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A Framework for Conducting a National Study of Substance Abuse Treatment Programs Serving American Indian and Alaska Native Communities

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Abstract

Background—Because of their broad geographic distribution, diverse ownership and operation, and funding instability, it is a challenge to develop a framework for studying substance abuse treatment programs serving American Indian and Alaska Native communities at a national level. This is further complicated by the historic reluctance of American Indian and Alaska Native communities to participate in research.

Objectives and Methods—We developed a framework for studying these substance abuse treatment programs (n = 293) at a national level as part of a study of attitudes toward, and use of, evidence-based treatments among substance abuse treatment programs serving AI/AN communities with the goal of assuring participation of a broad array of programs and the communities that they serve.

Results—Because of the complexities of identifying specific substance abuse treatment programs, the sampling framework divides these programs into strata based on the American Indian and Alaska Native communities that they serve: (1) the 20 largest tribes (by population); (2) urban AI/AN clinics; (3) Alaska Native Health Corporations; (4) other Tribes; and (5) other regional programs unaffiliated with a specific AI/AN community. In addition, the recruitment framework was designed to be sensitive to likely concerns about participating in research.

Conclusion and Scientific Significance—This systematic approach for studying substance abuse and other clinical programs serving AI/AN communities assures the participation of diverse AI/AN programs and communities and may be useful in designing similar national studies.

Keywords

Indians; North American; substance abuse treatment centers; research methods

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Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

INTRODUCTION

As the literature regarding substance misuse and its impacts on American Indians and Alaska Native (AI/AN) communities has grown over the last two decades, so has our knowledge on the optimal approaches to conducting this work. In particular, research regarding measurement, epidemiological methods, and implementation of participatory research approaches have received considerable attention (1–3). In contrast, we were unable to identify any papers focused on the methods for conducting national studies of substance abuse treatment programs with AI/AN communities.

This is concerning as such studies must address three critical challenges in their design to effectively study substance abuse treatment for AI/ANs at a national level: population characteristics, service system structure, and history of and attitudes towards research in AI/AN communities. In this article, we first provide background on each of these three issues and the solutions we developed in designing a national study of attitudes toward and use of evidence-based treatments (EBTs) in substance abuse programs serving AI/AN communities.

AI/AN Population and Service System Structure

AI/ANs are a diverse and heterogeneous population. There are over 560 federally recognized tribes in a population that numbered over 2.95 million in 2000 and over 4.1 million if people listing AI/AN in conjunction with other races are included (4). The AI/AN population is concentrated in the largest tribes, with the six largest tribal groupings accounting for 42% of the total AI/AN population (5). Equally important is the fact that the majority of AI/ANs now reside in urban/suburban areas (5).

Health care for AI/ANs was promised in many of the treaties between the U.S. government and tribes. In 1955, the Indian Health Service (IHS) was formed by the federal government, which placed clinics and hospitals in rural and reservation communities that could be utilized at no cost to eligible tribal members. Although all of these programs were initially operated directly by the IHS, the Indian Self-Determination and Educational Assistance Act (Public Law 93-638) has allowed tribes to take over their operation at their discretion. Because small tribes receive limited IHS funding (6,7), they often form consortiums with other nearby tribes for health services or contract with local non-AI/AN health service organizations for provision of health care. Health services in Alaska evolved differently. Services there are operated by the 21 AN Health Corporations that were formed through the Alaska Tribal Health Compact. Urban AI/AN Health Clinics, which were chartered by the IHS as a response to the large numbers of AI/ANs who migrated from rural and reservation communities in the 1950s and 1960s are typically operated as nonprofit entities. There are also several independent treatment programs that do not have an IHS charter and are unaffiliated with specific tribes or tribal entities (8).

These patterns in population and service structure create significant challenges in conducting a national study of substance abuse treatment programs for AI/AN communities. First, there is a mismatch of the distribution of programs and the AI/AN population, with services often concentrated in rural and reservation communities and fewer AI/AN-specific services in urban areas, where most AI/AN people now reside. Second, given the diverse structures and ownership of these substance abuse treatment programs, along with significant programmatic and administrative instability characteristic of many human services programs in AI/AN communities (7), the development and maintenance of a reliable directory of these programs is unfeasible, making the identification of programs currently in operation particularly challenging.

Attitudes toward Research

A final challenge for conducting a national study is the long-standing concerns that AI/AN people and communities have regarding research. These concerns have multiple roots, including the perceived ties of research to centuries of cultural genocide and oppression, the failure of research to address the high priority needs of AI/AN communities, the lack of dissemination of research findings to the AI/AN communities that participate in research, and tragic examples of research that has harmed AI/AN communities (2,9).

Researchers and AI/AN communities have responded to these concerns through the growing reliance on community-based participatory research methods to assure that AI/AN communities have a strong voice regarding the research that takes place in their communities and are fully informed on the outcomes and implications of this work (2). But such methods are highly resource intensive and focused on building collaborative mechanisms between researchers and specific AI/AN communities; something that is largely impractical in a large, national study involving hundreds of AI/AN communities. Similarly challenging is the garnering of necessary local approvals for research participation, which varies from simple administrative authorization from a program director to formal review by a research review board or IRB, or even approval by a board of directors or tribal council.

Study Overview

This study is focused on gathering information on use of EBTs among substance abuse treatment programs serving AI/AN communities. Despite their promise for improving the quality of care, EBTs present major challenges for substance abuse treatment programs serving AI/AN communities. For example, because EBTs were developed with limited involvement of AI/AN communities, their design and content may conflict with AI/AN beliefs and healing traditions. This may result in considerable resistance to their use by substance abuse treatment programs serving these communities. Additional challenges for the use of EBTs in these programs include the lack of human resources to implement EBTs as specified by their developers and the lack of infrastructure for evaluating their appropriate implementation [10]. See www.ucdenver.edu/caianh/ebp for further information about the project.

This project consists of three phases. In the first phase, we convened an advisory board consisting of administrators, clinicians, and researchers to discuss the major issues these programs confront in considering the use of EBTs and to refine the project design (10). In the second phase, we conducted a series of “program case studies” in which we visited 18 of these programs and utilized qualitative methods to explore the dynamics of program development and implementation and how the potential use of EBTs were considered in these processes. In the third and final stage of the project we conducted a national survey of AI/AN substance abuse treatment programs in which we explored their use of EBTs and factors that might impact evidence-based practice use (e.g., attitudes, resources, etc.). The study framework described in this article was developed specifically for this third and final phase of this project.

SAMPLING FRAMEWORK

In developing a sampling framework capable of addressing the mismatch of the distribution of programs and the AI/AN population and the diverse structures and ownership of substance abuse treatment programs, we made several key decisions that shaped our sampling framework. First, because our research is focused on understanding the attitudes toward and use of EBTs at the level of substance abuse treatment programs, we concluded that the unit of analysis needed to be the programs themselves rather than the communities that they serve. Second, to address the mismatch of program and population distribution, we

decided to utilize a stratified sampling approach. In stratified sampling, a population is divided into different groups, or "strata," based on key distinguishing characteristics (11). The resulting framework – displayed in Table 1 – is divided into five strata based on the size of the population served (e.g., the 20 largest tribes – Stratum I) and/or the underlying service system structure (e.g., substance abuse services operated by the AN Health Corporations – Stratum III).

Third, we decided to incorporate the use of a replicate strategy for Stratum IV (other tribes). A replicate is a random subset of a sample or stratum that enables researchers to concentrate their recruitment efforts on a manageable number of potential participants while assuring broad representation in the recruited sample. Because all programs contained within a replicate are contacted with full recruitment strategies prior to the release of additional replicates, the strategy also maximizes opportunity for inclusion among difficult-to-recruit participants. Replicate strategies are also useful when researchers are unsure how many potential participants they will need to contact to recruit a targeted number of participants (12).

In the replicate strategy included in this framework, we focused on assuring broad geographic representation or treatment programs within this stratum by dividing the United States into four geographic regions and randomly selecting tribes in replicates of 50 with proportional weighting of tribes by region based on the total number of tribes in each region.

PARTICIPANT RECRUITMENT FAMEWORK

The above sampling framework focuses on identifying tribes and organizations that operated or were connected to substance abuse treatment programs. Using existing tribal, organizational, and substance abuse program listings, consultation with IHS and state substance abuse treatment administrative staff, and the analysis of publically available information on the World Wide Web, we identified specific treatment programs that had the potential to provide substance abuse services to AI/AN communities. We then contacted each of these programs and determined whether the program provided such services. If the program did provide substance abuse treatment services to AI/AN communities, we described the project and asked whether there was a member of their staff whom we could ask to participate.

In designing our recruitment efforts, we used three key mechanisms to address concerns from potential participants regarding participation in research. First, we asked the members of our Advisory Board if we could publically acknowledge their involvement in this process. We hoped this would help potential participants feel more comfortable with this research given the prominence of several Advisory Board members in the AI/AN substance abuse treatment community. All Board members agreed to be publically acknowledged, and their names are listed on the project's Web site and on the informational packet we send potential participants. Second, we gave presentations regarding the project design and emerging results at two national meetings where substance abuse treatment staff and administrators were likely to attend (e.g., the annual IHS behavioral health conference), hoping to raise awareness of the project while publicly addressing any concerns. Third, we added a standard query to our recruitment letters and telephone scripts regarding the need of potential participants to obtain permission prior to their completion of the survey. We also included this query at the start of the survey questionnaire itself. If potential participants did indicate that they required administrative permission, we provided them with informational packages that summarized the study and survey (noting that the full survey could be accessed online from the project's Web site). If potential participants indicated that they needed research review board or formal approval from a local IRB, we provided all materials necessary for

such a review and offered our assistance with the process. We hoped that this acknowledgment of the importance of following local protocols in research projects such as this project, despite its national scope, would address potential participants' concerns about a project that did not involve the development of strong local partnerships.

IMPLEMENTATION RESULTS AND CHALLENGES

Four-hundred and forty-five programs were approached to participate in the project and 192 surveys were completed (a participation rate of 63%) (see Table 1). The major implementation challenge relates to the identification of specific programs and clinics and the complex, multistep process described above. Although most of the larger tribes and urban Indian health clinics have at least one substance abuse treatment program, many of the smaller tribes (stratum IV) either share services with other tribes in their area or refer to non-tribal entities. Indeed, 138 communities we contacted did not offer substance abuse services (with 88% of these in stratum IV) and are not included in this study, or the above participation statistics. This further documents the limited access that many AI/AN communities have to substance abuse services operated by a tribal entity. Although our study design did not allow us to specifically assess the success of our approach to addressing concerns about research, most individuals we reached were interested in the project and in participating. Those who required permission to participate appreciated the readily available materials to work through this process (as well as our availability to assist and/or lead this process). Only a small minority of individuals we contacted have refused to participate (11%) or did not respond to our invitation (15%).

Indeed, our participation rate of 63%, excellent by the standards of phone and online survey research (13), suggests that our strategy has been fairly effective, and that substance abuse treatment providers are more willing to participate in such research than we originally anticipated.

DISCUSSION

National studies of AI/AN substance abuse treatment programs encounter numerous challenges, most notably the lack of highly reliable program listings. The framework we developed for this project provides a structured approach to such work, approaching the problem of identifying programs by either focusing on community (e.g., Tribes) or a known organizational entity for health service delivery (e.g., AN Health Corporations). Although the effort to identify specific programs is complex, it is a critical component for such efforts as it greatly reduces the likelihood of overlooking programs that are not included in existing program lists or have changed their location or name. Stratum V (other local and regional programs) is perhaps the most challenging in this regard. Indeed, their lack of connection to a known tribal or health service entity means they can be easily overlooked, and we are much more dependent on existing lists, internet searches, and word of mouth to find these programs. However, it is our belief that there are very few such programs (our initial search suggests there are approximately 10 nonaffiliated AI/AN programs) and that because of their need to market their services to AI/AN communities, we expect that we will be able to readily identify them through the search strategy we developed through other strata. Finally, this framework focuses on substance abuse treatment programs that have a primary focus on serving AI/AN communities, but previous investigations suggest that a substantial proportion of AI/AN people seek services from programs that do not have this focus (14), which is consistent with the significant number of communities and health service entities we contacted that did not offer substance abuse treatment services. Researchers interested in understanding substance abuse treatment for AI/AN people at an even broader perspective than this study will need to take into account the need to include treatment programs without

an explicit AI/AN focus. Also, although we aimed at recruiting 100% of eligible programs, it may be possible to use this framework to develop representative subsamples of the different strata. For example, a research team could sample 100% of Strata I (large tribes) and II (urban clinics) and 50% of Strata III–V, substantially reducing participant recruitment efforts but still assuring a broad representation of programs.

Studies addressing other health issues in AI/AN communities are likely to be able to make use of this framework as the population, service system, and research attitude issues it is designed to address are likely to be comparable to that for studying substance abuse treatment. Although this framework may have components that may be useful for conducting studies with other marginalized communities (particularly those procedures for addressing concerns about participating in research), its design may require substantial adaption given the unique population and service system characteristics of AI/AN communities.

National studies of substance abuse treatment programs serving AI/AN communities have substantial potential for improving our understanding of the range of available services and related service delivery challenges that studies focusing on a single program or geographic area cannot provide. This framework has strong potential for standardizing such work, making such studies more efficient and comparable.

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TABLE 1

Sampling framework for substance abuse treatment programs serving American Indian and Alaska native communities.

Strata	Sub-strata	Participation rate (%)
I. Large tribes (20 largest, by population on reservation or service area [e.g., Oklahoma])	None	40
II. Urban Indian health clinics (36 members of NCUIH)	None	67
III. Alaska native health corporations (21 formed as part of Alaska Tribal Health Compact)	None	79
IV. Other tribes (federally recognized minus the 20 largest). Because of the large number of tribes (317) and the likely data collection challenges, tribes were selected in replicates of 50 with proportional weighting of tribes by region	Four geographic regions: (1) Pacific Coast; (2) Intermountain West and Southern/Central Plains; (3) Northern Plains, Midwest, and Northeast; and (4) Southeast and Mid-Atlantic	64
V. Other local and regional programs (independent nonprofit or for profit)	None	50

Notes: NCUIH ¼ National Center for Urban Indian Health. Overall participation rate was 63%.