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Cultural and Linguistic Adaptation of an Evidence-Based Tailored Navigation Intervention to Increase Cancer Screening Uptake Among Southeast Asian Women

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Abstract

Background: Southeast Asian immigrant women in the U.S. have high rates of breast and cervical cancer, yet they are the least likely of all racial/ethnic groups to get screened. To address this disparity, we adapted the evidence-based Tailored Intervention Messaging System© (TIMS©), which uses tailored messages and navigation by culturally and linguistically matched community health advisors to overcome barriers to cancer screening.

Objectives: This study describes the cultural and linguistic adaptation of TIMS© to improve breast and cervical cancer screening among Southeast Asian immigrant women in the U.S.

Methods: Guided by Stirman et al.'s adaptation framework, we conducted focus groups and in-depth interviews to identify key constructs related to cancer screening (knowledge, perceived barriers, perceived risk, benefits, self-efficacy). Using the TIMS© and the thematic content from qualitative data, we modified messages for content and context. Messages were divided into three categories: 1) existing messages identified in thematic analyses, 2) existing messages not identified in thematic analyses, and 3) new messages that emerged from thematic analyses.

Results: Contextual and content modifications were made to the TIMS© message library. Messages were translated into Lao, Khmer, and Vietnamese. Through an iterative process, the investigator, community health advisors, and cultural community advisory board members reviewed and revised the messages for translation accuracy, relevance, and clarity.

Conclusion: Using relatable language and context is critical to engaging women from Southeast Asian communities in improving breast and cervical cancer screening uptake. This adaptation approach can be applied to tailor interventions for other languages, cultures, and underrepresented groups.

Plain Language Summary

Southeast Asian women in the United States face a critical health challenge. Despite having high rates of breast and cervical cancer, they are the least likely of all groups to get screened for these cancers. To address this problem, we adapted an evidence-based program called TIMS© that uses personalized messages and community health workers to help women get cancer screenings. To make TIMS© more effective for Southeast Asian women, we needed to ensure it was culturally appropriate and available in their languages. We conducted group discussions and one-on-one interviews to understand what women knew

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about cancer screening, what barriers they faced, and their views on risks and benefits. Using what we learned, we reviewed the program's messages. Some original messages matched well with the women's experiences, while others did not fit their cultural context. We also created new messages based on what we learned from the community. All messages were then translated into Lao, Khmer, and Vietnamese languages. Working with community health advisors and a cultural community advisory board, we carefully reviewed each message to ensure they were accurately translated, clear, and meaningful to Southeast Asian women. This collaborative process helped us create messages that truly resonated with the community. To encourage people to get screened for cancer, programs must speak their language. This approach to adapting health programs could serve as a model for improving healthcare access for other communities as well.

Keywords
cancer screening, breast cancer, cervical cancer, early detection of cancer, cultural characteristics

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Introduction

Screening recommendations have led to early detection and reduced mortality from breast and cervical cancer in the United States (U.S.).[1] However, Asian American women have low cancer screening rates and are at significant risk for both cancers.[2,3] They are less likely to adhere to screening recommendations compared to other groups.[4,5] Breast cancer ranks first for cancer incidence and second in cancer mortality in Asian American women.[6,7] They also have significantly lower Pap test rates (70%) compared to that of Non-Hispanic White women (81%),[8] and screening trends are decreasing.[5]

Of all Asian Americans, Southeast Asian women, including Cambodians, Lao, and Vietnamese, have the highest cancer mortality rates and the lowest screening rates.[9] Barriers to screening include limited access to healthcare services, lack of health insurance, language barriers, cultural beliefs and misconceptions about cancer, fear of the screening process, and competing priorities such as family responsibilities and financial constraints.[4,10-12]

While interventions promoting breast and cervical cancer screening have been tested, a recent systematic review found that none of the interventions employed novel strategies targeting this population.[13] Patient-centered communication strategies can mitigate concerns, fears, and beliefs about cancer screening,[14] but questions remain about existing programs' cost-effectiveness and long-term sustainability.

Tailored messaging systems allow healthcare providers to assess individual health beliefs and deliver patient-centered health messages that enhance motivation and support positive health behaviors. These systems have successfully changed health behaviors[14] and improved cancer screening rates in primary care settings,[15] but their effectiveness in addressing the unique barriers faced by Southeast Asian women remains untested. Menon et al.[16] demonstrated that combining tailored messages with patient navigators improved appointment scheduling and a four-fold increase in colorectal cancer screening in a multicultural sample.

We adapted the evidence-based Tailored Intervention Messaging System© (TIMS©), which incorporates a combination of tailored messages delivered by community health advisors (CHAs) to overcome cancer screening barriers. CHAs, also known as community health workers, promotoras, or lay health workers, are members of the communities they serve. They provide health promotion and education and link communities to services.[17,18] Bilingual CHAs from the Southeast Asian community, specifically Cambodian, Lao, and Vietnamese, delivered the tailored navigation intervention. Navigation activities included scheduling clinic appointments, appling for insurance, and arranging transportation to clinic appointments. Given the low screening adherence among Southeast Asian immigrant women and the success of adapted versions of the TIMS©, we believed a similar program could address cultural and language barriers and improve cancer screening rates.

This paper describes the cultural and linguistic adaptation of a tailored navigation intervention to improve breast and cervical cancer screening uptake among Southeast Asian women in the Midwest. We describe our process and recommendations for future studies. This study was approved by the Institutional Review Board at the Ohio State University (IRB protocol number: 2018B0521).

Methods

TIMS©

The TIMS© is an educational program based on the Health Belief Model, delivered by phone, in-person, or computer[15,19] The TIMS© was initially designed to increase colorectal cancer screening among African American and non-Hispanic White adults.[15,19] The TIMS© uses a library of messages tailored to constructs of knowledge, perceived risks, barriers, benefits, and self-efficacy to change health behavior, specifically cancer screening. The tailored message library is contained within the evidence-based TIMS© program and incorporates a combination of tailored messages delivered either online or in person and navigation by a community health advisor to overcome barriers to complete cancer screenings. The intervention has been subsequently adapted, translated, and tested in trials with diverse populations,

including Hispanic/Latino (colorectal screening),[16] Chinese American (breast cancer screening),[20,21] and Korean American (breast and colorectal screenings) populations,[22] and American Indian.[23]

Using the TIMS© as our baseline and the thematic content from the qualitative study,[24,25] we modified the tailored message library for content and context using Stirman et al.'s framework for intervention adaptation.[26] The Framework for Reporting Adaptations and Modifications-Enhanced (FRAME) is an approach developed and recently expanded by Wiltsey Stirman and colleagues[27] to help researchers identify and report modifications to interventions or implementation strategies—planned and unplanned. The FRAME approach can be used to track and document aspects of the intervention's implementation such as why, when, and where the change occurred; the nature of the change; the target of the change; and, importantly, the goal of the change—for example, to improve effectiveness, increase reach or engagement, or reduce cost.[26,27] We modified context and content of the TIMS© intervention for the target populations. *Contextual* modifications include format, setting, personnel, and population. Whereas *content* modifications include changes to the intervention procedures, materials, or delivery. The areas of adaptation based on Sitrman et al.'s Adaptation Framework are described in Table 1. Working in collaboration with members of the Cultural Community Advisory Board (CCAB) and the CHAs, messages were modified for language and cultural context.

Adaptation of TIMS© for the Southeast Asian Population

Adapting the tailored navigation intervention, TIMS©, for Southeast Asian women involved two distinct studies. In our first study, our exploratory study, we conducted focus groups and in-depth interviews with Khmer and Lao women. Qualitative methods and results have been previously published.[24,25] In brief, we first conducted focus groups with women from two Southeast Asian communities about their barriers and facilitators in getting Pap testing.[25] Dyadic interviews were then conducted with mothers and daughters to understand how these women converse about women's health issues, specifically cancer and getting screened.[24] We selected constructs for tailoring based on data from the focus groups and interviews (details are described below). The current study encompassed adapting the tailored messages and working with the study's CCAB and CHAs to check for relevance, accuracy, and clarity.[28] Figure 1 illustrates our intervention adaptation process.

Cultural Community Advisory Board (CCAB)

We drew on the strength of our previous work with the Southeast Asian community and garnered assistance from our established CCAB to guide our research design and procedures.[29] The CCAB represents key leaders, healthcare professionals, and advocates from the local Lao, Khmer, and Vietnamese communities. The study investigators worked closely with the six-member CCAB from study conception to dissemination to ensure that the study was culturally responsive to the Southeast Asian community. Longstanding engagement with our CCAB members has been described elsewhere.[29,30] The CCAB's role in this study was to identify community assets to support the study, serve as a liaison between the research team and community members, provide guidance on culturally appropriate and relevant measures and data collection procedures, verify the accuracy of professionally translated materials, engage in problem-solving with the research team, and participate in the dissemination of findings.

Development of TIMS© Message Library

We developed themes based on focus groups and in-depth interviews with Southeast Asian women participants.[21,22] Guided by Menon et al.'s process for adaptation of the TIMS© message library,[23] we divided the messages into three categories: (1) Messages in the existing library also *identified* in the current thematic analysis; (2) Messages in the existing library that were *not identified* in the current thematic analysis; and (3) Messages not in the existing library that *emerged* in the current thematic analysis.

The messages are as follows:

Category (1) Messages in the existing library also identified in the current thematic analyses. For this category, we reviewed the messages with the study team (investigators and CHAs) and CCAB and made suggested revisions to phrasing and vernacular specific to Lao, Khmer, and Vietnamese to be included in the final message library. Common constructs that existed in both libraries included: knowledge, barriers, benefits, perceived risks, self-efficacy, and high-risk status.

Example of message:

Perceived Risk: Does not have relative with breast cancer

Message: *Being a woman and growing older puts you at risk for getting breast cancer. Many women who get breast cancer are like you – they don't have a history of it in their family. In fact, 3 out of 4 women who get breast cancer don't have a family history.*

Category (2) Messages in the existing library that were not identified in the current thematic analyses. For this category, decisions to retain the messages and modifications to language and vernacular were based on discussions with the study team and CCAB.

Example of message:

Benefits: Check symptoms (get screened to check symptoms)

Table 1. Areas of Adaptation Using the FRAME.[26]

Classification	Original TIMS©	Southeast Asian Women's Health Project
Contextual		
Format	Computerized messaging; program algorithms to match a specific response with a message; in English only	Written, hard copy and electronic; translated into Lao, Khmer, and Vietnamese
Setting	Primary care clinic	Community setting
Personnel	Trained research assistant	Trained community health advisors (CHAs); culturally and linguistically matched
Population	Adults aged 50 years or older, nonadherent to CRC screening, English-speaking	Women aged 21 years and older; nonadherent to breast and cervical cancer screening; Lao, Khmer, and Vietnamese women
Content		
Procedures	Recruitment in primary care clinic *Intervention Group* received tailored health education messages in the form of text messages *Control Group* received the self-administered computerized survey and no education	Recruitment in community locations *Intervention Group* received tailored navigation 1 week after enrollment up to 10 weeks; 12 and 18 month follow-up *Control Group* received screening guideline information 1 week after enrollment; 3, 12, and 18 month follow-up
Materials	Touchscreen laptop with swivel screens and touch screen pen	Hard copy of the tailored messages in both English and native language; electronic version also available for CHA to use on tablet
Delivery method	On touch screen laptop; data automatically saved; self-paced	Delivered by CHA via phone or in-person
Training and evaluation		
Training	One-day in person training with role play over phone; remote refresher sessions at 1-year interval	3 day in-person training; role play in person and remote sessions; refresher training, in person and remote as needed
Evaluation	Recorded tailored navigation calls were reviewed by study investigators; process evaluations conducted and strategies for improvement were discussed if needed	Recorded tailored navigation calls were reviewed by study investigators; process evaluations conducted and strategies for improvement were discussed if needed

Message: *Symptoms should always be checked by a healthcare provider. By checking symptoms, you can find out what maybe wrong and what you need to do. Most conditions, if caught early can be handled more easily. Not all symptoms are cancer either, so you may find out you don't have cancer which can give you peace of mind.*

Category (3) Messages not in the existing library that emerged in the current thematic analyses. This category includes issues that are unique to Southeast Asian women that were identified from the qualitative study. New themes included refugee experience, post-resettlement experience, relationship dynamics, and social networks. We developed new messages, which

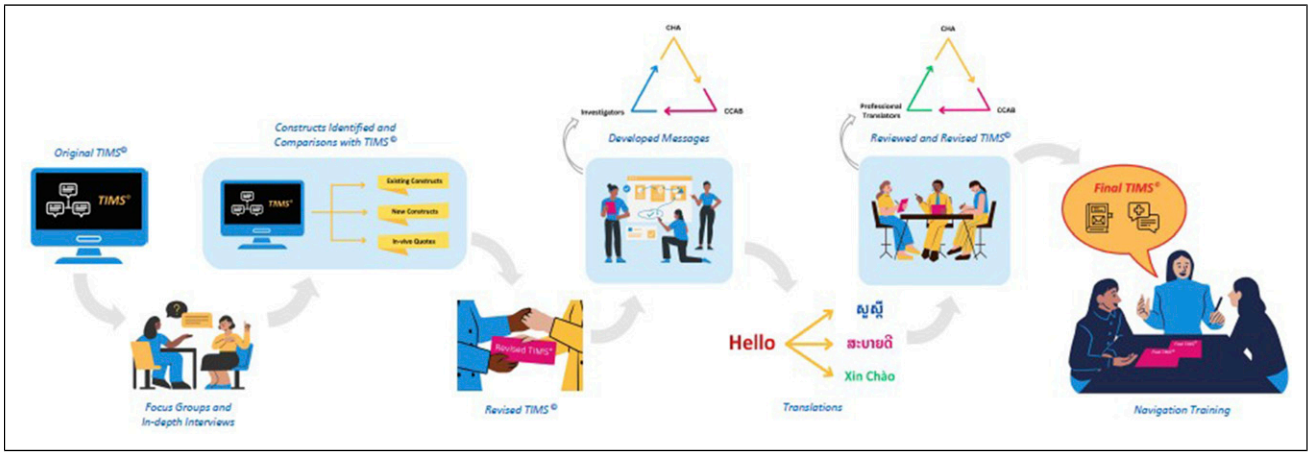

Figure 1. TIMS© Adaptation Process for Southeast Asian Women.

were then reviewed and modified by CHAs and CCAB members.

Example of message related to *Refugee Experience*:

Mistrust of Medical System: Mistrust of medical provider

Message: *It can be scary to go to the doctor if you've had bad experiences in the past. If it makes you feel more comfortable, you can take a family member or friend with you to your appointment. I can also help you find a healthcare provider or clinic that you'll be comfortable going to.*

Example of message related to *Post-resettlement Experience*:

Communication: Language as a barrier

Message: *When healthcare providers don't speak your language, it can be really frustrating. Sometimes, even if they are talking in English, it can be hard to understand all the medical language. You have a right to an interpreter when you go see a doctor. You can always ask to have a female interpreter during your Pap test appointment.*

Results

Type of Modifications

Stirman et al.[26,27] outline the types of *content modification*, which are changes made to the intervention procedures, materials, or delivery. We adapted the intervention originally designed for African American men to improve colorectal cancer screening to specifically address the beliefs and barriers faced by Southeast Asian women in obtaining breast and cervical cancer screening. See Table 1. These modifications were made at the population level, targeting a particular cultural, ethnic, clinical, or social group (contextual modifications).[26] In addition, we created culturally relevant participant profiles, including eligibility information, screening status, knowledge about cancer and screening, beliefs, and barriers, which we used during recruitment role-play training with CHAs.

The content modifications encompassed both cultural and linguistic tailoring of the messages. For example, we included the construct of the unique experiences of refugees and addressed issues related to mistrust of healthcare providers. To encourage mother and daughter dyad communication with each other, we incorporated personal reminder notecards in which a dyad partner would handwrite a personal message of reminder to get a mammogram or Pap test. Additionally, we lengthened the time CHAs would contact participants from the TIMS© of only one touch point to 10 weeks. We understood from our prior research the potential need to extend the amount of time to navigate women to screening in these communities.[31,32]

Message Translation

A professional translation company translated the message library from English into Lao, Khmer (spoken by Cambodians), and Vietnamese. Working together, native language speakers (e.g., Lao CHA and Lao CCAB members) reviewed the tailored messages in both the native language and English and revised messages for accuracy, clarity, and relevance. This was an iterative process between the CHA, CCAB, principal investigator, and professional translator until translated messages were acceptable by the research team and CCAB (see Table 2). The CHA, CCAB, and principal investigator reviewed and revised the messages through in-person and Zoom sessions, followed by e-mail exchanges with the professional translator until consensus was reached on the final translated messages.

Based on the success of our previous work, we took a consensus approach to translating materials.[33] It was essential for us to include CHAs and CCAB members to assist in this process rather than relying on back translation. By including native language speakers, we captured the nuances of not only the language and culture but also the intended approaches and meaning of messages. This insider knowledge from multiple individuals enabled us to be culturally mindful and inclusive of differing perspectives and language variations.

Navigation Training Using Adapted Tailored Message Library

The CHAs practiced extensively using the tailored message library with one another and other volunteers, both in English and their native language. We utilized mock participant profiles for role-play exercises. Each of these profiles contained potential scenarios CHAs could encounter in their respective communities. Using the tailored messages with a role-play volunteer, the CHAs addressed the barriers highlighted in the mock participant profiles. CHAs were evaluated on their performance using a standardized process evaluation form developed and implemented by the study team in prior studies.[15] Each CHA role-play was video recorded on Zoom and used for training. The investigators used the standardized rubric to evaluate the CHA's ability to properly identify barriers, respond to barriers and beliefs, and maintain overall conversation flow and professionalism.[15] A score above 90% indicated that the CHA was ready to begin recruitment and data collection. A score below 90% indicated that the CHA needed additional training or practice. After a week of review and practice the CHA could then be re-evaluated using the same process. The evaluation process was a critical part of our standardized intervention delivery and fidelity monitoring procedures. We incorporated refresher trainings for CHAs as needed.

The results of the clinical trial will be reported in a forthcoming publication. The efficacy of the tailored navigation will be evaluated through completion rates of Pap tests and/or mammograms. This outcome will be assessed through both self-reports by participants and verification of medical record checks. These results will provide critical evidence regarding the intervention's efficacy in improving cancer screening rates among this population.

Table 2. Tailored Message Development Process – Vietnamese Language Example.

Construct	Message development	CCAB[a] and CHA[b] review	Final message	Translation
Perceived Benefit	*We have seen a decrease in breast cancer deaths because it is being found early through screening.* *A mammogram is the best way to find breast cancer. A mammogram takes only 30 minutes to complete. It's the best way to find breast cancer early. Finding breast cancer early can improve your chances for successful treatment and improve your chances of living longer. We will work with you to protect your health.* *Most people who get screened find out that they do not have cancer. But, one of the best ways of finding breast cancer early is by getting a mammogram. Getting a mammogram done can help you have peace of mind.*	*If you notice a lump in your breast or changes in your breast tissue, it should never be ignored. It's really important to get it checked out. Your doctor may have you get a mammogram to check if the lump or change in tissue is cancer or not. A mammogram takes less than 30 minutes to complete. Most people find out that they don't have cancer. It's the best way to find breast cancer early. Finding breast cancer early can improve your chances for getting cured and may help you live longer.*	*Please don't ignore a lump or any changes in your breasts. You should let your provider know and do what is recommended for you. Many times your healthcare provider may say you need to have a mammogram. The mammogram, itself, will take less than 30 minutes for the actual test. Most people find out that nothing is wrong (that is most tumors or growth are not cancer), which can give you peace of mind. Also, most people do not have their breasts removed. Taking control of your health by getting checked early is very good for your long-term health.*	Xin đừng bỏ qua một khối u hay bất kỳ thay đổi nào ở bộ phận vú của quý vị. Quý vị nên cho nhà cung cấp của mình biết và làm những gì được khuyến cáo. Có thể nhà cung cấp dịch vụ chăm sóc sức khỏe của quý vị đã nhiều lần nói rằng quý vị cần phải chụp nhũ ảnh. Quá trình chụp nhũ ảnh sẽ mất chưa đầy 30 phút để kiểm tra trong thực tế. Hầu hết mọi người sẽ phát hiện ra rằng không có vấn đề gì (nghĩa là hầu hết các khối u hoặc chặ tăng trưởng không phải là ung thư), điều này có thể giúp quý vị yên tâm. Ngoài ra, hầu hết mọi người đều không phải cắt bỏ ngực của mình. Kiểm soát sức khỏe bằng cách xét nghiệm sớm sẽ rất tốt cho sức khỏe lâu dài của quý vị.

[a]Cultural Community Advisory Board.
[b]Community Health Advisor.

Discussion

The purpose of this paper was to describe the cultural and linguistic adaptation of a tailored navigation intervention to improve breast and cervical cancer screening uptake among women from three Southeast Asian communities in the Midwest. Southeast Asians are a heterogeneous population that makes up 14% of U.S. Asian American population and is one of the fastest-growing populations in the U.S.[34] Still, they may be overlooked when examining overall cancer morbidity and mortality and engagement in cancer screening intervention research. There is also a tendency to group all Asian immigrants under a ubiquitous rubric of Asian Americans discounting the differences between the many countries that comprise South and Southeast Asia.

From 1988-2013, breast cancer incidence rates among Asian Americans steadily increased at 1.5% annually with Southeast Asian women experiencing the sharpest increase in breast cancer incidence among all Asian American groups.[35] As rates of breast and cervical cancer continue to rise substantially in Southeast Asian Americans,[9,35] early detection and preventive screenings are more important than ever to reduce cancer deaths. Evidence points to the efficacy of culturally tailored navigation interventions to improve cancer screening and early detection among individuals who face obstacles in accessing preventive care.[14,36,37] The benefits of tailored navigation interventions are well documented, offering enhanced personalized strategies to address the unique challenges individuals face in accessing cancer screening.[38] However, implementation of tailored navigation interventions in Southeast Asian communities, specifically Lao and Khmer is still lacking.

Our study's success was largely due to our bilingual and bicultural CHAs who were integral in the adaptation process and later in the study implementation. Our CHAs were fluent in their native language, and all but one of them was a lifelong member of the local communities. The CHAs had little to no research experience; thus, exposure to community-engaged research provided opportunities for them to expand their knowledge and skills and be involved in research in the future. By engaging CHAs to intervene at the individual level, we expected to set a course to make behavior change happen. CHAs who share the same language and cultural background as the priority population can help overcome language barriers and cultural differences, facilitating community engagement in research.[16,29] Participants from communities that do not

normally engage in research may feel more comfortable and trusting when interacting with CHAs who understand their cultural norms, beliefs, and health practices. This rapport can foster community collaboration and buy-in from the target population, leading to greater participation in research and impactful research outcomes. CHAs can also provide valuable insights into culturally appropriate research methods, helping researchers to design studies that are respectful and relevant to the population's cultural context. Importantly, involving CHAs can build research capacity within the community by providing training and skill development opportunities for its members.[33] Research capacity building further fosters the sustainability of community-academic partnerships and future research collaborations.

Together with our CCAB, with whom we have had a long-standing relationship, CHAs and investigators created a culturally and linguistically relevant and acceptable library of tailored messages in three different Southeast Asian languages. The translation, interpretation, and message development process demanded careful attention and dedication, which took some time to complete thoroughly, as evidenced by an iterative process between investigators, research staff, CCAB, and professional translators. We approached translation through a consensus process between all stakeholders to develop the most relevant and impactful tailored messages. In our prior studies, we found this to be an effective and more inclusive method[33,39] and an adaptable approach for other languages.

Implications for Future Interventions and Research

The potential to adapt this approach to other underserved populations facing significant challenges in obtaining cancer screening is substantial. Expanding its application across different cancers and health areas could further enhance its impact. The process used in adapting and implementing the TIMS© should serve as a model for other investigators working with diverse populations. Future research should focus on long-term follow-up studies with the women who participated in the tailored navigation using TIMS© to assess its sustained impact. This will provide valuable insights into the long-term efficacy for broader application of the intervention.

Strengths and Limitations

There are notable strengths worth mentioning. We worked alongside medically underserved communities that have been largely left out of cancer screening engagement and research, particularly Lao and Cambodian populations, in this community-engaged study, first through the exploratory phase and then on adapting this tailored navigation intervention. The collaboration has spanned more than a decade. This is a testament to the commitment of the study team to engage community stakeholders in research and build capacity in these communities. By taking a community-engaged approach to the adapted TIMS©, we enhanced our research efforts' cultural relevance and acceptability.

This study is not without limitations. Our study population was based in Ohio; thus, some messages may not be relevant to Southeast Asian women outside of this geographic location. The population in Ohio may have differing perspectives and experiences related to mammography and Pap testing than other areas where Southeast Asian populations are more extensive and more diverse.

Conclusion

Overall, increasing cancer screening for underserved populations is essential for achieving health equity, improving health outcomes, and ensuring that all individuals can benefit from early cancer detection and treatment. Testing culturally tailored approaches to cancer screening involves critical areas to improve the accessibility, acceptability, efficacy, and effectiveness of these interventions for diverse populations. Several promising directions for this work include enhanced community engagement and collaboration, integration of technology, development of culturally tailored risk assessment tools, adaptive trial designs, training and capacity building, and focus on high-risk populations.

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Statements and declarations

Ethical Approval

This study was conducted in accordance with the ethical standards of the institutional review board (IRB) at The Ohio State University. Ethical approval for the study was granted by the Ohio State University's IRB (Protocol #2018B0521).

Informed Consent

All participants provided written informed consent prior to their involvement in the study. Participation was voluntary, and participants were informed of their right to withdraw from the study at any time without any consequences.

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Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author, Jennifer Kue, upon reasonable request. However, due to ethical considerations and participant confidentiality, access to data is limited to ensure the privacy of participants involved in the research. Aggregated and anonymized data may be provided upon request for research purposes.

Supplemental Material

Supplemental material for this article is available online.

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