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Internet-Based Breast Cancer Psychosocial Intervention

PRINCIPAL INVESTIGATOR: C. Barr Taylor, M.D.

CONTRACTING ORGANIZATION: Stanford University
Stanford, California 94305-5401

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13. Abstract ***(Maximum 200 Words)*** *(abstract should contain no proprietary or confidential information)*

The purpose of this project was to develop and evaluate an Internet-based psychosocial intervention for women with primary breast cancer. During the project (10/1/99 to 9/31/02), the following tasks were completed: (1) 9 women participated in a pilot of the Internet-based psychosocial intervention, and 92 women were randomized to the Internet-based psychosocial intervention or usual care (wait-list control group); (2) analyses of data collected from participants were completed; (3) preliminary text analyses of the support group messages were completed. Results: The 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. Participants with very little computer experience were able to rapidly learn how to use the intervention website. They found that the group offered them a forum for providing and receiving emotional support, forming new friendships, understanding that their problems were not unique, confronting difficult problems and fears, and discussing sexual concerns with other group participants. This study adds to the growing literature on the benefits of psychosocial interventions for primary breast cancer patients.

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FINAL REPORT

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

DAMD17-99-1-9387 – 10/01/99 -09/30/02

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 patient'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 experience a decrease in social support. Psychosocial interventions have been shown 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 patients, 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 were (1) to develop a comprehensive Internet-based psychosocial intervention for breast cancer patients, (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. 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 reduce participants' psychological symptoms, improve their coping skills, and may improve their adherence to medical regimens.

BODY

The following tasks were completed during the project:

Year 1 (10/1/99 to 9/30/00)

Task 1. To develop the Breast Cancer Psychosocial Support Group software, including the user interface, content, and media (audio, graphics, and video) components (months 1-6).

(a) Develop the structure of the intervention, including the translation of the face-to-face group intervention, to an electronic format.

As a first step, topics, issues, graphics and other material from the support groups and workbook, which were the sources for our on-line group, were presented to a formative evaluation group of breast cancer survivors. Formative evaluation group members reviewed content, recommended changes, and wrote and recorded personal recollections on these topics. The initial program was developed for the personal computer (PC and Macintosh) and tested with the same formative group. A second revision of the software was developed for a WebTV format. (WebTV was used so that individuals without access to the Internet could have it provided to them in their homes.)

(b) Coordinate the efforts of the content developers and programming team (significant underlying software algorithms had already been developed).

This was accomplished on time.

(c) Develop audio, video and graphic components.

This was accomplished on time. (Audio components were also transcribed to give users the material in written form if they preferred.)

(d) Develop graphic representations of emotional states for group members to use in their computer-mediated discussions.

Formative evaluation group members could not agree on a graphic representation of emotional states. In our efforts to be inclusive, we decided to use text descriptors of emotional states. We initially developed a "pop-up" list of emotions, but the pilot participants preferred instead a choice of descriptors.

(e) Develop graphic representations of patient self-assessments (e.g., anxiety levels) for patient self-monitoring.

See (d) above.

(f) Identify, select and meet with breast cancer patients who will participate in a formative group to provide feedback on audiovisual material, content, models, etc.

The group was formed 11/99 and met at least 6 times. The project director had frequent additional contact with 2 of the members who have reviewed content and new designs.

(g) Recruit 10-20 breast cancer patients for Phase 2.

Nine women were recruited for the Phase 2 trial. Because of the intensive feedback from the pilot group, we decided to limit the Phase 2 trials to this number.

Task 2. Pilot group/alpha field test software with a group of 10-20 breast cancer patients (months 7-12).

(a) Train group moderator on computer-mediated group facilitation skills.

The entire investigator team met weekly during the 12-week pilot group to review each week's session and to discuss how moderation should occur.

(b) Evaluate ease of use, comprehensibility of software, attractiveness of interface (graphics), and perceived benefit of the software.

We solicited feedback from participants on the design, content and interface at the mid-point and end of the trial. In general, participants were extremely positive about the program. However, sometimes they didn't or couldn't access the audio. We transcribed all the audio for this trial.

(c) Revise software based on feedback by subjects in the pilot study, advances in software/hardware technology and changes in medical knowledge.

The major changes based on feedback from the pilot group were: (1) the audio was transcribed so that it could be read, (2) assessments were placed online to reduce participant burden, (3) the frequency and specificity of moderator feedback was increased. However, as noted above, pilot subjects were very satisfied with the structure of the program. Advances in software/hardware led to moving from a text-based database to a sql database, which permits much greater ease of data handling.

Final program details of the intervention can be found in Winzelberg et al., in press, in Appendix II. Briefly: *Bosom Buddies* is a 12-week, structured, web-based support group moderated by a mental health professional. The program introduces a new topic related to breast cancer each week and the moderator facilitates a discussion on these topics and related concerns (see Table 1). (The program can be seen on http://bml.stanford.edu/multimedia_lab/.)

Table 1. *Bosom Buddies* Weekly Themes

Week	***Topic***
1	***Introduction:*** Participants are asked to introduce themselves by describing their illness and treatment, how they are doing now and what they hope to get from participating in the group. The moderator introduces herself and gives a perspective on what the group can offer to participants.
2	***Getting to know you:*** Participants are encouraged to ask each other questions in order to learn how to support and interact with each other, with a recommendation that they pay attention to the emotions participants post when they log in. Information is provided on how to understand painful emotions.
3	***Difficult emotions:*** Participants are encouraged to tell the group and write in their journals about any difficult emotions they are experiencing and what they have done to cope with them.
4	***Medical team:*** Participants are asked to focus on their relationship with their medical team, discussing their successes and frustrations in working with their doctors. Recommendations are given for how to get more help from their medical team.
5	***Uncertainty and helplessness***: Participants are asked to share any feelings of uncertainty and helplessness with each other, particularly fears of recurrence or fears about the future. Information is provided on why some people deny feelings of helplessness and strategies for coping with these feelings including prayer.
6	***Self and body image:*** Participants are invited to share the impact breast cancer has had on how they feel about their bodies, the feelings they have about this and what they have done to accept changes to their physical features.

7	***Romance and sexuality***: Participants are asked to share with the group how they feel about themselves as sexual persons, to discuss any changes they have noticed in their sexuality or with their partner since the diagnosis.
8	***Family:*** Participants are asked to share how cancer has affected their relationships with their families, the reactions of family members, talking to children about the illness, asking for help, and encouraging family members to seek support.
9	***Friends:*** Participants are asked to share how their friends and co-workers reacted to their diagnosis and how it has affected these relationships. Suggestions are given for how to ask for help from friends and co-workers.
10	***Fear of recurrence***: Participants are asked to think about and discuss their concerns and fears about a recurrence, how it may have already affected their lives and what they have done to cope with it.
11	***Meaning of life:*** Participants are asked to reflect on how their priorities have changed as a result of the cancer. They are asked to write a mission statement--a statement to describe their overall purpose or direction for their lives.
12	***Closure***: For the last week, participants are asked to reflect on what the group has meant to them, what they have gotten from the experience and to say goodbye to each other.

Bosom Buddies encouraged participants to openly and honestly express their thoughts and emotions, receive and offer support, and learn new ways to cope with adjusting to having cancer.

After logging onto the password-protected *Bosom Buddies* web-site, participants were able to read personal stories from survivors, share their own experiences, and keep a web-based personal journal that was closed to review by other group members. To facilitate each group member's ability to make emotional connections with other members, participants wrote a brief description of how they were feeling when they logged onto the web-site. Each group member could review all members' reported emotional states on a separate web-page called "My Buddies." Members' login times were posted to enable participants to see when other members last logged onto the web-site. The group format was asynchronous, meaning that the participants could log on and post comments at any time, without depending on others being online at the same time. Although a mental health professional 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. Participants were told they could contact the researchers for psychiatric referral for evaluation and treatment in the event of a psychiatric emergency.

The moderator's primary task was to keep the conversation on the theme of the weekly topic and to encourage members to support one another. The moderators paraphrased participants' comments, encouraged discussion and feedback between participants, and directed the conversation back to the weekly theme. Specifically, the moderators refrained from making psychological interpretations, providing medical or psychological advice, or developing a personal "therapeutic" relationship with participants. The moderator read messages posted to the support group at least twice per week. Each participant was encouraged to post a photograph of herself on the web-site. These images appeared next to participants' biographic summaries, as well as next to each message they posted to the support group

Year 2 (10/1/00 to 9/30/01)

Task 1. Continue recruitment (months 13-24).

(a) Seventy-two women with primary breast cancer were enrolled into the randomized trial. The intervention was extremely well received by the participants, as illustrated by the following comments (posted on the last day of the group):

> This will be a sad goodbye for me as I've felt so involved since we began this group and am wondering what I will focus on now...
>
> But I want to thank each of you for sharing your feelings with me and ways you coped with certain aspects of your life. It has certainly helped me in many ways and given me a new perspective on how to cope.
>
> I received the message about the group ending and it struck me how sad I am to see it go. This has been a really wonderful place to make friends, to share experiences, to learn and grow. I signed on today feeling distressed over the ending of the group and then I read your letters. You women have lifted me up. I am really going to miss this group. I do hope you are able to log onto the Yahoo mailbox and we can keep in touch that way.
> {{{{{{{{{{{{{{{{{Hugs to you}}}}}}}}}}}}}}}}}}

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

All 36 wait-list control (WLC) participants were offered an intervention group. Nineteen WLC group members participated in their own support group. 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 messages prior to posting them to the group (often spending more than an hour per message). They reported that the group became a large part of their lives and that they often shared 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 created an email distribution list on their own to facilitate their continued discussions.

(c) Data 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 (see Alpers et al., submitted, in Appendix II), 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 sum of 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 dictionary[1]), "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).

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 Alpers et al., submitted, Appendix II). 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 to 9/30/02)

Task 1. Complete recruitment of 100 women with primary breast cancer to the study.

(a) We completed enrollment with a final count of 101 women enrolled into the study.

Nine participated in an uncontrolled pilot trial, 72 participated in a randomized trial with a professional moderator, and 20 participated in a randomized trial with a peer moderator. We closed the randomized trial after 72 participants had enrolled into the study at the end of Year 2. We decided to use the last year of the study to evaluate the importance of professional moderation in the *Bosom Buddies* intervention. After observing five *Bosom Buddies* groups, it was unclear to us why the moderator needed to have psychological training if she was not going to make psychological interpretations. To explore this issue, we ran a small trial of the *Bosom Buddies* intervention using a peer moderator. A graduate from the previous *Bosom Buddies* group was invited to moderate her own group. The peer moderator we selected had no previous group facilitation experience or psychological training. By vocation she was an elementary school teacher. To train the moderator, we provided her with copies of all messages posted by

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[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).

the previous professional moderators. She was also provided with weekly email and telephone consultation with a professional moderator.

Task 2. Data Analysis

(a) Analysis of the randomized trial of the Bosom Buddies intervention with 72 women with primary breast cancer was completed.

The study is described in detail in Winzelberg et al., Evaluation of an Internet support group for women with breast cancer. *Cancer,* in press.

In summary, data analysis was conducted on the independent samples t-tests, using a two-tailed level of significance, comparing the two groups (immediate treatment versus WLC) on the baseline measures, including demographic characteristics, as well as on the outcome measures, to determine that the randomization procedure was effective and that no baseline differences existed between groups. Second, independent samples t-tests were conducted on baseline variables comparing completers and non-completers (those who did not complete post-test measures) on these variables. Third, using analysis of covariance (ANCOVA) with each baseline assessment of the independent variable of interest as a covariate, the intervention group was compared to the WLC group. We add the covariate to remove the variance in outcome that is explained by baseline scores and to detect the level of variance that is attributable to group. For dichotomous outcome variables, logistic regression is employed. Finally, an intention-to-treat analysis was performed inserting baseline scores for missing post-test data, using ANCOVA as previously described. Intervention effect size was calculated for each of the outcomes showing significant differences between treatment and WLC. These were computed in three steps: (1) calculating the change score for the intervention and control group between baseline and post-test on each outcome measure; (2) subtracting the change score for the WLC group from the change score of the intervention group; and (3) dividing this difference by the pooled standard deviation of the chosen measure at baseline.

Results. No baseline differences were found between the intervention and WLC groups on any measures. Of the 72 participants, 14 women did not complete their post-intervention assessment (8 intervention, 6 WLC). Two participants did not complete the post-assessments because they were out of the country during this period, and one participant's cancer progressed and she died prior to post-test data collection. No significant differences were found between dropouts and non-dropouts on any baseline measures. Participants logged onto the *Bosom Buddies* web-site an average of 34 times (SD=29, range=3-122) during the intervention. They posted an average of 36 support group messages (SD=38, range=1-146). The personal journal feature was not regularly used. Out of 36 participants, only 14 participants posted at least once to their personal journal (M=1.6, SD=2.7).

Compared to the WLC group, the intervention group reported significantly reduced depression [CESD ($\underline{F}$(1,55 = 6.0, $\underline{p} < .01$)], cancer-related trauma [PCL (F (1,55) = 8.36, $\underline{p} < .01$)], and stress [PSS (F (1,55) = 3.8, $\underline{p} < .05$] (see Table 2). Furthermore, for those participants in the support group who had a CES-D score that indicated significant depression at baseline, 53% (10/19) were no longer depressed at follow-up, compared to 29% (5/17) in the control group. Between group effect sizes for significant measures were as follows: CES-D=0.54, PCL=0.48 and PSS=0.38.

Table 2. Mean Scores and Analysis of Covariance F Values Comparing Intervention and Wait-List Control Groups for Women who Completed Both Pre- and Post-Test Assessments

	Control Group N=36		Intervention Group N=36		
Measures	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)	F
CESD	16.8 (9.9)	16.1 (10.4)	17.4 (11.0)	11.1 (7.4)	6.00**
PCL	33.1 (12.1)	33.4 (13.9)	32.5 (10.0)	27.9 (7.6)	8.36**
PSS	16.0 (7.4)	15.5 6.3)	16.4 (7.3)	13.2 (5.6)	3.88*

CES-D = Center for Epidemiological Studies–Depression Scale
PCL = PTSD Checklist-Civilian Version;
PSS = Perceived Stress Scale

Participants logged onto the *Bosom Buddies* web-site an average of 34 times (SD=29, range 3-122) over the 12 weeks of the intervention. They posted an average of 36 support group messages (SD=38, range 1-146). 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 (see Table 3).

Table 3. Participants' Evaluation of Their Group Experience

Participant Evaluation of Group Experience	Percent Reporting a Lot or a Great Deal
Getting support and encouragement	65%
Helping others	56%
Learn problems are not unique	56%
Develop new friendships	63%
Get advice	55%
Express true feelings	65%
Model myself after group members	30%
Confront difficult problems and fears	44%
Discuss sexual concerns	44%

The results of the pilot study indicate that *Bosom Buddies* participants actively participated in the web-based intervention, were able to use the group to obtain and provide emotional support, and were able to reduce their depression, stress and cancer-related trauma as a result of their participation. Details of the study can be found in Winzelberg et al., in press, in Appendix II.

(b) In the peer moderator pilot study, we recruited 20 women with primary breast cancer to participate in the Bosom Buddies intervention.

Once a participant completed her questionnaires, she was randomly assigned to either the immediate intervention group or the WLC. Although a sample size of 10 in each group would only have sufficient power (80%) to detect a very large effect size (1.36), we felt that the trial would shed light on the feasibility of providing peer moderation and help us identify potential problems to this moderation format.

Although the results did not identify any significant differences between the control and treatment group, the results mirrored the findings from the randomized trial with the professional moderator (see Table 4). The peer moderator needed very little supervision time. She reported being able to model her own postings to the support group on the list of moderator messages provided to her and spending about the same amount of time moderating her group as did the professional moderator. Subjectively, it appeared that the group participants interacted with her in much the same way that other groups interacted with a professional moderator. We believe the results are very promising and warrant further investigation in a larger scale trial.

Table 4. Mean Scores and Analysis of Covariance Comparing Intervention and Control Groups for Women who Participated in the Peer Moderated Pilot

	Control Group N=10		Intervention Group N=10				
Measures	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)	F	Sig	Effect Size
CESD	20.9 (9.4)	21.9 (11.5)	19.1 (9.1)	14.0 (11.5)	6.00	.161	0.67
PCL	35.1 (10.4)	35.8 (12.3)	33.8 (8.8)	29.2 (10.1)	8.36	.193	0.54
PSS	19.1 (7.6)	19.8 (7.3)	17.0 (5.9)	14.1 (6.1)	3.08	.098	0.54
STAI	42.5 (13.9)	44.6 (13.7)	37.1(8.4)	36.2 (11.3)	0.78	.346	0.26

CES-D = Center for Epidemiological Studies–Depression Scale
PCL = PTSD Checklist-Civilian Version;
PSS = Perceived Stress Scale; STAI = State-Trait Anxiety Inventory

(c) We are currently evaluating participant usage data to understand how participants used the Bosom Buddies intervention and communicated with one another in the support group. We anticipate submitting a manuscript in 2003 describing how participants used the intervention.

Preliminary analyses of the usage patterns of the 36 women assigned to the intervention group indicate that participants logged onto the *Bosom Buddies* web-site an average of 34 times (n=1234, SD=29, range 3-122) during the intervention. At login, participants were required to enter how they were feeling in a free-text entry box. Fifty nine percent (n=732) of login self-descriptors were categorized as emotions. Of the remaining logins, 13% (n=166) were categorized as physical symptoms, 4% (n=49) as cognitions (e.g., curious, concerned, pensive), and the remaining 23% (n=287) were either ambiguous or other (e.g., OK, rushed, so-so, better).

Of the emotion logins, 77% (n=56) were positive emotions, 23% (168) were negative emotions and one was rated as neutral (i.e., surprised). Of the physical logins, 84% (n=14) were negative (e.g., tired), 10% (n=17) were neutral (e.g., hot), and 5% (n=9) were positive (e.g., rested). Cognition words were fairly evenly split, with 39% (n=19) positive words (e.g., curious), 35% (n=17) neutral words (e.g., concerned), and 27% (n=13) negative words (e.g., reluctant, in limbo).

The most common logins were "happy" (16%, n=203), "OK" (12%, n=153), "fine" (8%, n=97), "tired" (7%, n=86), "good" (2%, n=29), "relaxed" (2%, n=29), "anxious" (2%, n=26) and "calm" (2%, n=24). Combining words with similar meaning found "happy" to account for 22% (i.e., joy + happy + elated + glad + good + great + pleased), "tired" to account for 9% (i.e., tired + exhausted + fatigue + tiring day + wiped out + lethargic + drained), and "content" to account for 6% (i.e., content + at ease + at peace + peaceful + relaxed + rested).

(d) We analyzed the support group postings with Pennebaker LIWC dictionaries (see Task 4, below).

Through this analysis we found that participants expressed positive emotions almost three times as often as negative emotions (4.5% vs. 1.5%). Cognitive mechanisms accounted for 7.5% of the text, with insight-related words being the most common (2.5%), followed by certainty (1.5%), and causation (1.0%). Over the course of the group, neither the percentage of positive or negative emotions predicted depression, cancer-related trauma, stress or anxiety scores. The percentage of emotions expressed each week was quite variable and depended, in part, on the theme of the week.

Task 4. Prepare reports and initial manuscripts.

(a) See Reportable Outcomes, below, for publications and presentations that have resulted from this project.

As noted above, we are also preparing a manuscript that describes the participation patterns of participants and the results of our analysis of the support group discussions using the LIWC software.

Task 5. Evaluate software and make recommendations for future modification of software and intervention protocols.

(a) Identify areas for improving the software and intervention protocols.

We have identified a number of improvements to the intervention. Planned improvements involve improving the user interface, adding security to the server, providing more detailed computer and group participation training to participants, and updating the content. We will also update the server that hosts the *Bosom Buddies* intervention so that it is HIPAA compliant (Health Insurance Portability and Accountability Act).

Participants provided a number of suggestions for improving the content of the web-page which we will incorporate into future versions of the intervention. These improvements include lengthening the "time-out" security features, simplifying the password system, and providing visual cues on the website for identifying which support group postings have been read. We developed a very rough moderation manual that was used by the peer moderator with remarkable success (see above). In the future, we will revise and index this manual for facilitating the moderation process. The format of the manual is designed so that it can be readily updated. We have used this approach in a study of another on-line intervention designed for college age women.

(b) Create software to expedite the analysis of support group messages with the LIWC dictionaries.

As noted above, we have become interested in the feasibility of evaluating the content of the support group messages through the use of the Pennebaker LIWC text analysis software. Because the Windows version of the LIWC Pennebaker analysis tool was inadequate to properly analyze the large volume of text in numerous messages used in the *Bosom Buddies* support group, we decided to write a software tool to perform the analysis ourselves. This software tool allowed us to analyze all messages at one time rather than running each individual message through the LIWC program. The software tool was written in the Perl programming language so that it would be platform-independent.

The Pennebaker analysis works by examining the words that appear in the block of text to be analyzed, and comparing them to a list of words in a dictionary. Each word in the dictionary is associated with one or more categories, which include things like "anger," "job," and "sexual," among numerous others. Additionally, some words in the dictionary allow for prefix matching--these entries will match against any word in the text containing that entry as a prefix. Before matching, the input text is tokenized by splitting on whitespace characters, and then all punctuation except for apostrophes, as well as certain formatting codes used for the message boards, are stripped from the words. Apostrophes are left in the words because some dictionary entries include apostrophes. Because the analysis is so simple and the LIWC provides an electronic version of the dictionary database, we feel very confident that the analysis provided by our tool is the same as that performed by LIWC. To verify the comparability between the Pennebaker LIWC software and the Perl program, we compared several support postings. No differences were identified.

LIST OF PERSONNEL

C. Barr Taylor, M.D.

Andrew Winzelberg, Ph.D.

Cheryl Koopman, Ph.D.

Parvati Dev, Ph.D.

KEY RESEARCH ACCOMPLISHMENTS

- Creation of a web-based intervention to provide psychosocial support to women with primary breast cancer.
- Development of a user interface that participants found easy to navigate and highly acceptable.
- Creation of a method to include "emotional" communications in on-line groups.
- Recruitment, randomization, and pre-post assessment of 72 women with primary breast cancer. Results suggest that the intervention significantly reduces depression, cancer-related trauma and stress in women with primary breast cancer (see Winzelberg et al., press, Appendix II).
- Demonstration that women with very little computer experience were able to rapidly learn how to use the *Bosom Buddies* website.
- Evaluation and development of an automatic text analysis program (see Alpers et al., submitted, Appendix II).
- Creation of a platform independent text analysis program using the Pennebaker dictionaries and the Perl programming language.
- Pilot evaluation of a peer-moderated web-based program to provide psychosocial support to women with primary breast cancer (n=20).
- Identification of the participation patterns of women who used the web-based intervention.

REPORTABLE OUTCOMES

Winzelberg AJ, Classen C, Roberts H, Alpers GW, Roberts H, Dev P, Koopman C, Adams R, Ernst H, Taylor CB. (in press). Evaluation of an Internet support group for women with breast cancer. *Cancer*.

Alpers G W, Winzelberg A, Taylor CB. (in press). Internet-Gruppen für Brustkrebspatientinnen. In R. Ott & C. Eichenberg (Eds.), *Klinische Psychologie im Internet*. Goettingen: Hogrefe.

Alpers GW, Winzelberg A, Classen C, Roberts H, Dev P, Koopman C, Taylor CB. (in submission). Evaluation of automatic text analysis in an Internet breast cancer support group.

Winzelberg A, Classen C, Roberts H, Alpers' G, Dev G, Koopman C, Taylor CB. "Evaluation of a web based breast cancer support group." Paper presented at the Society of Behavioral Medicine 23rd Annual Meeting, Washington D.C., April 2002. (See abstract in Appendix I.)

Winzelberg A. "Using the Internet to deliver psychosocial interventions." Invited presentation at the Symposium on the Internet for Counseling, Psychotherapy and other Mental Health Services, University of Queensland, Department of Psychiatry, Brisbane, Australia, March 2002.

Alpers GW, Winzelberg A, Classen C, Roberts H, Dev P, Koopman C, Taylor CB. "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

Alpers GW, Winzelberg AJ, Classen C, Dev P, Koopman C, Taylor CB. "Discourse analysis of a structured breast cancer support group." Paper presented at 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.)

CONCLUSIONS

This study suggests that women diagnosed with primary breast cancer are interested in participating in an on-line breast cancer support group. One hundred and one women were recruited to participate in an uncontrolled pilot (n=9) and a randomized trial (N=92). With less than two hours of training, inexperienced computer and Internet users were able to learn all the skills they needed to navigate the website and fully participate in the intervention.

The web-based intervention developed for this project was very positively received by participants and led to significant reductions in depression, cancer-related trauma and stress. Depression scores dropped 36% in the intervention group as compared to 4% in the WLC group. Twice as many participants dropped their CES-D scores below the depression cut-off of 16 in the intervention group than the WLC group (10 vs. 5). Intervention group members' post-traumatic stress scores decreased by 14% compared to an increase of 1% for the WLC group, and perceived stress scores dropped 20% for the intervention group members compared to a 3% drop in WLC group members. The effect size of the intervention was in the moderate range. In a sub-study, we assessed the feasibility of using peer-moderating to facilitate the on-line support group. Preliminary findings suggest that this form of moderation is well accepted and that the results mirror those found in the groups facilitated by a professional moderator.

Participants actively used the intervention, logging on almost three times a week and posting three messages a week, although the range of participation was quite wide. Participants reported being very satisfied with the intervention. They found that the group offered them a forum for providing and receiving emotional support, forming new friendships, understanding that their problems were not unique, confronting difficult problems and fears, discussing sexual concerns with other group participants, and modeling others' behaviors. Participants were more likely to log onto the website when they were feeling positive than negative.

This study adds to the growing literature on the benefits of various interventions for primary breast cancer patients, including the benefits of brief, unstructured, supportive-expressive group therapy, brief education-based groups, and brief cognitive-behavioral groups. Although the results of this trial are promising, more research is needed before this support group format can be recommended to women coping with a diagnosis of breast cancer. Several methodological limitations will need to be addressed by further research. Longer follow-up assessments are needed to determine whether the intervention effects are maintained. Medical diagnoses need to be confirmed by review of medical records, and better tracking of additional psychosocial interventions used by participants is needed. Furthermore, because the sample size was relatively small and participants were highly educated, the intervention should be tested with a larger and more diverse population. We do not know how effective the intervention would have been with less educated or less affluent women.

Directions for future research include examining participant and component features such as group size, duration of the intervention, level of structure, specificity of cancer diagnosis, group moderator training and experience, psychoeducational content, coping skill training, possible treatment mediators, and comparisons between web-based and face-to-face group interventions.

REFERENCES

None.

APPENDIX I

Abstracts

Alpers GW, Winzelberg AJ, Classen C, Dev P, Koopman C, Taylor CB. "Discourse analysis of a structured breast cancer support group." Paper presented at Society of Behavioral Medicine 22nd Annual Meeting, Seattle, WA, March 2001.

Winzelberg A, Classen C, Roberts H, Alpers G, Dev G, Koopman C, Taylor CB. (2002). "Evaluation of a web based breast cancer support group." Paper presented at the Society of Behavioral Medicine 23rd Annual Meeting, Washington DC, April 2002.

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.

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

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.
Behavioral Medicine Media Laboratory, Stanford University School of Medicine

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.

Presented at the Society of Behavioral Medicine 23rd Annual Meeting, Washington, DC, April 2002.

APPENDIX II

Papers and Chapter

Winzelberg AJ, Classen C, Roberts H, Alpers GW, Roberts H, Dev P, Koopman C, Adams R, Ernst H, Taylor CB. (in press). Evaluation of an Internet support group for women with breast cancer. *Cancer*.

Alpers GW, Winzelberg A, Classen C, Roberts H, Dev P, Koopman C, Taylor CB. (in submission). Evaluation of automatic text analysis in an Internet breast cancer support group.

Alpers G W, Winzelberg A, Taylor CB. (in press). Internet-Gruppen für Brustkrebspatientinnen. In R. Ott & C. Eichenberg (Eds.), *Klinische Psychologie im Internet*. Goettingen: Hogrefe.

Running head: AN EVALUATION OF AN INTERNET SUPPORT GROUP

***Cancer*, in press.**

An Evaluation of an Internet Support Group for Women with Primary Breast Cancer

Andrew J. Winzelberg, Ph.D.,[1] Catherine Classen, Ph.D.,[1]
Georg W. Alpers, Ph.D.,[1] Heidi Roberts, M.D.,[1] Cheryl Koopman, Ph.D.,[1]
Rob Adams, B.S.,[2] Heidemarie Ernst, M.D.,[1] Parvati Dev, Ph.D.,[2] C. Barr Taylor, M.D.[1]
[1]Department of Psychiatry and Behavioral Sciences
[2]Stanford University Medical Media and Information Technologies
Stanford University School of Medicine

Correspondence and reprint requests: Andrew J. Winzelberg, Ph.D., Department of Psychiatry and Behavioral Sciences, Room 1326, Stanford University School of Medicine, Stanford, CA 94305-5722. E-mail: winzel@stanford.edu

29 text pages (title page, text, references), 3 tables

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Condensed Abstract

Women with primary breast cancer were randomly assigned to a web-based, moderated, asynchronous social support group or control group. Compared to the control group, the intervention group significantly reduced their depression, cancer-related trauma and stress levels.

Abstract

Background. Women with breast cancer commonly experience psychological distress following their diagnosis. Women who participate in breast cancer support groups have reported significant reduction in their psychological distress and pain, and improvement in the quality of their lives. Web-based breast cancer social support groups are widely used, but little is known of their effectiveness. Preliminary evidence suggests that women benefit from their participation in web-based support groups.

Methods. Seventy-two women with primary breast cancer were randomly assigned to a 12-week, web-based, social support group *(Bosom Buddies)*. The group was semi-structured, moderated by a health care professional, and delivered in an asynchronous newsgroup format.

Results. The results indicate that a web-based support group can be useful in reducing depression and cancer-related trauma, as well as perceived stress, among women with primary breast cancer. The effect sizes ranged from 0.38 to 0.54. Participants perceived a variety of benefits and high satisfaction from their participation in the intervention

Conclusions. This study demonstrated that the web-based program, *Bosom Buddies*, was effective in reducing participants' scores on depression, perceived stress, and cancer-related trauma measures. The effect size of the intervention was in the moderate range. Although web-based social support groups offer many advantages, this delivery mechanism presents a number of ethical issues that need to be addressed.

Key Words: Internet, primary breast cancer, social support group, web

Introduction

Women with breast cancer commonly experience psychological distress following their diagnosis.[1-4] These symptoms can be longstanding.[5] To cope with their illness, many women participate in breast cancer support groups.[6-8] In controlled studies, women who participate in breast cancer support groups have reported significant reduction in their psychological distress and pain, and improvement in the quality of their lives.[9-18] Evaluation of community-based cancer support programs lend further empirical evidence that support groups are beneficial.[8, 19-22] However, not all empirical studies report positive outcomes.[20, 23]

Historically, face-to-face groups have been the primary method of delivering breast cancer support groups. Now, however, the wide availability of Internet-connected computers creates the opportunity for groups to be provided electronically. The Pew Foundation report on Internet use[24] found that 104 million American adults had Internet access at the end of 2000, 55% of those with Internet access (52 million persons) have sought health information from the web, and between 9% and 36% of health information seekers have participated in an online support group.

Hundreds of online groups now exist for cancer patients.[25, 26] Davison et al.'s[7] review of disease-related online support groups found that breast cancer support groups ranked third in the frequency of postings (an objective, but rough, measure of participation) for the disease-related online support groups he evaluated.

Web-based support groups offer a number of advantages over face-to-face groups. First, the modality of delivery is relatively flexible because they can be delivered synchronously (e.g., real-time chat rooms) or asynchronously (e.g., newsgroups).

Second, there are a variety of facilitation options. Compared to face-to-face groups, there is greater scheduling convenience and increased access to care for individuals who otherwise could not participate in such groups due to their health status, residence in remote areas, or social anxiety. Finally, comparatively fewer resources are required to moderate a group once a group is established, thus reducing costs. The disadvantages are that it requires that individuals have access to computers and the Internet, have some facility using computers, and are comfortable reading and writing in the language in which the group is provided. It is possible that participants could over-rely on their Internet-based relationships, resulting in increased social isolation.

Despite the many potential advantages, the few potential disadvantages, and the wide use of web-based group interventions, to our knowledge, only one randomized, controlled study has evaluated the effectiveness of a web-based breast cancer support group.[27] The few reports of web-based breast cancer groups that have been published have been either in the form of surveys, analysis of participants' communications,[28, 29] or uncontrolled studies.[30] Clearly more randomized trials are needed in order to demonstrate the effectiveness of these interventions, particularly regarding their psychological benefits.

Weinberg et al.[29] investigated the impact of a computer bulletin board on six women with breast cancer and found that group members actively used the support group to discuss their medical condition, offer support to each other, and to share their personal concerns. Weinberg described the discourse as having similar features to face-to-face support groups.

Similarly, Sharf,[28] reviewing the discourse of a breast cancer online newsgroup, found that members used the group to exchange information, provide social support, and enhance personal empowerment. Group members reported that the group was helpful because it facilitated a change in focus from feeling preoccupied with their own illness to thinking of others.

Finally, Lieberman et al.[30] evaluated a web-based synchronous (i.e., chat room) breast cancer support group in an uncontrolled study. Group members participated in the chat room for one and one-half hours a week for 16 weeks. The groups were moderated and unstructured. Between sessions, participants were able to read transcripts of the previous session and post messages to each other in a newsgroup. Participants reported significant reductions in depressed mood and subjective pain. Lieberman & Russo[31] found that the members of web-based breast cancer support groups interact in ways similar to those seen in face-to-face support groups.

The earliest and most extensively assessed web-based support group is the Comprehensive Health Enhancement Support System (CHESS) that was developed at and is maintained by the University of Wisconsin.[27, 32-35] Designed to provide health-related information, emotional support, and decision-making guidance to patients with various illnesses, CHESS support groups are unmoderated and unstructured. Initial findings indicate that women find CHESS beneficial and easy to use.[34] A recent randomized, controlled trial of the network was completed with 246 women under the age of 60 years who had been diagnosed with breast cancer within the last six months. Participants assigned to the CHESS intervention had access to the web-site for six months. Control group participants were given a copy of Dr. Susan Love's Breast

Book[36] Gustafson et al.[37] found that participants assigned to the CHESS condition reported increased social support and competence with seeking online information. There were no differences in quality of life (as measured by the FACT-B) or well-being. Furthermore, the psychological benefits of participation were greatest for women from underserved populations.[27]

Although the evidence for effective web-based breast cancer support groups is limited, online interventions have been found to be beneficial to patients seeking treatment for substance abuse,[38] sexual-abuse survivors,[39] smoking cessation,[40] general medical concerns,[7] parenting,[41-42] eating disorders,[43-45] and anxiety.[46]

The present study seeks to provide empirical evidence regarding the psychological benefits of online breast cancer support groups, particularly asynchronous support groups--the most common group format available on the Internet and one that easily adjusts to participants' varying schedules. In this study, we evaluated a 12-week, structured, moderated, web-based support group for women with breast cancer in a randomized clinical trial. We hypothesized that, compared to those in a wait-list control group, women who participated in the intervention would report improved psychological coping skills and decreased psychological distress.

Methods

Participants

Eligibility for the current study was determined by meeting all of the following criteria: 1) being female; 2) receiving a primary breast cancer diagnosis within the last 32 months; 3) having no suicidal ideation; 5) living in California, and 6) being able to communicate in written English. Because there is still ambiguity regarding the legal responsibilities of moderators of on-line support groups, we made a conservative decision to restrict eligibility to participants who resided in California—the state in which the moderators were licensed to practice psychology. Suicidal ideation was evaluated when participants completed baseline assessments. Participants endorsing suicidal ideation would be evaluated by one of the authors (CBT).

Participants were recruited through public service announcements on local radio and in newspapers and flyers distributed to oncology offices in the San Francisco Bay Area and Los Angeles. Eligibility was based on self-report. Confirmation of cancer diagnosis was not confirmed by review of medical records. One-hundred fifty-one women responded to our recruitment advertisements. Seventy-two women met the eligibility requirements and elected to join the study. Of the 79 women who did not enroll in the study, 24 were excluded because they lived outside of California, 13 were excluded because they did not meet the cancer diagnosis requirements, three could not make the time commitment, and the remaining 39 were uninterested once they knew the details of the study.

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) was separated. Participants were predominantly 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. On average, participants entered the study 12 months following their diagnosis (SD = 9 months, range = 1-32 months). Thirty-four percent of participants (9 WLC, 13 Intervention Group) were participating in another breast cancer support group or individual counseling at baseline. No data was collected on participation in psychological interventions at the post-test.

Procedure

Women interested in participating in the study were mailed a study information sheet and consent form. After signing and returning the consent form, each participant was assigned a password that allowed her to log onto the web-site to complete the baseline measures. Once a participant had completed her questionnaires, she was randomly assigned to either the immediate intervention group or the wait-list control (WLC) group. Participants were recruited in two waves (wave 1 had 44 participants, wave 2 had 32 participants).

At the termination of the group, participants completed an identical battery of measures. Participants experiencing computer problems were able to contact two members of the research team for assistance via e-mail or telephone. Participants who did not have access to a computer with Internet access were loaned, free of charge, a *WebTV* computer and were instructed on its use. Three consecutive groups were run (n=10, 11, and 15). One group was moderated by AW and two were moderated by CC. At the conclusion of the post-treatment assessment, participants who were assigned to the WLC group were invited to participate in their own support group intervention.

Description of the Intervention

Bosom Buddies is a 12-week, structured, web-based support group moderated by a mental health professional. The program introduces a new topic related to breast cancer each week and the moderator facilitates a discussion on these topics and related concerns (see Table 1). The themes for the weekly sessions and the theoretical underpinnings of the intervention are adapted from Spiegel's supportive-expressive group therapy for cancer patients[47-48] and Kreshka's text in her workbook-journal on coping with breast cancer[49-50] *Bosom Buddies* encourages participants to openly and honestly express their thoughts and emotions, receive and offer support, and learn new ways to cope with adjusting to having cancer. Participants with a variety of experiences and backgrounds (e.g., age, treatment choices, specific diagnosis, and time coping with their diagnosis) were encouraged to join the group with the assumption that the diversity of participants' experiences would be beneficial to the group.

After logging onto the password-protected *Bosom Buddies* web-site, participants were able to read personal stories from survivors, share their own experiences, and keep a web-based personal journal that was closed to review by other group members. To facilitate each group member's ability to make emotional connections with other members, participants wrote a brief description of how they were feeling when they logged onto the web-site. Each group member could review all members' reported emotional states on a separate web-page called "My Buddies." Members' login times were posted to enable participants to see when other members last logged onto the web-site. The group format was asynchronous, meaning that the participants could log on and post comments at any time, without depending on others being online at the same time. Although a mental health professional 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. Participants were told they could contact the researchers for psychiatric referral for evaluation and treatment in the event of a psychiatric emergency.

The moderator's primary task was to keep the conversation on the theme of the weekly topic and to encourage members to support one another. The moderators paraphrased participants' comments, encouraged discussion and feedback between participants, and directed the conversation back to the weekly theme. Specifically, the moderators refrained from making psychological interpretations, providing medical or psychological advice, or developing a personal "therapeutic" relationship with participants. The moderator read messages posted to the support group at least twice per week. Each participant was encouraged to post a photograph of herself on the website, although only half elected to do so (n=18). These images appeared next to participants' biographic summaries, as well as next to each message they posted to the support group.

Primary Measures

Center for Epidemiological Studies–Depression Scale (CES-D). The CES-D scale[51] is a 20-item self-report measure designed to assess depressive symptoms in the general population. It has been found to have high internal consistency (alpha = .89) with cancer patients[52] and adequate test-retest reliability. The instrument permitted comparison with other cancer studies that used this measure, was sensitive to intervention effects, and was easily administered.[52] As recommended by Ensel,[53] a cutoff score of 16 was used to identify depression.

PTSD Checklist-Civilian Version (PCL-C). The PCL-C[54] is a 17-item self-report measure of Posttraumatic Stress Disorder (PTSD) that has been used previously with cancer survivors. The items on the PCL-C correspond with the clinical symptoms used to diagnose PTSD. Participants were asked to rate on a 5-point Likert scale the degree to which they have felt bothered by each symptom in the last month. It has been shown to have excellent internal consistency (alpha=.97), test-retest reliability (.96), and evidence for convergent validity.

State-Trait Anxiety Inventory-State Scale (STAI). The STAI[55] has commonly been used as a global measure of state anxiety. The scale consists of 20 items that are rated on a four-point Likert scale and evaluates feelings of apprehension, tension, nervousness, and worry, which increase in response to physical danger and psychological stress. The reliability and validity of this tool for measuring anxiety has been well established. The overall median alpha coefficients evaluating internal consistency in normative samples have ranged from 0.86 to 0.92.[55]

The Perceived Stress Scale (PSS). The PSS[54] is 14-item self-report measure of global perceived stress during the previous month. Items are rated on a five-point Likert scale. Cohen et al.[56] report average alpha coefficients are 0.84 or greater, depending on the sample evaluated.

Participant Demographics. Participants' age, ethnicity, breast cancer diagnosis and treatment history, use of adjunct psychosocial services, and socioeconomic status were collected at baseline only.

Secondary Measures

Cancer Behavior Inventory (CBI). The CBI[57] focuses on the perceived ability to implement cognitive and behavioral strategies for coping (self-efficacy) with cancer as a serious illness. The CBI includes 51 items forming six subscales: (1) Maintenance of activity and independence; (2) Coping with treatment-related side effects; (3) Accepting cancer/maintaining positive attitude; (4) Seeking and understanding medical information; (5) Affective regulation; and (6) Seeking support. For each item, the respondent was asked to rate her confidence in being able to accomplish that behavior on a 1 to 9 scale for which 1 = "Not at all confident" and 9 = "Totally confident." Subscale scores were derived by summing scores for the items comprising particular subscales. This measure has been shown to have satisfactory internal consistency (alpha range = .75-.88) and there is good evidence supporting its validity.[57]

Mini-Mental Adjustment to Cancer Scale (Mini-MAC). The Mini-MAC[58] is a self-report questionnaire designed to assess specific ways of responding to cancer. The Mini-MAC has been widely used with breast cancer patients to determine the extent to which they have adjusted to living with cancer.[59-61] It is comprised of 29 items rated on a four-point Likert scale ranging from 1 = "Definitely does not apply to me" to 4 = "Definitely does apply to me." FIve subscales from the Mini-Mac were used: (1) Fighting Spirit; (2) Helpless/Hopeless; (3) Anxious Preoccupation; (4) Denial; and (5) Fatalism. Internal consistency of the subscales ranged from .65 (fatalism) to .84 (fighting spirit).

Group Experience. A nine-item questionnaire was completed by the women, which was designed to assess their perceptions of the group on dimensions found to be relevant to psychosocial support groups. The Group Experience measure is modeled after a measure used by Lieberman and Snowden.[62] The items assessed how much group participants felt support and encouragement, were able to help others, learned that their problems were not unique, developed new friends, offered advice, expressed feelings, modeled themselves after other group members, confronted problems and fears, and discussed sexual concerns. Each item was rated on a four-point Likert scale ranging from 1 = "None" to 4 = "A great deal."

Data Analysis

First, independent samples t-tests, using a two-tailed level of significance, compared the two groups (immediate treatment versus wait-list control) on the baseline measures, including demographic characteristics, as well as on the outcome measures, to determine that the randomization procedure was effective and that no baseline differences existed between groups. Second, independent samples t-tests were conducted on baseline variables comparing completers and non-completers (those who did not complete post-test measures) on these variables. Third, using analysis of covariance (ANCOVA) with each baseline assessment of the independent variable of interest as a covariate, the intervention group was compared to the WLC group. We add the covariate to remove the variance in outcome that is explained by baseline scores and to detect the level of variance that is attributable to group. For dichotomous outcome variables logistic regression is employed. Finally, an intention-to-treat analysis was performed inserting baseline scores for missing post-test data using ANCOVA as previously described. Intervention effect size was calculated for each of the outcomes showing significant differences between treatment and WLC. These were computed in three steps: 1) calculating the change score for the intervention and control group between baseline and post-test on each outcome measure; 2) subtracting the change score for the WLC group from the change score of the intervention group; and 3) dividing this difference by the pooled standard deviation of the chosen measure at baseline.

Results

No baseline differences were found between the intervention and WLC groups on any measures. Of the 72 participants, 14 women did not complete their post-intervention assessment (8 intervention, 6 WLC). Two participants did not complete the post-assessments because they were out of the country during this period, and one participant's cancer progressed and she died prior to post-test data collection. No significant differences were found between dropouts and non-dropouts on any baseline measures.

Participants logged onto the *Bosom Buddies* web-site an average of 34 times (SD = 29, range = 3-122) during the intervention. They posted an average of 36 support group messages (SD = 38, range = 1-146). The personal journal feature was not regularly used. Out of 36 participants, only 14 participants posted at least once to their personal journal (M = 1.6, SD = 2.7).

The means and standard deviations for the intervention and WLC groups are presented in Table 2. Significant group differences, indicative of improvement in the intervention group, were found on the following measures: (1) CESD ($F(1,55) = 6.0$, $p < .01$) (C.I. WLC 13.3-18.6, Intervention 8.6-14.1); (2) PCL ($F(1,55) = 8.36$, $p < .01$) (C.I. WLC 30.8-36.6, Intervention 24.7-30.7); and, (3) PSS ($F(1,55) = 3.8$, $p < .05$) (C.I. WLC 13.8-17.4, Intervention 11.6-14.9). Nineteen intervention and 17 WLC group participants scored above the 16-point cut-off for depression on the CES-D at baseline, whereas at post-test 10 intervention group participants dropped below this cutoff in comparison to five WLC group participants (Wald (1)=.99, p=.321,n.s.).

Intention-to-Treat Analysis

Intention-to-treat analyses were also performed. Significant group differences were found on the following measures: (1) CESD ($F(1,72) = 4.3$, $p < .04$) (C.I. WLC 13.5-18.1, Intervention 10.1-14.7); (2) PCL ($F(1,72) = 8.42$, $p < .01$) (C.I. WLC 31.4-36.3, Intervention 26.4-31.3); and (3) PSS ($F(1,72) = 4.9$, $p < .03$) (C.I. WLC 14.3-17.3, Intervention 11.9-14.9).

Intervention Effect Sizes

The effect sizes for significant measures were as follows: CES-D (0.54), PCL (0.45) and PSS (0.38), indicating a medium effect size.[63]

Secondary Analysis

To determine if participation predicted outcome, Pearson correlations were run between change scores on the significant measures (CES-D, PCL and PSS) and the number of logins and support group postings. No correlations were found to be significant (range $r = -0.03$ to -0.19). The amount of time from participants' date of diagnosis with breast cancer to beginning the intervention was not significantly correlated with changes in the above measures (range $r = -0.20$ to 0.09)

Intervention group participants 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 participants reported feeling comfortable discussing sexual concerns with other group participants and modeling others' behaviors (Table 3).

Discussion

This study demonstrated that the web-based program, *Bosom Buddies*, was effective in reducing participants' scores on depression, perceived stress, and cancer-related trauma measures. The effect size of the intervention was in the moderate range. These values are comparable to those effects found in recent studies of face-to-face groups.[11, 64] Contrary to our expectations, no significant changes were found on self-report measures of anxiety, nor in general and specific aspects of coping with cancer. In general, participants actively used the intervention logging on almost three times a week and posting three messages a week although the range of participation was quite wide. In general, participants benefited from their experience with the Bosom Buddies intervention regardless of their participation rates.

The improvement in depression and reduction in perceived stress is consistent with other studies of face-to-face groups.[11, 65-66] It may be that the intervention worked because it created a forum where participants could reduce their social isolation. In the support group participants could freely discuss their concerns without fears of burdening their social support network, and it allowed participants to offer specific coping suggestions to one another. This is consistent with participants' evaluation of their group experience. Participants expressed a level of enthusiasm and concern for one another that was not captured by the self-report measures. For example, participants' interest in each others extended beyond their cancer concerns and included such things as sharing and delighting in each others' wedding anniversaries, birthdays and important family events. They also wrote about their unease when others did not post to the support group on a regular basis, asked the group moderator and researchers to contact "missing participants" on their behalf, and sent get well cards to participants who were hospitalized during the group. Some participants met following the end of the group and developed their own ongoing on-line support group. It appears that participants were able to form fulfilling supportive relationships in an asynchronous format although messages were often disjointed and the conversations could be difficult to follow.

It is unclear, however, why participants in the Bosom Buddies intervention improved their depression, perceived stress and cancer-related trauma scores and not other measures. A few studies using the STAI as an outcome measure in breast cancer patients have demonstrated a lessening of anxiety with short term interventions.[67-70] There is little evidence for a long-term impact. However, studies conducted with other patient populations have shown that a change in depression is usually accompanied by a change in anxiety. On the other hand, our intervention did not directly address anxiety management. Future groups should focus more directly on anxiety management as an important component of general well-being.

Likewise, the intervention did not lead to a change in the different measures of the Mini-MAC. Outcomes in other studies vary: Fukui et al., the first to address the impact of a 6-week psychological, face-to-face intervention on Japanese women with primary breast cancer,[13] found significantly higher scores on fighting spirit, one subscale of the MAC, at the end of the intervention. On the other hand, a study using relaxation training, guided imagery, and biofeedback with American breast cancer patients, could not demonstrate statistically different changes in the MAC, although fighting spirit had increased.[71] Subscales such as helplessness/hopelessness, anxious preoccupation, cognitive avoidance, and fatalism, may be too global and not concrete enough to be treatment-sensitive. Future interventions will include psychoeducation to address specific coping skills. The CBI has yet to be tested by other investigators to prove it an effective measure in assessing women's ability to cope with their illness.

Although it is likely that the intervention content did not adequately address coping styles and self-efficacy, it may be that these constructs are resistant to change by a psychosocial intervention. Rather than addressing coping skills training, Bosom Buddies focused on the psychosocial consequences of breast cancer.

Although many advantages to the delivery of web-based support groups over face-to-face groups have been identified, disadvantages exist as well. There are technology challenges to conducting web-based support groups. For instance, some participants had difficulty connecting to the web-page, which required personal instruction (e.g., telephone consultations) to resolve. However, considering that use of this technology was new to many of the participants, the participation rates were striking. Future groups may want to use a limited practice phase prior to the start of the group for those members who were identified as needing additional help.

The majority (61%) of intervention group participants did not use the online journal. Participants may have recognized the potential of the program to communicate with others, while using other media for taking notes for themselves or writing in a private journal. Three of our participants required hospital stays or absences due to illness and recovery from treatment. As noted above, participants expressed concern when others failed to log-on for some time without warning. In the future, protocols should be established to instruct participants on how to prepare others for their absence. Despite our attempts to guide the weekly discussions, participants wrote about topics that often did not adhere to our recommended topics, although how this affected the outcome is unknown. It is unclear how important the weekly content was to the group participants, although some participants provided feedback that the weekly themes helped them to consider topics they might not have considered otherwise, as well as providing useful guidance in discussing these topics.

The use of web-based interventions presents a number of ethical issues. One of the most important ethical issues is how the participants understood of the limits of moderator's role. In this intervention, participants were told prior to joining the study that the intervention was a psychoeducational support group. Participants were specifically advised that the intervention was not a form of psychotherapy nor was the intervention meant to serve as a substitute for psychotherapy. Although group members offered each other psychological advice, the group moderator refrained from doing so. The moderator also advised group members that she did not read messages on a daily basis and that group members should not expect to receive immediate or personal feedback from her. Developers of web-based interventions need to be very clear about the level of psychological care they will provide and how they will handle psychiatric emergencies if any arise during the course of the intervention.

The privacy of the participants represents a second important ethical issue. It is important to set clear expectations and guidelines for the participants. In this intervention, participants were instructed not to disclose any information they learned about group members to others or to allow friends and family members to access the web-site. At the same time, participants were advised of the limits of confidentiality in a web-based intervention. The *Bosom Buddies* site is password-protected and every effort is made to ensure the security of the system. However, despite the fact that it is unlikely that these sites would be of interest to "hackers," no Internet-connected system is completely secure. The potential exists that the site could be breached and private member data stolen. A more likely threat to the privacy of the group participants, however, is the security practices of the group members themselves. The *Bosom Buddies* participants engaged in a number of behaviors which could have violated their and other members' privacy, including choosing obvious passwords and failing to adequately protect their passwords. Finally, the use of the Internet to deliver the intervention makes it impossible to prevent the group members from allowing non-group members to view the web-site, read the postings of other members, or see other members' photographs. Of course, in a face-to-face group, there is nothing to prevent group members from making similar disclosures, but the nature of the web-based group makes doing so significantly easier. Participants should be reminded on a regular basis of the limitations of confidentiality and that, in some ways, they should treat their postings as potentially public documents. Manhal-Baugus,[72] Childress,[73] and Humphreys et al.[74] have reviewed the ethical issues involved in web-based interventions

This study adds to the growing literature on the benefits of various interventions for primary breast cancer patients, including the benefits of a brief, unstructured, supportive-expressive group therapy,[75-76] brief education-based groups,[66] and brief cognitive-behavioral groups.[77] Although the results of this trial are promising, more research is needed before this support group format can be recommended to women coping with a diagnosis of breast cancer. Several methodological limitations will need to be addressed by further research. Longer follow-up assessments are needed to determine whether the intervention effects are maintained. Medical diagnoses need to be confirmed by the review of the medical record and better tracking of additional psychosocial interventions used by participants is needed. Furthermore, because the sample size was relatively small and participants were highly educated, the intervention should be tested with a larger and more diverse population. We do not know how effective the intervention would have been with less educated or less affluent women.

Directions for future research include examining participant and component features such as group size, duration of the intervention, level of structure, specificity of cancer diagnosis, group moderator training and experience, psychoeducational content and coping skill training, possible treatment mediators, and comparisons between web-based and face-to-face group interventions.

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Table 1

Bosom Buddies Weekly Themes

Week	Topic
1	***Introduction:*** Participants are asked to introduce themselves by describing their illness and treatment, how they are doing now and what they hope to get from participating in the group. The moderator introduces herself and gives a perspective on what the group can offer to participants.
2	***Getting to know you:*** Participants are encouraged to ask each other questions in order to learn how to support and interact with each other, with a recommendation that they pay attention to the emotions participants post when they log in. Information is provided on how to understand painful emotions
3	***Difficult emotions:*** Participants are encouraged to tell the group and write in their journals about any difficult emotions they are experiencing and what they have done to cope with them.
4	***Medical team:*** Participants are asked to focus on their relationship with their medical team, discussing their successes and frustrations in working with their doctors. Recommendations are given for how to get more help from their medical team.

5 ***Uncertainty and helplessness***: Participants are asked to share any feelings of uncertainty and helplessness with each other, particularly fears of recurrence or fears about the future. Information is provided on why some people deny feelings of helplessness and strategies for coping with these feelings including prayer.

6 ***Self and body image:*** Participants are invited to share the impact breast cancer has had on how they feel about their bodies, the feelings they have about this and what they have done to accept changes to their physical features.

7 ***Romance and sexuality***: Participants are asked to share with the group how they feel about themselves as a sexual person, to discuss any changes they have noticed in their sexuality or with their partner since the diagnosis.

8 ***Family:*** The focus of this week's topic is on how cancer has affected participants' relationship with their families, the reactions of family members, talking to children about the illness, asking for help, and encouraging family members to seek support.

9 ***Friends:*** Participants are asked to share how their friends and co-workers reacted to their diagnosis and how it has affected these relationships. Suggestions are given for how to ask for help from friends and co-workers.

10 ***Fear of recurrence***: Participants are asked to think about and discuss their concerns and fears about a recurrence, how it may have already affected their lives and what they have done to cope with it.

11 ***Meaning of life:*** Participants are asked to reflect on how their priorities have changed as a result of the cancer. They are asked to write a mission statement---a statement to describe their overall purpose or direction for their lives.

12 ***Closure***: For the last week, participants are asked to reflect on what the group has meant to them, what they have gotten from the experience and to say goodbye to each other.

Table 2 Mean Scores and Analysis of Covariance Comparing Intervention and Control Groups for Women Who Completed Both Pre- and Post-Test Assessments

	Control Group N=36		**Intervention Group N=36**			
Measures	Pre M (SD)	Post M (SD)	Pre M (SD)	Post M (SD)	F	Effect Size
CESD	16.8 (9.9)	16.1 (10.4)	17.4 (11.0)	11.1 (7.4)	6.00**	0.54
PCL	33.1 (12.1)	33.4 (13.9)	32.5 (10.0)	27.9 (7.6)	8.36**	0.45
PSS	16.0 (7.4)	15.5 6.3)	16.4 (7.3)	13.2 (5.6)	3.88*	0.37
STAI	47.8 (12.7)	48.2 (10.5)	46.8 (11.2)	47.8 (12.7)	0.78	-0.05
Cancer Behavior Inventory						
Seeking Support	20.7 (5.5)	21.5 (4.8)	20.8 (5.3)	20.8 (5.2)	0.59	0.15
Seeking Understanding	13.8 (3.8)	13.8 (3.2)	14.5 (2.8)	14.1 (3.4)	0.03	0.11
Coping	11.9 (4.1)	12.7 (3.4)	12.3 (3.3)	13.0 (3.9)	0.19	0.04
Affect Regulation	15.8 (3.4)	15.7 (3.2)	16.6 (2.1)	16.3 (3.3)	0.08	0.07
Positive Attitude	20.2 (5.6)	19.8 (4.8)	20.0 (4.5)	21.0 (5.2)	0.40	-0.28
Activity / Independence	12.6 (4.0)	12.6 (3.7)	13.9 (3.5)	13.4 (4.0)	0.00	0.13
Mini-Mac						
Helpless / Hopeless	10.6 (3.4)	11.3 (3.5)	10.9 (4.2)	11.3 (3.5)	0.21	0.08
Anxious Preoccupation	20.1 (5.7)	19.4 (5.2)	20.5 (5.8)	19.8 (4.8)	0.90	0.0
Fighting Spirit	13.6 (2.5)	13.4 (1.7)	13.3 (2.6)	13.9 (1.7)	0.95	-0.32
Cognitive Avoidance	8.0 (2.8)	8.5 (2.7)	7.6 (3.0)	7.7 (2.6)	1.02	0.14
Fatalism	12.2 (0.7)	12.8 (0.5)	12.7 (0.7)	13.2 (0.5)	0.45	0.03

**p* < .05; ***p* < .01.

Table 3

Participants' Evaluation of Their Group Experience

Issue	**Percent reporting "a lot" or "great deal"**
Getting support and encouragement	65%
Helping others	56%
Learn problems are not unique	56%
Develop new friendships	63%
Get advice	55%
Express true feelings	65%
Model myself after group participants	30%
Confront difficult problems and fears	44%
Discuss sexual concerns	44%

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Evaluation of Automatic Text Analysis in an Internet Breast Cancer Support Group[1]

Georg W. Alpers, Andrew J. Winzelberg, Catherine Classen,
Heidi Roberts, Parvati Dev, Cheryl Koopman, and C. Barr Taylor

Behavioral Medicine Media Laboratory
Stanford University

Short title: Text Analysis in an Internet Breast Cancer Support Group

Address correspondence to: Georg W. Alpers, Biological and Clinical Psychology, Julius-Maximilians Universität Würzburg, Marcusstrasse 9-11, D-97070 Würzburg, Germany. Email: alpers@psychologie.uni-wuerzburg.de. Tel.: +49-931-312840. Fax.: +49-931-312733.

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Abstract

Although support groups for women with breast cancer are widely available on the Internet, little is known about the conversations that occur in these groups. As part of a pilot study evaluating a semi-structured moderated breast cancer support group (Bosom Buddies), we analyzed group members' postings using two different approaches: 1) human raters; and 2) Pennebaker and Francis' Linguistic Inquiry and Word Count software. The computer and human ratings were moderately correlated for most categories. This suggests that automated text analysis programs can validly depict patterns of communication when compared to human raters. Automated text analysis programs for describing patterns of communication in on-line discussions may serve as a useful tool for group moderators and researchers seeking to understand the discussions that occur in on-line groups.

Twelve percent of women are diagnosed with breast cancer at some time in their life [American Cancer Society, 1996]. Being diagnosed with breast cancer is typically a life-changing event that often leads to a number of significant concerns [Spencer et al., 1999]. Medical treatment for breast cancer is usually accompanied by social challenges, physical discomfort, and psychological distress and it has been shown that 80 % of breast cancer patients experience significant distress (anxiety, anger, depression, and/or loss of social support) during initial treatment [Hughes, 1982; Irvine, Brown, Crooks, Roberts, & Browne, 1991].

A number of studies have found that support groups improve patients' psychological well-being [Berglund, Bolund, Gustafsson, & Sjoden, 1994; Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Classen et al., 2001; Fawzy et al., 1990; Spiegel, Bloom, & Yalom, 1981; Telch & Telch, 1986] and group interventions may even prolong life expectancy [Fawzy et al., 1993; Spiegel, Bloom, Kraemer, & Gottheil, 1989]. Support groups are generally designed to enable women with breast cancer to express their emotions. This has been shown to be associated with less distress and a better health outlook than avoiding expression of their emotions [Classen, Koopman, Angell, & Spiegel, 1996; Stanton et al., 2000]. In this therapeutic process, the sharing of difficult emotions is thought to be of central importance.

While most support groups meet face-to-face it is obvious that such groups can also be formed on the Internet. An Internet support group is usually conducted by members writing messages to one another. There is an impressive body of research on the effects of writing about stressful life events including benefits ranging from coping with grief, to improvement of immunological indices [Esterling, L'Abate, Murray, & Pennebaker, 1999;

Klein & Boals, 2001; Pennebaker, Mayne, & Francis, 1997; Richards, Beal, Seagal, & Pennebaker, 2000]. Writing about positive events may also be helpful, as research has shown that writing about anticipated positive events is helpful for pessimistic HIV-infected women [Mann, 2001]. Moreover, certain characteristics of the writing may have a particularly beneficial effect. Greater health improvements have been found to be associated with using a higher proportion of positive emotion words relative to negative emotion words [Pennebaker, 1993] or with using a high number of positive emotion words and moderate amount of negative emotion words [Pennebaker et al., 1997; Pennebaker & Seagal, 1999]. Independently, the use of certain kinds of cognitive words (depicting causality, e.g.,"…because…" or indicating self-reflection, e.g., "…understand…") is also linked to health improvement [Pennebaker, 1993; Pennebaker et al., 1997; Pennebaker & Seagal, 1999]. This body of research suggests that women's written emotional expression in an on-line support group may contain important indicators of the benefits of participation.

Women with breast cancer frequently seek information and emotional support from on-line breast cancer groups [Lieberman & Russo, 2001]. A number of studies have examined computer-mediated support groups for breast cancer [Gustafson, Wise, McTavish, & Taylor, 1993; Sharf, 1997; Weinberg, Schmale, Uken, & Wessel, 1996; Weinberg, Uken, Schmale, & Adamek, 1995]. However, little is known about the processes involved in such groups. Because all messages posted to Internet groups can be saved and subjected to analysis, it is possible to examine whether particular linguistic patterns predict positive outcome. The present study was undertaken to explore the usefulness of computer-assisted text-analysis [see Popping, 2000; West, 2001] to describe the pattern of the communication in such groups.

To increase the efficiency and accuracy of a content analysis describing the pattern of communication in a group, a computerized text analysis procedure can be used. Text analysis programs have become widely used to analyze the content of communication and to make predictions regarding psychological adaptation or other measures of health. Compared with face-to-face interactions, the analysis of the exchange in computer-based groups has one major advantage. In online groups 100% of the communication is reflected in the written text (unlike face-to-face communication, where the meaning of a communication is reflected in both verbal and nonverbal cues such as body language or voice tone). Various computerized methods of text analysis are available [see reviews by Alexa & Zuell, 1999; M. Bauer, 2000; Popping, 2000] with their main application being the parsing of Web-site content [e.g., C. Bauer & Scharl, 2000]. Today, computers are routinely used in keyword-indexing of texts for retrieval in databases [for a review of human versus machine indexing see Anderson & Pérez-Carballo, 2001a, 2001b].

Pennebaker and Francis' software, the Linguistic Inquiry and Word Count [LIWC, Pennebaker & Francis, 1999; Pennebaker & Francis, 1996; Pennebaker, Francis, & Booth, 2001] is the most widely used program for analyzing text in clinical psychology. It was designed to map psychological and linguistic dimensions of written language. Although there is preliminary data for the external validity of most of its categories [Pennebaker & Francis, 1999; Pennebaker & Francis, 1996; Pennebaker et al., 2001; Pennebaker et al., 1997], LIWC has not been validated for capturing the discourse between individuals. Indeed, there are concerns about the ability of computer programs to analyze linguistic information in complex communications. For instance, the LIWC computer program does not take context into account, which is important for interpreting the meaning of the written communication.

To evaluate whether the LIWC approach of using simple word counts is a useful method for analyzing the content of the written communication in an Internet support group, we examined three types of validity: content validity, construct validity and concurrent validity. Content validity was examined by determining whether the LIWC ratings picked up the categories that expert judges consider relevant to an on-line support group for breast cancer patients. Construct validity was assessed by comparing the LIWC scores of the on-line support group with LIWC scores of newspaper articles and LIWC scores of Pennebaker's emotional writing tasks. We tested concurrent validity by comparing LIWC ratings of our on-line support group for breast cancer patients against ratings of the on-line support group generated by a human rater.

Method

On-line support group intervention. Bosom Buddies is a 12-week semi-structured and moderated group for women with primary breast cancer. A randomized wait-list control trial is ongoing. The overarching goal is to enable patients to obtain social support and to have a forum in which to express their emotions and to discuss issues related to coping with breast cancer. On a weekly schedule, members receive new content on a different topic (e.g., sexuality, communicating with health care providers) that is designed to trigger discussion in a newsgroup embedded in the Bosom Buddies website. However, members are not restricted to discussing the week's topic. A trained moderator, but not necessarily a licensed therapist, facilitates the discussion.

Participants. Participants were nine volunteers (eight Caucasian one African American) who had been diagnosed with primary breast cancer within the previous two years. Their mean age was 53 (SD = 7 years). All but one were married, one had a graduate degree, four some college, two a college degree, and one some graduate school. Participants accessed the Bosom Buddies website at their convenience, including all times of the day and night during the on-line support group. They posted messages to introduce themselves, reported on the progress of their treatment, engaged in discussions on the weekly topic and other topics they generated, and shared their experiences from everyday life.

Software. We used the Inquiry and Word Count software 2001 version [LIWC, Pennebaker & Francis, 1999; Pennebaker et al., 2001] to categorize the communication into relevant 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 more than one of the 64 pre-defined categories. Therefore, the cumulative percentages of words detected in several categories can exceed the percentage of detected words.

Procedure. Following completion of the support group, the postings to the newsgroup (in HTML format) were loaded into a text processor, header information was transferred to a spreadsheet, and typing errors were edited with Microsoft's Spellchecker. All postings were saved as ASCII text files. These files were then analyzed using LIWC.

First, we used the results to examine the program's content validity by examining the descriptive pattern of the conversation. The number of messages posted and the word count were taken as an indication of participant involvement in the group. 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 dictionary[2]), "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 Issues", "death", and "body". To depict the pattern of the exchange between the members of the support group we analyzed messages from the patients only (excluding those provided by the moderator).

To assess construct validity, we compared the LIWC scores of our messages to the average values obtained from the program's authors using different writing instructions (emotional vs. control writing). So far, these scores provide the only *standard* for a direct interpretation of the program's output. However, because Pennebaker and Francis' numbers do not represent general population norms, we also chose other texts lending themselves for a reasonable comparison. For comparison we chose two New York Times newspaper articles on breast cancer. One has a technical focus on the genetics of breast cancer [Grady,

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[2] 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).

May 2, 2000]. Its profile was assumed to be very different from the profile of the communication in the newsgroup. The other is on the effects of a "fighting spirit" in breast cancer patients [Goode, October 19, 1999] and in addressing emotional issues it was assumed to have a more similar pattern to our texts.

The concurrent validity of the software scores was tested in a direct comparison with an external criterion. One hundred messages (with a mean of 125 words, SD = 148, ranging from 1 to 752 words) were randomly selected out of the 521 messages posted and rated by both human raters and LIWC. The messages were rated on several categories that are of interest to the study of support groups, several of which partially overlapped with the 25 LIWC categories describing psychological processes. The categories we compared are listed in Table 1.

INSERT Table 1 ABOUT HERE

The categories for the human raters were defined by detailed coding rules (for a brief summary see Table 1). The content of a given message was rated on how much it was characterized by each category on a scale from “0” ("none") to “3” ("a lot"). The rater was first trained on a set of other messages selected from the group’s postings. After we refined the rating system, we evaluated inter-rater reliability between the main rater (HR) and our lead author (GA). Correlations were calculated between the human ratings and LIWC scores and tested for significance. It was hypothesized that the global scores "Positive Emotions," "Positive Feelings," and "Negative Emotions" would correlate more highly with the human ratings for these categories because they included several sub-categories and were expected to be more reliable. Furthermore, we hypothesized that the LIWC category “Social Issues” may reflect the processes most relevant to our support group, namely asking for support and providing support, and thus we expected this LIWC category to be correlated with the judges ratings of "providing support." In addition, we expected a correlation between LIWC scores for the category "Body" and the judge's ratings of our category "Medical Aspects of Cancer".

Results

Descriptive statistics. The participants and the moderator posted a total of 521 messages during the course of the intervention. Individual participants composed a mean of 4.6 messages per week (range 2.4 - 7.9). The messages were of varying length (range 1-915) with an average of 126 words per message. Shorter messages during some weeks were compensated for by increased numbers of posted messages (see Figure 1) so that the total number of words per week was generally between 5,000 and 7,000 words.

INSERT Figure 1 ABOUT HERE

All but one participant participated regularly in the newsgroup. An exemplary posting is shown in

Table 2. It was written in week 2 and followed a series of messages discussing how group members reacted to being diagnosed with breast cancer.

INSERT Table 2 ABOUT HERE

Text Analysis. The LIWC dictionary captured 80.3 % of the words in the messages posted to the news group. Our added category "Medical Aspects of Cancer," captured an additional 3% of words.

LIWC "standard". Figure 2 shows a comparison of the profile we found compared with numbers given by the program's authors for analyses of texts written under different instructions.

INSERT Figure 2 ABOUT HERE

Visual inspection suggests that the Bosom Buddies pilot group's pattern is most similar to the pattern of the "emotional texts". In both of these kinds of texts, more words were counted in the category cognitive words (e.g., "cause", "know", "ought"), and social processes (e.g., "talk", "us", "friend") than in the "neutral" texts. Of note, there is a greater proportion of Positive Emotion words expressed in the Internet breast cancer support group than obtained using Pennebaker's emotional writing conditions. The focus of our group on breast cancer may be reflected in the somewhat increased frequency of words referring to the body.

Newspaper articles. The comparison of the LIWC analysis of the text of the Bosom Buddies pilot group with the two newspaper articles on breast cancer is depicted in Figure 2. Visual inspection provides some evidence for the specificity of this text analysis program. The one with a technical focus on the genetics of breast cancer has a different profile [Grady, May 2, 2000] in featuring a much smaller percentage of emotional words but a similar profile in the percentage of words referring to cognitive processes. The New York Times article on the "fighting spirit" in breast cancer [Goode, October 19, 1999] contained a greater percentage of Negative Emotion words than did the messages written by the women in our group.

Concurrent validity. The LIWC scores correlated significantly with the corresponding categories in the ratings done by the human reader for Negatively Valenced

Concepts (Spearman r=0.52; see the category descriptions and corresponding LIWC categories in Table 1), Sadness (r=0.45), Positively Valenced Concepts (r=0.37), and Cognitive Mechanisms (r=0.31), (all p <= 0.01). The correlation for Anger (r=0.24) and Positive Feelings (r=0.23) were small but significant (p=0.02). The LIWC computer scores for Anxiety were not significantly correlated with the corresponding ratings by the judge (r=0.17, p=0.08) or with Optimism (r=0.11, p=0.27). The LIWC category of "Body" was significantly correlated with the judge's ratings of Medical Aspects of Cancer (r=0.34, p <= 0.01) and the LIWC ratings of Social Issues were correlated with the judge's ratings for Providing Support (r=0.36, p <= 0.01).

INSERT Figure 3 ABOUT HERE

The inter-rater reliabilities of the human judges' ratings are also depicted in Figure 3.

Discussion

We view the results of this study as an encouraging first step in automated text analysis of Internet delivered support groups. The results suggest that it is possible to use a computer program to capture patterns of discourse that occur on Internet support groups. Although the correlations between human and computer raters are low to moderate in magnitude, they are in the right direction. Our results also indicate specific areas where further development is needed. In examining the validity of the Pennebaker system, we first looked at the distribution of words. As predicted [Pennebaker et al., 2001], LIWC captured the majority of the words in the Bosom Buddies messages. Thus, the LIWC dictionary appears capable of categorizing words written in our support group, despite this being very different from the program's original application of expressive writing about stressful experiences, mostly in student samples. We took this as evidence of its content validity.

We based our analyses on the material form participants that got involved in and contributed regularly to the group's discussion. The number of messages varied across the weeks but the number of words per week remained almost stable (between 5000 and 7000 words per week). The distribution of word categories for the on-line support group was similar to the normative data ("standard") on texts written under the instruction to report on emotional experiences reported by the program's authors [Pennebaker & Francis, 1999; Pennebaker et al., 2001]. With the one notable exception of Positive Emotions the two distributions differed by less than 2%. In the case of Positive Emotions, the differences were still only about 2.5%. On the other hand, the distributions of words written by our sample showed more differences to the normative data on non-emotional texts (typically descriptions of locations or everyday procedures), for which three categories differed by more than 3%. This provides some evidence for construct validity for applying the LIWC system to an on-line support group. Similarly, we found that the analysis of the on-line group yielded similar results to that of an article in the *New York Times* on "fighting spirit" for women with breast cancer. In this comparison, only one category differed by more than 2% (negative emotions.). Furthermore, an article on genetic issues related to breast cancer generated a very different profile. We expected the words written in the on-line group to be categorized more similarly to published text on “fighting spirit” in women with breast cancer than to a published text on scientific aspects of genetics related to breast cancer. Therefore, the results of these comparisons provide further construct validity to the text analysis. However, the different overall size of percentages between the categories is quite similar for different kinds of messages. For example, the categories Social Issues and Cognitive Mechanisms are frequent in all texts relative to some of the specific emotion categories. This is either due to basic linguistic properties of written text (some words are used frequently, some concepts may generally be described with fewer words than others) or properties of the LIWC dictionary (different number of words in the categories).

As a test of concurrent validity, we compared agreement between LIWC and human raters. The correlation coefficients found between ratings of LIWC and by human raters were in the range of $r = 0.12$ to $r = 0.53$, somewhat lower than the inter-rater correlations between our two human raters (range $r=0.47$ to $r=0.9$). The strongest correlations found between LIWC and human raters were for the categories of Negative Emotions, Sadness, Positive Emotions, Providing Support (Social Issues), and Medical Aspects of Cancer (Body). The weakest correlations were found for Anger, Anxiety, Positive Feelings (Positive feelings is a subset of Positive Emotion words). The different categories are broader or more narrowly defined and the LIWC dictionary has different numbers of words for different categories. For example, positive emotions category has 261 words whereas the positive feelings category has 43 words and Optimism 69. The rather specific categories Positive Feelings and Optimism had no concurrent validity although the reliability of human ratings was high for these categories. Even categories that are not explicitly covered by the dictionary, like Providing Support and Medical Aspects of Cancer, can be approximated by word counts of related LIWC categories.

The correlation coefficients found between computer generated frequencies of categories and ratings by human raters are generally lower than the Pearson productmoment correlations between LIWC and human rater's scores reported by the program's authors for the pooled analysis of essays in which the instructions were either to describe a stressful personal experience or to write about something neutral (Pennebaker range r=0.37 to r=0.75, our range r=0.12 to r=0.53). However, the magnitudes of our study correlation coefficients are similar to the average correlations found in more homogeneous samples of text in which Pennebaker and Francis analyzed the essays written under different instructions separately (range r=0.22 to r=0.41). The low to moderate correlations may partly be due to our conceptualization that restricted our human raters to coding Positive Emotions as present only when the writer appeared to describe positive emotional states, whereas the LIWC program coded positive words that did not necessarily refer to the writer's emotional state. Our correlations may have been further attenuated by low reliability of the human ratings. Low to moderate correlations should not be neglected, because higher correlations are rarely found between two different measures of the same construct and they resemble the size of correlations found between many well established connections in natural and social sciences [Meyer et al., 2001].

In theory, the categories that are most important to examine are those that Pennebaker and his colleagues have shown to have predictive validity. They have demonstrated that greater expression of words in the Positive Emotions category, as coded by LIWC, was associated with more positive outcomes. The low to moderate correlation found between the human raters and the LIWC program scores in the on-line support group raises the question of which coding method will be the better predictor of outcome. If there were a difference in predictive power, the source of differences would merit exploration. Another category that Pennebaker has found to be related to outcome is that of Negative

Emotions. They found an interesting U-shaped relationship between negative emotions and outcome. Here, the human and automatic texts were well correlated. Therefore, computer ratings might be satisfactory in tracking changes in expression of negative emotions in on-line groups. If so, the LIWC would offer an important tool to help with group process.

We did not report on changes in the percent of negative emotions over the course of the group because this could be an artifact of what we asked participants to discuss. Recall that in the first few weeks we ask members to talk about painful feelings. In future studies, we will examine the relationship of change in such negative emotions with change in the psychosocial indicators that are utilized to evaluate group outcomes.

Overall, it is likely that the low correlations between LIWC and human raters are partly due to human raters' taking context into account while LIWC ignores context. For example if a group member wrote about how angry a co-worker was about a lost contract, the use of LIWC would appropriately identify anger but would fail to consider the source and personal relevance. However, computer programs can be developed to search for words in a specific context of other terms [see, for example, Anderson & Pérez-Carballo, 2001b]. In the near future, this will most likely increase human-computer agreement. So far, our method is more likely to reflect the patients' self-report of how they felt or what they wanted to express.

Perhaps more sophisticated natural language processing software programs than LIWC will be able to help identify different patterns of text and group member interactions that unfold over time. These programs may be able to clearly identify for group moderators' messages that need personal review, such as potentially harmful patterns of interaction (rather than present percentages of words in pre-defined categories). Using computers for such a task has great potential for improving the effectiveness and ease of moderating groups because keeping track of the many postings is a challenging and time consuming task. A reason for automated text analysis is to be able to provide more cost-effective groups.

The analysis of such patterns has been shown to be useful with respect to news-reports and the prediction of political conflict [Jenkins & Bond, 2001]. Also, such programs will be more readily applicable if they require little or no text preparation before the text can be analyzed. In contrast, LIWC requires spell checking using other software and the stripping of extraneous author identifying text prior to its use in categorizing words. However, the program's simplicity makes it a user-friendly tool which can be easily modified by inclusion of new words or categories to serve specific research or possibly clinical purposes. However, a new list of words like our Cancer words need to be cross-checked on a different sample of messages.

Limitations of this validity study are that we collected data in the specific setting of a single breast cancer support group for women who may have a specific way of expressing themselves in writing. Also, the instructions for the written communication were not specific, with participants encouraged to write about any topic they chose. The length of the message was not standardized either, but varied widely. However, given that the percentage of detected words corresponds with the average rate found in a large number of studies reported by the program's authors, the program seemed to fairly well describe the dimensions of linguistic discourse of the group that were examined in this study. Future research should be conducted with other Internet support groups for women with breast cancer to determine the generalizability of these results. Furthermore, such research should include women of diverse cultural and social class backgrounds to determine whether the profile characterizing the group discourse varies by such characteristics.

The results of this study provide some evidence for the validity of the LIWC as a method for analyzing on-line support groups. Despite its limitations, use of LIWC in further research of on-line cancer support groups is warranted. Such research will be useful in contributing to our understanding of what occurs in these groups and how this relates to outcome. As a prerequisite step, it will first be important to demonstrate in randomized clinical trials the benefits of Internet-delivered breast cancer support groups. Once the patterns of text postings to such groups are better understood, real-time categorical data on individual members and group discourse patterns may provide moderators with useful information to guide the facilitation process. For example, understanding of typical group discussion patterns may allow moderators to offer new members guidelines for maximizing the benefit they receive from their participation. Also, for ongoing groups, such understanding may lead moderators to intervene when indicated by postings to suggest to group members that they focus on expressing positive emotions or reflect on the meaning of their experiences if this is found to result in positive changes. Research using LIWC and more advanced text analysis software programs has great potential to improve on-line support group interventions for helping cancer patients.

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Table 1: LIWC categories which were compared with human ratings.

Selected LIWC categories Method: Word count, percentage of words.	Categories for the human rater Method: Impression of emotion expressed by the author.
Word Count: Number of words in each message.	-
Words Recognized: Percentage of words found in the internal dictionary.	-
First person singular: A linguistic category; counting words like "I", "my", "me".	-
First person plural: "we", "our", "us"	-
Positive Emotions[1]: A broad category with words related to positively valenced concepts. Example words are "happy", "pretty", "good".	Positively valenced concepts: This is a broad category that includes **all positive** emotions and *all* expression referring to things or events with a **positive psychological value** (positively valenced). All positive affective states, all positive communication. But only the writer's expression/description of her **own personal experience.**
Positive Feelings: Counting words that are included in the Positive Emotions list, but refer more specifically to emotions. Examples are "happy", "joy", "love".	Positive feelings: Sub-category of positive concepts. Only explicitly described positive emotional states or reactions, **positive emotions**. Not only the description of positive events but there evaluation is to be considered. Interpreted within the **context.** But avoid to interpret/infer beyond things that are said explicitly. Coded only for the writer's expression/description of her **own personal experience**.
Optimism: A sub-categroy of Positive Emotions: "certainty", "pride", "win".	Optimism: Sub-category of **positive concepts.** Only explicitly described **emotions.** Not only positive events but their optimistic evaluation. The American Heritage Dictionary defines optimism as: "To expect the best possible outcome or to dwell upon the most hopeful aspects." Optimism can be coded for positive expectations for anytime in the future, including within the next day or two. Interpreted within the **context.** But avoid to interpret/infer beyond things that are said explicitly. Coded only for the writer's expression/description of her own personal experience. But if the writer is describing a positive expectation regarding a group that she is identifying with in her statement, this is optimism.
Negative Emotions[1]: A broad category of negatively valenced concepts like "hate", "worthless", "enemy".	Negatively valencedconcepts: This is a broad category that includes **all negative** emotions and *all* expressions or statements referring to things or events with **negative psychological value** (negatively valenced). All negative affect; all negative communication. Coded only for the writer's expression/description of her **own personal experience.**
Anxiety or Fear: A sub-category of negative emotions;	Anxiety and Fear: Sub-category of **negative concepts**. Only explicitly described emotions. Not scary news but its evaluation as

"nervous", "afraid", "tense".	threatening, worrisome, or alarming. Interpreted within the **context.** But avoid to interpret/infer beyond things that are said explicitly. Coded only for the writer's expression/description of her own personal experience.
Anger: A sub-category of negative emotions; "hate", "kill", "pissed".	Anger: Sub-category of **negative concepts**. Only explicitly described emotions. Interpreted within the **context.** But avoid to interpret/infer beyond things that are said explicitly. Coded only for the writer's expression/description of her own personal experience.
Sadness or Depression: A sub-category of negative emotions; "grief", "cry", "sad".	Sadness or Depression: Sub-category of **negative concepts**. Only explicitly described emotions. Not only difficult situation but its evaluation as sad, depressing or hopeless. Interpreted within the **context.** But avoid to interpret/infer beyond things that are said explicitly. Coded only for the writer's expression/description of her own personal experience.
Social: "talk", "us", "friend".	Providing support: Code if writer is **encouraging** other members, giving **advice**, providing **information**, supporting by **reinforcement**. Advice which is obviously given with good intentions is to be coded as "providing support" even if the rater thinks that this may not be the best advice (e.g., someone advising to avoid a certain situation instead of dealing with it in a more constructive manner.) Not only understanding and reflection of other's statements (that is empathy).
Cognitive Mechanisms: A psychological category distinct from emotional processes; "cause", "know", "ought".	Cognitive Processes: This category is not a sub-category of anything explained above. Thinking, understanding, expression of insight, reflection are coded here. This category does NOT include asking for information, insights, or understanding from other persons. This category does NOT indicate active listening to others' communications, but is about one's own thoughts or thinking processes. Coded only for the writer's expression/description of her own personal experience.
Body states, symptoms: A sub-category of Physical States and Functions (not analyzed here). Includes words like "ache", "heart", "cough".	Medical Aspects of Cancer: This category is specifically about the **medical** aspects of cancer. To qualify as relevant to this code, the speaker must make **explicit** reference to specific cancer **symptoms,** medical **diagnosis** of cancer or **treatment** (e.g., chemotherapy, hormonal therapy, radiation, surgery, or reconstruction), or side effects of treatment (e.g., allopecia (hair loss), nausea). It also includes symptoms and treatments of **other patients**, not only the speaker's. **Not** general mood or bodily states like fatigue, not other medical treatments like UTI or family's health if not cancer related.

[1] Although now more general the label was maintained from older versions for "historical" reasons (Pennebaker, personal communication).

Table 2: Example Message.

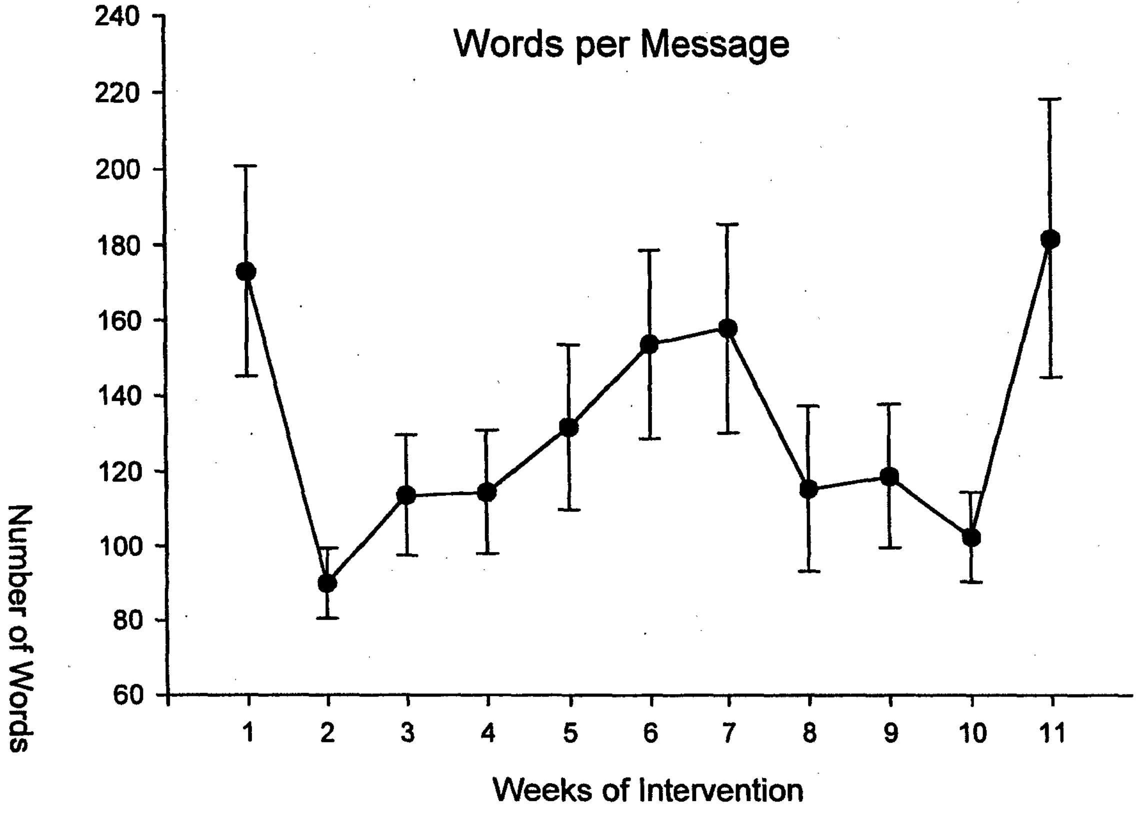
Example Message
Thanks for the nice posting. Of course it brought tears to my eyes! You're right, I don't think the tears are so much for me (feeling sorry for myself), but for other things. My emotions are just heightened to the point where everything has a much bigger impact than before. I'll just have to remember to always have my packet of Kleenex with me! I am concerned though about how it affects those around me when they see my tears. One acquaintance thought the tears were from depression and I don't think so. Maybe I am denying depression? There is a big difference in my mind in depression and sadness.

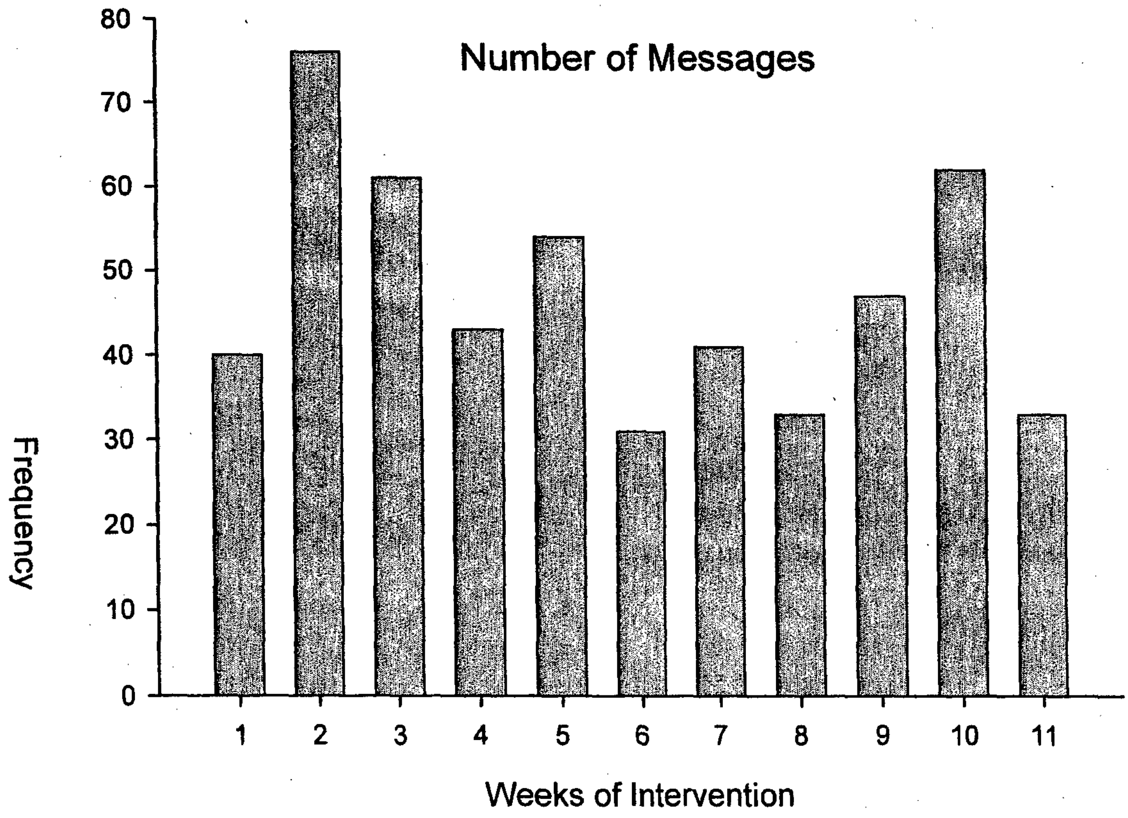
Figure legends

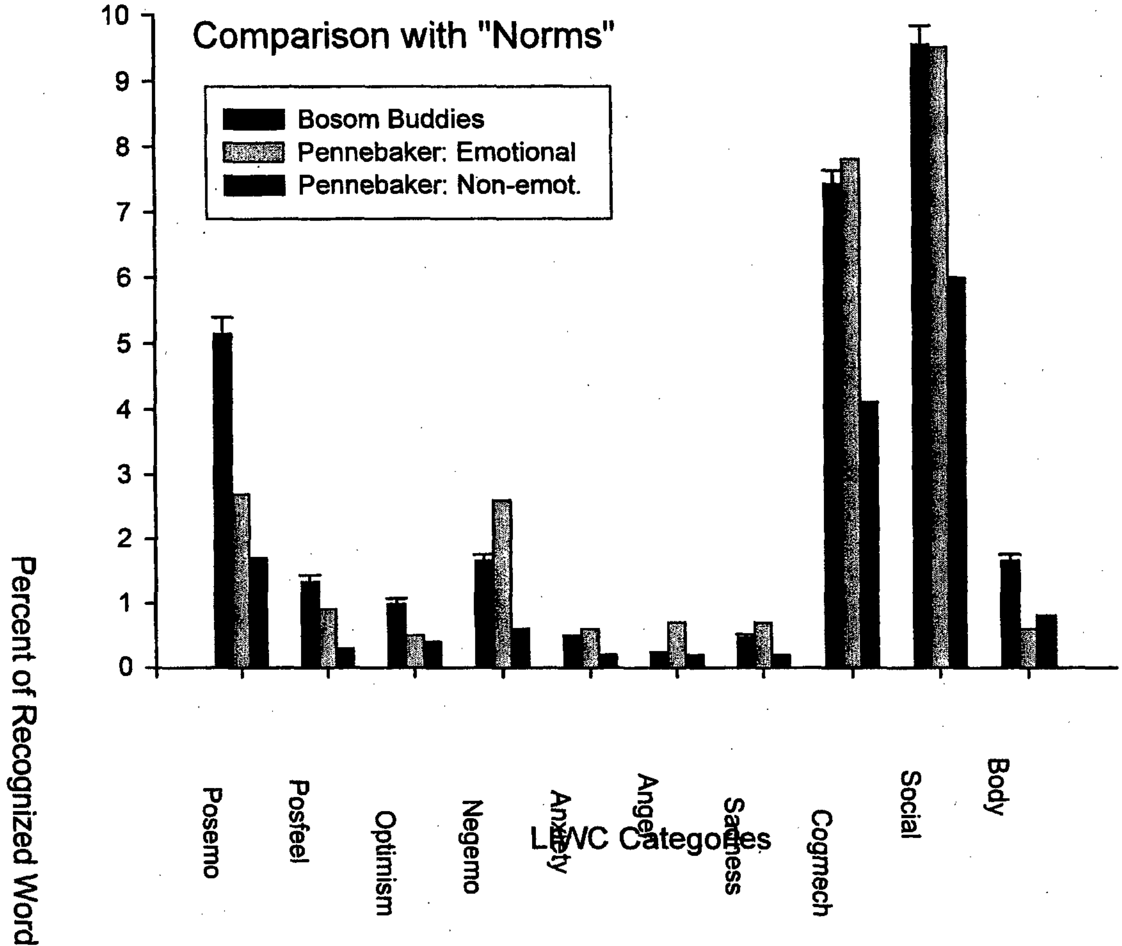
Figure 1: Number of words per message and standard errors (upper panel) and number of messages per week (lower panel) posted to the Internet support group.

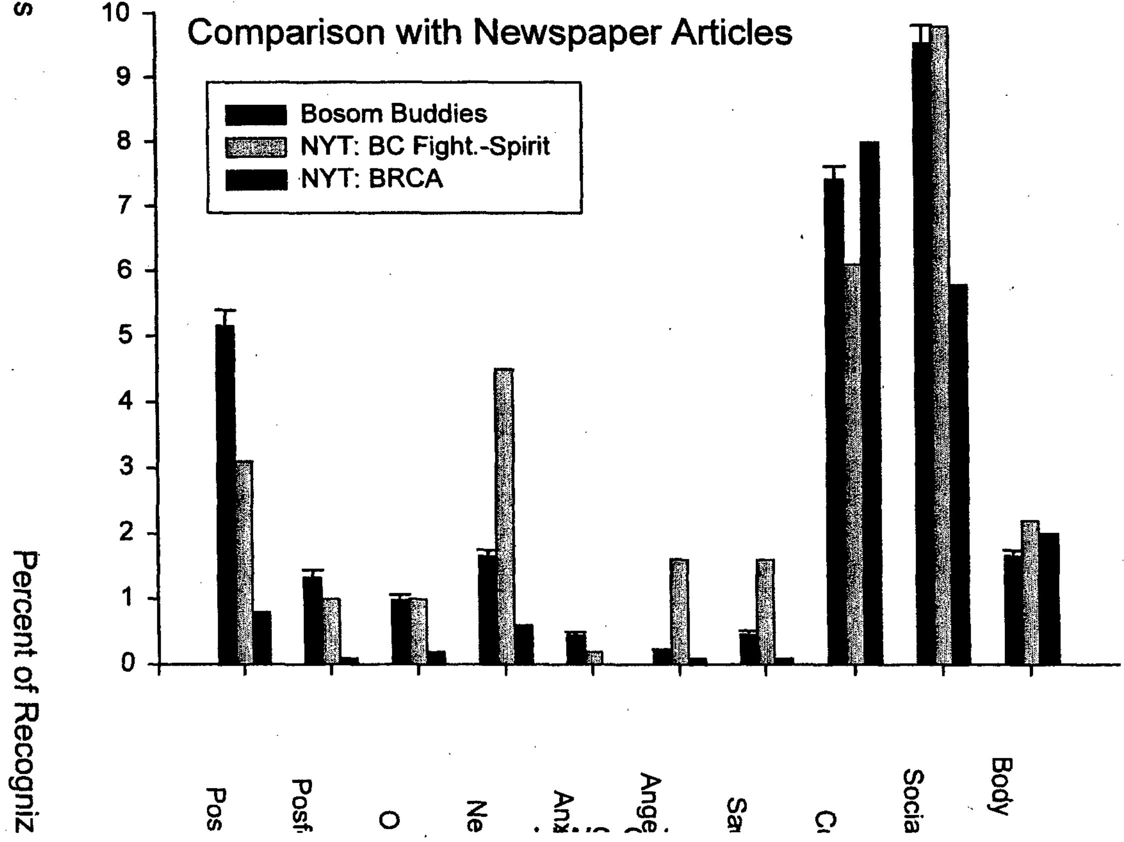
Figure 2: LIWC categories profile in participants' messages and in standards listed by the program's authors (upper panel). LIWC categories profile and profiles from two different newspaper articles on breast cancer (lower panel). One articles focuses on biological aspects (the gene BRCA), the other on emotional aspects of the disease ("fighting spirit").

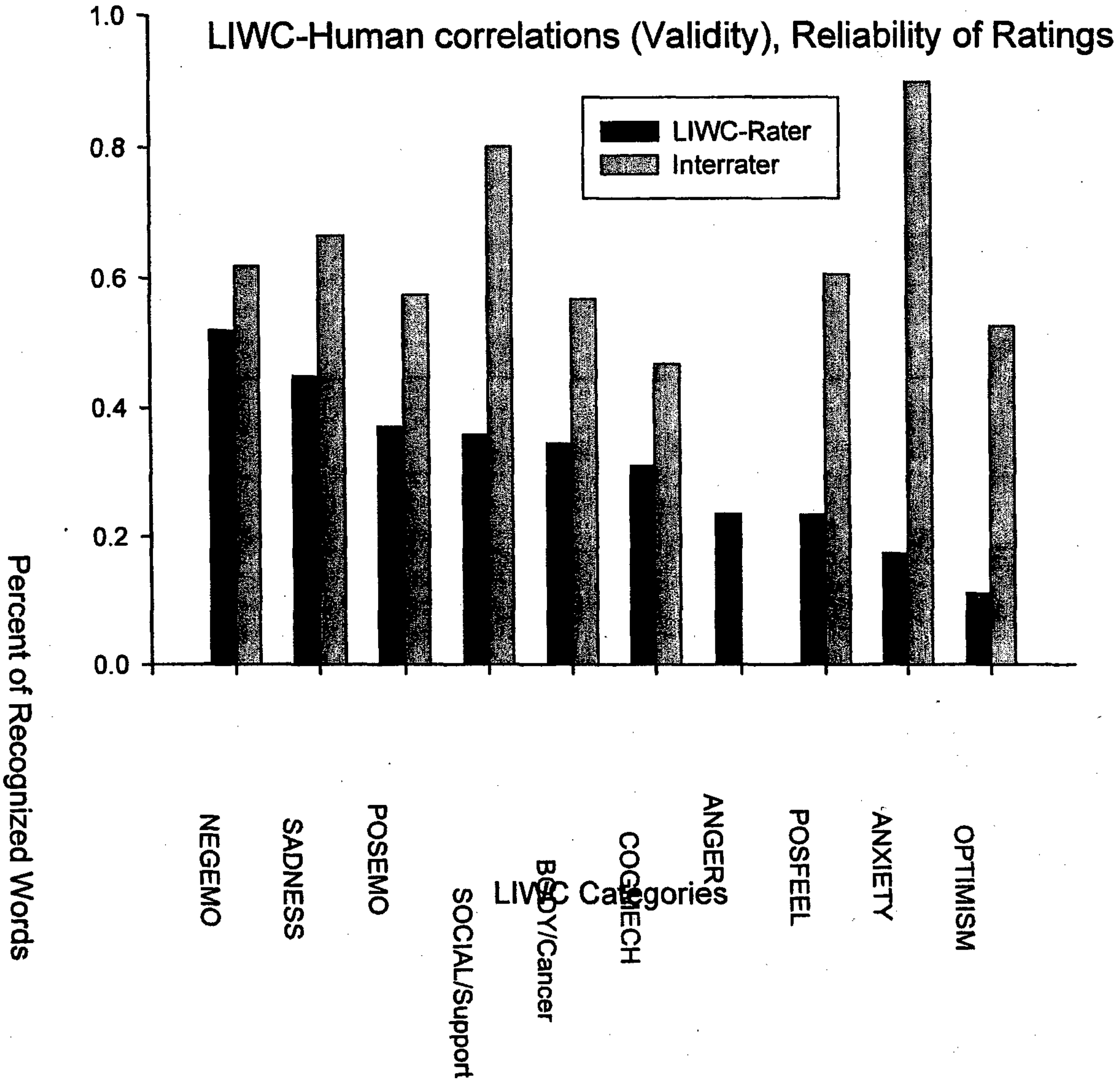
Figure 3: Correlation of LIWC word count scores and human judge's ratings (LIWC-rater). The categories are sorted by magnitude of correlation. The correlations of ratings from two different judges are also presented for each category (interrater).


Words per Message
Number of Words
240
220
200
180
160
140
120
100
80
60
1
2
3
4
5
6
7
8
9
10
11
Weeks of Intervention


Number of Messages
Frequency
80
70
60
50
40
30
20
10
0
1
2
3
4
5
6
7
8
9
10
11
Weeks of Intervention


Comparison with "Norms"


Comparison with Newspaper Articles


LIWC-Human correlations (Validity), Reliability of Ratings
LIWC-Rater
Interrater
1.0
0.8
0.6
0.4
0.2
0.0
Percent of Recognized Words
NEGEMO
SADNESS
POSEMO
SOCIAL/Support
BODY/Cancer
COGMECH
ANGER
POSFEEL
ANXIETY
OPTIMISM
LIWC Categories

1 Internet-Gruppen für Brustkrebspatientinnen

Georg W. Alpers, Andrew J. Winzelberg & C. Barr Taylor

Behavioral Medicine Media Laboratory[1]
Stanford University School of Medicine

Brustkrebs ist die häufigste Krebserkrankung bei Frauen. Bei einer von acht Frauen wird im Laufe ihres Lebens Brustkrebs diagnostiziert (American Cancer Society, 2001). Die Diagnose Brustkrebs bringt für betroffene Frauen enorme Belastungen mit sich. Inzwischen ist in mehreren Studien gezeigt worden, dass die Bewältigung dieser Stressoren durch psychosoziale Interventionen erleichtert werden kann. Während die Teilnahme an konventionellen Gruppen mit persönlichem Kontakt ("face-to-face") für Krebspatienten of schwierig ist, scheint das Internet eine geeignete Plattform für das Angebot von unterstützenden Gruppen zu sein.

In diesem Kapitel berichten wir über die verschiedenen Möglichkeiten, die positiven Erfahrungen mit konventionellen Gruppen auf Begegnungen im Internet zu übertragen. Als Beispiel wird ein Gruppenprogramm vorgestellt ("Bosom Buddies"), das wir im Behavioral Medicine Media Laboratory der Stanford School of Medicine entwickelt und in einer kontrollierten Studie erprobt haben. Darüber hinaus geben wir ein Beispiel dafür, dass bei Internet-Gruppen besondere Forschungsansätze eingesetzt werden können.

1.1 Psychische Belastung durch Brustkrebsdiagnose

Im Gegensatz zu vielen anderen medizinischen Diagnosen, bei denen die Patienten den Arzt mit einem starken Leidensdruck aufsuchen (z.B. wegen Schmerzen), geht der Diagnose Brustkrebs meist kein subjektives Leiden voraus. Dies ist nur der Fall, wenn die Diagnose erst in einem sehr weit fortgeschrittenen Stadium erfolgt. Setzt die Behandlung ein, beginnt damit also auch keine Linderung vorherigen Leidens. Im Gegenteil, es entstehen im Verlauf der Behandlung typischer Weise erhebliche körperliche und psychosoziale Belastungen. Dies hängt vor allem mit den extremen Nebenwirkungen zusammen, die die üblichen medizinischen Interventionen mit sich bringen. Die Diagnose Brustkrebs ist ein kritisches Lebensereignis, das eine Reihe ernster Sorgen mit sich bringt (Spencer et al., 1999).

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[1] Dieses Kapitel basiert auf Arbeiten, die in Zusammenarbeit mit Catherine Classen, Parvati Dev, Cheryl Koopman, Heidi Roberts und Rob Adams durchgeführt wurden. Zum Teil wurden diese Arbeiten vom US Department of the Army (grant # DAMD17-99-1-9387) finanziel gefördert.

1.1.1 Psychosoziale Probleme

Achtzig Prozent der Brustkrebspatientinnen berichten, dass sie zu Beginn der Behandlung unter bedeutsamen psychosozialen Belastungen leiden (Badger, Braden, Longman, & Mishel, 1999; Hughes, 1982; Irvine, Brown, Crooks, Roberts, & Browne, 1991). Diese Belastungen haben unter anderem damit zu tun, dass die Patientinnen sich vor dem erneutem Auftreten von Karzinomen fürchten (Koocher & O'Malley, 1981.; Mahon, Cella, & Donovan, 1990; Quigley, 1989; Rieker, Edbril, & Garnick, 1985), unter sexuellen Funktionsstörungen leiden (Maguire et al., 1978; Zarcone, Smithline, Koopman C, Kraemer H, & Spiegel, 1995) und häufig auch Einschränkungen ihrer Freizeitaktivitäten hinnehmen müssen (Tross & Holland, 1990).

1.2 Effekte von Gruppen

Neuere Forschungsergebnisse legen nahe, dass Interventionen, die Patientinnen helfen, die zahlreichen Herausforderungen zu bewältigen, die Lebensqualität deutlich verbessern können. So kann die gesteigerte Inanspruchnahme von sozialer Unterstützung die negative Stimmung in belastenden Zeiten verbessern oder sogar abwehren (Cohen, 1988; House, Robbins, & Metzner, 1982; Kessler & McLeod, 1985; Turner, 1983).

Gerade die krebsbedingten Beeinträchtigungen bringen aber Veränderungen der Lebensführung mit sich, die Sozialkontakte eher einschränken als steigern. Als typische Beispiele sind häufige Arztbesuche, ein gesteigertes Ruhebedürfnis und vielen Fällen eine Krankschreibung von der Arbeit zu nennen. Bei Krebspatienten schlägt sich diese Reduzierung der Sozialkontakte darin nieder, dass sie weniger soziale Unterstützung erfahren (Bloom & Spiegel, 1984). Die Befürchtungen und Unsicherheiten vieler Mitmenschen der Betroffenen tragen oft zur Verschlimmerung dieser Problematik bei (Peters-Golden, 1982; Wortman & Dunkel-Schetter, 1987). Insgesamt reduziert das einschneidende Lebensereignis der Krebsdiagnose damit die soziale Unterstützung, die für die Bewältigungsleistung der Patientinnen förderlich wäre.

1.2.1 Soziale Unterstützung in Gruppen

Während bislang die Betroffen oft gänzlich auf sich selbst gestellt waren, nehmen inzwischen viele Frauen an unterstützenden Gruppen teil, um Hilfe bei der Bewältigung ihrer Erkrankung zu bekommen (Cella & Yellen, 1993; Davison, Pennebaker, & Dickerson, 2000; Fawzy, Fawzy, Arndt, & Pasnau, 1995; Trijsburg, van Knippenberg, & Rijpma, 1992). Die Aufmerksamkeit der Kliniker für die Bedeutung von unterstützenden Gruppen wurde von engagierten Patienten selbst geweckt. Einer der Begründer dieser Forschungsarbeit berichtet darüber in einem belletristisch verarbeiteten Erfahrungsbericht (Yalom, 1999). Die Initiative basierte auf der Überzeugung von engagierten Patientinnen, dass sie von den Erfahrungen anderer Betroffener profitieren könnten und gemeinsam viele der Belastungen besser bewältigen könnten.

Die positiven Effekte solcher Gruppen auf die Reduzierung der psychischen Belastung und des Schmerzes sowie eine Verbesserung der Lebensqualität konnten in mehreren kontrollierten Studien nachgewiesen werden (Berglund, Bolund, Gustafsson, & Sjoden, 1994; Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Classen et al., 2001; Fawzy et al., 1993; Spiegel & Bloom, 1983; Spiegel, Bloom, & Yalom, 1981; Trijsburg et al., 1992). Darüber hinaus liegen einige Berichte über den erfolgreichen Einsatz solcher Gruppen in der Regelversorgung von Krebspatientinnen vor (Gray et al., 1998; Helgeson, Cohen, Schulz, & Yasko, 2000; McLean, 1995; Taylor, Falke, Shoptaw, & Lichtman, 1986). Obwohl demnach einige Hinweise auf die Wirksamkeit solcher Gruppen vorliegen, sind nicht alle Befunde gleichermaßen positiv (Edmonds, Lockwood, & Cunningham, 1999; Morgenstern, Gellert, Walter, Ostfeld, & Siegel, 1984)

Der beeindruckendste Befund ist vielleicht die gesteigerte Lebenserwartung der Teilnehmerinnen an Gruppen, die in einigen Studien gefunden wurde (Fawzy et al., 1993; Spiegel, Bloom, Kraemer, & Gottheil, 1989). Auch dieses Ergebnis ist jedoch nicht immer repliziert worden (Edelman, Craig, & Kidman, 2000; Goodwin et al., 2001).

Es wird allgemein vermutet, dass den positiven Effekten die erfahrene soziale Unterstützung und die Möglichkeit zum Verbalisieren belastender Emotionen zugrunde liegen. Dieser Zusammenhang zwischen dem Verbalisieren von Emotionen und weniger Leiden beziehungsweise gesteigerter Zuversicht für die gesundheitliche Besserung im Gegensatz zur Vermeidung von Emotionsausdruck ließ sich mehrfach belegen (Classen, Koopman, Angell, & Spiegel, 1996; Stanton et al., 2000).

1.2.2 Ausdruck von Emotionen

Es liegt inzwischen eine beeindruckende Befundlage vor, die zeigt, dass das Verbalisieren von belastenden Emotionen positive Effekte hat. Mit Blick auf internetgestützte Gruppen ist es besonders interessant, dass die Probanden in den meisten Studien aufgefordert wurden, über ihre Gefühle zu schreiben. Auch bei Internetgruppen erfolgt das Verbalisieren der Emotionen in schriftlicher Form.

Im typischen Experiment zum emotionalen Schreiben werden die Teilnehmer entweder gebeten, über problematische Erfahrungen und die damit zusammenhängenden Gefühle zu berichten, oder sie werden angehalten, über neutrale Gegenstände oder Ereignisse zu berichten. Positive Effekte fanden sich bei vielen komplexen Variablen, die von der Bewältigung von Trauer bis hin zur Verbesserung immunologischer Indikatoren reichen (Esterling, L'Abate, Murray, & Pennebaker, 1999; Klein & Boals, 2001; Pennebaker, Mayne, & Francis, 1997; Richards, Beal, Seagal, & Pennebaker, 2000). Selbst das Schreiben über positive Ereignisse kann hilfreich sein. In einer Studie profitierten HIV-infizierte Personen davon, dass sie über positive Ereignisse berichteten, die sie antizipierten (Mann, 2001).

Darüber hinaus scheint es einige Charakteristika der verfassten Schriftstücke zu geben, die besonders stark mit positiven Auswirkungen verknüpft sind. So wurde die größte gesundheitliche Verbesserung bei den Personen gefunden, die einen größeren Anteil positiver Emotionswörter im Vergleich zu negativen Wörtern benutzten (Pennebaker, 1993), und bei denen, die eine große Anzahl positiver Wörter und eine mittlere Anzahl negativer Wörter nutzte (Pennebaker et al., 1997; Pennebaker & Seagal, 1999). Unabhängig davon wurde auch der Gebrauch bestimmter kognitionsbezogener Wörter, die Kausalität ("weil") oder Selbstreflektion ("verstehe") ausdrücken, mit Gesundheitsförderung in Zusammenhang gebracht (Pennebaker, 1993; Pennebaker et al., 1997; Pennebaker & Seagal, 1999).

1.2.3 Probleme konventioneller Gruppen

Was oben als typische Gründe für die eingeschränkten Möglichkeiten zu Sozialkontakten dargestellt wurde, erschwert selbstverständlich auch die regelmäßige Teilnahme an konventionellen sozial unterstützenden Gruppen. Konventionelle Gruppen finden zu einer festgesetzten Zeit statt. Wenngleich die Organisatoren und Mitglieder solcher Gruppen wahrscheinlich größeres Verständnis für unregelmäßige Teilnahme haben, da sie wissen, dass die häufigen Arztbesuche und das gesteigerte Ruhebedürfnis durch die Erkrankung bedingt sind, sind sie der Entstehung von Gruppenkohäsion doch nicht zuträglich. Wegen solcher Schwierigkeiten ist es oft nicht einfach, solche Gruppen fortzuführen.

Bei Gruppen, die z. B. einmal in der Woche tagen, berichten Teilnehmer manchmal von der Schwierigkeit, die Ereignisse und Gedanken der Woche zu diesem Termin auch abzurufen und zur Diskussion zu stellen. Spontane Erlebnisse können nicht dann ausgesprochen werden, wenn sie vorfallen.

Zudem ist die Bindung konventioneller Gruppen an bestimmte Orte problematisch, da dies voraussetzt, dass sich an einem gegebenen Ort genügend Frauen finden, die in einer vergleichbaren Situation sind und Interesse haben, sich darüber auszutauschen. Frauen in ländlichen Gegenden werden ein geringeres Angebot an Gruppen vorfinden, während sich gute Angebote im städtischen Raum konzentrieren.

So wichtig die offene emotionale Aussprache für die gegenseitige Hilfe in Gruppen ist, so schwierig ist auch der erste Schritt zur Offenheit. Bei Gruppen, die am Wohnort der Teilnehmer durchgeführt werden, besteht oft eine große Hemmschwelle zur Teilnahme und zur persönlichen Aussprache. Während die Reaktionen eines Gegenübers die Offenheit fördern kann, so kann die Aufmerksamkeit auf die eigene verbale und körpersprachliche Darstellung oder die Angst vor Kontrollverlust beim Sprechen vor Gruppen besonders schwierig sein.

1.3 Soziale Unterstützung im Internet

Das Internet bietet Bedingungen, die einige der oben diskutierten Probleme beseitigt. Sind die technischen Voraussetzungen gewährleistet, bieten Internetangebote rund um die Uhr Zugang. Die unterschiedlichen Behandlungs- und Terminpläne der Teilnehmerinnen müssen daher nicht koordiniert werden. Nachrichten können dann geschrieben werden, wenn ein Problem besonders drängend ist (siehe auch das Beispiel einer spät nachts verfassten Nachricht bei Sharf, 1997). Räumliche Distanzen sind kein Problem. Auch in ländlichen Gegenden, wo sich in direkter Nachbarschaft nur schwer genügend Interessentinnen finden könnten, sind die technischen Erfordernisse (zusätzlich zum Computer in der Regel ein Modem und ein Telefonanschluss) dieselben.

Bei den Unterschieden zu konventionellen Gruppen spielt sicherlich die Anonymität eine Schlüsselrolle. Soziale Faktoren, die möglicherweise einen Einfluss auf die Interaktion in konventionellen Gruppen haben, wie die physische Attraktivität, ethnische Zugehörigkeit, stimmliche Charakteristika und manche sozialen Fertigkeiten werden in Internet-Gruppen neutralisiert.

Die computergestützte Darbietungsform erlaubt obendrein eine genauere Standardisierung der Intervention. Dabei können in naher Zukunft möglicherweise Algorithmen behilflich sein, die förderliche oder problematische Kommunikationsmuster identifizieren und somit die Steuerung erleichtern. Die fortlaufende Überwachung der Entwicklung der Gruppe birgt in der Verbindung mit detaillierten Manualen für die Moderatoren ein großes Potential für Verbesserungen. Bei routinierter Durchführung können mit diesen Angeboten eine große Zahl von Betroffenen bei minimalen Kosten erreicht werden.

Dass die Nutzung des Internets zumindest in den USA fast schon fast alltäglich ist, zeigt ein aktueller Bericht der Pew Foundation (PEW Internet and American Life Project, 2001). Demnach haben dort 104 Millionen Erwachsene Zugang zum Internet und dies schließt niedrigere Einkommensgruppen und ethnische Minderheiten der Bevölkerung nicht aus. International wird die Zahl der Menschen, die einen Zugang zum Internet haben, auf 500 Millionen geschätzt. Ein weiterer Bericht zeigt, dass im Internet häufig gesundheitsbezogene Informationen nachgefragt werden (84% der Nutzer, siehe PEW Internet and American Life Project, 2001), insgesamt mehr als online Einkäufe, Abfrage von Aktienständen und Ergebnisse von Sportereignissen. Immerhin 26% fragten Informationen über psychische Erkrankungen ab. Der Bericht der Pew Foundation ermittelte, dass dabei die Anonymität und die sofortige Verfügbarkeit der Informationsangebote die wichtigste Rolle spielen.

1.3.1 Hilfsangebote im Internet

Vor allem im englischsprachigen Teil des Internets eilt das Angebot an internetgestützten Interventionen der Forschung weit voraus. Die große Mehrheit der vorliegenden Berichte bescheinigt diesen Interventionen gute Wirksamkeit, obwohl wenig darüber bekannt ist, durch welche Mechanismen und unter welchen Umständen sie ihre Wirksamkeit entfalten. Inzwischen haben verschiedene Forschungsarbeiten eine Reihe von Bereichen beleuchtet: Krebs (Gustafson et al., 1993; Klemm, Reppert, & Visich, 1998; Sharf, 1997; Shaw, McTavish, Hawkins, Gustafson, & Pingree, 2000; Weinberg, Schmale, Uken, & Wessel, 1996), Sucht (King, 1994), Traumatisierung aufgrund sexueller Gewalterfahrung (Finn & Lavitt, 1994.), Raucherentwöhnung (Schneider, Walter, & O'Donnell, 1990), allgemeine medizinische Belastungen (Davison et al., 2000), Erziehungsfragen (Dunham et al., 1998; Mickelson, 1997), Angst (Glasser Das, 1999) und Essstörungen (Winzelberg et al., 2000; Winzelberg et al., 1998). Es ist anzunehmen, dass das Spektrum von Inhalten in Zukunft stark zunehmen wird, da mehr und mehr Menschen Zugang zum Internet erhalten.

1.3.2 Gruppen für Brustkrebspatientinnen

Viele Frauen mit Brustkrebs suchen soziale Unterstützung im Internet (Lieberman & Russo, 2001). Speziell für Krebspatienten existieren inzwischen hunderte von Internet-Gruppen, in denen sich Patientinnen austauschen können (Klemm, Hurst, Dearholt, & Trone, 1999; Miller, 1997). Im Vergleich mit anderen Listen, die sich auf diverse krankheitsbezogene Themen beziehen, rangiert die Frequentierung derjenigen, die sich auf Brustkrebs beziehen, ganz oben (Davison et al., 2000). Dieses grobe Maß der Nutzung von Internetgruppen kann einen Hinweis auf eine rege Beteiligung an diesen Gruppen bieten.

Das am besten untersuchte Internet-Angebot für Brustkrebspatientinnen ist das so genannte Comprehensive Health Enhancement Support System (CHESS), welches von der Universität Wisconsin, USA, betrieben wird (Gustafson et al., 1993; Gustafson et al., 2001; McTavish et al., 1995; McTavish et al., 1994; Shaw et al., 2000). Das Hauptziel dieses Angebots ist es, Patienten mit verschiedenen Krankheitsbildern einen einfachen Zugang zu wichtigen Informationen und damit Entscheidungshilfen zu beschaffen, aber auch emotionale Unterstützung anzubieten. Die dem Programm zugrunde liegende Annahme ist, dass die Flut von unverifizierten Informationen zur Verunsicherung der Patientinnen beiträgt, während gut organisierte und verlässliche Informationen eine Bewältigung positiv beeinflussen kann. Die Diskussionen sollen vor allem anstehende Entscheidungen zur weiteren medizinischen Behandlung erleichtern. Die CHESS Gruppen sind sämtlich unmoderiert und laufen ohne vorgegebene Struktur ab. Die ersten Befunde zeigen, dass das Angebot einfach zugänglich ist und gut akzeptiert wird. Eine jüngere, randomisierte Untersuchung belegte, dass die CHESS Bedingung zu mehr sozialer Unterstützung führt und die Teilnehmerinnen befähigt, relevante Informationen online zu beziehen (Shaw et al., 2000). Die psychologischen Effekte waren für Teilnehmerinnen aus den Bevölkerungsschichten am größten, die in Bezug auf medizinische und psychosoziale Angebote unterversorgt waren.

Es liegt eine weitere Untersuchung vor, die die Wirkung eines so genannten Computer Bulletin Board an einer kleinen Gruppe von Frauen untersuchte (Weinberg et al., 1996). Die sechs Teilnehmerinnen nutzten die Gruppe aktiv, um medizinische Probleme zu besprechen, sich gegenseitig Hilfe anzubieten und ihre persönlichen Sorgen zum Ausdruck zu bringen. Die Autoren beschreiben, dass sich in den Nachrichten ähnliche Kommunikationsmuster widerspiegeln, wie sie für konventionelle Gruppen mit persönlichem Kontakt typisch sind.

Diese förderlichen Kommunikationsmuster fanden sich auch in einem deskriptiven Bericht über eine weitere Brustkrebsgruppe (Sharf, 1997). Auch hier tauschten die Teilnehmerinnen Informationen aus und unterstützten sich gegenseitig. Die Gruppe förderte die selbst eingeschätzte Selbstwirksamkeit der Teilnehmerinnen. Besonders wichtig war für die Frauen, dass die Aufmerksamkeit für das Schicksal anderer auch dazu beitrug, das Grübeln über die eigene Krankheit zu unterbrechen.

Das Fazit ist, dass sich internetgestützte Programme wachsender Beliebtheit erfreuen, jedoch kaum Evaluationsforschung betrieben wurde. Fraglich ist, ob die positiven Effekte von konventionellen Gruppen mit persönlichem Kontakt ebenfalls mit Internet-Interventionen erreicht werden können.

1.3.3 Organisationsformen von Internet-Gruppen

Untersuchungen der Kommunikation, die in Internet-Gruppen stattfindet, weisen darauf hin, dass die Teilnehmer sich auf ähnliche Weise miteinander auseinandersetzen wie in konventionellen Gruppen, nämlich mit viel gegenseitiger Unterstützung, gegenseitiger Akzeptanz und positiven Gefühlsäußerungen (Salem, Bogat, & Reid, 1997; Winzelberg, 1997).

In diesem Abschnitt werden Aspekte angesprochen, die bei der Gestaltung einer Internet-Gruppe variiert werden können. Es ist dabei zu beachten, dass es hier nicht so sehr um stilistische Unterschiede oder Geschmacksfragen geht, sondern dass diese Gestaltungsmöglichkeiten die Wirkung der Intervention beeinflussen werden.

Es kann im Internet, wie bei konventionellen Gruppen mit persönlichem Kontakt solche geben, die alle Interessenten zum Gespräch und Informationsaustausch einladen, auch solche, die nicht persönlich an Brustkrebs erkrankt sind, z. B. Familienangehörige, Freunde und Kollegen von Patientinnen. Oder die Gruppen richten sich ausschließlich an die betroffenen Patientinnen. Viele Gruppen formieren sich spontan und werden von den Mitgliedern selbst organisiert. Im Internet sind einige Anbieter zu finden, die die technischen Voraussetzungen für die Durchführung von Internetgruppen ermöglichen, auch wenn die Teilnehmerinnen selbst nicht über die notwendige Technologie (Server) verfügen. Andere Gruppen sind professionell betriebene Angebote. Unser eigenes Angebot, Bosom Buddies, das wir im universitären Forschungssetting entwickelt haben, und dort evaluieren, wird im nächsten Abschnitt als Beispiel eines solchen professionellen Angebots dargestellt.

Die erstgenannten, selbstorganisierten Listen sind meist frei zugänglich, während der Zugang zu professionellen Angeboten die Teilnehmerschaft manchmal auf eine bestimmte, zu Beginn festgelegte Gruppe beschränkt ist. Im Fall einer Teilnehmerbeschränkung ist der Zugang oft durch ein individuell vergebenes Zugangskennwort geschützt. Selbstverständlich kann nur ein solches Kennwort die Vertraulichkeit innerhalb der Gruppe gewährleisten.

Frei zugängliche, offene Gruppen laufen meist kontinuierlich ab. Es werden ohne Beschränkungen neue Mitglieder aufgenommen, während andere Teilnehmer in unregelmäßigen Abständen ausscheiden können. Manche Mitgliedschaften bestehen über lange Zeit und die Gruppe kann kontinuierlich wichtige soziale Funktionen übernehmen. Andere Gruppen bestehen nur für eine bestimmte Zeitspanne, neue Gruppenprogramme beginnen mit neuen Mitgliedern. Hier steht im Mittelpunkt, dass Teilnehmerinnen Anregungen erhalten, die dann aber vor allem längerfristig in anderen Bereichen des sozialen Lebens umgesetzt werden.

Wie die oben geschilderte Initiative CHESS legen viele Angebote im Internet großen Wert auf die Bereitstellung von Informationen über die Krankheit und mögliche Behandlungen. Dies erfolgt vor allem mit Blick auf medizinische Aspekte oder Hilfsmittel. Andere Programme konzentrieren sich stärker auf psychosoziale Aspekte und bieten keine gezielte Fachinformation. Auch im zweiten Fall werden jedoch immer Fragen zu medizinischen Problemen diskutiert und Erfahrungen mit bestimmten Behandlungen (z.B. Nebenwirkungen der Chemotherapie) ausgetauscht werden. Wir halten es jedoch für außerordentlich wichtig, dass bei professionell organisierten Gruppenangeboten vor Beginn eine klare Entscheidung getroffen wird, wie mit solchen Anfragen umgegangen werden soll. Zunächst muss den Teilnehmerinnen klar gemacht werden, dass ein konkreter medizinischer Rat natürlich auch von Fachleuten nicht aufgrund von Ferndiagnosen gegeben werden kann. Aber auch bei der Vermittlung allgemeiner Ratschläge und Informationen muss das Ziel der Intervention berücksichtigt werden. Stehen psychosoziale Aspekte im Mittelpunkt, sollte die Art und Weise, wie die Teilnehmerinnen sich in der Zusammenarbeit mit dem sie betreuenden medizinischen Team Informationen beschaffen können, besprochen werden und der Rat nicht direkt erteilt werden.

Es gibt für Internetgruppen prinzipiell zwei Formate. Entweder erfolgt die Diskussion in einem so genannten Chat (vom englischen Begriff für plaudern bzw. Plauderei), der wie in konventionellen Gruppen zu einer bestimmten vorher verabredeten Zeit (synchron) stattfindet, oder in einer so genannten Newsgroup (vom englischen Begriff für Nachricht), wobei die Nachrichten zu jeder Zeit an die Gruppe gerichtet werden können und zu jeder Zeit von den Mitgliedern eingesehen und beantwortet werden können. Im Fall der Newsgroup müssen die Teilnehmer einer Gruppe nicht gleichzeitig mit dem Internet verbunden sein (asynchron). Die Newsgroup hat den offensichtlichen Vorteil, dass die Teilnehmerinnen ihre Terminplanung nicht aufeinander abstimmen müssen. Der Nachteil ist jedoch, dass ein Teil der Spontaneität verloren gehen kann, wenn die Nachrichten nicht in kurzen Abständen abgefragt und beantwortet werden. Eine Antwort auf eine Nachricht, in der starke Emotionen zum Ausdruck kommen, kann ansonsten die Adressatin z. B. erst zu einem Zeitpunkt erreichen, wenn ihre Stimmungslage bereits ganz anders ist und sie andere Bedürfnisse hat.

In selbstorganisierten wie in professionell geplanten Gruppen kann die Diskussion spontan und ohne Diskussionsleitung erfolgen. Während gleichzeitiges Sprechen in konventionellen Gesprächsgruppen zum Chaos führt, können zumindest die Newsgroups unmoderiert ablaufen, ohne dass die Bezüge verloren gehen. Beim synchronen Chat kann es jedoch ähnlich schwierig sein, einer unmoderierten Diskussion zu folgen. Wenn bestimmte Ziele angestrebt werden sollen, können erfahrene Moderatoren helfen, diese besser oder zumindest schneller zu erreichen. Moderatoren können die verschiedenen Fäden einer vielschichtigen Diskussion zusammenhalten und darauf achten, dass wichtige Themen nicht übersehen werden.

Die Modereration kann von erfahrenen Gruppenmitgliedern oder von Experten (psychologisch oder pädagogisch geschultes Fachpersonal) übernommen werden. Trotz Moderation kann die Themenwahl spontan erfolgen, oder es können den Teilnehmerinnen Themenvorschläge gemacht werden. Diese Themen können wiederum auf einer mehr oder weniger spontan variierenden Auswahl oder einer zuvor erarbeitete Struktur oder einem Manual basieren.

Welchen Einfluss diese Variablen auf den Ablauf und damit auch auf das Ergebnis einer Gruppenintervention haben, ist im Einzelnen zu erforschen. Auch die Forschungsergebnisse aus anderen psychologischen Gebieten werden eine immer solidere Grundlage für solche Entscheidungen bieten.

1.4 Ein Beispiel: Bosom Buddies

Im Folgenden wird ein aktuelles Beispiel für ein strukturiertes Gruppenprogramm dargestellt, das wir in einer randomisierten Studie an der Stanford University erprobt haben. Dieses Programm unterscheidet sich vom oben beschriebenen CHESS Programm (Gustafson et al., 2001) in einigen zentralen Punkten. Während CHESS die Deckung des Informationsbedarfs der Patientinnen als zentrales Ziel hat, spielt dieser Aspekt bei Bosom Buddies nur eine untergeordnete Rolle. Hier steht der Ausdruck eigener Emotionen im Vordergrund und die Kommunikation zwischen den Teilnehmerinnen ist das Herzstück der Intervention.

Das Programm "Bosom Buddies" (deutsch: Busenfreundin) wurde von professionellen Moderatorinnen begleitet und folgte über zwölf Wochen einem strukturierten Ablauf. Jede Woche wurde ein neues Thema zur Diskussion vorgegeben. Die Themen hatten einen engen Bezug zu bekannten Problemen von Brustkrebspatientinnen. Die Themengebiete wurden an bewährte Therapieprogramme (Classen et al., 1993; Kreshka & Graddy, 2000), die kürzlich positiv evaluiert wurden (Koopman et al., 2001, September), und aktuelle Richtlinien für psychosoziale Interventionen mit Brustkrebspatientinnen (Spiegel & Classen, 2000) angelehnt.

Obwohl die Moderation von erfahrenem Personal der Gesundheitsversorgung geleistet wurde, war die Intervention nicht als Psychotherapie konzipiert. Dieser Punkt erschien uns wichtig, um bei den Teilnehmerinnen keine falschen Erwartungen zu erwecken. Schwere depressive Verstimmungen und Suizidalität waren Ausschlusskriterien für die erste Studie.

1.4.1 Struktur von Bosom Buddies

Die Internetseiten von Bosom Buddies zeigen zunächst eine einleitende Seite. In der ersten Woche werden die Teilnehmerinnen hier von der Moderatorin begrüßt und das Ziel der Gruppe vorgestellt. Im Laufe des Programms werden hier die Themen eingeführt. Auf der linken Seite finden sich Verknüpfungen (Ikons), die zur eigentlichen Gruppe, einem persönlichen Tagebuch, einem Überblick über die Teilnehmerinnen und eine Informationsseite weiterführen.

Neben der Teilnahme an der Gruppe kann das Tagebuch dazu genutzt werden, Emotionen zum Ausdruck zu bringen. Diese Seite ist jedoch vor dem Zugriff der anderen Teilnehmer geschützt und bietet daher Raum für Notizen, die noch nicht mit der Gruppe geteilt werden können. Auf der Überblicksseite ("My Buddies") wird ein kurzer biographischer Überblick abgespeichert, den jede Frau vor Beginn der Intervention abfasst. Zusätzlich finden sich hier für jede Teilnehmerin das Datum und eine kurze Befindlichkeitseinschätzung zum Zeitpunkt des letzten Zugangs zur Internetseite. "My Buddies" kann also dazu genutzt werden, sich eine Teilnehmerin erneut ins Gedächtnis zu rufen und nachzusehen, wer die Seiten in der letzten Zeit besucht hat. Die kurze Befindlichkeitseinschätzung, die beim Zutritt zur Internetseite abgegeben wurde, gibt also anderen darüber Auskunft, wie sich die anderen Teilnehmerinnen fühlen, auch wenn diese beim gegenwärtigen Besuch der Internetseiten noch keine ausführlichere Nachricht geschrieben haben. Dieses Eingangsstatement ist auch als Aufforderung gedacht, in dieser Gruppe über eigene Gefühle zu schreiben, es soll den Einstieg dazu erleichtern. Auf freiwilliger Basis können die Teilnehmerinnen hier ein Foto von sich einfügen lassen. Erste Erfahrungen zeigen, dass ein Foto die Integration verschiedener Informationen zu einer Person erleichtert. Steht ein solches Portrait zur Verfügung, wird es mit jeder neuen Nachricht an die Gruppe mit dem Namen und der Zeitangabe eingeblendet.

Darunter ist ein Verweis auf eine umfängliche Informationsseite angebracht. Die Informationen bieten einen Überblick über allgemeinverständliche aber gut fundierte Literatur zu den psychosozialen Aspekten von Brustkrebs. Darunter befindet sich eine Anzahl von Erfahrungsberichten Betroffener. Zuletzt findet sich eine Verbindung zur Hilfefunktion, die typische Fragen erklärt und auf eine Kontaktadresse verweist.

Tabelle 1 listet die Themen auf, die zu Beginn einer neuen Woche vorgeschlagen werden.

Tabelle 1:
Themenvorschläge für Bosom Buddies, eine Internet-Gruppenintervention der Stanford Medical School, Kalifornien, USA:

Woche 1	**Einführung:** Die Teilnehmerinnen werden aufgefordert, sich der Gruppe vorzustellen. Dabei soll eine kurze Beschreibung des Krankheits- und Behandlungsverlaufs und der derzeitigen Befindlichkeit gegeben werden. Auch die Moderatorin stellt sich vor und beschreibt, was die Intervention für die Teilnehmerinnen leisten kann.
Woche 2	**Kennen lernen:** Die Teilnehmerinnen werden ermuntert, sich gegenseitig zu befragen, um sich besser kennen zu lernen, wie sie sich gegenseitig unterstützen können und wie sie miteinander interagieren können. Es wird empfohlen, dass die Emotionen, die beim Zugang zur Gruppe notiert werden, beachtet werden. Erste Informationen über Emotionen werden angeboten.
Woche 3	**Schwierige Emotionen:** Die Teilnehmerinnen werden aufgefordert, der Gruppe mitzuteilen und in ihrem Tagebuch aufzuschreiben, welche schwierigen Emotionen sie erleben und was sie bisher getan haben, um diese zu bewältigen.
Woche 4	**Medizinische Versorgung:** Die Teilnehmerinnen werden aufgefordert, sich mit den Beziehungen mit dem medizinischen Personal, das sie betreut, auseinanderzusetzen. Dabei sollen sowohl Frustrationen als auch Erfolgserlebnisse bei der Interaktion mit Ärzten diskutiert werden. Es werden Tipps angeboten, wie eine bessere Unterstützung durch das medizinische Personal erreicht werden kann.
Woche 5	**Unsicherheit und Hilflosigkeit:** Die Teilnehmerinnen werden aufgefordert, sich gegenseitig Gefühle der Unsicherheit und Hilflosigkeit mitzuteilen, besonders solche, die sich auf die Angst vor dem Wiederauftreten von Krebs oder Furcht vor der Zukunft beziehen. Es werden Informationen darüber angeboten, wieso manche Menschen ihre Hilflosigkeitsgefühle unterdrücken und wie mit solchen Gefühlen umgegangen werden kann.
Woche 6	**Selbstbild und Körperbild:** Die Teilnehmerinnen werden dazu eingeladen, der Gruppe mitzuteilen, welchen Einfluss die Krebserkrankung auf ihr eigenes Körperbild, ihre Selbstwahrnehmung hatte, und was sie bisher getan haben, um mit Veränderungen fertig zu werden.
Woche 7	**Liebe und Sexualität:** Die Teilnehmerinnen werden aufgefordert, mitzuteilen, wie sie ihre eigene Sexualität wahrnehmen, zu diskutieren, ob sie infolge der Krebsdiagnose Veränderungen in ihrem Sexualverhalten oder dem Sexualverhalten des Partners bemerkt haben.
Woche 8	**Familie:** Die Teilnehmerinnen werden aufgefordert, darüber zu schreiben, wie die Krebserkrankung ihre Beziehungen innerhalb

	der Familie verändert hat, welche Reaktionen auf Seiten der Familienmitglieder erfolgten, wie sie mit ihren Kindern über die Krankheit sprechen, wie sie um Hilfe bitten können, und wie sie Familienmitglieder ermutigen können, selbst Hilfe zu suchen.
Woche 9	**Freundschaften:** Die Teilnehmerinnen werden aufgefordert, mitzuteilen, wie ihre Freunde und Kollegen auf die Krankheit reagieren, und wie dies die Beziehungen mit Freunden und Kollegen beeinflusst hat. Es werden Vorschläge gemacht, wie Freunde und Kollegen um Hilfe gefragt werden können.
Woche 10	**Angst vor erneuter Erkrankung:** Die Teilnehmerinnen werden aufgefordert, über ihre Bedenken und Ängste bezüglich einer möglichen erneuten Erkrankung nachzudenken und zu diskutieren, wie dies ihr Leben beeinflusst hat, und was sie bisher zur Bewältigung unternommen haben.
Woche 11	**Sinn des Lebens:** Die Teilnehmerinnen werden aufgefordert, darüber nachzudenken, inwiefern sich ihre Prioritäten für das eigene Leben in der Folge der Erkrankung verändert haben. Sie werden gebeten, eine kurze Stellungnahme abzufassen, in dem sie ihre übergeordneten Lebensauffassungen und die Ausrichtung ihres Lebens darstellen.
Woche 12	**Abschluss:** In der letzten Woche werden die Teilnehmerinnen aufgefordert, zu reflektieren, was die Gruppe für sie bedeutet hat, was sie durch die gemeinsamen Erfahrungen gewonnen haben, und sich voneinander zu verabschieden.

Anmerkungen: Spontan aufkommende Diskussionen zu anderen Themen sind zu jeder Zeit möglich.

Obwohl die in Tabelle 1 genannten Themen zur Diskussion gestellt werden, ist darauf hinzuweisen, dass die Teilnehmerinnen selbstverständlich frei miteinander kommunizieren können. Wenngleich jede Woche viel Zeit mit den vorgeschlagenen Themen verbracht wird, tauchen andere Themenbezüge spontan auf, wie es aus konventionellen Gruppen mit persönlichem Kontakt bekannt ist.

Zu jedem Thema werden Auszüge aus Tonbandmitschnitten von Interviews mit Patientinnen angeboten, die über den eigenen Computer abgespielt werden können. In diesen Interviews äußern sich frühere Patientinnen, die bei der Entwicklung des Programms interviewt wurden, darüber, welche Aspekte für sie am belastendsten waren, als bei ihnen Brustkrebs diagnostiziert wurde, und schildern, welche Bewältigungsstrategien sich dabei bewährt haben. Die konzeptionelle Idee dahinter ist, dass solche Beiträge als soziale Modelle für die Teilnehmerinnen dienen können, die ihnen das Zur-Sprache-Bringen eigener Emotionen erleichtern sollen.

1.4.2 Ablauf von Bosom Buddies

Die Internetseiten von Bosom Buddies sind nur nach der Eingabe eines Kennworts zugänglich. Der Zugang kann zu jeder Tageszeit erfolgen, die Gruppe findet also asynchron statt und kommt nicht zu einem festgelegten Zeitpunkt zusammen. Anhand der "My Buddies"-Seite (deutsch: meine Freunde) kann aber abgelesen werden, wann andere Teilnehmerinnen zuletzt anwesend waren. Alle Mitglieder und die Moderatorin können neue Themen aufwerfen oder auf ältere Nachrichten Bezug nehmen. Sofort nachdem eine Nachricht an die Gruppe abgeschickt wurde, kann diese von anderen Mitgliedern eingesehen und gelesen werden. Eine Antwort wird durch einen Klick auf ein dafür vorgesehenes Symbol abgeschickt und es ist somit erkenntlich, welche Nachrichten sich aufeinander beziehen ("thread"), der "rote Faden" einer Interaktion geht damit nicht verloren.

Die Moderatorin kann von ihrem Arbeitsplatz am Computer jederzeit einsehen, ob und in welche Richtung sich die Interaktionen entwickeln. Ihre Aufgabe ist nicht die einer Therapeutin, worüber die Teilnehmerinnen auch informiert werden, sondern die einer Diskussionsleiterin. Werden Anfragen einzelner Teilnehmerinnen nicht beantwortet, kann sie daran erinnern, so dass wichtige Themen nicht übergangen werden. Ihre Rolle ist es, darauf zu achten, ob die angebotenen Themen angesprochen werden, oder ob sie die Gruppe gegebenenfalls dazu ermuntern muss, bestimmte Fragen gemeinsam zu reflektieren.

1.4.3 Evaluation von Bosom Buddies

Inzwischen liegen erste Daten einer randomisierten Studie mit dem Bosom Buddies Programm vor (Winzelberg et al., eingereicht). Die Teilnehmerinnen an einer Serie von Gruppen wurden innerhalb von 24 Monaten nach der Diagnose mit primärem Brustkrebs rekrutiert. Die Teilnehmerinnen wurden jeweils zufällig einer Bedingung mit sofortiger Behandlung zugeführt oder einer Wartelisten-Kontrollbedingung zugeordnet. Vor Beginn der Behandlung bestanden zwischen den Gruppen keinerlei Unterschiede bezüglich der abhängigen Variablen.

Es wurden insgesamt drei aufeinander folgende Behandlungsgruppen mit zehn, elf und 15 Patientinnen durchgeführt. Nach Abschluss der Behandlung wurden die Patientinnen der Wartelistengruppe eingeladen, an einer identischen Gruppe teilzunehmen, deren Daten aber nicht für die Ermittlung des Behandlungserfolges herangezogen wurde.

Im Vergleich mit der Kontrollgruppe berichtete die Behandlungsgruppe von signifikant verringerter Depression, krebsbezogener Traumatisierung und Stressempfinden. Die Teilnehmerinnen waren sehr zufrieden mit der Gruppe und bekräftigten in ihren frei formulierten Kommentaren, dass das Medium Internet sie nicht davor abgeschreckt hat, sehr persönliche Erfahrungen mit den anderen Teilnehmerinnen zu besprechen. Insgesamt bestand in allen Gruppen die einhellige Meinung, dass in den 12 Wochen der Intervention eine sehr große Gruppenkohäsion erreicht werden konnte. Obwohl nach dem Ende des Programms keine weiteren Kontakte zwischen den Teilnehmerinnen vorgesehen waren, tauschten manche Frauen spontan ihre Adressen aus.

1.5 Automatische Textanalyse

Internet-Gruppen bieten im Vergleich mit konventionellen Gruppeninterventionen eine Reihe besonderer Forschungsmöglichkeiten an. Ein Beispiel ist die automatische Textanalyse der Kommunikation in den Gruppen. Da 100% der Kommunikation in den gespeicherten Dateien festgehalten ist, geht bei der Auswertung keine Information verloren, wie dies bei der Transkription von Gesprächsprotokollen der Fall ist. Bei konventionellen Gruppen spielen Gestik, Stimmlage und Mimik eine große Rolle, finden bei der Textanalyse der Gesprächsprotokolle jedoch keine Berücksichtigung. Im Gegensatz dazu ist bei Internetgruppen die gesamte Kommunikation in den schriftlichen Produkten festgehalten. Im folgenden Abschnitt wird eine Studie dargestellt (Alpers et al., eingereicht), in der die Nützlichkeit von automatisierter computergestützter Textanalyse (siehe Popping, 2000; West, 2001) an einer Vorstudie (elf Wochen) zum Bosom Buddies Programm erprobt wurde.

1.5.1 Computerprogramme

Computerprogramme zur Textanalyse bergen ein großes Potential für die schnelle und akkurate Auswertung von großen Schriftstücken. Textanalysen werden in der klinischen Psychologie inzwischen häufig genutzt, wenn es um den Zusammenhang von Verbalisieren von Emotionen und psychologischer Anpassung oder Gesundheitsmaßen geht. Inzwischen steht eine ganze Reihe von benutzerfreundlichen Programmen zur Verfügung, die solche Anwendungen ermöglichen (einen Überblick bieten Alexa & Zuell, 1999; Bauer, 2000; Popping, 2000). Am häufigsten werden solche Programme genutzt, um den Inhalt von Internetseiten für Kategorisierungen aufzuarbeiten (siehe z.B. Bauer & Scharl, 2000) und die Katalogisierung von Stichwortlisten in Datenbanken zu automatisieren (zum Vergleich der Katalogisierung durch Mensch versus Maschine siehe Anderson & Pérez-Carballo, 2001a, 2001b).

Bei Anwendungen in der klinischen Psychologie hat bisher das Programm "Linguistic Inquiry and Word Count" (LIWC, Pennebaker & Francis, 1999; Pennebaker & Francis, 1996; Pennebaker, Francis, & Booth, 2001) die größte Verbreitung gefunden. Es wurde entwickelt, um eine Reihe linguistischer und psychologisch relevanter Dimensionen der Schriftsprache abzubilden. Obwohl die Autoren des Programms erste Hinweise auf die Validität bei Analysen von Aufsätzen geliefert haben (Pennebaker & Francis, 1999; Pennebaker & Francis, 1996; Pennebaker et al., 2001; Pennebaker et al., 1997), wurde LIWC noch nicht für die Analyse der Kommunikation zwischen mehreren Personen evaluiert. Es ist zweifelhaft, ob Computerprogramme in der Lage sind, komplexe Kommunikation zu analysieren. So berücksichtigt das Programm LIWC beispielsweise den Kontext einer Nachricht nicht, obwohl dies für Leser von geschriebenen Texten außerordentlich wichtig ist.

Das Programm LIWC hat ein vordefiniertes Wörterbuch mit 2290 Einträgen und kann in normalen Texten durchschnittlich 80% der Wörter bestimmten Kategorien zuordnen. Als Analyseergebnis erhält der Anwender Prozentanteile der erkannten Wörter, die den 64 vordefinierten Kategorien (25 psychologisch relevante Kategorien) zugeordnet werden konnten. Da viele Wörter zu mehreren Kategorien gehören, können die kumulativen Prozentwerte den Prozentwert der identifizierten Wörter bzw. 100% überschreiten. Die zu analysierenden Texte können nach einer Fehlerkorrektur als einfache Textdateien verarbeitet werden. Wir haben uns für die Werte der Kategorien "positive Emotionen", "positive Gefühle", "Optimismus", "negative Emotionen", "Angst", "Ärger", "Traurigkeit", "kognitive Mechanismen", "soziale Belange", "Tod" und "Körper" interessiert.

1.5.2 Validität Linguistic Inquiry and Word Count

Um zu evaluieren, ob die einfache Methode des LIWC, Wörter bestimmter Kategorien zu zählen, nützlich ist, haben wir drei Arten von Validitätsindizes überprüft. Die Inhaltsvalidität wurde anhand der deskriptiven Daten ermittelt. Wir fragten, ob die Skalenwerte Informationen, die für Internetgruppen relevant sind, erfassen. Die Konstruktvalidität wurde anhand eines Vergleichs zwischen Skalenwerten aus der Analyse der Texte unserer Gruppe mit den Skalenwerten aus der Analyse zweier Zeitungsberichte und aus den von den Programmautoren angeführten Vergleichswerten erfasst. Die Übereinstimmungsvalidität wurde durch den Vergleich der Skalenwerte aus der Analyse der Texte unserer Gruppe mit den Einschätzungen einer geschulten Leserin ermittelt.

Für diese Studie wurden die 521 Beiträge zur Newsgroup (durchschnittlich 126 Wörter lang) aus einer Vorstudie mit neun Krebspatientinnen herangezogen. Für die Übereinstimmungsvalidität wurden 100 Textbeiträge analysiert, die zufällig aus den 521 Beiträgen zur Newsgroup ausgewählt worden waren.

Insgesamt bestätigten die Ergebnisse, dass ein einfaches Computerprogramm für die valide Auswertung der Beiträge zu einer internetgestützten Gruppe nützlich sein kann. Obwohl die Korrelationen zwischen menschlichen Einschätzungen und den Computerergebnissen niedrig bis mittelhoch waren, gingen sie stets in die richtige Richtung. Auch in unseren Texten konnte das LIWC die große Mehrheit der Wörter einer Kategorie zuordnen, obwohl die Bedingungen hier sehr anders waren als bei den Aufsätzen, für deren Analyse das Programm entwickelt worden war. Die Prozentanteile für psychologisch relevante Kategorien entsprachen bei unseren Texten den Prozentwerten, die bei der Analyse von Aufsätzen gefunden wurden, wenn die Autoren instruiert waren, über emotional besonders relevante Erlebnisse zu berichten. Von Texten, die unter neutralen Instruktionen verfasst wurden, unterschieden sich unsere Beiträge deutlich. Auch bei den Vergleichen mit den Zeitungsartikeln fanden sich Ähnlichkeiten in den Profilen, die unseren Erwartungen entsprachen. Die Beiträge zu Bosom Buddies unterschieden sich deutlich von einem biologisch-wissenschaftlich orientierten Text, während die Ähnlichkeiten mit einem Bericht über die emotionalen Aspekte von Brustkrebs sehr deutlich waren.

Im Vergleich der Einschätzungen durch eine Leserin und den Computerwerten zeigte sich, dass auch komplexe Inhalte (soziale Unterstützung und medizinische Aspekte von Krebs), denen keine der vordefinierten Kategorien direkt entsprach, sich in inhaltlich verwandten Kategorien widergespiegeln ("soziale Belange" und "Körper").

1.5.3 Potentielle Anwendungen

In geplanten Studien werden wir genauer auf die Veränderungen im Sprachgebrauch der Teilnehmerinnen im Verlauf der Intervention eingehen. Wir versprechen uns, hieraus nützliche Anwendungen entwickeln zu können. Von besonderem theoretischem Interesse sind dabei diejenigen Kategorien, die von Pennebaker und seinen Kollegen als prädiktiv für positive Veränderungen identifiziert wurden (das Verhältnis von positiven und negativen Emotionen, sie 1.2.2

Ausdruck von Emotionen).

Falls sich mit dieser einfachen Methode hinderliche kommunikative Muster finden lassen würden, wäre die Software ein praktikables Hilfsmittel für die Kliniker, die Internet-Gruppen moderieren. Solche kostengünstigen Hilfsmittel könnten vor allem dazu beitragen, die Effizienz von Internet-Interventionen zu steigern. Wenn diese besonderen Potentiale der computergestützten Interventionen genutzt würden, könnte dies zur schnellen Verbreitung solcher Programme beitragen. Je komplexer eine Programmstruktur, desto nützlicher könnten solche Programme sein. Weitere Entwicklungen müssen vor allem darauf hinarbeiten, dass der Kontext von Wörtern miteinbezogen wird, um beispielsweise Negationen (z. B. "nicht traurig") und kontextabhängige Bedeutungen zu berücksichtigen.

Abbildung 1 demonstriert ein Beispiel, wie Veränderungen im Verlauf einer Intervention dargestellt werden können. Es sind Computerwerte (Prozent erkannter Wörter) für die Kategorien positive und negative Emotionen dargestellt. Diese Variablen sind in anderen Arbeiten mit positiven Veränderungen in Zusammenhang gebracht worden.

[Figure could not be opened]

Abbildung 1: LIWC Prozentwerte für die Kategorien "positive Emotionen" und "negative Emotionen" im Verlauf der elf Wochen einer Internetgestützten Gruppe mit neun Brustkrebspatientinnen. Bemerkung: Da die Anzahl der Wörter der einzelnen Kategorien unterschiedlich ist und die durchschnittliche Frequenz der Wörter in der natürlichen Sprache nicht gleich ist, können die Prozentwerte nicht zwischen verschiedenen Kategorien verglichen werden. Es sind lediglich die Veränderungen innerhalb einer Kategorie aussagekräftig.

Mit einfachen Mitteln können solche Darstellungen auch für einzelne Teilnehmer der Gruppen herausgefiltert werden. Solche Darstellungen können von Moderatoren von Internetgestützten Gruppen dann genutzt werden, um ihre Interventionen auf bestimmte Teilnehmer abzustimmen.

1.6 Fazit

Das Internet bietet eine viel versprechende Plattform für unterstützende Gruppen. Die Möglichkeiten werden derzeit bereits von einer großen Zahl von Patientinnen genutzt, wobei die Potentiale für noch nicht annähernd ausgereizt sind. In diesem Kapitel wurde ein Internet-Projekt für Brustkrebspatientinnen vorgestellt und geschildert, dass sich Verbesserungen der krebsbedingten Belastungen in mehreren standardisierten Tests nachweisen ließen. Der subjektive Eindruck der Teilnehmerinnen war ebenfalls überwältigend positiv. Auch die schwierigsten Themen wurden diskutiert. In allen Gruppen des Bosom Buddies Projekts wurde ein Zusammengehörigkeitsgefühl empfunden.

Es muss kritisch hinterfragt werden, ob ein rund um die Uhr bestehendes Angebot missverstanden werden kann. Während der Intervention muss ständig beobachtet werden, ob z.B. ein Hilferuf, der spät in der Nacht an eine Internetgruppe gerichtet wird und nicht schnell von anderen Mitgliedern beantwortet wird, zu Enttäuschungen und damit besonderen Risiken führen kann. Während in jeder Kommunikation Wortmeldungen und Beiträge übersehen oder gar zur Seite geschoben werden können, kann dieses Risiko besonders in Internet-Gruppen bestehen. Weitere Erfahrungen mit dem relativ neuen Medium Internet werden zeigen, ob die Teilnehmer dieselbe Verantwortung wahrnehmen wie in Gruppen, wo sich die Gesprächspartner im direkten persönlichen Kontakt gegenübertreten.

Es gilt zu untersuchen, inwiefern ungewollt eine Vorselektion der Teilnehmerinnen aufgrund vorheriger Computererfahrung stattfindet. Für unser Programm Bosom Buddies konnten wir einen kostenfreien Internetzugang über so genannte Web-TV Geräte (Sony) anbieten. Mangels Vorerfahrung taten sich die Nutzerinnen trotz der im Vergleich zum Personal-Computer vereinfachten Technik anfangs schwer. Wir planen für unsere weiteren Projekte, eine gezielte Hinführung an die Benutzung der Software und eine Vorlaufphase einzuschieben, um die Handhabung der Software zu üben, bevor der eigentliche Teil der Intervention beginnt.

Während die Anonymität der Teilnehmer, die im Vergleich zu konventionellen Gruppen zu bestehen scheint, für das Zusammengehörigkeitsgefühl der Gruppe nicht hinderlich ist, ist die Vertraulichkeit der Daten gegenüber Zugriffen von außen problematisch. Internetgestützte Gruppen können nur durch technisch aufwendige Maßnahmen (Firewall) geschützt werden. Die Übertragung der Kennwörter an den Server muss geschützt erfolgen und Kennwörter müssen nach Standards vergeben werden, die die Decodierung erschweren. Jede einzelne Teilnehmerin muss den Zugang zu ihrem Computer vor unbefugten Nutzern schützten. So müssen sich die Teilnehmerinnen verpflichten, keine Informationen auf der eigenen Festplatte abzuspeichern. Die Mitglieder und Moderatoren müssen sich nach dem Gebrauch der Software wieder abmelden, um Außenstehenden keinen Zugang zu ermöglichen. Es muss für jede Gruppe das optimale Zeitintervall festgestellt werden, nach dem die Zugangsberechtigung verfällt, wenn keine Eingabe erfolgt. Dies schützt davor, dass Unbefugte Zutritt erhalten, wenn Teilnehmerinnen ihren Rechner verlassen, ohne sich abzumelden. Wird dieses Zeitintervall zu kurz gewählt, kann es allerdings zu Irritationen führen, wenn eine Teilnehmerin längere Zeit liest, ohne eine Eingabe vorzunehmen. Auch zu Forschungs- und Supervisonszwecken dürfen Beiträge, die an die Gruppe adressiert wurden, niemals per Email verschickt werden, da diese Kommunikation in der Regel völlig ungeschützt ist.

Unsere Forschergruppe startet derzeit einen direkten Vergleich von einer konventionellen Gruppe ("face-to-face") und einer Internet-Intervention. Dabei wird angenommen, dass beide aktiven Behandlungsformen die Depression, psychische Belastung und krebsbezogene Traumatisierung im Vergleich mit einer Wartelisten-Kontrollgruppe lindern. Wir erwarten keine bedeutsamen Unterschiede zwischen den Behandlungsformen. Einem solchen direkten Vergleich mit der konventionellen Gruppe hielt bereits eine internetgestützte Intervention zur Reduzierung des Risikos für Essstörungen stand (Celio et al., 2000). In dieser Studie waren allerdings nur Studentinnen beteiligt, die allesamt ziemlich vertraut mit dem Medium Internet waren.

In dem geplanten nächsten Projekt sollen zudem ausführliche Katamnesen durchgeführt werden. Daneben werden in Zusammenarbeit mit Programmierern Softwarelösungen entwickelt, die eine kontinuierliche Analyse der Kommunikation ermöglichen, und damit dem Moderator als nützliches Hilfsmittel zur Verfügung stehen wird. Um aber die Bedeutung dieser Prozesse gezielt zu untersuchen, wird der Zusammenhang der beobachteten Kommunikationsmuster mit dem Behandlungserfolg analysiert. Beim direkten Vergleich der Interventionen wird selbstverständlich die Zufriedenheit mit dem Ablauf verglichen werden.

Online Interventionen bieten ganz besonders günstige Voraussetzungen für die Supervision der Moderatoren. Ohne zusätzliche Ton- oder Videoaufzeichnungen können Beiträge einzelner Teilnehmer und Interventionen der Moderatoren später wieder aufgerufen werden.

Georg W. Alpers

Gruppeninterventionen, die im Internet durchgeführt werden, bieten Möglichkeiten für die Erforschung spezieller Fragestellungen, da alle Kommunikation in Form der gespeicherten schriftlichen Mitteilungen vorliegt. Diese Mitteilungen können mithilfe automatischer Auswertungsprogramme auf interessierende Inhalte hin ausgewertet werden. Wir konnten zeigen, dass eine sehr einfache Textanalysesoftware valide Eindrücke über eine Anzahl von relevanten psychologischen Kategorien verschaffen kann.

In Zukunft werden solche Technologien die Durchführung von computergestützten Interventionen erleichtern. Bereits mit einfachen Modifikationen kann die Auswertung durch Textanalysesoftware online, d.h. fortlaufend während der Intervention, erfolgen. Internet-Interventionen könnten dadurch effizienter und zuverlässiger erfolgen, da automatisch vor Krisen gewarnt und bestimmte Interventionen vorschlagen werden können.

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DEPARTMENT OF DEFENSE
UNITED STATES OF AMERICA

DEPARTMENT OF THE ARMY
US ARMY MEDICAL RESEARCH AND MATERIEL COMMAND
504 SCOTT STREET
FORT DETRICK, MD 21702-5012

REPLY TO
ATTENTION OF

MCMR-RMI-S (70-1y) 1 July 03

MEMORANDUM FOR Administrator, Defense Technical Information Center (DTIC-OCA), 8725 John J. Kingman Road, Fort Belvoir, VA 22060-6218

SUBJECT: Request Change in Distribution Statement

1. The U.S. Army Medical Research and Materiel Command has reexamined the need for the limitation assigned to technical reports written for this Command. Request the limited distribution statement for the enclosed accession numbers be changed to "Approved for public release; distribution unlimited." These reports should be released to the National Technical Information Service.

2. Point of contact for this request is Ms. Kristin Morrow at DSN 343-7327 or by e-mail at Kristin.Morrow@det.amedd.army.mil.

FOR THE COMMANDER:

Encl

PHYLLIS M. RINEHART
Deputy Chief of Staff for
Information Management

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