

**SELF HELP GROUPS AND THE INTERNET:
BREAST CANCER NEWSGROUPS***

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ABSTRACT

Examined are the similarities and differences between self help groups (SHGS) and their Internet variant, the electronic self help group (ESG), which often takes the form of the online newsgroup or bulletin board. What are the advantages and pitfalls of the technology that provides an alternative setting of support to traditional SHGS? Studies of SHGs suggest that certain minimum conditions must be present in order for such groups to provide a helpful environment. These include the sense of similarity that provides for normalization of an illness, problem, or status, a modicum of stability of the group over time, provision of support, access to relevant information about the problem, a cognitive framework that provides an understanding of the problem and how it can be overcome, and the role of the indigenous leader(s). We address how self help expresses itself on the Internet; specifically, how effectively the above conditions are met online.

This study examines the similarities and differences between self help groups (SHGS) and their Internet variant, the electronic self help group (ESG), which often takes the form of the online newsgroup or bulletin board. What are the advantages and pitfalls of the technology that provides an alternative setting of support to traditional SHGS?

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Studies of SHGs (Lieberman & Borman, 1979) suggest that certain minimum conditions must be present in order for such groups to provide a helpful environment. These include the sense of similarity that provides for normalization of an illness, problem, or status, a modicum of stability of the group over time, provision of support, access to relevant information about the problem, a cognitive framework that provides an understanding of the problem and how it can be overcome, and the role of the indigenous leader(s). This article will address how self help expresses itself on the Internet; specifically, how effectively the above conditions are met online.

There is a large number and variety of newsgroups addressing physical and emotional illnesses. Many investigators have drawn parallels between SHG and the newly emerging nonprofessionally led newsgroups which address personal problems and health concerns. The study of online self help has, in the past few years, taken on added importance as there are currently over 100 million Americans using the Internet. For many Internet users, a major function of the Internet is as an information source for health problems. A recent PEW report (Fox, 2000) found that 52 million (55 percent of all who had access to the Internet) went online to find health related information for themselves or their family members. Of those accessing health information, 9 percent (4.7 million) participated in health related online support groups, making the Internet a source of information for people dealing with health issues as well as a venue to communicate with others who are facing similar situations. Most electronic support groups (ESGs) are asynchronous and involve postings to a bulletin board or e-mails distributed through a list serve, although some are synchronous (live chat rooms). Users can find ESGs on commercial servers (e.g., AOL) who make the groups available only to their subscribers, on the Internet at large, as well as on many of the health-related Web sites open to all.

How relevant is this analogy frequently drawn between SHG and Internet newsgroups? Can we think of the latter as simply a context difference? The designation "self help group" is commonly applied to a wide variety of activities (Killilea, 1976). Self-help, or mutual aid groups, is an ill-defined, unbounded area, in which arbitrary judgments rather than conceptual structure are the rule. The most parsimonious definition of SHG is that they are composed of members who share a common condition, situation, heritage, symptom, or experience. They are largely self-governing and self-regulating, emphasizing self-reliance and, generally, help that is easily available and accessible without charge. They tend to be self-supporting rather than dependent on external funding. By these standards, newsgroups certainly meet the criteria.

We thus set out to study the particulars of newsgroups, in hopes of isolating specific conditions and their "group's culture" by using the framework developed in a series of SHG studies (Lieberman & Borman, 1979). Specifically, we examined how newsgroups address some of the central tasks that were shown in SHG studies as conditions crucial for successful SHGs. To aid in our

understanding, we examined the characteristics of the ESG's in comparison to online professionally conducted therapeutic groups. Finally, we illustrate the power of the on-line SHG's by reporting some highly preliminary effectiveness data.

Prior to describing the findings we will review what is known about online support and help. Most of the studies to be reviewed involve some professional input, although the vast majority of health-related ESGs are not professionally facilitated. Several studies have shown that individuals participate in electronic support groups in ways similar to face-to-face groups. Online members offer support, information, validation, and encouragement. An analysis of messages posted to a bulletin board focusing on disabilities found that greater than half of the postings involved socioemotional exchange (Finn & Lavitt, 1999). Klaw, Dearmin, and Humphreys (2000) analyzed randomly selected messages to investigate the features, patterns, and functions of communication in an online mutual help group (OMHG) for problem drinkers. He reports that the most prevalent form of communication was self-disclosure, followed by providing information/advice. As in face-to-face groups, conflict was infrequent and communication was generally warm and supportive. Salem, Bogat, and Reid (1997) investigated gender differences in the use of an online mutual-help group for persons suffering from depression, as well as the similarity of the group's interactions and organizational features to those of face-to-face mutual-help groups. Participants in the online group communicated in ways characteristic of face-to-face groups; high levels of support, acceptance, and positive feelings. The content of men's posts were virtually identical to those of women's. In another study, Salem et al. (1997) used a qualitative methodology to describe the characteristics of an online mutual-help group for depression. The characteristics identified were related to: 1) group access (universal accessibility and technical difficulties); 2) lack of physical and auditory presence (anonymity, lurking, and lack of personal information); 3) access to archived information; and 4) members' roles (development of out-of-group relationships and dispersion of leadership).

Compared to traditional face-to-face support groups, ESGs offer some unique advantages. Due to its 24-hour availability and lack of geographic barriers, the Internet allows users to access support at times and places where traditional forms of support are unavailable. In a study of ESGs for individuals with eating disorders, two thirds of the messages posted to the newsgroup were between 6 P.M. and 7 A.M. (Winzelberg, 1997). Members of an online cancer support group reported that the freedom to participate at times convenient to them was a significant advantage of the group (Weinberg, Schmale, Uken, & Wessel, 1996). The time delayed nature of bulletin boards gives participants an opportunity to think about responses before posting, which may allow for more thoughtful interactions. Electronic communication provides maximal flexibility and opportunities for expression because individuals can post as frequently or infrequently as they want and can read or ignore whichever postings they choose. Anonymity

can facilitate the discussion of subjects thought too private and intimate for face-to-face venues and can give those individuals who have felt intimidated by face-to-face encounters an avenue to seek and give support. Dunham found that an ESG for single young mothers was used most frequently by those who were socially isolated (Dunham, Hurshman, Litwin, & Gusella, 1998). They also reported that prior computer experience and socioeconomic factors were not related to individual differences in use of the system in their study.

M. W. Miller (1997) suggests, after reviewing cancer patients' support groups, that the realtime nature of the communications in some cases may have a unique significance for the impact of the support. People who have never met in person—those who participate in online group interactions—can develop a sense of community and are able to offer a virtual shoulder. This virtual community is similar to a real community in some ways, and very different in others. For instance, people who engage in online groups tend to feel uninhibited in many ways, a feeling that facilitates fast, intimate disclosure and frank, authentic responses. Online groups address a variety of health problems: cancer (Sharf, 1997; Weinberg et al., 1995; Gustafson, Wise, McTavish, Taylor, et al., 1993), recovering addicts (King, 1994), sexual abuse survivors (Finn & Lavitt, 1994), bereaved parents and those coping with death (Schwab, 1995; Sofka, 1997), social phobia and avoidant personality disorder (King, Engi, & Poulos, 1998), obsessive compulsive disorders (Stein, 1997), eating disorders (Winzelberg, 1997), anxiety (Glasser Das, 1999), alcohol abuse (Lieberman & Humphreys, 2001), gender differences in online cancer groups (Klemm, Reppert et al., 1998), seeking social support (Mickelson, 1997).

Overall, the majority of published studies on Internet based support are positive. Studies of online support groups, such as one dealing with depression, have revealed that people communicate in them in ways that are characteristic of face-to-face communications; that is, with high levels of support, acceptance, and positive feelings (Klaw, Dearmin, & Humphreys, 2000; Salem, Bogat, & Reid, 1997). However, there is reason to treat the explosion of Internet use in general and Internet support groups with caution as well. A study of new Internet users found that greater Internet use correlated with larger reported increases in loneliness and depression among subjects (Kraut et al., 1998). Study investigators cite the replacement of strong ties for weak online ties as a possible cause. They explain that strong ties, supported by physical proximity and involving frequent contact, broad content, and feelings of obligation, generally buffer stress while weak ties with narrow focuses may not. It is important to note that this study looked at Internet use in general and not participation in online support groups specifically. It may also not be applicable to individuals who start out lonely and depressed. The same investigators, however, in a to-be-published study of a three year follow-up of the original sample in many respects contradicts his original research. Following up with the subjects of his first study, they found that the symptoms of depression had declined and that loneliness no longer appeared to be significantly associated

with Internet use (Kraut et al., 2002). Yet, despite the potential pitfalls of ESGs, anecdotal evidence shows that members seem to be generally satisfied with their participation. Members of computer-mediated cancer groups all agreed that the group was helpful (Weinberg et al., 1995).

Testimony from our own study of breast cancer (BC) newsgroups (to be described subsequently) echo Weinberg's study as well as demonstrate that what was helpful for these women reflects findings from studies of traditional SHGs. The women were asked to describe their thoughts about the value of the group and describe their "best experiences." These responses are shown in Table 1. The type of experiences they found helpful are very similar to those cited by participants in tradition SHG such as normalization of their illness or problem, finding people like themselves, and getting meaningful information and support.

From the responses we received, satisfaction with online groups appears high, and some of the processes commonly identified in face-to-face support occur online. For some, online is a preferable mode of working. People interact with

Table 1. Best Experiences

Experience	Number of respondents citing
Not feeling alone, knowing others in a similar situation	11
Getting encouragement, support	9
Getting helpful information	7
Ease of access	6
Friendship	5
Anonymity	3
Helping others	3
Sharing problems, feelings, concerns	3
Speed of feedback	3
Meeting women face-to-face	2
Gaining sense of hope	1
Laughter	1

each other on the Internet in the absence of cues indicating age, race, gender, and physical appearance. While this can become dangerous when abused, it can also foster the development of relationships based on shared interests instead of shared social characteristics. "Lurking," or reading messages without posting, allows individuals to become familiar with norms of the group and learn about members before disclosing.

THE STUDY

Methods

The target ESG of our study was breast cancer newsgroups. During October 1999 we identified, to the best of our abilities, the entire universe of such newsgroups. We wrote the Webmaster of each site, asking permission to post a message which provided a link to an online survey we developed for women with breast cancer. Numerous e-mails to each Webmaster yielded no response and because every board was open to the public and additional messages advertising studies and treatments were observed on the boards, we decided to precede with a single posting describing our interest in collecting information on online support groups for breast cancer patients. The message contained a link to our study Website and interested participants were asked to visit the Website constructed for our study. The Website detailed an explanation of our interest, provided information about the investigators of the study, and contained a series of questionnaires to be filled out anonymously.

A series of demographic questions, questions about computer/Internet use history, and overall satisfaction and/or dissatisfaction with online support group were included in the first part of the survey. Part 2 included a measure of Quality of Life, a standard method of assessing cancer patients. (*Quality of Life (FACTB)*): The Functional Analysis of Cancer Therapy, 44 items, measures multidimensional quality of life (QL) in patients with breast cancer (Tedeschi & Calhoun, 1996). Participants could choose to complete only Part 1 or both Part 1 and Part 2. As the study was advertised to various newsgroups, respondents were from numerous newsgroups, although which ones and how many is impossible to discern as all surveys were completed anonymously.

Samples

Sample 1

Sample 1 was comprised of 21 women who responded to our online survey. Their reported ages are as follows: 10 percent aged 31 to 40, 33 percent aged 41 to 50, 48 percent aged 51 to 60, and 10 percent over 60. Thirty-three percent of the respondents live in small towns, 24 percent in rural areas, and 43 percent dwell in

cities. They are by and large an educated group of women: 43 percent post college, 14 percent college graduates, 29 percent some college, and 14 percent high school graduates. Eighty-one percent of the women are married, 14 percent divorced, and only one woman is single. Fifty-seven percent work full time. Only 19 percent do not work outside the home. About one-third are new to the Internet, and another one-third have been online for three years.

Sample 2

Sample 2 was composed of women posting messages to one of three active BC newsgroups open to anyone with Internet access: Yahoo Club Breast Cancer Forum, IVillage Breast Cancer Message Board, and WebMD Breast Cancer Open Discussion. In November 1999 we downloaded all of the messages posted to the newsgroups we had identified. Our presence online was indicated to the members, we then accessed their archives for gathering the exchange of messages during the specified times. We found that many of the newsgroups appeared not to be actively functioning. For example, one group had only five members who posted only one message each and never posted again. The data to be reported focuses only on the three most active newsgroups. During the month of the initial sampling, the three groups collectively had 531 different respondents who posted one or more messages. The same newsgroups were again sampled in March 2000.

RESULTS

A. How ESG's Address the Critical Tasks of Developing and Maintaining a Productive Environment

1. Similarity

There must be a sense of shared similarity among the members based upon a common affliction or problem. SHGs and ESGs address the task of providing a sense of shared identity differently. The narrow similarity of affliction or condition is not characteristic of online groups. SHGs need not be demographically similar but the almost instantaneous experience of relating to and being understood by others in the group who experienced the same problems is critical. An example from our studies of SHGs is the case of Mended Hearts, a national self-help group providing support services to patients who have had open heart surgery. Mended Hearts was once faced with the dilemma of whether or not to admit patients who had heart valve replacements and at a yearly national convention debated opening up criteria for membership. A common theme that emerged during the debates was these patients would not be similar to open heart surgery patients because they did not undergo the identical surgical experience.

In the online groups we studied, not all the participants had breast cancer; some were family members (parents, husbands) as well as friends of a BC patient. The stage of cancer and time since cancer also varied, from stage one to stage four, from newly discovered cancers to those who had been diagnosed over 10 years ago. This diversity far exceeds the usual range in SHGs. We explored how these groups “solve” the task of creating a setting where almost instant identification with other could take place arises.

The following provides an example of responses to a new member, illustrating this process.

Where do I start. I just moved from a small town to a larger one for work in May. I only know ten people and no one really close for support. I had the following done: Aspiration of cysts, needle biopsy, stereo tactic core biopsy, then surgery to remove calcium deposits and cyst. The found lobular carcinoma, and invasive ductile carcinoma. They said it was microscopic and I would only need radiation and drug therapy. This is only the second mammogram I've ever had, and I'm just so scared. I don't want to die yet. I'm trying to cope with all this, but I just want it to go away. . . . I just feel lost and so alone. A word of encouragement would greatly help, and thanks for listening.

You said you moved to a small town a few months ago. How small is small? When was your lumpectomy. . . . It sounds like you haven't started radiation and drug therapy yet. There are lots of ladies here who are going through the same treatments, and I'm sure they will respond to you. Don't let your fear become overwhelming! Start by learning as much as you can about your type of cancer, surgery and treatments. . . . Please come back here and get to know some of the other ladies, and let us help you through this difficult time.

I'm new to the board also, but I can't tell you how much it has meant to me in the past couple of weeks. I have found that when I vent on the board and get all the great feedback from these wonderful ladies that I am able to go through the day without obsessing about the cancer. I am 12 hours away from all my closest friends and family, so I feel somewhat isolated too. . . .

Now that you have found this board and all the wonderful people here you are not alone. Post anytime you want to cry, scream or even laugh! I know this time is so hard but do try to keep your thoughts positive. A cancer diagnosis is NOT a death sentence. WE here are proof of that. You sound like you are taking care of yourself. Be positive with your mind as well as your body and you will get through this.

I was ucky because my parents came 1,000 miles to help me through. Call your best friend, favorite relative and talk to them when you need to. The cost of a phone call is very minor compared to your peace of mind. You can also contact Y Me or the American Cancer Society for support groups. Ask your doctor for info about support groups through your hospital. Talking to someone who has been there, like us on this board, will also help you. Good luck.

Hi You have come to a special place. I have been posting about 3 weeks and it is great support. I finished 8 cycles of chemotherapy after my lumpectomy and am now doing radiation. I have also started Tamoxifen. It has been a long road, but as I look back it has gone fast and I can see so many positive things that have come out of it. At first I had my time where I panicked and thought of my future and saw all the bad things that COULD happen. Don't do that. I believe prayer has what has kept me going. I gave all my worries and fears to God and I feel like he has a plan for me.

. . . It helps, helps, helps to talk with others. I understand your fears fully. Keep the faith.

. . . we don't mind telling you what we think, so PLEASE talk to us! I am 45, was diagnosed 6(?) years ago after being married for only 4 months. After my lumpectomy, I had radiation, then spent the past 5 years on Tamoxifen. It would be great to talk to you more, so if you would feel more comfortable e mailing me, please do at. . . .

This illustration shows the way newsgroups with a large membership provide a subgroup of women who have similar illness experiences. It also demonstrates the communication of an important group norm permission to express intense emotion. The messages sent to the new member provide the broad outlines of how the group will help: by providing advice, by providing information based on their experiences thereby making the new member experience similarity, and by providing acceptance and warmth.

2. *Membership and Stability*

For traditional self-help groups to continue through time there must be a mixture of old and new members. In our studies of various SHGs (Lieberman & Borman, 1979), we found that those closed to new members rarely last. The role of the old member is critical as they carry on the group's culture, history, and methods of working. Often these members serve as the unofficial leaders of the group.

The usual approach to assess membership in an SHG is not appropriate for online groups. In many online groups, although people register, they may not actually post any messages. Complicating assessing membership is the unique characteristic of most newsgroup that actively encourage people to "lurk"—to read posts but only post when they feel ready. Obviously, there is no adequate way of determining how many lurkers there are. We only know of their presence when they post.

The most reasonable approach to assessing "membership" is to count the number of posters and the frequency of their postings. Figure 1 shows the numbers of posters in November 1999 and March and April 2000. Several findings are worthy of note: a) The turnover in membership is high: for ALLHEALTH, 85 percent between Time 1 and Time 2, 71 percent between Time 2 and Time 3; for WEBMD, 75 percent; and for YAHOO, 61 percent and 63 percent. b) A core of

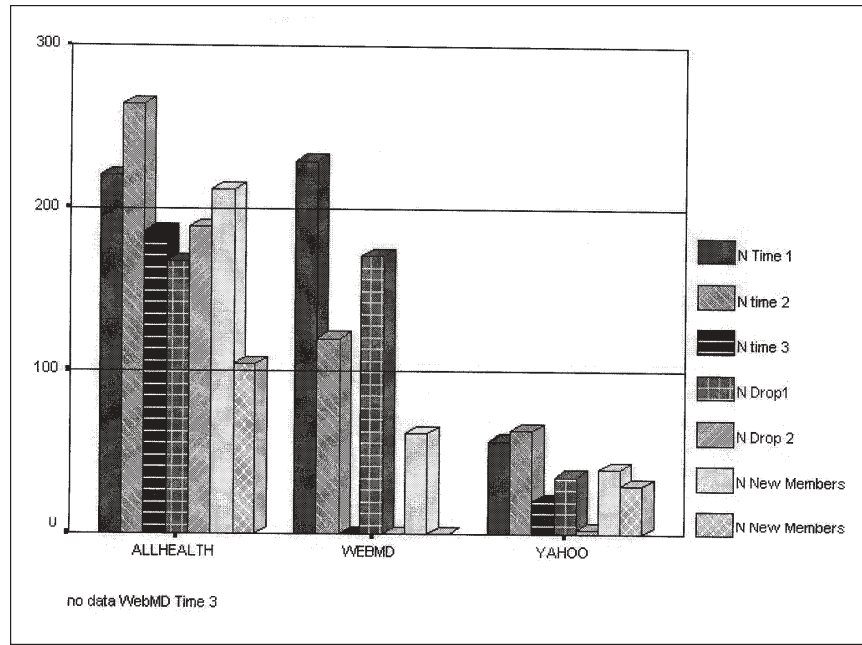


Figure 1. Number of members.

high posters remains over time. Many of these high posters, when examining their posts, are clearly performing leadership functions by greeting new members and transmitting the norms and culture of the group. The turnover rate in membership seen in SHGs we studied is 50 percent over one year (Lieberman & Borman, 1979).

These three groups appear to remain relatively stable in total membership over time; they are ongoing systems that, despite the turnover in membership, manage to keep a core of active members that provide continuity. The presence and mechanism of a core group that provides leadership and communicates the culture of the group over time is similar in both SHG and ESG. This continuity is contrasted to many of the online breast cancer support groups first visited in November which never appeared to coalesce and were not successful in recruiting more than a handful of participants. When we returned to their site in later months, many no longer existed. Unfortunately, we could not generate useful information on the differences between “successful” and “failure” groups.

Distinct in ESGs are their views of lurking, where a member reads messages but does not post messages. Although it is not uncommon for a new member of a SHG to be relatively inactive at the onset, this rarely extends beyond several meetings.

The avowed acceptance and even suggestion that new members lurk for a while has no parallel in SHGs. The following are examples of interactions typical in the groups.

You've been another lurker before posting. I think all of us were at one time or another. I'm glad to hear you are doing pretty good after the first chemotherapy. . . .

Why don't you do just a one liner like I am checking in and am ok. We don't know when you are lurking and worry about you. Know you aren't feeling good, but please let us know you are listening and we can send words of encouragement. . . .

Hello everyone. I have been lurking since my first few posts. Saw the oncologist for the first time yesterday and I have some decisions to make. Actually I have to have more tests, CT, bone scan, heart, sometime this coming week. . . .

For a while we had an OT who would post here, S. but I haven't seen her post lately. Hopefully she's lurking I'll post another message for her to see if she's still around.

As far as I am concerned, you are welcome here any time, but please post if you stop in don't be a "lurker," OK? . . .

Somewhere along the line of lurking. I recognize your post name. Mary gave you a good welcome, and I second that. Please join us anytime, we love company. Sometimes we're almost like a Coffee Klatch. and we do discuss a few other things besides our cancers occasionally!

You were lurking. You have really had a rough time of it. I have been messing around with problems too long, too, but nothing like yours. Glad to see you here. Don't go crazy trying to. . . .

L., if you're lurking, turn on Instant I did, but you were gone! My phone was busy, too, . . .

3. A Cognitive Framework

Required in all SHGs is a conceptual framework that provides an explanation of the illness and a framework for how to overcome their common problem. Some groups, such as Alcoholics Anonymous, communicate this very clearly, while for other groups the cognitive framework is implicit rather than explicit. However, whether implicit or explicit, the cognitive framework is a critical element in a successful SHG. Our analysis of the three BC newsgroups found that the core members share views that provide a framework of how to cope with the disease, involving the notion of fighting and actively combating the disease.

The idea of fighting spirit is illustrated in excerpts from all three groups.

We've come into another realization, I think, that we can "battle" cancer without going to war. That is where so many healing images have come into being. It is through. . . .

Still, there are some of us who must continue to use the battle imagery, fighting cancer with everything we have our anger, our fear, our hopes, our dreams. For those who Stay with us as we all fight this disease. We are more than delighted that you have chosen to join us.

We somehow pull together the inner strength to fight cancer. We should not feel so bad about showing our bald heads so we can be physically I think Karen's days were numbered at one point, but she won. I hate all the vocabulary that goes with breast cancer fight, battle, survivor. I don't feel like I had much of a battle cancer snuck up on me and I responded with a stealth attack. Surgery and chemotherapy.

. . . have something that I would like to send you. Whatever you do, don't quit. As long as you have a breath left in you, fight this damned disease. Do not go gently into that dark night.

I had never really doubted that I had won this fight, that the cancer was gone for good. . . .

Hi June, Good luck in your fight against cigarettes. You've already won the battle with breast cancer, so you can do this, too. You quit on my birthday 46 yesterday, so I'll always think of you on people walking around right now for which cancer is a distant memory. This is a fight that CAN be won.

. . . didn't even need a biopsy to know something was eating my boob up. Just have your moment and then get in there and fight. Read everything about your treatments.

I filled the prescription the day I realized that I not just my doctors needed to actively fight the disease prevent its return. . . .

Remember, I'll be holding your hand while you embark on this next step in your fight against this lousy disease.

4. Support

Crucial to the helping function of SHGs are a set of interrelated qualities members need—to be accepted and provided unconditional love and support. Many SHG scholars believe that being both the recipient as well as the provider of support maximizes benefit. In our studies of traditional SHGs, we additionally found that communicating with other members of the SHG beyond the formal meetings was linked to maximum benefit/outcome for participants.

Measurement of how supportive a group is experienced may be obvious to the participants yet difficult to conceptualize and measure. Support can be assessed by

ratings of member behavior toward one another or can be assessed through the perceptions of the recipient of the support. We approached this issue by generating several types of data, both direct and indirect assessments.

Perceptions of support—We asked online support group participants who visited our study Website to complete a general support questionnaire asking how well supported by family and friends each woman felt. The questionnaire also included four questions about their experience in their newsgroup. Each question was answered on a 7 point scale: 1 = very much disagree to 7 = very much agree. The four newsgroup items and the mean scores are: I can talk about my concerns with members of the Internet group [6.3 (0.94)]; I believe the members of the Internet support group understand my concerns [6.5 (0.8)]; I trust the advice I receive from the members of the Internet group [6.0 (1.1)]; I feel supported by the members of my Internet group [6.4 (1.0)]. To put these scores in perspective, we examined the means of all the other items of the questionnaire. They ranged from a high of “There is a special person with whom I can share my joys and sorrows [6.0 (1.4)]” to a low of “I can talk about my problems with my family. [4.8 (1.7)].” Clearly, those who responded to our online questionnaires saw the members of their newsgroups as providing a very high degree of support.

Indirect assessment of support—Although initially almost all members in the newsgroups go online with a pseudonym, this drops away very soon. One indirect measure of support was the number of e-mail exchanges between members, revealing an exchange of personal information and a certain level of comfort and trust. During the month of November 1999, 84 different participants posted their e-mail addresses directed toward another member in Yahoo, 176 in WebMD, and 111 in IVillage.

In examining the context of the e-mail listing, the overwhelming majority represented a supportive message to another newsgroup member. For example:

So sorry you aren't feeling well. I'm also sorry to hear about your swollen glands given what you mentioned to me in our last e-mail. I'm positive you are A OK. Please be positive. You will be receiving loads and loads of prayers from me and you will be in my thoughts constantly. Please e-mail me and let me know how your visit goes with the surgeon tomorrow and the oncologist on Thursday.

Good luck today! I'll be thinking about you. If you want to “vent,” please e-mail me. My address is. . . . I am in remission now, but I remember all too well the fear I felt prior to going to the surgeon. Please let us know how you make out.

Problem something else comes along to add insult to injury. But it does go away and one day, not too long from now, you will also be finished with the chemotherapy. Will you have radiation afterward? If you would like, e-mail me at . . . since we have similar treatments. Everyone is different of course,

but for me taking each day, one at a time, worked best. After each treatment, when I started to feel well again, I wouldn't even think about the. . .

5. Leadership

The role and designation of leadership in SHG is a highly understudied area. When we compared the number of published papers on group psychotherapy through 2000, of the over 16000, 1300 focused on the therapist; comparable figures for self help groups, of the over 2200 publications, only 59 addressed the topic of leadership. No studies are available for electronic SHGs. In examining the transcripts from the three groups studied, it was relatively easy to identify who were the group's central persons (usually more than one); they were much more active, from 10 to 15 percent of all messages and more often than not they were verbally acknowledged by the members. These women served the leadership functions by serving as a model for others, often by self revelation; they were frequently the expressive leaders of the group. They provided management of the interaction and above all communicated the norms and ideology of the group to new members. The following are excerpts from the leaders of the three groups.

I would like to thank everyone for a great chat tonight. Even though Yahoo was being quite rude! Welcome to all the new members. You will love it here. We have a great bunch of ladies and a few gentlemen. To the regulars its always nice to chat with you. Hope to see more for our big chat Friday at 8pm CST. I apologize to anyone that didn't get an invitation. Yahoo doesn't even seem to be able to do that correctly!

Welcome to the club. You have come to the right place, everyone here is very caring, loving, helpful and knowledgeable. Have you told your doctor about your arm? I did the exercises where you take your fingers and walk them up the wall, then put a mark there, and each time try going a little higher. But before trying anything new, please ask your doctor. Hope to see you in chat sometime. We are having our big chat this Friday at 8pm CST.

So sorry to hear you are feeling blue. I hope things get better for you. I can relate to this as I think we all have times like this. Hang in there and if you need me you have my e-mail address.

Welcome to the club. Sorry to hear about your mother. It is quite a shock when you are first diagnosed but things do get better. Did she have any lymph nodes involved? You have come to the right place for encouragement, compassion and great information. Will your mother be joining us also? We would love to have her as a member.

Welcome to the club. If you need answers you have come to the right place. I was not a candidate for tamoxifen but there are plenty of ladies in here that can tell you what you need to know.

All through my chemotherapy I used Simmontons Relaxation and Mental Imagery As Applies to Cancer Therapy. I truly believe it helped me get to

where I am today. I like his tape and use many of Bernie Siegels tapes also. Miss you.

Glad your mammogram is over. Sorry to hear there is something showing up. How about another opinion on the reading? Keep us posted.

Yes, chest x-ray results are ready just as soon as the film is developed. Usually pretty darn quick! You're gonna be just fine, sweetie! Don't you worry about a thing. Mama M. predicts! Didn't I tell you I can predict for others but certainly NOT myself?

Isn't how funny how quickly we connect with each other here? We all have a common bond, to which others just can't relate! Until a life-threatening illness touches your body, you just can't begin to relate to what someone else is feeling. I feel the same way about each and every woman on these boards. They're the warmest, most loving women I've ever met!

Go D! Go kick whatever-it- it's butt! You made the right choice to get the thing removed, no matter what. If it's nothing, then you'll have your peace of mind and will no longer have to be "Just nervous!" We D. and will be praying for you Friday!

So glad you're home! I'll be praying for benign stuff on the pathology report next week! I know you're glad to have this behind you now. Just remember, step by step one step at a time!

Would you mind terribly much sharing your story with me? What was it like. What was your cancer. What were your side effects. Tips to make it go more smoothly? I sure would appreciate it! I am duly humbled by your fortitude! And here I am whining and sniveling about a possible transplant! Would you mind e-mailing me at _____ I have a ton more questions for you! You are an amazing woman!

Way to go, girlfriend! I'm sure you're dancing around on cloud nine! Do a jig or two for me too, okay? I'm so happy for you! Please stop by from time to time. We'd love to keep hearing from you!

Just as they have special gifts for specific anniversary celebrations, I think we should have a special gift for the number of years of survivorship. We'll all need to come up with some good ideas. Then, we'll have to have milestones called the Silver, Gold, Diamond, etc. I'm sure you ladies can come up with some really good stuff. We're like L, we cost more but we're worth it. Check in with you later.

Went through 18 months of chemotherapy, double radiation, ten surgeries. Original expiration date was 8/96. I'm still here. Everyone is different so while we can tell you of our experiences, you can't base our experiences on your situation. But, that does not mean you should give up any hope. I'm living proof that God can work miracles. Know that there have been women with many more than 7 positive nodes who are with us. This board will archive soon and you may need to re-post your message on the new board. That way,

more ladies will be able to provide support. Get ready to answer a lot of nosy questions. We need to know all we can in order to advise. But, stay with us. We need you.

The old-self I grieve for is the one I had at 21. Next to it, the self I have now is who I am. You will never be the same, physically or emotionally. But, you will survive. And, you may be surprised at the person you become. G., as usual, has given you some good advice. You are now faced with becoming the new you. God never closes one door that he does not open another, better, door. Don't waste today looking behind you at a closed door. Open the new one and head forward.

Get to the doctor immediately. You will need mammogram and possible sonogram. No lump should be brushed off with the comment that it is "probably" anything. You need to know exactly what it is. While most lumps are NOT cancerous, you cannot afford to take that chance. Our board will archive tonight; however, we want to hear from you on Monday that you have the required tests scheduled. We'll continue to push you until you do. . . .

Comparisons to Professional Leaders

To gain some purchase on the nature of online leadership, we compared the behavior of these three SHG leaders to our study of online Internet groups for women with breast cancer conducted by trained professional group therapists (see Lieberman et al., (2002, in press) for a description of that study). To compare the behaviors, we used a computer-facilitated text analysis program LIWC (Pennebaker, 1999). The text analysis provides a method for studying the emotional, cognitive, and content components present in written speech samples. This data record includes eight affect and seven cognition categories (AFFECT: Positive Emotions, Positive Feelings, Optimism, Negative Emotions, Anxiety, Anger, Sad; COGNITIVE: Cause, Insight, Discrepancy, Inhibition, Tentative, Certainty). All the leaders' and member' verbal behavior were coded by the dictionary (the SHG sample consisted of 44 weeks of interaction; for the professional online groups, 114 weeks (4 groups)). We tested leader/member differences using multivariate analysis. Statistically significant differences were found between leaders and members in both settings. SHG multivariate affect $F = 2.6$ ($df = 8, 36$) $P = .05$, cognitive $F = 9.1$ ($df = 8, 36$) $P = .05$. For the professional groups affect $F = 1.81$ ($df = 8, 106$) $P = .08$, cognitive $F = 19.1$ ($df = 7, 107$) $P = .000$. In both settings, leaders/therapists expressed overall more cognitive behavior, especially by attributing causality, making insight directed statements, and expressing less certainty. There were also differences between leaders and members in the affect area for the SHGs, both SHG leaders and professions were similar in expressing more overall affects but specific affects did not reach significance among professional leaders. The SHG leaders expressed more angry

feelings than did the members. In general, the patterns of verbal behavior among leaders in both settings are highly similar and distinct from their members.

The two settings were compared on the content of their interaction. The LIWC was again used, applying as series of content categories (leaders were not included in this analysis). Overall, the professional and SHG's differed significantly (overall multivariate analysis $F = 4.01$ ($df = 12, 183$) $P = .00$).

Specifically, areas of differences were school, religion, body, sexuality and eating. Figures 2 and 3 show the content categories.

B. Effects on Participants

There are few formal studies published on the impacts of online SHGs. The problems of studying in situ groups of traditional SHGs has been well documented by others (Kyrouz & Humphreys, 1997) and will not be repeated here. The problems facing an investigator of online SHG are even more daunting because many groups use codenames (although, in the BC groups we studied, members soon gave up their anonymity to exchange phone and e-mail addresses), the turnover rate is high, and it is difficult to track members over time. Additionally, meaningful control groups are unavailable. Twenty-one women responded to our online survey about ESGs for women with breast cancer. As the online questionnaires were submitted anonymously, follow-up assessment was not

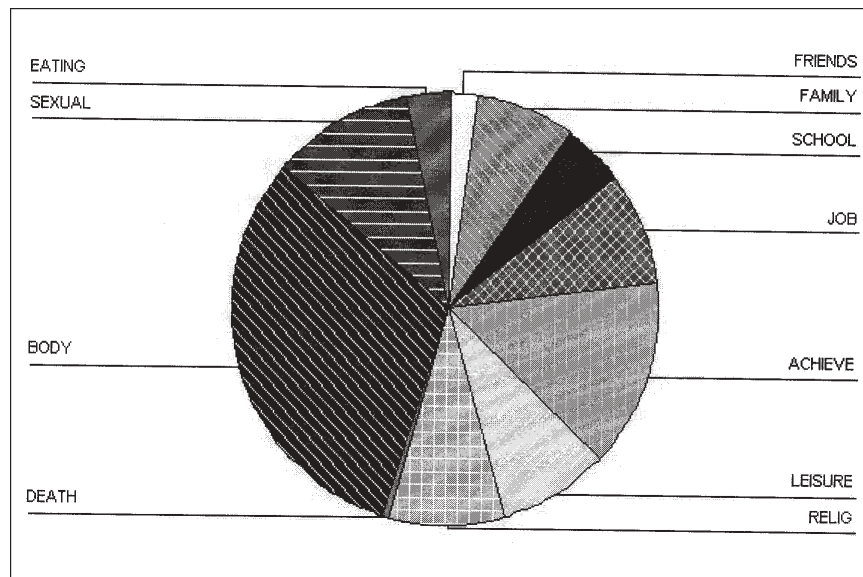


Figure 2. Content – Total = 100%.

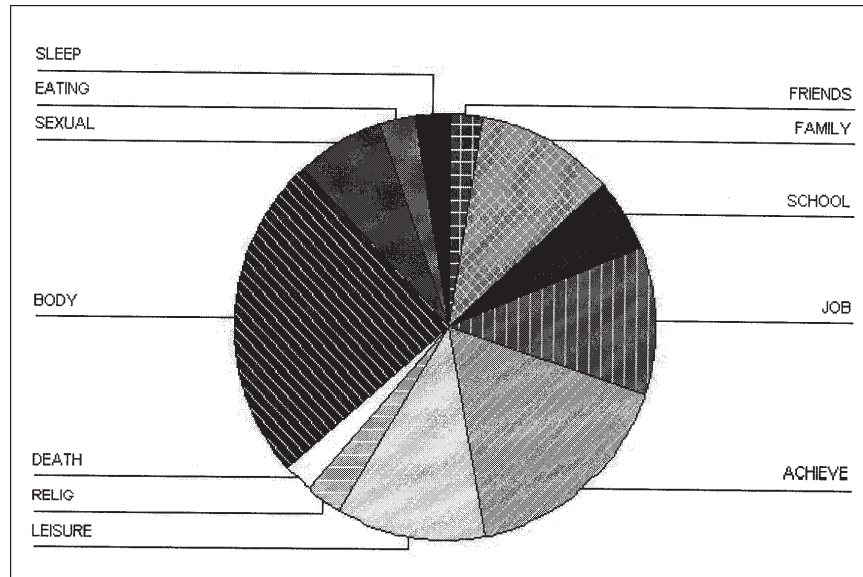


Figure 3. Content professional groups.

possible. The following results represent the status and level of functioning of the respondents at one point in time. Many of the respondents had been members of the online group six months or more, with a mean of 9.4 months.

We chose to compare the ESG results outcomes to our recent survey of participants of face-to-face groups of The Wellness Community (TWC), a national organization which provides professionally-led support groups to cancer patients. The sampling strategy was to request from each of TWC's centers distribution of 30 Q's to three of their groups, one new group (meeting less than three months and TWC mature groups (meeting over six months). A total of 302 questionnaires were completed. We drew a sample of the respondents, those with BC who had participated less than six months ($N = 31$) and those who were a member for over six months in the TWC groups ($N = 41$) and compared their scores on *Functional Assessment of Cancer Therapy general* (FACT) with the respondents of our survey. The FACT is a self report instrument designed to measure multidimensional quality of life (Q.) in patients with cancer in five subscales: social relationships, physician relationship, well being, functioning, and physical health. Validity and reliability data were obtained from a sample ($n = 295$). The alpha coefficient, total score ($\alpha = .90$), with subscale alpha coefficients ranging from .63 to .86. Table 2 shows the results of these comparisons.

A MANOVA comparing the newsgroup participants and the TWC groups of TWC participants found: significant differences among the three groups on scores

Table 2. Comparisons between Newsgroups and Professional Groups

Sample	Newsgroups	Two < 6 months	Two > 6 months
Physical problems	1.5 (.51)	2.4 (.85)	1.9 (.69)
Good social relationships	4.7 (.82)	3.6 (.84)	3.9 (.71)
Low well being	2.6 (.76)	2.2 (.83)	1.9 (.54)
Good functioning	4.0 (.36)	3.3 (1.0)	3.8 (.70)
Good relationship with physician	5.5 (1.5)	3.8 (.99)	4.5 (.62)

in all five areas ($F = 6.46$ ($df = 5, 83$) $P = .000$). Results of these cross sectional comparisons indicate that BC women when they first enter TWC are less well off compared to those who have participated in TWC groups for at least six months. The women in the newsgroups who responded to our survey and who had participated on average 9.4 months are doing significantly better than the TWC women early in the program. A pair-wise comparison from the MANOVA indicates no significant difference between TWC women participating over six months and women participating in the newsgroup on the scales measuring physical problems and level of functioning; the women participating in the newsgroup indicated better relationships with their physicians and social relationships but lower well being.

At best, this exercise comparing women's status as assessed by the quality of life measure suggests that those in the newsgroups are doing quite well at the time of measurement.

IMPLICATIONS

The observations made in the present study support the previous studies of online support groups described at the onset of this article. ESG groups mirror the processes and member perceptions found in traditional SHGs. Although differences imposed by the structure of online communication, size and diversity of membership in online groups, and above all, in the methods of communication, observations from our study do suggest that in many of the important ways ESGs function remarkably similar to SHGs. When we started the study, we wondered if people did form real and meaningful relationships with one another in cyber space. For us, this question has been answered in the affirmative. This in the face of concerns professionals express about online groups: "How can we understand the people in the group without be able to listen to their voice tones, see their facial expressions, and attend to their body posture? I may miss many subtle cues that are

critical for understanding what people are feeling and what they are experiencing in the moment.” There are obvious differences in these TWC settings, and to be successful ESG’s must develop strategies to overcome the limitations of limited cues.

The current study in concert with the limited number of other studies of online SHGs has only touched the surface of this rapidly expanding venue for providing service. Many questions require answers. Are there personal characteristics that would make online help more or less effective than traditional settings? What are the limits to psychological relationships on line? How effective are ESGs in providing help? Are there certain problem areas more suited to online help? What is informed consent and appropriate negotiations for researchers in this area? (See Humphreys, Winzelberg, & Klaw, 2000 for a recent discussion of this issue.)

Research on ESGs at one level is deceptively simple, yet the answer to the questions posed above are unfortunately complex and require innovative strategies.

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