

SELF-MANAGEMENT IN ONLINE SELF-HELP GROUPS FOR BREAST CANCER PATIENTS: FINDING THE RIGHT GROUP, A SPECULATIVE HYPOTHESIS

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ABSTRACT

A common strategy to maximize the effectiveness of psychotherapy is patient placement to a particular form or type of psychotherapy. Six online self-directed breast cancer groups ($N = 114$) were studied to explore the speculative hypothesis that participants select the particular group that best fits their needs. All the groups encouraged "lurking," reading the postings before joining. Seventy-four percent lurked, half of them for about a week, the other half from two to eight weeks. Forty-eight percent shopped for "the right fit" by trying out other Internet BC groups. We found that: 1) pre-post measures (six months) show substantial improvement; 2) analysis of between groups differences in outcomes was not significant; and 3) analysis of processes linked to positive outcomes (Helpful Group Experiences and negative emotional expression) differed among the groups. The findings may be explained by the prospective members' ability to sample a variety of groups and to select the one that they believe will be the most comfortable and helpful to them.

A common strategy used to maximize the effectiveness of professionally provided psycho-social intervention is matching a patient to a particular form or type of psychotherapy. For nearly 50 years clinicians have written about and studied criteria for such placement. An organized matching strategy is not an option for both traditional and online self-help groups. The goal of this study is to examine a speculative hypothesis: in online SHG groups, matching to a specific group occurs through the active choices made by participants. Specifically, the study explores the common practice of "lurking," reading the group members messages but not

actively participating for some period of time, as well as shopping and visiting other Internet groups prior to selecting one to join.

This study began with specification of effectiveness results based on six self-directed breast cancer bulletin boards (Lieberman & Goldstein, 2005). For a sample of 114 women followed for six months we found significant positive change on measures of depression, personal growth, and quality of life.

The logic for examining their speculative hypothesis is based on demonstrating that the six groups differed in significant therapeutic characteristics despite our finding that outcomes among the groups were similar. This study will: 1) test for outcome differences among the six breast cancer Internet SHG's; 2) compare the demographic, prior help seeking, and severity of the illness among the group participants; 3) compare the rating by participants of the important helpful group experiences (curative factors) that characterized their group; 4) examine the rate and intensity of negative emotions in each group (such expressions have been shown to be a critical therapeutic factor in groups for BC women); and 5) examine procedures, lurking and trying out other cancer bulletin boards and/or chat rooms, participants' use in online groups, to aid them in finding the right group for themselves.

BACKGROUND

Lurking

Lurkers, in studies of online communities addressing a variety of issues, health, hobbies, politics, and so forth, are reported to make up more than 90% of several online groups (Katz & Aspden, 1998; Mason, 1999). Nonnecke (2000) and Nonnecke and Preece (2000) report that lurkers made up to 45.5% of health support communities. Moreover, it was found that lurking rates were highly variable, with some communities having no lurkers, while others had rates as high as 99%.

Several investigators have provided information about both the number and reasons people lurk on Internet communities. Early studies of lurking focused only on people who post, and these people were considered to be "the community" (Beaudouin & Velkowska, 1999; King, 1994; Parks & Floyd, 1996). Internet researchers (Smith & Kollock, 1999) viewed non-posters as destructive to the community. Nonnecke (2000) and Nonnecke & Preece (2001) using in-depth interviews found that there are many reasons why people lurk; some are indeed unsociable or even selfish, but many are not, and some even have an altruistic basis. Lurking also enables new members to learn community norms, see if their concerns are relevant and obtain vicarious support without disclosing themselves (Walther & Boyd, 2002). Many lurkers empathize so strongly with the stories they read that they identify with the community and think of themselves as members (Nonnecke, 2000), particularly in patient support communities (Preece, 1999). Furthermore, recent studies show that most members of health support and

education support communities accept lurkers as members of the community (Abrams, 2003; Maloney-Krichmar, 2003; Maloney-Krichmar & Preece, 2003).

Matching

Piper, McCallum, Joyce, Rosie, and Ogrodniczuk (2001) used a randomized clinical trial of psychiatric outpatients with complicated grief to investigate the interaction of two patient personality characteristics (quality of object relations [QOR] and psychological mindedness [PM]) with two forms of time-limited, short-term group therapy (interpretive and supportive). Patients in both therapies improved. However, the investigators report a significant interaction effect was found between personality and therapy type. High-QOR patients improved more in interpretive therapy and low-QOR patients improved more in supportive therapy.

In contrast, Kaminer, Burleson, Blitz, Sussman, and Rounsaville (1998) found, among dually diagnosed adolescent substance abusers, no effects of matching using comorbid psychopathology. Specifically, they tested whether patients with externalizing disorders would have better outcomes when treated with cognitive-behavioral group treatment and Ss with internalizing disorders without comorbid externalizing disorders would fare better in interactional group treatment.

Kuehner, Angermeyer, and Veiel (1996) describe a self-selection study. They evaluated the Coping with Depression (CWD) course in a sample of patients who were pretreated for clinical depression on a psychiatric in- or outpatient basis. Results suggest that, through a process of self-selection, the program appealed especially to those patients who still displayed extensive depressive symptoms after discharge or who had experienced an early relapse into the depressive episode.

Zettle and Herring (1995) evaluated the treatment utility of the Sociotropy/Autonomy Scale by matching or mismatching to either individual or group cognitive therapy according to their dominant personality dimension. They reported that a higher proportion of matched Ss displayed marked improvement at follow-up.

Beutler, Machado, Engle, and Mohr (1993) studied the long-term efficacy of matching patient indicators to group cognitive therapy (GCT), focused expressive psychotherapy, and supportive, self-directed therapy (SSD) among patients with major depressive disorder. One-year follow-up supported assigning patients with externalizing coping styles and/or low resistance potential to GCT and patients with internalizing coping styles and/or high resistance potential to SSD.

Litt, Babor, DelBoca, and Kadden (1992) evaluated the clinical utility of alcoholic subtypes on outcomes with different treatments. Ss were randomly assigned to one of two types of aftercare groups: coping skills training or interactional therapy. Clinical differences between the two aftercare groups persisted two years after follow-up.

Matching patients to specific treatment conditions has been found by a number of investigators to be a fruitful strategy that often leads to improved clinical services. However, given the diversity of patient populations studied and the variety of treatment conditions examined, it is not surprising that higher order generalizations, a theory of matching, is not within the field's grasp.

Processes

Helpful Group Experiences

Beginning with Corsini and Rosenberg's 1955 publication, psychotherapy researchers for more than 45 years have studied and theorized about the transactions associated with patient/participant benefit in small face-to-face groups. A number of events and experiences are thought to be directly associated with such change. They are usually defined as elements of group therapy, self-help, or growth groups that contribute to improvement. Studies linking HGE to outcomes include Yalom (1985), Lieberman, Yalom, and Miles (1973), and Lieberman (1990).

Breast Cancer and Emotion

The second process area we chose was the expression of negative emotions. Such expressions have long been considered important for psychosocial well-being. Research has suggested that the primary emotions of fear, sadness, and anger are fundamentally adaptive and that expressing them in therapy can ultimately lead to a greater understanding of self and others (Greenberg & Foerster, 1996; Greenberg & Webster, 1982; Koch, 1983). It can also lead to a decrease in hostility (Greenberg & Webster, 1982), greater self-confidence and assertion (Greenberg & Forester, 1996), and greater positive effect (Koch 1983; McCallum, Piper, & Morin, 1995). Furthermore, the intensity of emotional arousal during therapy sessions may mediate this transformation (Mohr, Shoham, Salomon, Engle, & Beuiler, 1991).

Group therapy and support groups constitute common and successful resources for breast cancer patients. One of the more successful therapies is supportive—expressive group psychotherapy (SEGP), a therapeutic process designed to focus on feelings and emotions. By allowing a patient to express her emotions about such issues as her intimate relationships, death, cancer and its treatment, SEGP aims to enhance emotional adjustment (Spiegel & Kimerling, 2001). Randomized controlled trials have found that SEGP successfully improves the mood, the perception of pain, and relieves stress (Classen, et al., 2001; Goodwin et al., 2001; Spiegel, Bloom, & Yalom, 1981).

THE STUDY

Methods

Sample and Recruitment

New members to six breast cancer (BC) bulletin boards (BB) were recruited through BB postings and/or e-mails. They were asked to fill out questionnaires measuring depression, posttraumatic growth, and psychosocial well being when they joined the BB and again six months later. One hundred fourteen women were recruited from the boards; 80% ($N = 91$) completed the follow-up at six months; mean age 46.2 years ($SD = 8.1$).

Participants joined the board on average 10 months from their date of diagnosis, with a median of three months. Forty-six percent had attained a college or graduate degree, while 9% had received a high school diploma only. Eighteen percent of the women had sought professional psychosocial help prior to their participation in the BB. Finally, 38% of participants identified as stage I, 37% and 21% identified as stage II and III respectively, and 4% identified as stage IV, providing a distribution of breast cancer diagnoses. The vast majority of the sample had previously used the Internet to receive help with their breast cancer (97%), 19% had participated in an Internet chat group, and 40% in a previous BB for breast cancer.

Measures of Searching for the Right Group

Participants in the study were asked, before they posted, did they “lurk,” read others postings before posting themselves? If yes, how long did they lurk. They were also asked if they had, prior to posting in their current group, either actively or passively “lurked” in other breast cancer bulletin boards or chat rooms.

Measures of Outcomes

The Center for Epidemiological Study Depression Scale (CES-D)—The CES-D (Radloff, 1977) is a 20-item Likert self-report scale developed to measure depression in the general population. The CES-D shows high internal consistency, $\alpha = .85$ in the general population, and good reliability after six months $r = .54$).

Functional Assessment of Breast Cancer (FACT-B)—The FACT-B is a multi-dimensional quality of life questionnaire developed for breast cancer patients that assesses psychosocial well-being. It consists of the FACT-G, a measure designed for any cancer patient (Cella, Tulsky, & Gray, 1993) and a Breast Cancer sub scale.

The Posttraumatic Growth Inventory (PTGI)—The PTGI (Tedeschi & Calhoun, 1996) assesses positive changes experienced by traumatized individuals. It is a 21-item scale with higher scores indicating greater growth through a traumatic

event. Participants were asked to “indicate for each of the statements below the degree to which this change occurred in your life as a result of having cancer.” The overall internal consistency is $\alpha = .90$ and the test-retest reliability is $r = .71$.

Process Measures

We selected two processes that have been shown in previous studies of breast cancer groups to have an impact on outcomes. The first process variable was “curative factors,” helpful group experiences of participants during the group, often leading to positive change.

Measures of Helpful Experiences

The Helpful Group Experience Questionnaire used was first developed for the Encounter study (Lieberman, Yalom, & Miles, 1973) and modified for use with a variety of Self Help groups (Lieberman & Borman, 1979). This is a 25-item questionnaire with 6-point scales, from 0 being “not applicable” to 5 “one of the three most important.” The dimensions based on our previous research cited used 16 of the 25 items for the five scales shown below.

Support

Getting support and encouragement, Making contact with someone who I could call on for help, Belonging to and being accepted by the support group, Developing new friendships. $\alpha = .57$

Disclose

Talking about fears of death, Discussing sexual concerns, Expressing my true feelings. $\alpha = .67$

Existential

Owning up to maladjustment when it seems important, Deepening my spiritual life, Confronting difficult problems and fears. $\alpha = .66$

Cognitive-Information

Getting honest feedback from others, Gaining insight about myself, Getting new understandings or explanations, Getting direct advice, suggestions, or education, Gaining access to important information. $\alpha = .68$

Altruism

One item: Helping others.

Measures of Expressed Emotions

Two text analysis strategies were used to assess the emotional characteristics of the groups studied.

We used Psychiatric Content Analysis and Diagnosis Software (Gottschalk, 2000) to categorize the support group postings into relevant expressed emotional categories. The PCAD 2000 is a software program that performs content analysis of input text on scales developed by Louis A. Gottschalk and Goldine Gleser. The Gottschalk-Gleser Content Analysis Method for measuring the magnitude of various psychological states and traits from the content analysis of verbal behavior has been successfully applied to many different neuropsychiatric dimensions. The PCAD scales measure a variety of emotional and psychological states including anxiety, hostility, social alienation-personal disorganization, cognitive impairment, hope, depression, human relations, achievement striving, dependency striving, and health/sickness. Each of the primary dimensions is subdivided by a number of sub scales.

The analysis of PCAD scores was simplified using a factor analysis to reduce the scales into a smaller number of dimensions. Eight factors were extracted from the scales: 1) health/hope, 2) hostility, 3) somatizing anxiety, 4) self-accusations, 5) mutilation, 6) separation, 7) hopelessness, and 8) sickness. The PCAD scoring is based upon phrases, not a simple word count. The theoretical underpinnings of the system stem directly from psychoanalysis.

For the second analysis of emotions we used the Ekman-Lieberman dictionary of emotional words (1992) and the Dt-Search software. The dictionary contains 31 coded dimensions spanning a range of emotions. We searched for the usage of negative emotive words expressing fear (e.g., scary, afraid, 74 word stems), and anger (e.g., rant, fighting, 213 word stems). Contextual Emotional Expression. To provide a more nuanced examination of anger and fear we searched for these words within the context of cancer (within 10 words of words related to cancer and its treatment).

RESULTS

Outcomes

Participants showed statistically significant improvement [overall multivariate, df 82,3 $F = 7.29$, $P > .001$, $\eta^2 = .21$] on measures of depression (CESD), Quality of Life (FACTB), and posttraumatic growth (PTGI) (Lieberman & Goldstein, 2005). How long the women had cancer and their cancer stage had no effect on the outcomes. These findings compare favorably to previous studies of professionally facilitated BC online support groups that assessed many of the same measures (Lieberman et al., 2004; Winzlenberg, 2003).

Differences in Outcomes for the Six Self-Directed Groups

A repeat measure multivariate analysis, with a Bonferroni correction, examined the three outcome measures, with the independent variable, group. No differences among the different boards for outcomes were found [Between groups $F = 1.9$ (4,69) NS $\eta^2 = .01$. Within: Time $F = 5.01$ (3,76) $P = .003$ $\eta^2 = .19$. Time \times Group $F = 1.3$ (4,69) NS $\eta^2 = .09$].

Exploring Internet BC Groups

We found that 74% lurked prior to posting. In addition, 41% of the total sample had examined other Internet BC boards/chat rooms. Overall, only 16% of the sample studied had joined the group without evidence of prior lurking or examining other Internet resources.

A chi-square analysis between groups for lurking/exploring yielded χ^2 (df 5) of 4.2, NS. Did those who lurked and/or explored (shopped) differ from those who did not? A multivariate analysis of variance, with the dependent variables, time 1 scores on CESD, PTGI, and FACTB, shopping and group as the independent variables found that neither shop ($F = 2.0$, df 3,93) nor group ($F = 1.1$, df 5,95) nor the interaction shop \times group ($F = .92$, df 5,95) were statistically significant. We compared the “shoppers” with the non-shoppers on: age, marital status, education, how long they have had cancer, their cancer stage as well as prior professional psychotherapy associated with their cancer. None of these comparisons were statistically significant.

Demographic Characteristics of Group Participants

Did the different groups attract women who differed demographically or in the characteristics of their cancer? We tested: age, marital status, education, how long they have had cancer, their cancer stage as well as prior professional psychotherapy associated with their cancer and prior BC newsgroup or chat rooms. Only one of the comparisons reached an acceptable level of statistical significance, the proportion of women who had sought out professional psychotherapy differed by group. Overall, the populations the different groups attracted did not differ.

Helpful Group Experiences

A multivariate analysis with a Bonferroni correction was computed with the six dimensions of HGE as the dependent variable and group as the independent variable. We found an overall $F = 4.70$ (df 5,54) $P = .01$, $\eta^2 = .30$. Two of the six dimensions reached univariate statistical significance, Altruism ($f = 4.1$ (df 5,54) $P = .003$ $\eta^2 = .27$) and existential ($f = 2.4$, $P = .05$ $\eta^2 = .18$).

Thus, from the point of view of the participants, there were real differences in emphasis in what constituted important helpful experiences. All groups were similar on support $Mn. = 2.9 (1.0)$, cognitive-informational ($Mn. = 3.6 (.69)$), and disclosure ($Mn. = 2.3 (2.3 (1.1))$). Beyond these, the groups differed on the aforementioned two characteristics, altruism ($Mn. = 3.5 (1.4)$) and existential ($Mn. = 2.2 (1.0)$).

Emotional Expression, PCAD

Did the various groups differ in their expression of emotions? Analysis of the six PCAD factors in a multivariate analysis yielded an overall $F = 6.2, P = .001$. Three factors showed univariate significance: 1) death anxiety/somatic concerns, (V) separation anxiety/depression and (VI) hope/health. Table 1 shows these comparisons.

Expression of Fear and Anger

An analysis of the expression of fear and anger as well as fear and anger associated with cancer revealed that for anger and fear (multivariate analysis of variance, group $F = 2.3 (5,71) P = .05 \eta^2 = .14$, univariate significance only found for anger. A similar analysis on these emotions associated with cancer found group $F = 2.5 (5,71) P = .04, \eta^2 = .15$. Neither of the two univariates reached adequate statistical significance (see Table 1).

Mechanism for Self-Selection

Given the findings described: 1) pre-post measures show substantial improvement in the participants; 2) analysis of between groups differences in outcomes is not significant; and 3) analysis of processes, shown in previous studies, to be linked to positive outcomes among breast cancer patients (HGE and negative emotional expression) shows the groups differed somewhat in their emphasis on important processes. We believe that collectively, the finding may be explained by prospective members of the online groups' ability to sample a variety of groups and select the one that they believe will be the most comfortable and helpful to them.

This selection is enabled by the direct encouragement of the groups we studied for prospective members to lurk—to read the group's postings for several weeks before deciding to post (join) the groups. Of the 114 women in our sample at time 1, 74% lurked, half of them for about a week, the other half from two to eight weeks. In addition this "shopping for the right fit" can be seen by the number who had tried out other Internet groups for their cancer (48%).

The following are some excerpts from newsgroup posting about lurking and lurkers:

Table 1. Comparisons of Significant Differences among Groups; Mean Scores
Emotional Dimensions

Group	Anger		Fear		PCAD I		PCAD V		PCAD VI	
	Anger cancer	Anger	Fear cancer	Fear	Death anxiety/ somatic concerns	Separation anxiety/ depression	Separation anxiety/ depression	Separation anxiety/ depression	Hope/ health	Hope/ health
IVILLAGE	4.23	4.77	8.31	9.15	-.13	-.21	-.21	-.21	0	0
MSN	8.75	7.63	8.88	11.25	.15	0	0	0	0.11	0.11
YAHOO	3.21	4.14	8.71	10.07	.12	-.13	-.13	-.13	0	0
BCORG	4.25	7.71	12.5	14.13	0	0	0	0	0	0
BCANS	4.14	6.71	9.71	11.43	0	-.17	-.17	-.17	0	0
DELPHI	6.33	6.09	13	9.18	0	.13	.13	.13	0	0

I am kind of new here, to posting that is. Have been lurking for 7 months. Can't tell you how much help you all have been. Just thought filling this out would be a good intro. I have been lurking here for about 7 months and must tell you that I have gotten so much support from everyone by just reading. Guess I have been a little shy. But that is over now, so I will tell you about myself.

When I first started lurking, it was all the supportive messages I saw on here which prompted me to join, and it wasn't until after that when things suddenly seemed to change.

Here you log in and express yourself, ask questions yell a lot or just lurk when you want. Love and prayers for you as you start on this journey of adventure and discovery. You will learn a lot about the beast, yourself and life. Things you were.

Hi everyone, I have been lurking but not contributing a great deal lately. I feel like such a fraud, my issues seem so minuscule compared to what some of you ladies are experiencing. Never the less I have been feeling pretty low of late, and decided to come in from the cold.

About your building now, yep I have been lurking quietly for too long eh, and have found my typing fingers!!!! do you have health and safety departments as part of your company?

Oh, I want to give you a big cuddle. We are a week apart in our treatments and I am feeling the same, hence why I lurk around the site a lot, without participating. Next week is my last chemo, but I don't see me jumping for joy or even taking a lot of notice of it. My focus is right, ok, so what, now I have 6 WEEKS, radiation and 5 years tamoxafin. Like is there an end??? I can't see one??? I think this is the depressive chemo speaking, not ME!!!! It is not taking over my life, I just will . . .

I've just been lurking and reading lately. I saw my oncologist yesterday and my chemo has been put off as my blood hasn't recovered well enough, bummer!!!! It will be my last one too so that was a bit disappointing.

Certainly didn't witness me at my best, probably not my worst either, as I just lurked on those days, but thanks for all. My sun is high in the sky and shining brightly, there is light at the end of the day after all. Newbies, try and remember that.

I've started lurking BCANS about 2 months ago and posting about a month or so ago. I have had many questions answered here. I come here everyday now to look or query and I have found everyone to be very helpful.

Anyone have similar symptoms or answers?? Glad you are not lurking anymore. Welcome to our community. We are all sisters in this fight to survive. I'm sure you can give us a lot of inspiration and insight since you've been fighting this battle so long. Thanks for joining us.

I have been lurking, for a few days since I joined. I have enjoyed the list. I have a lot of medical problems and I'm disabled. Been thru 3 brain surgeries

amongst numerous other surgeries. I made it thru those knowing I stood a chance of not living long.

This is the first time I have written on this discussion board, or any. For the last 2 weeks I have been reading all of your posting trying to find out everything. You have already been as much help as my face-to-face support group.

Hi all. Have been lurking on the boards, haven't posted. Surgery is on Wed. Went and got blood work today. Trying to keep busy and diverted. Reading a lot of material but stopped because I got overwhelmed. Best to wait for a Diagnosis and then I will get into the group.

Have been lurking and reading everything but really haven't posted much. I had calmed down considerably but all of a sudden today I feel almost panic stricken about my surgery tomorrow.

I've been lurking here off and on, drawing inspiration and comfort from all of you. Thanks so much just for being here.

Since my biopsy, those 3 weeks between the mammogram and the biopsy were horribly nerve-wracking, and have been able to do a lot of research and make decisions. Not knowing was definitely the worst time for me. I've been lurking here for a little while and all of you seem so knowledgeable and comforting so I decided to post. Thanks for listening to me. Please feel free to post or just lurk whenever you want; there will always be someone to answer you very quickly. Hi Darlene, Sorry about your diagnosis but you have come to a wonderful board! Whatever surgical decision you make will be the one for . . .

Carla, I am, Judi, new to this board but you are already one of my hero's. I have been humbled by the strength and support of the women who share a special portion of their lives here. I usually lurk and read the postings, because when I feel depressed and blue about what is happening to me, I am uplifted by the remarkable spirit displayed by the women here! At times, I give myself a good kick in the pants because my battle is not . . .

Hi all. Well, I have been lurking since we started this new board. I only posted a few times on the old board as it is. I am currently getting my radiations and am just a little more than 1/2 way. Doing pretty good actually and feeling fine.

DISCUSSION

The data we have presented here fit our speculative hypothesis that unique to online SHGs is the ability of participants to locate for themselves a setting that matches their need and style. Unfortunately, we have no information directly from the participants what they were looking for in an online group, nor even information whether our speculations would match their reality. Obviously, the article is just a start in beginning to understand the dynamics and processes of self-directed Internet groups. Perhaps the next step would be to generate

information from participants at the time they join a group in order to understand, from their perspective, how the decision was made.

The power of the analysis of change found in the women we studied, was similar in power to studies reported for BC patients who participated in professionally led groups. Perhaps, the fact that in the SHGs, women's ability to find a fit between their needs and a group accounts in part for the effect we found in the online groups.

Many questions remain unanswered. Although effective working collaborations can be established with online groups, the degree of research control by the investigator is limited. For example, our study deals with women who joined the various BC bulletin boards. We have no knowledge of how many "lurkers" there where who read the postings for months without ever acknowledging their presence. Nonnecke and Preece (2000) report that lurkers made up 45.5% of health support communities. The first example of lurkers shown in the previous section is a testament to the power of just reading the messages. . . . "I have been lurking here for about 7 months and must tell you that I have gotten so much support from everyone by just reading. . . ."

There were probably many other women in the groups whose participation remains as a reader of messages. How many of them derive benefit would be important to study, but at present no information on such "silent participants" is available.

Online SHGs serve thousands of people with diverse and varied problems. In a previous article (Lieberman & Russo, 2001-2002), we noted that for breast cancer alone, we were able to locate 150 such groups. The new expression of self-help needs to be recognized by all those who are interested in the area. Such groups deserve increased scholarly attention.

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