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Internet Recruitment of Asian American Breast Cancer Survivors

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Abstract

The purpose of this paper is to identify practical issues in Internet recruitment of racial/ethnic minorities by analyzing an Internet intervention study conducted with Asian American breast cancer survivors, and to propose directions for recruitment of racial/ethnic minorities for future Internet research. Six practical issues were identified: (a) a relatively fewer number of Internet communities/groups; (b) hindrances in establishing authenticity; (c) difficulties in gaining entrée from the webmasters or website owners of Internet communities/groups; (d) the necessity of racially/ethnically matched research team members; (e) flexibility required in recruitment strategies; and (f) strategies to overcome the low response rate.

Keywords

Recruitment; Racial/Ethnic Minority; Asian American; Breast Cancer Survivors; Internet; Issues

With an increasing number of Internet-based studies, the Internet has become an important research medium and/or setting.¹ The benefits of the Internet as a recruitment setting have been documented with many other assets of the Internet as a research medium for educational interventions/tools, tutorials, survey methods, or focus group discussion.^{1–3} As a synchronous and asynchronous communication channel, the Internet certainly provides new

social and cognitive research space and methods.⁴⁻⁷ In addition, Internet recruitment has greatly expanded the pool of potential participants and accessibility to hard-to-reach participants, such as those suffering from rare diseases or diseases that one would want to discuss anonymously.^{1,8-10}

Despite the significant potential of the Internet as a research medium and/or setting,¹¹ a number of researchers have pointed out various issues in recruiting specific populations through the Internet.¹²⁻¹⁴ One of the recruitment issues is the difficulty in recruiting racial/ethnic minorities into research projects.¹³ Indeed, it could be even more complicated and difficult to recruit racial/ethnic minorities in Internet research than in traditional research because of inherent characteristics of Internet interactions and skewed sociodemographics of Internet users.^{15,16} For example, Internet interactions are typically not face-to-face interactions. Thus, the racial/ethnic identity of research participants must be determined mainly based on their self-reports.^{15,16} Although the sociodemographic composition of Internet populations has changed throughout the past decade, Internet users are still weighted toward selected groups of people such as high-income, highly educated Whites.¹⁷ Furthermore, with recent changes in Internet dynamics, people have become increasingly suspicious of the study announcements posted in Internet communities and groups.^{15,16} It is therefore important to identify strategies for successful recruitment of racial/ethnic minorities into Internet research. Effective strategies will enable researchers to recruit the desired sample size of research participants within the planned timeline in order to successfully complete the studies on racial/ethnic minority health.¹⁸

The purpose of this paper is to identify practical issues in Internet recruitment of racial/ethnic minorities by analyzing the issues identified in an Internet intervention study among Asian American breast cancer survivors, and to propose directions for recruitment of racial/ethnic minorities for future Internet research. By discussing the challenges involved in recruitment of racial/ethnic minorities in the Internet intervention study, this paper is expected to help researchers avoid many of the pitfalls of racial/ethnic minority recruitment in Internet research. First, some of the practical issues in Internet recruitment of racial/ethnic minorities that have been reported in the literature are concisely described. Then, the study that was the basis for the issues discussed in this paper is concisely summarized, and the method used to analyze the recruitment issues is described. The practical issues identified through the analysis are then discussed. Finally, suggestions for future recruitment of racial/ethnic minorities in Internet research are proposed based on the identified issues. In this paper, the federal definitions of race and ethnicity are used.^{19, 20} Thus, race refers to a social definition of race recognized in the U.S. and is not defined biologically, anthropologically, or genetically. The racial categories subsequently include racial and national origin or sociocultural groups. From 1997, the Office of Management and Budget (OMB) mandates federal agencies to use at least five race categories: White, black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or other Pacific Islander. Also, ethnicity refers to a social definition of ethnicity, and the OMB mandates federal agencies to use at least two ethnicities: "Hispanic or Latino" and "Not Hispanic or Latino." Here, Hispanic or Latino refers to "a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race."^{19, 20} Thus, rather than using separate categories of race and ethnicity, we use categories of race/ethnicity that

combine the federal and OMB definitions: non-Hispanic White, Hispanic, non-Hispanic African American, and non-Hispanic Asian Americans.

Issues in Internet Recruitment of Racial/Ethnic Minorities for Research in the Literature

The practical issues in Internet recruitment of racial/ethnic minorities that have been reported in the literature can be roughly categorized into the following four major issues: (a) authenticity, (b) trust-building, (c) low response rates, and (d) selected groups of racial/ethnic minorities.

Authenticity of the Participants

During the beginning stage of the Internet era, it was believed that Internet interactions would make the physical markers/characteristics of Internet users (e.g., race, gender, status, and age) irrelevant due to nature of their non-face-to-face interactions.²¹ However, as Internet usage became increasingly prevalent, it turned out that gender, race, and age could be prominent even in Internet interactions. Although people generally cannot see each other (setting aside exceptions such as video chatrooms and Skype), the social categories based on physical characteristics become apparent in Internet interactions through people's opinions, attitudes, and values related to specific phenomena and/or situations.^{15,16}

Despite the fact that people's physical markers/characteristics can be obviously reflected in Internet interactions, Internet recruitment of racial/ethnic minorities still depends on each individual's self-report. With advances in computer technologies and the use of cameras, face-to-face interactions have become easier than ever. However, even when a camera is used for Internet recruitment, it may often still be difficult to identify people's specific characteristics. For example, some researchers might have difficulties differentiating a Korean from a Chinese. Furthermore, racial/ethnic identity could be complicated by multiple complicated factors as seen with the recent case of Rachel Dolezal (the White woman who identified as a Black).²² In her case, although both of her biological parents were non-Hispanic White, she self-identified herself as a non-Hispanic African American and was even elected as the head of Spokane chapter of the National Association for the Advancement of Colored People (NAACP), which raises questions on how to deal with the cases where the person's self-identified race/ethnicity is different from that perceived by the society.

Trust-Building

Even in traditional research, contacting and building trust with informal leaders of a racial/ethnic-specific church or interest group has been emphasized as an important step in recruiting potential participants from racial/ethnic minority groups.²³ Researchers sometimes need to hire same-race gatekeepers as recruiters.²⁴ Trust-building in Internet research has also been an issue in recruiting research participants through the Internet.^{15,16} Im and Chee^{15,16} found that the moderators/owners of the Internet communities/groups for Chinese Americans rarely responded to a research assistant from a different racial/ethnic

group. However, when a Chinese research assistant with a Chinese name contacted the same Chinese Internet communities/groups, the research assistant received a prompt response.

Low Response Rates

Low response rates in Internet research have frequently been reported in the literature. In racial/ethnic minority research, some reported that direct recruitment strategies (e.g., face-to-face recruitment, massive personal mailing) worked better than indirect strategies (e.g., announcements through mass media, including newspaper, radio, and television).^{18, 25} Others reported that indirect recruitment strategies worked better than direct strategies.²³ In Internet recruitment, researchers have found direct recruitment to be effective so far.^{15,16} However, considering recent changes in Internet interactions (e.g., an increasing number of spam emails), it is not clear if a potential participant would open a study announcement that is directly emailed to them or if they would be willing to participate in a study announced by a stranger through emails.

Selected Groups of Racial/Ethnic Minorities

Recent reports on characteristics of Internet users provide an optimistic view of Internet recruitment of racial/ethnic minorities. The use of Internet by Asian Americans is reported to be greater than that of any other racial/ethnic groups. Furthermore, 68% of U.S. Hispanics and 71% of African Americans are Internet users.^{26, 27} Also, more than 76% of women in the U.S. are Internet users.²⁶ Although there have been concerns about the lack of women with low socioeconomic status on the Internet, recent studies indicate that 62% of women with annual household incomes less than \$30,000 are on the Internet and 83% of women with annual household incomes ranging from \$30,000 and \$50,000 are on the Internet.^{26, 27} The availability of mobile devices could also increase the generalizability of Internet research. Over 66% of Asians, 56% of Hispanics, and 55% of African Americans are smartphone users while about a half of each racial/ethnic group is tablet users.²⁷ Despite these recent changes, Internet populations are still a selected group of people (e.g., young, White, educated, wealthy, literate, and skilled computer users).^{1, 28, 29}

The Study as the Case Example

The pilot study, which was used as the case example in this paper, aimed to determine the preliminary efficacy of a culturally tailored Internet cancer support group for Asian American breast cancer survivors. The Internet cancer support group for Asian American breast cancer survivors aimed only at three sub-ethnic groups including Chinese, Korean, and Japanese. More detailed information on the study itself can be found elsewhere.^{30, 31} The study had two phases. In Phase 1, an expert review among six experts in breast cancer survivorship and a usability test among four Asian American breast cancer survivors (who were recruited from among the participants of the previous study by the research team) were conducted. Phase 2 used a randomized repeated measures pretest/posttest control group design among 57 women recruited through Internet communities/groups and physical communities/groups. The participants were breast cancer survivors aged over 21 years, who could read and write in English, Mandarin Chinese, Japanese, or Korean, had a breast cancer diagnosis during the past 5 years, and included all immigrant generations. The participants

were recruited through Internet communities/groups and local cancer clinics and organizations throughout the U.S. The retention rates were about 50% across the sub-ethnic groups by the end of the 3-month intervention, which is similar to other Web-based studies in the literature.^{32–34} The control group was asked to use only the Internet resources related to daily life (e.g., news in Asian countries, Asian businesses in the U.S.) and the American Cancer Society website while the intervention group was asked to use both the Internet cancer support group and the Internet resources (those related to daily life and those by the American Cancer Society).

Methods to Identify the Issues

To identify practical issues in recruitment of Asian American breast cancer survivors, we analyzed the memos and written records (e.g., research meeting minutes/memos) on issues that were discussed and recorded by each of the research team members. Throughout the research process, the research team held weekly group meetings, discussed emerging issues in the study, and recorded any recruitment issues in the minutes of the research team meetings as they arose. Individual team members' individual memos on the issues and possible reasons for the issues were also saved. Then, the memos and written records were reviewed and analyzed using the *content analysis technique* suggested by Weber.³⁵ Individual words were the unit of analysis. First, the memos and written records were coded using line-by-line coding. Then, the codes were categorized according to the content. Finally, idea categories were developed from the categorization process, and themes reflecting the practical issues in recruitment of Asian American breast cancer survivors were extracted.

Practical Issues in Internet Recruitment of Asian American Breast Cancer Survivors

Through the analysis, we identified the following six practical issues in Internet recruitment of Asian American breast cancer survivors: (a) a relatively fewer number of Internet communities/groups; (b) hindrances in establishing authenticity; (c) difficulties in gaining entrée from the moderators/owners of the Internet communities/groups; (d) the necessity of racially/ethnically matched research team members; (e) flexibility required in recruitment strategies; and (f) strategies to overcome the low response rate. The issues are discussed in detail below. Table 1 also summarizes the issues with implications for future research.

A Relatively Fewer Number of Internet Communities/Groups

Based on previous Internet studies on cancer patients, we expected that there would be numerous Internet communities/groups for Asian American breast cancer survivors, including general and racial/ethnic-specific Internet cancer support groups. In our previous study,³⁶ when we searched Internet cancer support groups, we found 1,968 Internet cancer support groups through Yahoo.com, Google.com, and MSN.com. However, when we searched the same search engines for this study, the number of Internet cancer support groups that we retrieved was significantly different from the number we retrieved previously. Furthermore, with a larger number of search engines including Yahoo.com, Google.com,

Bing.com, Aol.com, Ask.com, Wow.com, and Facebook groups, we just found 171 Internet breast cancer support groups. Among these support groups, about 62% did not have clear contact information for the webmasters or website owners; 58% were closed to only website members; 18% had cancer-related information postings only without any chat rooms or discussion boards; and 8% were dormant (no postings in the last 10 years).

A plausible reason for this decreased number of Internet cancer support groups would be recent changes in Internet interactions. People have become more cautious in their Internet interactions with strangers, and many people have thus lost interest in Internet communities/groups. Instead, people communicate with others through social networking sites such as Facebook and Twitter, using messaging functions rather than online forum functions, which make Internet interactions more private and confidential. Thus, we expanded our study announcement sites to include social networking sites such as *Facebook* and *WeChat*. However, it was still difficult to get the attention of potential participants through the Internet. For example, we made a study announcement through *Facebook*, and the statistics at *Facebook* indicated that the study announcement had reached to 8,283 potential participants, but yielded only 69 website clicks (clicks on our study website).

Hindrances in Establishing Authenticity

As discussed above, establishing authentic interactions in Internet recruitment is an important aspect that we needed to consider in our recruitment process. Internet communications are typically based on non-face-to-face interactions, and potential participants could be suspicious about our attempts to contact them. Asian American communities, in particular, tend to be closed to outsiders. As a result, it was difficult to get any response from the communities. Furthermore, it was also difficult to ascertain the authenticity of members' claims of belonging to a particular racial/ethnic group because they typically did not use their real names. Although some usernames could imply their racial/ethnic identity (e.g., usernames including common surnames of a specific race/ethnicity), it was still difficult to identify the potential participants' exact races/ethnicities because the links between usernames and races/ethnicities were unclear in most cases.

In several cases, we were also not sure about the authenticity of potential participants who self-identified as Asian American breast cancer survivors. For example, Phase 1 happened to include a White woman who later claimed that she did not recognize that the study focused on Asian American breast cancer survivors. In the process of participant reimbursement, we found that she was not an Asian American and subsequently communicated with her regarding her eligibility for the study. She agreed that she would not be eligible for the study and asserted that she did not know that it was a study focusing on Asian American breast cancer survivors. Thus, although we compensated her, we had to exclude her data.

Difficulties in Gaining Entrée from the Moderators/Owners

In the literature on racial/ethnic minority research, gaining entrée into a research setting through key gatekeepers is suggested as an essential component of the research. Furthermore, identifying and contacting key gatekeeper(s) who could allow or decline the researchers' access to the research setting are essential in racial/ethnic minority research.²⁴

Even in racial/ethnic minority research using traditional research methods (e.g., face-to-face surveys, interviews, etc.), contacting racial/ethnic minority groups to recognize and gain access to key gatekeepers is the first essential step.^{24, 37, 38} Subsequently, gaining and building trust with key gatekeepers has been highlighted for effective recruitment of racial/ethnic minorities.²³

In the study we have reported in this paper, key gatekeepers were webmasters or website owners of the Internet communities/groups as they were the first-line people we needed to contact. To recruit participants, Internet communities/groups for cancer patients and/or survivors as well as those for racial/ethnic minorities were searched between September and October of 2014 using the Google, Yahoo, AOL, Bing, Ask, and Wow search engines and Facebook groups. The identified communities/groups were initially visited online and verified against the evaluation criteria for Internet cancer support groups suggested by Im et al.³⁹ Then, a total of 171 verified Internet communities/groups were contacted and asked to post the study announcement. Only 6 among the 171 Internet communities/groups agreed to post the announcement. The webmasters/website owners of most Internet communities/groups (165 among 171) never responded to our e-mail.

As mentioned above, a plausible reason for this low response rate among the webmaster/website owners would be recent changes in Internet dynamics. With an increasing number of spam emails, the contact emails sent by researchers could be easily ignored. In the worst case, our emails could have been filtered by firewalls, which means they never reached the contacted gatekeepers and were automatically reported as spam emails. On the other hand, the low response rate can also be explained by the findings of previous studies on barriers to recruitment of racial/ethnic minority participants.⁴⁰ Webmasters or website owners and potential participants may distrust researchers or may not want their web users to be disturbed by research studies. In this study, a web master refused to announce the study because she did not want her members of the community to be “used” only as research subjects.

The Necessity of Racially/Ethnically Matched Research Team Members

As mentioned above, in recruitment of racial/ethnic minorities, gaining entrée into a research setting is important.²⁴ In our study, gaining the permission of the gatekeepers (web masters or website owners) was especially essential because the study was mainly announced through the Internet communities/groups where Asian American breast cancer survivors might participate. Although our initial attempt to contact the web masters or website owners did not work, we finally succeeded in getting permission from some web masters or website owners by using racially/ethnically matched research team members. Interestingly, Korean Internet communities/groups responded to Korean research assistants, and Chinese Internet communities/groups responded to Chinese research assistants. When they were contacted in their own language, the web masters or web owners were more likely to respond to the contact emails. One Chinese web owner never responded to the contact emails from a Korean or a Chinese research assistant that were written in English. However, when she was contacted by a Chinese research assistant via an email written in Chinese, she promptly responded to the contact email and announced our study to her Internet community/group

members. Potential participants also seemed to feel more comfortable when approached by research team members from their own racial/ethnic groups, and they thus tended to be more willing to help the research team members from their own racial/ethnic groups.

Flexibility Required in Recruitment Strategies

In racial/ethnic minority research, flexibility has been emphasized regardless of the study design.⁴⁴ In the study used as the case example in this paper, flexibility in the recruitment process was essential to recruit the targeted number of research participants. Because our original plan to recruit only through the Internet communities/groups did not enable us to recruit the target number of Asian American breast cancer survivors (only five Asian American breast cancer survivors were recruited through the original recruitment strategies), it was essential to change the recruitment plan.

To improve our recruitment, we chose to adopt flexibility in recruitment strategies as previous studies have suggested.^{10, 23} First, based on brainstorming among research team members and subsequent consultation with five experts in Asian American health and breast cancer survivorship, we extended the recruitment settings to local community clinics and community centers for Asian Americans across the nation. Also, through our consultants, we contacted local hospitals working with breast cancer survivors to announce the study across the nation. However, the actual number of Asian American breast cancer survivors in each hospital tended to be small (4 to 5 Asian American breast cancer patients per year), and it was difficult to recruit the research participants through only the hospitals. Thus, based on brainstorming among research team members, we also contacted cancer registries throughout the nation. However, only three offered help for study announcements through their lists. For each cancer registry, we needed to go through its own IRB approval process to get their cooperation for recruitment although we only asked them to announce the study through their email list or mailing list. Once we sent our IRB protocol to the contact person at each registry, she/he submitted the IRB protocol and obtained the approval for the study announcement on behalf of the research team. One of the registries required a high fee that could not be paid by a pilot grant, so we announced the study only through two registries. Additionally, we reached out to three cancer support groups in local communities via phone calls because they did not have a website or a contact email. Of the contacted stakeholders, two forwarded our study announcement to their department chairs for approval, and one circulated our study announcement to their members by e-mail. Through these new recruitment strategies combining Internet settings and physical community settings, we could recruit the target number of the participants.

Strategies to Overcome the Low Response Rate

As mentioned above, at the beginning stage of Internet research, researchers expected that recruitment through the Internet would be easier compared with traditional recruitment through physical communities/groups because of the nature of Internet communication (e.g., high speed, flexibility, easy access to potential participants, etc.).²¹ However, in our study, it was difficult to recruit Asian American breast cancer survivors only through the Internet communities/groups, and the response rate of potential participants only through these

channels was very low (0.2 %). To calculate this response rate, we recorded the number of e-mails that were sent to recruit participants and tracked the returned e-mails.

One plausible reason for this low response rate is that many potential participants who were members of the Internet communities/groups might be inactive members. They may have joined the communities/groups a long time ago when the communities/groups were active. The interactions could have diminished over the time, and thus they might not visit the communities/groups anymore. Furthermore, they might not have opened the study announcement e-mails from their communities/groups because of an increasing amount of spam e-mails.

Another plausible reason could be potential participants' unfamiliarity with Internet research or lack of their own computer skills. While many potential participants sent emails or called research team members and indicated their interest in participating in the study, they shared that they were hesitant to participate in the study because they were worried about their computer skills (e.g., typing in English, logging in and navigating the study website, etc.). The research team members explained in detail regarding what the participants would be required to do on the Internet and reassured that they would need just basic computer skills. The research team members also needed to assure that the research team members would be available and responsive if they had any questions about using the study website.

Implications and Conclusions

Based on these issues, we propose the following implications for recruitment of racial/ethnic minorities for future Internet research. First of all, considering the low number of Internet communities/groups for Asian American breast cancer survivors and the lack of response from webmasters or website owners of the Internet communities/groups, participant recruitment only through the Internet might not work anymore. We suggest that hybrid recruitment strategies, using both Internet and physical communities/groups, would work much better for recruitment of racial/ethnic minorities than those using only Internet communities/groups. We also suggest that researchers use multiple recruitment sources to contact racial/ethnic minorities as in traditional research among racial/ethnic minorities.⁴⁰ Researchers need to consider a broad scope of potential pools of racial/ethnic minorities, such as websites and blogs for racial/ethnic-specific churches, community centers, local businesses, associations, and organizations. Researchers also need to be flexible in their recruitment strategies and use creative recruitment and retention strategies.

Second, the difficulty in ensuring authenticity is still an inherent weakness of Internet research. With recent advances in Internet technologies, including computer accessories like digital cameras and microphones,⁴¹⁻⁴³ we can now engage in face-to-face interactions and recruitment through the Internet. However, this approach still has a feasibility issue because the entire process could depend on the participants' computer knowledge and skills as well as their access to computers and Internet. To adequately and appropriately deal with authenticity issues in Internet research, researchers need to regularly update their own knowledge and skills related to Internet interactions and technologies in various ways.

Frequent and careful monitoring of research process, including data collection and management process, would also help identify unauthentic cases.

Finally, we suggest that researchers use racially/ethnically matched research team members to contact Internet communities/groups for participant recruitment. In our study, it was obvious that racially/ethnically matched research team members received prompt responses from the gatekeepers and participants. Even in traditional research among racial/ethnic minorities, the use of racially/ethnically matched research team members has been strongly suggested and widely used.³⁶

In this paper, practical issues in recruiting Asian American breast cancer survivors through the Internet were identified by analyzing an Internet intervention study among Asian American breast cancer survivors. The issues included those related to a relatively fewer number of Internet communities/groups, difficulties in ensuring authenticity, a lack of response from the moderators/owners, the necessity of racially/ethnically matched research team members, flexibility required in the recruitment process, and a very low response rate. Based on the discussion on the issues, we proposed several implications for recruitment of racial/ethnic minorities for future Internet research.

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Table 1

Practical issues in Internet recruitment of Asian American Breast Cancer Survivors and implications for future research

Issues	Implications
A relatively fewer number of Internet communities/groups Difficulties in gaining entrée from the moderators/owners of the Internet communities/groups Strategies to overcome the low response rate	Hybrid recruitment strategies using both Internet and physical communities/groups Multiple recruitment sources to contact ethnic minorities Considering a broad scope of potential pools of ethnic minorities Flexibility in recruitment strategies and the use of creative recruitment and retention strategies
Hindrances in establishing authenticity	Regular updates of knowledge and skills related to Internet interactions and technologies in various ways Frequent and careful monitoring of research process
The necessity of racially/ethnically matched research team members	The use of ethnically/culturally matched research team members
Flexibility required in recruitment strategies	Flexibility in recruitment strategies and the use of creative recruitment and retention strategies