

Randomized Pilot of a Self-Guided Internet Coping Group for Women With Early-Stage Breast Cancer

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ABSTRACT

Background: Internet-based methods for provision of psychological support and intervention to cancer survivors hold promise for increasing the public impact of such treatments.

Purpose: The goal of this controlled pilot study was to examine the effect and potential mechanisms of action of a self-guided, Internet-based coping-skills training group on quality of life outcomes in women with early-stage breast cancer. **Methods:** Sixty-two women completed baseline evaluations and were randomized into either a small online coping group or a waiting-list control condition. **Results:** No main effects for treatment were observed at the 12-week follow up. However, there was a significant interaction between baseline self-reported health status and treatment, such that women with poorer self-perceived health status showed greater improvement in perceived health over time when assigned to the treatment condition. Linguistic analyses revealed that positive changes across quality of life variables were associated with greater expression of negative emotions such as sadness and anxiety, greater cognitive pro-

cessing, and lower expression of health-related concerns. **Conclusions:** These results demonstrate the potential efficacy of self-guided Internet coping groups while highlighting the limitations of such groups.

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INTRODUCTION

An increasing body of research suggests that adjuvant psychological therapies (APTs) for women with breast cancer improve quality of life, yet a number of barriers to utilizing these services have attenuated the potential public health impact of these interventions (1,2). Among those who are interested, such barriers include patient and institutional factors, including disease progression (3), unwillingness to make a commitment to attend regular meetings (4), distance (5), busy home and work schedules (6), substantial clinician time required to provide services, the relative dearth of trained psycho-oncology practitioners (7), and providers' lack of awareness of existing community resources (2). In addition, the overall impact of adjuvant psychological therapies may be hindered by a relatively poor understanding of the mechanisms by which such therapies exert positive influences on quality of life (8). The study of mechanisms of action may provide insight into possible associations between components of therapy (e.g., provision of treatment elements derived from social-cognitive theory) and subsequent changes in outcome (9). The use of the Internet to deliver adjuvant psychological therapies may uniquely address several

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of these issues by reducing barriers to care among those with access to the Internet and by providing readily available transcripts that can be used to examine potential mechanisms of action.

Although research on Internet-based interventions is nascent, several studies have documented the potential of the Internet to increase the impact of psychosocial services for cancer survivors. Survivors who are unable to participate in traditional face-to-face support groups—those who live at great distance from the clinic (e.g., rural communities), have demanding work hours, do not have a convenient means of transportation, or are too fatigued or physically debilitated to travel—may be more likely to participate in Internet-based APTs (10). Consistent with this hypothesis, results from a recent feasibility study suggest that women with breast cancer express higher levels of interest in Internet-based support groups than in face-to-face groups (5). Several studies have suggested that Internet-based support services, in addition to reducing barriers to obtaining supportive care, may be efficacious for improving quality of life outcomes (11,12). A randomized trial of an Internet discussion group for women with breast cancer demonstrated reduced depression, perceived stress, and cancer-related trauma among participants in a 12-week facilitated group (13). As a result, a number of community-based nonprofit organizations are now providing Internet-based groups and forums (e.g., the Virtual Wellness Community and the Association of Cancer Online Resources [2]). In this study we sought to extend the findings of previous studies by evaluating the efficacy of an online coping-skills training group for women with early-stage breast cancer. In contrast to previous studies, the groups described in this study were peer based, and coping-skills exercises were presented in a self-guided format.

An additional aim of this study was to identify mechanisms of action associated with changes in quality of life among participants in an online discussion group. Among participants in supportive-expressive group therapy for cancer, emotional expressiveness has been shown to be associated with reductions in total mood disturbance (14,15). However, distinctions between types of expressed emotion are likely to be important. Giese-Davis et al. suggested that participation in supportive-expressive group therapy promotes expression of negative affect while suppressing angry and impulsive emotional behaviors (15). Cunningham and colleagues (16) further postulated that degree of involvement or “psychological work” undertaken in group therapies is associated with improved emotional well-being among breast cancer survivors. Use of Internet-based APTs, by recording every interaction between the therapist and patient, provides a unique opportunity to evaluate the effect of the intervention on the patient’s behavior and, more important, to identify the relationship between the patient’s behavior and clinically meaningful outcomes. Traditionally, researchers have relied on questionnaires to determine the mechanisms by which psychological therapies related to changes in outcome. Internet-based therapies, by cataloguing written exchanges between group members, offer the additional opportunity to examine word choices as measures of psychological processes that may be associated with outcome.

Pennebaker and colleagues pioneered research on the relationships between linguistic variables associated with word choices and psychological processes (17). Among individuals asked to write about emotional or traumatic experiences, improved health has been ascribed to four patterns of word choice: (a) high use of positive emotion words (e.g., *happy, joyful*), (b) moderate use of negative emotion words (e.g., *sad, angry*), (c) increasing use of causal and insight words (e.g., *because, therefore*) (18), and (d) change over time in the use of personal pronouns (19). Although there is some evidence that expressive writing in women with breast cancer is associated with improvements in physical symptoms (20), little is known about the relationship between word choices and changes in quality of life in this population. In qualitative analyses, Klemm and colleagues (21) reported that women with breast cancer, when compared with men with prostate cancer, make greater use of the Internet for emotional expression and support seeking. We have recently applied linguistic analyses to online discussion groups to replicate these findings and have demonstrated that breast cancer survivors are more likely than men with prostate cancer to spontaneously exhibit the positive word choice patterns just described—namely, greater use of both positive and negative emotion words (22).

The study presented here employed a randomized, controlled design to pilot the efficacy of a self-guided coping-skills training and support intervention provided over the Internet to women with early-stage breast cancer. The intervention, which consisted of a small discussion board coping group, 12 weeks of self-guided delivery of coping-skills training exercises presented through a series of Web pages, and education on symptom management, was provided to women primarily receiving treatment and follow-up at the same medical center in the southeastern United States. Our overall goal was to determine whether the use of a self-guided rather than professionally facilitated intervention could result in similar quality of life improvements demonstrated in previous reports of face-to-face and online interventions. We hypothesized that participation in the intervention would result in significantly greater overall quality of life and perceived health status relative to control participants. However, given positive outcomes and high quality of life in women with early-stage breast cancer, we hypothesized that there would be significant interactions between baseline levels of distress and subsequent effects of intervention, such that participants with high levels of distress prior to the study would be most likely to benefit from participation.

A secondary aim of the study was to evaluate linguistic patterns predictive of improved quality of life among participants in the intervention. Given the findings pertaining to word use and emotional expression just described and the emphasis of the training exercises on emotional expression and cognitive coping efforts, we hypothesized that greater levels of expression of fear and sadness and greater evidence of cognitive processing in the online groups would be associated with improvements in quality of life. In addition, because the intervention itself was designed to promote approach-oriented coping strategies and discouraged discussion of specific medical treatments and procedures, we

further hypothesized that higher levels of expression of health-related concerns (e.g., tumor characteristics, treatments, etc.) could detract from use of the coping exercises and would be associated with less improvement in quality of life over time.

METHOD

Participants

At the outset of the study, women with histologically confirmed Clinical Stage 1 or 2 breast cancer were considered eligible for participation in the study. After randomization, it was discovered that a small number of participants were most likely Stage 0 or Stage 3 given their self-reported medical histories. Because these participants expressed a strong desire to be in the study and believed that they had early-stage breast cancer, they were included in the study (see Table 1). Women were not excluded on the basis of medical treatment, time since diagnosis, or previous psychiatric history. Participants were recruited primarily through direct patient contact with consecutively scheduled patients at a Hematology/Oncology outpatient clinic at a large academic medical center in the southeastern United States. Additional recruitment efforts are described elsewhere in detail (5). Survivors who expressed an interest in participating in the study ($n = 154$) later received a telephone call to confirm characteristics of their disease and to administer informed consent. Of the 154 survivors who expressed initial interest in participating in the study, 23 (14.9%) elected not to participate after being given further information about the study, 24 (15.6%) could not be reached after repeated telephone calls and e-mail messages, 11 (7.1%) did not feel comfortable enough using a computer to participate, and 1 (0.6%) was deemed to be ineligible due to participation in a competing trial (see Figure 1). Those participants who remained interested after speaking by telephone with the primary investigator ($n = 95$) provided consent and later received a baseline assessment by mail. Participants who completed the baseline assessment ($n = 62$; a 65.3% response rate among eligible and interested participants) were randomized into one of two conditions: a waiting-list control group ($n = 30$) or an Internet-based discussion group ($n = 32$).

Procedures

To form small groups for each condition, participants were recruited in six cohorts of up to 20 survivors. Participants in each cohort were randomized when the cohort size reached 20 or when the first participant in the cohort had been enrolled for approximately 4 weeks. Participants were then randomized using a random number generator to either the wait-list control condition or the online coping program. Investigators were not blinded to randomization status. After 12 weeks, all participants received a follow-up assessment in the mail. Wait-listed participants were then contacted by telephone to verify interest in remaining in the study and were enrolled as crossover participants ($n = 18$) in the next available treatment group. This procedure resulted in initial treatment group sizes of 5 to 13.

Participants assigned to the treatment group were contacted by e-mail and provided with a password for secure access to the Web site (<http://health.psy.uab.edu/survive>) and brief instruc-

tions for using the Web site. The Web site for the online coping group, developed using HTML and Practical Extraction and Report Language, offered a bulletin board for asynchronous group discussion, a dictionary of medical terminology, a database of breast cancer resources and Web sites, information and coping advice for management of common physical symptoms such as pain and fatigue, a forum for sharing artwork and poetry, and six structured coping-skills training exercises (each of which was presented across a series of Web pages). Each coping exercise was designed to be completed by participants over the course of 2 weeks and adapted from structured exercises provided in manuals used by face-to-face APTs (23,24). Consistent with the aims of other manualized interventions for cancer survivors, these coping exercises were primarily intended to facilitate the identification and expression of cancer-related emotions (e.g., detoxifying fears of recurrence or death, discussion of loss, etc.) and to promote cognitive efforts to more positively reappraise stressful cancer-related experiences. Coping-skills training exercises included identification of active and passive coping styles (e.g., using hypothetical breast-cancer-specific scenarios to define and recognize active behavioral, active emotional, and avoidant coping efforts); communication with family and friends (e.g., focusing on verbal and nonverbal cues that the participant uses to express needs or changes in mood); identification of relationships among stress, emotions, and behavior (e.g., completing automatic thought records associated with salient daily stressors); stress-management training (e.g., use of deep breathing and progressive muscle relaxation); assertiveness training (e.g., discussing experiences and difficulties associated with communicating information needs and preferences to health-care staff); and structured problem-solving training (e.g., identifying salient current problems, brainstorming potential solutions, and implementing and evaluating a chosen solution). To encourage participants to interact with the coping exercises and to ensure consistency across groups, we also developed a series of 39 prompts that were automatically sent by e-mail in regular intervals over the course of the 12-week program. Each prompt summarized a coping-skills training exercise that could be found on the Web site and suggested that participants post a message to the group to discuss their experiences with each coping exercise. Thus, treatment groups were self-guided rather than facilitated by a group leader. When submitting messages to other members of their group, participants were identified only by first name or an alias to protect confidentiality.

Assessments

Health-related quality of life. Health-related quality of life was assessed with the Functional Assessment of Cancer Therapy–Breast Cancer Form (FACT–B) and a quality of life thermometer. The FACT–B is a 27-item questionnaire that utilizes 5-point Likert scales to evaluate overall quality of life and individual domains that contribute to the overall score: social well-being, physical well-being, emotional well-being, functional well-being, and breast cancer-specific symptoms (25). This instrument has adequate internal consistency (overall $\alpha = 0.90$, subscale α s = 0.63–0.86) and good concurrent validity with

Eastern Cooperative Oncology Group (ECOG) performance status (26). The measure has also been demonstrated to be sensitive to longitudinal change in persons with cancer. The EuroQol-5D “feeling thermometer” is a single-item visual analogue scale designed to measure self-rated overall health (27). Participants were asked to rate their overall health on a scale ranging from 0 (*least desirable state of health you can imagine*) to 100 (*perfect health*). The measure has good test-retest reliability, concurrent validity, and sensitivity to change (28).

Distress. Psychological distress was assessed using the Impact of Events scale (IES). The IES is a 22-item, Likert-type scale designed to measure the intrusiveness of and avoidance of cancer-related thoughts and stimuli (29). The instrument has good internal consistency (Cronbach’s $\alpha = 0.79-0.92$) and has been shown to be sensitive to the effects of psychosocial intervention (30).

Physical well-being. Physical well-being was assessed using the Memorial Symptom Assessment Scale (MSAS). The MSAS is a 32-item inventory designed to measure prevalence, frequency, severity, and distress associated with symptoms commonly reported by those living with cancer (31). Adequate reliability has been reported (0.84–0.88), and the instrument has both good content and good construct validity. The instrument was developed and validated with a sample of cancer survivors.

Expectations/satisfaction with web site. Comfort with the Web site and perceived difficulty navigating the site was measured with thirty 7-point Likert items adapted from the Web Analysis and Measurement Inventory (32) and 9 open-ended questions assessing how the Web site could be improved. Women were also asked to describe their expectations of the online coping group with regard to whether they would like to primarily give support, obtain support from others with breast cancer, or both give and receive support.

Quality of participation. Written messages posted to the online coping group were stored on the host server and were scored using two separate programs to determine level of expressions of emotion, cognitive processing of the cancer experience, and health and treatment-related concerns. Use of words related to emotional expression and cognitive processing was measured using Linguistic Inquiry and Word Count (LIWC) (17,33). LIWC compares each word contained in a text file with words or word stems classified into 74 categories, and it calculates the percentage of the total number of words that are contained in each of the 74 categories. Interrater reliability of LIWC categories ranges from 0.86 to 1.00, and external validity of the emotional expression and cognitive processing word categories is good (33). In this study, 7 categories were retained for analysis: expression of any affect, positive emotions, negative emotions, anxiety, sadness, anger, and cognitive mechanisms. Cordova et al. (34) described the factor structure of the LIWC cognitive mechanisms variable as comprising two specific factors related to uncertainty and logic. We applied the factor load-

ings reported by Cordova et al. to standardized scores on the 6 categories composing the cognitive mechanisms domain to derive scores for two cognitive factors of uncertainty and logic. Word use related specifically to cancer treatment was determined using a supplemental LIWC category described by Owen et al. (22). Finally, general concerns related to health were measured using the automated Gottschalk–Gleser scales (PCAD2000) (35). Like LIWC, PCAD2000 parses text-based data into strings for comparison with word-based dictionaries, but PCAD2000 analyzes clauses rather than individual words as the unit of analysis. Rater-scored versions of the Gottschalk–Gleser scales have been validated in medical populations (36), and evidence for the reliability and validity of the computerized scales is promising (37). Although the computerized scales provide a number of variables associated with psychiatric states, we chose to analyze only the health concerns variable because it has been demonstrated to be sensitive to the effects of chemotherapy in women with breast cancer (38).

Data Analysis

Using SAS Version 8.00, general linear modeling was employed for all multivariate analyses of continuous dependent variables except where otherwise noted. Potential differences between the two groups on baseline values of all demographic, medical, and dependent variables were tested using *t* tests for continuous variables and chi-square frequency analyses for discrete variables. Multilevel modeling using SAS PROC MIXED was employed to evaluate whether the effects of the intervention differed across cohorts. Separate intercepts were estimated for each cohort using a random error term to take into account variability in cohort-specific intercepts. Significant clustering within treatment cohorts was not observed, and all subsequent analyses employed standard fixed parameter regression models. Because our sample was composed of participants with relatively high quality of life, we employed an analytic approach described by previous researchers (39,40) used to test the hypothesis that the intervention group had a stronger impact on participants most expected to benefit from the intervention (i.e., participants with greater self-reported distress). Accordingly, for each dependent variable, we regressed group assignment and the interaction between group assignment and baseline value of the dependent variable onto the Time 2 scores for the dependent variable. Effects of demographic and medical variables that were associated with baseline values of dependent variables were controlled by including them as covariates in these analyses. Baseline values for each dependent variable also were used as covariates in each model. Main effects of group assignment were only interpreted when the interaction term was not significant ($p > .05$). To compare our results with those reported elsewhere, effect sizes for change scores on each dependent variable were calculated using Cohen’s *d* (41) and applying the Hedges and Olkin (42) correction procedure for small sample sizes. Linguistic variables derived from text were calculated for each day in which a participant submitted a message to the online group. Summary scores were generated by averaging scores on linguistic variables across all messages submitted over the course of the

12-week intervention. Pearson correlations were used to evaluate the relationship between linguistic variables derived from written messages and change scores calculated for each dependent variable.

RESULTS

Participants

Figure 1 provides a detailed account of patient enrollment, allocation, follow-up, and attrition across the course of the study. Two hundred forty-three consecutive women living with breast cancer were assessed for eligibility and offered participation in the study (5). Of these women, 154 expressed interest in being involved in the study, but only 62 (25.5%) met eligibility criteria, consented to participate in the study, completed the baseline assessment battery, and were randomized into one of the two study arms (treatment, $n = 32$; control, $n = 30$). Nine women were lost to follow-up, leaving 26 participants in the treatment condition and 27 participants in the control condition who completed both baseline and follow-up assessments.

Demographic characteristics of the participants are shown in Table 1. There were no significant baseline differences between the two groups for any of the demographic or dependent variables. Participants in the treatment condition were significantly more likely than those assigned to the control group to have received some treatment with a chemotherapeutic agent, $\chi^2(1, N = 62) = 4.1, p = .04$. Participants' motivations for enrolling in the study were as follows: (a) to both give and receive help in coping with their cancer (74.6%), (b) to provide support to others (23.7%), and (c) to receive support from others (1.7%). Participants reported that the most commonly experienced complaints in the week prior to entering the study were fatigue (72%), sadness (60%), irritability (57%), worry (57%), poor concentration (57%), and difficulty sleeping (53%).

Use and Evaluation of the Web Site

Follow-up questionnaires asked participants in the treatment condition to evaluate different aspects of the Web site. Participants found the coping exercises to be most helpful (68.2% of participants), followed by the coping group/bulletin board (59.1%) and information about coping with specific symptoms (57.2%). Of the participants, 82% reported that either the coping exercises or the discussion group was helpful. Participants averaged 35.5 total logins to the Web site, 52.2 hits to the bulletin board, 9.5 postings sent to the bulletin board, 73.4 uses of the coping exercises, 3.4 hr spent logged in to the Web site, and 8.2 min per session over the course of the 12-week intervention. Use of each component of the intervention over time is displayed in Figure 2.

Effect of Intervention on Quality of Life

Baseline and follow-up scores on all primary dependent variables are provided in Table 2. No significant main effects of group assignment were observed for the primary outcome measures. Trivial or small effect sizes for the main effect of group were observed for cancer-related intrusive thoughts, symptom prevalence, self-reported health status, and breast-cancer-spe-

cific concerns. Interactions between group assignment and baseline quality of life, emotional well-being, breast-cancer-specific concerns, distress, and symptom prevalence were not observed. However, a significant interaction emerged between group assignment and baseline health status (EuroQol-5D) on follow-up health status, $F(1, 39) = 16.4, p < .001$, such that participants with a low self-reported health status at baseline who were assigned to the treatment condition (M baseline health status = 58.8, M final health status = 81.8) exhibited greater improvements in health status over time than did participants assigned to the wait-list control group (M baseline health status = 64.4, M final health status = 76.7; see Figure 3). Among those with better health status at baseline, no significant changes over time were observed for participants in either the treatment (M baseline health status = 90.3, M final health status = 88.0) or control groups (M baseline health status = 90.6, M final health status = 89.0). Post hoc analyses revealed that time since diagnosis was significantly correlated with baseline health status ($r = .26, p = .039$) such that women who were farther out from diagnosis reported significantly higher levels of health status. Moderate effect sizes were detected for the intervention for overall quality of life (FACT-B) and emotional well-being (FACT Emotional Well-Being subscale), although main effects of group assignment were not significant at the $p < .05$ level.

A repeated measures analysis of variance was employed to test changes over time in quality of life among all participants. Over time, participants in both groups exhibited improved health status, $F(1, 51) = 6.39, p = .015$; improved total quality of life, $F(1, 51) = 11.0, p = .0017$; and fewer physical symptoms, $F(1, 51) = 6.30, p = .0153$. Collapsing across groups, there was no significant effect of time for emotional well-being, breast cancer-specific symptoms, or intrusiveness of cancer-related thoughts.

Quality of Participation and Changes in Quality of Life

To test the hypothesis that linguistic indicators of emotional expression, cognitive processing, and health-related concerns would be associated with change over time in quality of life, correlations between linguistic variables (derived from messages posted to the online discussion group) and change scores for the primary dependent variables were calculated. These results are provided in Table 3. Greater expression of sadness, but not anxiety, anger, or overall negative affective states, was associated with improvements in overall quality of life ($r = .49, p = .023$). Greater expressions of anxiety, sadness, and overall negative affect were associated with improved emotional well-being ($r_s = .50-.61, p_s = .005-.02$). Similarly, expressing higher levels of anxiety and sadness, but not anger or overall negative effect, was associated with reductions in intrusive cancer-related thoughts ($r_s = .47-.60, p_s = .004-.02$). Emotional expression was not significantly associated with change over time in health status, physical symptoms, or breast-cancer-related concerns. Depth of cognitive processing in the posted messages was correlated with improved emotional well-being ($r = .54, p = .012$) but was not associated with overall quality of life, health status, intrusive

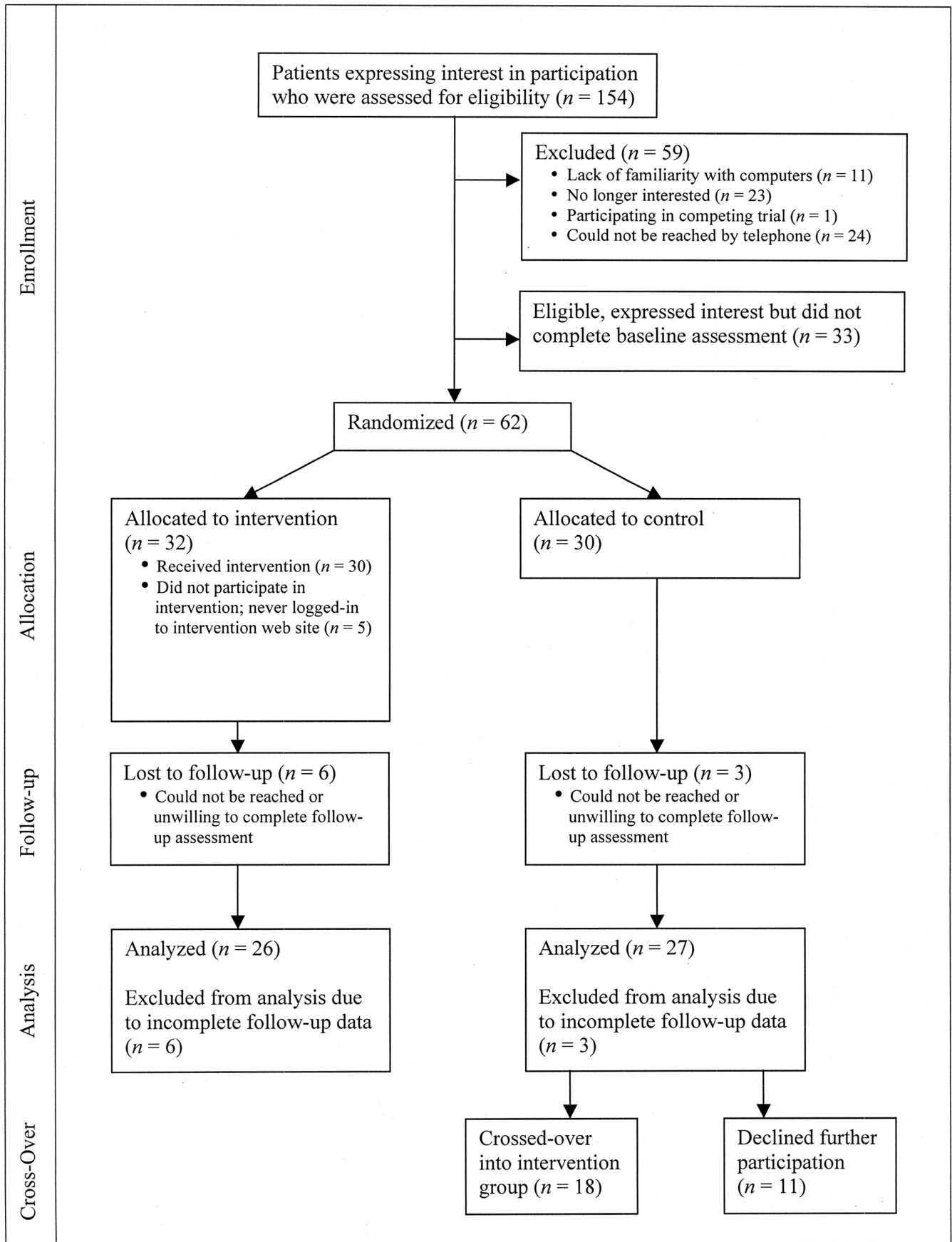


FIGURE 1 Participant enrollment, allocation, follow-up, and attrition.

TABLE 1
Demographic Characteristics of Participants

	Control Group ^a		Treatment Group ^b	
	<i>M ± SD</i>	%	<i>M ± SD</i>	%
Age, <i>SD</i> (years)	51.3 ± 10.5		52.5 ± 8.6	
Median annual household income (\$)	65,000 ± 24,407		65,000 ± 114,148	
Education (years)	15.3 ± 2.0		15.8 ± 2.2	
Race (% White)		100		95.8
Marital status (% married)		77.8		87.5
Distance to clinic (miles)	55.2 ± 66.3		107.5 ± 301.5	
Employment status (%)				
Employed full-time		46.7		42.9
Employed part-time		16.7		14.3
Not employed		36.6		42.8
Time since diagnosis (months)	31.8 ± 37.6		23.2 ± 28.4	
Breast conserving surgery (%)		33.3		27.8
Modified radical mastectomy (%)		60.0		63.9
Treated with radiation (%)		53.3		47.1
Treated with chemotherapy (%)		63.3		85.3*
Clinical stage of disease (%)				
Ductal carcinoma in situ		0.0		5.7
Stage I		33.3		28.6
Stage II		40.0		45.7
Stage III		3.3		2.9
Positive lymph nodes outside of breast (%)				
No positive nodes		53.6		48.5
One or more positive nodes		46.4		51.5
Use of complementary or alternative medicines (%)		20.0		11.4

^a*n* = 30. ^b*n* = 32.

*Significant between-group difference, *p* < .05.

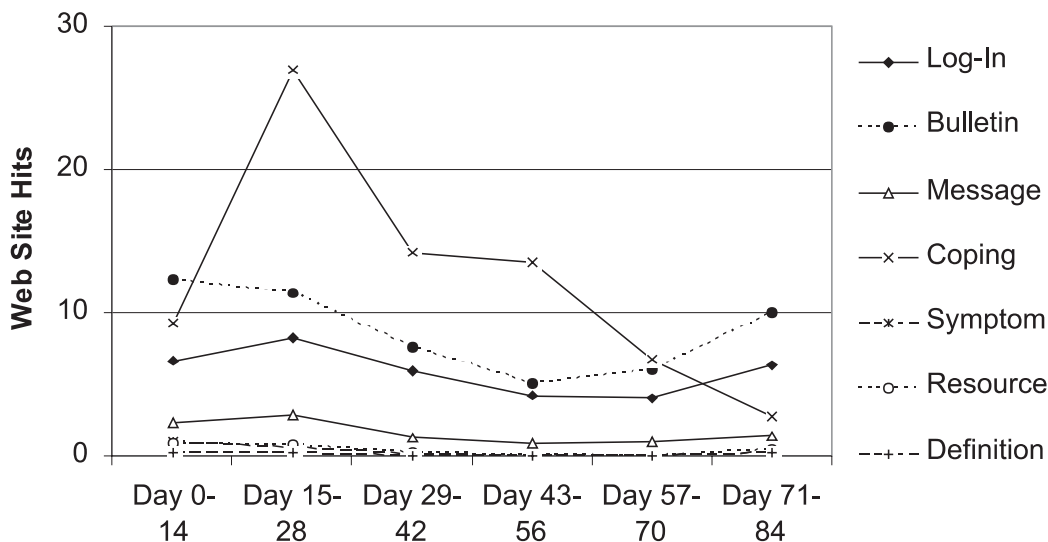


FIGURE 2 Use of the SURVIVE Web site over the course of the 12-week intervention study by women initially randomized into the treatment group (*n* = 32) and women assigned to the waiting-list control who later crossed-over into a treatment group (*n* = 18). *Note:* Log-In = mean number of times participants logged in to the Web site; Bulletin = mean number of times participants accessed the bulletin board support group; Message = mean number of messages posted by participants to the support group; Coping = mean number of coping skills training pages opened by participants; Symptom = mean number of times participants viewed pages associated with information about symptom management; Resource = mean number of times participants accessed breast cancer resource database Web pages; Definition = mean number of times participants viewed pages associated with definitions of cancer-related medical terms.

TABLE 2
Baseline and 12-Week Follow-Up Scores Across Outcome Measures by Treatment Group

Domain	Measure	Control Group ^a				Treatment Group ^b				F Value, Group × Baseline Interaction Effect (df)	Treatment Effect Size
		Pre M	SD	Post M	SD	Pre M	SD	Post M	SD		
Health-related	FACT–Total	81.0	14.3	85.3	11.8	78.3	15.7	88.7	10.8	0.33 (1, 45)	0.30
quality of life	EQ-5D Thermometer	78.4	17.2	83.5	17.1	75.6	20.2	85.4	9.9	16.40 (1, 39)**	0.13
Psychological	FACT EWB	15.4	4.0	15.3	3.6	14.8	3.9	16.5	2.6	1.00 (1, 45)	0.38*
well-being	IES total	0.96	0.6	0.95	0.7	1.10	0.6	0.95	0.6	1.63 (1, 47)	0.00
Physical	MSAS Symptom	10.9	7.4	8.7	6.2	11.6	7.6	8.4	6.3	1.85 (1, 41)	0.05
well-being	Prevalence										
	FACT Breast-Specific Concerns	23.1	5.8	23.9	6.3	22.2	6.5	25.5	4.8	2.17 (1, 48)	0.28

Note. FACT = Functional Assessment of Cancer Therapy–Breast Cancer Form; EWB = emotional well-being; IES = Impact of Events scale; MSAS = Memorial Symptom Assessment Scale; ^an = 27. ^bn = 26. *p < .10. **p < .001.

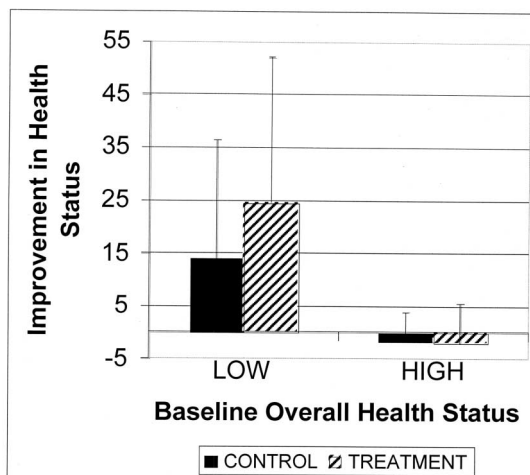


FIGURE 3 Interaction between group assignment and improvement in self-reported overall health as measured by the EQ-5D thermometer (Time 2 score – Time 1 score), significant at p < .001.

cancer-related thoughts, symptom prevalence, or breast-cancer-related concerns. More frequent mention of health-related concerns in postings to the online discussion groups was associated with worse outcomes for overall quality of life ($r = -.48, p = .027$), health status ($r = -.60, p = .006$), intrusive cancer-related thoughts ($r = -.56, p = .008$), and symptom prevalence ($r = -.43, p = .049$). More frequent use of words related to cancer treatment was associated with declines in emotional well-being ($r = -.55, p = .01$). Use of words related to health and cancer treatment was not associated with stage of disease or treatment variables. It should be noted that significance levels were not adjusted for experiment-wise type I error rate, so individual correlation coefficients should be interpreted with caution. Finally, clusters of linguistic variables related to cognitive processing (i.e., uncertainty and logic), affective processing (i.e., anxiety, sadness, anger, and positive emotions), and health-related concerns (i.e., health and cancer treatment) were entered into multiple regression models predicting change scores on the

dependent variables. As a set, these linguistic variables strongly predicted change scores across the dependent variables, particularly for emotional well-being ($R^2 = .91, F(8, 11) = 6.26, p = .003$), and cancer-related intrusive thoughts ($R^2 = .86, F(8, 11) = 3.17, p = .04$ (see Table 3).

DISCUSSION

As reported elsewhere (5), nearly 45% of women who were approached to participate in the study expressed a strong interest to do so. Only a small percentage of the participants were involved in support services of any kind at the time of study entry, suggesting that this Internet-based group improved the accessibility of supportive care options to this survivor population. Many participants expressed difficulty finding or being able to attend support services in their home communities, and average travel time to receive breast cancer treatment or follow-up was over 1 hr. Inherent to most studies of this nature, however, there were barriers to participation (i.e., the consent process, lengthy questionnaires to complete). Among those who expressed a strong interest in participating in the study, only 49% provided informed consent to enroll in the study, and 65.3% of these actually completed the baseline assessment. Thus, participation in this trial may underestimate participation in community-based programs, if information about such programs was provided routinely in medical settings in which women with breast cancer receive treatment and follow-up care.

Results of this pilot intervention provided mixed results for our hypotheses that participation in the self-guided Internet coping group would result in improved quality of life. No significant main effects were observed for the primary dependent variables. However, there was a trend toward greater improvement in emotional well-being for treatment relative to control participants, and effect sizes for overall quality of life, emotional well-being, and breast-specific concerns were modestly sized. In addition, participants with low health status at the beginning of the study who were provided with access to the treatment group demonstrated significantly greater improvement

TABLE 3
Pearson Correlation Coefficients Between Linguistic Variables Associated With Messages Posted to Online Support Groups and Change Scores on Dependent Variables

Linguistic Variable	Overall Quality of Life	Health Status	Emotional Well-Being	Cancer-Related Intrusive Thoughts	Symptoms	Breast-Cancer-Specific Concerns	M	SD	Range
All affect	0.03	-0.15	0.50*	0.08	-0.32	-0.02	4.44	1.3	2.6–9.0
Negative emotions	0.06	-0.01	0.51*	0.29	-0.26	-0.04	1.54	1.1	0–5.6
Anxiety	0.02	0.16	0.61**	0.47*	0.08	0.04	0.41	0.3	0–1.3
Sadness	0.49*	0.37	0.58**	0.60**	0.26	0.26	0.32	0.2	0–0.9
Anger	0.26	0.31	0.07	0.34	0.11	0.11	0.19	0.2	0–0.5
Positive emotions	-0.04	-0.29	0.14	-0.30	-0.20	0.00	2.87	0.7	1.4–4.2
Cognitive mechanisms	-0.15	-0.23	0.54*	-0.06	-0.12	-0.02	7.05	1.4	4.8–10.4
Uncertainty	-0.20	-0.25	0.22	0.07	-0.18	0.03	0	1.2	-2.0–2.4
Logic	-0.12	-0.15	0.40	-0.08	0.02	-0.02	0	1.2	-2.4–2.2
Health	-0.48*	-0.60**	-0.36	-0.56**	-0.43*	0.01	2.11	0.6	1.0–3.3
Cancer treatment	-0.07	-0.19	-0.55*	-0.11	0.21	0.00	0.87	0.5	0.3–2.5
Multiple R^2	0.72	0.37	0.91**	0.86*	0.61	0.58	—	—	

Note. Positive correlation coefficients indicate that a higher proportion of words related to the linguistic variable are associated positively with improvement on the dependent variable; multiple R^2 for Time 2 values includes variance associated with Time 1 score for the dependent variable, with significance tested for the set of linguistic variables after adjusting for Time 1 scores.

* $p < .05$. ** $p < .01$.

than women assigned to the control group. These results suggest that women living with early-stage breast cancer who feel that their overall health has been impacted by their cancer, particularly those who have been more recently diagnosed, are most likely to benefit from participation in this type of intervention. Our efforts to systematically identify and offer participation to eligible women may have resulted in a study sample that was less distressed than samples obtained by other researchers (5). This hypothesis is supported by our finding that the majority of participants in this study sought to serve as a provider of support to other women and offers additional explanation for the absence of main effects. Targeted provision of interventions of this type to women with identified distress could improve power to evaluate the effects of intervention.

It is important to note that this was a self-guided intervention in which the investigators monitored but did not participate in the online discussions. This self-guided approach was selected to address the perceived weaknesses of existing online and face-to-face resources for cancer survivors: (a) Although manualized, facilitated groups appear to have quality of life benefits for participants, such services are not widely available in the community for a variety of reasons addressed elsewhere (2), and (b) although there are many existing Internet-based forums that promote communication between cancer survivors, these forums do not provide the types of structured cognitive-behavioral or supportive-expressive exercises that have been demonstrated in the literature to be of benefit. Thus, we set out to create an online forum that would draw on the strengths of existing online forums (e.g., widely available and minimizing the need for intensive clinician involvement) while providing the kinds of exercises that have been shown to result in quality of life improvements. Active facilitation, although more costly, could be expected to increase the magnitude of effects observed in our study.

The study presented here is among the first to quantitatively characterize the relationship between levels of participation in psychosocial intervention for cancer and subsequent changes over time in quality of life. Consistent with our hypotheses, improvements over time in a number of quality of life domains were associated with three general patterns of word use: greater ventilation of feelings associated with anxiety and sadness, greater efforts to cognitively process the cancer experience, and less expression of somatic and treatment-related concerns. Our findings with regard to linguistic indicators of emotional expression mirror previously reported relationships between questionnaire-derived estimates of emotional expression and adjustment to breast cancer (14,44). Stanton et al. (45) provided a strong theoretical framework for the relationship between emotional approach coping and adjustment to stressful situations, suggesting that emotional approach may facilitate the habituation to and reappraisal of the stressor, promote social affiliation and support, and promote awareness of cues related to progress toward personal goals. General expression of cognitive words, but not specific linguistic indicators of cognitive processing, was associated only with improved emotional well-being. Although suggestive that active efforts to understand and cope with the cancer experience may reduce mood disturbance, further research to identify the relationships between linguistic indicators of cognitive processing and coping efforts is necessary. Expression of health-related concerns was associated with worse quality of life outcomes but was not associated with clinical stage, suggesting that effortful writing about these concerns reflects rumination or avoidance of alternative cognitive and emotional strategies for adjusting to the challenges associated with cancer. The high level of variance in change scores across dependent variables accounted for by the linguistic variables (R^2 s = .37–.91) suggests that textual analysis of naturalistic interactions in online support communities has substantial potential for improving

our current understanding of the mechanisms by which interventions improve outcomes and warrants further investigation.

Several limitations of our study are noteworthy. First and foremost, given relatively good baseline quality of life scores among participants in this trial, the small sample size limits the power of the study to detect potential group differences over time. Although comparable in size to similar studies (10,11,40,46), a larger sample may be necessary to detect main effects of treatment for variables that yielded modest effect sizes. Second, participants were on average 29 months post-diagnosis, and few of the women were in any form of active treatment at the time of the study. Levels of distress among women with early-stage breast cancer have been shown to decline considerably by 4 months postdiagnosis (30), and women with this disease have among the best longitudinal outcomes related to depression and anxiety in comparison with other cancer types (47). Although we believe that broad inclusion criteria are important to the development of group cohesion and opportunities for social modeling, those reporting substantial levels of distress (e.g., those with advanced disease, with fewer supports, or in active treatment) are more likely to participate in and more likely to benefit from Internet-based psychosocial treatments (40). Characterization of the recruitment procedures and final study sample is key to understanding the implications of the results. This sample consisted largely of women with good quality of life who sought to provide social support to others; thus, effect sizes may underestimate effects of this intervention on women with higher levels of distress. A full 24% of this sample were motivated to participate primarily to be a source of support to others.

Thanks to survival gains created by public health and medical science, there are a great many people living today with a cancer history. Continuing efforts to identify survivors with psychosocial needs and to provide accessible, efficacious, and effective care are needed to reduce their quality of life burden. Future efforts to identify the relative effects of professional facilitation, structured coping skills training exercises, and peer support will be important for the development of next-generation Internet-based support services.

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