Published in final edited form as:

Comput Inform Nurs. 2018 September ; 36(9): 424–429. doi:10.1097/CIN.0000000000000450.

What to Consider in a Culturally Tailored Technology-Based Intervention?

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Abstract

The purpose of this article is to identify practical issues in implementing a culturally tailored technology-based intervention among Asian American survivors of breast cancer. In a large-scale technology-based breast cancer intervention study, research team members wrote memos on issues in implementing a culturally tailored technology-based intervention and plausible reasons for the issues. Then, the content of the research diaries was analyzed, along with written records of the research team. The practical issues found in the research process included those related to: (1) technology literacy and preferences; (2) language issues; (3) cultural attitudes, beliefs, and values; (4) intervention staff competence; (5) security and confidentiality issues; and (6) time and geographical constraints. Based on the issues, several recommendations are proposed for future research using culturally tailored technology-based interventions among racial and ethnic minorities.

Keywords

Internet; technology; culturally tailored; intervention; issues; challenges; discussion

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Conflicts of Interest: None of the authors have any conflicts of interests to report.

BACKGROUND AND SIGNIFICANCE

Over the past 2 decades, the Internet has evolved from a way of using and transmitting documents to a method of providing content around the world.^{1–5} In recent years, with advances in computer and mobile technologies, several interventions using these technologies have been developed and widely adopted,^{6–11} even for racial and ethnic minority groups. In 1999, when use of the Internet was evolving as a new method in research, Senior and Smith¹² categorized Internet research into three major groups: (1) resource locators, (2) demographic surveys, and (3) empirical investigations. Now, a new category of behavioral interventions must be added.

In the beginning, the Internet was frequently used in healthcare as a resource locator or a demographic survey tool,^{13–16} yet providers rarely used the Internet as an intervention method.⁷ Now, thanks to easy, around-the-clock access, Internet-based interventions are being adopted and used as a medium for health-related interventions in an increasing number of studies. For instance, Bosak et al.¹⁷ tested the effectiveness of an Internet education program to increase physical activity among adults with metabolic syndrome. Chen and Yeh¹⁸ determined the efficacy of an Internet-based smoking cessation program among adolescents. Despite the increasing number of studies adopting the Internet as an intervention medium, its use for culturally tailored technology-based interventions is still relatively new to healthcare providers and researchers.⁷

As an essential component of technology-based interventions for racial and ethnic minority groups, cultural tailoring has been adopted, tested, and widely used in recent years.^{19–21} In contrast to generic programs, tailored programs can incorporate specific cultural aspects of racial and ethnic minority groups.^{22,23} Subsequently, culturally tailored programs can serve the special needs of a racial or ethnic minority group more efficiently than generic programs.^{22,23} Despite increasing availability, little is known about practical issues that researchers must consider when implementing a culturally tailored technology-based intervention in healthcare. A few publications have discussed general issues in Internet-based research,^{24–27} but a literature search using PubMed found no articles that discussed the specific practical issues of using computers and smart phones for culturally tailored technology-based interventions.^{24–27} Rather, the articles focused on methodological issues in conducting quantitative or qualitative descriptive studies using the Internet as a data collection method.^{24–27}

OBJECTIVE

The purpose of this article is to discuss practical issues in the implementation of a culturally tailored information and support program for Asian American survivors of breast cancer, and to provide directions for future research using culturally tailored technology-based interventions for racial and ethnic minority groups. First, the study that is the basis for the discussion is described; then, the method used to identify the practical issues is presented. The findings on practical issues follow the method section. Finally, implications for future research using culturally tailored technology-based interventions are proposed based on the issues.

THE STUDY: THE BASIS FOR DISCUSSION

The purpose of the study that was the basis for this project was to examine the efficacy of a culturally tailored technology-based intervention that was intended to improve survival rates among Asian American patients with breast cancer. The Institutional Review Board-approved study included only three sub-ethnic groups of Asian Americans: Chinese, Koreans, and Japanese. Chinese participants represented the largest sub-ethnic group,^{15, 16} Korean participants represented the most rapidly increasing sub-ethnic group,^{15, 16} and Japanese participants represented the sub-ethnic group with the highest risk of breast cancer among Asian Americans.^{17–20}

The study used a randomized, controlled, repeated-measures, pre- and post-test design. The target number of participants was 330 Asian American survivors of breast cancer, who were recruited through online support groups and communities. While the intervention group was asked to use the culturally tailored program and Web site on breast cancer by the American Cancer Society (ACS) for 3 months, the control group was asked to use only the ACS Web site for 3 months.

The intervention had three culturally tailored components: (1) three social media sites with chat function, specific to each sub-ethnic group; (2) culturally tailored online education sessions; and (3) culturally tailored online resources. All components were provided in four languages, including English, Mandarin Chinese, Korean, and Japanese. Culturally matched nurses (e.g., Chinese RN for Chinese participants) moderated the social media sites during the intervention using culture-specific examples from previous studies conducted by the research team (e.g., stigma attached to cancer, heavy burden of household work despite the disease). The education sessions were tailored to incorporate culture-specific information for each sub-ethnic group (e.g., acupuncture among Chinese, red ginseng among Koreans). The online resources included both general and specific sub-ethnic resources available in the U.S. and in the participants' countries of origin (Mainland China, Taiwan, Korea, and Japan).

The instruments included 14 questions on background factors (e.g., gender, education, religion, family income), and eight questions on disease factors (e.g., general health, diagnosis of breast cancer, length of time since diagnosis, and stage of cancer). Instruments used to measure outcome variables included the Support Care Needs Survey-34 Short Form,²¹ the Memorial Symptom Assessment Scale---Short Form,²² and the Functional Assessment of Cancer Therapy Scale---Breast Cancer.²³ All the instruments had established reliability and validity for Asian Americans; Cronbach's alphas were .76 to .96. The data analysis was conducted using an intent-to-treat linear mixed-model growth curve analysis.²⁴ The study is ongoing; more details are available in a separate publication.²⁸

MATERIALS AND METHODS

During the research process, team members kept records of meetings, memos, and diaries on practical issues in conducting a culturally tailored, technology-based intervention among Asian American survivors of breast cancer. A content analysis was conducted on these

documents to extract themes. Meeting minutes were usually one to two single-spaced pages; the team met approximately each week for 1 year (38 meetings), and approximately 40 pages were included in the analysis. Memos, written after a research encounter with a participant, were from one to three pages for individual encounters. Although encounters were recorded with participant permission, the memos were not transcriptions. Approximately 180 pages of single-spaced memos (26 to 80 pages per five team members for 1 year) were written as narratives, bullet points on recruitment and retention progress, and challenges. These materials were analyzed by an expert in qualitative research using Weber's content analysis method,²⁷ and codes and themes were reviewed and finalized through multiple meetings among the research team. Individual words in the minutes and diaries were used as the unit of analysis, with a line-by-line coding method. Then, categories representing practical issues were constructed, and six themes were extracted from the codes.

PRACTICAL ISSUES

Technology Literacy and Preferences

At the beginning of the Internet era, lack of literacy in technology was a major issue even for researchers.²⁹ For instance, in 1999, Bush et al.²⁹ reported that the major barrier to the use of a customized Web site for a breast and cervical health outreach program was lack of literacy among staff. In 2000, Duffy²⁹ reported that lack of technological literacy among researchers was a major barrier to the use of the Internet as a data collection method. Although computer and mobile technologies have advanced, and we expected that lack of technological literacy would not be a problem, the situation has not changed drastically. Both research team members and participants had difficulty with the technology-based intervention.

Because the intervention was designed to allow access through computers or smart phones, we thought that those without computers would not have problems in using the project Web site. However, some participants who used smart phones were not able to log in to the Web site or were uncomfortable using the software. Participants wanted to use familiar social networking site (SNS) applications (e.g., WeChat among Chinese participants from Mainland China, Line among Chinese participants from Taiwan and Japanese, Kakaotalk among Korean participants) to communicate with the researchers and view educational modules and links to Internet resources. All the SNS applications provided similar functionality: voice dictation, instant messaging, and free telephone calls, which allowed participants to communicate easily for individual coaching and support. Thus, the original plan to use the project Web site for coaching and support had to be changed.

Email communication also did not help; most participants did not have, or rarely checked, email accounts. Even though they were asked to create accounts, participants rarely responded to emails from the research team. Some participants withdrew from the study because of lack of computer literacy. In many cases, the research team had to guide participants through the intervention and surveys step by step while using the participants' preferred SNS apps and/or over the telephone. Consequently, peer discussions through the project Web site were simply impossible.

Language Issues

To tailor a technology-based intervention to a specific cultural group, use of the group's native language is essential. As mentioned previously, four languages were used: English, Mandarin Chinese, Korean, and Japanese. Although the technological adoption of multiple languages into the intervention was accomplished easily, the four languages could not sometimes cover the diversities within languages. For instance, even among Chinese Americans, their languages were different depending on their geographic point of origin. Traditional Chinese was used for Chinese immigrants who came from Hong Kong and Taiwan, while simplified Chinese was used for immigrants from mainland China. However, even the use of simplified and traditional Chinese could not accommodate all Chinese Americans; for instance, people from Hong Kong and Guangzhou, who constituted a large portion of early Chinese immigrants, spoke only the Cantonese dialect. Depending on the immigrant generation, translators selected different words to translate the same information with different sentence structures. Furthermore, whenever study materials were revised (e.g., informed consent), revisions in all language versions were needed, with subsequent IRB approvals, which had to be uploaded to the project Web site. This process required time and effort that was not anticipated at the beginning of the study.

All Asian languages incorporate phonetic translations, but this was more prominent in Japanese; when a specific word does not exist or the exact translation of the word is difficult, *katakana* (direct phonetic translation) is usually used instead. In addition, if a specific word in the language has some attached stigma, it is likely that the foreign term will be phonetically translated. For example, "survivor" or "survivorship" are not familiar concepts or terms in Japan, and the general word for "survivor" has negative connotations in Japanese. Thus, the phonetically translated word for "survivor" is generally used in the oncology setting in Japan, although some use the Japanese translational word for "survivor."

Cultural Attitudes, Beliefs, and Values

Although researchers tend to think of Asian culture as one culture,⁴⁰ there are more than 50 ethnic groups in China alone.⁴⁰ Despite the diversity, there are some commonalities across different sub-cultures. Confucianism, once prevalent in most Asian sub-cultures, aims at the unity of the self and *Ti n* (the traditional high god), which consequently directs people to live in harmonious relationships.⁴¹ Similar to Confucianism, Buddhism and Taoism, which are also bases for Asian culture, stress harmonious relationships between humans and nature, and intend to establish a balanced, orderly, and peaceful world.⁴² This cultural heritage predisposes Asian Americans to avoid conflict and uncertainty while pursuing harmonious relationships.

We found this tendency among participants; they were reluctant to discuss their personal experience and issues, and subsequently tended to give only positive and socially desirable answers. Even through the SNS apps, participants rarely discussed their experiences, although identity was shielded. There is a well-known stigma attached to breast cancer among Asians, so they rarely discussed their disease with others.^{30–34} However, since Internet communication is not conducted face to face, it has been reported to be effective for those with stigmatized conditions.^{2,35–39} The findings from this study did not support the

effectiveness of asynchronous interactions in persuading participants to disclose their personal experiences to others. When the participants give only socially desirable answers, it could be a source of systematic bias.⁴³ Thus, in this study, the research team emphasized that the participants could share any experience, their sharing would be kept confidential, and their experience would help other survivors.

Intervention Staff Competence

Another practical issue was difficulties in recruiting, training, and retaining competent staff for the intervention. Originally, we planned to use RNs who were bilingual in English and one of the three languages, culturally matched to the three sub-ethnic groups included in the study, and competent in using computers and smart phones. However, due to unexpected difficulties in identifying bilingual RNs in the local area where the study was conducted, qualifications for prospective team members had to be changed several times, finally settling on those with an associate or bachelor's degree in a health-related discipline. Nevertheless, the quality of the intervention was not compromised, because the research team developed a protocol to provide a standardized intervention. The protocol comprised templates and forms that could be used at each step of the intervention and each time point (i.e., at baseline, and 1 month and 3 months after the intervention). Although intervention staff members were expected to follow the protocol, they had some degree of latitude to modify it as needed.

Another issue relevant to staff competence was that participants often raised questions that were not directly related to breast cancer (e.g., family conflicts, religious issues). Sometimes intervention staff found it difficult to deal with complicated questions asked by the participants about their health and emotional issues. The general consensus was that participants were not asking for perfect solutions to their problems; rather, they might just need someone who could listen. When staff members identified participants who had serious physical and emotional health risks, they were referred to two medical experts on the team for a consultation. In addition, intervention staff attended biweekly support group meetings throughout the research period where they could express their stress and frustration, and provide professional and personal support to one another. The regular support meetings were perceived as beneficial in many aspects by intervention staff. Often, they encountered different issues depending on the participants to whom they provided coaching and support, but they usually had similar challenges (e.g., recruitment) and temporary resolutions. They took advantage of the support meetings to encourage each other and better understand study participants.

Security and Confidentiality Issues

From the beginning of the Internet research era, human subjects protection has been discussed.^{23–26} Major issues included informed consent, how to ensure privacy, copyright requirements, ethics and policies in Internet research, unanticipated consequences, and the impact of Internet information on future research.^{23–26} As a result, efforts were made to develop standardized guidelines for human subjects protection in Internet research around the world.^{22, 27} Despite these efforts, national or international standardized guidelines for human subject protection in Internet research are not readily available,²² and even standardized institutional guidelines rarely exist. For this study, we used existing national

guidelines related to Internet research, including the Health Insurance Portability and Accountability Act (HIPAA), the SysAdmin, Audit, Network and Security (SANS)/Federal Bureau of Investigation (FBI) recommendations, and the Ubuntu Linux security updates.

As described above, the project Web site was housed on the institute's central servers, so it was considered safe with regular updates and upgrades and careful monitoring by institutional staff. However, when some potential participants tried to enter the project Web site, they reported security messages indicating that the Web site was unsafe (e.g., delays in security certifications during regular updates). Subsequently, when they were contacted by research team members, they chose not to participate because they were afraid of losing their privacy. Although issues relating to security and confidentiality could happen in any technology-based intervention, these issues were especially important to this culturally tailored intervention because of the previously discussed cultural hesitance among Asian American survivors of breast cancer.

Time and Geographical Constraints

Because of the difficulty in recruiting an adequate number of Asian American survivors of breast cancer in the area where the study was conducted, participants were recruited nationally. A national approach meant that there were issues related to time and geographical constraints. Because the research team was in a Southeastern area of the U.S., potential participants in other geographical areas did not trust contacts. Often, we found that potential participants who promised the gatekeepers that they would join the project declined to participate when the research team contacted them directly.

At the beginning of the Internet research era, researchers were excited about the fact that potential participants could respond more promptly through the Internet, and time zone and geographical differences would not be barriers in using the Internet for research studies.¹⁷ However, after an increased number of studies using the Internet, many researchers have described issues with timing.^{8,39,44–46} In our study, time zone differences between the participants and intervention staff often interfered with implementation. Most participants worked during the day; as a result, they requested coaching and support sessions in the evening, often outside the working hours of intervention staff. Despite the benefits of personalized coaching and support, such a problem could result in participant burden, which raised questions about the sustainability of the intervention.

The participants' adherence and retention rates during major holidays (e.g., Christmas, New Year's, Easter, Chinese Spring Festival) and vacations (summer and winter) were also lower than those in non-holiday or vacation time periods. Some participants indicated that they could not participate in the group and individual coaching sessions during specific time periods because of their vacations or trips.

Another issue related to timing and geographical restrictions was that many participants who emigrated from different Asian countries tended to make international trips, which sometimes affected the continuity of the intervention. For instance, one participant was very cooperative in individual coaching and support sessions. After a few weeks, she said that she planned to travel to South Korea for 3 weeks. The research team thought that would be fine

since individual coaching and support could be administered wherever Internet connections were available. However, she preferred to halt the intervention during her visit to South Korea due to her busy schedule and a 13-hour difference in time zones. She resumed participation in the program when she returned to the U.S., but with a different intervention staff member, because while she was away there was a change in the research team. Because the intervention was standardized and there was a research diary that had recorded the participant's previous interactions with the intervention staff, individual coaching and support was started again without difficulty.

SUGGESTIONS FOR FUTURE RESEARCH

Based on the issues identified during the study, we propose the following implications for future research using culturally tailored technology-based interventions. First of all, we propose that researchers conduct a pilot study to prepare a detailed step-by-step information sheet for participants and intervention staff in the use of a culturally tailored technology-based intervention. Also, it is essential for researchers forge connections with computer system administrators and/or network administrators at their institutions, so that all those involved have the most updated information on the technical aspects of the project. In addition, researchers need to be familiar with not only new computer and smart phone technologies used in the research, but also newly reported threats to security and confidentiality derived from such technologies. This can be achieved by attending relevant seminars, workshops, continuing education sessions, panel discussions, and conference presentations.

Second, we suggest that researchers set rules for translation in the early stages of the study, and be flexible in language usage during the implementation process. It is essential for researchers to respond and make decisions promptly when unexpected issues arise with the use of multiple languages. However, at the same time, researchers need to set consistent principles for the translation process and ensure the congruence and equivalency of the content in research materials, as suggested in the literature.³⁷

Third, researchers need to consider possible cultural issues in implementing their technology-based interventions. In the past, researchers thought that cultural issues would not be relevant to asynchronous Internet interactions.^{2,3} However, in this study, cultural values, attitudes, and beliefs were vital to the implementation process. The participants' cultural hesitance was always an issue to consider.

Fourth, researchers need to factor in continuous training of intervention staff throughout the implementation process to provide the participants with appropriate emotional and informational support. We suggest developing a protocol for standardized interventions that includes regular training of staff members, through which intervention quality could be maintained despite varying competencies among intervention staff. As we did in this study, regular support group discussions among intervention staff members may be another useful means for quality assurance, allowing staff to strategize and share ideas. Also, including medical experts in the intervention process is necessary for consultations and useful advice

or resources whenever an immediate action is required to mitigate unexpected participant issues.

Fifth, researchers need to carefully design strategies to ensure the security and confidentiality of the study. Researchers need to check relevant IRB policies related to the use of the Internet in research and meet the requirements in advance. At the same time, researchers need to regularly train intervention staff to ensure security and confidentiality of interactions with participants, and monitor research records to ensure security and confidentiality of information. In addition, building trust with participants is essential to retention.

Finally, we suggest that future researchers consider potential time and geographical constraints, and plan the intervention implementation process around major holidays, weekends, and/or vacations, and time zone differences. Individualized interventions, such as coaching, must be scheduled at times preferable for both participants and staff in order to sustain high quality relationships throughout the intervention process. In this study, intervention staff members frequently arranged their schedules to meet participant needs because recruitment and retention were challenging. A balance between staff workload and participant convenience is essential for the success of the intervention.

CONCLUSIONS

This article discusses practical issues in implementing a culturally tailored, technology-based intervention among racial/ethnic minorities, based on an empirical study among Asian American survivors of breast cancer. Several implications were proposed for future research using culturally tailored technology-based interventions. Findings support the idea that culturally tailored, technology-based interventions would work very well among racial/ethnic minority groups, but future researchers need to consider several practical issues for successful implementation.

Acknowledgments

This study was funded by the National Institute of Health (NCI/NINR; 1R01CA203719-01).

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