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13. ABSTRACT (Maximum 200 Words)

The purpose of this project is to develop and evaluate an Internet-based psychosocial intervention for women with primary breast cancer. During this funding period (10/1/00 to 9/31/01), the following tasks were completed: (1) 72 women were randomized to usual care (wait-list control group) or psychosocial support group. Three twelve-week Internet-based psychosocial groups (8-12 members per group) were facilitated with intervention group participants and two groups were facilitated with wait-list control group participants; (2) preliminary analyses on data collected from participants were completed; (3) preliminary text analyses of the support group messages were completed. Results: The initial analyses found that in comparison to wait-list control group participants, intervention group participants significantly reduced their depression, post-traumatic stress, and general stress scores. Significance: Women with primary breast cancer are able to participate in Internet-based psychosocial interventions and receive substantial benefits from their participation. The next phase of the project will be to complete enrollment into the intervention, analyze completed outcome data, and continue our exploration of ways to capture and understand the discourse that occurred in the groups.

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**The Development and Evaluation of an Innovative Internet-Based
Breast Cancer Psychosocial Intervention**

DAMD17-99-1-9387 – 10/01/00-09/30/01

Principal Investigator: C. Barr Taylor, M.D.

INTRODUCTION

Breast cancer is the second leading cause of cancer death in women, exceeded only by lung cancer, and the leading cause of cancer death among women aged 40 to 55. The diagnosis of cancer is a universally upsetting event and a participant's response to this distress affects quality of life and treatment. While it has been found that social support may ward off or lessen emotional distress, women with breast cancer, because of their illness, treatment regimen and diminished social contact, frequently lose their social support. Psychosocial interventions have proved beneficial to improve quality of life and coping responses and to reduce psychological symptoms and pain in breast cancer participants. However, psychosocial interventions are often unavailable to cancer participants, particularly those living in rural areas or with transportation difficulties, too many competing responsibilities or other problems that would keep them from attending a group. The goals of this project are (1) to develop a comprehensive Internet-based psychosocial intervention for breast cancer participants, (2) to evaluate the feasibility, ease of use and perceived helpfulness of the new intervention with a group of women with breast cancer, and (3) to determine the effectiveness of this new approach with a small-scale, controlled pilot study. This program is an innovative approach to providing psychosocial interventions via the Internet. It employs 3 novel approaches to Internet-delivered programs: (1) structured, guided assignments rather than simply providing information, (2) a moderated support group rather than traditional unmoderated forums, and (3) use of email and telephone reminders to enhance program adherence. If effective, this approach has the potential to help improve the quality of life for women with breast cancer. It will provide a cost-effective intervention which may help reduce participants' psychological symptoms, improve their coping skills, and may improve their adherence to medical regimens.

BODY

The following task was scheduled for Year 2 (10/1/00 to 9/30/01) of the project:

Task 1. Complete small group outcome study (months 13-30).

(a) Recruit 100 women with primary breast cancer to the study.

The following basic procedures were used to recruit participants. To be eligible participants needed to (1) be diagnosed with primary breast cancer within the last two years, (2) have the ability to communicate in written English, (3) not have a current diagnosis of a major psychological disorder, (4) not be currently suicidal, and (5) live in California. Public service announcements were placed in local media,

flyers were sent to oncologists in the Bay Area and we had announcements placed in newsletters. One hundred fifty-nine women called or e-mailed to express an interest in the project. Seventy-six women were eligible and signed consent forms. Most commonly women were ineligible because they lived out of state or had advanced disease. We recruited in two waves until we had 30-40 women per wave.

(b) Randomize women to usual care (wait-list control group) or psychosocial support group (intervention group).

Five groups of 8-12 participants each have been facilitated. Seventy-two women were randomized into intervention or usual care and all have completed follow-up. Three intervention groups have been run to date. The group sizes have been 10, 11, and 15 members. An additional 18 women have been randomized to the intervention group or wait-list. The intervention is now being provided to these people.

(c) Intervention procedures.

The intervention was summarized during the last report. Briefly, the *Bosom Buddies* website allows participants to read personal stories from survivors, share their own experiences, and keep an online personal journal. To facilitate group members' ability to make an emotional connection with other members, participants entered their current emotional state at login and could review all members' reported emotional state, coded by login time, on a separate web page called "My Buddies." The group format is asynchronous meaning that the participants can log on and post comments at any time. Although a psychologist moderated the group, participants were informed that the group was not meant to serve as a form of psychotherapy or as an alternative to psychotherapy. The moderator's primary role was to keep the conversation on the theme of the weekly topic and encourage members to support one another. Participants were able to post a photograph of themselves on the website. These images appear next to a participant's biography and each support group message.

Of note, all intervention participants were able to navigate the website, use all features of the website, and participate in the on-going group. However, 1 woman (of 36) required a house call to teach her how to use the Web. Five other women needed telephone consultation to be able to identify the correct URL for the program.

Table 1. *Bosom Buddies* weekly themes

Week	Topic
1	Introduction
2	Deeper sharing: How members are feeling, diagnosis and treatment experiences
3	Identifying, accepting, understanding, & managing strong and difficult emotions
4	Dealing with your medical team
5	Dealing with uncertainty, helplessness and lack of control
6	Adjustment to changed self- and body-image
7	Romantic relationships and sexuality
8	Relating to family – spouses and children
9	Relating to the world: Friendships and other relationships
10	Fears of recurrences, concerns about ongoing health, vigilance
11	Meaning of life, changing priorities, and recording life values and personal goals
12	Closure: Beyond survival

(d) Wait-list

All participants who were randomized to the wait-list were offered the intervention about 4 months after randomization and 19 participated in the group. Two women needed home visits to be able to use and install the WEB-TV we provided for internet access. About four needed telephone consultation to be able to identify the correct URL for the program.

(e) Complete pre- and post-test assessments of participants.

Out of 72 participants who completed the baseline measures, half were randomly assigned to each group. Eighty percent (n=58) of the participants identified themselves as Caucasian, 4% (n=3) as African American, 4% (n=3) as Asian, 6% (n=4) as Hispanic/Latina, and 6% (n=4) as “other” ethnicities. The average age of participants was 49.5 years old (SD = 6.2; range = 30 to 69). Sixty-eight percent (n=49) were married, 15% (n=11) were single, 11% (n=8) were divorced, 4 % (n=3) were widowed, and 1% (n=1) were separated. Participants were highly educated. Thirty-six percent (n=26) had attended at least some graduate school, 28% (n=20) had completed a bachelor’s degree, 28% (n=20) had attended some college, 1% had completed trade school, and 7% (n=5) had a high school education or less.

Of the 72 participants who have completed the intervention, 14 women did not complete the post-intervention assessment (8 intervention, 6 waitlist). Two participants were out of the country during the post-assessment period and one member died prior to post-test data collection. It is unknown why the remaining participants did not complete the post-measures.

The means and standard deviations for the intervention and wait-list control groups are presented in Table 1. In comparison to the wait-list control group, intervention group participants significantly reduced their depression, post-traumatic stress and stress scores. Significant group differences were found for depression (CESD) ($F(1,55) = 6.0, p = .018$), post-traumatic stress (PCL) ($F(1,55) = 8.36, p = .006$), and general stress (PSS) ($F(1,55) = 3.88, p = .055$). There were not significant differences on the Cancer Behavior Inventory of the Mental Adjustment to Cancer inventory. Intervention effect size was calculated by taking the change scores for each outcome measure for the intervention between baseline and post-test, subtracting the change scores for the waitlist control group, and dividing this difference by the pooled standard deviation of the chosen measure at baseline. The effect sizes for significant measures were as follows: CES-D (0.54), PCL (0.33) and PSS (0.37).

Participants logged onto the *Bosom Buddies* web site an average of 33 times (SD=29, range 3-122). They posted an average of 35 support group messages (SD=34, range 1-138). Intervention group members reported that they used the group for providing and receiving emotional support, forming new friendships, understanding that their problems were not unique and confronting difficult problems and fears. To a lesser extent, group members reported feeling comfortable discussing sexual concerns with other group members and modeling others' behaviors.

(f) Wait-list debriefing.

One of the wait-list groups wanted to meet the investigators and to thank us for providing the program. We used this as an opportunity to obtain informal feedback about *Bosom Buddies*. Six participants were at this meeting. To our surprise, participants told us that they spent a great deal of time preparing their support group message prior to posting it to the group (often spending more than an hour per message). They reported that the group became a large part of their lives, often sharing the themes discussed in the group with their significant others. Although the intervention ended, group members intended to continue their relationship on-line and had on their own created an email distribution list to facilitate their continued discussions.

(g) Provide group intervention to wait-list control group participants.

All 36 wait-list control participants were offered an intervention group. Nineteen wait-list control group members participated in their own support group.

(h) Automated text analysis.

Although not part of the original work scope for Year 2, we began exploring ways to capture and understand the discourse that occurred in the support group. Our quest to automate this process led us to evaluate Pennebaker and Francis' Linguistic Inquiry and Word Count (LIWC) software program (1999, 2000), a commonly used text analysis program designed to categorize text into psychological categories. This software has an internal dictionary of 2,290 words and word stems that can recognize an average of 80% of words in normal texts. The output of the text analysis program is the percentage of recognized words belonging to each category. Many words belong to several of the 64 pre-defined categories. Therefore, the percentages of categories represented by a single word can exceed 100%.

To code the support group postings, we first loaded individual messages into a text processor where typing errors were corrected with Microsoft's Spellchecker. All postings were then saved as ASCII text files. These files were then analyzed using LIWC. Word categories that were theoretically relevant to our purpose were selected from the 25 pre-set dimensions describing psychological processes that are offered by the default dictionary. The categories reported here are: "Positive Emotions" (a large category comprising all positively valenced words in the dictionary¹), "Positive Feelings" (positive affect), "Optimism", "Negative Emotions" (all negatively valenced words), "anxiety", "anger", "sadness", "cognitive mechanisms" (words related to cognitive processes such as thinking and reasoning), "social", "death", "body". To depict the pattern of the exchange in the support group we analyzed messages from the participants only (excluding those provided by the moderator).

¹ Although more general positively valenced words are now included here the label "positive emotions" was maintained from older versions of the program for "historical" reasons (Pennebaker, personal communication).

As LIWC has not been used to understand the patterns of communication in on-line support groups, we first compared the results of the computer analysis with the scores of human raters (see Appendix I for abstract). The results of this analysis indicate that automated text analysis programs can depict patterns of communication when compared to human raters. We believe that automated text analysis programs for describing patterns of communication in on-line discussions may serve as a useful tool for group moderators (e.g., for monitoring ongoing groups and training new moderators) and researchers seeking to understand the discussions that occur in on-line groups. To date, we have presented the findings of this analysis at two conferences and have submitted a paper for publication.

Year 3 (10/1/01-9/30/02)

The next steps are to complete the controlled, randomized trial (the most recent group began the end of September), analyze the data, and write up the results.

CHANGES FROM ORIGINAL STATEMENT OF WORK: None.

KEY RESEARCH ACCOMPLISHMENTS:

- Creation of a Web-based program to provide psychosocial support to women with primary breast cancer.
- Creation of a method to include "emotional" factors in on-line groups.
- Recruitment, randomization, and pre-post assessment of 72 women with primary breast cancer. Preliminary results suggest that the intervention significantly reduces depression and distress in women with primary breast cancer.
- Evaluation and development of an automatic text analysis program (see abstract in Appendix I).

REPORTABLE OUTCOMES

Alpers, GW, Winzelberg, AJ, Classen C, Dev P, Koopman C, Taylor CB. Discourse analysis of a structured breast cancer support group. Society of Behavioral Medicine 22nd Annual Meeting, Seattle, WA, March 2001. Won citation award from Society of Behavioral Medicine for outstanding research. (See abstract in Appendix I.)

Alpers, G.W., Winzelberg, A., Classen, C., Roberts, H., Dev, P., Koopman, C., Taylor, C.B. Evaluation of Automatic Text Analysis in an Internet Breast Cancer Support Group. Poster presented at the annual conference of the American Psychological Association. San Francisco, CA, August 2001.

Winzelberg, AJ, Classen C, Roberts, H, Alpers, GW, , Dev P, Koopman C, Taylor CB. Evaluation of a Web-based breast cancer support group. Paper submitted for the Society of Behavioral Medicine 23rd Annual Meeting. (See abstract in Appendix II).

CONCLUSIONS

A Web-based program to provide psychosocial support to women with primary breast cancer has been very positively perceived by participants and has led to significant reductions in depression and distress. Depression scores dropped 36% in the intervention group as compared to 4% in the wait-list control group. Twice as many participants dropped their CES-D scores below the depression cut-off of 16 in the intervention group than the wait-list control group (10 vs. 5). Intervention group members' post-traumatic stress scores decreased by 14% compared to an increase of 1% for the wait-list control group, and perceived stress scores dropped 20% percent for the intervention group members compared to a 3% drop in wait-list control group members.

REFERENCES

None.

APPENDIX I

DISCOURSE ANALYSIS OF A STRUCTURED BREAST CANCER SUPPORT GROUP

Georg W. Alpers, Dipl.-Psych., Andrew J. Winzelberg, Ph.D., Catherine Classen, Ph.D., Parvati Dev, Ph.D., Cheryl Koopman, Ph.D., and C. Barr Taylor, M.D.
Behavioral Medicine Media Laboratory, Stanford University School of Medicine

Participation in support groups has been found to be beneficial for women with breast cancer. Thousands of support groups are offered on the Internet but there is little research examining if and how they work. This study evaluates the discourse of an on-line breast cancer support group. The group was an 12-week semi-structured and moderated program. Each week group members were presented with content germane to the topic and designed to trigger the discussion. The 9 participants who had been diagnosed with primary breast cancer (mean age 53.1) and the moderator posted a total of 521 messages during the intervention. Participants logged on to read or write throughout the week and at all times of day. Individual participants posted an average of 4.6 (range 2.4-7.9) messages per week averaging 126 words per message (range 1-915). To increase the efficiency and accuracy of content analysis, we used Pennebaker and Francis' (1999) software, which maps relevant psychological dimensions. Their dictionary captured 83% of the words in the messages. The discourse pattern was stable throughout the intervention. A high percentage of words referred to positive concepts (5.6%) and fewer to negative concepts (1.7%). Social issues was the category most frequently used (10.7%). Moreover, post-intervention evaluations indicate that participants felt supported and trusted each other. Participants reported appreciating the 24-hour accessibility of the group, and they participated at times when traditional face-to-face groups are not available. Future studies should examine if the discourse pattern can predict treatment outcome of online groups.

Society of Behavioral Medicine 22nd Annual Meeting, Seattle, WA, March 2001.

APPENDIX II

EVALUATION OF A WEB-BASED BREAST CANCER SUPPORT GROUP

Andrew J. Winzelberg, Ph.D., Catherine Classen, Ph.D., Georg W. Alpers, Dipl.-Psych., Cheryl Koopman, Ph.D., Heidi Roberts, M.D., Parvati Dev, Ph.D., C. Barr Taylor, M.D.
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Face-to-face breast cancer support groups have been found to be beneficial to women coping with a diagnosis of breast cancer. A number of breast cancer support groups are available on the Web, but none have been evaluated in randomized clinical trials. This study evaluates *Bosom Buddies*, a Web-based, structured, moderated, 12-week long support group for women with primary breast cancer.

Seventy-two women (mean age 47, range 27-70), with a diagnosis of primary breast cancer within the last two years, were randomly assigned to an intervention group (n=36) or a wait-list support group (n=36). Participants completed pre- and post-intervention measures of depression (CES-D), stress (Perceived Stress Scale), cancer-related trauma (PCL-C), and adjustment to cancer (Mini-MAC and Cancer Behavior Inventory).

Pre- to post-treatment effects were examined with 2 X 2 ANCOVAs, with the baseline score of the measure serving as the covariate. Intervention group participants significantly reduced their cancer-related trauma symptoms ($F= 8.36, p= .01$), depression ($F=6.00, p=.02$), and stress ($F=3.88, p=.05$). Adjustment to cancer scores did not improve. Twice as many participants in the intervention group compared to the wait-list control group reduced their depression level below a clinically significant value (10 compared to 5). Effect sizes were in the range of .5. Participants reported receiving significant emotional support from other group members and were very satisfied with their experience. The results of this preliminary investigation indicate that support groups can be delivered effectively through the Web and that women with primary breast cancer can reduce negative psychological symptoms through their participation in a moderated, Web-based support group.

Submitted 9/10/01 for Society of Behavioral Medicine 23rd Annual Meeting, April 2002.