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Forward steps and missteps: What we've learned through the process of conducting CBPR research in rural Alaska.

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Introduction

Historically, research in Alaska has disregarded community input, creating mistrust among tribal communities toward researchers, and resulting in communities limiting their involvement in research projects. Today, tribal communities are becoming more involved in the research process; including developing their own tribal review boards and approval processes. This has resulted in the development of rigorous tribal approval processes that protect both the tribal communities and the researchers. As researchers trained to conduct culturally relevant research with communities in Alaska, we have gained first-hand experience with tribal research protocols, research processes, and the iterative process of developing relationships, conducting research, and ensuring that findings are reflective of the community, its individual members, and the region. This paper will outline the tribal approval process in Alaska, highlight some of the challenges we have faced while conducting community-based participatory research (CBPR) with tribal communities in Alaska and share recommendations for researchers interested in working with Alaska Native communities or other tribal communities across the United States.

Approval process

The Alaska regional Indian Health Service (IHS) Institutional Review Board (IRB), referred to as the Alaska Area IRB (AAIRB), provides human subjects review of health-related research projects throughout Alaska. In addition to the AAIRB, University researchers have their own IRB. The waiting period for approval from the AAIRB can range from a few months to over a year depending on the involvement of the research project, the amount of sensitive information gathered, and the familiarity of the researcher with the approval process. Once researchers receive AAIRB and University IRB approvals, they must work with the regional health corporations (www.bia.gov). It is important to note authority originates with the tribe; the regional health corporations serve at the permission of the tribe, and both can determine the governing IRB for their region. Once approvals have been obtained from the regional health corporations, tribal councils must be consulted for their approval and input. For more details on the tribal approval process in Alaska, see Lewis & Boyd (2012).

CBPR Methodology

CBPR consists of core principles and characteristics, such as being participatory and cooperative, a co-learning and empowering process, and achieving a balance between research and action (Minkler & Wallerstein, 2008;

Israel et al., 2005). The first two principles of CBPR acknowledge the community as a unit of identity and builds on the strengths and resources within the community. The third and fourth principles, facilitating a collaborative, equitable partnership with co-learning in all phases of the research, are also highlighted in this article.

Challenges

When doing research in Alaska, researchers face numerous challenges, such as tribal review boards, academic expectations, language and geographic barriers, the sociocultural characteristics of the communities, and the time consuming nature of the research. The next section of this paper will highlight a few of challenges we have faced when conducting CBPR with tribal communities in rural Alaska.

There are often multiple perspectives to consider when conducting research with tribal communities in Alaska: the community, researcher, funder, governing IRB, and the home University, or institution, of the author(s). Each one of these entities has their own vested interest and support in the research, and balancing the competing demands of each one can be challenging. In this article, the 'community' is clearly the most important one and should be protected when it comes to conducting research, engaging them throughout the research process. The focus of this article is on the community and limiting the risk of potential harm from the research process. The needs and perspective of the community you are collaborating with are extremely important to consider and to respect their wishes in how research is conducted and shared, which is illustrated in this article.

Academic versus CBPR

One of the common challenges associated with conducting research within tribal communities is the differing viewpoints on how to conduct the study. In some instances, communities expect you to help them address their concerns as experts and to have the answers. We worked on an elder needs assessment project in Northwest Alaska and it became clear our community partners were looking for an expert-driven, or top-down approach, model assessment. They envisioned conducting the interviews in each community and sending a report with our findings and recommendations on what we believed was best for both the elders and communities. Our training taught us to engage in collaborative research and work with community members to design, implement, and report the findings. The goal of our assessment was to solicit the experiences and recommendations from the elders themselves and report back what we learned, rather than report what we believe was best for both the elders and communities. After some

discussions and clarifications we moved forward with a collaborative approach and delivered more culturally relevant and community specific findings and recommendations. For more on the Elder Needs Assessment project, see Lewis & Boyd (2012).

Translation

The State of Alaska is home to 11 Alaska Native cultural groups and 229 federally recognized tribal communities, each linguistically, culturally and geographically distinct and unique. Each community has its own unique dialect, making them distinct from their neighbors, even though they may speak a common Alaska Native language. For example, when you are working with a Yup'ik translator at the University, or elsewhere, it may pose a challenge if the dialects of Yup'ik Eskimo are different. For example, the Yup'ik Eskimo dialect from the Yukon Kuskokwim Delta is different from the dialect of Yup'ik Eskimo spoken in the Bristol Bay region. Due to these subtle differences, research documents translated into Yup'ik Eskimo for the elders must be translated into the local dialect or time will be spent re-translating the translated documents to reflect the unique dialect of the community you are working with.

When conducting interviews with Alaska Natives we found their level of English proficiency also presented a challenge. We wrote interview questions and tested them with an Alaska Native elder in an urban setting and it was not until we were in the field conducting our first interview that we realized the questions were not completely understood by elders in rural communities. Many elders are fluent in English, but it is their second language, and the language typically used in rural Alaska tends to be less academic and more functional than in the larger, urban settings.

This constant rewording of questions along with different interviewers (the two authors) asking the questions made fidelity to the questionnaire a challenge. We found the iterative process of writing, piloting, re-writing, piloting again, de-briefing, and re-writing the interview questions allowed us to ask questions that, in the end, captured the information we were looking for without alienating our participants.

Disagreement

The researchers' desire to publish their findings can be challenging when conducting CBPR with tribal communities, as the results are associated with multiple levels of approval. One component of the CBPR framework is soliciting support and approvals from participating communities on the study methods, recruitment strategy, results, professional presentations, and publications. In many

cases, engaging the community throughout the entire research process eliminates any complications or disagreements with presentations and publications, but there have been instances with communities not accepting or approving findings. We were faced with this challenge when one community we worked with disapproved of two abstracts we had accepted for presentation based on the findings of the needs assessment. The content of the abstracts were outside the scope of the needs assessment, but still relevant to the field of psychology. We submitted our conference accepted abstracts to share our findings and seek their input and approvals. Four of the five communities approved our abstracts and the fifth denied our request. We were disappointed, but we immediately went to work withdrawing our presentations from the conference agendas and worked on maintaining the relationships with the communities.

While working with the community who denied our request to ensure them we had their best interests at heart, we realized their system worked. We were relieved and impressed the village council took the time to consider the request, looked at the potential benefits and risks to the community and elders and chose not to allow the presentations. Perhaps our overzealous attempt to disseminate interesting research findings colored our judgment about the presentations, but because we set up the practice of collaborating and consulting with the community in advance and they felt empowered enough to voice their concerns, no harm was done.

Discussion

As more tribal communities come to understand the research process and become more involved in projects, we will see more collaborations developing between researchers and tribal communities. As researchers continue to work collaboratively with tribal communities, it is important to remember to involve a broad range of community collaborators throughout the entire research process, such as the tribal councils, Elders, and community members. This includes involvement from the formulation of the research question and study methodology to the analysis and dissemination of findings (Burhansstipanov, Christopher, & Schumacher, 2005).

In order to respect the cultural values and traditions of each tribal community, we need to include their knowledge, cultural values, and experiences when designing and implementing the research study. It is also important to develop and maintain relationships with the tribal councils in each community to seek their input, ideas, as well as changes throughout the life of the project. Middlebrook et al., (2001) concluded that programs work best if they are both culturally relevant and developed with major community, or local, input. Based on our experiences, we would advise working closely with the communities and

tribal councils to be sure they are comfortable with the project, have been given the opportunity to provide their input, and continue to feel engaged throughout the research process.

One requirement of doing CBPR in Alaska Native, and other indigenous communities, is to have a true partnership where community leaders and members are treated as co-researchers. The research process requires joint leadership between researchers and local community members who know local community preferences, customs, and practices. Therefore, CBPR is about relationships and begins with the approval process and continues through dissemination, publications, professional presentations, and hopefully in the next grant application and award.

Recommendations

When conducting research with tribal communities, our first recommendation is to present the proposed study for informal support before starting the approval process. This iterative process of approval and project modification can be laborious and time consuming. For more on the CBPR process and levels of approvals, see Lewis & Boyd (2012).

One of the lessons we have learned is the importance of developing relationships and working with Alaska Native tribal communities in a flexible, iterative fashion. Research with Alaska Native people is about relationships with community members, tribal councils, local tribal authorities, Elders, and other interested parties and this process cannot be rushed if trust and rapport is to be established and maintained. When beginning CBPR we recommend you take the time to visit your community partners, engage in local activities, and spend time in the community building relationships.

We also recommend working with a local bilingual speaker to create your research documents (i.e., consent forms, interview questions, and so on) to avoid further delays in your data collection. Along similar lines, it is critical to hire a local bilingual speaker to assist with the community meeting, focus groups, and presentations. To fully engage the community in your research project and interpretation of the findings, you need to be sure it is understood by everyone. Also taking the extra time to translate the findings will make the community feel engaged and that you value their input, recommendations, and suggestions on your presentation.

Conducting CBPR with tribal communities in Alaska is a very rewarding approach to research. The relationships we have developed with these communities are long lasting; we have come to respect and trust each other and the communities have reached out to us to continue working with them. CBPR with tribal communities is an iterative and time-consuming process, but the

lasting relationship and culturally relevant findings make it worth the effort.

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