Community-engaged research disruption: The impact of the COVID-19 pandemic on research with communities

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ABSTRACT:

Background: The pandemic has had dire consequences on community-engaged research.

Objectives: We describe research challenges imposed by the pandemic on our breast and cervical cancer intervention study with Southeast Asian immigrant women, and strategies used to maintain study continuity.

Methods: The pandemic's impact on the research team, recruitment and retention of participants, study design, and strategies executed to tackle these issues are described.

Results: Strategies employed to address research challenges include implementing COVID-19 protocols for conducting community research; recruiting participants online, outside of the planned community locations, and through social media; and enhancing the study design by using respondent-driven sampling. In addition to educating communities about early cancer detection, we also provided information and resources about COVID-19, including transmission mitigation, testing, and vaccination.

Conclusions: Continuing to engage the communities in our study is critical to our long-term goal of eliminating cancer screening disparities in Southeast Asian immigrant communities.

KEYWORDS: community-engaged research, COVID-19, pandemic, lessons learned, research disruption

Introduction

The COVID-19 pandemic has undoubtedly disrupted the lives of millions of people around the world. Globally, more than 356 million people have been infected by COVID-19 and over 5.6 million have died from the virus as of January 2022. The pandemic has had dire consequences on research, particularly on community-engaged research in which studies take place with communities in real-world environments. Community-engaged research is the process of collaboratively engaging with community members and stakeholders and community-based organizations that the community values as equal partners throughout the research process. This community-academic relationship is built on mutual interest, need, and respect. Importantly, community members are actively involved in the research planning, implementation, and dissemination of scientific discovery. The community-engaged research framework has been used to address various public health issues, such as cancer screening disparities, 4,5 diabetes 6,7 prevention and management, and most recently risk management of the COVID-19 pandemic. 8,9

Conducting community-engaged research with underserved, marginalized populations comes with challenges ¹⁰ but the pandemic exacerbated those issues and, in some cases, stalled community-engaged research completely. ^{11,12} We experienced this firsthand in our study on breast and cervical cancer screening with Southeast Asian women in the United States (U.S.). Our five-year study (2019-2023; RSG-CPHPS 131811) aims to test the efficacy of a tailored navigation intervention delivered by bilingual and bicultural community health advisors (CHAs) to increase breast and cervical cancer screening among intergenerational Southeast Asian immigrant mothers and daughters, specifically Lao, Khmer, and Vietnamese women living in Ohio. Similar to other community-engaged research studies ^{8,13} during the pandemic, we had to

develop creative solutions to keep our communities, participants, and research staff engaged in our study.

To refine study recruitment and retention strategies in community engaged studies, we conducted a literature search using PubMed and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) electronic databases. Search terms included community-engaged research, research disruption, impact of COVID-19 on research, and impact of COVID-19 on cancer screening/research. We found that other studies were experiencing similar research challenges during the pandemic in terms of recruitment, community outreach and engagement, access to healthcare resources, and financial support. 11,14-19 For some researchers, COVID-19 restrictions made it difficult for participants to travel and stay involved in the study. 15,20,21 Many researchers transitioned their in-person community participatory research to virtual formats to help participants stay engaged. 11,22-24 Researchers also worked with personal networks to share their study by word-of-mouth, used social media, or ResearchMatch.org (a nonprofit program funded by the National Institutes of Health to help connect people interested in research studies with researchers from top medical centers across the U.S.) to sustain study recruitment. ²⁵ A few studies that pivoted to online formats have found some success. ²⁶⁻²⁸ However, in several studies limited access to resources and use of technology continues to add to difficulties in the recruitment and engagement of participants. ^{10,29,30}

In this paper, we describe research challenges imposed by the pandemic on our breast and cervical cancer intervention study, and strategies used to maintain study continuity. Specifically, we detail the impact on the research team, recruitment and retention of participants, study design, and describe strategies executed to address these challenges. We recommend different outreach and recruitment strategies to keep participants engaged in a community research project.

The Southeast Asian Women's Health Project

Our study is a randomized controlled trial to test the efficacy of tailored navigation delivered by bilingual and bicultural CHAs from the community to increase mammography and Pap test uptake among Lao, Khmer, and Vietnamese mothers and daughters (RSG-CPHPS 131811; clinical trials NCT04086771). To be eligible for the study, participants must selfidentify as either a Lao, Khmer, or Vietnamese woman, at least 21 years old, and living in a Midwestern city. Participants were randomized to receive tailored navigation delivered by a bilingual CHA who was a member of the Lao, Khmer, or Vietnamese communities to obtain appropriate breast and/or cervical cancer screening (intervention group) or receive information regarding screening and reminders only (control group). General information on Pap testing and mammography from the American Cancer Society were mailed one week after enrollment to the control group participants and follow-up was conducted by CHAs at 3-, 12-, and 18-months. The study began January 2019 and participant recruitment started in September 2020 with a projected sample size of 540 participants in four years. The Institutional Review Board at [institution name to be added after blind peer review] approved the study with reliance agreements from [institution name to be added after blind peer review] Institutional Review Board. At baseline, we enrolled 123 participants, among whom only 65% had had a Pap smear test and only 36% had ever had a mammogram.

Our study draws on the strength of our Cultural Community Advisory Board (CCAB) convened for our previous exploratory study from 2013-2015 (R03CA175464-01A1) and with whom we continued to work closely on the current study. The CCAB's role was to provide guidance on culturally appropriate and relevant measures and data collection, identify

community assets to support the project, serve as a liaison between the research team and communities, identify potential recruitment locations, and participate in problem-solving with the research team. The board currently consists of individuals from the Khmer and Lao communities (3 females and 1 male) who are local leaders, knowledgeable about the culture and language of the communities, and interested in breast and cervical cancer and Southeast Asian women's health issues. Representatives on the CCAB from the Vietnamese community resigned due to competing professional demands. The recruitment of new CCAB members from the Vietnamese communities is ongoing. The CCAB actively engaged with our team from the conception of this study. They provided expert advice about culturally appropriate recruitment strategies and continue to provide input about how best to disseminate study results with the communities. Given their leadership within and knowledge of their respective communities, CCAB input was critical about strategies to access the community during and after pandemic restrictions.

Overcoming Pandemic Restrictions

We paused our study in March 2020 when stay-at-home orders were issued by the state's governor and our university quickly followed suit (see Figure 1). The shutdown affected our ability to recruit participants from targeted settings, such as temples, as the state prohibited large gatherings and the temples did not offer in-person services. When research activities resumed in September of 2020, our University Office of Research encouraged investigators to consider remote study procedures for such activities as informed consent and data collection. Our research team was equipped with technology (i.e., tablets, laptops) prior to the pandemic for data collection; thus, pivoting to working online was feasible. Weekly team and one-on-one staff

meetings continued to be held on the university's Zoom Meeting platform. Our research protocol incorporated electronic forms (e.g., consent, HIPAA, medical release, baseline survey) in REDCap, a secure, electronic data capture tool. Having an online platform already in place allowed for a smooth transition to working remotely. Other researchers discussed similar strategies to keep participants engaged. Nguyen and colleagues ²⁶ demonstrated that aging individuals with HIV rely on research to assist with their mental health and daily needs. Therefore, the need to shift their community-based participatory research to online benefited both the study and participants because it provided a remote option when face-to-face procedures were banned. ²⁶ Nguyen and colleagues used the connections that people on their team had with the communities, created a committee of experts who could provide feedback and review their study, formed trusting relationships with community members, worked closely with the IRB, and conducted the study virtually during the pandemic. ²⁶ In our study, CHAs used Zoom to enroll participants online. Participants were sent an email link. Both CHAs and participants reviewed and signed the consent, HIPAA, and medical release forms remotely by allowing screen share.

Figure 1. Participant Enrollment Timeline During the COVID-19 Pandemic COVID-19 PANDEMIC RESEARCH ACTIVITIES 3/9/2020 3/9/2020 First Coronavirus case confirmed in the state. University suspends in-person classes, changes made to class, work arrangements, travel and campus events. The university and medical center remain open for business. 3/16/2020 3/16/2020 The state closes schools and businesses. Public University closes facilities and requires all events larger than 100 people are banned. employees who can do so to work from home. Visitors to hospitals and nursing homes were Critical services remain open. 3/22/2020 Stay-at-home order issued for the state. 5/12/2020 - 5/31/2020 5/18/2020 The state slowly reopens business in groups. Health procedures can resume at dental and The University Office of Research developed a plan for stages of reopening of on-Campus veterinary offices. Retailers, barbershops, salons, Activities. Current research activities and and spas open. Restaurants, fitness centers, pools ongoing laboratory maintenance continued as can open with limited contact. Day camps and Stage 1. day care centers reopen. 6/1/2020 Stage 2 began evaluation for reentry that focused on highest priority activities to reopen, low to medium risk with procedures that were deferred. Stage 3 research activities began evaluation for reentry that are low to medium risk; including most wet lab research. 7/23/2020 (7/22/2020 Masks become mandatory in the state. Stage 4 research activities began evaluation for reentry (including SEAWHP). During Stage 4 most moderate and some high-risk activities resumed on campus. This included research with human participants that required face-to-face interaction (with use of PPE, physical distanced, etc.), where participants are not from high-risk 9/11/2020 First participant was recruited. 10/16/2020 First participant was enrolled. 11/19/2020 Nightly curfew to curb COVID-19 spread issued in 12/14/2020 12/14/2020 First COVID-19 vaccine arrives in the state. Enrollment total 11 participants. 5/23/2021 Delta variant detected in the state. 6/2/2021 6/2/2021 Enrollment total 37 participants. State health orders lifted. 10/15/2021 University requires every student, faculty and staff member to be vaccinated against COVID-12/11/2021 12/11/2021 Omicron variant detected in the state Enrollment total 78 participants.

8/19/2022

Enrollment total 132 participants.

By converting completely online for recruitment and enrollment, we had to consider the challenges for participants who did not have access to technology (computers or a smartphone), internet access, or were unfamiliar with using technology. The lack of technology and the internet access was common among older SEA women who had to rely on their daughter/s or other family members to access the web and use a smartphone and/or computer. Using Zoom was especially challenging for participants who had never used that video platform. We spent a considerable amount of time during staff training demonstrating how to sign recruitment forms over Zoom and explaining privacy when using the video platform. We learned from this experience that participants and staff need to have a thorough understanding of what privacy means in the Zoom space and to have that conversation before an enrollment call takes place such as in a private location even with a virtual background. ²⁰

Although moving to an online protocol may be practical, participants with limited English proficiency and older women still preferred to meet in person to sign recruitment forms because of their limited experience with technology. We took extra measures to engage older adults by meeting face-to-face when COVID restrictions relaxed. Meeting in-person allowed participants and CHAs to build the rapport needed to make participants feel more at ease. For a population for whom technology may pose difficulties, we recommend having hard copies of research materials available for data collection in the field.

We expanded our use of social media by creating a Facebook study page, posting in English, Lao, Khmer, and Vietnamese. Based on our understanding of the communities with whom we were working, along with input from CHAs and the CCAB, we knew that Facebook was frequently used to communicate with family and friends both in the U.S. and, for some, back in their home countries. We used Facebook to post our recruitment messages, photographs, and

videos, as well as to let followers know that we would be supporting other community events by taking part. We employed Facebook's video function to communicate with potential participants who frequently used Facebook as an alternative to a phone. For example, with the Vietnamese community, some of the younger participants communicated with the CHA by video chat on Facebook during the recruitment process. For the Khmer and Lao communities, each temple had its own Facebook page to share announcements about upcoming events with community members. Being connected to community Facebook groups allowed us to keep up with current events happening within each community as well as increased our recruitment by about 6% through new contacts. WeChat, WhatsApp, or Twitter social media platforms are not commonly used by our target populations; thus, we did not include these in our new recruitment strategy.

Community Outreach and Recruitment

The greatest impact, by far, on our study and others caused by the pandemic, was on recruitment and retention. ^{10,26,31} With traditional recruitment sites, such as temples, churches, and community events shut down during the pandemic, our CHAs were not able to conduct outreach and recruitment as planned. During this time, we relied on our CCAB to help problemsolve recruitment issues. Together with the CCAB, our team explored all recruitment avenues. The CCAB provided information about community events and services as the restrictions were lifted. The CCAB also introduced CHAs to business owners and other community leaders. Additionally, we broadened the settings for community outreach to include nail salons, Asian grocery stores, restaurants, university student organizations, Asian sororities and fraternities, community flu clinics, COVID-19 vaccine clinics, and nursing homes as they re-opened. CHAs

also held picnics in the park or student gatherings with their social networks and staffed study recruitment tables outside of Asian grocery stores.

The CHAs are active members of their communities and understood that community members often traveled between cities in this state and families were interconnected. Based on their input, we expanded our recruitment area outside of a Midwestern city to reach Southeast Asians in other major cities across the state.

Respondent Driven Sampling – a Novel Recruitment Strategy

Even with the increased presence on social media and new recruitment sites, enrollment remained low. Study investigators determined that in addition to the current sampling strategy, we would increase participation by having peers refer members into the study from their social networks to our protocol, also known as Respondent-Driven Sampling (RDS). RDS is a chainreferral strategy for recruiting hard-to-reach populations or in studies on sensitive subject matter; 11,32 both conditions exist in our project. We are currently using RDS with enrolled participants to serve as "seeds" who refer their network of peers into the study by introducing them to the study team. CHAs asked enrolled participants if they would be willing to refer other individuals, such as their peers or extended family members. If the participants agree, then the CHAs provided a brief overview of the study and eligibility criteria. The participants received three uniquely coded, non-replicable coupons to give to potential participants. For each person from their peer group that enrolled into the study, the participant (seed) received a \$20 gift card (up to \$60 total). The CHAs then followed the regular protocol for enrolling new participants. Once the CHA accepted and verified the coupon, the seed received payment for their referral. As these communities are small, potential participants may be approached by different people. Potential

participants can only be enrolled once into the study; thus, we compensate the seed whose coupon we received first.

Initially, our IRB had concerns with RDS as they perceived this method as paying participants a "finder's fee." However, as Heckathorn and others ^{33,34} have demonstrated, a finder's fee in research refers to a case with a power differential, such as physicians who are paid to recruit their patients into studies. In contrast, recruitment in RDS involves relationships among equals (peers and extended family members). There was no power differential. ³⁴ Using this logic, the university IRB approved the RDS strategy acknowledging that this method used a peer-to-peer strategy to expand study recruitment.

Addressing COVID-19 Concerns

As members of the community, our team also experienced COVID-19 concerns as they related to the study and their community interactions and on a personal level. CHAs had concerns and misconceptions about COVID-19 and the vaccine. When the vaccine became available, our university encouraged all employees to get vaccinated. Only one member of the CHA staff had a medical background. At first, CHAs were hesitant about the COVID vaccination, but after further clarification about how the vaccine was produced, its effectiveness, and method of action, staff were willing to be vaccinated. Once the COVID-19 restrictions were lifted and face-to-face recruitment returned, protection for both the CHAs and the potential participants was essential. Vaccine hesitancy is a real concern, not only for our staff but also for the communities in which we work. We wanted to be certain that staff could serve as resources for current information about COVID-19 when they attended community events. If our staff were to relay misinformation into the community, it could have resulted in health

problems or even cause major trustworthiness issues. Therefore, we had to ensure that our staff had an accurate and thorough understanding of the issues related to COVID-19 and the vaccine to appropriately address concerns within their communities.

COVID risk and education became integral during the height of pandemic restrictions. It was as important to provide information about mitigation strategies to potential participants as it was to describe the importance of cancer screenings. In addition to educating communities about early cancer detection and the importance of breast and cervical cancer screening, we felt an obligation, as public health professionals, to educate communities about COVID-19 including transmission mitigation, testing, and vaccination. We provided additional COVID-19 materials related to prevention, travel, and vaccination in Khmer, Lao, and Vietnamese and a list of local testing and vaccination sites to those who requested information.

When working with underserved communities, study personnel needed to flex their schedules and priorities to address fears relevant to the community, such as COVID-19 questions and fears. Often refugee and immigrant communities have limited access to accurate, timely, and linguistically appropriate COVID-19 prevention information or know how to seek treatment for COVID-19; thus, many are hesitant to seek care for COVID-19. ⁴⁵⁻⁴⁷ This meant that our study team had to also be informed about COVID-19 to accurately address concerns. We closely followed the latest CDC guidelines and requirements from our university medical center. We viewed sharing COVID-19 information with potential study participants as part of our responsibility as public health researchers.

Conclusions

The disruption in community-engaged research led to several setbacks in our study. As the COVID-19 pandemic continues to impact scientific research for the foreseeable future, community-engaged researchers must implement creative ways of recruitment and engagement.

10 The ultimate success of our strategies to meet enrollment goals is still unknown. To date, we continuing to engage the communities in which we work. The participants enrolled in our study are critical to our long-term goal of eliminating cancer screening disparities in Southeast Asian refugee and immigrant communities. Increasing breast and cervical cancer in refugee and immigrant communities strongly relies on the assistance of trusted CHAs.
48-50 These trusted community liaisons are critical to the success of community-engaged research with medically underserved and/or racial and ethnic minority populations. The strategies described here are intended to help community-engaged researchers minimize barriers to research with hard-to-reach populations during a public health crisis such as the COVID-19 pandemic.

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