

# **Characteristics and Benefits of Online Support Groups**

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This project sought affirmation of earlier findings of online disease-specific support groups. Support groups for Alzheimers, Breast Cancer, Esophageal Cancer, and Huntington's disease were studied. Literature suggests and this study agrees that group users are usually white, affluent, well-educated, and computer-savvy. The groups offer empathy, experiential knowledge, information, emotional nurturing, and a sense of control over disease. They are preferred over other support options. Altruistic behaviors are prevalent in groups - benefiting both giver and receiver. There is misinformation exchanged but it is quickly corrected. These groups improve the patient-physician relationship, fostering a team approach to disease, whereby patients receive a good education first, making more efficient use of their physician's limited time. However, most physicians do not suggest this alternative to patients. The project also investigated perceptions of privacy risk and whether real names are used in messages that may be archived and later retrieved from a personal computer.

**Headings:**

Information services -- Special subjects -- Disease  
Virtual communities -- Medical  
Information needs -- Medicine  
Information needs -- Self-help  
Surveys -- Information needs  
Use studies -- Internet

*To Aunt Alice and Guy, if only I had known this at the beginning of your battle.*

## **ACKNOWLEDGEMENTS**

This project would not have been possible without the help of the respondents, members of online support groups, taking time out of their busy lives to answer a survey. Participants were not compensated and were motivated solely by a desire to help. Most of the participants either have themselves dealt with, or have watched loved ones deal with, terrible disease. Some who responded to the survey have witnessed their loved one lose a battle with disease; others beat the odds. Many did not go through the ordeal in vain as they have continued to use their experiences to help others.

I believe that anyone who witnesses the power of online support groups will have a newfound respect for the benefits possible through technology and will be reassured that there is indeed much humanity left in this world.

So, I thank each and every respondent for telling such moving stories and showing others that there is hope even in the face of horrific circumstances. You gave your time and energy when you had little. Thank you.

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## **Characteristics and Benefits of Online Support Groups**

### **INTRODUCTION**

When people or their loved ones become ill, they grasp for information and support. They reach out to others who can empathize, who can help them answer their many questions, and to those who understand and can help them cope with their illness. They are looking for a lifeline. This lifeline is here and it comes in the form of online support groups.

The purpose of this paper is to present the results of a survey of members of health-related online support groups, and to discuss what was learned about how these people feel about their groups, how they came to find them, how it has changed them, and what their concerns are about them. The primary arguments set forth are that these groups are necessary, beneficial to the patient and family, and beneficial to the medical community. Support groups should be a part of every patient's treatment plan. All patients, regardless of income, race, or education should know how to find such groups and be given the means to at least try this type of support. Online support groups are found to be in tremendous need of protection policies, as members unknowingly post their medical records online -- fully indexed and searchable, for the entire world to see. We are so busy debating medical record privacy problems generated by industry that privacy problems generated by individuals have slipped through the cracks. This project serves to better understand online support groups, puts previous findings to the test, and uncovers new information about online support groups -- these little pearls nurtured by the open seas of the Internet.

## **BACKGROUND**

### **E-health Revolution**

The Internet has had a tremendous impact on all segments of society and the healthcare arena is, by far, not exempt. Healthcare professionals are by default becoming very aware that their patients are going to the Internet for a wide range of healthcare information and services. These include: sites devoted to health information (such as the well known [WebMD.com](http://WebMD.com)), online medical journals (e.g., BMJ), Medline, health newsgroups, health newsletters (e.g., American Healthline), and even chat rooms.<sup>5</sup> The numbers of Americans accessing the Internet for health-related information is large and rapidly increasing. There is great variance in different estimates of the number of people seeking health information online. Here are a few estimates in the literature:

- ◆ One estimate shows that 37 million individuals seek health-related information.<sup>16</sup>
- ◆ A Harris Poll found 70 million Americans went online to find health information in 1999.<sup>4</sup>
- ◆ California Healthline estimates the number to be as high as 98 million.<sup>12</sup>
- ◆ Other estimates say that as much as “one-quarter of all online activity is devoted to health and fitness.”<sup>5</sup>
- ◆ Yet another source states that “one-third of adults under age sixty are using the Internet at home to access [health] information.”<sup>7</sup>

According to a 1998 Cyber Dialogue report, 1 in 4 people who search the Internet for disease-related information also participate in online support groups.<sup>11</sup>

This interaction with health-related information causes behavior changes in patients. For instance, many patients are bringing in printouts from the Internet to show their doctor, are self-diagnosing their conditions, and at times are challenging doctor’s advice. According to one survey, patients who visited disease-specific sites took the following actions:

- ◆ 54% asked their doctor about a medication
- ◆ 50% urged a friend or family to see a doctor
- ◆ 46% altered his or her exercise or eating habits
- ◆ 45% made a treatment decision
- ◆ 41% visited their doctor
- ◆ 33% took their medication more regularly
- ◆ 20% purchased an over-the-counter product<sup>9</sup>

Some health professionals are thrilled to see their patients take more responsibility for their health, but some feel this form of information seeking is a burden.<sup>5,16</sup> Some patients seem to find valid information and save their physicians the time normally spent for patient education, while other patients bring in low-quality information that the doctor is then asked to sift through. Despite the mixed feelings that healthcare professionals have about the E-health revolution, they will inevitably have to deal with the situation. To help doctors and nurses handle patients' newfound treasure chest of health information, professional literature and resources are being developed and directed to them. The recommendations in the literature also suggest that whoever plays the role of patient educator in a particular healthcare setting has the responsibility to educate their patients on Internet-related health information. The American Academy of Family Physicians recently endorsed a set of patient educational guidelines that placed responsibility on physicians for: "evaluating and utilizing written, audiovisual and *computer-based* patient education materials" including "commercial education resources, such as brochures, books, audiotapes, videotapes and *Internet materials.*" [emphasis added by author] In addition, physicians are charged to stay "aware of emerging technologies."<sup>1</sup> Other peer professionals are encouraging patient educators to develop Internet resource lists and guides, set up their own Web sites, and actively help patients discern the quality of Internet materials.<sup>13,22,23,26</sup> Interestingly, much of the peer-pressure on doctors to embrace the e-health revolution is focused on static informational materials available on the Internet. There seems to be little pressure for doctors to specifically recommend online support groups – a much more interactive resource.

### **Support Groups**

People who are experiencing a traumatic event such as disease or grief, are in desperate need of an effective support system. Support systems can include friends, family

members, the church, a doctor, or other patients who are experiencing a similar event. Support groups have been in existence for a long time. Before the Internet, support groups were held in a physical location and members met on-site or face-to-face. Research on support groups finds significant correlation between participation in a support group and subsequent coping skills and health outcomes.<sup>3,11,15,28</sup> There is a wide range of documented benefit from a support system:

Social support is thought to buffer the adverse physical and psychological impact of disease by prompting endocrinological, cognitive, and behavioral adaptation (e.g., heightened immune competence, primary and secondary reappraisal of threat, increased compliance with treatment. [28, p 263]

Disease-specific support groups are especially important because research has shown that people prefer them to other types of support networks. Patients prefer peer-support, or support from people going through the same experience, because there is a greater degree of empathy in such a group.<sup>3,28</sup> Such groups provide other essential components important for coping, including: empowerment, information, messages of hope and inspiration, humor, an expressive outlet, advice, a sense of control, and a sense of being able to help others.<sup>11,14,17,26</sup> Support groups facilitate information exchange on the day-to-day management of disease, “help[ing] members resolve some of the most psychologically difficult issues for those with chronic diseases: whether to share information about their illness, whom to tell, and what to say.”<sup>17</sup>

Unfortunately, in the past, many people were not able to receive this valuable support because either the disease was too rare or the travel distance was too great. Today, these barriers are eliminated because of Internet technology.

### **Online Support Groups: Primary Benefits**

Online support groups can be defined as a topic-specific electronic mailing list where narrative messages are exchanged by a usually cohesive set of individuals that typically share a common ailment, problem, or concern. There are thousands of online support groups that address a vast array of specific health concerns and diseases.<sup>4,23</sup> In some ways, online support groups have been around longer than the Internet as the entity really began in the form of electronic bulletin board systems which pre-date the Internet (at least as we know it today).

There are many cited advantages to online support groups compared with their face-to-face counterparts.

**Convenience.** One of the most cited advantages is the convenience and accessibility of online support groups. Patients do not have to travel to participate in an online support group and there is no meeting-time-restriction - messages can be posted at any hour - and be responded to at any hour.<sup>3,26</sup> These are crucial factors when one considers rare diseases where the travel distance to an on-site support group would be unreasonable.<sup>17</sup> In addition, sick people and/or caretakers may not feel well enough either emotionally or physically to travel and present themselves in a face-to-face environment. Caretakers, in particular, have the additional burden of finding substitute care in order to attend a group away from their home.<sup>3</sup>

**Attributes of the Electronic "Medium".** Several benefits come just due to the nature of the online medium of exchange. In an online support group there is a frequent exchange of resources and information; all of this information is saved, indexed, and archived, creating powerful banks of knowledge that can be retrieved at a later date.<sup>17</sup> A new member of a rare skin disorder group states, 'I have found out more this past week from your [mailing list] than I was able to find in the previous 6 months.'<sup>17</sup> Contrary, in a face-to-face meeting, resource exchange is burdensome requiring writing down the information, and then photocopying the information for the group members. Another advantage unique to this medium is that the physical act of typing out feelings is *in itself* therapeutic.<sup>3</sup> Also, members can compose a message till it's "perfect" and then send it. With an online exchange, there is a natural springboard effect in the sharing of information. When users are already online, a link included in an e-mail can be followed instantly. Again, this sharing is more cumbersome in a face-to-face environment as someone would have to write the URL down on a piece of paper, remember to bring it to the group, group members would have to jot it down and then not lose it until they could get to a computer at a later time.

**Anonymity.** Many members who might be hesitant or shy to communicate in face-to-face setting report feeling freer to communicate in this anonymous "faceless" environment.<sup>3,11</sup> Some diseases cause significant changes in physical appearance and patients may be too self-conscious to even leave their homes.<sup>17</sup> Other patients, such as HIV-positive individuals, may not want anybody to know that they are sick, fearing additional

consequences of judgement. Interestingly, one study reported that men especially enjoyed the anonymity and felt much more comfortable communicating online as opposed to face-to-face.<sup>11</sup> Though there are many advantages unique to the online environment, it would be biased to not note some serious disadvantages.

### **Online Support Groups: Primary Disadvantages**

**Information Veracity.** The questionable veracity of information is one of the significant drawbacks that must be considered. One cited vulnerability of online support groups, especially those that are unmoderated, is that members may exchange erroneous or misleading information with other participants. This can be a problem as it has been shown that people tend to place a greater value on information that is received by word-of-mouth than information that is received through other more legitimate sources.<sup>4</sup> The individual posting the erroneous information might be well-intentioned or might be a quack or perpetrator trying to sell a magical cure to sick participants. A recent study examined Internet-based health information and classified “approximately one-third ... as having questionable value.”<sup>23</sup> However, it has been noted that when a group reaches a certain size, a sort of “intelligent-mass” forms and misinformation is stopped in its tracks.<sup>11</sup>

In a face-to-face support group it would be easy to tell if an intruder came into the group, this is much more difficult to determine in the online environment.<sup>4</sup> Luckily most online support groups catch on quickly to illegitimate users and “lock them out.” These groups also do not tolerate spammers. However, sometimes individuals join a group and fake a disease in order to reap the benefits of the nurturing that takes place on the support group.<sup>23, 27</sup> When such individuals are discovered, the group typically feels betrayed, mistrustful and suffers a setback.

**Privacy.** Another disadvantage of the online environment is that individuals’ privacy may be at great risk.<sup>6, 7</sup> Though some users think to use either only their first name or a pseudo-name in signing messages, many are naive and leave an identifying name in their raw e-mail address that is available to anybody. Considering the detail and nature of the narratives exchanged in online support groups, a breach of privacy could prove disastrous.<sup>12, 18</sup>

**Attributes of the Electronic “Medium”.** Advantages of the electronic medium also can be disadvantages and act as double-edged swords. For instance, a stated drawback to the

online environment is the lack of physical touch. Many times members would like to “reach out and give another member a hug” and feel frustrated that they can not do this. Another restriction of the electronic medium is that important non-verbal cues are lost and sometimes messages are misunderstood without the aid of tone, gesture, or facial expression.<sup>11</sup> One researcher noted conventions around this limitation such as using the smiley face, : - ) , to denote a lighter tone to a textual statement.<sup>11</sup>

**Equipment.** One important disadvantage is that in order to participate a person must own a personal computer or, at the least, an Internet access device; such as WebTV. The purchase of a computer may constitute a significant challenge to families who may already be burdened by vast medical expenditures, and reduced household income due to the illness. However, computers prices have dropped significantly in recent years, and may make them more easily affordable to many families. Furthermore, computers with Internet access in public libraries or other public and private institutions make access to the Internet available to an increasingly large number of people. However, respondents in this survey seem to prefer home-site access. It is important to note that there is also a pre-requisite for joining an on-site group – having a car or some other convenient means of transportation.

A final disadvantage cited in the literature is that some group members may become overly dependent on the support group and prolong a needed visit to a healthcare professional.<sup>11,23</sup> Despite these stated disadvantages, most agree that the advantages far outweigh the risks since online support groups are such powerful sources of information, friendship, and support to those in need.

## **METHODOLOGY**

The data collection methodology used in this study was that of an online survey. The survey contained a total of 39 questions. Thirty questions were guided-questions containing categories that could be selected with additional space for explanation. Only two questions were truly open-ended. However, the extensive use of the explanation section yielded much narrative-style data.

### **Survey group selection**

The most important decision for this study was the selection of specific support groups whose members were asked to participate in a survey about their engagement in these groups, as well as about the characteristics of their specific groups. The primary goal guiding the selection was that the groups were to cover significant but different diseases in order to facilitate the identification of commonalities and differences across groups, and to draw conclusions about the appropriateness of this medium for different types of diseases. The selection of groups dedicated to different diseases also allowed for the capturing of support group trends that cut across group types thus increasing validity across the findings.

The process of selecting groups for participation in the study began by identifying specific diseases to be examined. The four diseases that were selected were: Alzheimer's, Breast Cancer, Esophageal Cancer, and Huntington's Disease. The primary criterion for this selection was that each disease has significant impacts on the patient and/or the caregiver. Each disease also has great economic cost associated with it. A caregiver population was strongly desired as these persons have overwhelming support needs in dealing both with their own emotions and the day-to-day caregiving responsibilities for the patient, usually a close family member. One group was included as the author had seen firsthand what the ravages of the disease can do to a person when there is no effective support system in place. This particular disease fits the above criteria as well. It is reasonable to assume that across all of these groups one should find a diverse collection of people. As the selection of a well-



controlled sample was not possible, it was hoped that additional credence would be given to any trends found across these diverse populations.

To address online support issues of a caregiver population, members of online support groups for Alzheimer's and Huntington's Chorea were asked to participate. Alzheimer's and Huntington's share many characteristics: both are very slow degenerative diseases that cause great disturbance in the neurological and physical functioning of the patient. There are no cures and few treatments. Though each disease manifests itself very differently, the caregiving burden for both diseases can only be described as crushing. Alzheimer's is more common than Huntington's; it is estimated that there are currently 4 million individuals in the United States with Alzheimer's. This is important as there are perhaps more face-to-face support options available to these caregivers than for caregivers of Huntington's Chorea where the incidence is much lower with an estimated number of only 30,000 individuals with this disease in the United States and another 150,000 with a 50% risk of developing the disease. Because of the relative rareness of Huntingtons, it appeared likely that there are few face-to-face support group options available to caregivers and patients of Huntington's.

The two remaining groups, breast cancer and esophageal cancer were chosen for several reasons. Differences between men and women could be examined as breast cancer almost exclusively affects women and esophageal affects mostly men, though the gender split is not as great. Earlier literature suggested that men may be more comfortable in the online environment as it may provide a more comfortable format for them to express themselves. The survey attempted to ferret out such differences. The second reason for choosing these two groups was that differences in access to face-to-face support groups could be examined across two different patient populations. Esophageal cancer is relatively rare, while breast cancer is relatively common. Also, though treatment of both cancers involve aggressive surgery, radiation, and chemotherapy, they have very different survival rates. Breast cancer has a survival rate of 70% after five years while esophageal cancer has a five-year survival rate of less than 9%. People diagnosed with such a quick killer may feel more urgency to obtain informational support which takes a higher priority than emotional support.

After the selection of diseases, an Internet-based search was conducted to locate support groups for these diseases. The query, *online support group <disease name>* was

submitted to many of the popular search engines. Some support groups had their own website which was returned in the results set and others were linked from a general site about the disease. Several support groups were located for each disease. Attempts were made to subscribe to all groups located. Some groups do not allow a subscription without first receiving one's purpose for wanting to subscribe. As the IRB approval process was not complete, no correspondence was initiated. These groups were not considered in the selection process. Once subscriptions were in place on all remaining candidate lists, e-mail filters were created to sort incoming messages according to the list name. Statistics were gathered on these groups for several months. At the end of this monitoring process the most active list was chosen for each group. Highly active lists were defined based on three criteria. 1) the list received a high volume of messages with at least 25 messages sent to the list each day, 2) there were at least 100 unique individuals contributing to the list and 3) there was a reasonable amount of threading. A thread is a string of messages about one topic and is an indication that people are reading and responding to messages posted to the list. The depth of threads was not used as a strong criteria. The specific lists selected will not be mentioned here to protect the respondents' and lists' anonymity.

After the selection of the groups, the list owner of each group was sent an e-mail explaining the study and requesting permission to conduct an anonymous online survey, and for their cooperation (see Appendix A.1). All owners agreed and were quite supportive of the survey. A second e-mail was sent to list members requesting their participation (see Appendix A.2). The e-mail contained a link to a webpage containing a study description and consent page with a time-needed-to-read estimate at the top to encourage people to read this material (see Appendix A.3). At the bottom of the study description and consent page participants were asked to a click button labeled "I agree to participate." This took them to a page called "Final Consent Page" (see Appendix A.4) where they needed to click once more to go to the link where the survey resided. The survey was presented as an anonymous online form (see Appendix A.5).

The HTML code for all pages was validated using <http://validator.w3.org> to improve readability across multiple browsers. The survey requested that respondents not identify themselves or the name of their list. The survey was one long web page with a submit button at the bottom labeled "Submit Survey." After the submission button was clicked,

respondents received a confirmation page (see Appendix A.6). The survey results were passed to the university's ISIS server using a utility called "gform." The data were stored as a text delimited file in an invisible directory on an ISIS student account. Neither the directory name nor the file name bore any resemblance to the disease. Data for different diseases were kept in separate directories. An index.html file was created under the public\_html directory to hide the contents of the other disease directories and the data file was not put under the public\_html directory and was only accessible via a password. Each survey was left up for one week and then removed with a message indicating that the data collection was completed (see Appendix A.7). Each text delimited file was cleaned and imported into a Microsoft Excel format where descriptive statistics were calculated.

### **Survey Design**

The survey contained questions that covered a range of topics regarding online support groups including questions about 1) user demographic characteristics, 2) other user characteristics, 3) the process of becoming a group member, 4) usage characteristics, 5) other support options and preferences, 6) effects on the doctor-patient relationship, and 7) benefits received from participation in the group.

Demographic data obtained included age, gender, race, education, income, household size, and residence in a rural, urban, or suburban area. User characteristics included questions about why the person was a member of the group (patient, caregiver, researcher), computer comfort level and years using a computer, type of Internet connection, e-mail system used, and daily schedule/other time commitments. Questions about the process of becoming a member of the group examined where and how the member learned of the support option -- was it recommended to them or did they search the Internet themselves, how long after their diagnosis did they become a member, and the level of difficulty experienced in locating or subscribing to the group. Questions regarding usage characteristics included how members participate. Some specifics asked how much time they devote to list communication and whether they participate at certain times of the day or week, how long they have been a member, whether they were members of other online support groups, and their most and least favorite things about the list. Support options and preferences were examined by asking participants to compare the support received via their online group with other forms of support such as a psychologist or family member. The

availability of face-to-face support was specifically addressed. Members were asked whether they did or did not attend face-to-face support groups, and why not if they didn't. Users' doctor-patient relationships were examined by asking whether patients were referred to the group by a healthcare professional, and, if not, whether they would have joined sooner had they been referred. They were asked whether they were aware of physician participation in the group, whether they would welcome (increased) participation of a healthcare professional; whether their own participation in the group has had a positive or negative impact on their relationship with their healthcare provider; and whether they turned to the group with issues that they would normally pose to their HC provider (or would never pose!). Benefits received from the support group were examined by asking respondents whether they received informational support and/or emotional support; whether the group affected their quality of life; whether the group had saved their life (suicide prevention, treatment options), and whether they had received misleading information on the group. Finally, members' privacy concerns were examined by asking them about their concern that because of participation on the list they may receive increased spam, be the target of product salespersons, be "snooped on" by insurance companies, or have other people find information about them in the lists' archives. In addition, members were asked to indicate whether they used their real name in their e-mail address, and whether they think that online support group messages should be protected under medical privacy laws.

All questions were asked in an HTML form-based document. The format of questions was a mixture of discrete-choice questions (e.g. yes/no, radio buttons), multiple choice questions (e.g. check all that apply, checkboxes), and open-ended free-text questions (e.g. what do you think of ..., text areas).

An important quality of the survey design was that it was left very open with few limitations and no validation placed on allowable answers. People get frustrated if they are forced into an answer that doesn't fit their situation -- add one JavaScript error message and respondents may have gone straight to the "exit browser" button. In addition to the no-validation format, almost every question provided a free-text area to allow room for clarification. Overall, respondents reported over and over again appreciation of the survey design. When asked how the survey could be improved, many specifically expressed appreciation for the room to explain answers:

- *I really liked the boxes allowing further explanation. It is not possible to describe/quantify an individual's position in just a few possible answers. A prime example is question #21. I don't see how you could interpret my answers without recognizing that I use each group to address different issues. I fear that when you try to finally compile the survey, you will force answers into the allowed boxes and miss some important effects.*
- *i appreciated the opportunity to clarify some of my answers where I would not have answered at all if this had not been so.*

One final note concerns the coding and/or recoding of responses. The open-ended question design of the survey posed significant challenges. Whenever possible, responses were coded, or re-coded if necessary, to best reflect the most likely intentions of respondents. For example, there was a dilemma when the researcher read an explanation that clearly indicated a differential interpretation of the survey question on the part of the respondents. In some instances, data were recoded to incorporate information found in the 'further explanation section'. For example one participant selected "no" to the following question:

10. Is this the only support group that you subscribe to?  
 yes  no

If you feel that you need to clarify question 10, please do so here:  
*I belong to a support group in the community and do community education.*

In this case the response was recoded to *yes* because the question asked about participation in other *online* support groups (indicated by the keyword *subscribe*.) This participant indicates that she is in another support group but that it is in the community so it would count as a face-to-face support group, not an online group.

Wherever possible, data were also recoded if a respondent's "unusual" way of answering a question precluded the answer's otherwise valid inclusion in the calculation of summary statistics. For example one respondent answered this question as follows:

13. How long have you been using a computer? (please fill in the appropriate number of weeks, months, or years)

weeks  months  20+ years

A conservative estimate was used (20 in this case) in these instances. If ranges were provided in fields asking for an integer, average values were used instead for the calculation of summary statistics (e.g. 4-5 years was recoded to 4.5 years).

Finally, obvious grammatical and spelling errors were corrected in the narratives quoted in this paper.

## RESULTS

### Alzheimer's Group - Results

#### List characteristics

This list was the highest volume list of all surveyed with an average of 60.33 messages exchanged each day and approximately 230 members who were active participants over a three month period. In addition, this list has deep threads where a message posted typically receives lots of replies. Some members choose to receive their messages in digest form which comes as one very long text e-mail once per day.

#### User characteristics

Forty-three persons (of approximately 650) from the Alzheimers list responded to the survey. Of these respondents, 35 (81%) had a family member with the disease, 26 (60%) were caregivers of a person (usually family member) with the disease, one member (2%) was a member of the list because he/she has early onset of this disease, one had a friend with the disease, and one of the respondents was a doctor. The question gathering the above information allowed for multiple answers per respondent; some respondents are members of the online community for more than one reason, therefore the percentages above sum to more than 100 percent. Several members noted that they have stayed on the list even though their loved one has died because they enjoy being able to offer their support and advice. This form of altruism seems to be fostered in the online support community and has been noted in previous literature.

- *My husband has died but I still enjoy the friends made on the support group. Occasionally I have something to offer newbies.*
- *My mother has died from this disease; I'm staying on the list because I feel that sometimes I have things to contribute to the group due to my experiences.*
- *Actually, I WAS a caregiver -- my husband passed away 2 years ago, but I still occasionally attend meetings to be supportive to others.*

## Demographics

**Gender.** Most respondents (38, corresponding to 88 percent) were female. Five respondents were male.

**Age.** Respondents had the option of specifying their specific age or indicating a range. The mean age was 52 years with a minimum age of 33 years reported and a maximum of 82 years. Fourteen respondents opted to indicate an age range, with one between the ages of 30 and 39 years; 5 (12%) between the ages of 40 and 49 years; five (12%) between the ages of 50 and 59 years, and three (7%) between the ages of 60 and 69 years. Taking the middle value of each range (i.e. 34.5 years for the range, 30-39) and using it as part of the actual age data yields a similar mean of 53 years.

**Race.** In light of recent controversy on how to classify race, this question was left as a free text field. Most members (40, corresponding to 93 percent of respondents) reported their race as white/Caucasian. The remaining three responses included American Mut, human race, and one non-response.

**Education.** On average, respondents had a high level of education, with a mean education level of 16.3 years (i.e., more than a college degree). The educational range was 10 years (less than high school graduate) to 21 years (5 years graduate school). Six respondents (14%) had a college degree, while an additional 23 respondents (53%) also had some graduate education.

**Income.** On average, respondents also reported high incomes. Income was reported in ranges. Thirteen respondents (30%) had a pre-tax income above \$75,000. Six respondents (14%) had an income between \$50,001 and \$75,000. Eight respondents (19%) reported an income between \$40,001 and \$50,000. Six (14%) reported an income between \$ 30,001-40,000. Six respondents (a total of 14%) reported an income between \$20,001 and \$30,000 (three instances), and between \$10,001 and \$20,000 (three instances), respectively. One respondent (2%) reported an income under \$10,000. One respondent left the question blank.

**Household size.** The average household size reported was 2.9 persons. 37 percent of respondents lived in two-person households, and 23 percent lived in three-person households.



**Type of residence.** When asked about their location of residence, the plurality of respondents (21, 49%) lived in a suburban area. Nine members (21%) reported living in a rural area, and 12 members (28%) reported living in an urban area.

**Schedule.** Participants were asked about their daily schedules and were given the opportunity to select more than one option, hence the following percentages exceed 100%. Of the respondents,

- 26 (60%) I take care of home and family tasks full-time
- 19 (44%) I work full-time outside the home
- 9 (21%) I take care of home and family tasks part-time
- 5 (12%) I do not work at the present time
- 4 (9%) I work part-time outside the home
- 4 (9%) I work part-time for pay but do so from home (e.g. telecommute)
- 4 (9%) I am retired
- 4 (9%) Other (please specify):
- 1 (2%) I work full-time for pay but do so from home (e.g. telecommute)

By assigning time values to the various answers (i.e. 20 hours for part-time job, 40 hours for a full-time job), one gets a mean “committed time” of more than 65 hours per week. In other words, on average, respondents have more than full-time (non-leisure) time commitments, living very busy lives.

### **Participants’ computer background**

**Years using a computer.** On average members have been using a computer for a long time, 12.1 years.

**Comfort with computers.** Most respondents feel very comfortable with the ‘every day use’ of a computer. Thirty-six people (84%) strongly agreed with the statement, “I am very comfortable with everyday-use of the computer.” Four (9%) answered “somewhat agree”, one (2%) answered “somewhat disagree”, and 2 (5%) strongly disagreed with the statement.

**Software.** Participants reported using a variety of e-mail clients with 25 (58%) using Microsoft Outlook or Outlook Express, six (14%) using Eudora, four (9%) using AOL, three (7%) using Netscape, 2 (4%) using Yahoo, and one (2%) using WebTV.

**Connection speed.** 15 respondents (35%) participated on the list using DSL or cable connections; and twenty-four (56%) participated in the support group using 56K connections. Several respondents did not answer the question.

### **Membership history and characteristics**

**Duration of membership.** On average, respondents had been members of this support group for about two and a half years (134 weeks), though there was much variation. The newest member had been in the group for 2 weeks and the “oldest” member for eight years. A couple of members indicated that they had been members on and off.

**Join-time lag.** Members were asked how long after the diagnosis they joined the group. The average lag time between participants’ family member’s diagnosis with Alzheimers and their joining of this online group was about two years and four months. Two members had joined within three days after their diagnosis, the longest “lag time” was eight years. A couple of respondents noted that they suspected that their loved one was suffering from the condition and joined the group before learning the diagnosis for certain. Some appeared to have used information from the group to help them in diagnosing their loved ones’ conditions.

**Impetus for joining.** The survey contained several questions relating to how members came to join this Alzheimer’s online support group. When participants were asked “*Who gave you the idea to seek this form of support?*”, the overwhelming majority, thirty-four respondents (79%) answered “This was all my own initiative”. A friend or family member made the suggestion to 4 members (9%), and a nurse suggested the list to one other member (2%). Three respondents found a link to the site on the Internet, and one found it in a newspaper.

Five respondents (12%) indicated “other” for this category. Of these, most decided to go to the web for information on the disease and found a link to the group on another site. One member found the site listed in a newspaper article. Note that there seemed to be two interpretations of this survey question that became evident on reading the further explanations provided by respondents. Some members checked “own initiation” because by their own initiative they thought to turn to the Internet. From there they found a link to the online support group:

- *I was researching the illness online, and came across a reference to the group. Prior to that I had no knowledge that such a thing existed.*

Others took the question, “*Who gave you the idea...*” very literally and answered that in fact the *originator* of the idea was not *who* but *what*, what being the Internet-based resource that lead them to the support group; they did not consider the idea self-initiated but what is called in the field of Library Science goal-based searching versus known-item searching. The user has an information need but cannot name it until he or she sees it.

**Healthcare provider influence.** Respondents were asked if they would have joined the group sooner if their healthcare provider had suggested it. Twenty-eight responding (65%) indicated that they would have joined sooner had their healthcare provider suggested it. Eleven individuals (26%) would not have joined sooner. Three participants either selected NA or did not answer the question. There were several interesting explanations:

- *[yes] I stumbled upon this group in the course of a search, and otherwise may NEVER have found it.*
- *[yes] A simple yes to that question doesn't do it justice. I am quite bitter that I was unaware of this option for caregivers. Don't Doctor's know anything?*
- *[n/a] I am a HC provider - would recommend to others though*

**Finding the group.** Most respondents (33, corresponding 77 percent) found the group by initiating a general Internet search for information on their disease and “just happened” to stumble upon this particular online support group. Four people (9%) found the group by conducting a known-item (e.g., ‘support group’) search. Three members (7%) were given the specific website address by a friend (1 instance) or family member (2 instances). A healthcare provider gave one person the address.

Four members (9%) checked other. One member read a newspaper article about lists, one heard about it from a healthcare professional/speaker at a conference on the disease, one member, “Found reference in another support group,” and another said, “This support group was suggested to me by a person in a chatroom discussing the same disease.”

**Difficulty locating the group.** Responses to the statement “*I found it difficult to locate this support group*” were mixed. Sixteen respondents (37%) strongly disagreed with this

statement, 13 (30%) somewhat disagreed, 8 (19%) somewhat agreed, and 5 (12%) strongly agreed.

**Difficulty subscribing to the list.** Most people did not report difficulties subscribing once they had located the group. Thirty-seven or 86% disagreed with the statement *“I found it difficult to subscribe to this support group”*. Of those, 26 strongly disagreed and 11 somewhat disagreed. Four respondents (9%) said they somewhat agreed with the statement and one strongly agreed.

### **Participation characteristics**

**Messages sent.** On average, active members (those that reported sending at least one message) send about 5 messages per week to the list with a much lower median of only about 1 message per week. This number may include some individual-to-individual list correspondence. Several members noted that they read much more than they contribute, that they are mostly lurkers, that they would contribute more if their time commitments allowed, and/or that they are receiving messages in digest form. Additional comments included:

- *My time of great need has passed, because my loved one died over 2 years ago. I am still trying to understand the nuances of the disease and to figure out what to do with the knowledge that I have acquired. I also want to help people who are just starting out on the caregiving path, because I remember how I felt before I found the group and acquired a certain level of knowledge.*
- *It is my sole support at this time for going through the process of having a husband with a disability*
- *I am mostly what is referred to as a "lurker." In two years I have only posted about four times.*
- *Just a lurker on this particular site but active on two others.*

**Time spent.** Members on this list spend an average of 1 hour each day participating (reading, sending, researching) in some way on this list, ranging from 10 minutes to four hours. The median participation time was also 60 minutes.

**Participation time of day.** Participants were asked if there was a particular time of the day that they participated. A plurality of members 20 (47%) could not name a specific

range(s) and said that they participated at multiple times of the day. Ten members (23%) participated between 8PM and midnight; seven (16%) between 5AM and 8AM; eight (19%) between 8AM and 12PM; nine (21%) between 5PM and 8PM; and one (2%) between 12PM and 5PM. Some members selected more than one time slot so the percentages do not add up to 100%. Assuming that some people are working full-time between 8 AM and 5 PM, it appears that a few members may participate at their workplace while others seem to avoid this.

**Participation time of week.** Most members participate more on weekdays (29, corresponding to 67%), while 5 (12%) participate more on weekends. 9 respondents (21%) cited no difference. Several respondents noted that there are more messages during the week, and/or that they have to compete with family members for computer time on weekends. One member noted that weekend and weekday distinction had little meaning in her life:

- *with being a caregiver, the days are all the same. Weekends and weekdays do not differ. I participate when I have time.*

Several noted that there was “competition” for the computer and that this had some influence on when they could participate:

- *Husband is a computer professional, and uses the dedicated line for work more on Fri.-Sun.*
- *I received the digest on my work e-mail. I can access it from home, but am usually too busy with other things on the week end to check my work e-mail. Also I have to compete with my spouse and 2 teenaged kids at home for computer time. At work I have my own terminal.*

**Participation in other online groups.** Slightly fewer than half of the respondents (21, 49%) also subscribed to other online support groups; yet for the (slim) majority of members (22, 51%) this is the only support group they subscribe to. Two respondents are members of other support groups for other illnesses.

This group is primarily comprised of caregivers. In an explanation found in an earlier question, it appears a member of this group, a patient, created an offshoot group geared more for those with early onset Alzheimers vs. caregivers:

- *initially I participated more, but have founded a patient support group and spend more time there now*

### **Issues relating to healthcare providers**

**Healthcare professional participation.** Nearly all members reported that there are healthcare professional(s) on the list. When asked “Are you aware of any medical professionals who read or contribute to this list?” 42 members (98%) replied ‘yes’. Only 1 (2%) replied no. Members were also asked “Would you welcome the participation (or more participation) of a medical professional on this mailing list?” In response to this question, ALL members said yes. One provided the following qualifier:

- *Though not all medical professionals have good on line manners, or come across as CareGiver friendly. The fact that medical pros are accessible on line to answer general question, provide information and support is very reassuring to a CareGiver.*

Some ‘yes’s’ also expounded on their opinion.

- *Many already do and are well-known to the list and in the field. There is no pressing need for more professionals on the list although many are subscribed and post only rarely.*

**Communication channel changes.** Members were asked about their agreement with the statement, “*There are many times when I seek advice from this list that I would have only sought from my doctor in the past.*” Sixteen respondents (37%) strongly agreed, 17 (40%) somewhat agreed, 5 (12%) somewhat disagreed, and 1 (2%) strongly disagreed. Members were also asked to respond to the statement “*There are health-related questions that I ask on this list that I would never in the past nor in the present dream of asking my doctor.*” Eight (19%) strongly agreed, 8 more somewhat agreed, 15 (35%) somewhat disagreed and seven (16%) strongly disagreed.

**Reported effect on doctor-patient relationship.** The majority of respondents reported that the list has had a positive effect on their relationship with their physicians (31, 72%).

Nine respondents (21%) reported no effect. One respondent (2%) reported negative effects. The latter two provided the following information:

- **[Negative effect]** *Lost faith in health care providers totally*
- **[No Effect]** *The Dr. took care of his health needs. The support group helped me to manage the odd behavior manifestations of Alzheimer's Disease. It also provided me with caring, love, and advice as needed*

Many respondents who reported positive effects also volunteered additional information. The overriding theme was that they are actually very well educated and may help educate their physicians on this disease:

- *I knew specific things to ask for or about. It really, really helped to focus on things that I may not have had the courage or knowledge to ask about, as advocate for my Mom.*
- *It helps me to be a stronger advocate for my loved one, and allows the healthcare specialist to spend more time talking the specifics of my loved one's needs without having to spend time in educating me.*
- *He is not as up on things as he should be but is willing to listen when I bring something up*
- *I learned about a drug trial that I'm trying to get my husband into through this list. I wouldn't have known about it otherwise.*
- *It has given me alternatives that I would not have come up with on my own and has given me the courage to try some of them. This has resulted in a reduced stress level for both me and my LO, thus increasing quality of life for all concerned.*
- *I knew what questions to ask when visiting the doctor and knew more of what the doctor was talking about. The doctor could tell that I was knowledgeable on the subject and respected my input.*

**Other support vs. online support.** Participants were asked to compare the helpfulness of their support group to other potential support providers. Overall, respondents reported that the support group was more helpful to them than talking with family (74%) and friends (81%) who do not have this illness. Some report that the group is more helpful than talking with their doctor or nurse (51% and 30%, respectively). A somewhat smaller number of respondents (5% and 9%, respectively) find talking to a doctor or a nurse better than talking

to the group, while 35% and 47%, respectively, found it as helpful. The results are best shown in tabular form (see Table 1):

<b>Table 1. Alzheimers responses: support type preferences</b>	
<b>Support group is MORE helpful to me:</b>	
than talking with my friends who do not have my same ailment or predicament	35 (81%)
than talking with family members who do not have this ailment.	32 (74%)
than talking with my doctor (medical).	22 (51%)
than talking with my psychologist or counselor.	14 (33%)
than talking with a nurse	13 (30%)
than talking with my preacher (or clergy, priest, rabbi, or other spiritual advisor)	17 (40%)
than talking with other	3 (7%)
<b>Support group is <u>AS</u> helpful to me as talking with:</b>	
my friends who do not have my same ailment or predicament	2 (5%)
family members who do not have this ailment.	6 (14%)
my doctor (medical).	15 (35%)
my psychologist or counselor.	12 (28%)
a nurse	20 (47%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	10 (23%)
other	1 (2%)
<b>Support group is <u>LESS</u> helpful to me than talking with:</b>	
my friends who do not have my same ailment or predicament	5 (12%)
family members who do not have this ailment.	4 (9%)
my doctor (medical).	4 (9%)
my psychologist or counselor.	5 (12%)
a nurse	2 (5%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	5 (12%)
other	0 (0%)

Respondents also provided some narratives:

- *People here understand what you are going through. The average person on the street that is a non-caregiver HAS NO CLUE!*



- *Your friends and family can only listen so much about any given disease, and your emotional state, when dealing with such a long, drawn-out disease. Having an online support group frees up your time to interact with family and friends about other topics, which balances your life a bit more.*
- *As I stated before, I have not written to the group-I am just a lurker, but it has been very helpful to read other people's posts, as they often answer questions I have, or give me ideas to try with my loved one (LO)*
- *The list provided specific information about managing the disease on a day-to-day basis that you just can't get from someone unfamiliar with the disease; it also provides you a place to ask questions that might seem too "trivial" for the doctor.*

### **Quality and degree of support received**

It is reasonable to assume that members are receiving support from the group - due to the very fact that they continue their membership. Regardless, from a research standpoint the author felt it was important to firmly establish that support is received, and to identify the predominant types of support available to participants in the group.

**Support.** Participants were asked to indicate their agreement with the following statement, *"I get helpful information on how to manage my (or my loved one's) disease from this support group."* Thirty respondents (70%) strongly agreed with this statement and 12 (28%) somewhat agreed. One person did not respond. When presented with the statement, *"I get valuable emotional support that helps me cope with the stress of my (or my loved one's) disease"*, twenty-five (58%) strongly agreed; 16 (37%) agreed somewhat.

**Information quality.** Respondents were asked to respond to the following statement, *"I have received misleading information from the list on several occasions."* No respondent strongly agreed with this statement; 6 (14%) somewhat agreed; 12 (28%) somewhat disagreed; and 20 (47%) strongly disagreed.

- *There MAY be occasional misinformation, but this is quickly revealed as such.*
- *I check who is giving info and do not take the information as gospel, just as suggestions so mis-information is not a problem*

**Perceived effect on health.** Participants were confronted with the following statement, *“I would say that this online group has either directly or indirectly saved or prolonged my life (or that of my loved one).”* Eight (19%) strongly agreed, 12 (28%) somewhat agreed, 10 (23%) somewhat disagreed, and 9 (21%) strongly disagreed.

**Perceived effect on quality of life.** When asked about their opinion about the statement *“I would say that this online group has improved the quality of life for me or my loved one.”* Twenty-five (58%) strongly agreed, 13 (30%) somewhat agreed, three (7%) somewhat disagreed, and one (2%) strongly disagreed.

**Disease management.** Participants were presented the following statement to respond to, *“I do not know how people with my (or my loved one’s condition) could possibly manage without an online support group such as this one.”* Twenty (47%) strongly agreed; 10 (23%) somewhat agreed; 9 (21%) somewhat disagreed; and 1 (2%) strongly disagreed. Below are two comments from respondents.

- *I'm sure people could survive without online support, would be more difficult and time consuming, without getting almost immediate answers to questions.*

**Helping others.** When asked *“Helping others on this list is very important to me”*, seventeen (40%) of respondents strongly agreed, 20 (47%) somewhat agreed, and one (2%) somewhat disagreed.

### **Face-to-face support**

Participants were asked if they participated in a face-to-face support group and if they did not, why not. Eleven members (26%) attended a face-to-face group while 32 (74%) did not. Table 2 categorizes the reasons given:

Online group more convenient .....	17	(40%)
Too hard to find replacement caregiver for children or loved one .....	11	(26%)
Act of typing out thoughts was therapeutic in itself .....	10	(23%)
No face-to-face groups in respondent locale.....	7	(16%)
More comfortable using the online format .....	7	(16%)
Face-to-face group did not meet needs .....	5	(12%)
Other reasons (varied.....)	5	(12%)
Do not feel well enough .....	0	(0%)

Other responses included:

- *Did previously*
- *I plan to in the future.*
- *I am in a somewhat rural area and there are no support groups within a reasonable driving distance at a time when I could attend.*
- *Have been active in a support group for about 2+1/2 years*
- *The face-to-face support groups were hard to get out to and finding one with those that had caring situations to what I was going through was difficult.*
- *There are none available for the diagnosed ONLY for the caregiver*

Furthermore, some people stated that the member had not felt the need, had a schedule conflict with the meeting time, had time constraints preventing doing for both and the online is preferred. A couple indicated that they might attend a face-to-face support group in the future. The question sparked other comments:

- *I have attended a face-to-face support group in the past to encourage my mother's participation. I find it just as rewarding, if not more rewarding to participate online. It certainly is easier as far as time and logistics is concerned, especially since I get the digest and can review the messages at my leisure.*
- *The face-to-face support groups were hard to get out to and finding one with those that had caring situations to what I was going through was difficult.*
- *there are none available for the diagnosed ONLY for the caregiver*

- *I am in a somewhat rural area and there are no support groups within a reasonable driving distance at a time when I could attend.*

Respondents were asked to expound if they chose “*More comfortable using online format.*” Following are narrative explanations:

- *I am pretty introverted, and online communication suits me well.*
- *I tend to share more because of the nature of the Internet. Just words on a screen no face-to-face meetings necessary.*
- *I am shy and it takes me a long time to establish face-to-face relationships*
- *Can use alternate email addresses to protect my privacy*
- *Writing my thoughts and emotions down is much easier for me than to speak them to others. It allows me the freedom to explore and explain my situation, my LOs condition and problems I face. It gives me the time to be able to write them down more honestly and open especially on issues that are emotionally difficult.*

### **Most and least favorite thing**

Most favorite. Participants were asked “*What is your most favorite thing about this online support group?*” Table 3 displays some of the important themes of responses:

<b>Table 3. Alzheimers responses: favorite qualities of group</b>	
Talk to people who are going through same experience; not alone in this .....	7 (16%)
Information and current research .....	6 (14%)
Everyday practical advice of symptom management.....	6 (14%)
Caring and supportive atmosphere.....	6 (14%)
Banter, humor, wit, intelligence, personalities.....	4 (9%)
24/7 available.....	4 (9%)
Pooled wisdom from peoples common experiences .....	4 (9%)
Professionals' presence on list.....	4 (9%)
Diversity of membership.....	3 (7%)
Freedom of expression, understanding, compassion, mutual respect .....	3 (7%)
Honesty, frankness, candor .....	3 (7%)
Instantaneous nature of support .....	1 (2%)
Developing friendships with members.....	1 (2%)
Like a family .....	1 (2%)

The following messages state quite eloquently the recurring themes captured with this question.

- *The ability to know that others are coping with almost identical problems. Quite often someone else will have an answer to my question or current problem. Or I will have an answer for them. It's a guarantee that someone in the group currently is or has had the same problem that I am dealing with at any given time. So the amount of knowledge I receive from the group is better than any medical school.*
- *You can connect at any time of day or night when you really need to vent or if your loved one keeps you awake.*
- *Affirming the fact that there are many loved ones and their families and caretakers who are experiencing the same things that I am, and surviving and helping each other survive the horrors of the condition*
- *Broad spectrum of participants (laymen, professionals)*
- *Concise, direct answers provided by medical professionals who write in, also the friendly banter amongst some of the members, plus some of the humor and witticism displayed here in spite of the trying circumstances the caregivers live with.*

Least favorite. Participants were asked “*What is your least favorite thing about this online support group?*” Table 4 displays some of the important themes of responses:

<b>Table 4. Alzheimers responses: least favorite qualities of group</b>	
Off topic discussion .....	11
Flaming.....	4
E-mail manners - long posts me too posts .....	4
Volume of mail .....	3
Want to spend more time on list but time constraints - want to see members in person .....	3
Bickering .....	2
Privacy concerns .....	2
Off topic discussion of political nature .....	1
Hearing of a death of a loved one .....	1
Imposter .....	1

Several members provided comments that flesh-out the categories:

- *chattiness, personal conversations having nothing to do with subject*
- *The chit-chat that goes back and forth about nothing pertaining to the disease. People could do it privately but don't. It gets annoying when there are so many messages to read and so little time.*
- *It can be time consuming!*
- *That it is archived so future employers of myself and my children would possibly be able to find out this seems to be genetic in our family (if I would post that info).*
- *The off-topic posts (although I do think they are therapeutic for some of the other members, and that is important)*

### **Privacy concerns**

The nature of communication over the Internet raises many privacy issues. To explore members' perceptions of threats to privacy several questions were posed.

**Imposters with financial motives.** Respondents were asked, *“Are you concerned that a sales-type person, who pretends to be a legitimate support group member, may suggest that members purchase a specific health-related product on this list.”* A majority of participants were not concerned, 33 (77%), while some did express concern 9 (21%). However, the overall feeling of most all respondents is that imposters are quickly identified and properly ousted.

- *The attempt has been made several times, but the list-owner and some of the more vocal members have always put a stop to such abuses very swiftly.*
- *lots of snake oil on line*
- *some have tried this and been "booted" off the list*
- *It's happened. The spam gets reported. Misguided people who think they are offering us a "service" are given to understand that we do not appreciate their targeting us as a potential market.*
- *There are too many well-informed people on the list.*
- *Although this happens, we are generally savvy enough to recognize such ploys.*
- *It happens but does not bother me personally. I do worry about others in the support group that are taken in by these things.*

**Concern over increase in junk e-mail.** Respondents were asked, “*Are you concerned that people may subscribe to this list in order to get your e-mail address and then sell it to companies who send spam (spam = junk mail)?*” The majority of respondents were not concerned 34 (79%) while 9 (21%) expressed concern.

**Concern over insurance companies getting information.** Respondents were asked, “*Are you concerned that an insurance company may snoop on this list?*” A majority of respondents said they were not concerned, 32 (74%); while others did express concern 10 (23%). Several provided further explanation:

- **[concerned]** *As well as future employers...I think the archive concerns me in particular, although I see the use for the archive.*
- **[not concerned]** *had never thought of this before*
- **[not concerned]** *hadn't thought of it till you mentioned it*
- **[not concerned]** *I suppose, though, that people should be careful about the personal information that is revealed.*
- *One member involved in outside litigation had to turn over all of her email records. An insurance company would do this if they could.*
- *I never use my real name or real email address when posting \_sensitive\_ information (the medical or financial aspects of the disease).*
- *I am concerned that there are many types of less than reputable people who might access this information for less than honest reasons.*

**Archives.** Respondents were specifically asked, “*Are you concerned that if this list archives its messages that those archives may be used for unintended purposes?*” The majority of respondents were not concerned, 36 (84%) saying no, and 7 (16%) saying yes. One respondent provided this explanation:

- *It's a needle in a haystack thing. I can't spend my life worrying about unscrupulous people all the time because I can't begin to understand (nor want to) or conceive of their schemes.*

**Use of real name.** Respondents were asked, “*Does your real (first and last) name appear on this list (either discernable in the e-mail address, the "from" line, or in your signature)?*” Most respondents, 33 (77%) said that their name did appear, while nine (21%) said no.

**Desired legal protection.** Respondents were asked, “*Do you think that the personal medical information exchanged on a list such as this one should be protected under medical privacy laws?*” Most respondents said yes (25, 58%), but 16 members (37% of respondents) said no. Again, there was a range of responses to this question.

- *It would be nice, but I don't see how that could be done.*
- *Possibly. I haven't really thought about this and doubt it could be enforced, but it sounds like it might be a good idea.*
- *However, much of what is said is opinion of non-medically trained caregivers and should be recognized as not necessarily valid.*
- *This is an open list and those on the list understand that. If you start censoring or making the list more difficult to get on then you would limit those who would have gotten on otherwise.*



## **Breast Cancer Group - Results**

### **List characteristics**

This list was founded in 1994. Currently, the list has a high volume with about 30 messages exchanged each day. It appears that over 170 unique individuals sent messages to the list over several months. In addition, this list has deep threads where a message posted typically receives lots of replies. Some members choose to receive their messages in digest form, which comes as one very long text e-mail once per day.

### **User characteristics**

Fifty-three persons (of approximately 500 subscribers) from the breast cancer list responded to the survey. Of these respondents, 50 (94%) were members of the list because they either have or had breast cancer. Of these, three reported that their cancer was in remission. Five respondents (9%) had one or more friends with the disease, one respondent (2%) had a family member with the disease. Two responding list members (4%) were healthcare professionals, one of whom also has breast cancer. One member reported being a researcher and one member was at risk of developing breast cancer. The question gathering the above information allowed for multiple answers per respondent; some respondents are members of the online community for more than one reason, therefore the percentages above sum to more than 100 percent.

### **Demographics**

**Gender.** Nearly all respondents (51, corresponding to 96 percent) were female. One respondent was male and one respondent did not answer the question.

**Age.** Respondents had the option of specifying their specific age or indicating a range. The mean age was 54.5 years with a minimum age of 39 years and a maximum of 72 years. Twelve respondents opted to indicate a range with two (4%) between the ages of 40 and 49 years; seven (13%) between the ages of 50 and 59 years; and three (6%) between the ages of 60 and 69 years. Taking the middle value of each range (i.e. 35 years for the range, 30-39) and using it as part of the actual age data yields a similar mean of 55 years.

**Race.** This question regarding members' race was posed as a free text field. Most members (49, corresponding to 92 percent of respondents) reported their race as white. The remaining six responses included "Nordic", "white/native American", "bi-racial", "Irish/Indian/American", and "I am of the human race." One person did not answer the question.

**Education.** On average, respondents had a very high level of education, with a mean education level of 16.4 years. The educational range was 12 years (high school) to 21 years (5 years graduate school). Of the 53 respondents, seven had a college degree and 25 more had some graduate education.

**Income.** On average, respondents also reported high incomes. Income was reported in ranges. Twenty respondents (38%) had a pre-tax income above \$75,000. Twelve respondents (23%) had an income between \$50,001 and \$75,000. Five respondents (9%) reported an income between \$40,001 and \$50,000. Seven (13%) reported income between \$30,001 and \$40,000. One each reported incomes between \$10,001 and \$20,000 and between \$20,001 and \$30,000, respectively.

**Household size.** The average household size reported was 2.1 persons.

**Type of residence.** When asked about their location of residence, respondents were nearly evenly split across the three types of areas. Seventeen members (32%) reported living in a rural area, eighteen members (34%) reported living in a suburban area, and 18 members (34%) reported living in an urban area.

**Schedule.** Participants were asked about their daily schedules and were given the opportunity to select more than one option, hence the following percentages exceed 100%. Of the respondents,

- 18 (34%) reported taking care of home and family tasks full-time;
- 17 (32%) reported that they were retired;
- 17 (32%) took care of home and family tasks part-time;
- 15 (28%) worked full-time outside of the home;
- 9 (17%) are not currently working at a for-pay job;
- 7 (13%) work part-time outside of the home;
- 6 (11%) report other commitments such as volunteer work
- 4 (8%) work part-time for pay from their home
- 1 (2%) work full-time for pay from their home

By assigning time values to the various answers (i.e. 20 hours for part-time job, 40 hours for a full-time job), one gets a mean “committed time” of 38.8 hours per week. In other words, on average, respondents have full-time non-leisure time commitments and live somewhat busy lives.

### **Participants’ computer background**

**Years using a computer.** On average members have been using a computer for a long time, 12.7 years.

**Comfort with computers.** On average, respondents also reported feeling very comfortable with the ‘every day use’ of a computer. Thirty-seven people (70%) strongly agreed with the statement, *“I am very comfortable with everyday-use of the computer.”* Six (11%) answered “somewhat agree”, one person (2%) somewhat disagreed and 9 (17%) strongly disagreed with the statement.

**Software.** Participants reported using a variety of e-mail clients, with 16 (30%) using Microsoft Outlook, 13 (25%) using Netscape Messenger, eight (15%) using Eudora, and 6 (11%) using AOL. The remaining members used Pine, Yahoo, and Hotmail for interaction on the support group.

**Connection speed.** Only three participants (6%) had connections slower than 56K. (It was unclear how many users participated from their workplace as this question was not asked. Nonetheless, four participants (8%) indicated that they participated at work and at home and had high speed connections at work and 56K connections at home.) 22 respondents (40%) participated on the list using DSL, cable, or T1 connections; and 25 (45%) participated in the support group using 56K connections.

### **Membership history and characteristics**

**Duration of membership.** On average, respondents had been members of this support group for nearly three years (153 weeks) though there was much variation. The newest member had been in the group for 2 weeks and the “oldest” member for seven years.

**Join-time lag.** Members were asked how long after their diagnosis they joined the group. The average lag time between participants’ diagnosis with cancer and their joining of

this online group was about one year (52.3 weeks). There was much variation, with some members joining on the day of their diagnosis and some joining many years after.

**Impetus for joining.** The survey contained several questions relating to how members came to join this breast cancer online support group. When participants were asked “*Who gave you the idea to seek this form of support?*”, thirty-seven (70%) answered “This was all my own initiative”. A friend made the suggestion to six members (11%), and a family member suggested the list to 5 members (9%). Interestingly, this specific support group was publicized in print media giving three members the idea to join. Two members met strangers online (perhaps during the course of researching breast cancer) who referred them to this particular group. Only one member was referred by a member of the healthcare community --a cancer counselor at the hospital where she received treatment. No responding member was referred to this list by his or her medical doctor or a nurse.

**Healthcare provider influence.** Respondents were asked if they would have joined the group sooner if their healthcare provider had suggested it. Forty members (75%) indicated that they would have joined sooner had their healthcare provider suggested it. Nine individuals (17%) would not have joined sooner. Three respondents did not answer the question.

**Finding the group.** Many members (30, corresponding 57 percent) initiated a general Internet search for information on their disease and “just happened” to stumble upon this particular online support group. Six people (11%) found the group by conducting a known-item (e.g., ‘support group’) search. Six members (11%) were given the specific website address by a friend (3 instances) or family member (3 instances). One member listed receiving the address from a healthcare professional. Three members located the list address in print media; two were referred by people they met online or on another list.

**Difficulty locating the group.** Responses to the statement “*I found it difficult to locate this support group*” were mixed. Twenty respondents (38%) strongly disagreed with this statement, 14 (26%) somewhat disagreed, 16 (30%) somewhat agreed, and 2 (4%) strongly agreed.

**Difficulty subscribing to the list.** Most people did not report difficulties subscribing once they had located the group. Forty-three respondents (81%) strongly disagreed, and five

(9%) somewhat disagreed, with the statement “*I found it difficult to subscribe to this support group*”. Four respondents (8%) said they somewhat agreed, and 1 (2%) indicating strong agreement.

### **Participation characteristics**

**Messages sent.** On average, members reported sending about 20 messages per month to the list. This number may include some individual list correspondence. Several members considered themselves “lurkers” noting that they mostly just read the e-mails of others.

**Time spent.** Members on this list spend an average of 77 minutes each day participating (reading, sending, researching) in some way on this list. The median participation time was 60 minutes.

**Participation time of day.** Members were asked if there was a particular time of the day that they participated. Most members 30 (57%) could not name a specific range(s) and said that they participated at multiple times of the day. Ten members (19%) participated between 8 PM and midnight; nine (17%) between 5 AM and 8 AM; six between 8 AM and 12 PM; five between 5 PM and 8 PM; two between 12 PM and 5 PM; and one between 12 AM and 5 AM. Some members selected a couple of time slots so the percentages do not add up to 100%. Assuming that there are people who are working full-time work between 8 AM and 5 PM, it appears that some members participate at their workplace and some avoid participation at their place of employment.

**Participation time of week.** Most members participate on weekdays (35, corresponding to 66%), five (9%) participated mostly on the weekend, and 13 (25%) cited no difference.

**Participation in other online groups.** For more than half of the respondents (29, 55%) this is the only support group they subscribe to, while 23 members (43%) also subscribed to other online support groups. In comments to this question, it became evident that this group has created offshoot groups that address more specific topics related to the disease, or topics that are relevant only to some members.

### Issues relating to healthcare providers

**Healthcare professional participation.** Members reported that there are a few physicians and nurses on this list and occasionally will post or reply to messages. When asked “*Are you aware of any medical professionals who read or contribute to this list?*” 50 (94%) replied ‘yes’, 3 (6%) replied ‘no’. Members were also asked “*Would you welcome the participation (or more participation) of a medical professional on this mailing list?*” In response to this question, 50 (94%) of members said yes. One member said no and two did not answer.

**Communication channel changes.** Members were asked about their agreement with the statement, “*There are many times when I seek advice from this list that I would have only sought from my doctor in the past.*” Twenty-three respondents (43%) strongly agreed, 19 (36%) somewhat agreed, 5 (9%) somewhat disagreed, and 2 (4%) strongly disagreed. Members were also asked to respond to the statement “*There are health-related questions that I ask on this list that I would never in the past nor in the present dream of asking my doctor.*” Fourteen (26%) strongly agreed, 13 (25%) somewhat agreed, 14 (26%) somewhat disagreed and 8 (15%) strongly disagreed.

**Reported effect on doctor-patient relationship.** The majority of respondents reported that the list has had a positive effect on their relationship with their physicians (28, 53%). Eighteen respondents (34%) reported no effect. A few respondents (3, 6%) reported negative effects. Many respondents volunteered additional information saying that they now know the right questions to ask, are well-informed, and make efficient use of the time they have with their physician (“*I know what questions to ask and he knows I want to participate in my treatment choices.*”). They feel as if they are more respected and taken more seriously by their physician. Among the three respondents who reported negative effects, one said their physician discouraged any Internet use for medical information, one physician appeared “threatened” to the respondent and one seemed “resent[ful].”

**Other support vs. online support.** Participants were asked to compare the helpfulness of their support group to other potential support providers. Overall, the support group seems more helpful to most participants than talking with family and friends who do not have this illness. Some report that the group is more helpful than talking with their doctor or nurse (30% and 26%, respectively). A somewhat smaller number of respondents (13%

and 8%, respectively) find talking to a doctor or a nurse better than talking to the group, and nearly fifty percent report the support group to be as “helpful”. The results are best shown in Table 5 below:

<b>Table 5. Breast Cancer responses: support type preferences</b>	
<b>Support group is <u>MORE helpful</u> to me than talking with:</b>	
my friends who do not have my same ailment or predicament	46 (87%)
family members who do not have this ailment.	43 (81%)
my doctor (medical).	16 (30%)
my psychologist or counselor.	5 (9%)
a nurse	14 (26%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	12 (23%)
other	0 (0%)
<b>Support group is <u>AS helpful</u> to me as talking with:</b>	
my friends who do not have my same ailment or predicament	2 (4%)
family members who do not have this ailment.	4 (8%)
my doctor (medical).	26 (49%)
my psychologist or counselor.	9 (17%)
a nurse	24 (45%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	9 (17%)
other	0 (0%)
<b>Support group is <u>LESS helpful</u> to me than talking with:</b>	
my friends who do not have my same ailment or predicament	2 (4%)
family members who do not have this ailment.	3 (6%)
my doctor (medical).	7 (13%)
my psychologist or counselor.	2 (4%)
a nurse	4 (8%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	1 (2%)
other	0 (0%)

### **Quality and degree of support received**

It is reasonable to assume that members are receiving support from the group, due to the very fact that they continue their membership. Regardless, from a research standpoint

the author felt it was important to firmly establish that support is received, and to identify the predominant types of support available to participants in the group.

**Support.** Participants were asked to indicate their agreement with the following statement, *“I get helpful information on how to manage my (or my loved one's) disease from this support group.”* Forty-seven respondents (89%) strongly agreed with this statement and 3 (6%) somewhat agreed. When presented with the statement, *I get valuable emotional support that helps me cope with the stress of my (or my loved one's) disease”,* thirty-nine (74%) strongly agreed and 10 (19%) agreed somewhat.

**Information quality.** Participants were asked *“I have received misleading information from the list on several occasions.”* One person strongly agreed with this statement; 9 (17%) somewhat agreed; 18 (34%) somewhat disagreed; and 20 (38%) strongly disagreed.

**Perceived effect on health.** Participants were confronted with the following statement, *“I would say that this online group has either directly or indirectly saved or prolonged my life (or that of my loved one).”* Nine (17%) strongly agreed, 12 (23%) somewhat agreed, 11 (21%) somewhat disagreed, and 5 (9%) strongly disagreed.

**Perceived effect on quality of life.** When asked about their opinion about the statement *“I would say that this online group has improved the quality of life for me or my loved one.”* Thirty-three (62%) strongly agreed, 15 (28%) somewhat agreed, and one somewhat disagreed.

**Disease management.** Participants were presented the following statement, *“I do not know how people with my (or my loved one's condition) could possibly manage without an online support group such as this one.”* Fourteen (26%) strongly agreed; 19 (36%) somewhat agreed; 9 (17%) somewhat disagreed; and 6 (11%) strongly disagreed.

**Helping others.** When asked *“Helping others on this list is very important to me”,* thirty (57%) of respondents strongly agreed, 16 (30%) somewhat agreed, while 4 (8%) somewhat disagreed.



## Face-to-face support

Participants were asked if they participated in a face-to-face support group and if they did not, why not. Thirty-eight members (72%) did not attend a face-to-face group while 13 (25%) did. Table 6 provides reasons for not attending were as follows:

Online group more convenient .....	29	(55%)
Act of typing out thoughts was therapeutic in itself .....	20	(38%)
More comfortable using the online format .....	10	(19%)
Face-to-face group did not meet needs .....	7	(13%)
No face-to-face groups in respondent locale.....	5	(9%)
Too hard to find replacement caregiver for children or loved one .....	3	(6%)
Do not feel well enough .....	1	(2%)
Other reasons (varied).....	6	(11%)

Other reasons were given regarding face-to-face support group non-attendance with several implying that they are useful when they are in a more serious condition than they are presently. Also, several mentioned that there are features about face-to-face meetings that are difficult for them. Here are some interesting free text answers.

- *I am shy*
- *feel more in control*
- *I prefer to be anonymous, generally.*
- *I like having time to organize my thoughts and the ability to revise them*
- *I'm a writer*
- *most are in churches or Christian in nature, and I am not comfortable in that setting.*
- *I have trouble psychologically meeting people face-to-face*
- *The f2f meetings were usually dominated by 1 or 2 people.*
- *The list keeps me in contact with people from all over the world.*
- *Do not want another meeting to go to - sitting too long is very painful*
- *I feel guilty when I spend face-to-face time with those who are much more ill than I. I have been very lucky to have had my cancer found at a very early stage and my prognosis is excellent.*

- *Attended support group early on; but the inconvenience, as I moved into NED status, eventually outweighed the benefit. If my disease advances, I will no doubt seek out face-to-face again.*
- *Don't feel a need to attend a face-to-face since I'm not currently undergoing treatment.*
- *I did attend a group several years ago and I occasionally attend workshops and lectures. At present, I am more focused on information than support. If I get in trouble again, I will also look for a face-to-face support group*

### Most and least favorite thing

Most favorite. Participants were asked “*What is your most favorite thing about this online support group?*” Though the variety of responses is somewhat difficult to code, Table 7 displays some of the important themes of responses captured:

information on disease.....	N=14
friendships made on group.....	N=12
talking with people who can empathize.....	N=10
humor on the list.....	N=7
freedom to be one's self .....	N=6
diversity of group members .....	N=6
convenience of list.....	N=5
the annual get togethers.....	N=4
the non-judgmental atmosphere.....	N=3
the relative anonymity provided by the forum .....	N=2
knowing that others are there for you .....	N=2
knowing that there are survivors of disease .....	N=1

The following messages state quite eloquently the recurring themes captured with this question.

- *The unconditional love and understanding that one can only find within a group of similarly afflicted people. There is always someone who has gone through or who is going through the thing that is topmost on one's mind, no matter what it is. There are activists and educators, medical professionals and just plain folks, and we all appreciate each other and treat each other as equals. No one talks down to anyone.*

- *The openness, frankness, willingness to try and report on alternative methods, the overwhelming support and sense of community, the feeling that everyone is in my corner when I need them, there is no "wrong" way to treat the disease, emotional support, intellectual support, humor*
- *Access to cutting edge information about my treatment needs*
- *There's always a laugh here. Lots of humor for a very serious subject!*

Of course, emotional support and the atmosphere of sharing were implied and sometimes specifically stated in many, if not most, answers.

Least favorite. Participants were asked “*What is your least favorite thing about this online support group?*” Responses are categorized in Table 8 below.

<b>Table 8. Breast Cancer responses: least favorite qualities of group</b>	
Occasional flame wars.....	14
Off topic discussion.....	12
Sheer volume.....	7
Occasional unpleasant members .....	4
Death of a member.....	3
Imposters .....	2
Desire to meet with members more often.....	1
Discussion of alternative therapies.....	1
It is predominantly an American list making treatment comparisons difficult.....	1
Misleading information .....	1

There is some indication that though members are bothered by off-topic discussion it may also be the source of some of the humor, freedom, and personality of the list. Many lists encourage putting OT in the subject line of an off-topic thread. Several members provided keen insights on the issue with off-topic e-mail.

- *the volume of posts is truly excessive...lots of it is just chit chat and off topic, so for people desperately seeking info and advice it is very frustrating to have to plow through so much. Volume, in fact, is one of the reasons many of the MDs and some others have left this list.*
- *Occasionally I am irked by irrelevant off-topic threads. (Here I include religious viewpoints.) Actually, off-topic threads are terribly*

*important to the dynamic of the group. If cancer was all we knew about, we'd be a pretty dreary lot.*

- *Too many off topic discussions. Recently we have had many posts on the fact that mallomars (a type of cookie) are not shipped during the summer.*

### **Privacy concerns**

The nature of communication over the Internet raises many privacy issues. To explore members' perceptions of threats to privacy several questions were posed.

**Imposters with financial motives.** Respondents were asked, *“Are you concerned that a sales-type person, who pretends to be a legitimate support group member, may suggest that members purchase a specific health-related product on this list.”* A slight majority of participants were not concerned, 30 (57%), while some did express concern 21 (40%). However, the overall feeling of most all respondents is that imposters are quickly identified and properly ousted.

- *The suggestions about products usually come from patients who are members of the list (e.g. recommendations about complementary therapies). Messages from sales-type people are rare (and, usually provoke very negative responses - list members have a very low tolerance threshold for this sort of behavior!)*
- *It is an unmoderated list, and we do get infiltrated from time to time. Members are quick to recognize the intruders, who seldom last long.*
- *The members of our list are pretty sharp and do not allow snake oil salesmen to stay around very long.*

**Concern over increase in junk e-mail.** Respondents were asked, *“Are you concerned that people may subscribe to this list in order to get your e-mail address and then sell it to companies who send spam (spam = junk mail)?”* The majority of respondents were not concerned 35 (66%) while 18 (34%) expressed concern. Several noted that they did not think this has happened, as they don't get too much spam. For those that get a lot of spam, it doesn't bother them. These responses sum up the sentiment:

- *It hasn't been a problem so far...hope it doesn't occur.*

- *It really doesn't matter about the spam issue. I would take all the spam in the world as long as I could have the contact with the list.*
- *I know where the delete key is.*

Concern over insurance companies getting information. Respondents were asked, “*Are you concerned that an insurance company may snoop on this list?*” A slight majority of respondents said they were not concerned 30 (57%) while others did express concern 22 (42%). This list seems to do an effective job in reminding members about risks:

- *This is discussed openly and we are warned about divulging too much information for privacy protection. For example, genetic testing.*
- *List members are frequently warned to be cautious about posting the results of genetic tests.*
- *We do have archives and it would be impossible to block them completely. For this reason we are periodically advised not to post certain information to the list. Some do anyway, I do not.*

Archives. Respondents were specifically asked, “*Are you concerned that if this list archives its messages that those archives may be used for unintended purposes?*” The majority of respondents were not concerned with 33 (62%) saying no and 20 (38%) saying yes. The further explanation section of this question gave insight into different opinions:

- *I should live so long!*
- *People are often quite frank about financial concerns, health of family members, etc., in addition to their own medical status. This would not be a supportive list if personal stories weren't ... told. I think we all understand there is no confidentiality.*
- *Again, it probably could happen; but I could break my neck falling out of bed also.*
- *The List is archived, as are many others. If I didn't want others to know what I write, I wouldn't post to the List in the first place.*
- *Yes, [I am concerned] the archive of messages is wide open to the public.*

Use of real name. Respondents were asked, “*Does your real (first and last) name appear on this list (either discernable in the e-mail address, the "from" line, or in your signature)?*” Nearly all respondents, 45 (85%) said that it did while six (11%) said no.

Desired legal protection. Respondents were asked, “*Do you think that the personal medical information exchanged on a list such as this one should be protected under medical privacy laws?*” Most respondents said yes (35, 66%), but 13 members (25% of respondents) said no. Again, there was a range of responses to this question.

- *What's the big deal? We are writing to "friends," for the purpose of sharing information, getting and receiving help, supporting each other, etc. What privacy is there to protect? We are not medical professionals diagnosing a patient; so there is no breach of confidence.*
- *That would be nice... specifically concerning the issue of genetic testing for BRCA and insurance snoops who would deny coverage to first degree relatives of BRCA positive patients.*
- *SHOULD be, but I don't see how it CAN be*
- *I think that anyone who is very concerned about privacy should disguise their identity or only reveal such information on private emails.*
- *We talk about our experience with meds. etc. If you don't want anyone to know get off the list!*

## **Esophageal Cancer Group - Results**

### **List characteristics**

This list has a high volume with an average of about 25 messages exchanged each day. It appeared that over several months approximately 124 unique individuals were communicating on the list. In addition, this list has many threads develop where a message posted typically receives lots of replies. Some members choose to receive their messages in digest form which comes as one very long text e-mail once per day.

### **User characteristics**

Thirty-nine persons (of over 900 subscribed) from the esophageal cancer list responded to the survey. Of all respondents, 15 (38%) had a family member with the disease, eight (21%) were caregivers of a person (usually family member) with the disease, 22 members (56%) were members of the list because they have this disease, one (3%) had a friends with the disease, two (6%) were doctors who treat patients with the disease, and one was a long-time cancer survivor.

The latter respondent's motivation was expressed by the following statement:

- *I feel that my six years experience of being a cancer survivor can help others who find themselves diagnosed with a cancer condition.*

### **Demographics.**

**Gender.** Most respondents (21, corresponding to 54 percent) were female. Eighteen respondents (46%) were male.

**Age.** Respondents had the option of specifying their specific age or indicating a range. The mean age was 54.4 years with a minimum age of 34 years reported and a maximum of 78 years. Eleven respondents opted to indicate a range with six (15%) between the ages of 40 and 49 years; one (3%) between the ages of 50 and 59 years, and four (10%) between the ages of 60 and 69 years. Taking the middle value of each range (i.e. 34.5 years for the range, 30-39) and using it as part of the actual age data yields a similar mean age of 54.2 years.

**Race.** In light of recent controversy on how to classify race, this question was left as a free text field. Most members (37, corresponding to 95 percent of respondents) reported

their race as white or Caucasian. One respondent skipped this question, one other responded with “why”.

**Education.** On average, respondents had a high level of education, with a mean education level of 16.3 years. The educational range was 11 years (less than high school graduate) to 21 years (5 years graduate school). Thirteen respondents had a college degree and 15 additional people had some graduate education.

**Income.** On average, respondents also reported high incomes. Income was reported in ranges. Thirteen respondents (33%) had a pre-tax income above \$75,000. Eight respondents (21%) had an income between \$50,001 and \$75,000. Three respondents (8%) reported an income between \$40,001 and \$50,000. Two respondents (5%) reported an income between \$20,001 and \$30,000. One respondent each reported an income \$10,000 or under, and between \$10,001 and \$20,000, respectively. Two respondents left the answer to this question blank.

**Household size.** The average household size reported was 2.75 persons.

**Type of residence.** When asked about their location of residence, most respondents reported living in a suburban neighborhood (23, 59%). Nine members (23%) reported living in a rural area, and 6 members (15%) reported living in an urban area.

**Schedule.** Participants were asked about their daily schedules and were given the opportunity to select more than one option so the following percentages exceed 100%. Of the respondents,

- 15 (38%) take care of home and family tasks part-time;
- 14 (36%) work full-time outside the home;
- 11 (28%) are retired;
- 8 (21%) work part-time outside the home;
- 6 (15%) take care of home and family tasks full-time;
- 4 (10%) do not work at the present time;
- 2 (5%) work full-time for pay but do so from home (e.g. telecommute);
- 1 (3%) work part-time for pay but do so from home (e.g. telecommute);
- 4 (10%) Other

By assigning time values to the various schedule items (i.e. 20 hours for part-time job, 40 hours for a full-time job), one gets a mean “committed time” of 38 hours per week. Several people reported themselves as disabled.



### **Participants' computer background**

**Years using a computer.** On average members have been using a computer for a long time, 13.6 years, ranging from 2 to 30 years.

**Comfort with computer:** Respondents feel very comfortable with the 'every day use' of a computer. Twenty-eight people (72%) strongly agreed with the statement, "*I am very comfortable with everyday-use of the computer.*" Four (10%) answered "somewhat agree", one somewhat disagreed, and 6 (15%) strongly disagreed with the statement.

**Software.** Participants use a variety of e-mail clients with 16 (41%) using Microsoft Outlook or Outlook Express, four (10%) using Netscape Messenger, nine (23%) using AOL, 3 (7%) using Eudora, 2 (5%) using Telnet/Pine, and 1 using Yahoo. The remaining members used Groupwise, and MSN.

**Connection speed.** Two participants (5%) had connections slower than 56K. 10 (26%) participated on the list using DSL or cable connections; and the remaining 27 (69%) participated in the support group using 56K connections.

### **Membership history and characteristics**

**Duration of membership.** On average, respondents had been members of this support group for about one year, 8 months (87 weeks) though there was much variation. The newest member had been in the group for 3 weeks and the "oldest" member, for six years.

**Join-time lag.** Members were asked how long after their diagnosis they joined the group. The average lag time between participants' diagnosis with Esophageal cancer and their joining of this online group was only 15 weeks, with a minimum of one day and a maximum of 2 years. A couple of respondents noted that they joined the group before learning the diagnosis for certain.

**Impetus for joining.** The survey contained several questions relating to how members came to join this Esophageal Cancer online support group. When participants were asked "*Who gave you the idea to seek this form of support?*", twenty-seven (69%) answered "This was all my own initiative". A friend made the suggestion to 2 members (5%), and a family member suggested the list to 5 members (13%). Five respondents found a reference to the group elsewhere on the Internet.

**Healthcare provider influence.** Respondents were asked if they would have joined the group sooner if their healthcare provider had suggested it. Twenty-four respondents (62%) indicated that they would have joined sooner had their healthcare provider suggested it. Eight individuals (21%) would not have joined sooner. Seven participants either selected NA or did not answer the question. One participant provided an explanation for her answer:

- *[no, I wouldn't have joined sooner] I don't believe that I was able to deal with reading about things that had to do with my illness. I was doing everything I could to fight the disease.*

Another question revealed instances regarding people who do not want to join:

- *... We have many instances of family members who join the group when the patient will not. Even a few cases where the patient insists that the group member not post to the group. Or even not to subscribe under their real name.*

**Finding the group.** The results for this topic closely parallel the earlier section “Impetus for Joining.” Most (27, corresponding to 69 percent) found the group by initiating a general Internet search for information on their disease and “just happened” to stumble upon this particular online support group. Incidentally, the owner of this list reported that the list has a complementary website that is well indexed with search engines and is returned at the top of results set during an Internet-search on the disease. Three people (8%) found the group by conducting a known-item (e.g., ‘support group’) search. Seven members (18%) were given the specific website address by a friend (2 instances) or family member (5 instances). Three members (8%) checked other. One of them found the list not via a discrete search but were already established visitors of other online disease-specific resources and located the group through these contacts.

**Difficulty locating the group.** Responses to the statement “*I found it difficult to locate this support group*” were mixed. Fourteen respondents (36%) strongly disagreed with this statement, 13 (33%) somewhat disagreed, 9 (23%) somewhat agreed, and 1 (3%) strongly agreed.

**Difficulty subscribing to the list.** Most people did not report difficulties subscribing once they had located the group. Thirty (77%) strongly disagreed with the statement “*I*

*found it difficult to subscribe to this support group*". 5 (13%) somewhat disagreed. Only two respondents (5%) said they somewhat agreed with the statement.

### **Participation characteristics**

**Messages sent.** On average, members reported sending about 10 messages per week to the list with a median of 2 messages per month. This number may include some individual-to-individual list correspondence. Many members offered additional information providing rich clarifications into differing participation styles and preferences of members.

- *I'm a lurker and have only contributed to the 2-3 times, though I've corresponded person-to-person with individual members and received replies from them.*
- *although only reading at present, we (me and husband) do intend to 'post' when ready*
- *On average I receive 100+ emails per day and send about 50+. You must also consider many people will post and receive emails privately to individuals as opposed to being on list. I have a fair reputation as a searcher and receive many requests for information. I do not dispense advice but provide information backup with URLs from professional sites only*
- *I don't respond to many of the questions posted to the group when I know there are others who will. I do respond when people post questions that are unusual and which I have personally experienced: for example voice problems relating to EC surgery. I maintain many private correspondences. I believe there is a much greater volume of private correspondence for everyone. That is, someone will read a message and respond directly to the poster and not to the group as a whole.*
- *I am a lurker as I am not a direct caregiver of the person with EC. I try to learn more about the disease and how it affects people's lives. It is a great source of comfort, camaraderie and knowledge. Most of the knowledge given here is the kind I believe to most important -- such as how to live with the details.*

**Time spent.** Members on this list spend an average of about 67 minutes each day participating (reading, sending, researching) in some way on this list. The median participation time was 30 minutes.

**Participation time of day.** Participants were asked if there was a particular time of the day that they participated. Most members 21 (54%) could not name a specific range(s)

and said that they participated at multiple times of the day. Ten members (26%) participated between 8PM and midnight; four (10%) between 5AM and 8AM; five (13%) between 8AM and 12PM; one each between 12PM and 5PM and 5PM and 8PM; and two between 12 AM and 5 AM. Some noted that they participated while at work. Others noted that participation was influenced by other obligations.

- *I have small children...the night is easier once they go to sleep*
- *Family use of computer and part-time work affect my availability both ways*
- *During the week, more likely in the evening. On weekends, more likely during the day.*

**Participation time of week.** Most members participate on weekdays (17, corresponding to 44%), while 15 (38%) cited no difference and six (15%) participated mostly on the weekend. One member noted that weekend and weekday distinction had little meaning in her life:

- *I am on a 24/7 schedule 365 days a year.*

**Participation in other online groups.** For more than half of the respondents (26, 67%) this group is the only online support group; 12 members (31%) subscribe to other groups as well

### **Issues relating to healthcare providers**

**Healthcare professional participation.** Members reported that there are healthcare professional(s) on the list. When asked “*Are you aware of any medical professionals who read or contribute to this list?*” 15 (38%) replied ‘yes’. 24 (62%) replied ‘no’. One responded noted, “I am a nurse as well as caregiver.” Some members suspect that healthcare professionals subscribe to the list to help them stay current on the disease.

- *very occasional posts from people who identify themselves as physicians. always to ask a question NEVER to give information*
- *There are several medical professionals on lists I [use]. For some it's observational, and on two it's for the latest cancer research information. I subscribe to many professional online cancer journals such as the JCO and many others. I post the latest cancer links. many third world professionals subscribe.*

- *This has been very rare. We always have a few med pros as lurkers. We had one physician who was a patient and he was very active. I think the docs and nurses who are there to learn about EC. Not to give advice*

Members were also asked “*Would you welcome the participation (or more participation) of a medical professional on this mailing list?*” In response to this question, 36 (92%) of members said yes, while three said no. Several members provided textual responses.

- *[yes] Maybe. Only to answer questions for people*
- *[yes] But, I don't think it will happen. After all they are correctly loath to give out what might appear to be medical advice to someone they haven't examined. MDs are licensed by states and the 'net transcends state licenses*
- *[yes] Absolutely, especially if they participated in the list Q&As. It's a common expression from physicians with cancer, they learn more about their cancer on list than they do from their oncologists. For some people, a physician's involvement becomes too clinical and discouraging especially with my type cancer. But they're rarely wrong.*
- *[yes] i suspect physicians might see liability issues in contributing*

**Communication channel changes.** Members were asked about their agreement with the statement, “*There are many times when I seek advice from this list that I would have only sought from my doctor in the past.*” Thirteen respondents (33%) strongly agreed, 14 (36%) somewhat agreed, 5 (13%) somewhat disagreed, and 4 (10%) strongly disagreed. Members were also asked to respond to the statement “*There are health-related questions that I ask on this list that I would never in the past nor in the present dream of asking my doctor.*” Four (10%) strongly agreed, 7 (18%) somewhat agreed, 8 (21%) somewhat disagreed and 17 (44%) strongly disagreed.

**Reported effect on doctor-patient relationship.** The majority of respondents reported that the list has had a positive effect on their relationship with their physicians (27, 69%). Ten respondents (25%) reported no effect. Two respondents (10%) reported negative effects.

Many respondents volunteered additional information. Again, as with previous groups, the overriding theme was that the effect was positive because the patients went into the visit well-informed and knew what questions to ask.

*[Positive effect reported]*

- *People learn what questions to ask. Even how to ask them*
- *It has helped me stay more informed about this disease and enables me to know which questions to ask the DR.*
- *Many of the members have been down the same road, perhaps with differing treatments and can say what they were, allowing an inquiry to the doctor that we otherwise may not have known about, and/or understanding of the vernacular and expectations of what's to come.*
- *Information I get here I share with my doctor. He rolls his eyes at some of it, but is often genuinely interested in what I've found. We discuss it and if appropriate, add the info to our arsenal in the war against the cancer.*
- *Occasionally you'll come up with a symptom that 'seems' like something you were going through just prior to diagnosis. You can pose the problem to the group and even though you know that you should see your doctor and your scared about it, they all tell you, in the nicest way, that you know that need to have this checked out and we'll be here for you no matter what the diagnosis.*
- *Only positive in that I have the questions to ask them when they have the time to talk. They are not particularly responsive to suggestions or question I have, originating from participation in this online group.*

*[No effect reported]*

- *We have a marvelous doctor, and this group's info has not changed that in any way. He knows I participate and is pleased.*

*[Negative effect reported]*

- *I question the treatment he has prescribed for my father and his approach as no taking my father's treatment as seriously as he could based on the fact that my father is 77 and stage IV.*

**Other support vs. online support.** Participants were asked to compare the helpfulness of their support group to other potential support providers. Overall, respondents reported that the support group was more helpful to them than talking with family (79%) and friends (73%) who do not have this illness. Some report that the group is more helpful than talking with their doctor or nurse (48% and 43%, respectively). A somewhat smaller number of respondents (3% and 6%, respectively) find talking to a doctor or a nurse better than talking to the group. The results are best shown in tabular form (see Table 9).

<b>Table 9. Esophageal Cancer responses: support type preferences</b>	
<b>Support group is <u>MORE helpful</u> to me than talking with:</b>	
my friends who do not have my same ailment or predicament	32 (82%)
family members who do not have this ailment.	29 (74%)
my doctor (medical).	8 (21%)
my psychologist or counselor.	1 (3%)
a nurse	5 (13%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	9 (23%)
<b>Support group is <u>AS helpful</u> to me as talking with:</b>	
my friends who do not have my same ailment or predicament	3 (8%)
family members who do not have this ailment.	6 (15%)
my doctor (medical).	21 (54%)
my psychologist or counselor.	6 (15%)
a nurse	19 (49%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	5 (13%)
other (than my face-to-face support group, family member who has ailment, anyone that you mention)	1 (3%)
<b>Support group is <u>LESS helpful</u> to me than talking with:</b>	
my friends who do not have my same ailment or predicament	1 (3%)
family members who do not have this ailment.	1 (3%)
my doctor (medical).	5 (13%)
my psychologist or counselor.	2 (5%)
a nurse	3 (8%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	2 (5%)
other (than my face-to-face support group, family member who has ailment, anyone that you mention)	1 (3%)

### Group members often provided further explanation for their answers:

- *it's more helpful in that the health care professional's time, and to some extent knowledge, is limited. they generally talk about what they offer and less of what they don't. also they cannot possibly know everything about every disease and since i'm looking for information on every aspect of one subset of one disease entity i can do my own research and also learn from others that are doing theirs (as well as from others' experiences). this i sometimes take back and discuss with the health care providers. however i find that there are times when i'm bettered informed about certain things than they are. some docs are open to that and some are not. (i myself am a health care professional)*
- *medical staff don't know enough in this area to be able to help us properly and the experience from the group has been the best source of assistance*
- *Each of those groups supply some things somewhat different from each other and from on line support groups. There are things we come to expect or not expect from each*
- *I have much respect for my Medonc and RadOnc and will discuss anything with them. They grant me as much time as needed. I have full access to their records about me. If I have had a recent test, I expect them, and they do, to fully explain it too me. I also demand copies which I can further research. If there are no test results to discuss, I don't waste their time to chit chat, although they will listen.*
- *i discuss different issues which each of the groups specified. The online group is unsurpassed for advice on day-to-day issues.; example 1, How do you clean a feeding tube; example 2, how do you arrange your bed to avoid reflux/regurgitation; example 3, how do you handle/avoid dumping. My doctors: What is the best treatment modality for cancer at my staging? Why do you do this in surgery? My family members: I feel really depressed, like I'll never get better.*

### Quality and degree of support received

It is reasonable to assume that members are receiving support from the group - due to the very fact that they continue their membership. Regardless, from a research standpoint it was important to firmly establish that support is received, and to identify the predominant types of support available to participants in the group.

**Support.** Participants were asked to indicate their agreement with the following statement, *"I get helpful information on how to manage my (or my loved one's) disease from this*



*support group.*” Twenty-nine respondents (74%) strongly agreed with this statement and 8 (21%) somewhat agreed. One person strongly disagreed.

When presented with the statement, *I get valuable emotional support that helps me cope with the stress of my (or my loved one's) disease.*”, twenty (51%) strongly agreed; 13 (33%) agreed somewhat; 1 somewhat disagreed; and two disagreed strongly.

**Information quality.** There has been much talk about the veracity of information received online.<sup>24</sup> In order to get participants feedback on this issue they were asked to respond to the following statement, *“I have received misleading information from the list on several occasions.”* Four people (10% of respondents) strongly agreed with this statement; 6 (15%) somewhat agreed; 9 (23%) somewhat disagreed; and 18 (46%) strongly disagreed.

- *When erroneous information is posted, one can expect a large volume of responses indicating the error.*

**Perceived effect on health.** Participants were confronted with the following statement, *“I would say that this online group has either directly or indirectly saved or prolonged my life (or that of my loved one).”* Six (15%) strongly agreed, 15 (38%) somewhat agreed, 3 (8%) somewhat disagreed, and 7 (18%) strongly disagreed. One explanation gave insight into the respondent’s feelings regarding this question.

- *The group has been most helpful as I seek to understand my mother's illness through what other people have experienced. While I cannot say it has fundamentally changed her treatment in any way it has lead to me to be able to ask better questions of her docs, to create a network of knowledge that I share with my brother and sisters and contribute to some sense of control over our fight against the cancer.*

**Perceived effect on quality of life.** When asked about their opinion about the statement *“I would say that this online group has improved the quality of life for me or my loved one.”* Eighteen (46%) strongly agreed, 12 (31%) somewhat agreed, three somewhat and one strongly disagreed.

- *The list has had no effect on my quality of life, but I know it has for others.*

Disease management. Participants were presented the following statement to respond to, “I do not know how people with my (or my loved one's condition) could possibly manage without an online support group such as this one.” Eleven (28%) strongly agreed; 19 (49%) somewhat agreed; 3 (9%) somewhat disagreed; and 4 (10%) strongly disagreed. Below are comments from respondents.

- *[strongly disagree] ...of course People "could manage" without it, but SOME people manage better, or as an alternative, and I think all who use it benefit - or they'd quit using it!*
- *[somewhat agree] I guess we all manage - support group or not - to the extent we are able! I find this question difficult to answer - a bit too subjective*
- *[somewhat agree] ...People can and do manage without list help, but the support and advice from the long termers is invaluable...*

Helping others. When asked “Helping others on this list is very important to me.”, twenty (51%) of respondents strongly agreed, 15 (38%) somewhat agreed, and two (5%) somewhat disagreed.

### Face-to-face support

Participants were asked if they participated in a face-to-face support group and if they did not, why not. Only two members (5%) attended a face-to-face group while 37 (95%) did not. For those who did not the reasons are found in Table 10 as follows:

Online group more convenient .....	23	(59%)
No face-to-face groups in respondent locale.....	17	(44%)
Act of typing out thoughts was therapeutic in itself .....	14	(36%)
More comfortable using the online format.....	8	(21%)
Other reasons (varied).....	5	(13%)
Too hard to find replacement caregiver for children or loved one .....	4	(10%)
Do not feel well enough .....	1	(3%)
Face-to-face group did not meet needs .....	0	(0%)

Other reasons given were that the member had not felt the need, did not have the time, and one said, *“i felt i "outgrew" the [face-to-face] group - i no longer need support.”* Another stated, *I know of one. It meets in the evening and I don't care to go out in the evening.”* In an answer to a previous survey question a member noted:

- *...I was inclined to seek a support group right away. I found something local that worked fine. It was better in some respects. It was face-to-face, so much more personal and had a professional facilitator. OTOH. [on the other hand] It was cancer in general and not specific to my disease. So it was emotional support and general informational support. The Internet group has 100 times as many people and have practical experiential knowledge specific to the disease*

One member notes,

- *...There are no face-to-face groups that I am aware of in our sizeable city. EC is a very rare form of cancer and is particularly deadly. Other cancer support groups just would not-do not understand the incredible fear that accompanies EC.*

Respondents were asked to expound if they chose “More comfortable using online format.” Following are two narrative explanations:

- *I feel I can expand more on my feelings and questions...face-to-face I feel uncomfortable taking too much time from others*
- *I am shy in public*

### **Most and least favorite thing**

Most favorite. Participants were asked *“What is your most favorite thing about this online support group?”* Table 11 displays some of the important themes of responses:

**Table II. Esophageal Cancer responses: favorite qualities of group**

The sharing of information and symptom management .....	10 (26%)
Support received.....	9 (24%)
Talking to those who have experienced same thing .....	7 (18%)
Friendships I've made .....	7 (18%)
Dependability, group is always there, convenient.....	3 (8%)
Collective wisdom .....	3 (8%)
Humor .....	3 (8%)
Just knowing that there are survivors .....	3 (8%)
Being able to help others .....	3 (8%)
Immediate answers and information .....	2 (5%)
Positive outlook .....	2 (5%)
Candidness and sincerity of members.....	2 (5%)
Knowing that I am not alone.....	2 (5%)
Fun interesting people .....	2 (5%)

The following messages state quite eloquently the recurring themes captured with this question.

- *The positive postings from those who have beat the odds.*
- *Sharing feelings with people "walking in my shoes" and the friendships I have made with some of the participants.*
- *The essential humanity and deeply personal nature of the group.*
- *The helpful info about this disease that I have learned from those who know about it FIRST-HAND.*
- *the feeling of not being alone with the biggest problem we have ever had to face*
- *EC is so deadly and you already feel that it is too late once diagnosed. You need information in a hurry and the online group can give a lot the info you need (and support).*
- *the enormous breadth of experience constitutes a body of (anecdotal) knowledge that exceeds the experience of any single [person]*
- *One develops a strong sense of fellowship and community with equally active members although we rarely meet. I know from time to time i really help people, and the occasional, little 'thank you' note goes far in making the time spent worthwhile.*

Least favorite. Participants were asked “*What is your least favorite thing about this online support group?*” Several themes emerged and responses are categorized in Table 12 below.

<b>Table 12. Esophageal Cancer responses: least favorite qualities of group</b>	
bickering.....	15 (38%)
not a theme/hard to code.....	6 (15%)
censorship .....	2 (5%)
e-mail limits .....	3 (8%)
off-topic .....	3 (8%)
lurkers .....	2 (5%)
off-topic religious.....	1 (3%)
misinformation .....	2 (5%)
want more contact.....	2 (5%)
death of member.....	1 (3%)

However, several members provided comments that flesh-out the categories:

- *[1] people pissing each other off because they don't recognize the limitations and pitfalls of email [2] people going into too much gory detail without being asked/prompted*
- *some of the misinformation that some well intentioned but technically unknowledgeable folks put out there (which can be difficult to counteract). also people's religiousities can be tough to deal w/, especially when their beliefs are so different than my own and they want to push theirs at everyone else*
- *Not having the money to actually go and meet these wonderful people.*
- *The basic problems of online communication. Misunderstandings, misconstrued remarks. Misperceptions. I have learned that many people's communication skills are not up to the task. I've seen innocent looking misunderstandings escalate quickly into mini-spats. The majority of people don't have this problem. But, if 2 or 3 do (even in a group of hundreds), their messages quickly dominate the postings*
- *Not being able to put my arms around someone in pain, to bring in a dinner, to take care of their kids etc.*
- *Censorship attempts by list managers.*

- *Persons who push alternative medicine "cures" such as vitamins, herbs, and others that are not based on sound clinical research.*
- *Sometimes it gets a little scary when someone runs into a problem that no one seems to have an answer for.*

### **Privacy concerns**

The nature of communication over the Internet raises many privacy issues. To explore members' perceptions of threats to privacy several questions were posed.

**Imposters with financial motives.** Respondents were asked, *"Are you concerned that a sales-type person, who pretends to be a legitimate support group member, may suggest that members purchase a specific health-related product on this list."* A majority of participants were not concerned, 35 (90%), while only four express concern (10%). However, the overall feeling of most all respondents is that imposters are not a huge problem:

- *Every time anyone has asked about an item, several people have responded with what they each have used before. A salesman would have a lot of competition - and if 'his' "won" - OK.*
- *the welcome documents ... disallow [this]. Periodically, someone joins for the express purpose of a making a commercial posting. They are kicked off right away. In fact most unsub[scribe] immediately after posting.*
- *No because I can evaluate whether I want something or not, and it doesn't matter if a list member recommends it. I can spot salesmen!*

One of the list owners addressed this issue as well:

- *This concern is most urgent in the parent organization, and our reaction is to quietly delete the individual as soon as discovered. Too often the individual can join several list at once, but list managers are attuned to this possibility and warnings are passed quickly. Membership privacy is an absolute goal, but obviously impossible to achieve.*

**Concern over increase in junk e-mail.** Respondents were asked, *"Are you concerned that people may subscribe to this list in order to get your e-mail address and then sell it to*

*companies who send spam (spam = junk mail)?*” The majority of respondents were not concerned 31 (79%) while 8 (21%) expressed concern.

- *Never occurred to me that this would happen. Would not like it.*
- *Plenty of spammers already have my address, so it is too late to worry about that.*

Again the owner was kind enough to respond to me about this concern as well:

- *Absolutely, and these people are the most difficult to ferret out. It happens. Naturally, it's generally impossible to trace. From time to time we have people from .COMs with commercial interest join our lists. If I discover they're using my materials or contacting my list members, I'll join their list and confront them directly so all their members can see their actions. We quickly delete one another.*

**Concern over insurance companies getting information.** Respondents were asked, *“Are you concerned that an insurance company may snoop on this list?”* A majority of respondents said they were not concerned 29 (74%) while others did express concern 10 (26%). Several expressed mistrust of insurance companies:

- *I must be very naive. These things don't usually come into my thoughts.*
- *IT had never occurred to me*
- *As a former executive in corporate America, I have no faith whatsoever in the ends they'll go to for their own financial purposes. Our privacy statement urges people to discuss only what they want the world to hear, but I doubt few people read list or .COM privacy statements.*
- *I wasn't until you mentioned the possibility, but I'm not worried anyway. I already beat my insurance company and got treatment/cured.*

**Archives.** Respondents were specifically asked, *“Are you concerned that if this list archives its messages that those archives may be used for unintended purposes?”* The majority of respondents were not concerned with 27 (69%) saying no and 11 (28%) saying yes. The further explanation section of this question gave insight into different opinions:

- *Should I be?*
- *I think an individual or organization taking advantage of such a group would be sick.*
- *I trust the people who are handling the list.*
- *E-mail is out there for the world to see; I'm careful what I write.*
- *The archives are a data mine for insurance companies.*

Use of real name. Respondents were asked, “*Does your real (first and last) name appear on this list (either discernable in the e-mail address, the "from" line, or in your signature)?*” Nearly all respondents, 33 (85%) said that their name did appear, while six (15%) said no.

Desired legal protection. Respondents were asked, “*Do you think that the personal medical information exchanged on a list such as this one should be protected under medical privacy laws?*” Most respondents said yes (29, 74%), but 9 members (23% of respondents) said no. Again, there was a range of responses to this question.

- *I submit information. If I was concerned about privacy I won't.*
- *As a list user, you must be aware that any of the privacy problems mentioned above do exist. It is the price of a free flow of info.*
- *This is the Internet - lack of privacy is a given.*
- *But what corporation is not willing to break the law for its purposes? It's in the newspapers everyday. Individual medical privacy should be an absolute. There's also great value if all medical records, unidentified, could be put into a national data base for medical research. A dichotomy yes, but not unachievable.*
- *Yet I would hope that only those on the list are reading it!*



## **Huntington's Disease Group - Results**

### **List characteristics**

This list has a very high volume with about 48 messages exchanged each day. Over several months approximately 160 unique individuals contributed to the list. In addition, this list has deep threads where a message posted typically receives lots of replies. Some members choose to receive their messages in digest form, which comes as one very long text e-mail once per day.

### **User characteristics**

Sixty-three persons (of approximately 400) from the Huntington's list responded to the survey. Of these respondents, 45 (71%) had a family member with the disease, 36 (57%) were caregivers of a person (usually family member) with the disease, 10 respondents (16%) were members of the list because they have this disease, 7 (11%) had friend(s) with the disease, 6 (10%) have family members at risk for developing the disease, 5 (8%) are at risk for developing disease, 5 (8%) were caregivers for persons who have since died from the disease. None of the respondents were healthcare professionals. The question gathering the above information allowed for multiple answers per respondent; some respondents are members of the online community for more than one reason, therefore the percentages above sum to more than 100 percent.

### **Demographics**

**Gender.** Most respondents (51, corresponding to 81 percent) were female. Ten respondents were male and two respondents did not answer the question.

**Age.** Respondents had the option of specifying their specific age or indicating a range. The mean age was 45 years with a minimum age of 24 years and a maximum of 70 years. Twenty-three respondents opted to indicate a range with one between the ages of 30 and 39 years; 9 (14%) between the ages of 40 and 49 years; seven (11%) between the ages of 50 and 59 years, and four (6%) between the ages of 60 and 69 years. Taking the middle value of each range (i.e. 34.5 years for the range, 30-39) and using it as part of the actual age data yields a similar mean of 47 years.

**Race.** This question regarding members' race was posed as a free text field. Most members (55, corresponding to 87 percent of respondents) reported their race as white. The remaining six responses included: "American", "white/black/native american", "heinz 57 of cau. + some indian", "Dutch", "European-American", "human". Two people did not answer the question.

**Education.** On average, respondents had a high level of education, with a mean education level of 14.5 years. The range was from 10 years (less than high school graduate) to 21 years (5 years graduate school). Of the 63 respondents, fourteen had a college degree and 10 more had some graduate education.

**Income.** On average, respondents also reported high incomes. Income was reported in ranges. Eight respondents (13%) had a pre-tax income above \$75,000. Ten respondents (16%) had an income between \$50,001 and \$75,000. Eight respondents (13%) reported an income between \$40,001 and \$50,000. Five (8%) reported an income between \$30,001-40,000. Eleven respondents (17%) reported an income between \$20,001 and \$30,000. Six respondents (10%) reported an income between \$10,001 and \$20,000. Two respondents (3%) had an income under \$10,000. Several respondents left the question blank.

**Household size.** The average household size reported was 3 persons.

**Type of residence.** When asked about their location of residence, respondents were closely split across the three types of areas. Twenty-four members (38%) reported living in a rural area, 21 members (33%) reported living in a suburban area, and 16 members (25%) reported living in an urban area.

**Schedule.** Participants were asked about their daily schedules and were given the opportunity to select more than one option; hence, the following percentages exceed 100%. Of the respondents,

- 31 (49%) reported taking care of home and family tasks full-time;
- 20 (32%) worked full-time outside of the home;
- 15 (24%) took care of home and family tasks part-time;
- 10 (16%) are not currently working at a for-pay job;
- 9 (14%) reported that they were retired;
- 9 (14%) work part-time outside of the home;
- 7 (11%) work part-time for pay from their home;
- 4 (6%) report that they are students;
- 2 (3%) work full-time for pay from their home

By assigning time values to the various answers (i.e. 20 hours for part-time job, 40 hours for a full-time job), one obtains a mean “committed time” of 45.7 hours per week. In other words, on average, respondents have more than full-time non-leisure time commitments, living busy lives.

### **Participants’ computer background**

**Years using a computer.** On average members have been using a computer for a long time, 11 years.

**Comfort with computers.** Most respondents feel very comfortable with the ‘every day use’ of a computer. Forty-three people (68%) strongly agreed with the statement, *“I am very comfortable with everyday-use of the computer.”* Twelve (19%) answered “somewhat agree”, and 8 (13%) strongly disagreed with the statement.

**Software.** Participants use a variety of e-mail clients with 27 (43%) using Microsoft Outlook or Outlook Express, eight (13%) using Netscape Messenger, eight (13%) using AOL, 3 (5%) using Hotmail and 3 (5%) using Yahoo. The remaining members used Eudora, MSN, Compuserve, Juno, Pegasus, Virgilio-(based outside of U.S.) and Unix based clients.

**Connection speed.** Nine participants (10%) had connections slower than 56K. (It was unclear how many users participated from their workplace as this question was not asked. Nonetheless, a couple of participants stated that they participated at work and at home and had high speed connections at work and 56K connections at home.) 14 respondents (22%) participated on the list using DSL or cable connections; 35 (56%) participated in the support group using 56K connections. Some participants were unsure of how they were connected.

### **Membership history and characteristics**

**Duration of membership.** On average, respondents had been members of this support group for about two years, 7 months (2.58 years) though there was much variation. The newest member had been in the group for 1 week and the “oldest” member for twelve years. A couple of members indicated that they had been members on and off.

**Join-time lag.** Members were asked how long after their diagnosis they joined the group. To place the answers to this question into the “right” context, it is important to note that many respondents are members because they or family members are at risk for developing the disease. Huntington’s is a genetically inherited disease and symptomatic onset usually occurs in adulthood when a couple has already had children. The family only finds out about it when the relative displays symptoms. These children (or relatives) are at risk but will not know if they have the gene causing Huntington’s until they are tested. Getting the test or diagnosis can be emotionally very difficult for people so many are pre-symptomatic or may not even develop Huntington’s. With this notation made, the average lag time between participants’ diagnosis with Huntington’s and their joining of this online group was 3.58 years. Several noted that they learned of their illness before this support group was created. There was much variation, with some members joining before their (or their loved one’s) diagnosis and some joining many years after.

**Impetus for joining.** The survey contained several questions relating to how members came to join this Huntington’s online support group. When participants were asked “*Who gave you the idea to seek this form of support?*” thirty-three (52%) answered “This was all my own initiative”. A friend made the suggestion to 11 members (17%), and a family member suggested the list to 3 members (5%); a doctor suggested the list to two members (3%).

Twenty respondents (30%) indicated “other” for this category. Of these, six members initiated a general search and found reference to the group, and four members found a reference to the site in published print media (book). For two members it seemed that they were already established on the Internet and received online referrals to the group. In other words there was not a clear initiation of a discrete Internet search but rather interaction with a resource (a discussion forum) with which they were already familiar. Two members were referred by other healthcare professionals: one by a hospital social worker, and one by a mental health counselor. Other interesting responses in the “Other” category include:

- *Pastor found it*
- *person at national meeting*
- *a friend from a face-to-face support group meeting*

**Healthcare provider influence.** Respondents were asked if they would have joined the group sooner if their healthcare provider had suggested it. Forty members responding (63%) indicated that they would have joined sooner had their healthcare provider suggested it. Fifteen individuals (24%) would not have joined sooner. Eight participants either selected NA or did not answer the question. The explanations revealed an interesting trend. Several members seemed to indicate that the real reason that they did not join sooner was because they did not have a computer or Internet connection at the time. There was no specific comment about whether a doctor's recommendation would have spurred them to purchase the equipment necessary to join the group. There were several other interesting responses:

- *If I had known the diagnosis sooner, then yes.*
- *However, the Huntington's Disease Society of America was recommending AGAINST online information and support at the time I first joined Hunt-Dis*
- *I needed space to take in the information and I needed to be ready to search for help and answers on my own.*

**Finding the group.** The results for this topic closely parallel the earlier section "Impetus for Joining." Many (37, corresponding 59 percent) found the group by initiating a general Internet search for information on their disease and "just happened" to stumble upon this particular online support group. Nine people (14%) found the group by conducting a known-item (e.g., 'support group') search. Thirteen members (21%) were given the specific website address by a friend (10 instances) or family member (3 instances). Three members (5%) listed receiving the address from a healthcare professional. Three members located the list address in print media and three members were referred by "online associates/tions" such as a discussion forum or the official Huntingtons Disease Association website. One member was referred by an associate at a national conference on the disease.

**Difficulty locating the group.** Responses to the statement "*I found it difficult to locate this support group*" were mixed. Twenty-six respondents (41%) strongly disagreed with this

statement, 23 (37%) somewhat disagreed, 11 (17%) somewhat agreed, and 3 (5%) strongly agreed.

**Difficulty subscribing to the list.** Most people did not report difficulties subscribing once they had located the group. Fifty-six or 88% disagreed with the statement *“I found it difficult to subscribe to this support group”*. Of those, 40 strongly disagreed and 16 somewhat disagreed. Seven respondents (11%) said they somewhat agreed with the statement.

### **Participation characteristics**

**Messages sent.** On average, members reported sending about 35 messages per month to the list with a median of 5 messages per month. This number may include some individual-to-individual list correspondence. Several members noted that they read much more than they contribute.

- *I am involved in so many things at this point in my life, that I do much more reading than I do anything else. I would love to contribute more, but for now, I just love to keep up with everyone else's lives. They have become much more than family.*

**Time spent.** Members on this list spend an average of 2 hours each day participating (reading, sending, researching) in some way on this list. The median participation time was 60 minutes each day.

**Participation time of day.** Participants were asked if there was a particular time of the day that they participated. Most members 43 (68%) could not name a specific range(s) and said that they participated at multiple times of the day. Eight members (13%) participated between 8PM and midnight; seven (11%) between 5AM and 8AM; seven between 8AM and 12PM; four (6%) between 5PM and 8PM; and two between 12 AM and 5 AM. Some members selected more than one time slot so the percentages do not add up to 100%. Assuming that some people are working full-time between 8 AM and 5 PM, it appears that a few members may participate at their workplace while others seem to avoid this:

- *[I participate] Before work at 5 am and then whenever I am off.*
- *I work nights. So, I participate whenever I am not sleeping or working.*

**Participation time of week.** Most members participate on weekdays (35, corresponding to 56%), while 13 (21%) cited no difference and nine (14%) participated mostly on the weekend. The remaining respondents noted that their participation depended on the list topic and their other activities.

**Participation in other online groups.** For more than half of the respondents (36, 57%) this is the only support group they subscribe to; 27 members (43%) also subscribed to other online support groups. In comments relating to this question, it became evident that this group has created offshoot groups that address more specific topics related to the disease, or topics that are relevant only to some members.

### **Issues relating to healthcare providers**

**Healthcare professional participation.** A majority of members reported that there are healthcare professional(s) on the list. When asked “*Are you aware of any medical professionals who read or contribute to this list?*” 36 (57%) replied ‘yes’. In contrast, 26 (41%) replied no. Members were also asked “*Would you welcome the participation (or more participation) of a medical professional on this mailing list?*” In response to this question, 57 (90%) of members said yes. Two members said no and four did not answer. Some responding yes expounded on their opinion:

- *Participation, yes. If the individual presented him or herself as a genuine caring person they would be welcome to join in the discussions. I don't think our group would benefit by a 'know-it-all' professional attempting to sway our beliefs or instincts. Many of us have had to develop research skills in order to learn on our own. As a group we grasp for straws, so to speak, and are flexible enough not to discourage new ideas or treatments.*
- *Yes... But... A business will not allow an employee to GIVE away something that they feel they should getting INCOME from. So the For Profit Model wins out over the Humanitarian model.*
- *Absolutely would love to see correction by a professional of some of the myths or misleading info posted. I feel like I am discerning enough to tell the difference but I'm not so sure about some others on the list, especially those who are ill.*
- *I would basically like them to lurk.. and LISTEN to us.. and HEAR what WE have to say*

- *It may be beneficial for us to have someone answer questions we may have, and it may be beneficial for them to hear real life stories about how people and families are coping with the disease.*

Communication channel changes. Members were asked about their agreement with the statement, *“There are many times when I seek advice from this list that I would have only sought from my doctor in the past.”* Twenty-six respondents (41%) strongly agreed, 17 (27%) somewhat agreed, 7 (11%) somewhat disagreed, and 5 (4%) strongly disagreed. Members were also asked to respond to the statement *“There are health-related questions that I ask on this list that I would never in the past nor in the present dream of asking my doctor.”* Sixteen (25%) strongly agreed, 15 (24%) somewhat agreed, 13 (21%) somewhat disagreed and twelve (19%) strongly disagreed.

Reported effect on doctor-patient relationship. The majority of respondents reported that the list has had a positive effect on their relationship with their physicians (44, 70%). Fifteen respondents (24%) reported no effect. A few respondents (2, 3%) reported negative effects.

Many respondents volunteered additional information. The overriding theme was that they are actually very well educated and help educate their physicians on this rare disease:

- *[positive effect] To clarify, not all of the doctors my husband has seen have "appreciated" the information that I can bring to them. I have "fired" them. This is a complicated disease and we ALL need all the help we can get and if a doctor refuses to understand that and be a partner with me in my husband's care then I will choose another doctor. My husband's current doctor is great! He says, "why don't you ask your group....." often when we have a concern about a medication, etc.*
- *[positive effect] I've been educated and now they're getting educated.*
- *[positive effect] I have received scientific information even before they have.. at FIRST they were skeptical... now they trust me and my sources.*
- *[positive effect] I have been able to take information received from this group to my husbands Dr. and talk with him about alternatives to his care. The Dr. has always been very cooperative in reading the*



*information provided and visiting with me openly as to whether he felt that my husband would benefit and why.*

- *[positive effect] It's been positive because I am much more informed than I would be otherwise.*
- *[positive effect] helps me to know if I am on the right track for understanding what is happening with my loved one.*

The following clarifications were given for “negative” responses:

- *[negative effect] I am able to access new information that he does not have time or motive for and I think he feels less in control.*
- *[negative effect] Most Doctors are not up to speed on the rare diseases. When questioned from someone with a large knowledge base, most become defensive.*

**Other support vs. online support.** Participants were asked to compare the helpfulness of their support group to other potential support providers. Overall, respondents reported that the support group was more helpful to them than talking with family (79%) and friends (73%) who do not have this illness. Some report that the group is more helpful than talking with their doctor or nurse (48% and 43%, respectively). A much smaller number of respondents (3% and 6%, respectively) find talking to a doctor or a nurse better than talking to the group, while 25 and 16 percent, respectively, find it just as helpful. The results are best shown in tabular form (see Table 13 below).

<b>Table 13. Huntingtons responses: support type preferences</b>	
<b>Support group is <u>MORE helpful</u> to me than talking with:</b>	
my friends who do not have my same ailment or predicament	50 (79%)
family members who do not have this ailment.	46 (73%)
my doctor (medical).	30 (48%)
my psychologist or counselor.	23 (37%)
a nurse	27 (43%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	28 (44%)
other (than my face-to-face support group, family member who has ailment, anyone that you mention)	3 (5%)
<b>Support group is <u>AS helpful</u> to me as talking with:</b>	
my friends who do not have my same ailment or predicament	6 (10%)
family members who do not have this ailment.	12 (19%)
my doctor (medical).	25 (40%)
my psychologist or counselor.	14 (22%)
a nurse	16 (25%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	8 (13%)
other	0 (0%)
<b>Support group is <u>LESS helpful</u> to me than talking with:</b>	
my friends who do not have my same ailment or predicament	2 (3%)
family members who do not have this ailment.	1 (2%)
my doctor (medical).	2 (3%)
my psychologist or counselor.	4 (6%)
a nurse	4 (6%)
my preacher (or clergy, priest, rabbi, or other spiritual advisor)	4 (6%)
other	0 (0%)

### **Quality and degree of support received**

It is reasonable to assume that members are receiving support from the group - due to the very fact that they continue their membership. Regardless, from a research standpoint the author felt it was important to firmly establish that support is received, and to identify the predominant types of support available to participants in the group.

**Support.** Participants were asked to indicate their agreement with the following statement, *“I get helpful information on how to manage my (or my loved one's) disease from this*

*support group.*” Forty-seven respondents (75%) strongly agreed with this statement and 10 (16%) somewhat agreed. One person chose somewhat disagree and two selected strongly disagree.

When presented with the statement, *“I get valuable emotional support that helps me cope with the stress of my (or my loved one's) disease”*, forty (63%) strongly agreed; 15 (24%) agreed somewhat; three somewhat disagreed; and two disagreed strongly.

**Information quality.** There has been much talk about the veracity of information received online. In order to get participants feedback on this issue they were asked to respond to the following statement, *“I have received misleading information from the list on several occasions.”* Seven people (11% of respondents) strongly agreed with this statement; 5 (8%) somewhat agreed; 14 (22%) somewhat disagreed; and 33 (52%) strongly disagreed.

**Perceived effect on health.** Participants were confronted with the statement, *“I would say that this online group has either directly or indirectly saved or prolonged my life (or that of my loved one).”* Nineteen (30%) strongly agreed, 14 (22%) somewhat agreed, 6 (10%) somewhat disagreed, and 11 (17%) strongly disagreed. Twelve (19%) found this question to not apply to them for a variety of reasons (e.g., if they are pre-symptomatic). Two explanations gave insight into respondents’ feelings regarding this question.

- *The life that was prolonged was mine, the caregiver's, at a time when I was suicidally depressed.*
- *it was already pretty much too late to help my son in any way when I did find this group. But they did help me get thru one day at a time with much less stress which enabled me to be much more understanding and active with my son in his last months.*

**Perceived effect on quality of life.** When asked about their reaction to the statement *“I would say that this online group has improved the quality of life for me or my loved one”*, thirty-six (57%) strongly agreed, 17 (27%) somewhat agreed, three each (10% total) somewhat or strongly disagreed.

**Disease management.** Participants were presented the following statement to respond to, *“I do not know how people with my (or my loved one's condition) could possibly manage without an online support group such as this one.”* Thirty (48%) strongly agreed; 15 (24%)

somewhat agreed; 6 (10%) somewhat disagreed; and 6 (10%) strongly disagreed. Below are two comments from respondents.

- *[somewhat agree] I think that some people are not comfortable with writing to strangers about their intimate problems. For them, they would not find this a source of support.*
- *[strongly agree] I wish that the HDSA would raise funds to provide needy families with computers*

Helping others. When asked “*Helping others on this list is very important to me*”, forty (63%) of respondents strongly agreed, 10 (16%) somewhat agreed, five (8%) somewhat disagreed; and three (5%) strongly disagreed.

### Face-to-face support

Participants were asked if they participated in a face-to-face support group and if they did not, why not. Forty-one members (65%) did not attend a face-to-face group, while 21 (33%) did. For those who did not the reasons were as follows:

No face-to-face groups in respondent locale.....	23	(37%)
Online group more convenient.....	17	(27%)
More comfortable using the online format.....	13	(21%)
Act of typing out thoughts was therapeutic in itself.....	10	(16%)
Too hard to find replacement caregiver for children or loved one.....	7	(11%)
Other reasons (varied).....	5	(8%)
Face-to-face group did not meet needs.....	2	(3%)
Do not feel well enough.....	2	(3%)

Respondents were asked to expound if they chose “*More comfortable using online format.*” Following are the narrative explanations:

- *Seeing people in advance stages of HD reminds me of what I will become*
- *People with this disease are often emotionally unstable and it is easier not to deal with them in person*

- *Less embarrassing*
- *I would be too self conscious for face-to-face*
- *Less threatening when dealing with sensitive subjects*
- *I am shy person and can communicate better when people aren't staring at me*
- *Can take my time. use spell check etc*
- *Can participate or not as you like. Sift for useful/relevant things*
- *Able to scroll through info. that doesn't pertain. Scroll through the politics of groups.*

### **Most and least favorite thing**

Most favorite. Participants were asked “*What is your most favorite thing about this online support group?*” Though the variety of responses is somewhat difficult to code, Table 15 has some of the common themes:

<b>Table 15. Huntingtons responses: favorite qualities of group</b>	
helpful, sharing, support, understanding .....	N=15
information/latest research on disease.....	N=13
talking with people who can empathize/wisdom of collective experience.....	N=12
friendships made on group .....	N=10
“like a family” .....	N=8
diversity of group members.....	N=7
feelings of trust, non-judgmental, freedom to say how you feel .....	N=7
convenience of list .....	N=5
knowing that others are there for you when needed .....	N=5
getting to help others.....	N=2
humor on the list .....	N=2
meeting online people in person.....	N=1
flexibility (one can participate or not as time permits).....	N=1

The following messages state quite eloquently the recurring themes captured with this question.

- *This online support group has become my extended family. Without them, I do not believe that I could have survived the last years of my husbands life, emotionally or physically. I love the fact that we are 'family'. We can openly discuss any issue that is relative to our well being, and know that we are not going to be judged or chastised for our feelings, or beliefs. I know that I can talk to this 'family about whatever is going on, and that I am going to receive understanding, information to help me deal with the situation, and most importantly love and support. I love the easy chatter and banter that goes on at our 'kitchen table'. It helps me to know my family better, and to become even closer to them.*
- *To know that no matter how far a face-to-face is from me this support group is only a button away. And there most any time they are needed.*
- *It is the incredible wisdom that one gets from shared experiences*
- *Someone is always there .... immediate help, immediate understanding and usually immediate suggestions/answers*

Least favorite. Participants were asked “*What is your least favorite thing about this online support group?*” Several themes emerged:

<b>Table 16. Huntingtons responses: least favorite qualities of group</b>	
Too much “bickering” and arguing .....	20
Large volume of messages .....	7
Off-topic discussions of political nature.....	5
Off-topic discussions, nature not specified.....	5
Members who display maliciousness.....	5
Complaints sent by members .....	5
Off-topic messages of a religious nature .....	2
Too much nitpicking.....	2

Several members provided comments that flesh-out the categories:

- *Sometimes there is a lot of bickering between folks because there is a lot of personal/Non HD information being shared. But that is what makes this list so great. People have lives and are not afraid to share that HD doesn't rule every single corner of it and they can still expect and receive support with problems or situations that don't directly concern HD.*

- *[My least favorite thing is] When a newcomer feels overwhelmed by the number of posts they receive daily and so leave or sign off before they realize the fulfillment that being a part of this group can bring into their life.*
- *The stupid arguments that seem to crop up every once in a while, but then again they can be kind of humorous.*

### **Privacy concerns**

The nature of communication over the Internet raises many privacy issues. To explore members' perceptions of threats to privacy several questions were posed.

**Imposters with financial motives.** Respondents were asked, *“Are you concerned that a sales-type person, who pretends to be a legitimate support group member, may suggest that members purchase a specific health-related product on this list.”* A majority of participants were not concerned, 50 (79%), while some did express concern 12 (19%). However, the overall feeling of most all respondents is that imposters are quickly identified and properly ousted.

- *Individuals in this group are pretty savvy and pretty quick to research anything new that is mentioned. I don't think that a person such as you describe would have a chance here! LOL*
- *In the time I've been a member of this group, this has only happened once and the person was removed from the list by the list manager.*

**Concern over increase in junk e-mail.** Respondents were asked, *“Are you concerned that people may subscribe to this list in order to get your e-mail address and then sell it to companies who send spam (spam = junk mail)?”* The majority of respondents were not concerned 52 (83%) while 10 (16%) expressed concern.

**Concern over insurance companies getting information.** Respondents were asked, *“Are you concerned that an insurance company may snoop on this list?”* A majority of respondents said they were not concerned 38 (60%) while others did express concern 24 (38%). Several expressed their mistrust:

- *This is a big concern. I would like to think that insurance companies had more scruples than to do something of this nature, but, then that would not be very realistic on my part. I do know that insurance*

*companies will try to find any way that they can to deny benefits to someone with a connection to this disease. Been there done that.*

- *perhaps not likely, but i am mistrustful of insurance companies anyway.*
- *Genetic discrimination is a very big topic on our list. I guess sometimes I think that someone snooping is a possibility*

Some questioned the logistics more than the motive:

- *Would they really pay someone to take the time to read and read the volume of mail and try to match it to other data? Well, maybe...*
- *Since HD is a genetic disease, it is possible that insurance companies may try to join to see if any of their clients have the disease. However, it would be very time consuming, and I would hope they would have better things to do with their time!*

Archives. Respondents were specifically asked, “*Are you concerned that if this list archives its messages that those archives may be used for unintended purposes?*” The majority of respondents were not concerned with 46 (73%) saying no and 15 (24%) saying yes. The further explanation section of this question gave insight into different opinions:

- *It's very difficult to find anything in our archives!! Someone would really have to want to read through hundreds of threads each month to try to discern something. (We don't always stick to the thread either)*
- *I wasn't until you mentioned it*
- *It's possible, but you must be a member with a password to access the archives.*
- *Not if you have to be a member.*
- *I would not want them to publish my contributions without my permission.*
- *I have this concern about anything done in public on the 'net. One day it may come back to haunt you. I know people who have lost jobs because of indiscretions online already!*
- *Sometimes-more so recently due to increased media discussion of such possibilities.*



**Use of real name.** Respondents were asked, “*Does your real (first and last) name appear on this list (either discernable in the e-mail address, the "from" line, or in your signature)?*” Nearly all respondents, 55 (87%) said that their name did appear, while six (10%) said no.

**Desired legal protection.** Respondents were asked, “*Do you think that the personal medical information exchanged on a list such as this one should be protected under medical privacy laws?*” Most respondents said yes (45, 71%), but 13 members (21% of respondents) said no. Again, there was a range of responses to this question.

- *[no] I would be concerned that such protection could add a regulatory layer to administration of the list.*
- *[yes] absolutely, though I am rather cynical about the status of "medical privacy laws" these days. I feel we are less protected and more scrutinized all the time.*
- *[null] I don't know*

## **SUMMARY OF RESULTS**

Several themes emerged that cut across all groups surveyed. As earlier mentioned, consistencies across a diverse group of users will hopefully compensate some for a statistically non-representative sample.

### **Demographics**

**Race.** Of the total 198 participants, 179 clearly reported being white. Of the remaining 19, there were some “cute” answers (e.g. human race, American mut), but only the five following were possible minorities:

- ◆ Irish/Indian/American
- ◆ Bi-racial
- ◆ white/native american
- ◆ white/black/native american
- ◆ heinz 57 of cau. + some indian

**Gender.** Of 198 respondents, 161 (81%) were women. There were few male family members on any of the groups.

**Age.** The average age on most lists was 51.5 years.

**Income.** Ninety respondents (45%) had a gross income over \$50,000 while only 15 (8%) had an income under \$20,000.

**Education.** Thirty-three (17%) of respondents had a high school education or less while 88 (44%) had a college degree or higher.

### **Participants' computer background**

**Computer Use.** The average years using a computer across all 198 participants was 12.2 years and 170 (86%) agree that they are comfortable with computers.

## Group location

Across all 198 respondents, 131 or 66% reported that the idea to try an online support group was their own initiative.

Across all 198 respondents, 127 (64%) found the group during a search for general information about their or their family member's disease. Twenty-two or 11% posed a specific known-item query to a search engine (e.g. "online support groups for cancer").

Across all 198 respondents, 139 (70%) indicated that the group was not difficult to locate and 176 (89%) indicated that the subscription process was not difficult.

## Issues relating to healthcare provider

Across all 198 respondents, 132 or 67% reported that they would have joined the group sooner had their healthcare provider suggested to them, while, 43 (22%) would not.

Ninety-three percent (186, 93%) of respondents said that they would welcome more participation of a medical professional on the list.

For 130 (66%) respondents, participation in the support group has had a positive effect on their relationship with their healthcare provider. For 52 (26%) no effect was reported and for only 8 (4%) was a negative effect reported.

Of 198 respondents, 76 (38%) ranked talking with people on the support group as more helpful than talking with their doctors.

Many respondents ask things of the list that they used to (or would never) ask their doctor (see Table 17):

<b>Statement</b>	<b>Disagree</b>	<b>Agree</b>
There are many times when I seek advice from this list that I would have only sought from my doctor in the past.	34 (17%)	145 (73%)
There are health-related questions that I ask on this list that I would never in the past nor in the present dream of asking my doctor.	94 (47%)	85 (43%)

### Quality and degree of support received

Support received. Nearly all participants agreed with statements indicating benefits including symptom management benefits and emotional benefits. Table 18 provides a listing of statements and the numbers of people agreeing or disagreeing with them.

<b>Table 18. Summary of quality and degree of support received.</b>		
<b>Statement</b>	<b>Disagree</b>	<b>Agree</b>
I get helpful information on how to manage my (or my loved one's) disease from this support group.	4 (2%)	186 (94%)
I get valuable emotional support that helps me cope with the stress of my (or my loved one's) disease.	8 (4%)	178 (90%)
I would say that this online group has either directly or indirectly saved or prolonged my life (or that of my loved one).	62 (31%)	95 (48%)
I would say that this online group has improved the quality of life for me or my loved one.	15 (8%)	169 (85%)
Helping others on this list is very important to me.	15 (8%)	168 (85%)
I have received misleading information from the list on several occasions.	144 (73%)	38 (19%)
I do not know how people with my (or my loved one's condition) could possibly manage without an online support group such as this one.	44 (22%)	138 (70%)

The group is ranked as more or as helpful than other support systems in nearly every category especially more than friends and family members who do not have the disease or predicament. Of 198 respondents, 163 (82%) ranked the support group as more helpful than friends and 150 (76%) ranked the group as more helpful than non-sick family members

### Face-to-face support

Most participants, 148 (74%) do not attend a face-to-face support group in addition to the online participation. The table 19 below provides reasons for not attending face-to-face support.

**Table 19. Summary of reasons respondents do not attend face-to-face group**

Online group more convenient.....	86	(43%)
Act of typing out thoughts was therapeutic in itself.....	54	(27%)
No face-to-face groups in respondent locale.....	52	(26%)
More comfortable using the online format.....	38	(19%)
Too hard to find replacement caregiver for children or loved one.....	25	(12%)
Other reasons (varied).....	21	(10%)
Face-to-face group did not meet needs.....	14	(7%)
Do not feel well enough.....	4	(2%)

### **Privacy concerns**

Of all 198 participants, 166 (84%) use their real names in either their e-mail address, from field, or in their e-mail signature.

When asked, “Are you concerned that an insurance company may snoop on this list?” 129 respondents or 65% answered no. When asked, “Are you concerned that if this list archives its messages that those archives may be used for unintended purposes?”, 142 (72%) of respondents answered no. However, when asked, “Do you think that the personal medical information exchanged on a list such as this one should be protected under medical privacy laws?” 134 respondents or 68% answered yes.

### **Lurkers**

All of the groups had people who identified themselves as lurkers. A lurker is a slang term that refers to a member who quietly reads messages but does not post to the list. One might have the impression that lurkers are somewhat uninvolved and unengaged. It was surprising that a lurker would even respond to such a survey. In fact, lurkers seem to get just as much support vicariously by reading the experiences of others. Some seem to even feel a part of the group despite the one-sidedness of their participation.

### **Information-seeking behavior**

It seems that there are some who like the flexibility of this communication medium because it allows them to adopt a consumer-like role to the information -- picking and choosing topics that pertain to their unique circumstances. If there is a long thread about a topic they are uninterested in, they can skip over or delete these messages. One member stated how nice this was in contrast to a face-to-face environment where you would feel

compelled to feign interest and would have to listen to everybody. In contrast, it seems that there are others who diligently read each and every message posted to the list.

## **DISCUSSION**

A variety of health-related support groups is available to Internet users. This study examined the experiences and opinions of support groups for four specific diseases: breast cancer, esophageal cancer, Alzheimer's, and Huntington's disease. I surveyed members anonymously using online forms that were posted for one week, the (disease-specific) addresses of which were provided only to members of the respective support groups. The response rates were sufficiently large to draw some general conclusions about the characteristics of members of online support communities, as well as about the benefits and drawbacks of these venues for the sharing of health-related information.

The main findings from this study are:

1. Disease-specific online support groups are used by a variety of individuals affected by disease, including, but not limited to, persons who suffer from the disease, their family and friends, those who care for them, as well as professionals working in the field.
2. Most members of online support groups did not find out about the group from their doctor or other health care professional. The majority of members said they would have joined the group sooner if their health care provider had suggested it to them, and that the list has had a positive effect on their relationship with their health care provider.
3. Online support groups appear relatively homogenous with respect to demographic characteristics, particularly, race, education, income, and familiarity with computers.
4. Members found their groups in a variety of ways; most came across their respective lists searching for related information on the Internet.
5. Online support groups are powerful supportive communities that help members cope with the ravages of disease, and provide them with a wealth of information and other benefits.
6. Members value in particular the convenience, the help and understanding, the information available from list members and the collective experience, new friendships, and diversity in the group. The possibility of typing out the thoughts also appears to be a form of therapy.

7. Most respondents were not concerned with specific privacy issues mentioned in the survey, yet many preferred for the medical information shared on the list to be protected by medical privacy laws.
8. Misinformation in these venues *is* an issue. At least a few people reported having received false information though the group quickly corrected it.
9. The types of responses given to the 39 questions in this survey were surprisingly similar across the four groups.

Disease-specific online support groups are used by a variety of individuals affected by disease, including persons who suffer from the disease, their family and friends, those who care for them, as well as professionals working in the field. The distribution of these groups depends somewhat on the type of illness a specific group addresses. Most respondents are patients, followed by their caregivers. There were very few physicians among the respondents, possibly signifying their time commitments. The death of a family member or patient with the disease does not appear to necessarily end the participation of caretakers on the list, as a number of respondents reported that their loved one had already died, but that they continued their participation nonetheless.

It was surprising how few persons had been referred to the list by their doctor, their nurse, or another healthcare professional. The percentage of persons finding out about the list from any of these sources was under 10 percent on all four lists. This may partly be related to the fact that most members have been with the list for many years, while this type of support has only recently received more publicity. Most members who listed their health care provider as an impetus for joining joined the list within the past 3 years. This may indicate a shift over time in the perception of online support groups from the fringes of medical care to more “mainstream”.

Most respondents indicated they would have joined their support group sooner had they been told about it by their doctor. Most respondents were aware of medical professionals participating on the lists, yet most wished for more physician participation. Respondents appear to be more comfortable asking questions in a semi-anonymous environment, ask questions that would appear too simplistic in face-to-face encounters with their doctors, or even seek answers from the list to questions they would not have asked their doctor.



Members overwhelmingly report that participation in the group has had a positive effect on their relationship with their physicians as they are more informed and can ask better questions. It appears that the online support group fosters a more proactive patient or caregiver. Many patients and caregivers report that they are turning to their online groups for information that they would have only sought from their physician in the past. Having 24/7 access to a large group of people who are highly motivated and share a wealth of information and pooled experience is a powerful argument for doing so. However, some respondents noted negative effects and seemed particularly perceptive of how their physicians reacted. Physicians supposedly dismissed patients' sharing of information obtained on the group or appeared threatened by their patient's knowledge. Increased participation and visibility of physicians in support groups appears imperative in the longer-term, both as a way for physicians to become more familiar with the medium, with patients' thoughts and concerns, and to provide information or warnings about false, misleading, or incomplete information posted to the list. Perhaps some members view information from this list with a perception of more authoritativeness than may be warranted, with potentially negative consequences if the information turned out to be false.

While the motivation for joining may have differed substantially across respondents, the general characteristics of support group members are surprisingly homogenous. The "average" person on the list is a white female with a college education and a relatively high household income, who is very comfortable with the every-day use of computers. The observation that most respondents are female is consistent with the literature on caregiving: most caregivers for elderly parents are their daughters or daughters-in-law, with sons or sons-in-law forming a clear minority. This is often said to be the result of differential career and/or income opportunities between men and women, but may also be related to pre-imposed social roles. It is also possible that these lists have formed as a result of sorting of homogenous "equals": from respondents' answers it appears that many members prefer to talk with other members who can best understand what they are going through. At least three of the four groups had spun off sub-lists which people with specific needs migrated to. It is possible that this strong homogeneity is the result of members' desires to find "likes" to share their experiences with.

An alternative, and admittedly more likely, explanation for this homogeneity with respect to high income, high education, and white race in particular, may be the existence of a “digital divide” along these characteristics. If such divide is the reason for the observed distribution of demographic characteristics, access to this important resource appears very restricted for large parts of the population. It will be important for a future study to analyze whether the reason for the complete absence of ethnic and racial minorities, and for the under-representation of less-well educated and lower-income persons lies in differential response patterns, the lack of access to computers, or a general lack of information or knowledge about the existence and benefits of support groups.

Both the existing literature and the findings from this study indicated that users of online support groups are generally computer savvy. Nearly all members had many years of computer experience. So, it seems logical that most members turned to the Internet for general information about the disease. Most all members cited that at least an initial Internet search was their own initiative. Many respondents discovered a link to their current support group during such an Internet search for information relating to the disease. Some even mentioned that they did not know that such a thing existed and found it completely by accident. Others did a known item search, i.e., they searched specifically for this type of support. It does appear likely the word is also getting out through more traditional channels, as several members found their groups referenced in print media, including books, news, or magazines.

Online support groups bring enormous benefits to the users. The greatest benefits come in the form of emotional support, and in the form of information. In fact, many respondents felt that talking to the group was more helpful to them than talking to their doctor or nurse. The online support group form of support also was strongly preferred by most members over other support systems. Though many members had tried face-to-face support groups and found them advantageous in some ways, the online format was preferred because it was always available and was extremely convenient. For the more rare conditions, an online group is the only support group alternative. This is supported in the literature and found to be true in this study. Aspects inherent to the medium of exchange (e-mail) were often preferred as well. Members felt that it was easier to exchange information in this

manner as they could organize their thoughts. Shy and introverted members especially noted benefit from the fact that they were more comfortable than in face-to-face settings.

Apart from receiving support and information, it also appears that helping other people provides an enormous benefit to participants in these groups. Despite a high average workload of at least 40 hours per week across all groups, people made time for active involvement in the list, devoting one to two hours per day on average. In fact, many members stay on the list even if they are in remission from their disease or, for caregivers, even if their loved one has passed away. By definition, these members are kind and sharing people but the literature helps us understand this altruistic behavior. It seems that sharing their experiences gives them some kind of meaning and validates all that they have gone through. This behavior provides another frequently mentioned benefit from active participation in the group - the pooled experience. Several members noted that knowing that there were survivors out there was very important and gave them hope. Similarly, respondents really appreciated the wealth of information provided by persons who “have been there”.

While the vast majority of responses were positive, people did cite frustration at not being able to have physical contact and visit the close friends they made on the list. Some groups had worked around this with an annual get together and a few individual members visit each other on their own as they can. Many respondents also disliked the amount of “bickering” and arguing, and off-topic discussions.

The nature of communication over the Internet raises many privacy issues. This is particularly important in the case of diseases that are genetically transmitted. In fact, information provided by one individual could potentially “implicate” his/her entire family, with interest groups for this type of information ranging from pharmaceutical and insurance companies to current or potential employers.

Despite the recent significant increase in publicity that privacy issues (and violations) have received in the popular news media, respondents, on average, were not very concerned about privacy issues relating to their participation in the group. Most respondents reported that their real names showed up in their email addresses. Respondents were not concerned about the possibility that they could be targeted by spammers, or that an insurance company

could access the information. The majority of respondents also reported not being concerned about possible misuses of archived information. Posing questions about privacy concerns, however, raised awareness for the issue with several respondents, as they made very clear in open-ended fields intended for clarifications or additional information. A large majority of respondents favored the idea that personal medical information exchanged on these lists should be protected by medical privacy laws. It is unclear if the questions about privacy influenced this response of if the recent controversy in the media was the primary influence.

Fear of legal liability for advice given via the Internet may be a reason for the observed limited participation of medical professionals on disease-specific support groups. Fear of misinformation may be an important reason why medical professionals do not refer their patients to the Internet for information or support. Further research into these areas may be needed to provide a clearer picture of healthcare professional involvement in online support groups. To evaluate the extent to which group members are aware of instances in which false or misleading information was posted to the list, the survey inquired specifically about this issue. The question was asked in a very specific manner: *"I have received misleading information from the list on several occasions."* On all lists at least one respondent answered this question affirmatively. While there are many qualifiers, such as affirmations that they are quickly discovered and corrected by other list members, this finding raises concerns. More importantly, however, this finding supports the notion that, as more persons turn to these groups for health-related information, physicians should take a more proactive stance and join the arena, to limit the possibility of severe harm resulting from false or misleading information. It is quite apparent that many patients do join these groups regardless of whether or not they received a physician's recommendation. Hence, online support groups should become part of an integrated approach to managing the patient's disease and the caregiver's burden.

## **STUDY SIGNIFICANCE**

This research is valuable for several reasons and will make an important contribution to the field. First, the primary goal of our school of Information and Library Science is to train its students to be information professionals. One of the dominant concerns of the information professional is that information users have access to the information resources that they need. When an individual is diagnosed with a serious disease, such as cancer, he or she will have an immediate and desperate need for critical information about the disease. Research has shown that the ability to get information effectively yields a sense of empowerment that is itself an important element in coping and healing.<sup>26</sup> There is evidence that not all patients take advantage of the Internet to gain health-related information and there is a disparity or “digital-divide” between the haves and have-nots.<sup>8</sup> Because this disparity may affect something so important as a person’s health and well-being, this disparity should be of great concern to information professionals and policy-makers. In addition, online support groups are interesting to study in their own right as Internet phenomena. Their study falls under the rubric of broad topic areas such as Social Issues and Internet and Communications. In fact, the idea for this topic was formed after the completion of several required assignments that studied online discussion groups.

Secondly, in the healthcare setting there are many different professionals who may be responsible for disseminating disease-specific information to patients. These patient educators may be doctors or nurses who have other patient duties. Dissemination of information may rest on the shoulders of someone with the formal title of health or patient educator. These individuals are being confronted with perhaps the newest and most powerful information source ever, the Internet. Patient educators are scrambling to get a handle on whether and how to help patients use this new information tool. In the future, information professionals such as the students trained at our school, will be finding that they have a new role to play in the healthcare setting -- helping patient educators traverse this new territory, the Internet.<sup>23</sup> Information professionals might either be hired as full-time staff or

as consultants to healthcare organizations. They can “level the playing field” by finding obscure bits of information and little-known support groups that an inexperienced web searcher would have little chance of finding. Further, hospitals and medical offices will begin establishing their own office-based web sites and will need to work with a range of technical and informational staff in order to establish credible and secure sites with appropriate health related resources and moderated support groups for all of their patients.

## **CONCLUSIONS**

### **Future research**

Several recommendations naturally emerge from this study. The first is that much more research is needed. For instance, a well-controlled study needs to be conducted that contains a statistically representative sample population of support-group users and non-users across multiple diseases. Results from such a study would determine better who is using online support groups. Since online support groups are very different resources than other Internet health resources -- such as static websites, chat rooms, and newsgroups -- a future study might include other resource-types in addition to online support groups.

Another important study would be to determine what conditions should exist in order for a list to be successful. The lists in this survey appear to be successful as people on them are happy with the benefits that they receive. Is this because there is a critical mass of communication and membership? Because there are list owners controlling spam, imposters, and out-of-control flames? Because there are medical professionals lurking who correct misinformation? Because there are educated people on them who communicate effectively? Because the lists are easy to find and subscribe to? Would groups composed mostly of uneducated people have more problems with misinformation? Would too diverse groups “not get along” making the lists fail? Is an online group the right choice for everyone? These are all important questions with significant implications.

Finally a study should be done for ex-members that asks why they discontinued participation. Is it because they got well and didn't need the group anymore? Did they or their loved ones pass away? Did they get offended? -get their feelings hurt? -get ostracized? -get enough “bad” advice that they felt unsafe? As one can see, the most serious limitation of this study may be a bias due to the mere fact that the only people questioned were current members of support groups.

### **Implications for the healthcare community**

It is clear that the respondents in this study have found their groups enormously helpful, that the groups have had positive effects on their relationships with their doctors, that their doctors had not recommended this type of support, and that respondents would have sought the support sooner had they received such a recommendation from their respective doctor. It is also clear that many members are asking things of their list members that in the past they would have only asked of their doctor. There are even things that they ask that they would never ask their doctors about. All of these findings suggest that the medical community should be concerned. For example, are they overlooking an important treatment option? What informational functions are being replaced by the online support group? Does this replacement lighten the physician workload? Does it put patients at risk? Could doctors be learning how to improve services from these lists? Can they learn how to be more empathetic to patients? If a physician recommended this option would he/she be liable for misinformation on the list? Again, these questions are critical ones that need to be addressed. It is also unclear whether a recommendation by a doctor would be enough to convince a patient to purchase a computer or pursue some other means of going online.

### **Implications for the information community**

Online users are not taking the necessary steps to protect their privacy. They are using their real names in their e-mail addresses, in their e-mail preferences, and in their signature. However, it is not appropriate for an information professional to say, "We have warned them to be careful about privacy, so it is their own fault for not listening." The appropriate response is, "Wow, whatever we are doing is not working, let's find a system that works to get users to take this privacy thing more seriously." When one joins such a list he/she receives a long text welcome-message with subscription information. Often embedded in this e-mail are stern privacy warnings. Members of these online lists are obviously not reading these welcome messages or are reading them but not taking them seriously. Nearly all of these lists are archived in some fashion and searchable by either standard search engines or through an interface specific to the group. Without trying to be an alarmist, here is how the privacy threat might play out:

Mrs. Jane Douglas sends a message to the list expressing concern that her son Kevin is at risk for developing a genetic condition. In her message, she mentions his name a couple of times. Her message is archived for the



benefit of others to learn about this condition. Her e-mail address is stored as jdouglas@hotmail.com as is her full name, as found in the from line of the e-mail. This message is stored as a text file. Several years later a potential employer of Kevin decides to learn more about this young applicant and poses a query to a search engine such as Google and retrieves the e-mail record sent by Jane Douglas three years ago. The record is easily retrieved based on a simple term-frequency formula. The employer means well, but this information colors his judgement as he is always under pressure to keep his company's costs down.

Is this scenario extremely far-fetched? Doubtful. Does Kevin Douglas deserve discrimination based on the desperate e-mail sent by his "naive" mother five years earlier? Doubtful. So, what should informational professionals do? One way that information professionals could handle this problem would be to make a simple validation form that a user must complete when subscribing to the list. For example,

WELCOME TO THE WE CARE ONLINE SUPPORT GROUP MAILING LIST

You must read the following in order to be subscribed.

I understand that if my name is discernable in my e-mail address or resides in my e-mail preferences, then it is VISIBLE, SEARCHABLE, and AVAILABLE to the world when I send an e-mail to this list. The world could include insurance and drug companies and employers.

[Click here](#) to learn how to create an anonymous e-mail and change e-mail preferences for common e-mail programs.

<< [Click here to continue and subscribe](#) >>

Another solution is to run a randomization program on the *e-mail* and *from* fields of each e-mail header. For instance, Jane Douglas would always be stored as nusoij or be given a pseudo name as is done in chat rooms. This should be easy to do and prevent the retrieval of e-mail during an Internet search. This should be done on pre-existing archives as well.

### **Implications for the policy makers**

There are two implications for policy makers. The first is that they need to figure out where the communication that happens among these groups fits into medical privacy laws. Will it be lawful for people to be denied coverage based on evidence gleaned from the Internet? If a support group's policy message states that this is disallowed, can this be upheld in court? The medical privacy laws that are currently so inadequate will certainly not be able to address broader issues that may present themselves down the line if they are unable to respond to those mentioned above.

The second implication is that having access to a computer and the Internet should no longer be considered a luxury. Disparities that government and organizations fight so hard to eradicate are only going to grow deeper unless everyone knows where and how to get to information that they need. This survey uncovered powerful benefits that many people may not have access to. Bold examples of the specific disparities caused by the digital divide need to be made clear to policy makers. Instead of thinking in the abstract, lawmakers should consider two individuals, the cancer patient who has 24/7 support and the cancer patient who has to drive two hours for support available at monthly meetings.

### **Implications for online support group members**

Online support group members provide a compassionate, open, non-judgmental environment for those who need it most. However, it seems that there is a little room for improvement for some members to practice better online manners (Netiquette). There is obviously too much “bickering” occurring on these lists and nobody seems to like it. Nearly one-third of all 198 people responding across all groups cited this as their number one complaint. This may be unavoidable as these support groups have so many people with various backgrounds. “Bickering” may even have some benefit in defining a personality for the group and in ultimately airing and settling issues. It should come as no surprise that this kind of interaction, on occasion, may naturally occur among people involved in long-term social situations such as support groups, be they face-to-face or virtual.

All in all, it appears that the advantages seem to far outweigh the disadvantages of online support group membership and while this phenomena is not yet perfect, it serves a valuable function for those seeking added or alternative sources of often hard-to-find disease-specific information, comfort, and support. I hope that this research contributes to a better understanding of these entities, and that it will spawn additional research and policy changes that result in a better integration of online support groups into mainstream care, while protecting the patient’s privacy and preserving the character of this new medium.

## **APPENDIX A**

## Appendix A.1. Letter to list owner

Dear List-Owner:

I am a master's student in the School of Information and Library Science at the University of North Carolina at Chapel Hill. I would like your permission to ask your list members to participate in a one-time, anonymous 15-minute survey about online support groups. As a student, I cannot provide individual compensation but would like to make a donation to a non-profit organization of your members' choosing to express my most sincere appreciation.

My primary goal for doing this research survey is to describe the benefits of groups like this one in helping their members cope with illness and the distress it brings. I hope to be able to suggest that physicians and nurses recommend this type of support to all their patients and/or their patients' caregivers.

To participate in this study, members will be asked to complete a one-time-only online survey which can be completed in as few as 15 minutes and will be kept absolutely anonymous and confidential. I will not be collecting e-mail addresses, IP addresses, or names. In other words, the survey will be completely anonymous. This study has been approved by the Academic Affairs Institutional Review Board of the University of North Carolina at Chapel Hill.

I ask that you not share these goals of the survey with members of your group as that may bias their answers and reduce the value of this study. I am sharing the information in order to assure you that the intentions of this research are benevolent ones.

If you are willing to let me do this study, I would appreciate it if you could send a message to the list letting them know that you have communicated with me and you endorse this research. At the end of the study, I will be happy to send the results to the list members. If I am able to publish the results, I will send you the citation so your members can read the article.

Please feel free to contact me by phone (919-933-6520) or e-mail (agnel@ils.unc.edu) if you have any questions or if you would like to see the actual survey and survey description. You may also contact my faculty advisor, Dr. Claudia Gollop, at 919-962-8362 or e-mail, gollop@ils.unc.edu, with any questions about this study.

I sincerely appreciate your consideration and look forward to hearing back from you.

Respectfully yours,  
Laura Agnew

## Appendix A.2. Letter to list member

Dear Online-Support-Group Member,

I am conducting a 15-minute web survey about online support groups for my masters thesis. The objective of this survey is to learn more about these important entities, who uses them, how they came to use them, and what their effects are. This research will help a wider audience get insight into online support groups and their role in helping people cope with the impact of disease.

In order to participate, you will need to click on the link at the bottom of this message. This link will take you to a webpage that will give more information about the study. Please note that participating in the study only involves filling out one online survey that is completely anonymous and will take only about 15 minutes to complete. I will be collecting data for about 1 week from the date of this letter.

As a student, I cannot compensate individuals for participation. However, as an expression of my gratitude, I would like to make a donation to a nonprofit organization of list members' choosing at the end of the study.

I hope you will consider participating. Without your assistance, this important research would not be possible.

Sincerely,  
Laura Agnew, Master's student  
School of Information and Library Science  
The University of North Carolina at Chapel Hill

Please follow this link to learn more:  
[http://www.unc.edu/~lagnew/alh\\_proj/study\\_description.html](http://www.unc.edu/~lagnew/alh_proj/study_description.html)

### **Appendix A.3. Study Description and Consent Page**

## UNC Online Support Group Study Study Description and Consent Page

Please take 5 minutes to read this description. Note, you must use your scroll bar in order to read the entire page. There is a button at the bottom that will take you to the next step.

### Introduction to the Study:

You are invited to be a part of a research study of online support groups by completing one 15-minute web survey. Evidence suggests that online support groups are very beneficial in helping people suffering from an illness or people coping with the illness of a friend or loved one. However, not much is known about online support groups such as, who participates in these groups and how they came to do so.

Laura Agnew, a masters student in the School of Information and Library Science at the University of North Carolina at Chapel Hill, and Dr. Claudia Gollop, her faculty advisor, are doing this study.

### Purpose:

The objective of this study is to learn more about the importance of online support groups, who uses them, how they came to use them, and what the groups effects are on things like coping, and whether members have any concerns about them. This research will help a wider audience get insight into online support groups and their role in helping people cope with the impact of disease.

### What Will Happen During the Study:

If you agree to participate after reading the remainder of this page, then you will be asked to 1) click on a button labeled "I agree to participate."

The action of clicking this button will take you to a different webpage that will have a link that will take you to an online survey with questions and places to answer the questions. The questions will ask you about yourself, about your use of the online support group, about your perceptions of the group, and about any concerns you have about communicating in this unique forum. It is estimated that the survey can be completed in as little as 15 minutes.

After you complete the survey, you will have to press a button labeled "Submit Survey".

If you have any questions about the survey, you may call or e-mail [Dr. Claudia Gollop](#) (919-962-8362) or [Laura Agnew](#) (919-933-6520). As this survey is anonymous, you may give a false name. If you are unable to reach either Dr. Gollop or Laura Agnew and wish to leave a number and receive a call back,

then your phone number will be shredded after we have returned your call. If you choose to e-mail one of us, then any e-mails exchanged will be deleted after the question has been addressed.

#### **Your Privacy is Important:**

- Every effort will be made to protect your privacy.
- Neither your name, your e-mail address, nor your IP address will be collected - this survey is anonymous.
- You must be at least 18 years old to participate.
- No comparison will be made between information provided in the survey and e-mails exchanged on the online support group.
- Information gained from this survey will be presented in summarized form. The specific name of the mailing list will not be mentioned.
- Since every effort will be made to protect your privacy, we ask you to agree that information gained from this survey can be used for publication and/or education purposes.

#### **Risks and Discomforts:**

We do not know of any personal risk or discomfort you will have from being in this study.

#### **Your Rights:**

- You decide on your own whether or not you want to complete the 15-minute survey.
- You will not be punished or treated any differently if you decide not to complete the survey.
- If you **do** decide to complete the survey, you will have the right to stop completion of the survey at any time.
- If you decide not to complete the survey or to stop completion the survey, this will not affect you in your role as a member of this online support group in any way.

#### **Institutional Review Board Approval:**

The Academic Affairs Institutional Review Board (AA-IRB) of the University of North Carolina at Chapel Hill has approved this survey.

If you have any concerns about your rights in completing this survey you may contact the Chair of the AA-IRB, [Barbara Davis Goldman, Ph.D.](#), at CB# 4100, 201 Bynum Hall, UNC-CH, Chapel Hill, NC 27599-4100, (919) 962-7761 email: [aa-irb@unc.edu](mailto:aa-irb@unc.edu).

#### **Summary:**

This is a research study to learn about online support groups.

- You will be asked to click on the button at the bottom of this message that is labeled "I agree to participate in this study."



- The action of clicking this button will take you to a webpage with a link to an online survey with questions and places to answer those questions. The questions will ask you about yourself, about your use of the online support group, about your perceptions of the online support group, and about any concerns you have about communicating in this unique online support forum. It is estimated that the survey can be completed in as little as 15 minutes.
- Although completing as many questions as possible adds to the value of the study, you may skip any questions that you wish.
- After you complete the survey, you must press a button labeled "Submit Survey" located after the last question. Pressing this "Submit Survey" button will represent completion of your participation and no answers will be sent before you press this button. You may quit at any time before this point by closing your Internet Browser.
- You have had the chance to call and ask any questions you have about this study, and if so, they have been answered for you.

**I have read all of the information on this consent form, and**

I agree to participate in this study.

**Appendix A.4. Final Consent Page**

## UNC Online Support Group Study Final Consent Page

Thank you for agreeing to participate!

[Click Here To Begin Filling Out the Online Survey](#)

If at any time you change your mind and decide not to participate, simply close your web browser.

## **Appendix A.5. Online Support Group Survey**

## UNC Online Support Group Survey

**Directions:** please complete the questions below. Please do not indicate your name or the name of your online support group anywhere on this form!

When you finish, you **must click on the button at the bottom labeled "SUBMIT SURVEY"** in order for your responses to be sent. If you have any questions about the survey, you may call or e-mail [Dr. Claudia Gollop](mailto:Dr.ClaudiaGollop@unc.edu) (919-962-8362) or [Laura Agnew](mailto:LauraAgnew@unc.edu) (919-933-6520). Thank you very much for your participation.

### Your Support Group Usage

#### 1. Why are you a member of this support group? (check as many as apply)

- I suffer from the illness that this support group addresses
- A friend suffers from the illness that this support group addresses
- A family member suffers from the illness that this support group addresses
- I am a caregiver of someone with the illness that this support group addresses
- I am a doctor or healthcare professional who treats patients who suffer from the illness that this support group addresses (note, questions 2-38 may not apply to healthcare professionals)
- Other (please specify):

If you feel that you need to clarify question 1, please do so here:

#### 2. Who gave you the idea to seek this form of support? (check as many as apply)

- A doctor
- A nurse
- Another type of healthcare provider (please specify):

This was all my own initiative

- A friend
- A family member

Other (please specify):

If you feel that you need to clarify question 2, please do so here:

#### 3. How long have you been participating in this support group? (please indicate either the approximate number of days, weeks, months, or years )

Enter the approximate number of days, weeks, months, or years.

day(s)  week(s)  month(s)  year(s)

If you feel that you need to clarify question 3, please do so here:

**4. How long after the diagnosis of your (or your loved one's) condition did you join this support group? (please indicate either the approximate number of days, weeks, months, or years.)**

day(s)  week(s)  month(s)  year(s)

If you feel that you need to clarify question 4, please do so here:

**5. Would you have joined this online support group SOONER if your doctor, nurse, or healthcare provider had suggested it to you?**

Yes  No  Not applicable (my healthcare provider DID suggest it)

If you feel that you need to clarify question 5, please do so here:

**Please complete the sentences below indicating your type of and amount of participation:**

6. On average, I SEND about  messages to this mailing list every [  day  week  month].

7. On average, I receive about  messages to this mailing list every [  day  week  month].

8. On average, I SPEND about  hours,  minutes each [  day  week  month] participating in some way on this mailing list (please include time just reading others' messages or researching things for the list).

If you feel that you need to clarify questions 6, 7, or 8, please do so here:

**9. Do you usually participate more on weekends or weekdays?**

more on weekends  more on weekdays.

If you feel that you need to clarify question 9, please do so here:

**10. Is this the only support group that you subscribe to?**

- Yes  No

If you feel that you need to clarify question 10, please do so here:

**11. How did you locate this particular online support group?**

- A friend found it for me and gave me the website address
- A family member found it for me and gave me the website address
- A healthcare professional gave me the website address
- I specifically searched for an online support group using a search engine
- I was searching for any information and/or help on the web and just happened to find this group
- Other (please specify):

If you feel that you need to clarify question 11, please do so here:

**12. Indicate your agreement with the following statements below:**

	strongly disagree	somewhat disagree	somewhat agree	strongly agree
a. I found it difficult to locate this support group.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I found it difficult to subscribe to this support group.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I am very comfortable with everyday-use of the computer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you feel that you need to clarify question 12, please do so here:

**13. How long have you been using a computer? (please fill in the appropriate number of weeks, months, or years)**

week(s)  month(s)  year(s)

If you feel that you need to clarify question 13, please do so here:

**14. What e-mail program do you usually use to send or read messages on the list (e.g. Netscape Messenger, Microsoft Outlook)?**

**15. What kind of Internet connection do you have (e.g. cable modem, 56K modem, digital subscriber line (DSL))?**

**16. What time do you usually participate (either reading, responding, or sending messages)?**

a. <input type="checkbox"/> 5:00 AM - 8:00 AM	d. <input type="checkbox"/> 5:00 PM - 8:00 PM
b. <input type="checkbox"/> 8:00 AM - 12:00 Noon	e. <input type="checkbox"/> 8:00 PM - 12:00 Midnight
c. <input type="checkbox"/> 12:00 Noon - 5:00 PM	f. <input type="checkbox"/> 12:00 Midnight - 5:00 AM
	g. <input type="checkbox"/> There is no specific time, I participate at varying times of the day and night

If you feel that you need to clarify question 16, please do so here:

**17. Are you aware of any medical professionals who read or contribute to this list?**

Yes  No

If you feel that you need to clarify question 17, please do so here:

**18. Would you welcome the participation (or more participation) of a medical professional on this mailing list?**

Yes  No

If you feel that you need to clarify question 18, please do so here:

**19. Do you also attend a face-to-face support group locally in your area?**

I do  I do not

If you feel that you need to clarify question 19, please do so here:



**19b. If not, please indicate why not (please check all that apply):**

- There is not a face-to-face support group in my immediate area
- I tried a face-to-face support group but it did not meet my needs
- I don't feel well enough to attend the support group in my area
- It is too much trouble to find a caretaker for my children or sick friend/relative during my absence
- I like the convenience of being able to send messages to the list at any hour of the day
- The act of writing (typing) out my feelings is therapeutic
- I am just more comfortable communicating in an online format (please explain):

- Other reason (please explain):

If you feel that you need to clarify question 19b, please do so here:

**20. Below please indicate the degree to which you agree or disagree with the statements below:**

	strongly disagree	somewhat disagree	somewhat agree	strongly agree	N/A
a. I get helpful information on how to manage my (or my loved one's) disease from this support group.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I get valuable emotional support that helps me cope with the stress of my (or my loved one's) disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. There are many times when I seek advice from this list that I would have only sought from my doctor in the past.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. There are health-related questions that I ask on this list that I would never in the past nor in the present dream of asking my doctor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I would say that this online group has either directly or indirectly saved or prolonged my life (or that of my loved one).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. I would say that this online group has improved the quality of life for me or my loved one.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. I have received misleading information from the list on several occasions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

h. Helping others on this list is very important to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. I do not know how people with my (or my loved one's condition) could possibly manage without an online support group such as this one	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you feel that you need to clarify question 20, please do so here:

**21. Discussing issues and interacting with members of this online support group is less helpful, as helpful, or more helpful to me than talking ... (check as many as apply)**

	LESS helpful	AS helpful	MORE helpful	Doesn't Apply
a. ... with my friends who do not have my same ailment or predicament	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ... with family members who do not have this ailment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ... with my doctor (medical)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ... with my psychologist or counselor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ... with a nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ... with my preacher (or clergy, priest, rabbi, or other spiritual advisor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ... other (please specify): <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you feel that you need to clarify question 21, please do so here:

**22. Has the information and support that you receive through this forum had a positive or negative effect on the relationship that you have with your (or your loved one's) healthcare provider?**

- Positive
  Negative
  No effect at all

Please take time to explain:

**23. What is your most favorite thing about this online support group?**

24. What is your least favorite thing about this online support group?

**Personal Information**

25. Please indicate your gender:  Male  Female

26. What is your age?  years old. (You may give a range below if you prefer)

range:	a. <input type="radio"/> under 20*	c. <input type="radio"/> 30-39	e. <input type="radio"/> 50-59	g. <input type="radio"/> 70-79
	b. <input type="radio"/> 20-29	d. <input type="radio"/> 40-49	f. <input type="radio"/> 60-69	h. <input type="radio"/> over 80

27. How would you describe the town or city where you live?

- Rural or country-side
- Suburban or a neighborhood near a metropolitan area
- Urban (city or metropolis)

If you feel that you need to clarify question 27, please do so here:

28. How would you describe your race/ethnicity (examples might include black, white, hispanic)?

29. Education completed (please select the highest grade completed below)?

Grade School								High School				GED		College				Graduate School				
1	2	3	4	5	6	7	8	9	10	11	12	yes	no	13	14	15	16	17	18	19	20	21
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Please select your approximate household income level (before taxes):

a. <input type="radio"/> \$ 0-10,000	c. <input type="radio"/> \$ 20,001-30,000	e. <input type="radio"/> \$ 40,001-50,000	g. <input type="radio"/> Over \$ 75,000
--------------------------------------	---	---	---

- b.  \$ 10,001-20,000    d.  \$ 30,001-40,000    f.  \$ 50,001-75,000     Leave Blank

**31. How many people are in your household?**

person(s).

If you feel that you need to clarify question 31, please do so here:

**32. What is your daily schedule like? (check as many as apply)**

- I take care of home and family tasks part-time
- I take care of home and family tasks full-time
- I work part-time outside the home
- I work full-time outside the home
- I work part-time for pay but do so from home (e.g. telecommute)
- I work full-time for pay but do so from home (e.g. telecommute)
- I do not work at the present time
- I am retired
- Other (please

specify):

If you feel that you need to clarify question 32, please do so here:

**Privacy Concerns**

Questions #33-38 are asked to determine the level of privacy-concern by members of online support groups. Though answers cannot be linked to individuals, remember that all questions are optional.

**33. Are you concerned that a sales-type person, who pretends to be a legitimate support group member, may suggest that members purchase a specific health-related product on this list?**

- Yes     No

If you feel that you need to clarify question 33, please do so here:

**34. Are you concerned that people may subscribe to this list in order to get your e-mail address and then sell it to companies who send spam (spam = junk mail)**

- Yes     No

If you feel that you need to clarify question 34, please do so here:

**35. Are you concerned that an insurance company may snoop on this list?**

- Yes  No

If you feel that you need to clarify question 35, please do so here:

**36. Does your real (first and last) name appear on this list (either discernable in the e-mail address, the "from" line, or in your signature)?**

- Yes  No

If you feel that you need to clarify question 36, please do so here:

**37. Are you concerned that if this list archives its messages that those archives may be used for unintended purposes?**

- Yes  No

If you feel that you need to clarify question 37, please do so here:

**38. Do you think that the personal medical information exchanged on a list such as this one should be protected under medical privacy laws?**

- Yes  No

If you feel that you need to clarify question 38, please do so here:

**39. What did you think about this survey? Please give your suggestions for improvement:**

### Submitting your survey

1. To submit your survey, click on the "SUBMIT SURVEY" button below.

1. To submit your survey, click on the "SUBMIT SURVEY" button below (please click once only).

SUBMIT SURVEY

2. If you have changed your mind and prefer not to answer the survey, please exit your browser.

***Thank you very much for your participation!***

## **Appendix A.6. Survey Received Confirmation**

**UNC Online Support Group Study**  
**Survey Received Confirmation**

Thank you! Your survey has been received. We appreciate your participation in this study. You may exit your web browser at this time.



## **Appendix A.7. Survey Closed Notice**

## **UNC Online Support Group Study**

**Survey Collection is Closed**

Thank you for your interest. When the analysis phase is complete, we will send the results the group. If you have any questions, please contact [Dr. Claudia Gollop](#) (919-962-8362) or [Laura Agnew](#) (919-933-6520).

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