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Community Based Participatory Research to Reduce Oral Health Disparities in American Indian Children

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Abstract

Community based participatory research is an approach aimed to equitably involve community members, representatives, and academic researchers in all aspects of the research process. Using this methodology can help integrate cultural knowledge into interventions, supporting researchers to effectively partner with communities in addressing health disparities. The Center for Native Oral Health Research (CNOHR) collaborates with two American Indian (AI) tribes to advance oral health knowledge and practice, including the conduct of randomized controlled clinical trials of culturally sensitive behavioral interventions for primary prevention of early childhood caries (ECC). This manuscript describes the development of researcher–community partnership, and the development and implementation of the two clinical trial in the community. It also gives a detailed account of the strategies developed through the community input in recruitment and retention of the study participants and finally the lessons learnt during the study implementation.

Keywords: Community based participatory research; American Indian; Community advisory board; Center for native oral health research; Early childhood caries

Introduction

In recent years, an alternative paradigm of public health research focusing on gathering data within cultural contexts, as opposed to the traditional "outside expert" approach, has seen increasing support due to its validity and ability to address complex health problems [1]. Community based participatory research (CBPR) is an approach that aims to involve community members and representatives from community organizations, with academic investigators in all aspects of the research processes, thereby ensuring the relevance of interventions and approaches, and ultimately enhancing integration of the produced knowledge into the community [2]. CBPR principles required for meaningful and relevant research were compiled by Israel et al., and can be broadly summarized as follows: "recognition of a community as a unit of identity; facilitate collaborative, equitable partnership in all phases of the research, achievement of balance between knowledge generation and intervention for mutual benefit of all partners, capacity building among all partners, and a focus on local relevance of public health problems and long term sustainability [3]". Employing a CBPR approach may prove to be a successful strategy in addressing several key obstacles in engaging diverse groups in health research [4].

CPBR approach ensures the relevance of the research data to the community and expedites approaches for effectively translating community interventions into public health policies and prevention into wide spread preventive practice at a community level [5]. Since this form of partnership elicits mutual ownership of the research process and its products, specific facets of the intervention that are a priority from the community's perspective may be more cogently and realistically addressed, creating an ideal system for facilitating prevention [5, 6]. This method has been successful in addressing a variety of health outcomes and reducing health disparities in many ethnic-minority groups [5].

American Indian (AI) communities are strongly supportive of CBPR and express less enthusiasm for research processes that are not based on participatory practices [7]. In fact, as tribal nations assert their sovereignty in the area of research, the use of CBPR has become less an option and more a precondition for research [8].

In addition to the characteristics of CBPR mentioned, there are other advantages of community based research in AI communities. First, CBPR is consistent with strong tribal values of sovereignty and self-determination. The methodology allows tribal governmental control over some aspects of the research process and prioritizes community interests in driving the research design. Self-determination is kept intact since partnerships between communities and researchers facilitate the dissemination of research results to improve community programs and services [9]. Researchers are required to thoroughly and transparently define the project, including its ethical ramifications and potential benefits to the community [10]. This orientation to research also empowers the AI community to design and test its own interventions or programs, tailoring such efforts to the priorities of community members.

Though CRPR methodology is being used broadly in research focused on prevention of a variety of health problems, its use in oral health research has been limited, and only a few recent studies have reported CBPR to be a priority in the development of oral health interventions [11, 12, 13].

This manuscript describes researcher—community partnership in developing culturally-acceptable and effective strategies to prevent early childhood caries (ECC) in AI children and to improve implementation for the two clinical trials.

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Table 1: CBPR components for the two clinical trials at Center for Native Oral Health Research.

Components	Clinical Trials	
	CNOHR Study I	CNOHR study II
Partnership titles		
CAB	+	+
CAC	+	+
Parent councils	-	+
Representatives involved in CAB		
Tribal Education specialist	-	+
Health board members	+	+
Members of organizations serving trial communities	+	+
Members of tribal research review board	-	+
Parents participating in the study	+	-
Dental hygienist working in the community	+	-
Head Start programs	-	+
Facilitators of the meetings		
Primary investigators/faculty	+	+
Project managers	+	+
Field staff	+	+
Dissemination of results and study updates		
Tribal Review Boards	+	+
Tribal Leaders	+	+
Tribal Health and Human Services Committee	+	+
Tribal Health Administration	+	-
Head Start Centers	-	+
Tribal, National and International conferences	+	+

Methods

In 2008, the Center for Native Oral Health Research at the University of Colorado Anschutz Medical Center was funded by the National Institute for Dental and Craniofacial Research (U54DE019259) to develop and test interventions for preventing ECC among AI populations. ECC prevalence is most extreme in American Indian children, suggesting disparate risk and the need for effective, culturally-acceptable interventions [14]. Through two separate clinical trials, CNOHR Study I and CNOHR Study II, each in a separate reservation-based tribe, CNOHR investigators have worked closely with AI communities to create meaningful oral health interventions by adapting to CBPR approaches. CNOHR's mission is to work with AI communities to conduct, facilitate, and disseminate the next generation of AI oral health intervention research, with an initial focus on oral infections and their complications – primarily dental caries, or decay.

The first trial, "Behavior Change for Oral Health in AI Mothers and Children (CNOHR study I) in a Northern Plains tribe [15]", assesses the effectiveness of motivational interviewing (MI) to encourage prevention of dental caries in children through behavior change in new mothers. We hypothesized that children of AI mothers randomized to the MI intervention will achieve greater reduction of dental caries compared to children of those randomized to receive community services alone. Six hundred mothers or caregivers of newborns are currently enrolled in the study and randomized to one of the two intervention groups; the caregiver—child dyads arebeing followed for 3 years. The intervention is delivered by trained community members.

The second trial, "Preventing Caries in Preschoolers: Testing a Unique Service Delivery Model in American Indian Head Start Programs [16]", is an innovative community-based trial in Head Start Centers in a Southwestern tribe. A total of 1016 children enrolled in 52 Head Start Centers across a large, rural reservation were recruited into the study. This 3-year, cluster-randomized trial (2 years of intervention plus an additional year of outcomes assessment) compares outcomes for a fluoride varnish and oral health promotion intervention provided by tribal members trained as Community Oral Health Specialists (COHS) with usual care in the community.

The primary outcome measure in both studies is the level of dental caries; secondary outcomes are oral health-related behaviors, knowledge, attitudes and oral health-related quality of life, as well as other mediators and moderators associated with dental caries. Both the clinical trials use CBPR approach and engage the tribal communities in all aspects of research from development to dissemination. Both the studies received approval from tribal and University institutional review boards initially and have approved continuing review subsequently. This manuscript has also received approval from both tribal research review boards.

Community partnership development

Before the grant application was submitted, several planning and advisory session were held for members of the tribes and communities with whom we expected to work, including tribal representatives and other AI community members, health board representatives, education board representatives, members from tribal governance, and Indian Health Service representatives. Feedback from such individuals provided critical input to our decisions related to priorities for addressing AI oral health. We also sought input for the general plans, the draft mission statement, and specific aims, as well as the conceptual framework that had been drafted for CNOHR thorough a planning and feedback process.

After funding was received and CNOHR was established, a community advisory committee (CAC) that provides input on all CNOHR research activities, and a community advisory board (CAB) that provides input on the two clinical trials were formed. Apart from these committees, tribal members serve as key informants, field staff, MI interventionists (CNOHR Study I) and Community Oral Health Specialists (CNOHR Study II) Table 1.

In the development of the studies, before their implementation, the study investigators presented the research design, recruitment

Table 2: How did participants hear about CNOHR Study I.

How did you hear about us?	Frequency	Percent
In person	232	69.25
Referral	61	18.21
Print Media (Posters and newspaper)	16	4.78
Radio	12	3.58
Electronic media (Facebook and emails)	9	2.69
Others	5	1.49

methodology, and community outreach activities to the tribal groups, CAC, and CAB members. The CAB and CAC members suggested changes in research design to accommodate cultural and tribal norms and priorities. Throughout the implementation of the studies, the study investigators and field staff remain actively engaged with community partners for recommendations and valuable feedback.

The over over-arching goal of the CAB is to represent experiences, insight, and perspectives of AI people and communities, as well as tribal governments, and their health and education organizations. These contributions are essential for conducting relevant and productive community-based research aimed at reducing oral health disparities experienced by AI communities. The objectives of the CAB includes: shaping the intervention, advocating for the communities' participation in the projects, and advising the study staff and investigators regarding recruitment and retention strategies. CAB members included board members of the Indian Health Services, a tribal education specialist, Head Start liaisons, and other community members (Table 1). The CAB meets annually, and the meetings are held on the reservations for both the studies (Table 1).

The CAC has a more general oversight role; they monitor the overall progress of CNOHR. CAC contributions include development and planning of the research projects and other efforts to address AI disparities in oral health. They advised about the value of this work to the community; suggest strategies to overcome obstacles to completing the work such as challenges to retention of participants, and other issues related to community perceptions. CAC members include the President of a tribal college; and individuals who represent tribal governments, AI-serving health organizations, and other community clinical and social settings. The CAC meets annually.

The field offices for the research studies are managed by tribal/community members who have good community relationships—essential for building trust in the community—and active community participation. The Motivational Interventionists and the Community Oral Health Specialists who deliver the interventions are from the community and live on or near the Reservations. During in-depth interviews conducted with the CNOHR Study I field staff members, they confirmed that being from the community makes it easier for them to build rapport with participants and their families, more effectively engage the participants, and locate study participants [17]. Community Oral Health Specialists are lay community members trained to deliver oral health health promotion intervention to Head Start children and their parent/caregivers. They are familiar with the local customs and geography of the Reservation, speak the local tribal language, and are sensitive to the families' life-circumstances. These characteristics allow them to better understand and meet the needs of the study participants [16].

Results

Community contributions for CNOHR Study I

The recommendations from the CAB, CAC and other community partners have been critical in developing several strategies to initiate the studies. During the development of CNOHR Study I, members recommended that we translate the study's name to the local language and use the translated name on all community outreach material including flyers, pamphlets, billboards and other participant-relevant materials. Also, they suggested that all of the art work on the community outreach materials be designed by AI artists to depict actual circumstances of the people participating in the study [18]. The tribal review board and the CAB and CAC members strongly recommended not having a pure control group in the study. Our community partners argued that there would be limited, if any, community support for a project that did not improve oral health for all families. Consequently, a strategy was proposed whereby the project enriches oral health information and services available to all of the families in the community. In practical terms, moreover, we believe that building community programs through expanding awareness of the simple changes we are recommending will increase the effectiveness of the MI work focused on maternal behaviors related to their children's oral health. By enhancing community services, we lay the ground work on which our intervention is built. We provide all children in the trial (whether they are assigned to the MI component or not) with oral health exams and referrals. We also provide age-appropriate dental health aids (such as tooth brushes, gum wipes, and tooth paste) for all family members.

CAB members also advocated for the use of multiple community venues to recruit participants and increase oral health awareness. These included Women, Infant and Child (WIC) offices, school-based programs, Native Women's Health (NWH) clinics, and the maternity ward at the Indian Health Services hospital. The CAB and the CAC members also recommended that we use media in the form of newspapers, radio advertisements, and public service announcements to connect with people in the community. Community events like basketball games, Pow Wows, health fairs, after-school events, and lunch programs for mothers were also used as forums to spread oral health awareness.

Table 2 describes data that were collected by the CNOHR Study I staff on the effectiveness of using media in recruitment of study participants. The most effective recruitment strategy was in-person recruitment. The majority (69 percent) of the participants were recruited by personal contact with the field staff at various venues in the community. Interestingly, over 18 percent of the participants were referred by other participants in the study. This may speak to the interconnectedness of this Northern Plains tribal community. Media advertisements, which included newspaper, radio, posters, and even Facebook, helped to recruit 11 percent of the participants. In an age of increasing popularity of social media, nothing worked better than in-person recruitment through a staff member, many of whom were community members.

Among the 95 participants who provided detailed information about recruitment location, the majority (54 percent) were approached at the IHS maternity (OB) ward. Other recruitment sites included the

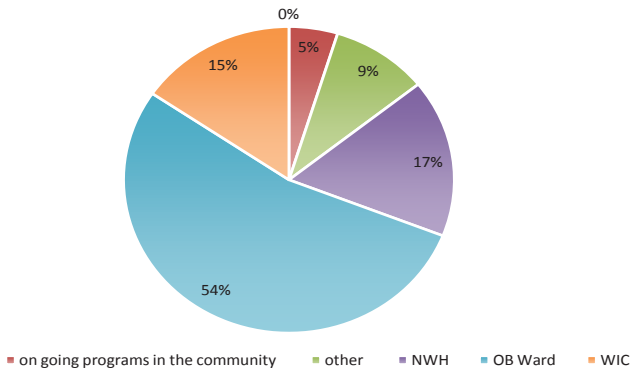

Figure 1: Where did CNOHR I field staff recruit study participants**.**
OB ward: Research staff recruited participants at the maternity ward at the Indian Health Services Hospital.
Women, Infant and Child program (WIC): Research staff recruited participants at the WIC.
Native Women's Health (NWH): Research staff recruited participants at the NWH.
Ongoing programs in the community: Research staff recruited participants from other programs in the community.
Other: Random contact with staff in the community, recruitment at immunization clinic and walk-ins to the field office.

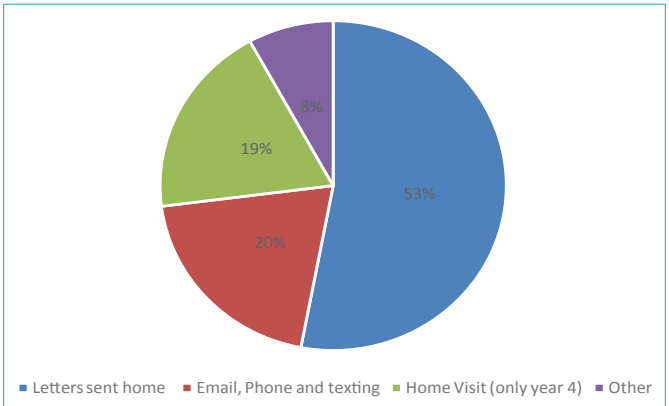

Figure 2: How were participants retained in CNOHR Study II.
Letter sent home: personalized letters sent to each participant's house.
Email, Phone and texting: Phone calls, email, or text message from staff member asking participant to make an appointment.
Home Visit: Unscheduled drop-in visit to participant home.
Other: Includes participant remembering about the study from previous contact, hearing a radio ad, running into a staff member during another home visit, and word of mouth.

NWH clinic (17 percent), WIC (15 percent), and community events (5 percent) (See Figure 1).

In ongoing CAB meetings, members confirmed that our challenges in retaining participants were common issues within the community. They gave several recommendations on how to improve retention efforts through enhanced community services, by adding more billboards on the reservation with oral health messages and specified suitable locations for the billboards; by airing interviews with the study PI and field staff on the local tribal radio, and by using new and simpler oral health messages for parents and grandparent such as "lift the lip" of your child to check for spots on teeth. CAB members also suggested adding respondent compensation for dental screenings conducted on all of the children in the study. This suggestion was implemented in September 2012 with a significant impact on recruitment and retention, thereafter.

Community contributions for CNOHR Study II

During the implementation of CNOHR Study II, CAB and the CAC members played a vital role in shaping the research design, the intervention and later in developing recruitment and retention strategies for study participants. They suggested sending out personalized letters to participating families to remind them of upcoming enrollment events, and emphasized the importance of an annualre-consenting of participants to remind them of what the study was about. CAB members with relationships with the Head Start Centers suggested developing strong working relationships with Head Start teachers and staff to have them help in the recruitment of new and retention of already-enrolled families. Participants in the study were first recruited through the Head Start program. Information letters were given to Head Start teachers at the beginning and end of each school year to inform them of the upcoming school year's project activities. As suggested by CAB members, phone texting was added as a communication strategy, as it was less expensive when compared to receiving calls on a cell phone.

Each year CNOHR Study II staff surveyed returning participants regarding how they became aware of upcoming retention events. Figure 2 gives an overview of how participants were reached over the entire period of CNOHR Study II. As predicted by the CAB and CAC members, personalized letters were an effective retention strategy for 53 percent of returning participants. Other strategies were telephone calls, text and/or email (20 percent), and home visits (19 percent). The recruitment strategies of home visits and text messages came directly out of the demands of board members and study participants. These numbers illustrate how community input and suggestions were essential in retaining participants throughout the study period.

When it was seen that parent attendance at the oral health promotion parent events was low, this issue was presented to the CAB and CAC. Members recommended several strategies to improve parent participation in CNOHR Study II. This included the following strategies:

- Increased communication with the parents - COHS often had to do reminder calls to the parents, and teachers assisted by helping the COHS remind the parents.
- Partnering with local parent committees - COHS attended the local parent committee meetings and the monthly agency parent community meetings and provided study presentations for them.
- Scheduling events to accommodate work schedules - Having flexibility with calendars, alternate locations, and spacing of events helped.
- Using culturally relevant imagery–For example, CAB members suggested using culturally relevant puppets, so a horse with big teeth for the children was ordered and used.
- Advertising the study in the newspaper and radio, and making the communications more personalized.

Community contributions regarding study dissemination strategies

A critical piece of CNOHR's work is bringing their research findings back to the communities with whom they work. Our work is conducted to improve the oral health outcomes of our community partners and reduce the oral health disparities they experience. CNOHR aims to develop and improve mechanisms for disseminating results of research at the interface of health and culture. This could have a greater likelihood of application for the benefit of the local populace and would enhance transfer of the requisite knowledge, skills, and attitudes to other researchers working in AI communities to reduce oral health disparities. Investigators and staff have disseminated the baseline results and updates on the progress of the studies to community partners at tribal research conferences, parent councils, Head Start Centers and tribal review boards. Final results of the study will be similarly disseminated when they are available.

Dissemination of the study interventions and research findings within the oral health research community is also important. CNOHR investigators have produced numerous peer-reviewed publications and presented baseline results at national and international academic conferences. In compliance with tribal IRB regulations, all the manuscripts, abstracts, and presentations are reviewed and approved by tribal IRBs before they are submitted.

Investigators at CNOHR also recognized the need to create community-academic enrichment activities that could contribute to the dissemination of our research experiences. CNOHR has held several oral health disparities seminars and invited investigators who work to improve overall health of AI/AN populations, as well as oral health disparity investigators working with other indigenous populations such as Aboriginal communities in Australia. These platforms provide venues for sharing results and meaningful discussions of common challenges faced in working with indigenous communities globally.

Discussion

Several lessons were learned during the implementation of these studies. First, it is imperative to invest time to create these academic—community partnerships; it takes years to build relationships based on trust [8, 19]. CNOHR is a part of the Center for American Indian and Alaska Health (CAIANH), which has been working to promote the health and well-being of AI/AN communities for many years; thus, CNOHR benefits from these relationships that have been built by CAIANH over many years.

We learned that long approval times must be anticipated, because approvals have to be obtained from many organizations including the Indian Health Service IRB, tribal council or tribal health boards, tribal IRBs and other community partners such as Head Start Centers. In CNOHR study II, we sought acceptance by about 50 groups, including, the Head Start Schools, chapter houses, the different agencies (districts) on the reservation, which took about a year. Tribal IRBs have over sight for research projects, thus it is important to respect the schedule of review boards and plan in advance for submission for protocol, manuscripts, and other documents.

It is important to have effective and alternate communication systems in place for all community partners. Reservation-based field-offices and offices for the tribal IRBs and or health boards may not have street addresses and may depend on PO Box numbers; also the feasibility of having electronic communications systems such as email, and cell phone may be difficult or inconsistent in a rural location. This may delay the delivery of documents and other materials sent to them, thus several forms of communication should be used to connect with the community partners; however emphasis should be placed on face to face communication by attending tribal IRB meeting and other community events. It is essential to follow both institutional and tribal guidelines for dissemination of results and publication policies. Data should be disseminated in a respectful manner, guided by the communities, and the results should be reported back in a way that is meaningful and useful to them.

Working with AI communities benefits from, and indeed, requires working cooperatively with communities, working from a perspective of respect and trust, spending time with communities to develop partnerships, and ensuring that tribal members are involved in all stages of the research [7]. Though CNOHR involved the tribal communities during the planning phase by conducting advisory meeting and discussing priorities of the communities and the general mission; they stopped short of asking for significant commitments of time or input prior to funding. After the funding was received, CNOHR involved AI communities as true partners in oral health research by intricately involving them in research design, designing interventions, initiation, implementation, recruitment, retention and dissemination of data.

Strategies that were developed with the input of the community members helped to increase recruitment and retention for both the studies and also to increase oral health awareness in the community in general. CBPR holds great promise for research in Indian country as it can produce useful and culturally appropriate prevention interventions, and it can provide AI communities with the data and tools to develop new solutions to reduce oral health disparities. Because the approach is consistent with tribal values and goals, we believe it may eventually represent the only acceptable approach to carrying out research within these communities where the needs are so great, but also so specific in terms of the manifestations of health problems and the cultural requirements related to the acceptability of interventions.

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