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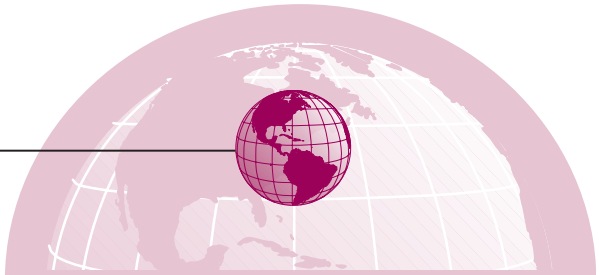
FEATURE ARTICLE



Evaluation Criteria for Internet Cancer Support Groups

EUN-OK IM, PhD, MPH, RN, CNS, FAAN
WONSHIK CHEE, PhD
HSIU-MIN TSAI, PhD, RN
HYUN-JU LIM, MSN, RN
ENRIQUE GUEVARA, MSN, RN
YI LIU, MSN, RN

Despite positive reports about Internet cancer support groups, studies have rarely addressed how to choose an appropriate Internet cancer support group to conduct research. The purpose of this article was to propose evaluation criteria for selecting Internet cancer support groups from which to recruit research participants. The authors developed proposed criteria while conducting an Internet-based study of cancer pain experience among cancer patients recruited through Internet cancer support groups. During recruitment and data collection, the researchers conducted bi-weekly discussions about recruitment progress and kept detailed records about issues that arose in the process of identifying, contacting, and announcing the study in Internet cancer support groups. Then, the written records were analyzed using content analysis to develop the evaluation criteria. The evaluation criteria developed were (1) private or public domains, (2) mission and purpose of the Internet cancer support group, (3) target users of the Internet cancer support group, (4) scope of the Internet cancer support group, (5) contents of the Internet cancer support group, (6) logistics for study announcements in the Internet cancer support group, (7) dynamics within the Internet cancer support group, and (8) credibility and authenticity of the owner/administrator of the Internet cancer support group. Because these criteria were developed from experiences gained during only one study, further development and refinement of the evaluation criteria are essential.

KEY WORDS

Criteria • Evaluation • Internet cancer support groups

With about 2.3 million people worldwide who are living with cancer and using the Internet as a medium of communication,[1,2] it can be seen that an increasing number of cancer patients will be coming online.[3] This surge in access to e-mail and the World Wide Web has also led to an increase in the number of Internet cancer support groups (ICSGs).[3] Internet cancer support groups are a type of electronic support group that offers psychosocial support and understanding, a forum for discussing both conventional and alternative cancer treatments, information on new treatments and adverse effects of treatment, and encouragement and hope for cancer patients and their caregivers.[4,5] Although they may have various purposes, ICSGs are effective in empowering cancer patients and increasing their quality of life.[6,7]

Internet cancer support groups have become an important repository of data for researchers working with cancer patients, especially those who wish to recruit study participants on a national and international scale.[4] Although the number of studies about ICSGs has increased recently,[3] emphasis has been on the quality and accuracy of the information found on the Internet rather than on how to choose ICSGs for research purposes such as recruitment of participants and data collection through Internet interactions. For example, Hargrave et al[8] evaluated the quality of pediatric neuro-oncology information on the Internet and reported that only 5% of the Web sites they examined provided one or more inaccurate

Author Affiliations: School of Nursing (Dr Im, Ms Lim, Mr Guevara, and Ms Liu) and College of Engineering, The University of Texas at Austin, (Dr Chee); and School of Nursing, Chang Gung Institute of Technology, Taiwan (Dr Tsai).

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Corresponding author: Eun-Ok Im, PhD, MPH, RN, CNS, FAAN, School of Nursing, University of Texas at Austin, 1700 Red River, Austin, TX 78701 (eim@mail.utexas.edu).

pieces of information. Esquivel et al[9] evaluated messages posted on ICSGs; most information was accurate, and participants in the support group rapidly corrected most false or misleading information in subsequent postings. However, these studies did not provide advice on choosing appropriate ICSGs for announcing studies to recruit cancer patients into research or for collecting data.

The purpose of this article was to propose evaluation criteria for selecting ICSGs from which to recruit research participants. The authors developed proposed criteria while conducting an Internet-based study of cancer pain experience among cancer patients recruited through ICSGs. In this article, the study that is the basis for this article is concisely presented first. Then, the method used to develop the evaluation criteria is described. Finally, the evaluation criteria for choosing ICSGs through which to recruit research participants are proposed.

THE STUDY

This article is based on an Internet survey study of cancer pain experience among patients recruited through various ICSGs. The purpose of the study was to develop a standardized decision-support computer program (DSCP), based on cancer patients' own views and experiences, that could be used by nurses as an assessment support tool for dealing effectively with gender and ethnic differences in cancer pain experiences. Throughout this article, the study is referred to as the DSCP study.

The DSCP study had two phases: (1) data collection and (2) development of the DSCP. The evaluation criteria proposed in this article are based on an analysis of the written records made during the recruitment and data collection process of the first phase of the DSCP study. The methods and results of the DSCP study are described in more detail elsewhere.[10–14]

The DSCP study was grounded in a feminist perspective, which theoretically guided the research process. For instance, gender and ethnicity were viewed as critical factors influencing the cancer pain experiences in four ethnic groups in the United States (Hispanic, non-Hispanic [N-H] white, N-H African American, N-H Asian). The methods used to collect data via the Internet included (1) a quantitative Internet survey of 480 cancer patients recruited through general and ethnic-specific ICSGs and cancer clinics and cancer support groups in actual physical communities across the nation and (2) four 6-month-long qualitative online forums involving about 30 participants per ethnic group who were recruited from among those 480 participating in the Internet survey.

The recruitment process through general (non–ethnic-specific) and ethnic-specific ICSGs was as follows. At the time data collection was initiated, the search engines Google, MSN, and Yahoo retrieved about 200 000 general ICSGs, 29 500 Hispanic-specific ICSGs, 82 800 African American–specific ICSGs, and 73 200 Asian-specific ICSGs. The research team members visited each of the retrieved ICSGs and determined eligibility for the study by reviewing each Web page of the ICSGs. Then, lists of the eligible general and ethnic-specific ICSGs were made. The first 100 general ICSGs and the first 75 ethnic-specific ICSGs retrieved through the Internet searches (25 per ethnic group among three ethnic minority groups) on the lists were initially contacted and asked to post a study announcement. Ethnic imbalance was prominent at the end of the first month, so an additional five ethnic-specific ICSGs (those specific for the underrepresented ethnic group) on the lists mentioned above were contacted to recruit more ethnic minority participants. This process continued until all the ICSGs available on the list were contacted.

METHODS

During the recruitment process of the DSCP study, the researchers held biweekly discussions on progress made in recruiting research participants and individually kept detailed notes on decision trails and issues that arose in identifying, contacting, and announcing the study in ICSGs. To develop the criteria for evaluation of ICSGs, the records of these discussions and the individual notes were analyzed using Weber's[15] content analysis. The unit of analysis was the individual word included in the written records. For example, the words included "authenticity," "identity," "gender," and "cancer diagnosis." These words were coded as "identifier." The decision trails and issues were classified into categories that emerged during the coding process. The researchers then used these categories to formulate the evaluation criteria. The evaluation criteria from the analysis process came to be (1) private or public domains, (2) mission and purpose of the ICSG, (3) target users of the ICSG, (4) scope of the ICSG, (5) contents of the ICSG, (6) logistics for study announcements in the ICSG, (7) dynamics within the ICSG, and (8) credibility and authenticity of the owner/administrator of the ICSG. In the remainder of this article, these evaluation criteria are discussed in detail. The evaluation criteria are summarized by category in Table 1.

THE EVALUATION CRITERIA

Private or Public Domains

To evaluate the suitability of an ICSG for placing study announcements to recruit research participants, a researcher needs to first determine whether it is in a private

Table 1

Evaluation Criteria for Internet Cancer Support Groups

Evaluation Criteria	Questions to Ask
Private or pubic domain	• Is the ICSG closed or open to the public? • Is membership in the ICSG determined by the Web owner/administrator? • Are there any difficulties in obtaining contact information for the Web owner/administrator? • Are there any difficulties receiving timely communications from the Web owner/administrator?
Mission and purpose	• Is the ICSG for-profit or nonprofit? • Is the ICSG associated with a specific institution? • Does the ICSG provide mechanisms for social interactions? • Does the ICSG provide information only? • Does the ICSG provide emotional support?
Target users	• Who are the users targeted by the ICSG? • Who are the actual users of the ICSG? • Do the target users include the target research population?
Scope	• How many members does the ICSG have? • How many hits per day does the site get? • How many messages are posted per week or month? • Are members of underserved populations active in the ICSG (eg, ethnic minorities, low-income populations)? • What language is used in the ICSG?
Contents	• Is the ICSG authentic (eg, if it is a commercial site, does it really serve the populations that it claims to)? • Does the information provided in the ICSG come from reliable sources? • Do the Web links in the ICSG go to credible resources? • Are the contents of the messages posted in the ICSG appropriate? • Is the site regularly updated? • Is the information that is provided in the ICSG the most current that is available?
Logistics for the study announcement	• Is there a fee for the study announcement? Is the fee appropriate? Any hidden fees? • Are there any other requirements for the study announcement (eg, institutional review board approval letter, a banner, donation, etc)?
Dynamics	• Is the ICSG dominated by a small number of members? • Is the ICSG dominated by the Web owner/administrator? • What is the level of activity in the ICSG (eg, inactive during the past month? How long has it been dormant?)?
Credibility and authenticity of the Web owner/administrator	• Who is the Web owner/administrator (eg, a healthcare professional, a cancer patient, or neither)? • What are the qualifications of the Web owner/administrator? • Is up-to-date contact information for the Web owner/administrator readily available? • Is the Web owner/administrator easy to contact? • Are there any problematic interactions between the Web owner/administrator and members of the ICSG? • Are there any potential problems with the research team communicating with the Web owner/administrator?

or public domain. Given exaggerated expectations of privacy in cyberspace, the blurred distinction between public and private domains has long been an issue in social and behavioral research involving human subjects on the Internet.[16] Indeed, defining an ICSG as a private or public domain was not an easy task in the DSCP study. Even in traditional research that uses questionnaires and face-to-face interviews, the distinction between public and private domains is important for researchers to determine the appropriateness of a specific research setting. Collecting data from the public domain, such as television, public records, radio, printed books, conferences, or public spaces (eg, parks, shopping centers), is usually regarded as appropriate, and the researcher may be exempt from obtaining consent for collecting such data. Therefore, using the ICSGs that are open to the public for research is supposed to avoid the issue of privacy protection.

To make study announcements for recruitment of research participants through ICSGs, it is important for

researchers to determine first if a specific ICSG is in the private or public domain. This information helps researchers determine whether they could directly contact potential participants through the contact information provided (if the ICSG is in the public domain) or if they need to contact webmasters to get permission to contact potential participants or to announce the study (if the ICSG is in the private domain). In the DSCP study, more than half of the identified ICSGs were closed to the public, and their membership was determined by the Web site owner/administrator. Subsequently, researchers needed to contact webmasters first to get permission to contact potential participants indirectly or directly through the ICSGs. All webmasters who responded to the e-mail contacts by the researchers gave permission to announce the study through their Web sites or e-mail lists. Yet, even when some ICSGs were identified as in public domains, researchers needed to double-check with Web site owners/administrators to see if researchers could announce the study to their members. Actually, at first, researchers did not contact Web site owners/administrators of the first several ICSGs that were identified as in public domains, but three potential participants from the ICSGs contacted the researchers, asked about how the researchers got their e-mail addresses, and expressed discomfort about being contacted, despite their contact information being openly available in the ICSGs.

Missions and Purposes of Internet Cancer Support Groups

Another evaluation criterion upon which to evaluate the suitability of ICSGs for study announcements is the mission and purpose of the ICSG. Researchers need to consider whether a specific ICSG is for-profit or nonprofit, whether it is solely a social site, whether it provides information only, and/or whether it provides emotional support to its members. Some ICSGs are composed primarily of friends who chat about their daily lives and health status. Other ICSGs just provide information and nothing more. Thus, evaluating the mission and purpose of an ICSG is an essential step that researchers need to take before contacting the owner/administrator of an ICSG for research purposes. For example, many of the ICSGs contacted in the DSCP study were associated with either a for-profit or nonprofit institution catering to cancer patients (eg, American Cancer Society), which were usually managed by a healthcare professional from that institution. These types of ICSGs did not allow study announcements to be posted on their sites. In addition, posting study announcements in the ICSGs that are strictly for socializing might result in selection bias because members are usually linked socially or biologically. Posting study announcements in the ICSGs that provide only information might also result in bias in recruitment because of the educational information provided by the ICSG.

Target Users of Internet Cancer Support Groups

The information on target users of ICSGs also helps determine the eligibility of the ICSGs for study announcements to recruit research participants. If the users targeted by a specific ICSG do not match the population targeted by the researcher, then the ICSG is obviously not appropriate for the study. For example, at one point in the DSCP study, researchers specifically targeted Asian cancer patients because they were underrepresented in the study. Thus, researchers specifically sought to recruit in general and ethnic-specific ICSGs that targeted Asian cancer patients. However, of the 130 eligible Web sites that researchers identified in the search, only five were specifically targeted at Asians. Subsequently, researchers extended their searches to other potentially appropriate Internet communities/groups that might have Asians as members and carefully reviewed and identified the target users of each Internet community/group retrieved through the searches.

Scope of Internet Cancer Support Groups

The scope of an ICSG—the number of members, the number of hits per day, and the number of messages posted per week—is another area to evaluate. In the DSCP study, more than 50% of the ICSGs had fewer than 10 members, which is most likely not going to provide an adequate sample for a large epidemiological study. In addition, some ICSGs with a large number of members were not active (ie, no posting for several months, and/or no hits for several weeks). In these ICSGs, the response rate of potential participants was very low. The scope of the ICSG would not be a critical issue for researchers interested in conducting a small pilot study with a small number of cancer patients. However, if a researcher plans a large national or international study, or an epidemiological or population study, an ICSG with a small scope would not be appropriate.

Another challenge that researchers face when evaluating the appropriateness of an ICSG for study announcements would be determining whether underserved populations are active members. In the DSCP study, the researchers found it difficult to identify and recruit ethnic minorities in the ICSGs. This may be because the ICSGs are usually conducted in English only (many ethnic minorities do speak English, but for those for whom English is a second language, or who have not yet

learned English, having English-only Web sites is a barrier). Hargrave et al[8] reported that few Web sites offered information in languages other than English and that readability statistics showed that these sites required an average reading level at US grade level 12+. Consequently, those who did not speak English fluently or whose education level was lower than grade 12 might not participate in most of the ICSGs.

Contents of Internet Cancer Support Groups

The contents of ICSGs also give important information to researchers who are considering specific ICSGs for recruitment of research participants. First, by reviewing the contents of an ICSG, the authenticity of the ICSG could be gauged. As mentioned previously, some of the ICSGs that the researchers contacted in the DSCP study were not actually ICSGs. Rather, they were commercial sites unrelated to cancer patient support.

Researchers also need to evaluate whether information provided by an ICSG comes from reliable sources and whether links provided are to credible resources. In their evaluation of the quality of the content of Web sites providing pediatric neuro-oncology information, Hargrave et al[8] reported that the sources of information were institutional in 46%; commercial, 35%; charitable, 15%; support group, 2%; and alternative medicine, 2%. They also reported that 5% of the Web sites contained one or more inaccuracies. Therefore, the credibility of information provided by ICSGs also needs to be carefully reviewed because that information may provide insight about the credibility of the ICSG itself.

In addition, the content of messages posted in ICSGs needs to be evaluated for accuracy, legitimacy, and timeliness. In a content analysis of postings made in an ICSG, Esquivel et al[9] discovered that there were some false or misleading messages posted on the discussion board. In their study, 10 of 4600 postings (0.22%) were false or misleading. In the DSCP study, only commercial messages had been posted within the past month in 10% of the ICSGs, indicating that they might not be active.

It is also important to determine whether Web sites that host ICSGs are regularly updated and that the information they provide is current. In the DSCP study, about 30% of the ICSGs reviewed had not been updated for several years. According to the bulletin boards in these ICSGs, they had been active in the past, but members had disappeared, resulting in few updates and poor maintenance. Some ICSGs had pornographic contents posted in their discussion boards, and others were actually matchmaking sites (especially, those retrieved using key words such as "African American," "Hispanic," and "Asian"). Very few ICSGs (about 2.5%) included disclaimers stating that information posted on their Web sites may not be current or correct.

Logistics for Study Announcements in Internet Cancer Support Groups

In the DSCP study, the following questions related to the logistics of posting a study announcement in an ICSG were used to determine if the specific ICSG was appropriate for the study announcement: (1) Does the ICSG charge a fee to post a study announcement? If so, how much is it? (2) Are there any extra or hidden charges? and (3) Is anything else required of the researcher to post an announcement? In the DSCP study, most ICSGs managed or administered by a cancer patient did not request a fee to post a study announcement. Some nonprofit ICSGs requested a donation in lieu of a fee. In these cases, the researchers needed to request an invoice from the ICSG stating that a donation was solicited instead of a fee. Some ICSGs requested a very high fee for posting a study announcement (eg, $5000–$10 000). In two cases, the ICSGs requested that the researchers provide a banner for the study announcement. One ICSG helped the researchers develop the banner. The other ICSG required an additional fee for the banner, so the researchers withdrew their request to post a study announcement.

Dynamics Within Internet Cancer Support Groups

The dynamics among the members of an ICSG need to be evaluated as well. Any evaluation of the dynamics in an ICSG needs to include a review of its level of activity. In the DSCP study, researchers reviewed the messages posted in each ICSG before requesting that a study announcement be posted. Some ICSGs were obviously dominated by just a few members, often close friends of the Web owner/administrator. Some ICSGs were dominated by just one member—usually the Web owner/administrator. These ICSGs would not be worth the time because only one or a few participants could be recruited from them. Thus, the researchers requested to post study announcements only through ICSGs with more than 10 members.

Credibility and Authenticity of Web Owners/Administrators

Scrutinizing the identity and qualifications of the owner/administrator of an ICSG is also important in selecting ICSGs for study announcements. In the DSCP study,

researchers asked the following questions to ensure credibility and authenticity of Web owners/administrators: (1) Are they a healthcare professional or cancer patient? (2) What are their qualifications to serve as a Web owner/administrator of the ICSG? (3) Do they provide appropriate and adequate contact information? (4) Are they easily contacted? (5) Are there any problems in their interactions with the members of the ICSG? and (6) Are there any issues in communicating with the research team?

An ICSG may be only as credible and authentic as its owner/administrator is. If researchers cannot trust the Web owner/administrator, then that ICSG would not be good for recruiting research participants. In the DSCP study, there were several cases in which the credibility and authenticity of the Web owner/administrator were questionable. In one case, the owner/administrator of an ICSG claimed to be a cancer patient when he was contacted by the research staff member for the study announcement. Then, during the data collection process, the administrator himself posted a message saying that he was not actually diagnosed with cancer. The administrator only believed that he was a cancer patient without having had a proper diagnosis of cancer, which raised a question about the authenticity of that specific ICSG as well as about the authenticity of the administrator.

CONCLUSIONS AND IMPLICATIONS

Despite the increasing number of ICSGs in cyberspace, virtually no guidelines are available to researchers who wish to recruit research participants by announcing the study in ICSGs. In this article, a set of criteria for evaluating ICSGs for recruiting research participants is proposed. The findings reported in this article (with the evaluation criteria) support many of the findings from other studies about ICSGs. There was a lack of clarity in the definitions of public and private domains. Some ICSGs were generally limited to close friends or family members. A number of ICSGS were inactive or dormant. Some ICSGs charged a high fee to post study announcements. Some Web owners/administrators were inauthentic and were not trustworthy, thus impacting the quality of the ICSGs they sponsored. As in previous studies,[2,6,9] it was also found that the quality of ICSGs was variable, depending on the Web owner/administrator. These findings clearly support the need for continued development of the criteria to evaluate ICSGs for study announcements to recruit research participants, and the evaluation criteria that are proposed in this article are a first step toward developing them. Yet, because these criteria were developed based on only one study, and the Internet environment and its dynamics change daily, evaluation criteria need to be further developed and refined through future studies.

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