J Cancer Surviv (2008) 2:190–204
DOI 10.1007/s11764-008-0058-x

Addressing the needs of young breast cancer survivors at the 5 year milestone: can a short-term, low intensity intervention produce change?

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Received: 13 November 2007 / Accepted: 21 May 2008 / Published online: 1 August 2008
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Abstract

Background Today, the 5-year relative survival rate for cancer is 65% and there are 10.5 million survivors. The largest group of survivors are those of breast cancer. Reductions in mortality are occurring at a greater rate for women under age 50 at diagnosis than among older women.

Aims Our goal was to design a socio-educational intervention for 5-year survivors aged 50 or younger at diagnosis and test the hypotheses that women in the intervention group would show greater improvement than controls with respect to (1) knowledge of breast cancer, its treatment, and long-term health concerns; (2) lifestyle habits (i.e., exercise and diet); and (3) communication with family and physicians.

Methods Using a randomized controlled trial with a pre-post design, 404 women who were 5 years from diagnosis and cancer-free (response rate 54%) were randomly assigned to an intervention or delayed intervention (control) group and were assessed at pre-test (baseline) and 6 months later (96% retention). The intervention consisted of three 6-h workshops over a 3 month period. Four series of workshops were held at different geographical areas in the greater San Francisco Bay Area. The workshops included activities and information to promote physical, social, emotional, and spiritual well-being. The intervention design was based on findings from focus groups and a survey of 185 cancer-free 5-year survivors that assessed changes since the early months after diagnosis in physical, social, emotional, and spiritual concerns (response rate 73%).

Results Consistent with our first hypothesis, at post-test, women in the intervention group, on average, had greater knowledge regarding breast cancer, its treatment, and their own future health than did those in the control group ($p=0.015$). Hypothesis 2 was partially supported as women in the intervention group were more likely than the control group to report an increased amount of physical activity ($p=0.036$), but not significant dietary changes. Social support was related to increased self report of physical activity. With the exception of the last series of workshops, the intervention group did not report improved communications with family, friends, and physicians (hypothesis 3).

Conclusions A short-term intervention can affect knowledge levels and physical activity but not diet or communication in the family.

Implications for Cancer Survivors The intervention was related to greater knowledge related to breast cancer, and increased report of physical activity. The program was not related to changes in reported diet or family communication.

Keywords Young breast cancer survivors · Socio-educational intervention for breast cancer survivors

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The study was funded by the NIH, NCI R01-CA 078951. The authors gratefully acknowledge the contributions of Ingrid Oakley-Girvan, Ph.D., Merrilee Morrow, Ingrid Peterson, M.P.H., Subo Chang, M.S. and Monica Johnston, M.S.

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Introduction

Due to earlier diagnosis and improved treatment, the 5-year relative survival rate for all types of cancer combined is 66%. Current estimates are that more than 10.8 million persons living in the United States are cancer survivors. Excitement about this progress has been accompanied by a myriad of questions about the unmet needs of long-term survivors and interventions that may assist them. This paper contributes to the growing body of research in this area by reporting the design, delivery and effects of an innovative workshop series for young breast cancer survivors as they reached the 5-year milestone.

At 22.5%, women who have had breast cancer constitute this nation's largest group of cancer survivors [1]. Approximately 23% of new diagnoses are in women under the age of 50 [2] and between 1990 and 2004, the breast cancer mortality rate in this age group declined by an average of 3.3% per year compared to 2% among older women [2]. The number of young breast cancer survivors, therefore, is increasing.

Health and quality of life among long-term breast cancer survivors

While the body of literature on the physical, psychological, and social health of survivors is growing, only a few studies have focused on long-term breast cancer survivors [3–6]. Of these, most do not analyze findings by age, and only two have focused exclusively on women age 50 or younger, [7–8]. Many studies of longer-term survivors include women whose length of survivorship varies widely. In other research, the longest follow-ups have been between five to 10 years, or in one case, 15 years after diagnosis [9]. With a few exceptions [4, 10], studies published before 1998 [6] were small (less than 75 participants) and employed cross-sectional designs with different measures of quality of life, while later studies tended to be larger and more numerous [11].

Despite methodological differences, these studies consistently have found that the majority of breast cancer survivors are doing well and that quality of life (QOL) for most has improved since their time of diagnosis [6]. Two studies report QOL scores comparable to healthy controls [10, 12]. However, not inconsequential numbers of survivors have reported lingering effects of their treatment, especially menopausal symptoms [4, 8, 13, 14], arm and chest wall problems [7, 10, 15], weight gain [7], cognitive impairment [7], sexual difficulties with partners [4, 8, 10, 15–17], problems with obtaining and maintaining health insurance, and fears of recurrence [8, 15, 18]. Almost a third of the women continue to report psychological distress, primarily depression [15–21]. In one study, women reported being more socially isolated than before diagnosis [15], while another reported receiving inadequate emotional support [16]. Another found that the perception of satisfactory social support was associated with less anxiety and dysphoria [17]. Three longitudinal studies reported that 5–10 years following cancer treatment, the social networks of young survivors were smaller [7, 10, 22].

Effects of breast cancer treatment

The density of breast tissue in women under 50 makes mammography screening difficult, and due to resulting controversy about screening recommendations for this age group [23], some young women are never screened. Newly diagnosed young breast cancer patients are more likely than older women to be offered multi-modal treatments, which can be more toxic, cause more abrupt onset menopause [24–26] and may affect women's health and QOL years later. Total mastectomy has been associated with higher distress levels than partial mastectomy in women under age 50 whereas the reverse relationship was observed among older women [7, 10]. In a recent study, Ganz et al. reported that past systemic adjuvant chemotherapy was significantly associated with poorer quality of life in several domains 5 to 10 years after diagnosis with breast cancer [4]. As young survivors age, the effects of multi-modal breast cancer treatment also may increase their risk for heart problems [27], osteoporosis [28], and other chronic diseases [7].

Interventions for breast cancer survivors

We identified more than 100 intervention studies for breast cancer survivors, but most were for women who were either undergoing treatment or had recently completed treatment. The few that focused on longer-term survivors evaluated group psycho-social interventions (e.g., cognitive behavioral therapy to reduce psychological symptoms [29–31]) or efforts to improve nutrition [32], exercise [33–35], reproductive health [36], and communication skills between women and their physicians during medical visits [37, 38]. Additionally, one study compared the effects of education, a peer discussion group, and a combined education–discussion group on adjustment after breast cancer treatment [39]. The finding that education alone was more effective than the other approaches replicated results from an earlier study with Hodgkin's disease patients [40]. None addressed more than one cluster of the needs and concerns identified by young breast cancer survivors.

Significance of the 5-year survivorship milestone

Reaching the 5-year survivorship milestone is widely acknowledged by the general public to signify a substantial reduction in the risk of recurrence. Achieving this milestone thus may assuage anxiety among young survivors, but also prompt them to reflect on their breast cancer experience, take stock of their present situation, and think about the future. However, partners, children, other family members, friends, and co-workers usually are eager to get past the disruptions created by the discovery of breast cancer and its treatment so that life can return to normal [7]. They therefore may view the 5-year milestone as the completion of the survivor's physical and psychological recovery, as well as a welcome end to a difficult albeit time-limited era. When this is the case, these significant others may discourage further discussion of breast cancer, leaving women to work through their unresolved questions and feelings in isolation [3]. A recent study found family avoidance of communication about cancer to be fairly common and negatively associated with mental health in breast cancer survivors [41]. Although life appears to return to normal on the surface, barriers to communication may diminish QOL for survivors by impeding the resolution of current or future problems.

Study goals and specific aims

The 5-year survivorship anniversary may provide a "teachable moment" for young breast cancer survivors at the same time that the cancer-related social support available decreases. These circumstances define the potential need and opportunity for intervention pursued in this study. Our goals were to assist young survivors in assessing their physical and psychosocial recovery from breast cancer and its treatment and equip them with the knowledge and the skills for identifying and making changes needed to protect and enhance their health and quality of life both at the present and in the years ahead. Specific aims were to improve (1) knowledge about breast cancer, its treatment, and long-term effects, (2) diet and physical activity, and (3) communication with family, friends, and physicians.

Conceptual framework

The intervention was conceptualized through the lens of social support, a theoretical construct which refers to the resources generated through mutual obligations and reciprocal relationships with family members, friends, and acquaintances, including co-workers, who comprise one's social network [42–44]. The resources supplied by a social network may include, but are not limited to: (1) informational support—the provision of new and helpful information such as the name of a physician who specializes in menopause; (2) instrumental support—practical assistance, such as the loan of money in an emergency or a ride to a medical appointment; and (3) emotional support—showing that one is loved, esteemed, valued, and cared for.

While social support can facilitate change through adaptive coping [22, 45], the bio-physiological pathways mediating outcomes are not well understood. Notwithstanding, three considerations identified social support as an appropriate framework to guide the development of the 5-year survivorship intervention. First, a substantial body of prior research has demonstrated the importance of social support to women after a breast cancer diagnosis, through treatment, and in subsequent years. Regardless of the effects of breast cancer treatment [3, 45–48], social support assists women with the psychological and social adaptation to the disease and its treatment [49–52], buffers the stresses they face [45], improves their quality of life [49–51], and ultimately helps them adjust to their mortality [9, 52]. For example, emotional support reduces anxiety and psychological distress [17, 22, 53]. Appraisal support, or the disclosure of one's thoughts and feelings to significant others, helps alleviate intrusive thoughts [54].

Second, studies have shown that the size of women's social networks influences the availability of social resources needed to keep them informed about the latest developments in breast cancer treatment and to maintain a healthy life style [52, 55, 56]. However, our preliminary [7] and prior research [12] indicates that the social networks of young breast cancer survivors become smaller over time suggesting that their supply of social resources also may diminish.

In combination, this body of research led to a third set of considerations underlying this research. Could an intervention increase the social support available to young 5-year survivors? If this were done, would these young women become more knowledgeable about breast cancer, its treatment, and the late effects of treatment? Would they make lifestyle changes to improve their present and future health? Would they strengthen their natural social support system through better communication of their needs to family, friends, associates, and physicians? We hypothesized that intervention would produce significant improvements in these outcomes within 6 months.

The widely recognized significance of 5-year cancer free survival focused attention on this anniversary as a unique opportunity to help young survivors reassess their physical and psychosocial recovery, to integrate the lessons learned from their breast cancer experience, to address unanswered questions, to contemplate their goals for the future, and to initiate changes important to goal achievement. Conducting the intervention with groups of young survivors would provide the social support to undertake these short-term tasks through interactions with each other and with experts on topics of common interest. Based on the two most relevant studies found in the literature [39, 40] and our review of other research, an approach that combined informational and emotional support was expected to be most effective, while instrumental support seemed less important to young cancer-free 5-year survivors. Because achieving longer-term change in life style habits usually requires sustained support, the intervention included advice about strengthening relationships with members of survivors' existing social networks, as well as information about community resources that could contribute to network expansion.

Methods

Design

We designed a randomized controlled trial using a pre-post test design in which eligible women were randomly assigned to the intervention or control (a delayed intervention) group. Women randomized to the intervention group participated in a series of three 1-day workshops that took place at monthly intervals. Women in the control (delayed intervention) group were invited to attend a 1-day educational workshop following the end of the post-test assessment.

Sample

A total of 404 women (54% response rate) were randomly assigned to the intervention (n=201) or control group (n=203) and were assessed at pre-test (baseline) and 6 months later (96% retention rate). These women had been diagnosed with breast cancer and reported to the Greater Bay Area Cancer Registry in 1995–97 [57]; many had participated in an earlier study [58]. Of the 940 women who were screened for the current study, 194 were ineligible, mainly due to having a recurrence or new cancer. The 746 eligible women who were cancer free 5 years after diagnosis at age 50 or younger were asked to participate in a minimum of two monthly workshops and two interviews. Of these, 27 could not be scheduled for interview and 315 refused; 260 were interested in participating in the research but could not commit to the requirements of the study.

Development of the intervention

Data from a survey of a separate sample of 185 young 5-year cancer-free survivors (73% response rate) were used to inform the design of our intervention and to develop a survey instrument to be used to test the effectiveness of the intervention. In addition to being interviewed, some participated in focus groups. Finally, they were all invited to participate in a pilot study of the intervention. Details of the sampling strategy and the findings have been reported elsewhere [7].

Empirical generalizations from the survey are as follows.

- The women stressed the need for education about breast cancer treatment and the need for second opinions.
    - Women reported using complementary and alternative treatments.
    - Many reported regrets about the type of treatment they had received.
    - Concerns reported about their sexuality included lack of desire (56%) and difficulty with arousal (46%), enjoyment (35%), or orgasm (38%).
    - Reporting of hormonal symptoms of menopause was common (hot flashes (63%), sleep problems (56%), sweats (51%), and vaginal dryness (49%)).
- Diet and exercise were important tools to cope with cancer after treatment.
- Women reported having less emotional support and a smaller social network than in the first months after diagnosis. For many, their family and friends were their greatest source of support.
- Women reported communication problems with their physicians.
    - Physicians didn't listen to them.
    - Physicians were insensitive to the psychological aspects of having breast cancer.
- Five years later, a vast majority of these women thought they were in excellent physical and psychological health.

Qualitative analyses of the survey data and comments in the focus groups revealed that many women had regrets about the type of breast cancer treatment that they had received, and consequently, they stressed the need for education about breast cancer treatment and the importance of second opinions. Many women also reported using complementary and alternative treatments, identifying the need for education about their effectiveness, side effects, and safety. Most focus group participants reported out-of-pocket medical expenses for these treatments, counseling and/or Tamoxifen.

Based on these findings and experience with the previous study at the time of diagnosis [58], the research team expected that potential participants were mostly working and likely unable to attend weekly sessions, most did not need a support group, albeit the availability of support for those that needed/wanted it should be available, and that they were highly educated and relatively sophisticated in their informational needs. From the educational component of the psycho-educational support groups in which many of these women participated soon after diagnosis, we knew that they did not want general diet information, but were interested in complementary and alternative medicine (e.g., herbal remedies and megavitamins [58]).

Using the information from the survey and focus groups, the research team designed a series of three 6-h long workshops to be conducted on Saturdays at one month intervals. Given the findings from the survey and these other considerations neither a focus on psychological dysphoria nor a focus on sexual counseling seemed feasible or warranted. Pragmatic decisions with regard to the outcomes that could be expected from three 6-h workshops were also considered in selecting workshop topics.

Finally, all participants in the survey and focus groups were invited to a 1-day workshop where we piloted most of the talks and activities. In many cases participants selected between two activities (e.g., yoga or Qi Gong). Based on their input, changes were made in both content and format.

Intervention design and delivery

To commemorate the 5-year milestone, the three workshops were organized to honor the young survivor's past, present, and future. Through a variety of activities and presentations, each workshop also addressed four cross-cutting themes, addressing unmet informational needs, promoting exercise and nutrition, improving communication skills, and providing and receiving emotional support. Each of these themes was introduced at the first workshop and further developed at subsequent ones (Table 1).

For example, in the first workshop, the theme of addressing informational needs was initially introduced by a medical oncologist, specializing in breast cancer, who provided an update on the epidemiology, diagnostic, and treatment information relevant to survivors of breast cancer. This information described improvements in survival, new treatments, and included a discussion of some of the myths regarding treatment and survivorship. In the second workshop, a pharmacist discussed the use of herbal remedies and nutritional supplements. In addition, two attorneys presented information about the rights of breast cancer survivors as individuals covered under the Americans with Disabilities Act and relevant state law, and demonstrated ways to address problems with health insurance and assert their rights when claims were turned down. In the third workshop, a gynecologist with expertise in menopause discussed relevant issues regarding experiencing menopause without hormone replacement therapy, sexuality and sexual functioning, and the impact of menopause on bone mineral density and the need for exercise to counteract this potential problem. Each of these information presentations generated interaction between participants and the speaker and, often, discussion between participants.

The second theme was promoting healthy behaviors, with an emphasis on exercise. In the first workshop an exercise physiologist spoke about the importance of weight-bearing physical activity, gave examples of weight-bearing exercises, and led the women through a 30 min exercise session using exercise stretch bands. At lunch, the women discussed ways to increase exercise in their daily routines and the importance of healthy eating. After lunch, a representative of the Women's Healthy Eating and Living (WHEL) study [32] discussed the importance of healthy eating and invited them to participate in their study. During a break, they took a walk around the grounds of the meeting facility. In the second workshop, all of the women received a personal assessment by the exercise physiologist and an exercise prescription [33]. In addition, women exchanged information about barriers to regular exercise and techniques they had found useful in increasing their exercise. In the third workshop, the exercise component was again reinforced by further exchange of exercise "progress reports." The fitness instructor also led them in exercises during a break. At each workshop, a lunchtime discussion about incorporating more fruits and vegetables in one's diet focused on handouts from the WHEL study that included tips on low fat cooking and ways to increase fruit and vegetable intake [32, 59].

The third theme was improving communication skills. At one workshop, a skit of a difficult interaction between a physician and patient provided the focus of a discussion of communication principles that could be used in working through communication problems with physicians. Another focus was an emphasis on the woman becoming her own advocate. At the third workshop, based on the earlier survey, a presentation of the findings on sexual difficulties faced by the women was presented. Following this presentation, problems in communication with close friends/partners were discussed along with suggestions on how to overcome them.

Tying these themes together was our focus on generating emotional support and making the workshops pleasurable experiences. This was accomplished by providing music, decorations, food and making opportunities to socialize. Women were encouraged to share their breast cancer stories and insights gained, and initiate changes to protect and improve their health and QOL. At the end of each workshop, the women were given information and gifts (e.g., a pink baseball cap). All of the topics covered focused on improvement in the women's quality of life. Activities and exercises in each workshop focused on inner peace in order to improve their emotional well-being. For example, in the second workshop the women brought quilt pieces that they had made and discussed their meaning in terms of their lives post breast cancer diagnosis and treatment. In the third workshop women were invited to talk about their biggest problems in the past 5 years. Further activities were the use of restorative yoga to enhance flexibility as well as

Table 1 Workshop themes and activities

Theme	Workshop		
	1. Honoring our past	2. Honoring our present	3. Honoring our future
Addressing informational needs	Current research on breast cancer and its treatment—what it means for survivors (medical oncologist)	Effects of nutritional supplements and herbal remedies (pharmacist)	What survivors need to know about taking care of their health (medical oncologist)
	The Young Survivors study (principal investigator)	Taking control of insurance and employment issues (two attorneys)	Menopause and symptom management (gynecologist)
			Study data on sexuality and sexual functioning among young survivors (statistician)
	Table with take-away resource materials	Table with take-away resource materials	Table with take-away resource materials
Promoting healthy behaviors	Importance of weight-bearing exercise (exercise physiologist)	Conversational warm-up: barriers to exercise in daily life and tips for overcoming them	Tips on low-fat cooking, and handout of WHEL study resource materials
	Importance of Healthy Eating invitation to participate in WHEL study (nutritionist/researcher)		30 min group exercise session—Yoga (certified instructor)
	30 min exercise session using stretch bands (gifts to women)	Personal fitness assessment (exercise physiologist)	Healthy morning refreshments, highlight fruits and vegetables served at lunch
	Tips for fitting exercise into daily routine (luncheon discussion)	30 min group exercise: QiGong—connecting mind, body, and spirit (doctor of Chinese medicine)	Stretch break—"Movin' with Music." Exercise progress reports
	30 min after-lunch walk to "benefit body, mind, and friendship"		
	Healthy morning refreshments, highlight fruits and vegetables served at lunch	Healthy morning refreshments, highlight fruits and vegetables served at lunch	
Improving communication skills	Skit of difficult interaction with MD and discussion of communication principles	Sharing wisdom about relationships (luncheon table talk)	Communications and intimacy (2 oncology social workers)
		Being your own advocate, skit and discussion	Communication problems and possible solutions (luncheon table talk)
Emotional support	Conversational warm-up: sharing breast cancer stories	Survivors who completed a quilt square show and discuss meaning in their lives	Conversational warm-up: future goals and reasons for choosing them
	Honoring survival and our wisdom; introduction of quilt square activity	Other interactions (see above)	Discuss biggest problem in last 5 years. Presentation of completed quilt Closing poem, gift of potted flowers, and participant comments

a relaxation exercise; Qi Gong, which also enhances flexibility and an individual's sense of control; and a closing exercise to enhance the integration of the workshops into the women's everyday lives.

Implementation of the intervention

The intervention was presented successively in four different locations within the greater San Francisco Bay Area on Saturdays. Women were invited to the setting closest to where they lived, but were allowed to go to any of the locations, especially if they missed a session.

To reduce the number of women who did not participate actively in the intervention, three different strategies were used. First, at the time of informed consent and prior to randomization, women were asked to commit to attending at least two sessions. Second, women who missed a session were advised of the dates and location of the other sessions and invited to come to an alternate location. Finally, handouts and hard copies of overheads were mailed to each participant who did not attend a session. Thus, all women received information presented at the workshops albeit those who missed a session did not participate in the interactive aspects of the workshops (e.g., physical activity assessments, exercises, dietary discussions, and interactive activities relating to communication problems with partners, family members, and physicians).

Measurement

Measures of outcomes

1. Breast cancer information—21 Likert-formatted items were developed for this study that focused on myths and facts about breast cancer and its treatment. Some examples are: (a) “Tamoxifen causes depression,” (b) “Chemotherapy can cause heart problems,” (c) “Hormone replacement therapy prevents heart disease,” (d)”You can be fired from your job for having breast cancer,” and (e) “There is no time limit for having breast reconstruction.” Women could respond that they “strongly disagree,” “somewhat disagree,” “somewhat agree,” or “strongly agree.” Responses were coded as 1=correct (i.e., agree with a true statement or disagree with a false statement); 0=incorrect (i.e., not agree with a true statement or not disagree with a false statement), and summed to create a score. “Don’t know” or “refused” responses were counted as incorrect.
2. Physical activity—Women reported the number of days per week they got at least 30 min of physical exercise. The amount of physical activity was also measured by indicating on a scale from 0 (never) to 4 (frequently) how often in the past month, while not on the job, participants had engaged in walking, standing and stretching exercise, weight bearing exercises involving strength training, non-weight bearing exercise (such as yoga or stretching), and active weight bearing and non-weight bearing recreation; a sum of the items, weighted by number of metabolic equivalents (METs), was formed to obtain a total [60]. At post-test, participants reported specific changes in physical activity in the past 6 months, including whether or not they had increased the amount of physical activity and whether or not they had started a physical exercise program [60].
3. Diet—Women reported how many fruits and vegetables they ate each day and how often they tried to eat non-fat or low-fat foods. They also completed Block’s Fruits and Vegetables and Fat screeners [61, 62], which were used to validate the two measures of dietary change. At post-test they reported specific changes in diet in the past 6 months, including whether or not they had started eating more fruits and vegetables and whether or not they had started a low-fat or low-calorie diet.
4. Patient–physician communication—Problems in patient–physician communication were measured by four items from the Breast Cancer Problems Scale developed by Schain [63]. This scale contains 23 Likert scaled items with a Cronbach’s alpha of 0.85. The four items relate to the amount and comprehensibility of information given, the amount of emotional support offered, and feeling comfortable with the decisions made by physicians. This scale, formed by summing the four items, was used in the analyses (Cronbach’s alpha=0.86 in our sample). In addition, women reported whether or not they communicated their health needs in each of seven specific ways; the total number (0–7) was used in analyses.
5. Communication with family—Communication of feelings and needs to spouse/partner was measured on a Likert type scale from 1 (frequently) to 4 (never). Communication issues with children were reported using four items (reaction to illness, need for emotional support, need for information, and what to tell about illness), which were summed to form a scale (Cronbach’s alpha=0.82 in our sample) [63].

Measures of covariates

6. Socio-demographic information—Included were: (a) the women’s age at diagnosis; (b) race/ethnicity (Euro-American versus African American, Latina, or Asian); (c) marital status (married or partnered versus single); (d) education (high school or less, some college, college graduate); and (e) employment status (working either part-time or full-time versus not working outside the home).
7. Diagnostic and treatment information—Information on stage of disease (in-situ, local, regional, or remote) was obtained from the Greater Bay Area Cancer Registry. Type of surgical treatment (a mastectomy or breast conserving treatment) and receipt of adjuvant therapy (chemotherapy, radiation, and/or hormone treatment, (i.e., tamoxifen)) was obtained in the screening interview.
8. Social support—The Berkman–Syme Social Network Index [64] was used to assess the number and frequency of social contacts. The index has been widely used to explore social networks in both patient and community samples and has been found to predict morbidity and mortality in community samples [65], as well as breast cancer survival [66].

Analysis

Basic descriptive statistics and frequency distributions were computed for each variable. The validity of reported increases in physical activity at post-test was assessed by comparison with pre-post change in total non-work physical activity (*t*-test) and beginning an exercise program (chi-square test). Similarly, a reported increase in eating fruits and vegetables was compared with pre-post test change in fruit and vegetable consumption and fiber consumption, and starting a low-fat or low-calorie diet with change in fat consumption. Intervention effects were assessed for outcomes pertaining to specific targets of the intervention (e.g., frequency of exercise, consumption of fruits and vegetables, communication with physician). McNemar's tests were used to assess pre-post test change in binary variables and paired *t*-tests were used to assess pre-post test change in numeric variables, stratified by study arm. To evaluate the intervention, *t*-tests were used to compare the intervention and control groups with respect to changes in numeric variables between pre-test and post-test, as well as their post-test values. Chi-square tests were used to compare the study arms with respect to binary variables at post-test, and *z*-tests were used to assess differences in pre-post test changes in binary variables. For communication variables, stratified analyses were performed for workshops 1–3 and workshop 4 separately in order to evaluate the effect of more engaged interactions on outcomes.

To evaluate the joint effects of the intervention and other covariates, a multiple regression analysis was performed that modeled change in knowledge as a function of study arm, pre-test level of knowledge, demographics, stage of disease, treatment, and social support. Similarly, a logistic regression analysis was performed that modeled reported increase in physical activity as a function of study arm, pre-test frequency of exercise, demographics, stage of disease, treatment, and social support. All analyses were performed on an "intent to treat" basis, that is, intervention group participants that did not attend the workshops were included in the analyses.

Results

Participation at pre-test, intervention study, and post-test

The participation rate was 54%. We analyzed the reasons why women refused to participate and found two explanations. Of the 315 women who were eligible to participate, but did not, 55 (18%) indicated that they wanted to put the experience behind them, did not want to think about it, etc. The remainder (260 women) indicated that they were willing to participate and wanted to be kept informed regarding our findings, but were unable to commit to attending at least two workshops, were unavailable on Saturdays due to general commitments (e.g., child's soccer games, classes they were taking, husband's work and resultant child care responsibilities) or could not participate on the specific dates the workshops were to be held in their community. Women that were too busy to make that commitment or were not available when the workshops were to be held were not randomized.

Of the women randomly assigned to the intervention group, approximately half attended two or more of the workshops and about one-third did not attend any of the workshops.

Socio-demographic characteristics of the sample

The sample consisted of 404 women. In this sample, 42% were under age 45 at diagnosis; 76% were Euro-American, with the next largest ethnic groups being Asian (10%), Latina (7%), and African American (5%). The sample was highly educated (88% had more than a high school diploma). Most women were married or had a partner (80%); most were employed (80%). The initial staging of participants' breast cancer was 18% in-situ, 54% local, 26% regional, and 1% remote. More than half were surgically treated with a mastectomy (52%); 55% had chemotherapy, 55% had radiation therapy, and 39% had tamoxifen (Table 2).

Table 2 Five-year survivors diagnosed with breast cancer at age 50 or under: Socio-demographic and treatment characteristics (n=404)

Measure	Number	Percent
Age at diagnosis		
23–39	51	13
40–44	117	29
45–50	236	58
Ethnicity		
Euro-American	308	76
African American	19	5
Latina	29	7
Asian	41	10
Other	7	2
Education		
High school or less	46	12
Some college	107	27
College graduate	239	61
Married or have partner	322	80
Employed at least part time	322	80
Type of surgical treatment		
Mastectomy	208	52
Lumpectomy	193	48
Stage		
In-situ	73	18
Local	217	54
Regional	105	26
Remote	4	1
Adjuvant therapy		
Chemotherapy only	86	21
Radiation only	86	21
Chemotherapy and radiation	137	34
Tamoxifen	158	39

Validation of reported changes at post-test

Women who at post-test reported having started a physical exercise program were much more likely to report having increased their amount of physical activity (77% vs. 38%, $p<.0001$). Change in total non-work physical activity was positively associated with starting an exercise program ($p=0.012$) and having increased physical activity ($p=0.0002$) [54]. Women who at post-test reported having started to eat more fruits and vegetables showed greater increases in consumption of fiber ($p=0.025$) and fruits and vegetables ($p=0.0011$) than those who did not. However, beginning a low-fat or low-calorie diet was not associated with change in fat consumption [61, 62].

Process evaluation

A process evaluation was conducted on the 201 women who were randomized to the intervention group. Even though all of the women randomized to the study had agreed that they would attend one of the four series of monthly workshops, approximately half of the women attended two or three of the workshops. Women who advised project staff of their inability to attend a particular workshop were invited to attend the one

Table 3 Five-year survivors diagnosed with breast cancer at age 50 or under: Intervention effects on knowledge, exercise, diet, and communication

Measure	Control				Intervention			Intervention–control difference
	n	Pre-test	Post-test	*p*-value[b]	Pre-test	Post-test	*p*-value[b]	*p*-value[c]
Knowledge								
Knowledge score: mean (standard deviation (SD))	386	9.98 (3.38)	9.23 (3.59)	0.002	10.17 (3.19)	10.11 (3.45)	0.80	0.044
Exercise								
Exercises 2 or more days/week at least 30 min	385	77%	79%	0.47	71%	77%	0.10	0.40
Started a physical exercise program[a]	387		35%			38%		0.56
Increased amount of physical activity[a]	387		47%			57%		0.036
Diet								
Eats 5 or more servings of fruits/vegetables per day	386	35%	32%	0.30	27%	31%	0.32	0.15
Started eating more fruits and vegetables[a]	387		41%			37%		0.45
Eats low-fat or non-fat foods most of the time	384	65%	61%	0.26	58%	58%	0.88	0.48
Started a low-fat or low-calorie diet[a]	387		21%			23%		0.66
Communication								
Patient–physician communication problems: mean (SD)	379	0.64 (1.09)	0.76 (1.12)	0.15	0.70 (1.20)	0.69 (1.13)	0.94	0.26
Number of ways communicates health needs: mean (SD)	385	3.73 (2.04)	4.04 (1.83)	0.040	3.90 (1.73)	4.13 (1.79)	0.073	0.73
How often communicates feelings to spouse/partner (higher score indicates lower frequency): mean (SD)	300	1.41 (0.60)	1.35 (0.59)	0.22	1.46 (0.63)	1.48 (0.62)	0.71	0.27
Communication issues regarding children: mean (SD)	285	2.40 (3.20)	2.07 (2.98)	0.12	2.08 (2.58)	2.03 (3.01)	0.84	0.40

[a] Refers to the past 6 months and only asked at post-test

[b] *p*-value from McNemar's test or paired *t*-test

[c] *p*-value from *z*-test (difference in change in proportion from pre- to post-test), *t*-test, or chi-square test (difference in post-test proportion)

they missed in another location, and many did. Some of these women came from great distances to attend the workshops that they missed.

Knowledge levels of the women were not affected by the number of sessions attended, a fact that we attribute to the mailing of information to the non-attendees. We also evaluated each workshop session. Responses to the evaluations improved over time. Thus, the last series of workshops which occurred in Berkeley received the best evaluations. While this finding was generally true for all aspects of the intervention, it was specifically true for the efforts to improve the communication skills of the women in their relationship with family members, friends, and the medical care system.

Effects of the intervention

The post-test was administered 3 months following the third and final workshop of the series in each location. In total, the post-test was administered to 387 women (96% retention rate). Consistent with our first hypothesis, at post-test, women in the intervention group compared to those in the control condition, on average had greater knowledge regarding breast cancer and its treatment and their own future health ($p=0.015$) and retained more knowledge from pre- to post-test ($p=0.044$, Table 3). Models including demographic and treatment variables indicated that, given the level of pretest knowledge, having more education and belonging to the intervention group were associated with greater gains in knowledge (Table 4).

Consistent with the second hypothesis, women in the intervention group were also significantly more likely than those in the control group to indicate that they had increased their physical activity ($p=0.036$, Table 3). Multiple logistic regression models indicated that women who had a mastectomy were less likely, while those who exercised more frequently at pretest (four or more times per week) and those with larger social networks were more likely to report having increased physical activity at post-test (Table 5). However, we did not find the dietary changes we predicted.

In three of the series of workshops we found no support for the third hypothesis that there would be improved communication with family members or physicians. In the fourth of the series of workshops, women in the intervention group reported a greater increase in the number of ways they communicated health needs and had fewer patient–physician communication problems at post-test than did those in the control group. However, they also reported a greater decrease in communication frequency with their partner and greater increases in thinking that their children needed more information and in worrying how their children were reacting.

Discussion

Participation of survivors

We were able to contact 83% of women who were identified at the time of their diagnosis and who participated in our previous study [58]. We believe this is the result of our efforts to keep in touch with them over the 5 years and that this was not a highly mobile population. Most of

Table 4 Five-year survivors diagnosed with breast cancer at age 50 or under: Effects of intervention status, baseline characteristics, disease stage, and treatment on change in knowledge of breast cancer and its treatment from pre- to post-test ($n=370$)

Predictors	Change in knowledge		
	Coefficient	Standard error	*p*-value
Intervention group	0.90	0.31	0.004
Age<40 at diagnosis vs. 45−50	0.37	0.50	0.45
Age 40–44 at diagnosis vs. 45−50	0.04	0.35	0.90
Non-Euro-American	−0.43	0.37	0.25
Employed at least part time	−0.40	0.39	0.31
Married or have partner	0.29	0.42	0.50
Some college vs. high school or less	1.53	0.57	0.007
College graduate vs. high school or less	1.41	0.53	0.008
Local stage vs. in-situ	0.11	0.49	0.82
Regional or remote stage vs. in-situ	0.60	0.64	0.35
Mastectomy	0.33	0.46	0.47
Had chemotherapy	−0.01	0.42	0.99
Had radiation	0.14	0.47	0.77
Had tamoxifen	0.63	0.36	0.08
Social network index	−0.30	0.16	0.07
Knowledge of treatment at pretest	−0.50	0.05	<0.001
Adjusted R^2	0.22		

Table 5 Five-year survivors diagnosed with breast cancer at age 50 or under: Effects of intervention status, baseline characteristics, disease stage, and treatment on increased physical activity at post-test (*n*=370)

Predictors	Increased physical activity at post-test	
	Odds ratio[a]	95% confidence interval[a]
Intervention group	1.56	(1.01, 2.42)
Age<40 at diagnosis vs. 45−50	1.48	(0.73, 2.99)
Age 40–44 at diagnosis vs. 45−50	1.01	(0.61, 1.67)
Non-Euro-American	0.94	(0.55, 1.59)
Employed at least part time	1.16	(0.67, 2.01)
Married or have partner	0.74	(0.41, 1.33)
Some college vs. high school or less	1.00	(0.45, 2.21)
College graduate vs. high school or less	0.88	(0.42, 1.85)
Local stage vs. in-situ	1.41	(0.71, 2.82)
Regional or remote stage vs. in-situ	1.59	(0.64, 3.96)
Mastectomy	0.38	(0.20, 0.74)
Had chemotherapy	0.61	(0.34, 1.10)
Had radiation	0.60	(0.31, 1.18)
Had tamoxifen	1.17	(0.71, 1.91)
Social network index	1.38	(1.10, 1.74)
Exercise 2–3 times/week at pretest vs. once/week or less	0.84	(0.45, 1.55)
Exercise>=4 times/week at pretest vs. once/week or less	1.78	(1.04, 3.04)

[a] Adjusted for all independent variables shown

the potentially eligible women who were lost had moved out of the area.

A third of the women never attended a workshop. But due to our strategy of sending all of the women the materials—hard copies of slides and other handouts—this group of women was kept informed. The intervention results do not indicate that active participation in the workshops increased the women's breast cancer knowledge. This finding is consistent with other studies that found no differences in disease specific knowledge between those who received information at home and those who attended an socio-educational group sessions [39, 40]. Individuals who participated in the workshops did indicate that the experience was enjoyable.

Type of intervention

In this study, we designed an intervention to improve quality of life by providing information about what to expect as late effects of their cancer experience. The outcomes for women in the intervention group who did not attend the workshop, but received materials from the workshop were equivalent to those who did attend the workshop. This suggests that the information was more important than the interaction between the workshop participants and the speakers. We found that a short-term intervention can improve quality of life by increasing knowledge levels and begin efforts toward lifestyle improvements such as exercising. However, we also found that more intensive and longer interventions are needed to augment and sustain lifestyle and interaction style changes.

Intensity of the intervention

How much change can one expect from the intervention? The workshop offered opportunities to learn about the changes in cancer treatment, issues regarding survivors' legal rights and health insurance and the implications of treatment (standard treatment as well as complementary medicine) for their health and well-being. We expected to find differences in knowledge and we did. Our finding of a knowledge effect is consistent with other studies [39, 40] We also offered participants the opportunity to practice new skills (exercise, communication with physicians and family members). We found some differences in the amount of exercise that the women reported at post-test. We did not find differences between the participants and the comparison group in communication skill improvements except in the fourth series of workshops. The improvements in communications in our last workshop suggest that results from earlier workshops represented implementation problems. This interpretation is consistent with findings from our process evaluation. It is also plausible that three sessions, albeit 6-h sessions, are not sufficient to change communication patterns that may have existed for many years. The intervention may not have been sufficiently long, intense, or required more skill and training on the part of the intervention team. In this study, while we cannot distinguish between explanations, our finding regarding the final workshop in the fourth series suggests that participants might have been able to incorporate new skills due to serendipity. In this last series of workshops, not only were our speakers were very engaging, but also the survivors provoked an intense and extended discussion with the speakers and with each other. Evaluations of the workshop support this view. Successful communications interventions in the literature have been narrowly focused on preparing women for a specific medical consultation and occurred immediately before the medical appointment [37, 38]. This raises the issue as to whether it was realistic to assume that amount of time focused on communication issues was sufficient given the difficulties of changing long standing communication patterns.

We also expected to find lifestyle changes in diet and exercise. We found that women reported increasing the amount of exercise but not the number of sessions per week. It is interesting to note that in a companion study of these young women's sisters who had not been diagnosed with cancer [67], we found a reported change in exercise pattern as well as an increased number of times per week of exercise as a function of a less intense but more personalized intervention (an individualized motivational telephone counseling session). Several studies have reported lifestyle changes resulting from a program focused on either nutrition or exercise [33, 59, 68–70]. Future socio-educational programs should design their interventions based on lessons learned from these more focused programs.

Limitations

There are some limitations to the study that may have affected the results. One third of the women never attended a workshop even though they had agreed to come to at least two. While they missed the opportunity to interact with other 5-year survivors and with our speakers and facilitators, they did receive all of the written information and copies of the slide presentations. Since this was an "intent to treat" approach, all of the women randomized to the intervention group were included in the analyses. Our results remained essentially the same when we reanalyzed the data excluding the non-attendees. Therefore, we do not think that differences in participation rates affected the results.

A second limitation was the unavailability of the same speakers for all of the workshop locations due to, for example, the unexpected surgery of one speaker. In this case, the substitute speaker used the same overheads as the originally scheduled one; however, differences in style cannot be prevented. Nor can one control differences due the interaction between speakers and attendees.

It is possible that our lack of an intervention effect on diet was in part due to participation in the WHEL study by women in both study arms. A total of 16 of the women (ten assigned to the control group and six assigned to the intervention group) indicated in the pre- or post-test questionnaire that they were following the WHEL study diet. It is plausible that the results of the assessment of consumption of fruits and vegetables and of dietary fat were affected by their participation in the WHEL study, which focused on increasing vegetable intake and reducing the amount of fat in the diet. However, to our knowledge, only 4% of the women in our study participated in the WHEL study, making substantial contamination unlikely.

Only one of the physical activity measures showed a statistically significant intervention effect. Since this measure was the response to a direct question regarding a desired outcome, the difference between the study arms may have been in part due to a greater desire to please the interviewers on the part of intervention group participants. Nevertheless, women in the intervention group who reported increasing their amount of physical activity showed a significant mean increase in a previously validated measure of total non-work physical activity [60]. The lack of consistency in measures with respect to statistical significance may be due to an overall weak intervention effect.

Finally, was the 5-year anniversary of a young woman's diagnosis and treatment for breast cancer a "teachable moment?" Since the 5-year mark generally is viewed as when cancer recurrence is significantly decreased, we thought it would be. However, it is possible that the majority of women had already made changes in lifestyle in order to reduce the risk of recurrence. Indeed, at pretest about three-quarters of participants reported exercising at least 2 days per week, and about 60% were eating low fat foods most of the time.

Reflections

On reflecting about the content of the intervention study, it is clear that a longer, possibly more intensive intervention is needed to change long term habits such as eating, exercising, and communicating with physicians and family members. As a result of our findings, our team is currently focusing on exercise in a longer, more intensive intervention for young women with breast cancer [71]. We are also focusing on another teachable moment—the end of adjuvant treatment when interactive support from the medical team is significantly reduced.

Evidence from this study suggests that the information component may be delivered either in person or in print form. The latter is undoubtedly a more cost-efficient strategy. It will be important in the future to determine for whom interactive versus non-interactive approaches work best (i.e., providing information by an expert in a setting that allows for interaction versus sending print materials to keep survivors up to date on information relevant to their health). Organizations such as the Wellness Community [72] may be appropriate for the former group while the internet maybe more appropriate for the latter group.

Conclusions

Five years after diagnosis, young breast cancer survivors who remained cancer-free enjoyed good health and improved quality of life. Therefore, we designed an intervention focused on the expressed concerns and needs for new information regarding breast cancer and its treatment, lifestyle changes to improve their physical health, and improving communication with their physicians and their family. Overall, the findings of the intervention are weak. A short-term intervention can affect knowledge levels and begin efforts toward behavioral change, but a more intensive and possibly, longer intervention is needed for sustained change. While those who participated in a socio-educational intervention demonstrated greater knowledge of breast cancer, its treatment, and knowledge related to the concerns of 5-year survivors (e.g., symptoms of menopause and related psycho-sexual issues) compared to controls, the difference was due to decrements in knowledge in the control group. And our finding of a significant increase in exercise in the intervention group is based on a single indicator. Finally, change in communication skills was found only in the fourth series of workshops and may have been due to idiosyncratic factors—interaction between the speakers and the survivors.

As many of the continuing concerns of survivors reflect the type of treatment they received for their cancer and the development of chronic health conditions, it is important for women to be provided with relevant health information and tools regarding lifestyle change, especially diet and exercise. Our findings suggest that a supportive environment as provided in our workshops can affect knowledge, but providing the information using other modalities such as newsletters or through the internet may be equally effective. Regardless, the need for updated information must be addressed so that young breast cancer survivors will continue to be resilient as they age.

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