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Internet Cancer Support Groups:

A Feminist Analysis

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Abstract

Internet Cancer Support Groups (ICSGs) are an emerging form of support group on Internet specifically for cancer patients. Previous studies have indicated the effectiveness of ICSGs as a research setting or a data-collection method. Yet recent studies have also indicated that ICSGs tend to serve highly educated, high-income White males who tend to be at an early stage of cancer. In this article, a total of 317 general ICSGs and 229 ethnic-specific ICSGs searched through Google.com, Yahoo.com, http://Msn.com, AOL.com, and ACOR.org are analyzed from a feminist perspective. The written records of group discussions and written memos by the research staff members were also analyzed using content analysis. The idea categories that emerged about these groups include (a) authenticity issues; (b) ethnicity and gender issues; (c) intersubjectivity issues; and (d) potential ethical issues. The findings suggest that (a) researchers adopt multiple recruitment strategies through various Internet sites and/or real settings; (b) researchers raise their own awareness of the potential influences of the health-related resources provided by ICSGs and regularly update their knowledge related to the federal and state standards and/or policies related to ICSGs; and (c) researchers consider adopting a quota-sampling method.

Keywords

Analysis; Cancer; Feminist; Internet; Support groups

As the number of Internet users has increased, the Internet Cancer Support Groups (ICSGs) have also increased dramatically, not only in number but, according to recent studies, also popularity among cancer patients. Currently more than 400,000 ICSGs exist, each having up to 2,065 members. They have become an important resource for researchers working with cancer patients who reside in different geographical areas nationally and internationally.^{2,4}

Internet Cancer Support Groups have a range of purposes, including offering psychosocial support and understanding, providing a forum for discussing both traditional and alternative cancer treatments, disseminating information on new treatments and side effects of treatment, and providing encouragement and hope for cancer patients and their care-givers. ⁵-8 Internet Cancer Support Groups do not use a facilitator; however, they usually are managed or owned by an individual with computer expertise who may be a cancer survivor. ⁵ The role of the owner

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is primarily to subscribe and unsubscribe participants, answer the questions related to the ICSG, and troubleshoot online problems.

As more ICSGs form, a number of articles on them have been recently published. ^{5,9}-12 Some of the articles reported the benefits of ICSGs over their traditional face-to-face counter-parts because ICSGs help people obtain information, share experiences, receive general support, vent feelings, and gain accessibility to other cancer patients. ⁶-8 Meanwhile others reported negative aspects of ICSGs. Participants often must endure others' expressions of negative emotions (eg, hostile messages), they receive large volumes of e-mail, and they lack physical contact and proximity. ⁶-8 Despite these arguments on positive and negative aspects of ICSGs, all studies have indicated the effectiveness of ICSGs as a research setting or a data-collection method. ^{5,9}-12

Recent studies, yet, have indicated that ICSGs tend to serve highly educated, high-income White males who tend to be at an early stage of cancer. Consequently, when ICSGs are used in research to support dominant androcentric views and interests, those who are not part of this dominant group (eg, ethnic minorities, women) are marginalized, and their issues are either not considered relevant for study or not reflected accurately in research and healthcare practice. When nursing research is uncritically conducted using ICSGs as a research setting or data-collection method, the nursing knowledge that will result will definitely mislead nursing practice. Therefore, it is imperative to analyze ICSGs critically from a feminist perspective, especially at this early stage in Internet research, in order to develop a firm foundation for later work.

In this article, ICSGs that were searched through http://Google.com, Yahoo.com, Msn.com, AOL.com, and ACOR.org are analyzed using a feminist perspective. The analysis of ICSGs was purposefully conducted while considering 5 evaluation criteria for rigor in feminist research by Hall and Stevens ¹⁶: (a) intersubjectivity, (b) reflection of women's voices, (c) reflexivity and contextuality, (d) dependability, and (e) adequacy and credibility. In other words, throughout the analysis process, we tried to view ICSGs in terms of how they provide a research setting and/or data-collection method that meet these 5 evaluation criteria. At the same time, the memos and group discussion records that were written during the analysis of ICSGs were also analyzed with the criteria. Thus, this analysis reported in this article tends to be limited to these five criteria. This article is organized in the following way. First, the method used to search, retrieve, and analyze ICSGs is described. Then, the issues raised during the analysis process are discussed. Then, directions for future use of ICSGs in nursing research are proposed on the basis of the discussion of the issues.

■ Method

Internet Cancer Support Groups were searched using the key words, "cancer," "support," and "group," through 5 major Internet search engines: Yahoo.com, Msn.com, Google.com, AOL.com, and ACOR.org (Tables 1 and 2). A total of 918 general ICSGs (those for patients with all types of cancer) and 1953 ethnic-specific ICSGs (those for cancer patients from a specific ethnic group such as Hispanic, non-Hispanic African American, and non-Hispanic Asian) were retrieved. Each of the retrieved ICSGs was visited and their eligibility determined on the basis of their content (eg, bulletin boards for cancer patients, chat groups for cancer patients, information resources). When ICSGs included content related to cancer support, they were regarded as eligible ICSGs. A total of 317 general ICSGs and 229 ethnic-specific ICSGs were found to be eligible. Each eligible ICSG was visited again, and its characteristics were analyzed (see a sample of the Web site analysis in Table 3).

Throughout the analysis process of ICSGs, research staff members recorded issues as they arose and wrote memos regarding the issues in the usage of ICSGs for research from a feminist

perspective. Weekly group discussions were conducted, and the written records of these discussions were kept. These memos and written records were also analyzed. As mentioned above, the analysis of ICSGs purposefully focused on the evaluation criteria for rigor in feminist research by Hall and Stevens. Thus, the analysis of these weekly group discussions and written memos also focused on issues related to the evaluation criteria. The written memos and records were reviewed and analyzed using the content analysis technique suggested by Weber. The unit of analysis was individual words, and the memos and written records were analyzed using line-by-line coding. Then, the codes were categorized according to the contents, and idea categories were developed from the categorization process. The idea categories included (a) authenticity issues; (b) ethnicity and gender issues; (c) intersubjectivity issues; and (d) potential ethical issues. Our findings from the analysis of ICSGs are discussed according to these idea categories as follows.

■ The Feminist Analysis

Authenticity Issues

A potential issue related to credibility in using ICSGs for research is related to their authenticity. The authenticity issues related to ICSGs that were found through this analysis include (a) vague definitions of ICSGs; (b) authenticity of interactions in ICSGs; and (c) a lack of contextual information. First, during the Internet search for ICSGs, it was not clear which Web sites could be defined as ICSGs. Thus, as described in the "Method" section, after the ICSGs' Web sites were retrieved, each was visited and its eligibility checked before the analysis. Many terms were being used on Internet to refer to ICSGs. These terms included (a) "virtual communities for cancer patients," (b) "online support forums for cancer patients," (c) "online discussion groups for cancer patients," (d) "electronic mailing lists for cancer patients," (e) "bulletin boards for cancer patients," and (f) "electronic newsgroup networks for cancer patients." These terms can be possibly confusing to Internet users who want to find an interesting ICSG.

Another authenticity issue related to credibility was unique social interactions in ICSGs. Research assumes authentic interactions between researchers and research participants, ¹⁹ yet it was questionable how authentic the interactions and the phenomenon reported and/or explored through ICSGs were. As described above, for this analysis, ICSGs were identified through several Internet search engines, and only eligible ICSGs were sorted and analyzed. However, there was no way to validate that the participants of ICSGs were the real persons for whom the researchers were searching. It was assumed that all the participants of ICSGs were real cancer patients because they were signing on to ICSGs. In reality, it might be possible that some participants were not real cancer patients. In some cases, they might be family members living with cancer patients. In some other cases, they might pretend to be cancer patients out of interest or because they are seeking fun.

Another authenticity issue was related to a lack of contextual information. Through the bulletin boards and chat groups provided by ICSGs, contextual data about the cancer experiences of the members might be possibly obtained by a researcher, and the collected data could provide more detailed and richer data than traditional support group discussions. However, since ICSGs were based on non-face-to-face interactions, ICSGs could not provide any information about the environments where their members were when they participated in the bulletin boards and chat groups provided by ICSGs. Data-collection environments would possibly influence the discussions of the members of ICSGs. If a participant posts a message in a rush, she or he would not have enough time to think about the topic or might be distracted by other interruptions such as noise and visitors/intruders. If a participant posts a message with her or his colleagues at work or family members at home, her or his messages might not be the same as when she or he posts the message by herself or himself. The lack of contextual information could raise questions about the authenticity of interactions on Internet.

Ethnicity and Gender Issues

All feminists assert that researchers should value women and validate women's experiences, ideas, and needs; researchers should recognize the existence of ideologic, structural, and interpersonal conditions on interactions that oppress women; and researchers should have a desire to bring about the change of oppressive constraints on interactions through criticism and political action. Postmodern feminists emphasize that research questions should reflect the concern of particular marginalized groups of women, and research needs to be conducted for the purpose of finding answers for the marginalized groups. They also assert that the researcher's history, assumptions, motives, interests, and interpretations are explicitly scrutinized in the process of study. Therefore, from a feminist perspective, a lack of women's and/or specific marginalized groups' voices in research is problematic. A critical point found through this analysis of ICSGs was issues related to ethnicity and gender. The ethnicity and gender issues include (a) the lack of ethnic minority members in ICSGs; (b) a larger number of women-only ICSGs than men-only ICSGs; (c) gender differences in patterns of online participation; (d) difficulty in identifying ethnicity and gender of the participants; and (e) gender differences in emotional tone or type of messages.

Among ICSGs that were determined as eligible, 229 were ethnic-specific ICSGs, as described above. However, most of those identified as ethnic-specific ICSGs were, in fact, general ICSGs whose members were predominantly Whites, and only 24 ICSGs were actually ethnic-specific ICSGs (see Table 2). Among the 24 ICSGs, 8 ICSGs were for African Americans, 8 were for Asian Americans, and 8 were for combined ethnic minority groups. These figures may reflect the overall ethnic composition of Internet populations, which tend to be dominated by Whites. This certainly implies that ICSGs may not represent research populations of interest when researchers target a large number of ethnic minority cancer patients. This lack of ethnic minority members in ICSGs is certainly problematic when viewed from a feminist perspective, because their experience may not be easily found and/or discussed through research among ICSGs. 5,9

An ICSG can be easily placed into 1 of 3 groups according to its gender specificity: (*a*) a general ICSG aimed at both men and women; (*b*) an ICSG for women (eg, breast cancer groups, ovarian cancer groups, cervical cancer group, endometrial cancer group); or (*c*) an ICSG for men (eg, prostate cancer group). Considering the recent statistical report on the gender composition of Internet populations (gender-balanced), it might be expected that most of the ICSGs would admit both women and men. However, more women-only ICSGs exist than ones for men. In light of previous reports about the distribution of gender online, 23,24 this was a very interesting finding. One possible reason for this finding would be recent initiatives supporting women's health research, especially increasing funding opportunities for breast cancer research.

Another gender-related issue was gender differences in the patterns of participation in ICSGs. Female participants tended to share their stories and seek emotional support. In a women-only ICSG with 842 members, *Women's Cancer Forum*, 40 messages were posted during the past 6 months: 12 introduced new members, 2 reported that old members were leaving the group, and 19 asked for advice or emotional support (eg, "if somebody could chat with me regarding my newly diagnosed cancer," "waiting for results for a new test," "any advice on sick leave," "scared with more tests"), and the remainder was administrative messages. Male participants tended to seek information and resources. For example, in a men-only ICSG, *Prostate Cancer Awareness and Support*, which has 222 members, 78 messages were posted in the past 6 months. Thirty-two were about information sharing on prostate cancer, clinical trials, new vaccine, hormone refractory prostate cancer, plenaxis, diet control, thalidomide, risk factors of prostate cancer, radiation, Zoladex, PSA 256-Chemotheray, and Laparoscopic surgery. Twenty-one messages were administrative—e-mails, including the introduction of new members, descriptions of a new join policy, updates of the Web site, message board supports,

and problems in posting. The rest were announcements made by outsiders (eg, unsolicited commercial messages). The interesting finding was that the overall participation rate of the members of ICSGs in discussions through the message boards was very low regardless of gender, and that there were many postings about how much time existed for chatting and when they were having the next chat groups. In many cases, the message boards were being used solely to announce the next chat time, and the participants preferred to chat instead of posting messages on the message boards. Yet, the chat groups were not publicly accessible and visible as the message boards were.

On the women-only ICSGs, participants were certainly discussing women's own experiences with cancer. Yet the ICSGs for both men and women rarely represented women's voices and experiences. It proves difficult for the visiting observer to determine if a member was a woman or man, although many of the members used female names and male names as a part of their user names. The gender of the participants could be inferred from the user names, but it could not be ensured that the names reflected the actual gender of the participants. Subsequently, identifying men's and women's voices was difficult because of the difficulty in identifying the gender of the members. It was necessary to assume that the members with user names including a female name or a female symbol were women, and the members with user names including a male name or a male symbol were men.

Despite the difficulty in identifying the gender of the participants, the emotional tone or type of messages was related to whether the user name was female or male. For example, the messages posted by the persons with female user names tended to be warm and supporting (see a sample message by a person with a female user name in Fig 1). The messages by the persons with male user names tended to be very concise and informative (see a sample message by a person with a male user name in Fig 2). Despite this difference by user names, no differences in their participation rate in the discussion boards by user names were noticeable. The only one noticeable gender difference was that the persons with female user names were more likely to respond to a posted message than the persons with male user names, and the responses by the persons with male user names tended to be shorter than those by the persons with female user names.

Intersubjectivity Issues

This analysis indicates some issues related to intersubjectivity in using ICSGs for research. Intersubjectivity between researchers and research participants and the mutual creation of data are essential components of research from a feminist perspective. ^{15,16,21} Consequently, feminists strongly suggest that research should not be conducted on the basis of distant relationships between researchers and research participants. In the terms of a feminist perspective, research participants are always "doing research" in a sense because they construct the meanings that become data for later interpretations by researchers. Feminists also propose that traditional scientific research methodologies rely on creating and maintaining distance between researchers and participants, while in feminist research, "intersubjectivity" is emphasized. One consequence is that findings are usually shared with the participants. ^{1,25,26} The intersubjectivity issues that were found through this analysis include; (a) a low participation rate; (b) unbalanced relationships between researchers and research participants; and (c) difficulty in getting contact information.

Messages in bulletin boards and chat group messages tend to be dominated by only a few participants. On the message board of *Cancer Care Network* with 353 members, 5 to 7 members dominated the discussion board. Except these dominant members, the participation rate of most members of ICSGs tended to be very low. During the past 6 months, the highest number of messages posted in the retrieved ICSGs was 552, and the lowest number of messages posted in the retrieved ICSGs was 0. Considering that most ICSGs tended to have very few messages

(5-10 messages) per month, it might be difficult for researchers to recruit participants and collect data only through the ICSG. Furthermore, most ICSGs did not provide individual members' e-mail addresses unless the researcher became a member of the ICSG. Even if individual e-mail addresses were available, it would be difficult to motivate potential participants to respond because non-face-to-face interactions through electronic communication could be easily ignored, and because some would not even open the e-mail messages while assuming the messages were spam mails. Sometimes, individual e-mails containing the study announcement can be possibly regarded as spam depending on the policies and regulations of each ICSG.

Internet Cancer Support Groups can also easily result in unbalanced relationships between researchers and research participants. Since ICSGs are usually owned by an individual or a small group of administrators, ICSGs offer their owners significant control over who can contribute to their group. Sometimes, the owners can review all requests and messages, forbid anyone from contributing to the list if they are not on the list themselves, and even censor specific messages that they do not want to post on their Web sites. This ability can be not only beneficial for researchers who need to control group discussions, but also problematic when researchers are investigating research participants' own experiences because the control by list owners can influence the whole research process by forcing their biases.

It was also very difficult to find contact information on most of the Web sites. The researchers sometimes needed to spend more than 30 minutes to determine who was the contact person for a Web site. Contact information for ICSGs on a specific Internet group, other than the e-mail address of the listserv itself, was also difficult to obtain. It was also hard to determine if the e-mail sent through the available e-mail addresses of the listservs reaches the list owners or facilitators/moderators. It was difficult to access some of the ICSGs because of slow connections due to busy transactions on the Web server. Furthermore, some Web sites of ICSGs even led the users to a noncancer Web site for a commercial purpose. Many Web sites changed their Web addresses very often, which could possibly frustrate users.

Potential Ethical Issues

Potential ethical issues found through the analysis include (a) relevance issues and (b) confidentiality issues. Feminists emphasize "relevance" as a major component of research that is related to intersubjectivity, reflexivity, adequacy, and credibility, ¹⁶ which is also related to ethical issues. Relevance can be defined as whether research questions can serve research participants' own issues and interests in improving their lives. In terms of "relevance," ICSGs could be excellent sources for nursing research because ICSGs are developed and managed by cancer patients themselves. Furthermore, some ICSGs were providing essential information related to a specific type of cancer that members of ICSGs were experiencing. In this regard, ICSGs could be an excellent research setting or a data-collection method from a feminist perspective. However, it was difficult to determine if each ICSG was really reflecting members' own interests and issues. Moreover, the analysis indicated that information resources provided by ICSGs tended not to be validated by health professionals. In some cases, the Web owners or masters of ICSGs clearly indicated that they were not healthcare professionals, and the information that they were providing on the Web site was not validated by healthcare professionals. Because there currently exist no standardized policies and/or regulations related to the accuracy of information provided by ICSGs, this kind of issue can be easily raised when using ICSGs as a research setting or a data-collection method. A Web owner who designs a usable Web site might still present inaccurate information. Another potential ethical issue related to "relevance" was that some ICSG members might not be interested in the research project. Therefore, recruiting research participants through ICSGs could intrude on the physical and psychological privacy of the members, who might not want to see the announcement of

the study (considering it an intrusion on physical privacy). They might also feel uncomfortable about receiving the announcement of the study (considering it an intrusion on psychological privacy).

Another potential ethical issue was that most of the Web sites did not ensure the confidentiality of the interactions. Very few Web sites mentioned confidentiality or had regulations aimed at preserving the confidentiality and anonymity of members as they interacted. Some Web sites placed a disclaimer at the bottom of their Web pages stating that they were not to replace professional treatment but were to be used for educational purposes only. Some Web sites used "site disclaimer" or "privacy" as terms for user information on confidentiality issues. For example, on the bottom of the Web sites, all of the ICSGs on Yahoo.com and 2 of the ICSGs on Msn.com used a disclaimer that was written in relatively smaller fonts than the regular fonts. Some Internet users might not pay attention to this description and possibly trust the information on the Web without further clarification. In contrast, some Web sites such as http://www.webwhispers.org and http://ppml.acor.org/PCA%20primer1.html used a larger font in red for the disclaimer. Some other Web sites used confidentiality and privacy policies to ensure participants' right of nondisclosure without permission. Only one Web site warned users not to post anything of a confidential nature that he or she did not wish hundreds of other people to know about.

■ Conclusions

The findings of the analysis on ICSGs reported in this article indicated that ICSGs may not be credible sites for research for several reasons: the vague definitions of ICSGs, the uncertain authenticity of interactions in ICSGs, and the lack of contextual information. Also the findings indicate several ethnicity and gender-related issues, specifically a larger number of womenonly ICSGs compared with men-only ICSGs, gender differences in the participation pattern, difficulty in identifying ethnicity and gender of the participants, and gender differences in emotional tone or type of messages. The analysis also indicated some issues related to intersubjectivity including a low participation rate of ICSG members, unbalanced relationships between researchers and research participants, and difficulty in getting contact information. On the basis of these findings, the following suggestions are offered for the future use of ICSGs for oncology nursing research.

Recent studies have indicated that ethnic minorities, especially African Americans, attach stigma to cancer. ^{27,30} In light of this stigma, recruiting ethnic minorities would be difficult in real settings because those studies are based on face-to-face interactions. In light of studies indicating that Internet is an excellent medium to reach hidden populations with stigmatized conditions, ³¹ ICSGs might also be an excellent setting for research on cancer among ethnic minorities. However, it is suggested that researchers also be aware of the limitations in using ICSGs. As the findings of the analysis demonstrate, very few ethnic-specific ICSGs were available on Internet, and ethnic minorities tended to be very passive in their participation in ICSGs. Consequently, a large number of ethnic minorities would not easily be recruited through ICSGs. Thus, if a researcher is going to recruit a sizable sample of ethnic minorities, it is suggested that the researcher consider using multiple recruitment strategies through various Internet sites and/or real settings rather than relying on ICSGs as the only source of recruitment.

Second, it is suggested that researchers consider the potential influences of the health-related resources provided by ICSGs and regularly update their knowledge on the standards and/or policies related to ICSGs. The analysis reported in this article indicated the inaccuracy of the information provided in ICSGs, and warned about the related potential ethical issues. Some of the Webmasters of ICSGs indicated that the information that they provide might not be accurate or that the person providing the information is not a healthcare professional. However, most

ICSGs provided information and links without a proper validation. The inaccuracy of the information provided by ICSGs is problematic because most of the members of ICSGs might not easily recognize those limitations, and the information could possibly influence their knowledge level and attitudes in biased ways. Additionally, as reported in this article, using ICSGs for research purposes requires considering some potential ethical issues. Furthermore, Internet technologies advance on a daily basis. Thus, researchers who want to use ICSGs for their research need to keep up with the daily changing Internet technologies, especially security technologies, and the federal and state policies and standards related to ICSGs.

Finally, for researchers who want to use ICSGs to recruit research participants, a quota-sampling method is recommended. Internet populations tend to be highly educated, high-income, White males. Eurthermore, as the analysis reported in this article indicated, interactions in ICSGs tend to be dominated by a few active members. Because of the nature of Internet demographics and interactions, Internet researchers may frequently meet selection biases very easily. As Burns and Grove posited, quota sampling could help ensure the inclusion of subject types that are likely to be underrepresented in the convenience sample, such as women, minority groups, the aged, the poor, the rich, and the undereducated, subsequently reducing potential selection bias.

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From: Sent: 10/2/2003 10:28 AM I read this poem and thought of Mary, She is always huggin lol. I thought I would share it. ³⁹ Hugs & It's wonderous what a hug can do A hug can cheer you when you're blue A hug can say "I love you so" Or "Gee I, hate to see you go." A hug is "Welcome back again" And "Great to see you where've you been?" A hug can soothe a small child's pain And bring a rainbow after the rain. The hug there is just no doubt about it We scarcely could survive without it. A hug delights and warms the charms--It must be why God gave us arms. Hugs are great for Fathers and Mothers, Sweet for sister, swell for brothers And chances are your favorite aunts Love them more than potted plants. Kittens crave them, puppies love them, Heads of State are not above them. A hug can break the language barrier And make your travel so much merrier. No need to fret about your store of them The more you give the more there's more of 'em, SO stretch those arms without delay And give someone a hug today!

Figure 1.

■A sample message by a person with a female user name.

From: Sent: 9/11/2003 10:45 PM

Check out this news story:

http://www.comcast.net/News/HEALTHWELLNESS//XML/1500 Health medical/f92ec848-9671-496e-8a26-5f3360ed2fc1.html

Figure 2.

■ A sample message by a person with a male user name.

Table 1A Summary of Retrieved Web Sites of General ICSGs From June 23 to October 21, 2003

Searching Engines	Yahoo.com	Google.com	Msn.com	ACOR.org	AOL.com
Total retrieved Webs	280	303	150	150	35
No. of eligible Web sites	75	102	24	109	7

Table 2A Summary of Retrieved Web Sites of Ethnic-Specific ICSGs From June 23 to October 21, 2003

Searching Engines	Yahoo.com	Google.com	Msn.com
Total retrieved Webs	950	728	290
No. of eligible	148	59	26
Web sites			
African American	6	0	2
Asian American	5	0	3
Hispanic	0	0	0
Diverse ethnic	7	0	1
General	130	59	20

Table 3

A Sample of the Web Site Analysis

Analysis Categories	Characteristics	
Name of Web site	American Cancer Society (ACS)	
Name of organization	The same as Web site name	
Web address	http://www.cancer.org	
Language	English, Spanish	
Ethnicity	Not specific	
Online support group	On-line message boards	
Administrator/Webmaster/contact person	NA	
Contact e-mail	Webmaster@acscsn.org	
Target population	Cancer patients, families, health professionals	
Online health information/resources Others	Information about different types of cancer, risk factors, prevention, treatment, and more A community-based voluntary health organization Rich information about ACS history, fact sheets	