THEORY AND METHODS

Virtual research with urban Native young women: Cautionary tales in the time of a pandemic

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ABSTRACT

Background: Community Based Participatory Research (CBPR) is a particularly powerful approach to research with American Indian and Alaska Native (AIAN) communities who have been subject to a history of mistreatment and unethical research. In person meetings, discussion, and engagement with tribal members and the community have become an essential component of CBPR in AIAN communities. With the advent of the COVID-19 pandemic, AIAN communities have moved to close or sharply curtail in-person activities, precluding in-person research methods. Current best practices for research with AIAN communities assumes in-person engagement; little guidance exists on engaging AIAN communities in research using virtual technologies. Our study, Native WYSE CHOICES, was intentionally designed prior to the pandemic to be virtual, including recruitment, enrollment, intervention, and assessment with urban AIAN young women.

Objectives: We present our perspectives on virtual research with AIAN communities, including the critical role of our advisory partners to inform the virtual intervention design and recruitment methods in the formative stages of our project.

Methods: Experiential reflection among research team and community partners.

Conclusion: Virtual technologies, such as videoconferencing, social media, and mobile health apps, offer many tools to reach communities, especially in a pandemic. The virtualization of research with AIAN communities requires a significant investment in time, resources and planning to mitigate disadvantages; it cannot fully replace in-person-based CBPR approaches, but may offer many strengths and unique advantages for research, especially in a pandemic.

Community Based Participatory Research (CBPR) is an orientation to research committed to equitable engagement of partners throughout the research process.[1] This approach ensures research is relevant to the needs of the community, knowledge and resources are equally shared, and findings can be used to inform efforts to address health outcomes.[2] CBPR is a particularly powerful approach with American Indian and Alaska Native (AIAN) communities who have been subjected to a history of mistreatment and unethical research.[3,4] In-person meetings and engagement with tribal members and the community have become essential components of CBPR.[4,5] Many reservation-based AIAN communities, attendant to their status as sovereign nations, require tribal approval of research often contingent on the integration of CBPR within protocols, and on proper assurances of community confidentiality since past research disclosing tribal identities has socially, economically, and culturally damaged tribal nations.[3] Over 70% of AIANs in the US reside in urban settings—away from reservation-based communities—and as such, tribal research review and approval is not required.[6] Nevertheless, many urban based AIANs are still affiliated with their respective tribal communities, therefore similar protections and stipulations of CBPR as those who reside on reservations are warranted.[7] However, with the advent of the COVID-19 pandemic, AIAN communities, both urban and reservation-based, have moved to close or to sharply curtail in-person activities—researchers are searching for virtual ways (including social media, video conferencing, and telephone) to continue to authentically engage AIAN communities in research. Still other researchers, with little prior experience with AIAN-focused research, see the move to virtual research as an opportunity to include AIAN participants at levels previously unobtainable using common data collection strategies. While a great deal of prior research has documented best practices for research with AIAN communities, most of this work assumes in-person engagement; little

guidance exists on how best to engage reservation-based and urban AIAN communities in research using virtual technologies.[8-10] Telehealth and other virtual platforms are increasingly used to expand mental health and health care access in AIAN communities; findings of the effectiveness of these approaches strongly support the diffusion and uptake in AIAN communities.[11-13] Although virtual engagement and data collection is an option when working with AIAN urban and reservation-based communities, both during and beyond the pandemic, it must take place with approval of the community. Moreover, it is important for researchers to respect the communities' request for space, time, and revision to research procedures.

Native WYSE (**W**omen, **Y**oung, **S**trong, **E**mpowered) CHOICES (**C**hanging **H**igh-risk alcoh**O**l use and **I**ncreasing **C**ontraception **E**ffectiveness **S**tudy) is an AIAN centered alcohol-exposed pregnancy prevention program which translates CHOICES into a mobile health (mHealth) national delivery for urban Native young women.[14] CHOICES is an evidence-based alcohol exposed pregnancy (AEP) preventive intervention supported by the CDC. The CHOICES intervention was culturally adapted to ensure relevance to young AIAN women and adolescents of a tribe in the upper Midwest. The intervention outlined in this paper, Native WYSE CHOICES (NWC), builds directly on this work. NWC aims to develop a social media-based recruitment strategy, deliver adapted intervention via mHealth delivery and rigorously evaluate the effectiveness of the mHealth translation of CHOICES through a randomized controlled trial (RCT). Importantly, NWC is geared towards urban AIAN young women age 16-20 making it the only known AEP prevention program for urban AIAN young women. In this study, approved by the Colorado Multiple Institutional Review Board (protocol # 18-0574), our focus is on urban AIAN young women; no tribal review and approval was sought since the focus population resides outside of tribal council or tribal research review jurisdiction (the exception is

Anchorage, under the purview of the Southcentral Foundation, for which we are currently seeking an approval). For this manuscript, we focus on the formative phase of the study, in which we engaged community to translate the adapted CHOICES into a virtual platform and to provide feedback on the recruitment, enrollment, and assessment phases of our RCT. Through this process, we have grappled with many challenges of virtual research well before the pandemic; our experiences may be useful as others re-tool efforts for virtual research. Here, we present our perspectives on the critical role of our advisory partners, participant engagement to inform intervention design, recruitment of study participants through social media, and strategies for research participation.

Community Advisory Board

We assembled a Community Advisory Board (CAB) of twelve leaders and researchers at both national and urban AIAN community levels to inform the design, implementation, and evaluation of our study. CAB members were recruited through existing networks among members of our research team—which includes indigenous and non-indigenous community leaders, scholars, and researchers, many of whom have been in the field of AIAN adolescent health practice and research for more than 20 years. The CAB includes well-respected representatives from AIAN clinical and behavioral health service organizations, urban Indian community centers with ongoing youth programs, experts in mHealth approaches, including programs and services specifically for AIAN youth. In addition, two urban AIAN young women, in their late teens, were recruited to assist advisory activities by offering perspectives on AEP prevention needs and concerns among urban AIAN young women.

All CAB members have the capacity to access technology for virtual participation. The composition of our CAB was critical to achieve the range of expertise required during the

formative phase of this virtual project. Indeed, participation of CAB members came early, in the proposal writing stage. Many of them provided important detail on potential virtual recruitment processes, types of interests of urban AIAN youth in mHealth engagement, and electronic translation of in-person, AIAN-serving programs. We have regularly engaged our CAB members through formal virtual meetings convening all advisory board members, ad-hoc virtual meetings or electronic correspondence with individual CAB members who had the expertise needed to accomplish various aspects of our project, and regular calls with our youth representatives for their input.

At the beginning of the project, we convened all CAB members in a 2-day in-person meeting to assist us in ensuring the suitability of our research to AIAN communities. At this meeting, we clarified roles and also had a dialogue about members' positions relative to community relationships. First, we acknowledged that, to their constituents, members' participation implied trust in our project, and we would hold ourselves accountable – and to the members –for honoring that trust. Second, we discussed the challenge of CAB members for AIAN-focused research; members made clear they could not represent the diversity of cultures included in the project. Both the CAB and the project team committed to avoiding pan-Indian approaches and to integrating in creative ways cultural adaptations to our project. In our subsequent formal CAB meetings, held virtually 2-3 times a year, we have revisited and affirmed those commitments. In short, like in-person-based CABs, virtual CAB engagement with our project helped to align priorities and strategies with community needs, even while we identified inherent limitations to engagement given the national scope and the virtual approach. While we had the luxury of a first in-person meeting, the agreements and CAB roles established were based on CBPR principles and were employed in the move to virtual meetings. Importantly, the

CAB input through our virtual meetings have improved design, content, measures, and will eventually assist our interpretation and dissemination of results – results critical to any project, but perhaps more so in an online environment since virtualized protocols may be new to the community.

In addition to our formal meetings with the group at-large, we have had frequent informal calls and ad hoc virtual meetings with individual CAB members, depending on their area of expertise, to discuss content and materials; strategies to pilot our surveys and app; best approaches to recruit participants for our intervention through social media; platforms such as Facebook, Instagram, and Twitter; and to review and provide feedback on our control arm material. Our engagement of the CAB was not only to provide guidance on our study, we were also able to build the capacity of our CAB members and increase their skills and knowledge of best practices to translate an in-person program to a mobile platform, effective recruitment strategies through social media, and prevention of fraudulent hits to online surveys. Additionally, the CAB meetings supported networking opportunities among members, creating connections at a national level.

Intervention design

In addition to CAB engagement, to solicit more information to inform both methodology and content in our mobile health app, we conducted three rounds of iterative in-depth interviews (IDIs) with urban AIAN young women about social media usage, alcohol/birth control use, and the importance of Native culture. We recruited participants for IDIs through advertisements on popular social media platforms such as Facebook and Instagram. We targeted urban areas with relatively large populations of AIANs through social media advertisements. We screened participants based on self-identified race (AIAN; sole race or in combination with some other

race), age (16-20-year-old), sex (female), place of residence (urban area with population greater than 50K), language spoken (English), currently not pregnant and not living on tribal land or reservation. In addition to social media advertisements, we also distributed study flyers via community organizations and attended local Native American community events (pre-pandemic). We used *REDCap* (Research Electronic Data Capture) for screening for eligibility and for collecting screener data. Participants who were interested in participating in IDIs were directed to a URL to begin a REDCap screener survey to answer questions to determine eligibility. Screener survey participants were consented and were provided an overview of the project and a statement about eligibility, prior to answering the questions to determine their eligibility. In total, we received 815 hits on the REDCap eligibility screener, of which 115 were eligible for IDIs. Out of the eligible participants, 32 participants completed the screener page but did not provide contact information, and 51 participants rescheduled or did not respond to scheduling attempts. We were successful in completing IDIs with the remaining 32 participants. Prior to conducting the IDIs, the interviewer reviewed with eligible participants the consent form and confirmed their interest.

We found social media advertisements to be an effective tool for recruitment for urban AIAN young women, and as such, we will pursue social media as a platform to recruit participants into our study. We would also like to emphasize for our IDI study population, our presence at various local community events prior to the pandemic such as powwows and festivals and partnering with local community organizations increased our trustworthiness and visibility within the community and boosted our IDI recruitment efforts. Post-pandemic, we shifted our work to further building our virtual presence in preparation for recruitment of our

RCT, for example through social media posts, and partnering with other AIAN-focused online organizations in outreach events, like virtual powwows, or twitter chats.

Social media recruitment

Through the formative phase of our study, we have found that social media offer several advantages to recruitment. For instance, researchers can reach participants beyond specific geographies that are dispersed across a given geography, as in the case of urban AIANs. Additionally, relevant to the time of this writing, during the COVID-19 pandemic, potential study participants as well as the research team could avoid exposure to pandemic risk. For research projects focused on reservation-based communities – virtual recruitment can avoid the current dangers of exposure but should not replace responsibility for community review and engagement, including adhering to tribal research review requirements when working with reservation-based communities.[15-17] In urban settings, community review is often vital for success, although the formality of the process may vary considerably.[18] The scope of Native WYSE CHOICES is national, so local urban community review is not feasible. In our project, we called on our CAB to review our project recruitment protocols. Specifically, we asked CAB members about their input on how to best recruit urban AIAN young women while attending to urban AIAN community expectations of research. Their feedback resulted in the following recruitment protocol for our IDIs, and eventually for our RCT, we designed a participant screening protocol to ensure reasonable checks to confirm urban recruitment of study participants. First, participants had to indicate their residence in high population areas (populations of 50,000 or more), and thus unlikely to be tribal lands. Second, because some tribal communities are located within urban boundaries, we further asked participants if they lived on tribal lands; if endorsed, participants would be ineligible for our project. Finally, based on

feedback from the CAB we did not collect information on tribal affiliation; that is, we did not ask participants about their affiliation of particular sovereign nations or cultural groups. The CAB recommended this approach to protect cultural confidentiality and preclude possibilities of stigmatizing specific AIAN cultural groups based on alcohol use, sexual activity, or other sensitive topics.

Virtual research participation

Recruiting research participants electronically can be time consuming and costly. Targeting advertisement can help, of course, and platforms such as Facebook or Instagram provided some options for directing advertisements to particular demographic groups, including age or gender. However, our experience has indicated such strategies generate only limited interest among our population of interest – urban AIAN young women – and in fact produced bursts of fraudulent hits to our IDI screener. We have found creating a social media presence, that is, building a brand for the project that is recognizable and trusted, greatly assists in generating interest in participation in research. To build our brand and social media presence we had frequent ad hoc meetings with social media experts employed at the organization of our CAB member who is the director of a trusted and well-respected virtual portal for Native youth health programs. They provided insight into relevant content for our population of focus, and also followed our social media accounts and frequently liked or reposted our content—resulting in an increase of followers of our social media platforms. Further, internally we have a team of young adults from both indigenous and non-indigenous backgrounds on our research team who meet on a weekly basis to develop and post fresh content, select messages consistent with our branding that is also visually appealing, introduce our team members to show the personable side of our virtual work, and provide information on the overall goal of helping urban AIAN young

women to make healthy decisions for themselves and generations to come. We have also had to be nimble in working across multiple social media platforms and integrating new ones as favored outlets change quickly. We determined which platform is preferred based on continuous tracking of the number of follow and likes we have of our material. In addition, our broader CAB partners have assisted building trust in our social media presence by liking our social media handles and by retweeting and forwarding our content. As social media presence extends, responsibility and vigilance for attending to the project's integrity increases, as does our responsibility to organizational partners hosting or forwarding our content; with expanded presence, there is greater probability of inappropriate comments or comments questioning our validity which can quickly move through social media. These social-media-related efforts, including generating creative new content and monitoring responses, require extensive investment in time and resources.

Challenges and Barriers

The virtualization of research with AIAN communities requires a significant investment in time, resources and planning to mitigate the disadvantages, including loss of direct community contact and engagement, and truncated bi-directional learning.[19] We experienced directly several substantial challenges. For example, we encountered difficulty with the registration of our app with digital distribution services due to institutional technical issues. Also, the process of translating our curriculum posed challenges: adapting an in-person curriculum to an interactive, engaging, and culturally relevant app required several iterations of animation videos and storyboards. However, we were able to successfully overcome these challenges by contracting with an app development company and a graphic designer—expenses that must be considered when developing and using virtual technology for an intervention. Further, while the

focus of our study was urban young AIAN women and most in this demographic have increased levels of internet and wireless connectivity, many in rural and tribal communities do not. Connectivity is often a major concern in virtual research—as those most in need are likely excluded. Finally, for studies that include children, careful consideration to parental consent is critical – but also complicated – in virtual research.[20]

Conclusion

The continued stress placed on AIAN communities by the pandemic will require novel virtual approaches to expedite care and support for those affected, not just from loss of health, but because of wider – and likely vast – social, economic, and cultural changes.

Virtual technologies, including videoconferencing, social media, and mobile phone applications, cannot fully replace in-person-based CBPR approaches, but may offer many strengths and unique advantages for research, especially in times of a pandemic. Now might be an especially important time to reach out to the AIAN communities to assess needs and offer resources, and virtual platforms can provide a medically safe way to do that.

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