

**ORIGINAL ARTICLE**

**ANN M. GEIGER, MPH, PhD**  
*Southern California Permanente  
Medical Group  
Pasadena, Calif*

**ELIZABETH S. MULLEN**  
*Women's Information Network  
Against Breast Cancer  
Covina, Calif*

**PATRICIA A. SLOMAN, RN, MS**  
*Fontana Medical Center  
Kaiser Foundation Hospital  
Fontana, Calif*

**BRADFORD W. EDGERTON, MD**  
*West Los Angeles Medical Center  
Southern California Permanente  
Medical Group  
West Los Angeles, Calif*

**DIANA B. PETITTI, MD, MPH**  
*Southern California Permanente  
Medical Group  
Pasadena, Calif*

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*Edited by Steven Woloshin, MD,  
MS*

# Evaluation of a Breast Cancer Patient Information and Support Program

**CONTEXT.** Women with newly diagnosed breast cancer seek answers to many questions about their disease, treatment options, and prognosis. Failure to meet these needs may cause dissatisfaction with the care process.

**OBJECTIVE.** To evaluate the impact of a support and information program for women with newly diagnosed breast cancer.

**INTERVENTION.** A support and information program that featured a program coordinator, information resources, and mentoring from a breast cancer survivor.

**DESIGN AND OUTCOME MEASURES.** Women in whom breast cancer was diagnosed at program sites ( $n=111$ ) and a random sample of women whose breast cancer was diagnosed at nonprogram sites ( $n=277$ ) were surveyed by mail to ascertain their level of satisfaction with various aspects of their medical care. The response rates were 74% and 81%, respectively.

**RESULTS.** 75% of women at program sites used the information resources, and 60% requested a patient mentor. Demographic characteristics and satisfaction with non-breast cancer care were almost identical among program and non-program site respondents. For overall breast cancer care, 71% of program site respondents but only 56% of non-program site respondents were very satisfied. More than half of program site respondents rated presurgery care, provision of information, and support received as excellent, versus about 40% of non-program site respondents. Program site respondents were consistently more likely to rate the amount of reassurance and support provided by physicians and nurses as excellent and were less likely to want a second opinion (35% vs. 51%).

**CONCLUSIONS.** The support and information program appears to have had a positive impact on satisfaction with breast cancer care.

**W**omen with newly diagnosed breast cancer seek answers to many questions about their disease and treatment options.<sup>1,2</sup> Failure to meet these needs may cause dissatisfaction with the care process. Physicians and other health care professionals play a key role in providing support and information,<sup>2,3</sup> but communication may be difficult. In one study, 84% of 97 women with stage I or II breast cancer reported difficulties in communicating with their medical team. Difficulties in understanding information and expressing feelings to and asking questions of physicians were the most common.<sup>4</sup> Given that patient complaints about physicians often arise from communication problems,<sup>5</sup> improved support and information should result in higher patient satisfaction with care.

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In 1994, there were a number of reports from patients and health care professionals of widespread dissatisfaction with breast cancer care at Kaiser Permanente Southern California (KPSC). In response, KPSC and the Women's Information Network Against Breast Cancer (WIN-ABC) formed a partnership that led to the implementation of the Breast Buddy Breast Care Program. Anecdotal evidence from within the health plan and from external sources suggested that the main source of dissatisfaction was lack of information and social support from health care professionals and, by extension, the health plan. Thus, the program's central concept was that providing support and ready access to detailed information about breast cancer treatment options to patients with newly diagnosed breast cancer would increase satisfaction with medical care.

The program was evaluated by determining whether women whose breast cancer was diagnosed at program sites were more satisfied with their breast cancer care than were women whose disease was diagnosed at other sites. Improved satisfaction was selected as the outcome of interest not only because it was the primary goal of the program but also because satisfaction is widely recognized as a legitimate measure of health care,<sup>6-8</sup> particularly managed care.<sup>9</sup> Patient satisfaction also has been associated with improved patient compliance with therapy that presumably leads to better health outcomes.<sup>6,7,10</sup>

## Methods

### Overview of the Breast Buddy Breast Care Program

The Breast Buddy Breast Care Program is a multidisciplinary effort of physicians, nurses, administrative staff, and community activists to inform and support women with breast cancer throughout their course of treatment. The information and social support provided was intended to affect four components of the Health Belief Model.<sup>11</sup> 1) Perceived benefits of breast cancer treatment were addressed by clearly defining the treatment decision-making process and the patient's role in this process. 2) The guidance provided for the treatment decision-making process included step-by-step information intended to cue women to action. 3) Women's self-efficacy was addressed by verbal reinforcement and empathetic support intended to reduce anxiety. 4) Perceived barriers to breast cancer treatment were overcome by reassurance and countering misinformation. Interactions with women with newly diagnosed breast cancer were explicitly designed to incorporate four broad types of social support: emotional (empathy), instrumental (tangible services), informational, and appraisal (affirmation).<sup>12</sup>

**Table 1** shows an overview of the program components. The program includes three key components: a

program coordinator, information resources, and mentoring from a breast cancer survivor. The program was selected as a model program in breast cancer care by the Best Practices in Women's Health effort. A detailed description of the program is provided on the American Association of Health Plan's and WIN-ABC's web pages.<sup>13,14</sup>

### Study Sites

The choice of where to implement the program could not be random because clinician and staff participation in program development and implementation could not be forced. At the time of program implementation, KPSC operated six service areas defined by service to geographically distinct populations. Because of the size and integration of southern California's population, the demographic characteristics of members with breast cancer in each service area are roughly similar. Each service includes one to three hospitals with satellite outpatient clinics. Each service area provides full cancer care with the exception of radiation oncology, which is centralized at two facilities (a KPSC facility for greater Los Angeles and a contract facility for San Diego).

The program was initially implemented in the first service area to meet the following criteria: no existing effort to comprehensively address the information and support needs of women with breast cancer, several hundred incident breast cancer diagnoses annually, geographic proximity of hospitals within service area and to WIN-ABC office, and willingness to permit clinicians and staff to participate in program development efforts. Because the first service area to qualify (the Inland Empire Service Area) contained two medical centers, the program implementation dates were staggered to permit full focus on one medical center at a time. The remaining five service areas did not receive the program.

### Participants

All participants in the evaluation were members of the Kaiser Foundation Health Plan in southern California. All women who received a breast cancer diagnosis at the first implementation site from October 1995 through March 1996 and at the second implementation site from February to April 1996 were invited to participate in the evaluation, regardless of their level of participation in the program. A random sample of women whose disease was diagnosed at non-program sites was selected at a ratio of 2.5 non-program site women for each program site woman. The ratio was increased above two to ensure adequate statistical power, given the potential for a low response rate. The sample of non-program site women was frequency-matched to program site women

TABLE 1

**Components of the Breast Buddy Breast Care Program\***

COMPONENT	DESCRIPTION
Program coordinator	<p>One at each site (both of whom are registered nurses)</p> <p>Meets with all patients at time of diagnosis to introduce the program and ascertain level of interest in other components</p> <p>Available for consultation at any time during the course of treatment at the request of the patient or their physician or mentor</p> <p>Recruits, trains, and supervises patient mentors</p> <p>Does not function as a case manager or coordinate care</p>
Information resources†	<p>“Bag of books” given to patients at time of diagnosis; includes two guides to breast cancer (one from California and one from KPSC); an extensive community resource guide with bibliography; brochures on breast anatomy, breast self-examination, prostheses, and sexuality; a relaxation audiotape; videotapes on tamoxifen and post-lumpectomy and post-mastectomy exercises; and NCI-approved books on surviving cancer</p> <p>A lending library that includes all of the publications listed in the resource guide plus a range of video, laser disc, and interactive CD-ROM programs on treatment decision-making topics and cancer survivorship issues</p>
Patient mentors	<p>KPSC members with personal history of breast cancer treated at least 1 year previously</p> <p>Complete initial 16 hours of training incorporating the American Cancer Society’s Reach to Recovery Program,<sup>15</sup> extensive information on breast cancer treatment and related psychosocial issues, an orientation to problem solving and decision making, and guidelines to using the KPSC medical care system</p> <p>Commit to minimum of 1 year for each buddy</p> <p>Encouraged to contact buddy at least once weekly; file regular contact reports with program coordinator</p> <p>Matched to patient buddy by coordinator according to various factors, including similar breast cancer diagnosis, spiritual beliefs, and geographical proximity</p>

\*KPSC = Kaiser Permanente Southern California; NCI = National Cancer Institute.

†A complete list of materials in the “bag of books” and the lending library is available from the corresponding author.

by month of diagnosis. Breast cancer patients at program and non-program sites were identified by using the medical center cancer registries. **Table 2** lists the characteristics of the women in the study sample.

### Program Evaluation

The evaluation compared the satisfaction of women whose breast cancer was diagnosed at Breast Buddy Breast Care Program sites with that of women whose disease was diagnosed at nonprogram sites (**Figure 1**). Our primary hypothesis was that patient satisfaction with breast cancer care and patient assessments of information and social support from medical staff would be higher at program sites than at nonprogram sites. The evaluation was approved by the KPSC Institutional Review Board for the Protection of Human Subjects.

Women eligible for the evaluation received a mailing 4 months after their breast cancer diagnosis. The

mailing included a cover letter explaining the purpose of the evaluation; a survey; and an addressed, stamped return envelope. Neither the letter nor the survey mentioned the program, but instead stated that the purpose of the survey was to help KPSC better meet women’s need for high-quality breast cancer care. Nonrespondents to the initial mailing received an identical mailing 2 weeks later. Nonrespondents to both mailings received a reminder telephone call 4 weeks after the first mailing, and a third survey was mailed on request.

### Outcome Measures

Because validated instruments to measure satisfaction with breast cancer care could not be identified at the time that this survey was initiated, an instrument was developed specifically for this study. Questions were modeled after the Group Health Association of America Consumer Satisfaction Survey.<sup>16</sup> As described by Rosenthal and Shannon,<sup>6</sup> the survey asked about global

**TABLE 2**  
**Characteristics of the Study Sample\***

CHARACTERISTIC	PATIENTS AT PROGRAM SITES (n = 82)	PATIENTS AT NON-PROGRAM SITES (n = 225)
Mean age ± SD, yr	58.5 ± 13.1	60.1 ± 12.8
<b>Level of education</b>		
Less than high school	5.0%	11.4%
High school graduate	68.8%	56.4%
College graduate	16.3%	21.4%
Postgraduate degree	10.0%	10.9%
<b>Race/ethnicity</b>		
White/Caucasian	76.8%	71.6%
Black/African American	4.9%	11.1%
Hispanic/Latina	12.2%	9.3%
Asian	3.7%	6.2%
Other/unknown	2.4%	1.8%
<b>How breast cancer was first detected</b>		
Self-examination	38.3%	38.0%
Mammography	45.7%	43.3%
Other	16.1%	18.8%
<b>AJCC stage of breast cancer at diagnosis</b>		
0	15.2%	15.8%
I	48.1%	45.7%
II	32.9%	31.2%
III or IV	3.8%	7.2%
<b>Type of surgical treatment received</b>		
Mastectomy	61.5%	53.7%
Lumpectomy	38.5%	46.3%
<b>Receiving or planning to receive radiation therapy</b>	35.4%	38.6%
<b>Receiving or planning to receive chemotherapy or hormonal therapy</b>	55.0%	67.7%

\*AJCC = American Joint Committee on Cancer. Blue type indicates  $P < 0.05$ .

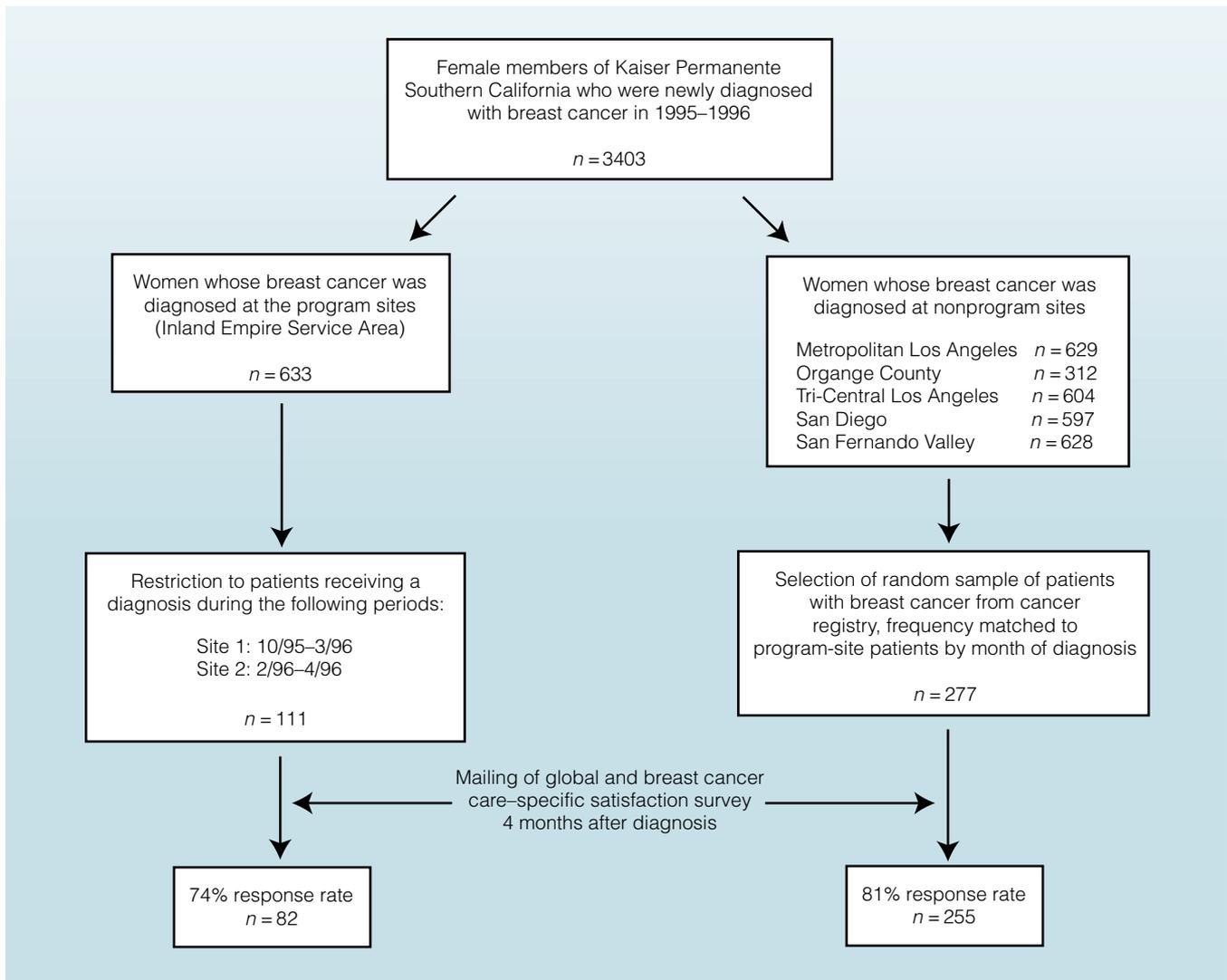
(overall satisfaction with breast cancer and non-breast cancer care) and service-specific satisfaction (diagnostic process, treatment decision-making, surgery, and adjuvant therapies). Because the intervention targeted only breast cancer services, we hypothesized that satisfaction would improve only in breast cancer-related areas. To better discriminate among the high categories, service-specific satisfaction was measured by using a five-point Likert scale with the categories poor, fair, good, very good, and excellent.<sup>6,9</sup> Because we wanted to explicitly ask women to rate their satisfaction and sought to distinguish clearly between satisfied and dissatisfied women, global satisfaction was measured by using a four-point Likert scale with the categories very dissatisfied, dissatisfied, satisfied, and very satisfied. A copy of the survey instrument is available from the corresponding author.

### Statistical Analysis

The statistical significance of differences between program and nonprogram sites was assessed by using the chi-square test for categorical data, such as demographic characteristics; the Wilcoxon rank-sum test for ranked data, such as satisfaction measures; and the Student *t*-test for continuous data, such as age and utilization. Nonparametric tests were used for ranked data because the distributions were skewed. All tests were two-tailed, and *P* values less than 0.05 were considered statistically significant.

### Results

Overall, 388 women were eligible for the survey. Eighty-two women at program sites (74% response rate) and 225 at nonprogram sites (81% response rate) completed the



**FIGURE 1. Overview of the evaluation for the Breast Buddy Breast Care Program.**

survey, for an overall response rate of 79%. Respondents from the program sites were similar to respondents from nonprogram sites in terms of age, education, race/ethnicity, cancer diagnosis, and treatment details ( $P > 0.05$  for all comparisons) with one exception: Fewer program site respondents received chemotherapy or hormone therapy (55% vs. 68%;  $P = 0.04$ ) (Table 2).

As hypothesized, ratings of satisfaction with non-breast cancer care did not differ significantly between program and non-program site respondents (60% vs. 53% were “very satisfied” with non-breast cancer care;  $P = 0.4$ ) (Table 3). On the other hand, in areas targeted by intervention, program site respondents gave higher satisfaction ratings than did non-program site respondents. Compared with non-program site respondents, program site respondents assigned statistically significant higher satisfaction ratings for overall breast cancer care (71% vs. 56% were “very satisfied”), presurgery care (53% vs. 39% rated this care as “excellent”), provision

of information (54% vs. 38% gave a rating of “excellent”), and emotional support (49% vs. 38% rated this support as “excellent”). No differences in satisfaction were found in ratings of the diagnostic process and surgical care.

A higher percentage of program site respondents than non-program site respondents rated the provision of information and social support as excellent (Table 4). The proportion of program site respondents and non-program site respondents who rated delivery of breast cancer diagnosis (49% vs. 36%), explanation of mastectomy (61% vs. 42%), and presurgery support from various health care providers, including the primary physician, surgeon, and special breast care nurse, as “excellent” differed significantly. Differences that approached statistical significance were found for explanation of radiation therapy and chemotherapy and for postsurgery support from various health care providers. Fewer program site respondents than non-program site respondents desired and obtained a second opinion.

TABLE 3

## Measures of Satisfaction with Breast Cancer Care\*

ITEM BEING RATED	PATIENTS AT PROGRAM SITES (n=82)	PATIENTS AT NON-PROGRAM SITES (n=225)
<b>Non-breast cancer care and services</b>		
Very dissatisfied/dissatisfied	6.1%	4.1%
Satisfied	34.2%	43.2%
Very satisfied	59.8%	52.7%
<b>Overall breast cancer care and services</b>		
Very dissatisfied/dissatisfied	6.1%	8.3%
Satisfied	23.2%	35.8%
Very satisfied	70.7%	56.0%
<b>Diagnostic process</b>		
Poor or fair	8.8%	12.7%
Good or very good	38.8%	42.7%
Excellent	52.5%	44.6%
<b>Presurgery care</b>		
Poor or fair	3.9%	7.5%
Good or very good	42.9%	53.8%
Excellent	53.3%	38.7%
<b>Surgical care</b>		
Poor or fair	10.7%	11.7%
Good or very good	45.3%	44.9%
Excellent	44.0%	43.4%
<b>Provision of information</b>		
Poor or fair	9.2%	15.0%
Good or very good	36.8%	46.9%
Excellent	54.0%	38.2%
<b>Reassurance and emotional support received</b>		
Poor or fair	8.7%	18.7%
Good or very good	42.0%	43.5%
Excellent	49.3%	37.8%

\*Blue type indicates  $P < 0.05$ .

## Discussion

The Breast Buddy Breast Care Program was developed by KPSC in partnership with WIN-ABC to improve patient satisfaction with breast cancer care by addressing the support and information needs of patients with newly diagnosed breast cancer. The results of the program's evaluation suggest that its goals were met. Patient satisfaction with overall breast cancer care at program sites was higher than that at nonprogram sites. Service-specific areas targeted by the program, such as care before surgery and provision of information and social support, were rated more highly at program sites than at nonprogram sites. No differences in satisfaction were observed for areas not targeted by the program, such as the diagnostic process and surgical care.

Several published reports support the potential benefits found in the evaluation. The program addressed

many of the needs of breast cancer patients that were outlined by Ganz,<sup>17</sup> including a coordinator to function as an advocate and efforts to address common communication problems and the complexity involved in breast cancer treatment decision making. The program components were consistent with the communicative, emotional, and collaborative efforts of health care professionals who have been linked to improved patient adjustment and prognosis.<sup>2</sup> The patient mentoring aspect of the program may be similar to or extend the beneficial effects of support group participation, as described by several investigators.<sup>18-20</sup> The program encompasses and extends the Reach to Recovery program, the benefits of which have been reported anecdotally.<sup>15</sup>

Although we could not identify published studies that specifically addressed the impact of support and information programs on satisfaction with breast cancer care, several related studies have been published. In one

TABLE 4

## Ratings of Provision of Information and Social Support\*

ITEM BEING RATED	PATIENTS AT PROGRAM SITES (n = 82)	PATIENTS AT NON-PROGRAM SITES (n = 225)
Diagnosis delivered in excellent manner <sup>†</sup>	48.8%	35.8%
Excellent explanation of advantages and disadvantages of:		
Mastectomy <sup>†</sup>	61.2%	42.0%
Lumpectomy	56.7%	45.4%
Radiation therapy	53.1%	37.0%
Chemotherapy	50.0%	32.7%
Hormonal therapy	43.9%	34.5%
Excellent presurgery reassurance and support from:		
Primary physician <sup>†</sup>	68.6%	42.6%
Surgeon <sup>†</sup>	75.0%	53.7%
Other physicians and nurses	52.2%	38.3%
Special breast care nurse <sup>†</sup>	66.7%	41.0%
Excellent postsurgery reassurance and support from:		
Primary physician	64.4%	46.6%
Surgeon	73.1%	51.5%
Other physicians and nurses <sup>†</sup>	55.2%	42.7%
Special breast care nurse	60.0%	46.2%
Desired or obtained a second opinion	35.0%	50.7%

\*Blue type indicates  $P < 0.05$ .

<sup>†</sup> $P < 0.01$ .

study, nurse provision of information and emotional support increased patients' sense of control.<sup>21</sup> One study identified health care providers and Reach to Recovery volunteers as essential components in generating social support and, in turn, increased quality of life among breast cancer survivors.<sup>22</sup> A clinical trial of interventions after breast cancer diagnosis reported that support from a dedicated nurse from diagnosis forward decreased psychological morbidity,<sup>23</sup> although methodologic problems have raised concerns about this finding.<sup>24, 25</sup> Trijsburg and colleagues<sup>26</sup> summarized 22 studies and concluded that various psychological treatments have been shown to improve some aspects of the psychological health of women with newly diagnosed breast cancer. Finally, some evidence suggests that emotional social support (defined as having a confidant, particularly one who was a physician or nurse) increased survival among women with breast cancer.<sup>27</sup>

The conclusions of the evaluation must be considered in light of several possible limitations. First, baseline differences across program and nonprogram sites may explain some of our findings. For example, some clinic sites might be more interested in breast cancer care than others; this interest could be reflected in a willingness to participate in the Breast Buddy Program, and the observed level of patient satisfaction relative to that seen at nonprogram

sites might reflect the initial interest rather than any effect of the program. We have no reason to believe this to be the case, but the fact that we could not randomly assign service areas to the program makes it impossible to eliminate the potential for an underlying site effect. A preprogram comparison of satisfaction with breast cancer care between program and nonprogram sites would have allowed stronger inferences; however, it would have delayed program implementation by at least 1 year.

Baseline differences in patient populations served by the clinics could also affect our findings. The lack of difference in demographic characteristics and satisfaction with non-breast cancer care at program and nonprogram sites, however, suggests that the underlying populations did not substantially differ.

As is often true of satisfaction surveys,<sup>9</sup> we focused on operation needs rather than classical research hypotheses. Other end points, such as health-related quality of life, psychological morbidity, and survival, were not assessed because improving satisfaction with care was the stated main goal of the program. Near the end of the evaluation, concern about women with breast cancer led to some efforts to implement isolated components of the program at nonprogram sites. As a result, a few persons were designated to act in roles similar to that of the program coordinator and/or additional written materials began to be

provided to women. The quality of these efforts varied considerably, however, and they were not based on any health behavior model or consistently integrated into the care process. Nonetheless, had it been possible to prevent this “contamination,” the magnitude of differences in patient satisfaction might have been greater.

We are unable to fully explain the less frequent use of chemotherapy or hormone therapy at program sites. We found no differences in overall satisfaction with breast cancer care between those who did and those who did not use these therapies, and stratification by these therapies did not alter our conclusions about satisfaction differences between program and nonprogram sites. For example, of chemotherapy or hormone therapy users, 61% were very satisfied with their overall cancer care compared with 59% of nonusers ( $P = 0.4$ ). Because our survey combined these two therapies into one question, we are unable to separate the two types of adjuvant therapy. All intervention and mentor training materials were approved by a multidisciplinary team; it is therefore unlikely that the written materials included a systematic bias against chemotherapy or hormonal therapy. A subtle bias against these therapies may have crept in to mentor–patient relationships, but no evidence substantiates or disproves this theory. Moreover, a greater proportion of program site patients than non–program site patients rated the explanation of the advantages and disadvantages of chemotherapy and hormone therapy as excellent, although these differences were not statistically significant.

Our evaluation has several strengths. The response rate was high for a study of patient satisfaction; reported rates range from 30% to 60% or 70%.<sup>6,9</sup> Moreover, the level of program participation seems to have been high: All women with newly diagnosed breast cancer were contacted, about 75% used the lending library at least once during their initial course of treatment, about 40% requested a patient mentor at the time of diagnosis, and 20% requested a patient mentor at the time of chemotherapy. Most important, the study assessed the effect of the program on the entire population of women whose breast cancer was diagnosed at program sites, without considering the level of program participation. If we had evaluated only women assigned mentors or frequent users of the lending library, the increase in satisfaction may have been higher. However, because the program was designed to contact all women with newly diagnosed breast cancer at least once, we felt that the program should be held to the higher standard of improved satisfaction for all women, regardless of their level of program participation.

A key consideration of program implementation is cost. We estimate the initial direct annual cost of the program to be \$100,000 total for our two program sites. Most

of this money is expended on salary support for the program coordinators. The remaining money is spent on informational materials. Indirect costs occur in the form of an office, telephone, and supplies for the coordinator and space for the library. Once the program is implemented, including training a group of patient mentors, salary support for the coordinator will decrease because of the reduced labor burden. Foundations and pharmaceutical companies may also help defray the costs of materials. Depending on the size of the breast cancer patient population, background of the program coordinator, and availability of other funds for materials, the annual cost of a fully functioning program at a single hospital with several hundred new breast cancer cases annually will probably range from \$25,000 to \$75,000.

The results of this program evaluation were disseminated throughout KPSC. The two implementation medical centers continued to offer the program, and it was adopted by one other medical center. Several other medical centers have added the patient mentor component of the program to their local permutations of a program coordinator and information provision. The program is also being tested among indigent women in a county health care setting. For health care professionals and administrators concerned about the experience of women with breast cancer, the Breast Buddy Care Program offers a model for provision of information and social support that appears to improve patient satisfaction.

## Take-Home Points

- **Information and social support are important to women with newly diagnosed breast cancer. However, such support is often not available from health care professionals.**
- **We developed and tested a multicomponent program to make informational and social support available at several sites in the Kaiser Permanente health care system in southern California.**
- **Key components of the program were a program coordinator, information resources, and mentoring from a breast cancer survivor.**
- **During the study period, all women in whom breast cancer was diagnosed at program sites were made aware of the program; of these women, 75% made use of informational materials and about 60% requested a patient mentor.**
- **Compared with women at nonprogram sites, program site patients were more satisfied with their breast cancer care, particularly presurgery care; provision and delivery of information; and social support.**

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## Correspondence

Ann M. Geiger, MPH, PhD, Research and Evaluation Department, Southern California Permanente Medical Group, 100 South Los Robles Street, Pasadena, CA 91188; telephone: 626-564-3453; fax: 626-564-3430; e-mail: [ann.m.geiger@kp.org](mailto:ann.m.geiger@kp.org).