Lessons from a Culturally Tailored Technology-based Intervention Study among Asian American Breast Cancer Survivors

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Presenter Disclosures
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No relationships to disclose
Funding Acknowledgement

• The study that provided the basis for discussion on the issues is funded by:
  • the National Institute of Health (NCI/NINR; 1R01CA203719-01).
Asian American breast cancer survivors are more likely to report a lower quality of life. Mainly due to inadequate pain and symptom management.

Technology-based interventions including Internet cancer support groups have been known to be:

- Effective in providing support and coaching;
- Effective in improving survival rates and quality of life; and
- Easily accepted by marginalized populations.
Background

- **Known Challenges in Technology-based interventions**
  - Potential bias in sample selection: capacity of using technology
  - Low controllability of actual usages of the interventions
  - Low retention rates
  - Lack of technological expertise of research team members
  - High development costs

- **The gap in the literature**: Little is still known on practical Issues in Culturally Tailored Technology-based program for Asian American breast cancer survivors.
Objectives

- To provide an open-forum to discuss possible challenges in using a culturally tailored Internet-based intervention program for Asian American breast cancer survivors.

- To propose directions for future research using a culturally tailored Internet-based intervention.
The Study:
A technology-based information and coaching/support program for Asian American breast cancer survivors (TICAA)
• **Purpose of the Study**
  - To test the efficacy of TICAA among Asian American breast cancer survivors.

• **Study Design**
  - A randomized controlled trial.
    - **Control group**: required to regularly visit the American Cancer Society (ACS) website in multiple languages
    - **Intervention group**: required to use both TICAA and the ACS website.
Samples and Settings

• **Samples**: 330 Asian American breast cancer survivors who:
  • Had a breast cancer diagnosis within the past 5 years;
  • Are aged over 20 years old;
  • Are self-identified Chinese, Korean, or Japanese;
  • Can read English, Mandarin Chinese, Korean, or Japanese; and
  • Have access to computers or mobile phones.

• **Settings**: Internet communities/groups and local communities/groups for Asian Americans
Instruments

- Questions on baseline information;
- Personal Resource Questionnaire;
- Perceived Isolation Scale;
- Support Care Need Survey;
- Mishel Uncertainty in Illness Scale;
- Cancer Behavior Inventory;
- Brief Pain Inventory, and Pain Beliefs; and
- Perceptions Inventory.
Data Collection Procedures

- Procedure flow chart

![Procedure Flow Chart]

- Participants (n=330)
  - Consent
  - Screen
  - Randomization
  - Intervention Arm (Interactive online forum, Online education sections, One-on-one coach, Online resources)
  - Control Arm
  - Online resources
  - Baseline Data
  - Post 1-month intervention Data
  - Post-3-month Intervention Data
Methods

1. Research team members wrote individual research diaries.

2. The research team held weekly group meetings to discuss and recorded emerging issues in the study.

3. The memos and written records were reviewed and analyzed using the content analysis technique suggested by Weber
   - Coding → categorization → extract themes
Results and Discussion

1. Technology Literacy
   - Not have a computer.
   - Not want to access the project website.
   - Wanted to use their SNS programs.
   - Not have an email account or rarely checked their emails.

Implications
   - Prepare the information sheet.
   - Get connected with their institutions’ computer system administrators and/or network administrators.
   - Attend related seminars/workshops, continuing education sessions, panel discussions, and conference presentations.
Results and Discussion

2. Language Issues

- Adopted four languages: English, Mandarin Chinese, Korean, and Japanese.
- Not sometimes cover the diversities within languages.
- Phonetic translations in languages.

Implications

- Set the rules for translation at the early stage of the study.
- Need to be flexible in language usages during the implementation process.
Results and Discussion

3. Cultural barriers
   - Confucianism that prescribes people live in harmonious relationships; subsequently, the participants were reluctant to discuss their personal experience and issues and had a tendency to give only positive and socially desirable answers.

Implications
   - Need to consider cultural values, attitudes, and beliefs in its design and implementation throughout the research process.
Results and Discussion

4. Interventionists’ competence

- Unexpected difficulties in identifying bilingual RNs in the local area.
- Needed to change the qualifications of the interventionists (from RN to health-related majors).
- Difficulty to deal with some complicated questions.

Implications

- Need to factor in continuous training of interventionists.
- Develop a protocol for standardized interventions with regular training of interventionists.
- Plan regular support group discussions.
- Include medical experts in the intervention process.
Results and Discussion

5. Security and confidentiality issues
   - Received security messages indicating that the website was unsafe (e.g., delays in security certifications during regular updates)

Implications
   - Carefully design several strategies to ensure security and confidentiality.
   - Check their institutions’ IRB policies.
   - Need to regularly train their research staff.
   - Conduct regular monitoring of the research process
6. Time and geographical constraints
   - Potential participants in other areas did not trust the contacts by the research team.
   - Lower adherence and retention rates during major holidays (e.g., Christmas, New Year’s Eve, Easter, Chinese Spring Festival) and vacations (summer and winter).

Implications
   - Consider potential time and geographical constraints.
   - Considering major holidays, weekends, and/or vacations, and time zone differences.
   - Schedule an individualized intervention.
Conclusions

* This study suggests that researchers need to consider possible challenges in using a culturally tailored technology-based intervention among racial/ethnic minorities.