

Translational Issues in Psychological Science

Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized Controlled Trial

--Manuscript Draft--

Manuscript Number:	TPS-2018-0336R1
Full Title:	Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized Controlled Trial
Abstract:	Chinese immigrant breast cancer survivors face various challenges due to cultural and socioecological factors. Research efforts to develop culturally sensitive interventions have been limited by lack of knowledge regarding successful recruitment and implementation practices among Chinese immigrant populations. This paper documents strategies utilized during the development and implementation of a randomized controlled trial of a culturally sensitive psychosocial intervention for Chinese immigrant breast cancer survivors. In partnership with a community agency, we developed culturally and linguistically appropriate research materials, recruited participants from community channels, and conducted longitudinal data collection. Key strategies include building equitable research partnerships with community agencies to engage participants; being responsive to the needs of community agencies and participants; considering within-group diversity of the research population; utilizing recruitment as an opportunity for relationship-building with participants; and developing key strategies to promote retention. Successful participant engagement in cancer intervention research is the result of collaboration among breast cancer survivors, community leaders and agencies, and academic researchers. The engagement process for this study is novel because we have emphasized cultural factors in the process and taken a relational approach to recruitment and retention.
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<p>Response to Reviewers:</p>	<p>June 15, 2018</p> <p>Sabrina R. Liu Associate Editor, Translational Issues in Psychological Science</p> <p>RE: TPS-2018-0336, Revision 1, "Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized Controlled Trial"</p> <p>Dear Ms. Liu:</p> <p>Thank you for the opportunity to revise and resubmit our manuscript, and for the constructive feedback provided by the reviewers. We have considered the reviewers' comments in our revision. In the attached response, we explained how we have addressed them in the revised manuscript, or our rationale for choosing not to incorporate their suggestions. We hope you agree that our efforts have significantly improved the quality and clarity of the manuscript and that you feel that the revised manuscript is now acceptable for publication. Please do not hesitate to contact us with any remaining questions or concerns.</p> <p>We thank you for your consideration. We look forward to hearing from you at your earliest convenience.</p> <p>Sincerely,</p> <p>Christine Wu (on behalf of the authors)</p>
<p>Order of Authors:</p>	<p>Christine S. Wu, B.S.</p> <p>Krystal M. Warmoth, Ph.D.</p> <p>Bernice Cheung, B.A.</p> <p>Alice Loh, B.A.</p> <p>Lucy Young, M.S.</p> <p>Qian Lu, M.D., Ph.D.</p>

June 15, 2018

Sabrina R. Liu

Associate Editor, *Translational Issues in Psychological Science*

RE: TPS-2018-0336, Revision 1, “Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized Controlled Trial”

Dear Ms. Liu:

Thank you for the opportunity to revise and resubmit our manuscript, and for the constructive feedback provided by the reviewers. We have considered the reviewers’ comments in our revision. Below, we explained how we have addressed them in the revised manuscript, or our rationale for choosing not to incorporate their suggestions. We hope you agree that our efforts have significantly improved the quality and clarity of the manuscript and that you feel that the revised manuscript is now acceptable for publication. Please do not hesitate to contact us with any remaining questions or concerns.

We thank you for your consideration. We look forward to hearing from you at your earliest convenience.

Sincerely,

Authors

Reviewer 1's feedback	Response
<p>On page 4, paragraph 1, line 1: add the word "psychosocial factors" to identify the influence of the selected variables on the population in the study. Beginning on the last sentence on page 3, the revision would read: Lower social support, higher social constraints, and greater emotional ambivalence have been found to be psychosocial factors associated with lower quality of life and higher distress among Chinese and Chinese American breast cancer survivors (Lu, Man, You, & LeRoy, 2015; You & Lu, 2014a, 2014b). The addition of the word, psychosocial factors aligns with psychological challenges featured on page 4, paragraph 1, line 4.</p>	<p>We added the phrase to the sentence. It now reads: "Psychosocial factors such as lower social support, higher social constraints, and greater emotional ambivalence are associated with lower quality of life and higher distress among Chinese and Chinese American breast cancer survivors (Lu, Man, You, & LeRoy, 2015; You & Lu, 2014a, 2014b)."</p>
<p>On page 4, before paragraph 2: create a new heading entitled, Literature Review. The content on page 4, paragraph 2 through the top of page 6 provides a substantial analysis, synthesis, and evaluation of the literature.</p>	<p>We chose to not include the heading for the following reasons. First, the content prior to page 4, paragraph 2 is also literature review. Second, because it is an implicit expectation that the introduction would contain a literature review, we did not feel it would be necessary to explicitly label this section as such.</p>
<p>On page 6, following the literature review and before the Method section, create a new heading entitled, Theoretical Framework. In this section, identify and discuss the theoretical lens in qualitative research guiding the study which was introduced as community-based participatory research in the section, "Intervention Overview", page 6, paragraph, 2, line 1.</p>	<p>We added a paragraph on pg. 6 to discuss community-based participatory research as the theoretical framework guiding our study. However, we chose not to add a heading to this section as it was not a substantial aspect of the introduction.</p>
<p>In the section, "Recruitment and Eligibility Screening", page 8, paragraph 1, line 6: identify the study eligibility criteria, specifically the inclusion criteria and exclusion criteria.</p>	<p>We added the eligibility criteria to the paragraph on page 9: "Staff members directly contacted individuals from their client database who met the inclusion criteria for the study: 1) self-identified to be comfortable speaking Chinese (Mandarin or Cantonese); 2) breast cancer diagnosis of stages 0-III; and 3) completed primary treatment (e.g., surgery, chemotherapy, radiotherapy) within the last 36 months. Participants were excluded if they did</p>

	not meet the inclusion criteria.”
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Reviewer 2's feedback	Response
<p>Pg 3 - I'm curious if there are ethnic disparities in survival rates for Asian Americans or Chinese Americans in particular? If not, what are some factors that prevent equitable health care services for Chinese immigrants? (e.g., language, cultural mistrust)</p>	<p>In paragraph 1 of page 3, we removed the sentence referring to racial and ethnic disparities in survival rates. We recognize this sentence was misleading as there are not disparities in survival rates for Asian Americans and Chinese Americans in particular. We reframed this sentence to focus on racial and ethnic disparities in factors which affect quality of life among breast cancer survivors, which Asian Americans and Chinese Americans do experience. The sentence now reads: “Nevertheless, racial and ethnic disparities in factors affecting quality of life persist among breast cancer survivors (Ashing-Giwa & Lim, 2009; Giedzinska, Meyerowitz, Ganz, & Rowland, 2004).”</p> <p>We also clarified in paragraph 2 of page 3 that there are disparities in mortality rates between immigrant and U.S.-born Chinese Americans: “Chinese immigrant breast cancer survivors have a higher mortality rate than their U.S.-born counterparts (Gomez et al., 2010).”</p> <p>Lastly, we framed paragraph 3 of page 3 as a discussion of various factors that impact the psychosocial challenges experienced by Chinese immigrant breast cancer survivors. The topic sentence of this paragraph now reads: “Chinese immigrant breast cancer survivors confront specific psychosocial challenges due to immigration, socioeconomic factors, and cultural values.” In this discussion, we explained how language barriers, health literacy, and socioeconomic status impact access to equitable health care services.</p>
<p>Pg 3 - would be great if you could elaborate on why breast cancer is stigmatized</p>	<p>We added an explanation of why breast cancer is stigmatized in Chinese culture on page 4, paragraph 1: “Social support seeking is also impacted by cancer stigma in Chinese culture, where cancer may be viewed as the result of karma or considered bad luck because of its association with death (S. Lee et al., 2013;</p>

	Warmoth et al., 2017; Wong-Kim, Sun, Merighi, & Chow, 2005).”
<p>It would be important to frame the intro so that there is more emphasis on the social inequalities and disparities that make it more difficult for Chinese immigrants to cope with breast cancer so that we do not further marginalize Chinese immigrants. For instance, you could mention that lower social support is due to the migration process (if that is the case). This is a nuanced point, but an important one to consider. In particular, on pg 4, there is a paragraph on difficulties engaging Asian American population in health related research. It's important to consider the cultural mistrust and mistrust in the medical field because of their minority status.</p>	<p>Thank you for bringing this point up. As discussed above, we reorganized paragraph 3 of page 3 as a discussion of how Chinese immigrant breast cancer survivors’ experiences are impacted by contextual factors like immigration and socioeconomic status, in addition to cultural factors. We also explained how social support is shaped by both migration and cultural factors. Lastly, in paragraph 1 of page 5, we added cultural mistrust as a potential barrier to research participation: “Previous studies have reported several recruitment and implementation barriers, such as mistrust of institutions (Giarelli et al., 2011), limited English proficiency (Nguyen, Somkin, & Ma, 2005), a lack of exposure to research studies (Han, Kang, Kim, Ryu, & Kim, 2007), concerns about time commitment (Maxwell, Bastani, Vida, & Warda, 2005), and the fears of being a ‘guinea pig’ (Nguyen et al., 2005).”</p>
<p>Pg. 8 would be great if you could provide an example of what the feedback you got from the focus group was to improve cultural responsiveness of research materials.</p>	<p>On paragraph 2 of page 9, we clarified that the feedback we received from the focus group was related to the wording of Chinese translations. The sentence now reads: “The focus group made suggestions to improve the wording of Chinese translations.” The suggested changes were in Chinese and did not affect the English translated meaning. We did not include an example of a suggested change for that reason.</p>
<p>I'm curious about the acculturation level of the participants. Do you have such info you could include? (could be years in U.S.) It would be great if you could include a brief paragraph on the need to consider acculturation levels when modifying interventions for cultural responsiveness.</p>	<p>The acculturation level (years in the US) of participants in the first two waves of the study have been added on pg. 7, paragraph 1: “Participants in the first two waves of our study had lived in the US for an average of 16.23 years (<i>SD</i> = 9.72) and spoke Mandarin or Cantonese as their primary language, which is similar to the acculturation levels of participants reported in previous studies with similar samples (Warmoth et al., 2017; Wong & Lu, 2016).”</p>

	<p>Because the focus of our paper is on modifying research methods rather than interventions, we did not discuss the need to consider acculturation when modifying interventions. Rather, we added sentences throughout the paper to explain how acculturation affects research participation and to clarify how we addressed these factors. We highlighted throughout the introduction that our population of interest was Chinese immigrant breast cancer survivors, and we discussed how factors related to acculturation (e.g., English ability, health literacy) affect both the survivorship experience and research participation. Throughout our “Successful Strategies” section starting on paragraph 3 of pg. 11, we described how our strategies considered participants’ levels of acculturation.</p>
<p>I’m wondering how much of the cultural adaptations would be generalizable to other Chinese immigrant population, versus more context/study specific. If you could contextualize your cultural adaptations with the social etiquette or values, that might make your adaptations more generalizable to other studies.</p>	<p>We added several sentences on pg. 14, paragraph 2 to explain that context-specific adaptations to our research methods may not generalize, but that the overall principle of working collaboratively with community members is something to emulate rather than our specific adaptations: “However, we caution that this approach may be specific to our particular sample and may not generalize to other research efforts with Chinese immigrant populations. Cultural adaptation often involves balancing context-specific adaptations with generalizability (R. M. Lee, Vu, & Lau, 2013). As such, we emphasize the general principle of valuing the knowledge of community members throughout the research process.”</p>
<p>How did gender play a role in the study? Did all the researchers, community partners, translators identify as women?</p>	<p>We added a sentence clarifying the gender identities of research personnel on pg. 8, paragraph 1: “All personnel identified as female except for one graduate student translator who identified as male.” We also clarified on pg. 9, paragraph 2, line 1 that all focus group members identified as female.</p>
<p>How was the orientation sessions received? -</p>	<p>We did not collect systematic data from</p>

considering that breast cancer is stigmatized and participants had to be with others who were also diagnosed, did you get a sense of if this was helpful (feeling supported) or stigmatizing (needing to disclose to others who were also at the orientation)?

participants on how they perceived the orientation sessions, as the orientation was not part of our intervention. We imagine that being with other breast cancer survivors at the orientation sessions would not be stigmatizing, as participants from a pilot study of the intervention previously reported that being with other breast cancer survivors helped reduce stigma (Lu et al., 2014). However, we have not discussed whether the orientation was helpful in creating support and reducing stigma because doing so would suggest that the orientation was part of the intervention, when the orientation was not intended to be part of the intervention.

Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized
Controlled Trial

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Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized

Controlled Trial

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Abstract

Chinese immigrant breast cancer survivors face various challenges due to cultural and socioecological factors. Research efforts to develop culturally sensitive interventions have been limited by lack of knowledge regarding successful recruitment and implementation practices among Chinese immigrant populations. This paper documents strategies utilized during the development and implementation of a randomized controlled trial of a culturally sensitive psychosocial intervention for Chinese immigrant breast cancer survivors. In partnership with a community agency, we developed culturally and linguistically appropriate research materials, recruited participants from community channels, and conducted longitudinal data collection. Key strategies include building equitable research partnerships with community agencies to engage participants; being responsive to the needs of community agencies and participants; considering within-group diversity of the research population; utilizing recruitment as an opportunity for relationship-building with participants; and developing key strategies to promote retention. Successful participant engagement in cancer intervention research is the result of collaboration among breast cancer survivors, community leaders and agencies, and academic researchers. The engagement process for this study is novel because we have emphasized cultural factors in the process and taken a relational approach to recruitment and retention.

Keywords: Chinese Americans; breast cancer; community-based participatory research; intervention studies; recruitment; retention

Public Significance Statement: The present study describes successful strategies for recruiting and retaining Chinese immigrant breast cancer survivors in intervention research. Rates of intervention research participation can be enhanced through consideration of sociocultural factors and partnerships with community agencies.

Successful Strategies for Engaging Chinese Breast Cancer Survivors in a Randomized Controlled Trial

Breast cancer is one of the most common forms of cancer in the United States and was estimated to account for the second highest cancer death rate among women in 2015 (American Cancer Society, 2015). In the last two decades, breast cancer has become more of a chronic disease rather than a terminal one, due to improvements in treatment and supportive care. Nevertheless, racial and ethnic disparities in factors affecting quality of life persist among breast cancer survivors (Ashing-Giwa & Lim, 2009; Giedzinska, Meyerowitz, Ganz, & Rowland, 2004). Due to such disparities, more research and culturally sensitive interventions are warranted to address the psychosocial challenges that minority breast cancer survivors encounter.

Interventions are particularly needed for Chinese American immigrant breast cancer survivors, given that Chinese Americans comprise the largest ethnic group in the rapidly growing Asian American population (US Census Bureau, 2012), breast cancer incidence rates are increasing among Asian American women (American Cancer Society, 2015), and Chinese immigrant breast cancer survivors have a higher mortality rate than their U.S.-born counterparts (Gomez et al., 2010). However, research efforts to develop culturally sensitive interventions have been limited by lack of knowledge regarding successful recruitment and implementation practices among Chinese immigrant populations. This paper documents strategies utilized during the development and implementation of a randomized controlled trial of a culturally sensitive psychosocial intervention for Chinese immigrant breast cancer survivors.

Chinese immigrant breast cancer survivors confront specific psychosocial challenges due to immigration, socioeconomic factors, and cultural values. Chinese immigrant breast cancer survivors report fatalistic beliefs about cancer and significant body image concerns (Lu, Yeung,

You, & Dai, 2016). Furthermore, they have difficulties navigating the healthcare system, due to language barriers and low health literacy (S. Lee, Chen, Ma, & Fang, 2012; Warmoth, Cheung, You, Yeung, & Lu, 2017). Low-acclimated (e.g., limited English language ability) Chinese immigrant breast cancer survivors also report lower levels of financial and social resources related to cancer treatment, compared to high-acclimated Chinese immigrants, U.S.-born Chinese, and European Americans (Wang et al., 2013). In addition to socioeconomic and structural challenges, Chinese breast cancer survivors have decreased social support due to language barriers, separation from friends and family living in their native countries, and fear of burdening others (S. Lee et al., 2013; Warmoth et al., 2017). Social support seeking is also impacted by cancer stigma in Chinese culture, where cancer may be viewed as the result of karma or considered bad luck because of its association with death (S. Lee et al., 2013; Warmoth et al., 2017; Wong-Kim, Sun, Merighi, & Chow, 2005). Psychosocial factors such as lower social support, higher social constraints, and greater emotional ambivalence are associated with lower quality of life and higher distress among Chinese and Chinese American breast cancer survivors (Lu, Man, You, & LeRoy, 2015; You & Lu, 2014a, 2014b). Therefore, these psychosocial challenges need to be addressed to improve the breast cancer survivorship experience among this population.

Despite the need, limited research efforts have aimed to develop culturally sensitive interventions that address the psychosocial needs of Chinese immigrant breast cancer survivors. Furthermore, these efforts are complicated by the difficulty of engaging the broader Asian American population in health-related intervention research. Asian Americans are more likely to resist participating in research, compared to other ethnic groups (Ashing-Giwa, Padilla, Tejero, & Kim, 2004). The same immigration and acculturation factors that impact the psychosocial

challenges of Chinese immigrant breast cancer survivors may also impact their participation in research. Previous studies have reported several recruitment and implementation barriers, such as mistrust of institutions (Giarelli et al., 2011), limited English proficiency (Nguyen, Somkin, & Ma, 2005), a lack of exposure to research studies (Han, Kang, Kim, Ryu, & Kim, 2007), concerns about time commitment (Maxwell, Bastani, Vida, & Warda, 2005), and the fears of being a ‘guinea pig’ (Nguyen et al., 2005). At the community level, a lack of cooperation with community gatekeepers also can compromise the implementation of research protocols (Han et al., 2007).

Although some research teams (e.g., Ahmad, Cameron, & Stewart, 2005; Carney et al., 2014) have successfully increased the acceptance and feasibility of health-related research among Asian Americans, most of them did not illustrate how they overcame the common barriers listed above. Therefore, future research teams do not have sufficient guidelines to design and implement feasible health intervention research among Asian American populations. With specific regard to Chinese Americans, only two articles reported the strategies that they used to conduct research. In a physical exercise study among Chinese immigrants, Taylor-Piliae and Froelicher (2007) optimized their recruitment rate by establishing a partnership with a community-based agency, distributing bilingual information about the study with a multi-media approach, and communicating with participants using their preferred languages. They also managed to maintain retention by personalizing feedback for all assessments, using bilingual personnel, and scheduling interventions with consideration of Chinese festivals. Dong and colleagues (2011) conducted a community-based participatory research in an elderly Chinese American population to investigate their specific pressing health issues. They suggested that prior working relationships with Chinese communities and humble attitudes were important, and

that the involvement of researchers from different regions of China was necessary (Dong, Chang, Wong, & Simon, 2011). While these two studies contribute to the literature on health intervention research with minority communities, both studies targeted Chinese Americans with no severe illnesses and did not involve randomized controlled trials with complex protocols.

Only three studies have reported psychosocial interventions among Chinese immigrant breast cancer survivors (Lu et al., 2017; Lu, You, Man, Loh, & Young, 2014; Lu, Zheng, Young, Kagawa-Singer, & Loh, 2012). However, no previous study has reported strategies to design and conduct intervention research among Chinese immigrant breast cancer survivors with consideration of their psychological needs and cultural beliefs. Therefore, the purpose of this current paper is to describe successful strategies used during the first year of development, recruitment, and implementation of an intervention study (namely, a randomized controlled trial of a culturally sensitive psychosocial intervention designed for Chinese immigrant breast cancer survivors). These strategies can provide suggestions for researchers to build relationships with Chinese American and other minority communities, design culturally sensitive study materials, and facilitate recruitment and implementation of psychosocial interventions among minority cancer survivors.

Given the recruitment and implementation barriers described above, we utilized a community-based participatory research (CBPR) approach (Israel, Schulz, Parker, & Becker, 1998) to design and conduct the randomized controlled trial. The CBPR paradigm emphasizes collaborative, equitable partnerships between academic researchers and community members in all aspects of research design and implementation. Furthermore, community members are valued as a legitimate source of knowledge. In this paper, we focus on the use of CBPR specifically for cultural adaptation of recruitment and retention strategies, rather than the intervention itself.

Method

Intervention Overview

The Joy Luck Academy (JLA) is a culturally sensitive intervention for Chinese American immigrant breast cancer survivors. Participants in the first two waves of our study had lived in the US for an average of 16.23 years ($SD = 9.72$) and spoke Mandarin or Cantonese as their primary language, which is similar to the acculturation levels of participants reported in previous studies with similar samples (Warmoth et al., 2017; Wong & Lu, 2016). The content of the pilot JLA intervention has been previously described (Lu et al., 2014). As the study is currently still ongoing, this paper describes our methods and successful strategies from the first year of study implementation.

Using CBPR principles (Israel et al., 1998), the study was designed and implemented in collaboration with a non-profit organization serving the Chinese immigrant population in Southern California. The organization provides a variety of cancer support services, including prevention education, cancer screening, Chinese-language publications on cancer, and support groups and workshops for cancer patients and survivors. Relevant aspects of study development and implementation are described below and summarized in Table 1, along with feasibility recommendations.

Development of Research Study Materials

To ensure the cultural feasibility of this study, we devoted six months to the development of research materials seen by participants during recruitment and data collection. These documents included recruitment flyers and scripts, consent forms, quantitative and qualitative measures, and debriefing statements.

A variety of personnel participated in the development and translation process, including undergraduate research assistants, graduate students, the principal investigator, full-time research staff, and community research staff. Team members included native English speakers as well as bilingual (Chinese-English) individuals whose native language was Chinese. We also hired a consultant who was a bilingual (Chinese-English) breast cancer survivor and community advocate who had previously worked as an oncology nurse to assist with development of materials. Overall, our team included native Chinese speakers from multiple Chinese-speaking countries (China, Taiwan, Hong Kong) and represented proficiency with multiple dialects (e.g., Mandarin, Cantonese) and character forms (i.e., traditional, simplified). All personnel identified as female except for one graduate student translator who identified as male.

Given the various types of research materials prepared, we used several different procedures for development and translation. To ensure the inclusion of important technical language and phrasing, some documents (i.e., consent forms and debriefing statements) were originally written in English. Following translation to Chinese, we made modifications to Chinese versions of documents to improve linguistic and cultural appropriateness and modified English versions of documents accordingly. Other documents (i.e., recruitment scripts and qualitative interview guides) that were more conversational in nature were originally written in Chinese to maintain native phrasing and sentence structures.

In developing participant questionnaires, we first sought to use measures with validated Chinese translations. All translations were double-checked by pairs of native English and bilingual speakers, and translations were modified as necessary prior to their inclusion in the questionnaire. For measures lacking validated Chinese-language versions, items were translated by a smaller team, which consisted of the principal investigator, graduate students, and a

research staff member. The team translated items together and resolved regional differences in phrasing.

The consent form and questionnaire were piloted with a focus group of five female Chinese breast cancer survivors recruited through a local non-profit organization serving Chinese cancer patients. All focus group participants were bilingual (Chinese-English), and the focus group included individuals from China, Taiwan, and Hong Kong. Due to time constraints, not all research materials were reviewed with the focus group. The focus group made suggestions to improve the wording of Chinese translations.

Throughout the development and translation process, community research staff reviewed drafts of research materials. Staff provided feedback to improve the cultural appropriateness of written documents and increase comprehension of documents with technical or research-specific language, such as the consent form.

Recruitment and Eligibility Screening

Community research staff conducted participant recruitment. The study was advertised to the local community through flyers at medical offices and local conferences for cancer patients and survivors. Community research staff also advertised the study to its database of individuals who had previously contacted the organization or used its services. The organization announced the study in its monthly newsletter and cancer support group meetings. Staff members directly contacted individuals from their client database who met the inclusion criteria for the study: 1) self-identified to be comfortable speaking Chinese (Mandarin or Cantonese); 2) breast cancer diagnosis of stages 0-III; and 3) completed primary treatment (e.g., surgery, chemotherapy, radiotherapy) within the last 36 months. Participants were excluded if they did not meet the inclusion criteria.

Community research staff followed a standard outline for conducting recruitment calls. Before each call, staff familiarized themselves with the individual's background information (e.g., treatment history, stage of cancer) if the individual was from the organization's database. Recruiters opened each call by introducing themselves and inquiring further about the individuals' health, well-being, and family. Recruiters then introduced the research study, described basic study procedures and timeline, and invited the individual to consider participation. Recruiters also addressed individuals' concerns or potential barriers to participation and allowed opportunities for individuals to ask questions. After individuals expressed interest in participation, recruiters screened for eligibility.

Study Implementation

Orientation session. Once participants had verbally agreed to participate in the study and were screened for eligibility, they attended an in-person three-hour orientation session with community research staff and other potential participants. The purpose of the orientation was for potential participants to complete consent forms and other study paperwork, ask questions about the research study, receive instruction on study procedures, and complete the first study questionnaire. Given the length of orientation and the time demands of staff, orientation sessions were conducted in groups. Staff members arranged individual orientation sessions with participants when scheduling conflicts arose.

First, staff members discussed the consent form, study purpose, and study procedures and obtained written consent from participants. Next, participants were given the option of completing another form, which authorized the research team to request medical information from their doctors. To verify participants' self-reported cancer diagnosis information, we specifically requested the date of diagnosis, stage of cancer, and cancer treatments received.

Third, participants received instruction on collecting saliva samples using Salivette devices¹. Lastly, participants completed the first study questionnaire at their own pace in a large, quiet room. Snacks and beverages were provided, and participants were encouraged to take breaks or use the bathroom as needed. Participants were free to leave as soon as they completed the questionnaire.

Throughout research study. As participants progressed through the research study, research staff maintained contact with participants through phone calls. Reminder phone calls were made five days before each scheduled data collection point. Phone calls were conducted by both academic and community research staff. Staff members notified participants that follow-up questionnaires and saliva collection materials would be sent by mail in the upcoming week. After research materials were mailed, staff members followed up with additional phone reminders for participants to complete and return their assessments in a timely manner. They also called participants to schedule qualitative interviews after completing the final questionnaire. Community research staff used a variety of additional methods to contact participants, including emails, text messages, and WeChat, a widely used mobile messaging application in the Chinese community.

Successful Strategies for Engaging Chinese Breast Cancer Survivors

In this section, we describe strategies and principles that facilitated participant engagement in the intervention study. We also describe adjustments to our research protocol in response to lessons learned in the field, and we provide recommendations for researchers planning to conduct research with similar populations. All of our strategies and recommendations (see Table 2) reflect our consideration of how participants' acculturation levels

¹ Saliva samples were collected and assayed for cortisol to provide objective measures of stress.

may influence factors (e.g., language barriers, health literacy) that, in turn, impede research participation.

Build equitable research partnerships with community agencies

Our partnership with a community agency was vital to the successful recruitment and retention of participants in four ways. First, the involvement and input of community research staff during the study design stages ensured that the research design was ecologically valid. As community advocates, immigrants, and Chinese breast cancer survivors themselves, they offered multiple perspectives on the specific needs of our target population. Their perspectives informed decisions on the study design and protocol. For example, we expanded the study inclusion criteria based on their feedback. Originally, individuals with a breast cancer diagnosis between stage I and III were eligible. However, during the first wave of recruitment, several individuals with a stage 0 diagnosis expressed interest in research participation. Community research staff commented that individuals with stage 0 breast cancer also viewed themselves as cancer survivors, and some feared cancer recurrence. We concluded that these individuals might also benefit from participating in a psychosocial intervention and adjusted our eligibility criteria to include individuals with a stage 0 diagnosis.

In addition, participant identification numbers did not contain the numbers “13” or “4” based on input from community research staff. They expressed how these numbers had superstitious connotations in Chinese culture. The number “13” is considered unlucky, and the character for “4” is a homophone with the character for death. As superstitious beliefs are emphasized in Chinese culture (Simmons & Schindler, 2003), we avoided these numbers to avoid intensifying participants’ fears of cancer recurrence (Wang et al., 2012) or fatalistic beliefs about cancer (Lu et al., 2016).

Second, the community agency functioned as a gatekeeper to relationships with other community members. The agency's regular programming and community outreach events included monthly newsletters, cancer support group meetings, and an annual conference for Chinese breast cancer survivors. Through these programs, the organization had established relationships with Chinese-speaking doctors and other community advocates who were willing to help advertise the research study. Furthermore, these programs allowed the agency to establish relationships with potential participants and provided additional channels for advertising the study.

Third, community research staff interacted directly with participants during recruitment and data collection, thus serving as a liaison between participants and the academic research team. The role of community research staff in data collection helped reduce the power differential that often exists between academic researchers and research participants, particularly for an immigrant sample with limited English ability, and ultimately this may have improved the internal validity of data. For example, participants felt comfortable approaching community staff to clarify questionnaire items. Lastly, our partnership with the community agency provided a channel to share and interpret research findings. While dissemination will not occur until study conclusion, the potential access to study findings serves a strong motivation for research participants.

Be flexible and responsive to the needs of community agencies and participants

Through our partnership with a community agency, we learned to be flexible and responsive to the agency's input and needs. As the study was implemented and our understanding of research participants evolved, we adapted our research protocol to better accommodate both community research staff and participants. For example, an internal review of

orientation sessions found that it was a significant time burden for community research staff and participants, with much of the time devoted to answering questions from participants. Therefore, we made several changes to the orientation presentation to increase participant comprehension and reduce the staff workload. We developed “Frequently Asked Questions” handouts, based on questions asked by participants from previous cohorts. An extended version for staff members was created for reference, and an abbreviated version was distributed to participants. This document helped improve the efficiency of orientation and reduce the time burden for participants and community research staff. We also added extra slides to the orientation PowerPoint to clarify specific questionnaire items that participants frequently found confusing.

In addition, we learned to describe the compensation schedule by focusing on potential opportunities for gain, rather than loss. Compensation was distributed on a graded basis, such that participants received a portion of compensation after returning an assessment at each time point. Originally, participants were informed that they would not receive their portion of compensation if they did not return completed questionnaires on a timely basis. However, we received feedback that participants interpreted this approach as potential punishment. Thus, we rephrased our explanation of compensation, where participants were told they would have the opportunity to complete future questionnaires and receive greater compensation if they returned their assessments in a timely manner. Participants received the shift in emphasis as a more encouraging approach to participation. However, we caution that this approach may be specific to our particular sample and may not generalize to other research efforts with Chinese immigrant populations. Cultural adaptation often involves balancing context-specific adaptations with generalizability (R. M. Lee, Vu, & Lau, 2013). As such, we emphasize the general principle of valuing the knowledge of community members throughout the research process.

Consider within-group diversity of Chinese breast cancer survivors when developing research materials

The diversity among Chinese immigrant breast cancer survivors impacted the amount of time and effort devoted to developing research materials. Our participants included both native Mandarin and Cantonese speakers from Taiwan, Hong Kong, and multiple provinces of China. As we developed and translated research materials, we considered the differences in phrasing and vocabulary across regions and dialects. Although we planned for material development and translation to take two months, this process actually lasted approximately six months. Thus, we recommend future researchers to build in extra time for translation when working with Chinese participants representing multiple regions and dialects. In addition, when selecting translators, we recommend considering the match between the national and/or linguistic backgrounds of participants and translators.

Second, we encourage researchers to consider within-group socioeconomic diversity that may impact the phrasing and comprehension of written research materials. As previously described, we conducted a focus group with Chinese breast cancer survivors in southeast Texas to gain feedback on select research documents. After revising documents based on the focus group's suggestions, community research staff suggested that the phrasing and vocabulary was too formal for the research population. While the women in the focus group were highly educated, research participants in our sample, who were recruited from southern California, were more likely to have attained a lower level of education. We recommend that materials distributed to participants should be considerate of the potentially wide range of socioeconomic and educational backgrounds, thus written and explained in simple, clear, and concise terms.

Relational approach to recruitment

We approached recruitment as an opportunity to build relationships and establish rapport with potential participants. This approach was important because participants' acculturation levels could affect their familiarity with research and trust of researchers. The most effective strategy for engaging potential participants was through individual phone calls. Recruiters' first priority was to establish an environment in which individuals felt personally cared for. Prior to any mention of the study, recruiters took time to inquire about the individual's life and listen to her. After introducing the research study, a significant portion of each call was devoted to identifying barriers to research participation and addressing concerns or questions. Several common barriers included transportation to the intervention site and study time commitment. Recruiters addressed transportation barriers by discussing family or friends who could offer a ride or attempting to arrange carpools for individuals if they decided to participate. Recruiters also described the indirect benefits of research participation, such as contributing to research that would benefit the well-being of future breast cancer patients and survivors. In addition, recruiters highlighted the research funding mechanism (i.e., NIH funding) to emphasize the potential significance of the research and prestige of receiving this grant funding. For individuals who did not meet inclusion criteria or declined participation for various reasons, recruiters made sure they were aware of other resources available for breast cancer survivors.

While the relational approach helped care for participants beyond the purpose of study participation, we acknowledge that it was a significant time investment for community research staff, with each phone conversation lasting 15-30 minutes on average. For researchers who wish to emulate this approach, we recommend factoring in extra time for recruitment and providing resources to support increased staff effort during recruitment.

Strategic approaches to retention

The orientation session was an effective strategy for engaging research participants at study entry and promoting retention. Given the study design, tasks required, and time commitment, it was important to clearly explain the study procedures and to do so at a pace appropriate for the participants, many of whom had little experience with research participation. The in-person completion of paperwork (e.g., consent form, release of medical information authorization form, questionnaire) at orientation allowed community research staff to offer immediate clarification and answer questions. Participants were walked through each form section-by-section and viewed corresponding PowerPoint slides which provided further detail on each section.

The orientation session also provided an opportunity to clarify the purpose of collecting saliva samples. In addition to instructing participants on saliva collection, community research staff explained that saliva samples would be assayed for cortisol to provide objective measures of stress. Chinese immigrants with limited English proficiency have lower levels of health literacy (Sentell & Braun, 2012), and Chinese breast cancer survivors express fears of cancer recurrence in more extreme language compared to White women (Wang et al., 2012). Thus, it was important to clarify that the saliva assays were not a diagnostic test and did not provide any information relating to their cancer symptoms. Community research staff also explained the basic diurnal cortisol rhythm to emphasize the importance of adhering to the saliva collection schedule.

While phone calls were an effective recruitment strategy, they also were instrumental for retention as participants progressed throughout the study. Participants received phone reminders when questionnaires were mailed and were contacted to schedule qualitative interviews. These calls served a practical function as they encouraged timely completion of assessments.

Furthermore, the phone calls served a relational purpose as they allowed community research staff to continue building rapport with participants. The use of WeChat for reminders was also effective as it was an ecologically valid method of communication for Chinese immigrants.

Conclusion

The present paper demonstrates successful engagement of Chinese immigrant breast cancer survivors in a randomized controlled trial through collaboration among breast cancer survivors, community leaders and agencies, and academic researchers. We provide an example of participant engagement methods in clinical trial research, by describing how to build an equitable research partnership, being flexible and responsive to the needs to community agency and participants, and considering within-group diversity. The engagement process for this study is novel because we have emphasized cultural factors in the process and taken a relational approach to recruitment and retention, as Chinese culture is a “relational culture” (Yau, 1988). Due to the dearth of clinical trials among Asian American cancer survivors, the study fills an important gap in the literature and practice by illustrating how to engage underserved populations in clinical trials.

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Table 1

Phases of Study Development and Implementation

<u>Phase</u>	<u>Research activities related to participant engagement</u>	<u>Feasibility and effort recommendations for researchers</u>
1. Development of research materials	<ul style="list-style-type: none"> • Develop and translate written research materials • Assemble team of native English and bilingual (Chinese-English) individuals for translation • Pilot research materials with focus group • Community research staff review research materials 	<ul style="list-style-type: none"> • Timeline: 6-12 months • 40-50 hours/month aggregated between 2-3 full-time community staff with different expertise and responsibilities • 10 hours per week from all individuals involved in translation • Translation team (recommendations based on our team structure) <ul style="list-style-type: none"> ○ 4 bilingual (Chinese-English) individuals ○ 2 native English speakers
2. Recruitment and eligibility screening	<ul style="list-style-type: none"> • Distribute recruitment flyers at medical offices and community events • Advertise research study at community organization's regular events and monthly newsletter • Community research staff conduct recruitment calls and screen for eligibility 	<ul style="list-style-type: none"> • Timeline: 3 months for each cohort • 40-50 hours/month or in total aggregated between 2-3 full-time community staff with different expertise and responsibilities
3. Study implementation ^a	<ul style="list-style-type: none"> • Conduct research study orientation session with participants • Conduct reminder phone calls to participants regarding follow-up assessments • Schedule qualitative interviews 	<ul style="list-style-type: none"> • 40-50 hours/month aggregated between 2-3 full-time community staff with different expertise and responsibilities

^a Only activities directly related to participant engagement in research are listed in this table. During study implementation, community research staff were also responsible for intervention delivery and data collection, which required a significant amount of effort in addition to the time listed here.

Table 2
Successful Strategies and Lessons Learned

<u>Strategy</u>	<u>Impact on our protocol and methods</u>	<u>Recommendations for researchers</u>
Build equitable research partnerships with community organizations (e.g., trust, respect)	<ul style="list-style-type: none"> • Study inclusion criteria and system of assigning participant identification numbers were modified • The community agency was a gatekeeper to potential participants and community members who helped advertise the study • Community research staff served as a liaison between participants and academic research during recruitment and data collection 	<ul style="list-style-type: none"> • Establish a plan for frequent, regular communication between researchers and community partners • Communication should occur throughout all stages of study design and implementation
Be flexible and responsive to the needs of community agencies and participants	<ul style="list-style-type: none"> • Description of the compensation schedule was reframed 	<ul style="list-style-type: none"> • Review research protocols with community partners on a regular basis to identify areas for improvement
Consider within-group diversity (linguistic, socioeconomic, etc.) of Chinese breast cancer survivors when developing research materials	<ul style="list-style-type: none"> • Translation of research materials took six months • Select research materials were piloted with a focus group, but their suggested linguistic modifications were found to be too formal for our research population 	<ul style="list-style-type: none"> • Allow extra time for translation • Consider the match between national and/or linguistic backgrounds of participants and translators • Research materials should reflect the educational background of participants
Recruitment as an opportunity for relationship-building	<ul style="list-style-type: none"> • Community research staff invested a significant amount of their efforts into recruitment, spending an average of 15-30 minutes per recruitment phone call 	<ul style="list-style-type: none"> • Factor in extra time for recruitment in study timeline • Provide resources to support increased staff effort during recruitment

- Develop strategies to promote retention
- An orientation was conducted to obtain informed consent, have participants fill out paperwork, and instruct on saliva collection procedures
 - Participant contact was maintained throughout the study using phone reminders
 - Consider ways to increase face-to-face or verbal communication between participants and community research staff in study protocol
-