.2	0.23	3.7	3.7	0.95
Participation in treatment decisions regarding surgery	2.7	3.1	0.30	3.5	3.4	0.46	3.4	3.7	0.23
Participation in treatment decisions regarding adjuvant therapy	2.0	3.2	0.09	2.7	2.5	0.47	2.0	2.4	0.13
Should go along with doctor even if you disagree	1.6	1.8	0.48	1.9	2.1	0.15	2.1	1.8	0.04

Table 37: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Stage at Diagnosis at 12 Months

	Stage								
	Insitu			Local			Distant/Regional		
Outcomes	C Mean	T Mean	P Value	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	125.0	120.9	0.56	117.1	114.4	0.39	110.4	103.5	0.21
Physical Well Being	28.5	25.7	0.14	24.4	23.6	0.29	23.1	21.0	0.21
Social/Family Well Being	25.8	23.2	0.16	23.1	23.1	0.98	23.5	23.0	0.69
Functional Well Being	25.7	24.8	0.55	22.6	21.0	0.08	20.6	19.3	0.39
Emotional Well Being	17.0	17.1	0.99	17.4	17.0	0.38	16.5	15.4	0.21
Relationship with doctor	7.3	7.2	0.93	6.7	7.0	0.31	6.1	6.0	0.78
Additional Concerns	24.7	26.4	0.45	25.2	25.6	0.67	23.8	23.0	0.63
Norm-based SF-12 Mental Component	43.7	42.5	0.75	47.1	43.4	0.20	46.8	41.7	0.02
Physical Component	52.9	55.3	0.54	49.4	46.0	0.04	43.2	43.5	0.90
CES-D	9.6	9.3	0.92	9.3	10.2	0.57	11.8	15.2	0.17
Illness Intrusiveness	22.2	26.5	0.59	26.0	26.3	0.90	36.9	37.2	0.96
Satisfaction Scale	4.4	4.1	0.41	3.9	4.0	0.94	3.6	3.6	0.97
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2	4.1	0.69	4.1	4.1	0.67	4.1	3.7	0.13
Should go along with doctor even if you disagree	1.8	1.8	1.0	2.3	2.1	0.33	2.2	2.1	0.56

Table 38: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Type of Surgery at 3 Months

	Surgery					
	Lumpectomy			Mastectomy		
	C	T	P Value	C	T	P Value
FACT—Overall	11.8	107.6	0.19	109.8	113.2	0.38
Physical Well Being	21.3	21.4	0.91	22.4	22.1	0.75
Social/Family Well Being	23.2	22.5	0.37	24.0	23.7	0.74
Functional Well Being	20.2	20.0	0.83	20.0	21.6	0.14
Emotional Well Being	16.9	16.7	0.67	16.6	16.6	0.97
Relationship with doctor	7.1	6.5	0.02	6.4	6.9	0.04
Additional Concerns	25.5	23.8	0.15	24.5	25.4	0.46
Norm-based SF-12 Mental Component	49.4	45.9	0.04	50.8	49.4	0.45
Physical Component	46.9	46.0	0.58	44.6	44.3	0.87
CES-D	11.9	12.9	0.47	8.5	9.5	0.60
Illness Intrusiveness	33.1	36.5	0.28	32.9	28.4	0.20
Satisfaction Scale	4.0	3.9	0.62	4.1	4.2	0.50
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2	4.0	0.23	4.2	4.2	0.82
Participation in treatment decisions regarding surgery	3.2	3.5	0.16	3.6	3.4	0.44
Participation in treatment decisions regarding adjuvant therapy	2.5	2.6	0.55	2.4	2.4	0.77
Should go along with doctor even if you disagree	1.9	1.9	0.67	2.0	2.0	0.78

Table 39: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Type of Surgery at 12 Months

	Surgery					
	Lumpectomy			Mastectomy		
	C	T	P Value	C	T	P Value
FACT—Overall	114.8	109.8	0.14	116.6	116.7	0.97
Physical Well Being	23.3	22.7	0.46	25.2	23.9	0.15
Social/Family Well Being	23.2	22.5	0.38	2.9	23.7	0.89
Functional Well Being	21.8	20.4	0.12	22.8	22.0	0.44
Emotional Well Being	17.1	16.2	0.07	17.0	17.0	0.91
Relationship with doctor	6.8	6.6	0.40	6.2	7.0	0.05
Additional Concerns	24.3	24.4	0.95	25.1	25.9	0.49
Norm-based SF-12 Mental Component	46.0	42.4	0.01	47.2	46.7	0.79
Physical Component	48.7	46.6	0.22	47.5	46.9	0.78
CES-D	11.3	12.6	0.42	7.9	9.0	0.51
Illness Intrusiveness	28.2	29.6	0.67	29.9	28.2	0.65
Satisfaction Scale	3.8	3.8	0.90	3.9	4.1	0.35
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	4.0	0.57	4.1	4.1	0.98
Should go along with doctor even if you disagree	2.0	2.0	0.70	2.4	2.2	0.25

Table 40: Test for Interaction Between the Intervention and Whether the Reconstructive Surgery Status Controlling for Education and Living Situation at 3 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Reconstructive Surgery Status P value	Interaction: Txt vs. Cont by Resonstructive Surgery Status P value
F.A.C.T			
Overall	P=0.32	P=0.44	P=0.34
Physical Well- Being	P=0.68	P=0.82	P=0.43
Social and Family Well-Being	P=0.86	P=0.57	P=0.53
Functional Well-Being	P=0.04	P=0.55	P=0.21
Emotional Well-Being	P=0.56	P=0.72	P=0.64
Relationship with Doctor	P=0.06	P=0.87	P=0.16
Additional Concerns	P=0.84	P=0.42	P=0.85
Normed-Based SF-12			
Mental Component	P=0.31	P=0.33	P=0.91
Physical Component	P=0.22	P=0.40	P=0.10
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.67	P=0.15	P=0.86
Illness Intrusiveness Scale	P=0.30	P=0.55	P=0.29
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.54	P=0.86	P=0.11
Satisfaction scale**	P=0.25	P=0.64	P=0.57
Participation in decisions about surgery	P=0.28	P=0.60	P=0.72
Participation in decisions about adjuvant therapy	P=0.40	P=0.80	P=0.22
Should go along with Dr even if disagree	P=0.95	P=0.74	P=0.53

Table 41: The Test for Interaction Between the Intervention and Reconstructive Surgery Status Controlling for Education and Living Situation at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Reconstructive Surgery Status P value	Interaction: Txt vs. Cont by Resonstructive Surgery Status P value
F.A.C.T			
Overall	P=0.99	P=0.54	P=0.72
Physical Well- Being	P=0.62	P=0.31	P=0.32
Social and Family Well-Being	P=0.54	P=0.48	P=0.60
Functional Well-Being	P=0.99	P=0.36	P=0.58
Emotional Well-Being	P=0.62	P=0.95	P=0.77
Relationship with Doctor	P=0.16	P=0.99	P=0.73
Additional Concerns	P=0.60	P=0.42	P=0.69
Normed-Based SF-12			
Mental Component	P=0.29	P=0.07	P=0.69
Physical Component	P=0.39	P=0.51	P=0.29
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.26	P=0.11	P=0.76
Illness Intrusiveness Scale	P=0.65	P=0.71	P=0.80
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.53	P=0.85	P=0.34
Satisfaction scale	P=0.19	P=0.63	P=0.19
Should go along with Dr. even if disagree	P=0.57	P=0.92	P=0.92

Table 42: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Reconstruction Surgery Status at 3 Months

	Reconstruction Status					
	No Reconstruction			Reconstruction		
	C	T	P Value	C	T	P Value
FACT—Overall	111.6	112.0	0.92	110.2	118.6	0.36
Physical Well Being	22.8	22.5	0.76	21.9	22.9	0.67
Social/Family Well Being	24.0	23.5	0.52	23.6	24.8	0.54
Functional Well Being	19.8	20.9	0.29	20.9	24.8	0.12
Emotional Well Being	17.2	17.1	0.91	14.9	14.0	0.62
Relationship with doctor	6.6	6.8	0.56	7.0	8.1	0.09
Additional Concerns	24.9	24.9	0.98	24.9	24.2	0.71
Norm-based SF-12 Mental Component	51.0	48.8	0.23	52.4	50.2	0.63
Physical Component	44.4	43.9	0.78	44.6	49.5	0.22
CES-D	9.8	10.9	0.52	8.5	9.7	0.78
Illness Intrusiveness	32.6	31.9	0.83	30.7	24.7	0.43
Satisfaction Scale	4.0	4.1	0.41	4.2	4.5	0.44
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.2	4.2	0.97	4.4	4.7	0.37
Participation in treatment decisions regarding surgery	3.7	3.5	0.40	3.6	3.2	0.36
Participation in treatment decisions regarding adjuvant therapy	2.4	2.4	0.71	2.7	3.3	0.43
Should go along with doctor even if you disagree	1.8	1.8	0.62	2.3	2.4	0.94

Table 43: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions Controlling for Living Situation and Education Stratified by Reconstruction Surgery Status at 12 Months

	Reconstruction Surgery Status					
	Without Reconstruction			With Reconstruction		
	C	T	P Value	C	T	P Value
FACT—Overall	117.3	116.1	0.74	120.8	121.0	0.98
Physical Well Being	25.3	23.8	0.09	25.3	25.2	0.99
Social/Family Well Being	24.2	24.0	0.83	23.9	23.0	0.61
Functional Well Being	22.4	21.8	0.60	25.0	25.1	0.94
Emotional Well Being	17.2	17.1	0.94	16.8	15.8	0.51
Relationship with doctor	6.5	7.0	0.19	6.8	7.6	0.33
Additional Concerns	25.2	25.5	0.79	26.0	26.9	0.73
Norm-based SF-12 Mental Component	46.7	45.4	0.46	53.2	49.7	0.23
Physical Component	48.0	47.5	0.81	46.0	51.1	0.27
CES-D	8.53	9.55	0.52	5.4	8.4	0.33
Illness Intrusiveness	28.6	27.0	0.63	27.9	28.1	0.98
Satisfaction Scale	3.9	4.0	0.93	3.9	4.4	0.25
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	4.1	0.68	4.2	4.5	0.37
Should go along with doctor even if you disagree	2.3	2.1	0.45	2.9	2.8	0.70

Table 44: Test for Interaction Between Intervention and Chemotherapy Status Controlling for Education and Living Situation at 3 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Chemotherapy Status P value	Interaction: Txt vs. Cont by Chemotherapy Status P value
F.A.C.T			
Overall	P=0.30	P=0.01	P=0.57
Physical Well- Being	P=0.45	P=0.0003	P=0.60
Social and Family Well-Being	P=0.09	P=0.67	P=0.69
Functional Well-Being	P=0.79	P=0.23	P=0.26
Emotional Well-Being	P=0.17	P=0.13	P=0.17
Relationship with Doctor	P=0.24	P=0.75	P=0.80
Additional Concerns	P=0.27	P=0.0006	P=0.63
Normed-Based SF-12			
Mental Component	P=0.12	P=0.67	P=0.54
Physical Component	P=0.89	P=0.48	P=0.46
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.58	P=0.82	P=0.89
Illness Intrusiveness Scale	P=0.30	P=0.0004	P=0.30
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.15	P=0.16	P=0.94
Satisfaction scale**	P=0.47	P=0.05	P=0.87
Participation in decisions about surgery	P=0.18	P=0.03	P=0.40
Participation in decisions about adjuvant therapy	P=0.20	P=0.88	P=0.06
Should go along with Dr even if disagree	P=0.80	P=0.05	P=0.71

Table 45: Test for the Interaction between the Intervention and Chemotherapy Controlling for Education and Living Situation at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Chemotherapy status P value	Interaction: Txt vs. Cont by Chemotherapy Status P value
F.A.C.T			
Overall	P=0.32	P=0.22	P=0.68
Physical Well- Being	P=0.76	P=0.02	P=0.62
Social and Family Well-Being	P=0.11	P=0.09	P=0.40
Functional Well-Being	P=0.37	P=0.59	P=0.91
Emotional Well-Being	P=0.29	P=0.72	P=0.80
Relationship with Doctor	P=0.31	P=0.30	P=0.44
Additional Concerns	P=0.71	P=0.01	P=0.40
Normed-Based SF-12			
Mental Component	P=0.01	P=0.08	P=0.97
Physical Component	P=0.62	P=0.61	P=0.82
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.26	P=0.27	P=0.76
Illness Intrusiveness Scale	P=0.91	P=0.01	P=0.64
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.06	P=0.02	P=0.62
Satisfaction scale**	P=0.50	P=0.03	P=0.72
Should go along with Dr. even if disagree	P=0.14	P=0.23	P=0.78

Table 46: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions at 3Months Controlling for Living Situation and Education Stratified by Chemotherapy Status

	Chemotherapy Status					
	No Chemotherapy			Chemotherapy		
	C	T	P Value	C	T	P Value
FACT—Overall	115.4	109.4	0.29	103.9	102.2	0.69
Physical Well Being	23.8	22.4	0.25	19.5	19.2	0.85
Social/Family Well Being	24.6	22.5	0.14	23.0	22.1	0.30
Functional Well Being	19.2	18.9	0.85	17.7	18.9	0.30
Emotional Well Being	18.1	16.3	0.05	16.2	16.3	0.89
Relationship with doctor	6.7	6.5	0.62	6.7	6.2	0.21
Additional Concerns	27.6	25.9	0.29	22.5	21.7	0.58
Norm-based SF-12 Mental Component	50.7	46.7	0.22	47.4	45.6	0.39
Physical Component	44.2	42.9	0.65	43.1	44.0	0.64
CES-D	11.6	13.0	0.64	11.7	12.3	0.72
Illness Intrusiveness	24.5	33.2	0.10	44.9	44.3	0.86
Satisfaction Scale	4.3	4.1	0.41	3.9	3.8	0.71
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.9	4.5	0.21	4.0	3.8	0.26
How were decisions made regarding surgery	3.3	3.5	0.56	3.5	3.6	0.40
How were decisions made – additional	2.3	2.9	0.14	2.4	2.2	0.67
Should go along with doctor even if you disagree	2.2	2.2	0.84	1.9	1.8	0.67

Table 47: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions at 12 Months stratified by Chemotherapy Status

	Chemotherapy Status					
	No Chemotherapy			Chemotherapy		
	C	T	P Value	C	T	P Value
FACT—Overall	114.1	111.4	0.61	112.7	107.4	0.24
Physical Well Being	24.2	24.0	0.84	22.9	22.2	0.56
Social/Family Well Being	23.1	20.7	0.12	23.3	22.7	0.54
Functional Well Being	20.7	20.2	0.74	21.2	20.1	0.33
Emotional Well Being	17.9	16.9	0.30	16.2	15.8	0.58
Relationship with doctor	7.0	6.9	0.94	6.8	6.2	0.12
Additional Concerns	24.9	26.3	0.30	23.3	22.8	0.70
Norm-based SF-12 Mental Component	50.7	46.4	0.11	45.4	41.7	0.04
Physical Component	43.7	44.6	0.77	45.6	46.9	0.58
CES-D	8.3	10.3	0.43	11.1	13.2	0.28
Illness Intrusiveness	26.1	30.9	0.32	38.6	36.5	0.63
Satisfaction Scale	4.2	4.1	0.75	3.8	3.7	0.40
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.3	4.1	0.50	4.2	3.8	0.03
Should go along with doctor even if you disagree	2.4	2.1	0.40	2.1	1.9	0.25

Table 48: Test for the Interaction Between the Interaction and the Tamoxifen Status Controlling for Education and Living Situation at 3 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Tamoxifen status P value	Interaction: Txt vs. Cont by Tamoxifen Status P value
F.A.C.T			
Overall	P=0.78	P=0.23	P=0.41
Physical Well- Being	P=0.75	P=0.14	P=0.23
Social and Family Well-Being	P=0.16	P=0.62	P=0.61
Functional Well-Being	P=0.94	P=0.82	P=0.88
Emotional Well-Being	P=0.94	P=0.62	P=0.99
Relationship with Doctor	P=0.20	P=0.79	P=0.42
Additional Concerns	P=0.72	P=0.02	P=0.14
Normed-Based SF-12			
Mental Component	P=0.06	P=0.98	P=0.90
Physical Component	P=0.47	P=0.02	P=0.28
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.76	P=0.08	P=0.32
Illness Intrusiveness Scale	P=0.44	P=0.10	P=0.93
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.17	P=0.40	P=0.03
Satisfaction scale	P=0.51	P=0.77	P=0.18
Participation in decisions about surgery	P=0.56	P=0.35	P=0.56
Participation in decisions about adjuvant therapy	P=0.26	P=0.87	P=0.82
Should go along with Dr even if disagree	P=0.82	P=0.56	P=0.96

Table 49: Test for Interaction Between the Intervention and the Tamoxifen Status Controlling for Education and Living Situation at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Tamoxifen status P value	Interaction: Txt vs. Cont by Tamoxifen Status P value
F.A.C.T			
Overall	P=0.11	P=0.39	P=0.76
Physical Well- Being	P=0.09	P=0.67	P=0.32
Social and Family Well-Being	P=0.08	P=0.39	P=0.05
Functional Well-Being	P=0.05	P=0.50	P=0.82
Emotional Well-Being	P=0.48	P=0.17	P=0.97
Relationship with Doctor	P=0.94	P=0.36	P=0.89
Additional Concerns	P=0.95	P=0.52	P=0.88
Normed-Based SF-12			
Mental Component	P=0.03	P=0.53	P=0.49
Physical Component	P=0.19	P=0.14	P=0.06
Center for Epidemiologic Studies Depression Scale (CES-D)--Short Form	P=0.06	P=0.05	P=0.75
Illness Intrusiveness Scale	P=0.91	P=0.002	P=0.66
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.39	P=0.57	P=0.17
Satisfaction scale	P=0.54	P=0.82	P=0.10
Should go along with Dr. even if disagree	P=0.39	P=0.37	P=0.24

Table 50: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions at 3 Months stratified by Tamoxifen Status

	Tamoxifen					
	No Tamoxifen			Tamoxifen		
	C	T	P Value	C	T	P Value
FACT—Overall	109.5	110.9	0.82	111.8	109.4	0.51
Physical Well Being	20.8	21.5	0.71	22.6	21.4	0.27
Social/Family Well Being	24.7	23.1	0.26	23.7	23.1	0.57
Functional Well Being	20.0	20.1	0.95	20.5	20.4	0.92
Emotional Well Being	16.7	16.6	0.87	16.5	16.7	0.72
Relationship with doctor	7.5	6.9	0.13	6.6	6.4	0.46
Additional Concerns	22.9	24.9	0.45	25.6	24.7	0.45
Norm-based SF-12 Mental Component	51.9	48.4	0.27	51.1	48.2	0.11
Physical Component	41.1	41.8	0.81	47.2	44.4	0.13
CES-D	12.2	11.4	0.79	9.1	10.6	0.36
Illness Intrusiveness	38.9	40.5	0.76	28.0	29.5	0.65
Satisfaction Scale	4.4	4.1	0.19	4.0	4.1	0.54
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	5.0	4.3	0.01	4.0	4.2	0.45
Participation in treatment decisions regarding surgery	3.4	3.6	0.66	3.3	3.4	0.62
Participation in treatment decisions regarding adjuvant therapy	2.4	2.7	0.57	2.3	2.5	0.49
Should go along with doctor even if you disagree	2.1	2.1	0.95	1.9	2.0	0.64

Table 51: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, and Participation in Treatment Decisions at 12 Months stratified by Tamoxifen Status

	Tamoxifen Status					
	No Tamoxifen			Tamoxifen		
	C	T	P Value	C	T	P Value
FACT—Overall	118.4	111.5	0.29	115.9	111.6	0.25
Physical Well Being	23.8	23.2	0.74	24.8	22.3	0.009
Social/Family Well Being	24.5	21.3	0.03	23.2	23.4	0.88
Functional Well Being	23.2	21.2	0.22	22.5	20.8	0.09
Emotional Well Being	17.0	16.5	0.65	17.0	16.8	0.62
Relationship with doctor	7.0	7.0	0.99	6.7	6.7	0.98
Additional Concerns	25.4	25.0	0.82	24.2	24.5	0.81
Norm-based SF-12 Mental Component	51.0	46.7	0.09	47.1	45.0	0.21
Physical Component	46.0	46.7	0.83	49.4	43.9	0.004
CES-D	9.3	12.7	0.28	7.5	9.7	0.14
Illness Intrusiveness	39.1	38.3	0.90	27.1	28.1	0.76
Satisfaction Scale	4.1	3.7	0.14	3.8	4.0	0.40
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.3	3.9	0.14	4.0	4.1	0.67
Should go along with doctor even if you disagree	2.4	2.2	0.28	2.3	2.3	0.98

Table 52: Perceived Helpfulness of Peer Support Volunteer by Intervention (% Very Helpful and Helpful)

How much did the buddy help you in the following areas?	Control % Very Helpful and Helpful (n)	Treatment % Very Helpful and Helpful (n)	Chisquare
Get the information you needed	43.1 44	60.9 78	0.007
Understand your breast cancer diagnosis	33.0 34	56.3 72	0.001
Decide what treatment(s) to have	19.4 20	19.5 25	0.98
Communicate better with your doctor	24.3 25	28.9 37	0.43
Know what questions to ask your doctor	24.5 0.09	34.9 45	0.09
Take better care of yourself	25.5 26	38.6 49	0.04
Find out about and use the Kaiser resources better	21.6 22	36.2 46	0.02
Deal with job stress	7.9 8	9.5 12	0.69
Deal with family relationships	15.7 16	18.8 24	0.54
Deal with sexual relationships related to breast cancer	7.8 8	7.1 9	0.83

Table 53: Perceived Helpfulness of Peer Support Volunteer by Intervention Stratified by Level of Participation in Program (% Very Helpful and Helpful)

	Level of Participation											
	No Participation (n=76)			Low Participation (n=87)			Moderate Participation (n=50)			High Participation (n=32)		
Outcome	C %	T %	P value	C %	T %	P value	C %	T %	P value	C %	T %	P value
Get information you needed	6.7	7.1	0.95	64.9	47.6	0.12	100.0	68.3	0.05	71.4	92.0	0.15
Understand your breast cancer diagnosis	6.7	13.3	0.42	40.5	42.9	0.84	77.8	68.3	0.57	71.4	87.5	0.31
Decide what treatment(s) to have	6.7	7.1	0.95	18.9	11.9	0.39	55.6	29.3	0.13	42.9	24.0	0.33
Communicate better with your doctor	4.4	0.0	0.42	32.4	19.1	0.17	33.3	31.7	0.93	71.4	56.0	0.46
Know what questions to ask your doctor	4.4	6.7	0.73	37.8	19.1	0.06	33.3	43.9	0.56	57.1	64.0	0.74
Take better care of yourself	4.4	0.0	0.42	29.7	23.8	0.55	88.9	46.3	0.02	42.9	72.0	0.15
Find out about and use the Kaiser resources better	6.7	7.1	0.95	21.6	19.1	0.78	44.4	43.9	0.98	71.4	68.0	0.86
Deal with job stress	4.4	0.0	0.42	2.8	7.1	0.38	44.4	9.8	0.01	0.0	16.7	0.25
Deal with family Relationships	4.4	0.0	0.42	16.2	14.3	0.81	44.4	17.1	0.07	42.9	36.0	0.74
Deal with sexual issues related to breast cancer	4.4	0.0	0.42	8.1	4.8	0.54	22.2	2.4	0.02	0.0	20.8	0.19

Table 54: Perceived Helpfulness of Peer Support Volunteer by Intervention Stratified by Age (% Very Helpful and Helpful)

	Age Category								
	30-49 years (n=80)			50-64 years (n=145)			65-90 years (n=67)		
	C %	T %	P Value	C %	T %	P Value	C %	T %	P Value
Get information you needed	42.4	64.5	0.08	40.9	67.1	0.005	48.0	37.5	0.45
Understand your breast cancer diagnosis	33.3	64.5	0.01	27.3	61.1	0.001	42.3	32.0	0.45
Decide what treatment(s) to have	15.2	19.4	0.66	18.2	26.0	0.33	26.9	0.0	0.006
Communicate better with your doctor	21.2	35.5	0.20	20.5	28.8	0.32	34.6	20.8	0.28
Know what questions to ask your doctor	30.3	35.5	0.66	15.9	38.4	0.01	32.0	24.0	0.53
Take better care of yourself	27.3	54.8	0.03	20.5	35.6	0.08	32.0	26.1	0.65
Find out about and use the Kaiser resources better	15.2	32.3	0.11	18.2	41.1	0.01	36.0	26.1	0.46
Deal with job stress	6.10	12.9	0.35	6.8	11.1	0.44	12.5	0.0	0.07
Deal with family Relationships	9.1	22.6	0.14	13.6	17.8	0.55	28.0	16.7	0.34
Deal with sexual issues related to breast cancer	3.0	9.7	0.27	9.1	6.9	0.68	12.0	4.2	0.32

Table 55: Perceived Helpfulness of Peer Support Volunteer by Intervention Stratified by Education (% Very Helpful and Helpful)

	Education					
	High School Graduate and Less (n=46)			At Least Some College (n=241)		
	C %	T %	P Value	C %	T %	P Value
Get information you needed	60.0	53.3	0.69	40.0	62.5	0.002
Understand your breast cancer diagnosis	47.6	46.7	0.96	30.0	58.0	0.001
Decide what treatment(s) to have	33.3	13.3	0.17	16.3	20.5	0.45
Communicate better with your doctor	42.9	20.0	0.15	20.0	30.4	0.11
Know what questions to ask your doctor	40.0	26.7	0.41	21.3	36.3	0.02
Take better care of yourself	40.0	26.7	0.41	22.5	40.5	0.009
Find out about and use the Kaiser resources better	45.0	33.3	0.49	16.3	36.9	0.002
Deal with job stress	15.0	6.7	0.44	6.3	9.9	0.38
Deal with family Relationships	45.0	20.0	0.12	8.8	18.8	0.05
Deal with sexual issues related to breast cancer	15.0	0.0	0.12	6.3	8.1	0.63

Table 56: Perceived Helpfulness of Peer Support Volunteer by Intervention Stratified by Race/Ethnicity (% Very Helpful and Helpful)

	Race/Ethnicity					
	Women of Color (n=70)			White (n=222)		
	C %	T %	P Value	C %	T %	P Value
Get information you needed	62.5	64.3	0.89	37.2	60.0	0.003
Understand your breast cancer diagnosis	45.8	53.6	0.58	29.1	57.0	0.001
Decide what treatment(s) to have	25.0	39.3	0.27	17.7	14.0	0.50
Communicate better with your doctor	33.3	46.4	0.34	21.5	24.0	0.70
Know what questions to ask your doctor	41.7	42.9	0.93	19.2	32.7	0.04
Take better care of yourself	45.8	46.4	0.97	19.2	36.4	0.01
Find out about and use the Kaiser resources better	33.3	50.0	0.23	18.0	32.3	0.03
Deal with job stress	17.4	25.0	0.51	5.1	5.1	0.98
Deal with family Relationships	33.3	46.4	0.34	10.3	11.0	0.87
Deal with sexual issues related to breast cancer	20.8	14.3	0.53	3.9	5.1	0.70

Table 57: Perceived Helpfulness of Peer Support Volunteer by Intervention Stratified by Living Situation (% Very Helpful and Helpful)

	Living Status					
	Living with Someone (n=221)			Living Alone (n=68)		
	C %	T %	P Value	C %	T %	P Value
Get information you needed	42.5	63.6	0.005	38.5	55.0	0.30
Understand your breast cancer diagnosis	34.1	62.5	0.001	15.4	42.5	0.08
Decide what treatment(s) to have	20.5	23.9	0.59	7.7	10.0	0.81
Communicate better with your doctor	23.9	29.6	0.39	23.1	27.5	0.75
Know what questions to ask your doctor	24.1	34.1	0.15	23.1	36.6	0.37
Take better care of yourself	26.4	39.1	0.08	15.4	37.5	0.14
Find out about and use the Kaiser resources better	21.8	33.3	0.09	7.7	42.5	0.02
Deal with job stress	8.1	11.4	0.47	0.0	5.1	0.41
Deal with family Relationships	16.1	20.5	0.46	7.7	15.0	0.50
Deal with sexual issues related to breast cancer	8.1	6.8	0.76	0.0	7.7	0.30

Table 58: Perceived Helpfulness of Peer Support Volunteer by Intervention Stratified by Maritial Status (% Very Helpful and Helpful)

	Marital Status					
	Not Married (n=107)			Married or DP (n=185)		
	C %	T %	P Value	C %	T %	P Value
Get information you needed	39.3	50.0	0.36	44.6	68.0	0.004
Understand your breast cancer diagnosis	25.0	42.0	0.13	36.0	65.4	0.001
Decide what treatment(s) to have	17.9	14.0	0.65	20.0	23.1	0.64
Communicate better with your doctor	28.6	26.0	0.81	22.7	30.8	0.26
Know what questions to ask your doctor	28.6	35.3	0.54	23.0	34.6	0.11
Take better care of yourself	28.6	32.0	0.75	24.3	42.9	0.02
Find out about and use the Kaiser resources better	17.9	38.0	0.06	23.0	35.1	0.10
Deal with job stress	7.1	6.1	0.86	8.2	11.5	0.50
Deal with family Relationships	17.9	16.0	0.83	14.9	20.5	0.36
Deal with sexual issues related to breast cancer	7.1	10.2	0.65	8.1	5.1	0.50

Table 59 : Test for Interaction Between Intervention and Level of Participation in Treatment Decisions controlling For Education and Living Situation at 3 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Level of Participation P value	Interaction: Txt vs. Cont by Level P value
F.A.C.T			
Overall	P=0.85	P=0.99	P=0.92
Physical Well- Being	P=0.91	P=0.98	P=0.27
Social and Family Well-Being	P=0.41	P=0.61	P=0.97
Functional Well-Being	P=0.29	P=0.59	P=0.60
Emotional Well-Being	P=0.60	P=0.41	P=0.78
Relationship with Doctor	P=0.50	P=0.55	P=0.99
Additional Concerns	P=0.71	P=0.37	P=0.47
Normed-Based SF-12			
Mental Component	P=0.06	P=0.83	P=0.93
Physical Component	P=0.98	P=0.71	P=0.70
Center for Epidemiologic Studies Depression Scale (CES-D)—Short Form	P=0.44	P=0.62	P=0.76
Illness Intrusiveness Scale	P=0.75	P=0.80	P=0.60
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.54	P=0.86	P=0.11
Satisfaction scale	P=0.89	P=0.40	P=0.31

Table 60:The Relationship Between Participation in Treatment Decisions about Surgery and Quality of Life and Satisfaction with Health Care at 3 Months

	How were decisions made regarding your surgery for breast cancer?					P-Value
Outcomes	The Dr made the decisions	Dr. considered me	Equal Basis	I considered Dr.	I made decisions	
FACT Scale Overall	109.5	106.8	108.9	111.2	100.	0.27
Physical Well Being	22.6	19.7	21.3	22.1	21.5	0.13
Social/Family Well Being	23.1	23.0	22.9	23.4	20.3	0.15
Functional Well Being	20.2	19.6	20.1	19.9	17.5	0.42
Emotional Well Being	16.3	16.7	16.8	17.0	15.8	0.52
Relationship with doctor	6.7	6.8	7.0	6.3	6.1	0.13
Additional Concerns	24.3	24.0	24.7	25.9	22.5	0.24
Norm-based SF-12 Mental Component	47.4	50.0	48.8	49.6	43.9	0.17
Physical Component	46.2	43.6	44.4	45.7	43.9	0.59
CES-D	11.6	12.3	11.7	10.2	13.3	0.67
Illness Intrusiveness	33.5	34.8	32.3	32.5	38.8	0.68
Satisfaction Scale	4.0	4.1	4.1	3.8	4.0	0.37
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	4.1	4.3	4.0	4.0	0.54

Table 61: The Relationship Between Participation in Treatment Decisions About Surgery and Quality of Life and Satisfaction with Health Care at 12 Months

	How were decisions made regarding your surgery for breast cancer					P-Value
Outcomes	The Dr made the decisions	Dr. considered me	Equal Basis	I considered Dr.	I made decisions	
FACT Scale Overall	112.1	110.3	114.4	116.5	109.7	0.50
Physical Well Being	23.4	23.2	23.5	24.4	24.1	0.80
Social/Family Well Being	23.1	22.3	23.5	23.8	20.1	0.07
Functional Well Being	21.1	21.0	21.4	21.9	20.6	0.88
Emotional Well Being	16.5	16.4	16.8	17.2	16.3	0.66
Relationship with doctor	6.6	6.7	6.8	6.6	6.6	0.96
Additional Concerns	24.2	24.1	25.4	25.3	25.6	0.63
Norm-based SF-12 Mental Component	46.7	44.4	45.3	44.8	44.0	0.57
Physical Component	44.7	45.1	48.5	47.9	49.6	0.13
CES-D	10.7	12.6	10.4	10.6	13.3	0.66
Illness Intrusiveness	31.7	30.2	26.2	27.1	27.1	0.42
Satisfaction Scale	3.7	3.9	4.0	3.9	3.8	0.38
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.0	4.0	4.1	4.1	4.0	0.95

Table 62: The Relationship Between the Participation In Treatment Decisions about Adjuvant Therapy and Quality of Life and Satisfaction with Health Care at 3 Months

	How were decisions made regarding any adjuvant therapy you considered?					P-Value
Outcomes	The Dr made the decisions	Dr. considered me	Equal Basis	I considered Dr.	I made decisions	
FACT Scale Overall	107.2	103.6	111.5	109.6	110.0	0.49
Physical Well Being	22.1	21.5	21.8	21.8	22.0	0.99
Social/Family Well Being	22.1	21.4	23.5	23.1	23.3	0.32
Functional Well Being	18.2	19.2	20.7	19.9	19.4	0.47
Emotional Well Being	17.5	14.5	16.9	17.0	16.8	0.003
Relationship with doctor	7.0	6.8	7.1	6.4	6.2	0.007
Additional Concerns	24.6	24.1	25.2	24.3	25.3	0.79
Norm-based SF-12 Mental Component	51.0	45.5	50.4	47.8	48.0	0.17
Physical Component	48.5	44.3	44.7	45.0	46.4	0.70
CES-D	12.8	14.3	11.5	10.5	10.0	0.28
Illness Intrusiveness	23.4	33.5	32.6	32.5	35.8	0.44
Satisfaction Scale	4.3	3.8	4.2	4.0	3.8	0.03
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.7	3.9	4.3	4.1	3.9	0.02

Table 63: The Relationship Between Decisions about Adjuvant Therapy and Quality of Life and Satisfaction with Health Care at 12 Months

	How were decisions made regarding any adjuvant therapy you considered?					P-Value
Outcomes	The Dr made the decisions	Dr. considered me	Equal Basis	I considered Dr.	I made decisions	
FACT Scale Overall	113.6	109.5	114.6	114.9	115.7	0.78
Physical Well Being	23.0	24.2	23.3	23.9	24.6	0.69
Social/Family Well Being	23.0	21.9	23.3	23.3	22.9	0.79
Functional Well Being	20.2	20.2	21.9	21.7	21.6	0.66
Emotional Well Being	16.8	15.5	16.9	16.9	17.3	0.26
Relationship with doctor	6.8	6.7	7.0	6.6	6.0	0.14
Additional Concerns	26.8	24.6	24.8	25.1	25.9	0.75
Norm-based SF-12 Mental Component	52.8	43.0	46.4	44.7	44.8	0.02
Physical Component	39.7	48.4	46.7	48.3	48.2	0.17
CES-D	9.3	10.8	10.5	10.7	10.8	0.99
Illness Intrusiveness	26.3	29.9	28.6	27.4	29.2	0.96
Satisfaction Scale	3.9	3.8	4.0	3.8	3.8	0.71
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.3	3.9	4.2	3.9	4.0	0.19

Table 64: Test for Interaction Between Intervention and Participation In Treatment Decisions Controlling for Education and Living Situation at 12 Months

Scale	Main effect: Treatment vs. Control P value	Main effect: Level of Participation P value	Interaction: Txt vs. Cont by Level P value
F.A.C.T			
Overall	P=0.18	P=0.14	P=0.10
Physical Well- Being	P=0.11	P=0.29	P=0.28
Social and Family Well-Being	P=0.36	P=0.50	P=0.50
Functional Well-Being	P=0.09	P=0.40	P=0.11
Emotional Well-Being	P=0.10	P=0.21	P=0.13
Relationship with Doctor	P=0.71	P=0.66	P=0.26
Additional Concerns	P=0.72	P=0.11	P=0.77
Normed-Based SF-12			
Mental Component	P=0.02	P=0.48	P=0.23
Physical Component	P=0.20	P=0.009	P=0.54
Center for Epidemiologic Studies Depression Scale (CES-D)—Short Form	P=0.22	P=0.59	P=0.53
Illness Intrusiveness Scale	P=0.63	P=0.05	P=0.56
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	P=0.43	P=0.48	P=0.78
Satisfaction scale	P=0.86	P=0.26	P=0.80

Table 65: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, Controlling for Living Situation and Education Stratified by Participation in Treatment Decisions at 3 Months

	Participation in Treatment Decisions					
	Low Participation (N=121)			High Participation (N=133)		
Outcome	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	108.8	106.9	0.63	110.4	109.7	0.85
Physical Well Being	21.7	20.6	0.35	21.8	22.5	0.49
Social/Family Well Being	23.1	22.5	0.50	23.4	22.9	0.49
Functional Well Being	19.5	20.2	0.53	19.6	20.1	0.63
Emotional Well Being	16.7	16.2	0.44	16.8	16.7	0.90
Relationship with Doctor	6.7	6.4	0.24	6.8	6.7	0.67
Additional Concerns	23.9	23.7	0.85	25.8	25.0	0.41
Norm-based SF-12 Mental Component	49.5	45.9	0.07	50.2	47.9	0.19
Physical Component	45.9	45.6	0.87	44.4	44.9	0.78
CES-D	11.0	12.0	0.60	10.8	11.9	0.45
Illness Intrusiveness	34.1	37.2	0.43	31.7	31.3	0.91
Satisfaction Scale	4.2	4.0	0.17	3.9	4.0	0.45
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	3.9	0.30	4.3	4.2	0.58

Table 66: The Effect of the Intervention on the Quality of Life, Satisfaction with Health Care, Controlling for Living Situation and Education Stratified by Participation in Treatment Decisions at 12 Months

	Participation in Treatment Decisions					
	Low Participation (N=114)			High Participation (N=123)		
Outcome	C Mean	T Mean	P Value	C Mean	T Mean	P Value
FACT Scale Overall	110.4	111.2	0.85	120.7	112.7	0.03
Physical Well Being	23.4	23.3	0.94	25.1	23.2	0.03
Social/Family Well Being	22.6	22.3	0.81	24.4	23.2	0.19
Functional Well Being	20.9	20.9	0.99	23.2	20.8	0.02
Emotional Well Being	16.7	16.6	0.91	17.5	16.3	0.03
Relationship with Doctor	6.5	6.6	0.72	6.9	6.7	0.64
Additional Concerns	23.2	23.8	0.64	26.1	26.0	0.90
Norm-based SF-12 Mental Component	47.7	45.0	0.15	47.3	43.6	0.01
Physical Component	45.4	43.8	0.45	49.1	48.0	0.52
CES-D	10.9	12.0	0.56	9.0	11.4	0.18
Illness Intrusiveness	32.7	31.3	0.74	24.2	27.3	0.30
Satisfaction Scale	3.8	3.7	0.54	4.0	3.9	0.85
Overall Satisfaction with care received at Kaiser Permanente to treat and diagnose breast cancer	4.1	3.9	0.32	4.1	4.0	0.54

Personnel Receiving Pay From Research Effort

Principal Investigator
Carol P. Somkin

Project Coordinator
Beth Eshelman

Volunteer Coordinators
Hannah Wedgley
Sheila Kennedy
Jackie Green
Beth Arvidson
Bernie Calden
Martha LeRoy
Lynn Brissette

Programmer/Analyst
Elisabeth Gruskin

Biostatistician
Charles Quesenberry

Research Assistant
Pat A. Ross
Sidney Krafft
Gary Salyer

Data Entry
Bonnie Loera
E. Alonga
C. Adams
F. Gomez
L. Santos
V. Contreras
Z Geliberrte
J. Hunter
W. Thomas

Administration
Jeffrey W. Bailey
Dominique Lampert

APPENDIX 1

KAISER PERMANENTE

BREAST CANCER PEER SUPPORT PROJECT QUESTIONNAIRE

Please answer the following questions and return the survey in the enclosed prepaid, self-addressed envelope. **All the information you provide in the survey will be kept completely confidential.** Your answers will not be shared with your doctor or employer, become part of your medical record, or affect your Health Plan membership or dues.

1. Overall, how would you rate your current understanding of breast cancer and its treatment?

1☐ Poor 2☐ Fair 3☐ Good 4☐ Very good 5☐ Excellent

2. How important is each of the following types of information to you:

		Not Important 1	Somewhat Important 2	Important 3	Very Important 4	Essential 5
a.	Simple and clear explanations of technical and medical terms	☐	☐	☐	☐	☐
b.	Articles from scientific or medical journals about breast cancer	☐	☐	☐	☐	☐
c.	What are the expected results of each treatment option	☐	☐	☐	☐	☐
d.	Information about how breast cancer can be spread	☐	☐	☐	☐	☐
e.	Examples of cases where the treatment has ***not*** been effective	☐	☐	☐	☐	☐
f.	Why a particular treatment option ***is or is not*** appropriate for me	☐	☐	☐	☐	☐
g.	What are the possible side effects of treatments(s)	☐	☐	☐	☐	☐
h.	Statistical information about how likely it is that I will benefit from a particular treatment	☐	☐	☐	☐	☐
i.	Statistical information about how likely I am to have a recurrence	☐	☐	☐	☐	☐
j.	Information about how others in my situation dealt with their breast cancer	☐	☐	☐	☐	☐
k.	What my doctor believes is the best treatment for me	☐	☐	☐	☐	☐

3. **Check the sentence that best describes your point of view:**

1☐ I want ***only*** the information needed to treat my breast cancer.
2☐ I want additional information only if it is ***good*** news.
3☐ I want as ***much*** information as possible, good or bad.

4. **To what extent do you agree or disagree with each of the following:**

		Disagree Strongly 1	Disagree Somewhat 2	Agree Somewhat 3	Agree Strongly 4
a.	I usually ask my doctor a lot of questions.	☐	☐	☐	☐
b.	I have difficulty getting emotional support from my doctor (getting my doctor to understand my feelings).	☐	☐	☐	☐

5. **Check the sentence that best describes your point of view:**

During a medical care visit, if a doctor or nurse practitioner says something that I don't agree with:

1☐ I have never or rarely disagreed with a doctor.
2☐ I usually let it pass.
3☐ I talk to someone else about it.
4☐ I talk directly to my doctor and let him or her know what I think.

6. **How often do you do each of the following?**

		Never 1	Sometimes 2	Often 3	Always 4
a.	Prepare a list of questions in advance when you visit your doctor	☐	☐	☐	☐
b.	Discuss with your doctor any personal problems that may be related to your illness	☐	☐	☐	☐
c.	Discuss any problems you had following a treatment plan, such as taking a medicine or following a special diet	☐	☐	☐	☐
d.	Call your doctor(s) between visits if you have problems	☐	☐	☐	☐

7. **After they have all the information they need about their illness and possible treatments, some people prefer to leave the final decisions about their treatments to their doctors, while others prefer to participate in making these decisions.**

Which statement best describes what you believe would be ideal?

1☐ The doctor(s) should make the decisions using all that is known about treatments.
2☐ The doctor(s) should make the decisions but strongly consider my opinion.
3☐ The doctor(s) and I should make the decisions together on an equal basis.
4☐ I should make the decisions, but strongly consider the doctor's opinions.
5☐ I should make the decisions using all that I know or learn about the treatments.

8. **To what extent do you agree with the following statement:**

"You should go along with the doctor's advice even if you disagree with it."

1☐ I agree strongly 2☐ I agree somewhat 3☐ I disagree somewhat 4☐ I disagree strongly

9. **How many relatives and friends do you have that you feel close to (relatives and friends that you feel at ease with, can talk to about private matters, can call on for help)?** *(Check one box for relatives and one box for friends.)*

	Relatives	Friends
None		
1 or 2		
3 to 5		
6 to 9		
10 or more		

DEMOGRAPHIC INFORMATION

The information from these last questions will help us better understand the needs of our different patients. No names or other identifying information will ever be used.

10. What is your date of birth?

_______/_______/_______
month date year

11. What is the highest level of school you completed?

1☐ 8th grade or less
2☐ 9-11th grade
3☐ 12th grade (high school graduate/GED)
4☐ Some college or technical school
5☐ Completed 4-year college (e.g. BA, BS)
6☐ Completed graduate degree

12. What is the your race or ethnicity? *(You are encouraged to check all that apply.)*

- ☐ White
  - ☐ North American
  - ☐ European
  - ☐ Middle Eastern
  - ☐ North African
  - ☐ Other (please specify:____________)
- ☐ Black or African American
  - ☐ US Black or African American
  - ☐ Caribbean
  - ☐ Central or South American
  - ☐ North African
  - ☐ Sub-Saharan African
  - ☐ Other (please specify:____________)
- ☐ Native American or Indigenous People
  - ☐ North American Indian
  - ☐ Eskimo
  - ☐ Aleut
  - ☐ Native Hawaiian
  - ☐ Native Samoan, Guamanian, or other Pacific Islander
  - ☐ Other (please specify:____________)
- ☐ Hispanic/Latina
  - ☐ Mexican American or Chicana
  - ☐ Puerto Rican
  - ☐ Cuban
  - ☐ Central or South American
  - ☐ Other (please specify:____________)
- ☐ Asian or Pacific Islander
  - ☐ Chinese
  - ☐ Filipino
  - ☐ Korean
  - ☐ Japanese
  - ☐ Vietnamese
  - ☐ Asian Indian
  - ☐ Other (please specify:____________)
- ☐ Other (please specify:__________________)

13. Do you consider yourself to be multi-racial or multi-ethnic? 1☐ Yes 2☐ No

14. **What is your current marital status?**

1☐	Single	4☐	Divorced
2☐	Married	5☐	Separated
3☐	Domestic Partner	6☐	Widowed

15. **What is your sexual orientation?**

1☐ Heterosexual　　2☐ Lesbian　　3☐ Bi-sexual

16. **Which of the following best describes your living arrangement? (Check only one answer.)**

1☐ Live alone
2☐ Live with partner, family, or friends
3☐ Other

17. **What is your current work status?**

1☐ Working full-time (35 hours or more per week)
2☐ Working part-time (less than 35 hours per week)
3☐ Homemaker
4☐ Student
5☐ Temporary medical leave
6☐ Permanently disabled
7☐ Retired (e.g. not currently employed and not looking for work)
8☐ Not currently employed and looking for work

18. **If you have <u>ever</u> worked outside the home** *(please print)*:

a. **In what kind of business, industry, profession or occupation have you usually worked?**

____

b. **What has been your usual job title?**

____

c. **What have been your most important duties or activities? That is, what have you actually done at your usual work?**

____

19. What is your religious background?

1☐ Protestant
2☐ Jewish
3☐ Catholic
4☐ Muslim
5☐ Buddhist
6☐ Other (please specify:_____________)
7☐ None

20. How important is *organized religion* in your life?

1☐ Very important
2☐ Somewhat important
3☐ Not very important
4☐ Not at all important

21. How important is *spirituality* in your life?

1☐ Very important
2☐ Somewhat important
3☐ Not very important
4☐ Not at all important

22. Do you speak a language other than English in your home? 1☐ Yes 2☐ No

If YES:
a. What language do you prefer?

1☐ Spanish 2☐ Tagalog 3☐ Cantonese 4☐ other (please specify:_____________)

b. How comfortable do you feel in speaking English at the doctor's office?
1☐ Very comfortable
2☐ A little comfortable
3☐ Not at all comfortable
4☐ Other (please specify:_____________)

Name (Please Print) ____

Address ____

____

Telephone Number (___) ____ - _____ Medical Record Number __________

Thank you for completing the questionnaire. Please return it in the pre-addressed, postage-paid envelope to:

Sheila Kennedy, MA
Division of Research, Kaiser Permanente, P O Box 12916, Oakland, CA 94604-9921

KAISER PERMANENTE

BREAST CANCER PEER SUPPORT PROJECT THREE MONTH QUESTIONNAIRE

Please answer the following questions and return the survey in the enclosed prepaid, self-addressed envelope. **All the information you provide in the survey will be kept completely confidential.** Your answers will not be shared with your doctor or employer, become part of your medical record, or affect your Health Plan membership or dues.

1. Overall, how would you describe the care you received at Kaiser Permanente to diagnose and treat your breast cancer?

1 ☐ Poor 2 ☐ Fair 3 ☐ Good 4 ☐ Very good 5 ☐ Excellent

BREAST CANCER TREATMENT

2. Which of the following treatments have you had or do you plan to have?

	Had in past/ having now 1	**Plan to have** 2	**Do not plan to have** 3	**Undecided** 4
a. Mastectomy	☐	☐	☐	☐
b. Lumpectomy (breast conserving surgery)	☐	☐	☐	☐
c. Breast reconstruction	☐	☐	☐	☐
d. Radiation therapy	☐	☐	☐	☐
e. Chemotherapy	☐	☐	☐	☐
f. Tamoxifen (hormonal therapy)	☐	☐	☐	☐

3. Were you interested in obtaining a "second opinion" with another surgeon to discuss your treatment options?

1 ☐ No 2 ☐ Yes, and I got one. 3 ☐ Yes, and I didn't get one.

4. **Once at home, how prepared were you to do the following?**

	Not at all prepared 1	**Not very prepared** 2	**Somewhat prepared** 3	**Very prepared** 4	**Does not apply** 5
a. Care for the drain	☐	☐	☐	☐	☐
b. Perform arm exercises	☐	☐	☐	☐	☐
c. Know the signs of infection	☐	☐	☐	☐	☐
d. Deal with any pain or numbness	☐	☐	☐	☐	☐

5. **How useful did you find the following breast cancer resources and services?**

	Very useful 1	**Somewhat useful** 2	**Not Very useful** 3	**Not at at all useful** 4	**Did not use** 5
Kaiser Health Education materials (pamphlets, videos, etc.)	☐	☐	☐	☐	☐
Shared Decision Making video for breast cancer surgery	☐	☐	☐	☐	☐
Shared Decision Making video for breast cancer adjuvant treatment	☐	☐	☐	☐	☐
Kaiser psychiatrist, psychologist or psychiatric social worker	☐	☐	☐	☐	☐
Breast Care Coordinator	☐	☐	☐	☐	☐
American Cancer Society Reach to Recovery Program	☐	☐	☐	☐	☐
Kaiser peer support program	☐	☐	☐	☐	☐
Support group for women with breast cancer	☐	☐	☐	☐	☐
Educational and support services for family and friends	☐	☐	☐	☐	☐
Other ____________________	☐	☐	☐	☐	☐

DECISION MAKING

6. **How were the decisions made regarding your surgery for breast cancer, that is, whether to have matstecomy or lumpectomy?**

1 ☐ The doctor(s) made the decisions
2 ☐ The doctor(s) made the decisions but considered my opinion
3 ☐ The doctor(s) and I made the decisions together on an equal basis
4 ☐ I made the decisions, but strongly considered the doctor's opinions
5 ☐ I made the decisions using all I knew or learned about the treatments that were available

7. How were the decisions made regarding any additional (adjuvant) therapy you considered, such as chemotherapy or Tamoxifen?

1 ☐ The doctor(s) made the decisions
2 ☐ The doctor(s) made the decisions but considered my opinion
3 ☐ The doctor(s) and I made the decisions together on an equal basis
4 ☐ I made the decisions, but strongly considered the doctor's opinions
5 ☐ I made the decisions using all I knew or learned about the treatments that were available

8. To what extent do you agree with the statement: "You should go along with the doctor's advice even if you disagree with it.":

1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree

9. To what extent to you agree or disagree with each of the following:

	Disagree Strongly 1	**Disagree Somewhat** 2	**Agree Somewhat** 3	**Agree strongly** 4
a. I understood the advantages and disadvantages of each treatment option:				
1. Mastectomy	☐	☐	☐	☐
2. Lumpectomy (breast conserving surgery)	☐	☐	☐	☐
3. Breast Reconstruction	☐	☐	☐	☐
4. Radiation Therapy	☐	☐	☐	☐
5. Chemotherapy	☐	☐	☐	☐
6. Tamoxifen (hormonal therapy)	☐	☐	☐	☐
b. I understood why some treatment options were not available to me	☐	☐	☐	☐
c. I had enough time to make my treatment decisions	☐	☐	☐	☐
d. I wish I had had more information about my treatment options	☐	☐	☐	☐
e. I am satisfied with my treatment decisions	☐	☐	☐	☐

10. I discussed my treatment options with:	**Not at all** 1	**A little bit** 2	**Quite a bit** 3	**A lot** 4
a. My family	☐	☐	☐	☐
b. A close friend	☐	☐	☐	☐
c. A breast cancer survivor	☐	☐	☐	☐
d. A peer support volunteer	☐	☐	☐	☐

11. **To what extent to you agree or disagree with each of the following:**

	Disagree Strongly 1	Disagree Somewhat 2	Agree Somewhat 3	Agree Strongly 4
a. I usually ask my doctor a lot of questions	☐	☐	☐	☐
b. I have difficulty getting emotional support from my doctor (getting my doctor to understand my feelings)	☐	☐	☐	☐
c. I have difficult getting the information that I need from my doctor	☐	☐	☐	☐

12. **How often do you do each of the following?**	Never 1	Sometimes 2	Often 3	Always 4
a. Prepare a list in advance when you visit your doctor	☐	☐	☐	☐
b. Discuss with your doctor any personal problems that may be related to your illness	☐	☐	☐	☐
c. Discuss any problems you had following a treatment plan, such as taking a medicine or following a special diet	☐	☐	☐	☐
d. Call your doctor(s) between visits if you have problems	☐	☐	☐	☐

13. **Overall, how would you rate your current understanding of breast cancer and its treatment?**

1 ☐ Poor 2 ☐ Fair 3 ☐ Good 4 ☐ Very good 5 ☐ Excellent

14. **Below is a list of statements that other people with your illness have said are important. By checking one box per line, please indicate how true each statement has been for you during the <u>past 7 days.</u>**

Physical well-being	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I have a lack of energy	☐	☐	☐	☐	☐
b. I have nausea	☐	☐	☐	☐	☐
c. Because of my physical condition, I have trouble meeting the needs of my family	☐	☐	☐	☐	☐
d. I have pain	☐	☐	☐	☐	☐
e. I am bothered by side effects of treatment	☐	☐	☐	☐	☐
f. I feel sick	☐	☐	☐	☐	☐
g. I am forced to spend time in bed	☐	☐	☐	☐	☐

h. Looking at the above 7 questions, how much would you say your **PHYSICAL WELL BEING** affects your quality of life?

0 1 2 3 4 5 6 7 8 9 10

not at all — very much so

Social/Family Well-Being

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I feel distant from my friends	☐	☐	☐	☐	☐
b. I get emotional support from my family	☐	☐	☐	☐	☐
c. I get support from my friends and neighbors	☐	☐	☐	☐	☐
d. My family has accepted my illness	☐	☐	☐	☐	☐
e. Family communication about my illness is poor	☐	☐	☐	☐	☐
f. I feel close to my partner (or the person who is my main support)	☐	☐	☐	☐	☐
g. Have you been sexually active during the past year? **No** ________ **Yes** ________ If yes, I am satisfied with my sex life	☐	☐	☐	☐	☐

h. Looking at the above 7 questions, how much would you say your **SOCIAL/FAMILY WELL-BEING** affects your quality of life?

0 1 2 3 4 5 6 7 8 9 10
not at all — very much so

Relationship with Doctor

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I have confidence in my doctor(s)	☐	☐	☐	☐	☐
b. My doctor is available to answer my questions	☐	☐	☐	☐	☐

c. Looking at the above 2 questions, how much would you say your **RELATIONSHIP WITH YOUR DOCTOR** affects your quality of life?

0 1 2 3 4 5 6 7 8 9 10
not at all — very much so

Emotional Well-Being

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I feel sad	☐	☐	☐	☐	☐
b. I am proud of how I'm coping with my illness	☐	☐	☐	☐	☐
c. I am losing the fight against my illness	☐	☐	☐	☐	☐
d. I feel nervous	☐	☐	☐	☐	☐
e. I worry about dying	☐	☐	☐	☐	☐
f. I worry that my condition will get worse	☐	☐	☐	☐	☐

g. Looking at the above 6 questions, how much would you say your **Emotional WELL-BEING** affects your quality of life?

0 1 2 3 4 5 6 7 8 9 10
not at all — very much so

Functional Well-Being

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I am able to work (include work at home)	☐	☐	☐	☐	☐
b. My work (including work in home) is fulfilling	☐	☐	☐	☐	☐
c. I am able to enjoy life	☐	☐	☐	☐	☐
d. I have accepted my illness	☐	☐	☐	☐	☐
e. I am sleeping well	☐	☐	☐	☐	☐
f. I am enjoying the things I usually do for fun	☐	☐	☐	☐	☐
g. I am content with the quality of my life right now	☐	☐	☐	☐	☐

h. Looking at the above 7 questions, how much would you say your **Functional Well-Being** affects your quality of life?

0 1 2 3 4 5 6 7 8 9 10

not at all … very much so

Additional Concerns

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I have been short of breath	☐	☐	☐	☐	☐
b. I am self-conscious about the way I dress	☐	☐	☐	☐	☐
c. My arms are swollen or tender	☐	☐	☐	☐	☐
d. I feel sexually attractive	☐	☐	☐	☐	☐
e. I have been bothered by hair loss	☐	☐	☐	☐	☐
f. I worry about the risk of cancer in other family members	☐	☐	☐	☐	☐
g. I worry about the effect of stress on my illness	☐	☐	☐	☐	☐
h. I am bothered by a change in weight	☐	☐	☐	☐	☐
i. I am able to feel like a woman	☐	☐	☐	☐	☐

j Looking at the above 9 questions, how much would you say your **ADDITIONAL CONCERNS** affects your quality of life?

0 1 2 3 4 5 6 7 8 9 10

not at all … very much so

Your Health

	Excellent 3	Very Good 2	Good 3	Fair 4	Poor 5
15. In general, would you say your health is:	☐	☐	☐	☐	☐

16. **The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *(Check an answer for each activity)***

	HOW LIMITED YOU ARE		
	Not at all 1	A little 2	A lot 3
a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
b. Lifting or carrying groceries	☐	☐	☐
c. Climbing several flights of stairs	☐	☐	☐
d. Walking several blocks	☐	☐	☐

17. **During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health:**

a. Accomplished less than you would like 1☐ Yes 2☐ No

b. Were limited in the kind of work or other activities 1☐ Yes 2☐ No

18. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of emotional problems (such as feeling depressed or anxious):**

a. Accomplished less than you would like 1☐ Yes 2☐ No

b. Didn't do work or other activities as carefully as usual 1☐ Yes 2☐ No

19. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

1☐ Not at all 2☐ A little bit 3☐ Moderately 4☐ Quite a bit 5☐ Extremely

20. **During the past 4 weeks, how much of the time has your physical health or emotional problems limited your social activities (like visiting with friends, relatives, etc.)?**

1☐ All the time 2☐ Most of the time 3☐ Some of the time 4☐ A little of the time 5☐ None of the time

21. **For EACH of the following questions, please CHECK the answer that comes closest to the way you have been feeling and how things have been with you during the past 4 weeks.**

How much of the time during the past 4 weeks:	**All of the time** 1	**Most of the time** 2	**A good bit of the time** 3	**Some of the time** 4	**A little of the time** 5	**None of the time** 6
a. Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
b. Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
c. Have you felt downhearted & blue?	☐	☐	☐	☐	☐	☐
d. Have you felt very anxious or nervous?	☐	☐	☐	☐	☐	☐

22. **Check the box for each statement which best describes how often you felt or behaved this way during the <u>past week</u>**

During the <u>past week:</u>	**Rarely or None of the Time (Less than 1 Day)** 0	**Some or a Little of the tTme (1-2 Days)** 1	**Occasionally or a Moderate Amount of Time (3-4 Days)** 2	**Most or All of the Time (5-7 days)** 3
a. I was bothered by things that usually don't bother me	☐	☐	☐	☐
b. I did not feel like eating; my appetite was poor	☐	☐	☐	☐
c. I felt that I could not shake off the blues even with help from my family or friends	☐	☐	☐	☐
d. I felt that I was just as good as other people	☐	☐	☐	☐
e. I had trouble keeping my mind on what I was doing	☐	☐	☐	☐
f. I felt depressed	☐	☐	☐	☐
g. I felt that everything I did was an effort	☐	☐	☐	☐
h. I felt hopeful about the future	☐	☐	☐	☐
I. I thought my life had been a failure	☐	☐	☐	☐
j. I felt fearful	☐	☐	☐	☐
k. My sleep was restless	☐	☐	☐	☐
l. I was happy	☐	☐	☐	☐
m. I talked less than usual	☐	☐	☐	☐
n. I felt lonely	☐	☐	☐	☐
o. People were unfriendly	☐	☐	☐	☐
p. I enjoyed life	☐	☐	☐	☐
q. I had crying spells	☐	☐	☐	☐
r. I felt sad	☐	☐	☐	☐
s I felt that people disliked me	☐	☐	☐	☐
t. I could not get going	☐	☐	☐	☐

SOCIAL SUPPORT

23. **People sometimes look to others for help, friendship, or other types of support. Next are some questions about the support that you have. How often is each of the following kinds of support available to you if you need it?**

	None of the time 1	A little of the time 2	Some of the time 3	Most of the time 4	All of the time 5
a. Someone you can count on to listen to you when you need to talk	☐	☐	☐	☐	☐
b. Someone to give you good advice about a problem	☐	☐	☐	☐	☐
c. Someone to take you to the doctor if you need it	☐	☐	☐	☐	☐
d. Someone to help you understand a problem when you need it	☐	☐	☐	☐	☐
e. Someone to help with daily chores if you are sick	☐	☐	☐	☐	☐
f. Someone to share your most private worries and fears	☐	☐	☐	☐	☐
g. Someone to do something fun with	☐	☐	☐	☐	☐
h. Someone to love you and make you feel wanted	☐	☐	☐	☐	☐

24. **How many relatives and friends do you have that you feel close to (feel at ease with, can talk to about private matters, can call on for help).** (Check one box for relatives and one box for friends.)

	Relatives	Friends
None		
1 or 2		
3 to 5		
6 to 9		
10 or more		

25. **Is this more or fewer than before your breast cancer diagnosis?**

1 ☐ More relatives/friends than before diagnosis
2 ☐ Fewer relatives/friends than before diagnosis
3 ☐ Same number of relative/friends always had

27. How much does your ***breast cancer and its treatment*** **currently interfere with different aspects of your life? CIRCLE the number that best describes your present life situation.**

If an item is not applicable, circle number 1 (one) to indicate that this aspect of your life is not affected very much. ***Please do not leave any item unanswered.***

	Not Very Much						Very Much
a. Health	1	2	3	4	5	6	7
b. Diet (*e.g. The things you eat and drink*)	1	2	3	4	5	6	7
c. Work	1	2	3	4	5	6	7
d. Active recreation (*e.g. Dancing, sports*)	1	2	3	4	5	6	7
e. Passive recreation (*e.g. Reading, listening to music*)	1	2	3	4	5	6	7
f. Financial situation	1	2	3	4	5	6	7
g. Relationship with spouse or partner	1	2	3	4	5	6	7
h. Sex life	1	2	3	4	5	6	7
i. Family relations	1	2	3	4	5	6	7
j. Other social relations	1	2	3	4	5	6	7
k. Self-expression/self-improvement	1	2	3	4	5	6	7
l. Religious expression	1	2	3	4	5	6	7
m. Community and civic involvement	1	2	3	4	5	6	7
n. Planning for the future	1	2	3	4	5	6	7

OVERALL SATISFACTION

28. Overall, how would you rate the following aspects of your breast cancer care at Kaiser Permanente:

	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Does not Apply 6
a. Your care before surgery	☐	☐	☐	☐	☐	☐
b. Your care in the hospital for surgery	☐	☐	☐	☐	☐	☐
c. Your care during chemotherapy or Tamoxifen	☐	☐	☐	☐	☐	☐
d. Your follow-up care	☐	☐	☐	☐	☐	☐
e. The amount of information you received	☐	☐	☐	☐	☐	☐
f. The amount of emotional support you received	☐	☐	☐	☐	☐	☐

Thank you for completing the questionnaire.

Please return it in the pre-addressed, postage-paid envelope to:

Carol Somkin, PhD, Division of Research, Kaiser Permanente,
P.O. Box 12916 Oakland, CA 94604-9921

Anything Else?

Is there anything else you would like to tell us about your breast cancer experience? If so, write your comments here.

KAISER PERMANENTE

BREAST CANCER PEER SUPPORT PROJECT TWELVE MONTH QUESTIONNAIRE

Please answer the following questions and return the survey in the enclosed prepaid, self-addressed envelope. **All the information you provide in the survey will be kept completely confidential.** Your answers will not be shared with your doctor or employer, become part of your medical record, or affect your Health Plan membership or dues.

1. Overall, how would you describe the care you received at Kaiser Permanente to diagnose and treat your breast cancer?

1 ☐ Poor 2 ☐ Fair 3 ☐ Good 4 ☐ Very good 5 ☐ Excellent

BREAST CANCER TREATMENT

2. Which of the following treatments have you had or do you plan to have?

	Had in past/ having now 1	**Plan to have** 2	**Do not plan to have** 3	**Undecided** 4
a. Mastectomy	☐	☐	☐	☐
b. Lumpectomy (breast conserving surgery)	☐	☐	☐	☐
c. Breast reconstruction	☐	☐	☐	☐
d. Radiation therapy	☐	☐	☐	☐
e. Chemotherapy	☐	☐	☐	☐
f. Tamoxifen (hormonal therapy)	☐	☐	☐	☐

3. Overall, how would you rate your current understanding of breast cancer and its treatment?

1 ☐ Poor 2 ☐ Fair 3 ☐ Good 4 ☐ Very good 5 ☐ Excellent

DECISION MAKING

4. To what extent do you agree with the statement, "You should go along with the doctor's advice even if you disagree with it":

1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree

5. To what extent do you agree or disagree with each of the following:	**Disagree strongly** 1	**Disagree somewhat** 2	**Agree somewhat** 3	**Agree strongly** 4
a. I understand the advantages and disadvantages of each treatment option:				
1. Mastectomy	☐	☐	☐	☐
2. Lumpectomy (breast conserving surgery)	☐	☐	☐	☐
3. Breast Reconstruction	☐	☐	☐	☐
4. Radiation Therapy	☐	☐	☐	☐
5. Chemotherapy	☐	☐	☐	☐
6. Tamoxifen (hormonal therapy)	☐	☐	☐	☐
b. I understand why some treatment options were not available to me	☐	☐	☐	☐
c. I had enough time to make my treatment decisions	☐	☐	☐	☐
d. I wish I had had more information about my treatment options	☐	☐	☐	☐
e. I am satisfied with my treatment decisions	☐	☐	☐	☐
f. I usually ask my doctor a lot of questions	☐	☐	☐	☐
g. I have difficulty getting emotional support from my doctor (getting my doctor to understand my feelings)	☐	☐	☐	☐
h. I have difficulty getting the information that I need from my doctor	☐	☐	☐	☐

6. How often do you do each of the following?	**Never** 1	**Sometimes** 2	**Often** 3	**Always** 4
a. Prepare a list in advance when you visit your doctor	☐	☐	☐	☐
b. Discuss with your doctor any personal problems that may be related to your illness	☐	☐	☐	☐
c. Discuss any problems you had following a treatment plan, such as taking a medicine or following a special diet	☐	☐	☐	☐
d. Call your doctor(s) between visits if you have problems	☐	☐	☐	☐

7. **How useful did you find the following breast cancer resources and services?**

	Very useful 1	**Somewhat useful** 2	**Not Very useful** 3	**Not at all useful** 4	**Did not use** 5
a. Kaiser Health Education materials (pamphlets, videos, etc.)	☐	☐	☐	☐	☐
b. Kaiser psychiatrist, psychologist or psychiatric social worker	☐	☐	☐	☐	☐
c. Breast Care Coordinator	☐	☐	☐	☐	☐
d. American Cancer Society Reach to Recovery Program	☐	☐	☐	☐	☐
e. Kaiser peer support program	☐	☐	☐	☐	☐
f. Support group for women with breast cancer	☐	☐	☐	☐	☐
g. Educational and support services for family and friends	☐	☐	☐	☐	☐
h. Other ____________________	☐	☐	☐	☐	☐

Below is a list of statements that other people with your illness have said are important. By checking one box per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>

8. Physical Well-Being

	Not at all 1	**A little bit** 2	**Somewhat** 3	**Quite a bit** 4	**Very much** 5
a. I have a lack of energy	☐	☐	☐	☐	☐
b. I have nausea	☐	☐	☐	☐	☐
c. Because of my physical condition, I have trouble meeting the needs of my family	☐	☐	☐	☐	☐
d. I have pain	☐	☐	☐	☐	☐
e. I am bothered by side effects of treatment	☐	☐	☐	☐	☐
f. I feel sick	☐	☐	☐	☐	☐
g. I am forced to spend time in bed	☐	☐	☐	☐	☐

h. Looking at the above 7 questions, how much would you say your **PHYSICAL WELL-BEING** affects your quality of life?

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all very much so

9. Social/Family Well-Being

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I feel distant from my friends	☐	☐	☐	☐	☐
b. I get emotional support from my family	☐	☐	☐	☐	☐
c. I get support from my friends and neighbors	☐	☐	☐	☐	☐
d. My family has accepted my illness	☐	☐	☐	☐	☐
e. Family communication about my illness is poor	☐	☐	☐	☐	☐
f. I feel close to my partner (or the person who is my main support)	☐	☐	☐	☐	☐
g1. Have you been sexually active during the past year? No ________ Yes ________					
g2. IF YES: I am satisfied with my sex life	☐	☐	☐	☐	☐

h. Looking at the above 7 questions, how much would you say your **SOCIAL/FAMILY WELL-BEING** affects your quality of life?

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all — very much so

10. Relationship with Doctor

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I have confidence in my doctor(s)	☐	☐	☐	☐	☐
b. My doctor is available to answer my questions	☐	☐	☐	☐	☐

c. Looking at the above 2 questions, how much would you say your **RELATIONSHIP WITH YOUR DOCTOR** affects your quality of life?

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all — very much so

11. Emotional Well-Being

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I feel sad	☐	☐	☐	☐	☐
b. I am proud of how I'm coping with my illness	☐	☐	☐	☐	☐
c. I am losing the fight against my illness	☐	☐	☐	☐	☐
d. I feel nervous	☐	☐	☐	☐	☐
e. I worry about dying	☐	☐	☐	☐	☐
f. I worry that my condition will get worse	☐	☐	☐	☐	☐

g. Looking at the above 6 questions, how much would you say your **EMOTIONAL WELL-BEING** affects your quality of life?

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all — very much so

12. Functional Well-Being

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I am able to work (include work at home)	☐	☐	☐	☐	☐
b. My work (include work in home) is fulfilling	☐	☐	☐	☐	☐
c. I am able to enjoy life	☐	☐	☐	☐	☐
d. I have accepted my illness	☐	☐	☐	☐	☐
e. I am sleeping well	☐	☐	☐	☐	☐
f. I am enjoying the things I usually do for fun	☐	☐	☐	☐	☐
g. I am content with the quality of my life right now	☐	☐	☐	☐	☐

h. Looking at the above 7 questions, how much would you say your **FUNCTIONAL WELL-BEING** affects your quality of life?

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all very much so

13. Additional Concerns

	Not at all 1	A little bit 2	Somewhat 3	Quite a bit 4	Very much 5
a. I have been short of breath	☐	☐	☐	☐	☐
b. I am self-conscious about the way I dress	☐	☐	☐	☐	☐
c. My arms are swollen or tender	☐	☐	☐	☐	☐
d. I feel sexually attractive	☐	☐	☐	☐	☐
e. I have been bothered by hair loss	☐	☐	☐	☐	☐
f. I worry about the risk of cancer in other family members	☐	☐	☐	☐	☐
g. I worry about the effect of stress on my illness	☐	☐	☐	☐	☐
h. I am bothered by a change in weight	☐	☐	☐	☐	☐
i. I am able to feel like a woman	☐	☐	☐	☐	☐

j Looking at the above 9 questions, how much would you say your **ADDITIONAL CONCERNS** affects your quality of life?

(circle one number)
0 1 2 3 4 5 6 7 8 9 10
not at all very much so

Your Health

	Excellent 1	Very Good 2	Good 3	Fair 4	Poor 5
14. In general, would you say your health is:	☐	☐	☐	☐	☐

15. **The following items are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?** ***(Check an answer for each activity.)***

	HOW LIMITED YOU ARE Not at all 1	 A little 2	 A lot 3
a. <u>Moderate activities</u>, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
b. Lifting or carrying groceries	☐	☐	☐
c. Climbing <u>several</u> flights of stairs	☐	☐	☐
d. Walking <u>several</u> blocks	☐	☐	☐

16. **During the <u>past 4 weeks</u> have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>:**

a. <u>Accomplished less</u> than you would like 1☐ Yes 2☐ No
b. Were limited in the <u>kind</u> of work or other activities 1☐ Yes 2☐ No

17. **During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities <u>as a result of emotional problems</u> (such as feeling depressed or anxious):**

a. <u>Accomplished less</u> than you would like 1☐ Yes 2☐ No
b. Didn't do work or other activities as carefully as usual 1☐ Yes 2☐ No

18. **During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?**

1☐ Not at all 2☐ A little bit 3☐ Moderately 4☐ Quite a bit 5☐ Extremely

19. **During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional</u> problems limited your social activities (like visiting with friends, relatives, etc.)?**

1☐ Not at all 2☐ A little bit 3☐ Moderately 4☐ Quite a bit 5☐ Extremely

20. **For EACH of the following questions, please CHECK the answer that comes closest to the way you have been feeling and how things have been with you during the <u>past 4 weeks</u>.**

How much of the time during the <u>past 4 weeks:</u>	**All of the time** 1	**Most of the time** 2	**A good bit of the time** 3	**Some of the time** 4	**A little of the time** 5	**None of the time** 6
a. Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
b. Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
c. Have you felt downhearted & blue?	☐	☐	☐	☐	☐	☐
d. Have you felt very anxious or nervous?	☐	☐	☐	☐	☐	☐

21. **Check the box for each statement which best describes how often you felt or behaved this way during the <u>past week</u>.**

During the <u>past week</u>:		**Rarely or None of the Time (Less than 1 day)**	**Some or a Little of the Time (1-2 days)**	**Occasionally or a Moderate Amount of Time (3-4 days)**	**Most or All of the Time (5-7 days)**
		0	1	2	3
a.	I was bothered by things that usually don't bother me	☐	☐	☐	☐
b.	I did not feel like eating; my appetite was poor	☐	☐	☐	☐
c.	I felt that I could not shake off the blues even with help from my family or friends	☐	☐	☐	☐
d.	I felt that I was just as good as other people	☐	☐	☐	☐
e.	I had trouble keeping my mind on what I was doing	☐	☐	☐	☐
f.	I felt depressed	☐	☐	☐	☐
g.	I felt that everything I did was an effort	☐	☐	☐	☐
h.	I felt hopeful about the future	☐	☐	☐	☐
I.	I thought my life had been a failure	☐	☐	☐	☐
j.	I felt fearful	☐	☐	☐	☐
k.	My sleep was restless	☐	☐	☐	☐
l.	I was happy	☐	☐	☐	☐
m.	I talked less than usual	☐	☐	☐	☐
n.	I felt lonely	☐	☐	☐	☐
o.	People were unfriendly	☐	☐	☐	☐
p.	I enjoyed life	☐	☐	☐	☐
q.	I had crying spells	☐	☐	☐	☐
r.	I felt sad	☐	☐	☐	☐
s	I felt that people disliked me	☐	☐	☐	☐
t.	I could not get going	☐	☐	☐	☐

SOCIAL SUPPORT

22. People sometimes look to others for help, friendship, or other types of support. Next are some questions about the support that you have. How often is each of the following kinds of support available to you if you need it?

	None of the time 1	A little of the time 2	Some of the time 3	Most of the time 4	All of the time 5
a. Someone you can count on to listen to you when you need to talk	☐	☐	☐	☐	☐
b. Someone to give you good advice about a problem	☐	☐	☐	☐	☐
c. Someone to take you to the doctor if you need it	☐	☐	☐	☐	☐
d. Someone to help you understand a problem when you need it	☐	☐	☐	☐	☐
e. Someone to help with daily chores if you are sick	☐	☐	☐	☐	☐
f. Someone to share your most private worries and fears	☐	☐	☐	☐	☐
g. Someone to do something fun with	☐	☐	☐	☐	☐
h. Someone to love you and make you feel wanted	☐	☐	☐	☐	☐

23. How many relatives and friends do you have that you feel close to (feel at ease with, can talk to about private matters, can call on for help). (Check one box for relatives and one box for friends.)

		23a. Relatives	23b. Friends
1	None		
2	1 or 2		
3	3 to 5		
4	6 to 9		
5	10 or more		

24. Is this more or fewer than before your breast cancer diagnosis?

1 ☐ More relatives/friends than before diagnosis
2 ☐ Fewer relatives/friends than before diagnosis
3 ☐ Same number of relative/friends always had

25. How much does your *breast cancer and its treatment* currently interfere with different aspects of your life? CIRCLE the number that best describes your present life situation.

If an item is not applicable, circle number 1 (one) to indicate that this aspect of your life is not affected very much. *Please do not leave any item unanswered.*

	Not Very Much						Very Much
a. Health	1	2	3	4	5	6	7
b. Diet (*e.g. The things you eat and drink*)	1	2	3	4	5	6	7
c. Work	1	2	3	4	5	6	7
d. Active recreation (*e.g. Dancing, sports*)	1	2	3	4	5	6	7
e. Passive recreation (*e.g. Reading, listening to music*)	1	2	3	4	5	6	7
f. Financial situation	1	2	3	4	5	6	7
g. Relationship with spouse or partner	1	2	3	4	5	6	7
h. Sex life	1	2	3	4	5	6	7
i. Family relations	1	2	3	4	5	6	7
j. Other social relations	1	2	3	4	5	6	7
k. Self-expression/self-improvement	1	2	3	4	5	6	7
l. Religious expression	1	2	3	4	5	6	7
m. Community and civic involvement	1	2	3	4	5	6	7
n. Planning for the future	1	2	3	4	5	6	7

Peer Support

26. In the past year, have you talked to a breast cancer survivor about your experience with breast cancer? 1☐ Yes 2☐ No, I preferred not to 3☐ No, I didn't know a survivor

27. IF YES, was this woman: (Please check all that apply.)

a. A family member	☐
b. A friend	☐
c. An acquaintance or co-worker	☐
d. A Reach to Recovery Volunteer	☐
e. A Kaiser Peer Support Volunteer	☐
f. Other (please specify) ____________________	☐

28. Over the past year, how often did you have contact with a peer support volunteer (either Reach to Recovery or Kaiser)? (Please check the box that applies.)

	Not At all 1	Once or Twice 2	3-5 Times 3	5-10 Times 4	More Than 10 Times 5
a. Telephone calls	☐	☐	☐	☐	☐
b. In person visit(s)	☐	☐	☐	☐	☐

29. Was this:

1 ☐ Less contact than you wanted

2 ☐ About as much contact as you wanted

3 ☐ More contact than you wanted

30. If you had a Reach to Recovery or a Kaiser Peer Support Volunteer, how much did she help you in the following areas?

	Very Helpful 1	Somewhat Helpful 2	A little helpful 3	Not at all Helpful 4	Does Not Apply 5
a. Get the information you needed	☐	☐	☐	☐	☐
b. Understand your breast cancer diagnosis	☐	☐	☐	☐	☐
c. Decide what treatment(s) to have	☐	☐	☐	☐	☐
d. Communicate better with your doctor	☐	☐	☐	☐	☐
e. Know what questions to ask your doctor	☐	☐	☐	☐	☐
f. Take better care of yourself	☐	☐	☐	☐	☐
g. Find out about and use the Kaiser resources better	☐	☐	☐	☐	☐
h. Deal with job stress	☐	☐	☐	☐	☐
I. Deal with family relationships	☐	☐	☐	☐	☐
j. Deal with sexual issues related to breast cancer	☐	☐	☐	☐	☐

31. How much do you agree or disagree with the following about your peer support volunteer?

	Strongly Agree 1	**Agree** 2	**Neutral** 3	**Disagree** 4	**Strongly Disagree** 5
a. I could ask her questions that I couldn't ask anyone else	☐	☐	☐	☐	☐
b. She lifted my spirits	☐	☐	☐	☐	☐
c. Her background was too different from mine so it was hard to talk to her	☐	☐	☐	☐	☐
d. Talking with her made me feel less afraid	☐	☐	☐	☐	☐
e. Talking with her made me worry more	☐	☐	☐	☐	☐
f. Talking with her made me feel more hopeful	☐	☐	☐	☐	☐
g. Her breast cancer experience was too different from mine so it was hard to talk to her	☐	☐	☐	☐	☐
h. Talking with her made me feel less alone	☐	☐	☐	☐	☐
I. She helped me solve practical problems (such as where to get a prosthesis)	☐	☐	☐	☐	☐

32. What do you see as the main benefits of having a Reach to Recovery or a Kaiser peer support volunteer? (*Please attach another sheet of paper if you would like.)*

33. What do you see as the main drawbacks of having a Reach to Recovery or a Kaiser peer support volunteer? (*Please attach another sheet of paper if you would like.*)

____

____

____

____

____

____

OVERALL SATISFACTION

34. Overall, how would you rate the following aspects of your breast cancer care at Kaiser Permanente:

	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Does not Apply 6
a. Your care before surgery	☐	☐	☐	☐	☐	☐
b. Your care in the hospital for surgery	☐	☐	☐	☐	☐	☐
c. Your care during chemotherapy or Tamoxifen	☐	☐	☐	☐	☐	☐
d. Your follow-up care	☐	☐	☐	☐	☐	☐
e. The amount of information you received	☐	☐	☐	☐	☐	☐
f. The amount of emotional support you received	☐	☐	☐	☐	☐	☐

Thank you for completing the questionnaire.

Please return it in the pre-addressed, postage-paid envelope to:

Carol Somkin, PhD, Division of Research, Kaiser Permanente,
P.O. Box 12916 Oakland, CA 94604-9921

APPENDIX 2

BREAST CANCER PEER SUPPORT PROGRAM. DEVELOPMENT AND IMPLEMENTATION PHASES

Carol P. Somkin, PhD

Kaiser Permanente Division of Research
Oakland, California 94611-5714

This study addresses the critical issue of how best to design an affordable intervention that improves psychosocial outcomes. Since 1969, the American Cancer Society Reach to Recovery Program has provided volunteer peer support to newly diagnosed women with breast cancer. Historically, Reach to Recovery has been limited to one or two contacts with a volunteer visitor to provide short-term information and support. This program has been very well received, although no controlled studies of its effectiveness have been conducted. In the years since its development, important changes have occurred in the treatment of breast cancer and the delivery of health care which suggest ways to augment the program to better meet the needs of breast cancer patients today. The major aim of this study is to determine whether it is worthwhile to provide an expanded, organizationally-specific, peer support program to women beginning at the time of diagnosis and continuing for up to one year.

The overall goal of the study is to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer at a large health maintenance organization. This program augments and complements the American Cancer Society's Reach to Recovery Program. In addition to providing emotional support, this experimental program is designed to help patients: (a) gain the information and skills needed to participate effectively in their treatment planning; and (b) learn how to navigate a complex medical care delivery system in order to obtain the treatment that they want.

Keywords: Quality of Life, Peer Support, Patient Decision making, Sociodemographic Factors, Intervention

This work was supported by the U.S. Army Medical Research and Materiel Command under DAMD-17-94-4334.

We ask four research questions:

1. Does an expanded peer support program improve
    a) quality of life with breast cancer?
    b) participation in treatment decisions?
    c) satisfaction with care?
2. How do patient sociodemographic characteristics influence these outcomes?
3. What are the main benefits of a peer support program?
4. Does participation in treatment decisions improve quality of life?

Women recruited into the study in five Kaiser Permanente medical centers are randomly assigned to the intervention or control group. Participants in the intervention group are paired with a trained breast cancer survivor (Peer Support Volunteer) who provides them, beginning at diagnosis, with ongoing peer support along with specific information and skills to help them navigate the Kaiser Permanente Medical Care Program (KPMCP). Participants in the control group receive the usual support services offered to women newly diagnosed with breast cancer, which in most cases includes a referral to Reach to Recovery.

KPMCP Peer Support Volunteers receive the standard one-day Reach to Recovery training, in addition to a specially developed two-day skills training devoted to increasing their problemsolving, decision making and advocacy skills. For example, a "decision making inventory" was developed for use during the training in a role-playing exercise. Use of the inventory guides volunteers in the process of assisting newly diagnosed women in making informed choices. Whether these choices are related to medical treatment or other life choices, the process is aimed at assisting the woman in determining for herself what information and other resources she needs make a decision with which she can live.

Data are being collected using questionnaires at entry into the study, at 3 months, and at 12 months. Quality of life is assessed using a number of measures including the Medical Outcomes Study Short Form (SF-12); the Center for Epidemiologic Studies Depression Scale (CES-D); and David Cella's FACT scale. We also collect qualitative feedback from both the participants and the volunteers about the usefulness of the program. Our analysis will take into account other sources of information and support.

We are currently in the third year of a four-year project. In the first year we: (1) conducted focus groups with women (who were diagnosed and treated at Kaiser Permanente) to ascertain their information needs, barriers to participation in treatment decisions and ways to address these barriers; (2) designed the research measures to evaluate the effectiveness of the program; and (3) recruited and trained the peer support volunteers. The second year and third years have been devoted to patient enrollment; continued volunteer recruitment, training and supervision; and data collection. The fourth year will be devoted to continued data collection, data analysis and report writing.

BREAST CANCER PEER SUPPORT PROGRAM. DEVELOPMENT AND IMPLEMENTATION PHASES

Carol P. Somkin, PhD

Kaiser Permanente Division of Research
Oakland, California 94611-5714

The overall goal of this randomized controlled trial is to develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer at a large Health Maintenance Organization. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year.

Participants in the intervention group are paired with a trained breast cancer survivor (Peer Support Volunteer) who provides them with ongoing support as well as specific information and skills to help them navigate the Kaiser Permanente Medical Care Program. Study volunteers receive the standard Reach to Recovery training, in addition to a two-day skills training devoted to increasing their problemsolving, decision making and advocacy skills. Participants in the control group receive the usual support services offered to women newly diagnosed with breast cancer, which usually includes a referral to Reach to Recovery. The major outcomes for the study include quality of life, participation in treatment decisions and satisfaction with care. We also collect qualitative feedback about the usefulness of the program from both the participants and the volunteers.

This study addresses the critical issue of how best to design an affordable intervention that improves psychosocial outcomes. It is directed at filling the gap in our understanding about how the provision of information and support by other women living with breast cancer benefits newly diagnosed women.