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Dickerson, Daniel

Parker, Jennifer

Johnson, Carrie

et al.

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Recruitment and Retention in Randomized Controlled Trials with Urban American Indian/Alaska Native Adolescents: Challenges and Lessons Learned

Daniel L. Dickerson, D.O., M.P.H.¹, Jennifer Parker², Carrie Johnson³, Ryan A. Brown², Elizabeth J. D'Amico²

¹UCLA, Integrated Substance Abuse Programs (ISAP) University of California Los Angeles, Los Angeles, CA, USA

²RAND Corporation, 1776 Main St, Santa Monica, CA, USA

³Sacred Path Indigenous Wellness Center, Los Angeles, CA, USA

Abstract

Background: Although the majority of American Indians/Alaska Natives reside in urban areas, there are very few randomized controlled trials analyzing culturally centered substance use prevention interventions for this population.

Methods: We describe methods employed to recruit and retain urban American Indian/Alaska Native adolescents into a randomized controlled trial, which was focused on testing the potential benefits of a substance use prevention intervention for this population. We also report challenges encountered in recruitment and retention of participants and strategies employed addressing these challenges. Data collection occurred from August 2014 to October 2017.

Results: We partnered with two community-based organizations in different cities in California. We utilized American Indian/Alaska Native recruiters from communities, placed flyers in community-based organizations, and asked organizations to post flyers on their web and social media sites. We also offered gift cards for participants. Our initial recruitment and retention model was moderately successful; however, we encountered five main challenges: 1) transportation, 2) increasing trust and interest, 3) adding research sites, 4) getting the word out about the project, and 5) getting youth to complete follow-up surveys. Strategies employed to overcome transportation challenges included shortening the number of sessions, offering sessions on both weekends and weekdays, and increasing bus tokens and transportation options. We hired more staff from American Indian/Alaska Native communities, added more research sites from our previously established relationships, and were more pro-active in getting the word out on the project in American Indian/Alaska Native communities. We also utilized more field tracking, and emailed

Corresponding author: Daniel Dickerson, D.O., M.P.H., Associate Research Psychiatrist, UCLA, Integrated Substance Abuse Programs (ISAP), 11075 Santa Monica Blvd., Ste. 200, Los Angeles, CA 90025, phone: 562-277-0310, fax: 310-312-0552.

Trial registration

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Declaration of conflicting interests

The authors declare that they have no competing interests.

and mailed survey invitations to reach more participants for their follow-up surveys. Because of our efforts, we were nearly able to reach our initial recruitment and retention goals.

Conclusions: Although our research team had previously established relationships with various urban American Indian/Alaska Native communities, we encountered various recruitment and retention challenges in our study. However, by identifying challenges and employing culturally appropriate strategies, we were able to collect valuable data on the potential effectiveness of a substance use prevention intervention for urban American Indian/Alaska Native adolescents. Findings from this study assist toward the development of potentially successful strategies to successfully recruit and retain urban American Indian/Alaska Native adolescents in randomized controlled trials.

Keywords

American Indians; Alaska Natives; randomized controlled trials; recruitment; retention

Background

Approximately 70% of American Indians/Alaska Natives reside in urban areas [1]. However, there are few randomized controlled trials with this population that analyze the potential benefits of substance use prevention interventions [2]. Randomized controlled trials analyzing the potential benefits of substance use prevention interventions among urban American Indian/Alaska Native adolescents are also quite limited, and most randomized controlled trials have been conducted on reservations and with older American Indian/Alaska Native participants [3]. In a recent study describing funded studies of prevention interventions for American Indians/Alaska Natives under the National Institutes of Health (NIH) mechanism, Intervention Research to Improve Native American Health (PAR-14-260), only one of thirty-one studies focused on analyzing the benefits of an intervention among urban American Indian/Alaska Native teens using a randomized controlled trial design [4]. Furthermore, there is little work describing the experiences of conducting randomized controlled trials in urban settings with American Indian/Alaska Native adolescents. As a result, there are few well-developed strategies that address recruitment and retention of urban American Indian/Alaska Native adolescents in randomized controlled trials.

Inherent challenges exist in conducting randomized controlled trials with American Indian/Alaska Native populations as researchers in the past often conducted studies with American Indians/Alaska Natives unjustly and without community input. Community interest was typically not considered, which led to a mistrust of the research process within many American Indian/Alaska Native communities [5]. For example, in one study conducted in an Alaska Native village during the 1970s, researchers released findings of high alcohol rates to a major news source prior to discussion with community members [6] resulting in a negative media portrayal of their community. Also, in a study conducted with the Havasupai tribe in 1990, researchers obtained DNA samples to analyze potential genetic clues to the tribe's high rate of diabetes without consent to investigate other aspects of their lives, including theories of the tribe's geographical origins. The researchers then published findings without the tribe's consent suggesting that contrary to the tribe's origin story, its ancestors migrated

across the Bering Sea [7,8]. Furthermore, past “helicopter research” sought to exploit American Indians/Alaska Natives by swooping into American Indian/Alaska Native communities, gathering data, and leaving them without recommending any changes. As a result, researchers took their data and then left American Indian/Alaska Native communities without any resources to implement, disseminate, or sustain promising interventions [8,9]. Furthermore, most researchers in health promotion research are not American Indian/Alaska Native, which dampens community trust necessary for successfully conducting studies within this population [4,10,11,12].

Another challenge conducting randomized controlled trials with American Indians/Alaska Natives in urban areas is that the population is small and widely dispersed across large urban environments, making it more difficult to find and recruit participants. Visible American Indian/Alaska Native neighborhoods rarely exist in urban areas [13], and there are very few American Indian/Alaska Native retail clusters, cultural resources, art centers, or community centers that exist within the urban setting. This population has also been described as being unrecognized and “invisible” to both the general population and policy makers [14]. Urban American Indians/Alaska Natives may also find it challenging to connect with other American Indians/Alaska Natives, and clinics and organizations where they may be able to learn about potential research opportunities [15]. In addition, urban American Indians/Alaska Natives experience high rates of poverty and unemployment [1], which may decrease feasible transportation options necessary for research participation. Thus, significant barriers may exist for researchers seeking to successfully recruit and retain urban American Indians/Alaska Natives into randomized controlled trials.

Motivational Interviewing and Culture for Urban Native American Youth (MICUNAY)

Our team worked together with several American Indian/Alaska Native communities in the state of California to develop and test Motivational Interviewing and Culture for Urban Native American Youth (MICUNAY), an alcohol and other drug use prevention intervention program that integrates motivational interviewing and American Indian/Alaska Native traditional practices [16,17]. The foundation of MICUNAY is based on extensive community-based work conducted by Daniel Dickerson and Carrie Johnson [18,19,20, 21], Kurt Schweigman [22], Ryan Brown [23,24,25], and Elizabeth D’Amico [26,27,28,29]. MICUNAY targets a variety of behaviors, including reducing alcohol and other drug use and increasing well-being, spirituality and cultural identification. All MICUNAY workshops use a motivational interviewing approach and different motivational interviewing strategies, such as discussion of the pros and cons of alcohol and other drug use and rulers [30]. MICUNAY also utilizes the Northern Plains Medicine Wheel, which is a conceptual, culturally acceptable model [31] routinely utilized in health clinics serving urban American Indians/Alaska Natives in California. The Northern Plains Medicine Wheel focuses on emotional, mental, physical, and spiritual aspects of well-being and helps to provide participants with a visual representation of session content.

The purpose of this article is to describe how we successfully conducted a randomized controlled trial in American Indian/Alaska Native urban communities with American Indian/Alaska Native adolescents across the state of California. We discuss how we incorporated

feedback from focus groups with the MICUNAY community advisory board and the adolescent community advisory board to address initial challenges in starting up the project, the challenges we encountered over the course of the project in recruitment and retention of participants in the randomized controlled trial, and the strategies we employed to address these challenges.

Methods

Research Team

The research team was comprised of co-Principal Investigators Dr. Daniel Dickerson from University of California, Los Angeles, Integrated Substance Abuse Programs (ISAP), Dr. Elizabeth D'Amico from RAND, Dr. Ryan Brown, co-Investigator from RAND, and the RAND Survey Research Group . We also collaborated with our community partner, Sacred Path Indigenous Wellness Center (SPIWC), led by Dr. Carrie Johnson. Dr. Dickerson is an Alaska Native (Inupiaq) addiction psychiatrist known for his research on the development and implementation of culturally centered substance use treatment and prevention interventions [16,21]. Dr. D'Amico is recognized for her work developing and implementing motivational interviewing interventions with vulnerable adolescent populations [32,33,34], and Dr. Brown has conducted field research with marginalized youth populations around the world, including five years of fieldwork among the Eastern Band of the Cherokee Indian [25,29]. The RAND Survey Research Group team was led by Ms. Parker, Senior Survey Coordinator, who oversaw research activities. Survey Research Group has extensive experience interviewing people of various ethnic backgrounds in diverse settings and collaborating with community-based organizations. SPIWC is a non-profit (501c3) organization that provides consultation and service-related assistance for research entities and organizations conducting research within American Indian/Alaska Native communities led by Dr. Johnson. Dr. Johnson is Wahpeton Dakota, and has worked within the American Indian/Alaska Native community for over 20 years. SPIWC helps to ensure that research and services provided are culturally appropriate. SPIWC also employs recruiters and facilitators in different communities to assist with community engagement, which ensures that individuals are familiar with their community and are well respected and trusted.

Research Overview

The NIH mechanism, Intervention Research to Improve Native American Health (PAR-14–260) funded the MICUNAY research study. The purpose of this funding opportunity announcement was to develop, adapt, and test the effectiveness of health promotion and disease prevention interventions in Native American populations. This funding opportunity announcement sought intervention approaches that targeted both individual behaviors and intervened at social and institutional levels. This funding opportunity announcement required that researchers employ a community-based participatory research approach, focusing on intervention development during the first year. Researchers would then conduct the randomized controlled trial, followed by analysis of the potential benefits of the intervention [35].

As part of the intervention development phase, prior to the randomized controlled trial, our team worked with several urban American Indian/Alaska Native communities and organizations to finalize the development of MICUNAY, learn about challenges facing urban American Indian/Alaska Native adolescents, and discuss recruitment and retention strategies for the randomized controlled trial [16,36]. We used the feedback from these focus groups to modify our approach in order to enhance recruitment and retention. We conducted focus groups with American Indian/Alaska Native adolescents, providers, parents, and the MICUNAY community advisory boards at several research sites. We had an adult community advisory board, which consisted of American Indian/Alaska Native leaders in the community, elders and community members, and an adolescent community advisory board, which consisted of teens who provided feedback throughout the project. Focus groups discussed all project materials and recruitment plans. The project employed Robert Young (Pueblo of Acoma), an American Indian graphic artist to design various options of project logos. These logos were then vetted by community members to select the final project logo. This assisted with community engagement and initial interest in the project.

Next, we conducted the MICUNAY randomized controlled trial. We invited youth in two urban areas in northern and southern California between the ages of 14 and 18 to participate in the project (See Overall Demographics on Table 1). All youth who enrolled in the randomized controlled trial completed a baseline survey. We administered the survey on paper, and youth who completed it received \$25 cash. We held survey sessions at community partner sites when possible. We randomly assigned youth to one of two groups. We asked youth assigned to the control group to attend a community wellness gathering. We also asked youth assigned to the intervention group to attend both a community wellness gathering and the MICUNAY intervention workshops. Community wellness gatherings consisted of community gatherings with various cultural events aimed toward promoting healthy behaviors and an alcohol/drug free lifestyle. MICUNAY workshops incorporated traditional American Indian/Alaska Native teachings with motivational interviewing. A group facilitator experienced in working with American Indian/Alaska Native populations led each of the three, two-hour workshops. We offered youth who randomized to the control group the opportunity to attend MICUNAY workshops after data collection was completed. We asked all youth to complete follow-ups at 3-and 6-months. Youth completed follow-up surveys via web or on paper [17].

Initial Recruitment Approach

To ensure community engagement and successful recruitment of youth, we worked with SPIWC to hire American Indian/Alaska Native recruiters and facilitators who were from the communities where we were conducting the research. We asked community partner staff at organizations that serve American Indian/Alaska Native adolescents to place flyers. We also asked them to post the flyer on their web and social media sites. We trained site staff on how to present the project to interested youth, and ask interested youth to complete a Consent to Contact form that staff would then fax and send via FedEx to RAND. The Consent to Contact forms asked for basic contact information to give RAND Survey Research Group permission to call the parent/guardian to explain the project and ask for consent.

RAND Survey Research Group hired interviewers from outside the community to conduct baseline survey sessions based on our discussions with the community. This was because surveys asked about personal information such as substance use. Based on our discussions and focus groups, it was clear that having people outside the community was important for the survey component so that teens felt comfortable handing in completed surveys, which was more likely if they could hand them in to a stranger, versus someone from their community who may know a family member.

Initial Retention Approach

In order to encourage attendance at baseline survey sessions and the MICUNAY workshops, we initially offered bus tokens or train reimbursement to assist with transportation costs. In addition, the research team gave teens who attended all three MICUNAY sessions a certificate of completion and a MICUNAY hoodie. At community wellness gatherings, we conducted raffles for prizes like re-usable water bottles, project t-shirts, and project hoodies, and one \$50 gift card per gathering. We also provided adolescents with a \$50 gift card for completing the 3-month survey and a \$75 gift card for completing the 6-month survey.

Results

Challenges encountered

We encountered five main challenges during initial recruitment: 1) transportation, 2) increasing trust and interest, 3) adding research sites, 4) getting the word out about the project, and 5) getting youth to complete follow-up surveys. In order to address these challenges, we developed several different strategies. We describe each challenge and the strategies we employed in the following paragraphs.

Modified Recruitment and Retention Approaches

Transportation: Initially, we had planned to offer six one-hour MICUNAY workshops. Prior to conducting our randomized controlled trial, we received feedback from focus groups that transportation to workshop locations could be challenging for youth. For example, one provider stated, “I think in [our community], transportation is a big issue.” Based on these discussions, we decreased the number of workshops from six one-hour sessions to three two-hour sessions. One urban American Indian/Alaska Native youth stated, “I think more [sessions] on the weekends than on the weekdays because people would come at 7 o’clock [p.m. during weekdays].” In response to this feedback, and in order to maximize attendance at the MICUNAY workshops, we also held sessions on weekends in addition to weekdays. This allowed teens with conflicts during the week to attend sessions. Reduced weekend traffic also eased the burden on parents to be able to bring their son or daughter to sessions. To further assist with transportation issues, we also increased the amount of bus tokens and train reimbursements offered. In the youth focus group, one urban youth suggested, “Provide rides like we do here. They pick us up and drop us off.” After further discussion with our community partner organizations, when sites offered transportation, we provided stipends to assist organizations with costs as necessary. These modifications increased the chances that these urban American Indian/Alaska Native teens could attend MICUNAY sessions.

Increasing trust and interest—Burdened with their own workloads, community partner staff who agreed to help distribute flyers and present the project to teens indicated that it was difficult to take time to explain the project to youth given their day-to-day work requirements. In meeting with our community partners, we quickly learned that we would need to hire dedicated staff from the American Indian/Alaska Native community to help with recruitment and increasing interest and trust in the community. Survey Research Group and SPIWC worked together with several American Indian/Alaska Native organizations in each city to identify American Indian/Alaska Native community members and respected individuals in the community to approach potential participants in a culturally appropriate manner in order to increase comfort levels. We emphasized to all the communities our plans of returning to present our findings and obtain feedback on their view of the project and interpretation of findings. We also emphasized that they could use data from our project for future grants to support their organizations as data on urban American Indian/Alaska Native adolescents are very limited.

Adding research sites—Due to lower than expected recruitment early on in the randomized controlled trial, the project approached a multitude of other community-based organizations and added several new research sites in California. Dickerson and Johnson had several previously established relationships with American Indian/Alaska Native communities and organizations throughout California. Their presence in community meetings and discussions at new research sites helped to garnish trust among community members. These community partners were particularly encouraged that we offered MICUNAY workshops to teens randomized to the control group upon completion of data collection, thus highlighting that our project wanted to ensure that everyone who wanted the intervention was able to receive it. Community partners also appreciated our willingness to share de-identified, aggregate data once analyses were completed. Given our community-based participatory research approach, we were able to partner with organizations in 10 cities across northern, central, and southern California.

Getting the word out about the project—In order to increase recruitment, dedicated staff created a social media presence for the project by maintaining a Facebook page of project related events. We also set up informational events with our community partners where we would present the project to staff and the communities they served. We always provided food at these events, and we had entertainment when feasible. During these presentations, we would explain to staff that the project would not compete with their current programming, but could help supplement programming and be an additional resource. We also discussed the importance of research on urban American Indian/Alaska Native teens, and how programs could use our aggregate data to help with future funding opportunities. Prior to conducting our randomized controlled trial, feedback from the community advisory board focus group suggested a wider recruitment approach. For example, one community advisory board member stated, “I think in terms of recruiting, that’s why we focus the different areas that are close to here, just so you have a wider group of kids to select from...so that’s why we try to disperse the people to [section of community] and to [section of community] to have a wider pool of kids that would be less duplicated.” Applying this feedback, our recruiters attended more community events such as

Pow Wows, American Indian/Alaska Native gatherings, and established American Indian/Alaska Native youth and parent groups to help get the word out about the project. The project set up informational tables at these events so recruiters could introduce the project to teens and their families. In order to encourage teens to approach the MICUNAY table, we purchased giveaways, such as colored pencils that changed color when touched, re-usable water bottles with the project logo, and T-shirts. Feedback from our community advisory board focus group highlighted the importance of incentivizing participants. Thus, we added an incentive of either a \$5 Target gift card or a free movie pass for teens who attended each session. For community wellness gatherings, we assisted organizations by paying the presenters they brought in, which allowed them to enhance the cultural programming for their communities.

Getting youth to complete follow-up surveys—When we began fielding the 3-month follow-up survey, we initially experienced a low response rate of survey completion, which was surprising to us given the incentive (\$50) and that the survey could be completed via the web. We therefore began to use both email and mailed survey invitations, increased the number of mailings, added in phone follow-ups, and employed field tracking for the hard-to-reach teens. Through field tracking, we found that by using mobile phone technology, teens were mostly at home and were willing to complete the survey. In talking with teens and families about why they had not completed the survey, many indicated that barriers to completing the survey on the web and via mail were mostly due to lack of internet access and lack of experience with and motivation to use “snail mail.”

Recruitment and retention results

Our initial goal when we started the project was to enroll 200 teens. We enrolled 185 youth during the randomized controlled trial period, which was 92.5% of our goal N of 200. Of these 185 youth, we randomized 115 to receive both the community wellness gathering and MICUNAY (MICUNAY group) and 70 the community wellness gathering only (community wellness gathering group). In terms of retention, 69 of the MICUNAY group (60%) and 44 of the community wellness gathering group (63%) attended a community wellness gathering within 3 months of the baseline survey, for a total of 113 youth (61%). Of MICUNAY group teens, 66 (57%) attended all three intervention sessions within 3 months, and 94 youth (92%) attended at least one session within 3 months. Overall, we were able to reach 76% for follow-up surveys at 3 months, and 82% at 6 months [17].

Discussion

This study provides crucial data on understanding and overcoming challenges that exist when conducting randomized controlled trials with urban American Indian/Alaska Native adolescents. Although our research team was well prepared to carry out the proposed research activities, we experienced many challenges that affected both recruitment and retention during the randomized controlled trial. These challenges included transportation, increasing trust and interest, adding research sites, getting the word out about the project, and getting teens to complete follow-up surveys. However, because we worked closely with our community partner, SPIWC, and with the individual urban communities, we were able

to develop strategies to address these challenges, which helped us nearly reach our initial recruitment goal. In addition, we had good retention rates at both three- and six-month follow up. Given that few randomized controlled trials are conducted with urban American Indian/Alaska Native teens, findings provide important information on how to successfully conduct a randomized controlled trial among a marginalized population. We hope that our experience can assist toward the development of more formalized strategies to successfully engage vulnerable populations in randomized controlled trials.

Despite our team's previously established community relationships, we still encountered numerous recruitment and retention challenges. For example, the small population size of urban American Indians/Alaska Natives compared to other racial/ethnic groups and lower visibility required us to add more sites to meet our recruitment goals. Furthermore, we had to be proactive with our strategies by conducting community forums in each location. During these forums, we clarified the purpose of the randomized controlled trial, and the crucial need for more culturally centered prevention programs for this population to ensure the community felt comfortable with the research. We also discussed with each community how to best address transportation barriers and other socioeconomic disadvantages that exist among this population. For example, we addressed the lack of internet access by using mobile phone technology for some participants. Overall, even with our team's extensive experience in collaborating with these communities, we still took numerous steps to build community trust and understanding of the project.

Use of these community-based participatory research methods allowed our research team to garnish trust and interest and fully engage these urban American Indian/Alaska Native communities in California, which was necessary to successfully conduct our study. We accomplished this by involving the community at the start of the project, providing community presentations, training new MICUNAY facilitators within communities, and hiring community workers. We also offered the opportunity for adolescents randomized to the control condition to participate in MICUNAY after their participation in the study, and we scheduled presentations in each community to present the findings from the project.

Given our previous work with these populations, we had established relationships with American Indian/Alaska Native communities that created an opportunity to add more research sites and work effectively in partnership with 10 different urban American Indian/Alaska Native communities. In addition, it was crucial to have research team members of American Indian/Alaska Native descent, which helped increase the trust of the communities in the research process, and led to the development of new relationships.

We further enhanced our recruitment efforts by proactively reaching out to the community for help. Our research team was comprised of very dedicated community members in each city who were part of American Indian/Alaska Native organizational staff and who attended numerous American Indian/Alaska Native community events and meetings to share information on the MICUNAY project. We also assisted these communities by providing funds for gatherings to have different presenters (e.g., beading workshop, hoop dancing, storytelling) for the community wellness gatherings, which significantly enhanced the cultural programming that these communities were able to provide to families.

Our initial low retention rates were surprising given that follow-up surveys were web-based and incentivized. However, our proactive outreach efforts, including mailing reminders, phone calls, and field tracking helped reverse this trend and provide a better understanding of how to increase the number of completed surveys. As a result, we were able to obtain retention rates similar to other randomized controlled trials conducted among other urban racial/ethnic youth populations [34,37,38,39,40,41]. Although this study provides important information on engaging urban American Indian/Alaska Native populations in randomized controlled trial research, there are some limitations. First, we conducted this study in California, thus, we cannot generalize results to other urban areas in the United States. For example, urban areas in other states may not experience the same barriers that we did in California (e.g., some urban areas have excellent public transportation), and they may also have barriers that we did not experience. In addition, our team had two American Indian/Alaska Native investigators who had extensive experience conducting research and working in these community-based settings. Other projects may not have the same level of experience or connections with the community.

In conclusion, findings from this study significantly build on our knowledge about effective recruitment and retention strategies for randomized controlled trials focused on analyzing the potential benefits of substance use prevention interventions conducted among urban American Indian/Alaska Native adolescents, thereby helping to address a significant and under-recognized public health issue in the United States. We hope that our results will contribute to the development and implementation of future randomized controlled trials among this population. Findings highlight the importance of developing collaborative and meaningful relationships with urban American Indian/Alaska Native communities, and emphasize that by working closely with community members, it is possible to design a culturally appropriate randomized controlled trial, thereby increasing success, which can lead to better prevention and intervention programming for this under recognized and vulnerable population.

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Table 1.

Demographics of Total Sample (n=185)

Age	n, %
14	51 (28%)
15	38 (21%)
16	45 (24%)
17	31 (17%)
18	19 (10%)
Gender	
Female	105 (57%)
Male	80 (43%)
Race/Ethnicity [^]	
Hispanic/Latino	83 (45%)
American Indian/Alaska Native	150 (81%)
Asian/Asian American/Pacific Islander	8 (4%)
Black/African American	21 (11%)
White/Caucasian	32 (17%)
Other	8 (4%)
Mother's education >=High school graduate	120 (65%)
Father's education >=High school graduate	94 (51%)

[^] Note that all youth had to self-identify as American Indian/Alaska Native to be part of the project. They then completed a survey asking them to label their race/ethnicity. These numbers and percentages reflect what youth reported on the survey and can overlap if they identified more than one race/ethnicity. Thirty-five youth did not check American Indian/Alaska Native on the survey, although they self-identified verbally as American Indian/Alaska Native to be in the study.