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Internet Communities for Recruitment of Cancer Patients into an Internet Survey: A Discussion Paper

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Abstract

The purpose of this paper is to provide future directions for the usage of Internet communities (ICs) for recruitment of research participants based on issues raised in an Internet survey among 132 cancer patients. 317 general and 233 ethnic-specific Internet Cancer Support Groups and 1,588 ethnic-specific ICs were contacted to recruit cancer patients. Research staff recorded issues and wrote memos during the recruitment process. The written memos and records were later analyzed using content analysis. The issues included: (a) difficulty in identifying appropriate ICs and potential participants, (b) meta-tags, (c) dominant white and women groups, (d) dynamics inside ICs, (e) difficulty in trust building, and (f) potential selection bias. The findings suggest that researchers thoroughly review the ICs' information, be recognizant of potential gender and ethnic issues and current trends in Internet interaction, and consider potential selection bias.

Keywords

Internet Communities; Cancer Patients; Recruitment; Internet Research

What Is Already Known About This Topic?

- Psychological and sociological studies have indicated the effectiveness of Internet communities (ICs) as a research setting, a research intervention, or a data collection method.

What This Paper Adds?

- This paper will add the information on the effectiveness of research recruitment through ICs, and issues and challenges in the recruitment through ICs.

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The Internet has made it possible for millions of people worldwide to exchange information and interact with each other [1]. Millions of people are connecting themselves and their families to the Internet through their personal computers, telephone lines, and usually a portal company such as America-On-Line.[2] Kraut et al. posited that interpersonal communication is the number one use of the Internet at home.[3] Baumeister and Learly mentioned that one of the most basic interpersonal needs is belonging to a group of people with similar interests and goals who value the person as a member, and having friends, and close, intimate relationships.[4] Tesser, Martin, and Cornell supported other basic interpersonal needs met by having positive feelings about oneself and a sense of self-worth.[5]

Partially due to these interpersonal needs, a number of Internet communities (ICs) have been established on the Internet, that include chat rooms, message boards, newsgroups, and e-mail lists [6]. In this paper, ICs mean a variety of social groups interacting via the Internet. The number of people participating in ICs is substantial and growing rapidly [2]. The Internet's potential for multi-way information transmission is one reason for the increasing number of ICs because they provide a mechanism for the formation of shared interest groups or communities.[6] Hagel and Armstrong posited that the notion of community has been at the heart of the Internet since its inception.[7]

ICs are similar to organizational communities in that they allow for social interaction among members using various Internet tools and exhibit certain community standards and rules.[8] Hagel and Armstrong proposed four types of members' needs that ICs meet: (a) interest, (b) relationship building, (c) transaction, and (d) fantasy. According to them, ICs are formed by individuals with shared interests, expertise, and passions in a wide range of areas such as interior design, sports cars, or bird watching. Also in ICs, social and personal element are strongly developed because ICs are formed by individuals who often encounter a need to share a particular intense life experience such as the death of a loved one, divorce, or the diagnosis of a life-threatening disease [7–10]. The major transaction of ICs is the exchange of information and support [7–10]. Some ICs also provide people with the opportunity to explore new identities in imaginary worlds of fantasy [7–10].

Psychological and sociological studies have recently indicated the effectiveness of ICs as a research setting, a research intervention, or a data collection method [11–15]. However, very little is known about the effectiveness of recruitment through ICs, and issues and challenges in the recruitment through ICs have rarely been discussed. Especially, very little is known about the feasibility of recruiting cancer patients through ICs.

The purpose of this paper is to provide future directions for the usage of ICs for recruitment of research participants based on issues raised in the recruitment process of an Internet survey study among cancer patients. First, the recruitment process of the Internet survey is concisely described to provide background information on the recruitment issues that are the focus of this paper. Then, the method used to explore the recruitment issues is described, and the issues in recruiting cancer patients for the Internet study are discussed. Finally, future directions for the usage of ICs for research projects are proposed based on the discussion on the issues.

Recruitment Process

The purpose of the study was to develop a standardized decision support computer program (DSCP) (an expert system) that can be used by nurses as an assessment support tool for dealing effectively with gender and ethnic differences in cancer pain experiences based on cancer patients' own views and experiences. This study utilized a cross-sectional design with two simultaneous segments: (a) data collection including an Internet survey and online forums; and (b) development of the DSCP. In this paper, only the issues raised in the recruitment process

of the Internet survey in the first phase are presented. This study was approved by the Internet Review Board of the University of Texas at Austin.

The Internet survey was conducted among online cancer patients in the U.S. "Being online" meant that the patients were familiar with the Internet as a medium of communication and had regular access to e-mail and the web. To recruit participants for the Internet survey, 317 general (not ethnic specific) Internet Cancer Support Groups (ICSGs), 233 ethnic-specific ICSGs (ICSGs specific for ethnic minorities including African Americans, Asians, and Hispanics), and 2,059 ethnic-specific Internet communities (ICs) (websites for ethnic-specific churches, community centers, cultural centers, profit and non-profit organizations) were contacted through their Web sites/pages, and those who agreed to cooperate were asked to announce the study through the Internet and e-mail system (see Tables 1 & 2). These ICSGs were specifically contacted because all members were supposed to be cancer patients. Ethnic-specific ICSGs and ICs were contacted separately from general ICs as recent studies have indicated that ICs including ICSGs usually serve highly educated, more affluent, White males who tend to have easy access to computers and the Internet [16–18]. Thus, in order to reach an adequate number of ethnic minority cancer patients online, it was essential to contact ethnic-specific ICSGs and ICs.

General and ethnic-specific ICSGs were searched using the key words, "cancer," "support," and "group," through five major Internet community/group sites: Yahoo.com, Msn.com, Google.com, AOL.com, and ACOR.org. Through the search process, a total of 918 general ICSGs and 1,968 ethnic-specific ICSGs were retrieved. After retrieving the website addresses, each of the retrieved ICSGs was visited, and their eligibility was determined based on their content (e.g., bulletin boards for cancer patients, chat groups for cancer patients, information resources specific for ethnic minorities). When ICSGs included content related to cancer support, they were regarded as eligible ICSGs. Through this process, 317 general ICSGs and 233 ethnic-specific ICSGs were found to be eligible ICSGs.

Ethnic-specific ICs were also searched using key words of "group," "community," "ethnic minority," "African-American," "Asian," and "Hispanic" through three major Internet search engine sites: Yahoo.com, Msn.com, and Google.com. A total of 2,059 ICs were retrieved, and 1,588 ICs (632 for African Americans, 222 for Asians, and 734 for Hispanics) were found to be eligible through the search process. Each of the retrieved ICs was also visited, and their eligibility was determined based on their content (e.g., bulletin boards for ethnic minorities, chat groups for ethnic minorities, information resources specific for ethnic minorities). When ICs included content related to support and/or information for ethnic minorities, they were regarded as eligible ICs.

Among the contacted general ICSGs, only 33 general ICSGs posted the announcement with a fee or without a fee. Among the contacted ethnic-specific ICSGs, 14 ethnic-specific ICSGs agreed to announce the study, yet only 5 posted the announcement with a fee or without a fee. Among the contacted ethnic-specific ICs, only 13 agreed to announce and post the study announcement.

The Internet survey (a total of 126 items) included self-administered questions on sociodemographic characteristics (8 items), ethnic identity (10 items), and disease status (8 items), Verbal Descriptor Scale (1 item), Visual Analog Scale (1 item), Wong-Baker Faces Pain Scale (1 item), McGill Pain Questionnaire-Short Form (17 items), Brief Pain Inventory (15 items), Memorial Symptom Assessment scale (32 items), and Functional Assessment of Cancer Therapy Scale (33 items). For the Internet survey, a Web-site was developed and maintained while conforming to the guidelines and policies of the HIPAA regulations and the SANS/FBI recommendations. Potential participants who saw the study announcement through

general ICSGs, ethnic-specific ICSGs, and ethnic-specific ICs were asked to visit the project website (the website address will be added here). When they visited the project website, they were asked to get a copy of the informed consent sheet, provide their consents by clicking the 'I agree to participate' button through the Web-site, and answer the Internet survey questions by entering their answers through the Web-site. The participants were informed that data collected through the Internet survey would remain confidential unless a participant appeared at risk for harm. It took about 30 to 45 minutes for a participant to complete the survey. By announcing the study through all the ICs including the general and ethnic-specific ICSGs and ethnic-specific ICs; a total of 361 visited the project website and only 132 participants who were screened to be eligible for the study, have completed the Internet survey. The participants who completed the study included 107 Whites, 12 Hispanics, 10 Asians, and 3 African Americans.

Method

Throughout the recruitment process of the study, research members recorded issues in recruiting ethnic minorities as they arose and wrote memos regarding the recruitment issues and possible reasons for the issues. Weekly group discussions were conducted, and written records of these discussions were kept. The literature related to the raised issues was also carefully reviewed throughout the research process. The written memos and records were reviewed and analyzed using the content analysis method suggested by Weber [19]. 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.

Findings

The recruitment issues included: (a) difficulty in identifying appropriate ICs and potential participants, (b) potential issues related to meta-tags, (c) dominant white and women groups, (d) dynamics inside ICs, (e) difficulty in trust building, and (f) potential selection bias. The recruitment issues that were found through the recruitment process are discussed as follows according to the six idea categories.

Difficulty in Identifying Appropriate ICs and Potential Participants

During the Internet search of ICs, it was difficult to identify which websites could be defined as general, ethnic-specific ICSGs, or ethnic-specific ICs. Many terms including "online groups," "virtual communities," "online forums," "online discussion groups," "electronic mailing lists," bulletin boards," "electronic newsgroup networks," etc, were being used to refer to the ICs. In addition, research assumes authentic interactions between researchers and research participants [20] but it was difficult to determine whether the participants of the ICs were the real cancer patients for whom the researchers were searching. Also in question was the authenticity of the interactions and the phenomenon reported and/or explored through the ICs. Thus, it was just assumed that all the participants recruited through ICs were real cancer patients based on their self-report, always cognizant of the possibility that some participants were not genuine cancer patients. They might be the family members living with cancer patients, they might pretend to be cancer patients out of interest, or because they are seeking fun [10]. Actually, it was found during the online forum discussion that one participant who completed the Internet survey was not an actual cancer patient who was medically diagnosed. He was just thinking that he had cancer because of his risky life styles.

Despite the use of Internet search engines to search for the ICs, most of the ICs retrieved using the Internet search engines were not relevant to our inquiry as reported in previous studies [21, 22]. About 80% of 1,588 ethnic-specific ICs retrieved through Google.com, Yahoo.com,

and Msn.com were not concerned with ethnic minorities despite their claims. This finding supports the previous finding by [23] Tsai et al. in their analysis of ethnic specific Internet groups of cancer patients: nearly 90% of the retrieved websites were not intended for specific ethnic minority cancer patients [23].

Approximately 10% of the retrieved websites, furthermore, had disappeared by the end of the recruitment process, which was also reported in previous studies. Tan, Foo, and Hui claimed that a certain percentage of websites would disappear over a reference period [24]. Among 105 websites that were analyzed, 4% of websites disappeared and 50% of websites were changed in a one-month period. Carmichael also indicated that websites' links might frequently change or disappear over night [22].

Potential Issues related to Meta-Tags

Some of the ethnic-specific ICs (ranging from 10–20% depending on the ethnic group) that were retrieved through the Internet search process using the Internet search engines contained sexual content. These sites were found listed along with female prevalent ICs that focused on emotional or informational support for women. This finding was supported by Finke who found nearly half of the Internet entries advertising female pornography when "women and the internet" were queried as a title [25]. Finke further claimed that the same type of harassment and sexual exploitation of women found in actual communications can be found in these virtual communications and related this to the libertarian culture of the Internet [26]. Regardless of the search engine or title query that was used to locate ethnic-specific ICSGs and ICs; unsolicited, vulgar, and distasteful websites were sometimes placed in a relatively high ranking on the search engine's result pages. Since the focus of the paper is given to the feasibility of recruiting cancer patients through ICs rather than gender-specific issues such as sexuality on the Internet, we did not further explore the sexuality issues in this paper. However, it was certain that these kinds of gender-related and sexuality issues were prevalent on the Internet. [27, 28]

Questions arose about the ranking process utilized by the search engines and the use of "meta-tags". Meta-tags mean HTML elements used to provide structured metadata about a web page, and these HTML elements are placed as tags in the head section of an HTML document (http://en.wikipedia.org/wiki/Meta_tag). Internet search engines continue to struggle with ranking web pages that enable individuals to research their subject more quickly and effectively, thereby encouraging the use of that specific search engine. Yet, the ethnic minority title pages queried were often ambiguous and key terms in the content section did not clearly describe the web page or site. This ambiguity was possibly the result of competition by websites to gain top rankings on search engines to obtain more "hits" [26, 29]. This ranking allowed the websites to be viewed more often, even if the website was advertising something unrelated to the individual's query. Ranking by the websites is crucial to these "hits" and advertisers have used various tactics to increase their rankings on the search engine results pages from "meta-tags" to listing various websites with the same content or product. The "meta-tags", no longer in popular use by most search engines, still provided an opportunity for some websites to gain an unfair advantage by using hidden "tags" of information in specific sections of their web page submitted to search engines that would increase their rankings on search results[30]. It is unlikely that all of the unsolicited advertising through the search results will disappear as it offers a non-paid listing for these websites and increases the "hit" potential [31].

Dominant White and Women Groups

Ethnic and gender imbalance in ICs was an additional recruitment issue. As described above, among ICSGs that were determined as eligible, 233 were ethnic-specific ICSGs, however, most of the eligible ethnic-specific ICSGs were, in fact, general ICSGs that targeted Whites, and

only 24 ICSGs were actually ethnic-specific ICSGs. Also, among 2,059 ethnic-specific ICs retrieved through the Internet, only 1,588 ICs were actual ethnic-specific ICs (see Table 2).

Gender imbalance was also prevalent in ICs. An ICSG can be easily placed into one of three groups according to its gender specificity: (a) general ICSGs aimed at both men and women; (b) ICSGs for women (e.g., breast cancer groups, ovarian cancer groups, cervical cancer, endometrial cancer group); or (c) ICSGs for men (e.g., prostate cancer group) [10]. When ICSGs were divided into the three categories, it was found that more women-only ICSGs (about 80%) exist than ones for men (20%), which supported recent findings by Wei et al [32]. This is an interesting finding perhaps from recent initiatives supporting women's health research, particularly increasing funding opportunities for breast cancer research [10].

Dynamics inside ICs

The overall participation rate of the IC members in discussions through the message boards of the ICs was very low, and there were many postings about chatting groups that were held by the ICs. Because of the very low response rates of webmasters to the study announcement emails, the ICs were re-visited to see individual group dynamics. Through the revisits, it was found that many of the ICs were inactive or the Internet users tended to converse in chat rooms. Individual members of Aol.com or Msn.com preferred to communicate their thoughts and/or experiences in these chat rooms because of immediate responses or feedback from other members currently logged into the chat room. The message boards of the ICs were found to be mainly utilized for posting advertisements or announcement messages from the site owners or webmasters [10]. Yet, the chat groups were not publicly accessible or visible as were the message boards.

The messages in bulletin boards and chat groups tended to be dominated by only a few participants. On the message board of *Cancer Survivor Online*, 5 to 7 members dominated the discussion board. Except for these dominant members; the participation rate of other members tended to be very low. Most ICs did not provide individual members' e-mail addresses unless the researcher became a member of the ICs and when emails were sent to the retrieved email addresses, about 50% of the individual emails were bounced because of blocking by spam filters and/or the email addresses were inactive or incorrect. Im et al's analysis of ICSGs suggested that even if updated, current individual e-mail addresses were available; it might be difficult to motivate potential participants to open, read, and respond [10]. These non face-to-face interactions through electronic communication could be easily ignored, assumed to be spam mail, and/or remain unopened [10].

It was also found that individuals tended to join several related ICs at the same time. As a result, individual emails that the researchers sent for the study announcement were duplicated, and individuals who were members of multiple Internet groups/communities received several emails with the same content and could also be misinterpreted as spam mail.

Difficulties in Trust-building

Difficulties in trust building have been reported as a major inhibitor to all self-report studies. In all self-report studies, researchers need to assume that the participants are eligible candidates for their studies based on their personal self-reports. In the case of Internet research, trust building is a more difficult aspect of recruitment because Internet interactions are based on non face-to-face interaction [33]

In the study reported here, there were challenges in establishing trust with the webmasters and potential participants. ICs are usually owned by an individual or a small group of administrators, and ICs tend to give their owners significant control over who can contribute

to their group [13,18]. The owners who are frequently web-masters can review all requests and messages, deny access to anyone's 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 websites [33]. Therefore, to recruit research participants through ICs, it was very important to build trust with the webmasters. First of all, it was difficult to find contact information on most of the websites. Five of the webmasters who were contacted were concerned about the main research study, although many of them were willing to announce the study with or without a fee. In three cases the webmasters requested minor changes to the study announcement to attract the participants' attention. A few of the webmasters themselves visited the project website, reviewed all the materials on the web, and sent their feedback on the project website to the researchers before announcing the study through their ICs. In two cases, the fee that the webmasters requested was too high (one requested $5,000; and the other requested $10,000) despite the researchers' clarification that the study was not a commercially sponsored study. The study announcement requests were rescinded from these two websites because of their exorbitant fee requirements.

A second factor that influenced the trust-building between the researchers and the potential participants was spam mail. Since the U. S. Government enacted the CAN-Spam Act of 2003 that requires e-mailers to be truthful in their subject lines [34], the researchers sent out the study announcement with the subject lines of "Internet survey study on cancer pain." According to the definition of the CAN-Spam Act of 2003, the study announcement emails were not spam. However, each IC had its own policies that defined spam and many states had already enacted legislation related to spam mail with provisions related to definitions of commercial electronic mail, prohibitions relating certain electronic mail messages, unsolicited mail messages, deceptive trade practices, and civil or criminal liability [35]. Consequently, many of the study announcement emails were identified as spam mail and were filtered before reaching the potential research participants. To prevent the filtering, the researchers were required to redefine their email as nursing research, and the study announcement and subject line of the email were rewritten several times to assure potential participants that these emails were not spam or commercially related.

Potential Selection Bias

As in other Internet studies, potential selection bias was a critical issue to consider throughout the recruitment process. The existing Internet studies have reported inconsistent findings on the response rate. Some reported a moderate to high response rate (45% to 96%) in Internet recruitment [9, 36–38] while others reported a low to very low response rate (0.3% to 19%) [39–41]. As discussed above, the study reported in this paper showed a very low response rate of the webmasters to the emails asking their cooperation to the study announcement. The response rate of general ICSGs was about 10%; that of ethnic-specific ICSGs was about 6%; and that of ethnic-specific ICs was less than 1% (see Tables 1 & 2). The low response rate of the webmasters was potential selection bias to the study. Characteristics of the webmasters and/or ICs that responded to the researchers' requests were possibly different from those of the webmasters and/or ICs that did not respond to the researchers' requests.

Studies have indicated that to recruit research participants as an outsider of the communities where potential participants belong, the researchers need to establish professional relationships with key informants and/or gate keepers for the success of accessing and recruiting individuals into research projects [42]. The research staff's lack of previous relationships with most of the ICs was considered a possible reason for their lack of responses. However, considering the large number of ICs, it was practically impossible to build trust with the ICs in advance.

The existing Internet studies, furthermore, have reported that Internet populations tend to be a selected group of people [33, 43] and White male dominance in online interactions has been reported [16,44]. Although recent studies have indicated changes in Internet populations [43,

[45], in the study presented in this paper, most of the participants who were recruited through the ICs were highly educated White cancer patients. Indeed, the researchers had recruited the targeted number of White cancer patients through the ICs without any problems. This implied that researchers focused on recruitment of ethnic minority cancer patients through the ICs pay particular attention to the recruitment process and potential selection bias.

Conclusion and Implications

This paper indicated several recruitment issues to consider when using the ICs to recruit cancer patients. The issues included: (a) difficulty in identifying appropriate ICs and potential participants; (b) potential issues related to meta-tags; (c) dominant white and women groups; (d) dynamics within ICs; (e) difficulty in trust building; and (f) webmasters' lack of response and selection bias. Many of the ICs were not the ICs that they claimed to be, and many of the ICs disappeared during the recruitment process. Regardless of the changes in indexing, all of the search results retrieved using several Internet search engines were found to contain some degree of inappropriate ethnic minority sexual contents in their listings, possibly related to meta-tags. The researchers found more women-only ICs compared with the men-only ICs, and very few actual ICs for ethnic minorities. The ICs themselves were suffering from their members' lack of participation, and trust building with the webmasters of the ICs was a critical factor to consider in the recruitment process. The recruitment through the ICs allowed for achieving the targeted number of White cancer patients, but not ethnic minority cancer patients, which implies potential selection bias. Based on the issues discussed above, this paper concludes with the following implications for future research using the ICs as recruitment settings.

First, researchers should review the ICs' information before starting recruitment through the ICs in order to ensure that the ICs are those that serve the study's targeted population. As discussed above, there exist some potential issues related to meta-tags, and Internet searches using the currently available search engines frequently result in a list of inappropriate ICs that the researchers did not intend to retrieve. Also, a number of researchers have recently raised an issue related to the information provided by the ICs, and suggested a formal processes of review and approval of the ICs' contents so that Internet users can ensure the accuracy of the information [22,46, 47]. However, there is no way to ensure the accuracy of the information provided by the ICs, which may make it difficult for researchers to obtain appropriate information about the ICs.

Second, researchers need to be aware of potential gender and ethnic issues embedded in the Internet interactions. Researchers may easily and unknowingly incur selection biases. Also, researchers need to be recognizant of potential power issues in the Internet interactions and try to build trust with potential participants and potential gatekeepers (usually webmasters of the ICs).

Third, researchers need to be recognizant of current trends in Internet interactions. As discussed above, the members' lack of participation in the ICs was noticeable despite literature reporting them to be very active. Internet interactions continue to be a dynamic process and without an understanding of current trends in Internet interactions; it will be difficult to plan effective recruitment strategies through the ICs.

Finally, researchers need to consider potential selection bias related to recruitment through the ICs. Digital divide has recently been pointed out in Internet research as the inequality between technology "haves" and "have nots" [48]. The "have nots" frequently include ethnic minorities. As reported above, the White cancer patients were easily recruited through the ICs without any problems; but were unable to obtain the targeted population of ethnic minority cancer patients

through the ICs, perhaps as a result of the current Internet digital divide. In other words, the ICs are still being predominately utilized by Whites. Discounting or not recognizing this digital divide in the usage of the ICs might lead researchers to overlook this potential selection bias.

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Table 1

A Summary of Retrieved Websites of Internet Cancer Support Groups (ICSGs)

Searching Engines	Yahoo.com		Google.com		MSN.com		ACOR.com		Aol.com		Total	
	General ICSGs	Ethnic-specific ICSGs	General ICSGs	Ethnic-specific ICSGs	General ICSGs	Ethnic-specific ICSGs	General ICSGs	Ethnic-specific ICSGs	General ICSGs	Ethnic-specific ICSGs	General ICSGs	Ethnic-specific ICSGs
Total Retrieved Webs	280	950	303	728	150	290	150		35		918	1968
Eligible Websites	75	148	102	59	24	26	109		7		317	233
African-A		6		0		2						8
Asian-A		5		0		3						8
Hispanic		0		0		0						0
Diverse ethnic		7		0		1						8
General		130		59		20						209

Table 2

A Summary of Retrieved Websites of Ethnic-Specific ICs (Internet Communities)

Search Engines	Total Retrieved Webs	Eligible Websites		Actual Ethnic-Specific ICs
MSN.com, Google.com, Yahoo.com	2,059	African-A Asian-A Hispanic	632 222 734	8 8 8
Total	2,059		1588	24