

Commentary on Montag et al. (2017): The Importance of CBPR in FASD Prevention with American Indian Communities

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USE OF COMMUNITY-BASED PARTICIPATORY RESEARCH WITH FASD PREVENTION

PRENATAL ALCOHOL CONSUMPTION is a public health concern due to potential lifelong physical and cognitive effects in offspring, often presenting in the form of fetal alcohol syndrome (FAS) or other fetal alcohol spectrum disorders (FASD). FASD is the continuum of lifelong outcomes in those born prenatally exposed to alcohol and includes a diagnosis of FAS, which is diagnosed through facial abnormalities, growth retardation, and delayed brain growth (Hoyme et al., 2016), as well as secondary disabilities such as conduct disorders, mental illness, and psychosocial functioning. Although local, community-specific surveillance data are generally lacking, FASD is of particular concern for many American Indian/Alaska Native (AI/AN) communities, and rates of FAS among Northern Plains AI/ANs range as high as 9 per 1,000 live births (May et al., 2002).

Therefore, prevention of FASD and alcohol-exposed pregnancy among AI/AN communities is essential. Previous FASD prevention projects within AI/AN communities have focused almost exclusively on women prior to pregnancy (Hanson et al., 2017), pregnant women (May et al., 2008), or on broad community education (Williams and Gloster, 1999). Many of these FASD prevention efforts with AI/AN communities highlight the need for community-based participatory research, commonly referred to as CBPR. A recent article by Montag and colleagues (2017) features CBPR strategies used to engage AI/AN communities in FASD prevention.

CBPR is a theoretical model that informs the scientific process of research (Israel et al., 2005; Minkler and

Wallerstein, 2008). CBPR is built on teamwork and endeavors to include community members, representatives, and researchers in all aspects of the research project, from initiation to final project dissemination. The goal of CBPR is to utilize community strengths and resources to facilitate capacity building while benefiting all participants (Israel et al., 2005). This partnership-based approach aims to integrate research and action.

CBPR is an important part of public health program development for any population, but particularly for AI/AN communities. AI/AN communities have a convoluted history with research. Historical trauma caused by broken treaties and the exploitation of culture has led to an overall distrust of non-Natives (Heart et al., 2011). In conjunction, negative experiences with research, including the Barrow Alcohol Study (Foulks, 1989), misuse of blood samples from the Havasupai Tribe (Mello and Wolf, 2010), and “helicopter research” practices, have reinforced a wariness of research and researchers. In relation to substance use, the Barrow Alcohol Study aimed to describe violence, accidental death, and suicide and their correlation with alcohol in rural Alaska. However, the research did not employ validated measures and failed to adequately include the community in the research process. Interpretations of the study were construed and immensely overgeneralized, and failed to recognize cultural, social, historical, and political context (Foulks, 1989).

These traumatic events have highlighted the importance for active community input at all stages of research and have pointed researchers toward implementation of CBPR methods. It is difficult to argue that CBPR is an innovative approach with AI/AN tribes, as multiple research projects have been based on CBPR principles. More specifically, the CBPR model has been used fairly extensively with AI/AN communities regarding alcohol consumption. Several of these CBPR studies with AI/ANs have focused on reducing drinking among youth (Barlow et al., 2012) and AI/AN college students (Thomas et al., 2011). However, only a few CBPR-based studies have focused solely on substance use in AI/AN women of childbearing age (Hanson and Poirier, 2015).

Therefore, the article on reducing risk for alcohol-exposed pregnancies in AI/AN women in Southern California is

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Received for publication September 11, 2017; accepted October 5, 2017.

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DOI: 10.1111/acer.13524



timely (Montag et al., 2017). The goal of the Montag and colleagues (2017) article was to describe the process of modifying an existing web-based screening and brief intervention into a culturally appropriate intervention for AI/AN women. The Montag team provided citations related to a long-standing relationship with tribal communities in California, and the team had several other published studies on AI/AN-focused interventions. An existing team of local AI/AN staff helped to build and maintain trust with the community, and the Montag team extended this collaboration by including a CBPR-focused methodology within the modification process.

MONTAG TEAM'S USE OF CBPR

Montag and colleagues (2017) utilized several aspects of CBPR when working with AI/AN women of childbearing age in Southern California. To evaluate the extent to which CBPR was used by the Montag team, a conceptual framework for understanding and assessing the effectiveness of the CBPR process was utilized (Israel et al., 2012). This framework includes several concepts, including environmental characteristics, structural characteristics, and group dynamic characteristics, all which help to develop the partnership intervention. While the intermediate and output measurements of the effectiveness of the Montag team intervention have been published elsewhere (Montag et al., 2015), the purpose of this article was to outline the successful use of CBPR in developing a web-based FASD prevention effort using community input.

First, use of CBPR includes *environmental characteristics*, including evidence of previous collaborations with the community and also the community's response to the problem. As was noted above, Montag and her team have worked with the California tribes for several years and have several publications resulting from this work (Gorman et al., 2013; Montag et al., 2015). This indicates the community's interest and involvement in the prevention of FASD, as well as their involvement in the dissemination of the projects' results through the publications listed above. Regarding the community response to FASD prevention, in general AI/AN communities are quite engaged and interested in developing community-based FASD prevention efforts (Hanson and Pourier, 2015). While FASD is seen in all racial and socioeconomic groups, many AI/AN communities, California tribes included, are progressive and assertive in dealing with prenatal alcohol exposure.

In addition, *how* the data were collected utilized a CBPR approach as an important way to gauge the community's response to FASD. For example, data collection was completed by qualitative means, a more holistic way of assessing environmental characteristics. Open-ended questions allowed the researchers to more fully understand the issue of FASD from a community perspective in depth and detail and provided a framework for the participants to respond in ways that accurately and thoroughly highlight their opinions

about the web-based intervention. In general, focus groups and other qualitative methodology are especially important with AI/AN participants as the researcher may not be familiar with the variety of responses this population deems relevant. Many cultural elements can only be uncovered through open-ended, qualitative interviews.

Second, CBPR was used by Montag and team through the use of a diverse sample, an important *structural characteristic*, in efforts to develop their web-based FASD intervention. This included AI/AN women of childbearing age who would potentially be directly impacted by the web-based intervention, but also community leaders, tribal elders, and clinic staff that worked directly with AI/AN women. Care was given to include people in each group who would feel comfortable with each other. For example, separate focus groups were held for young women and elders. In particular, it was vital to gather input from tribal elders when working with AI/AN communities. Native elders are the transmitters of culture and values from one generation to another, and it is through oral traditions shared by elders that social values and beliefs are preserved (Barrios and Egan, 2002). Elders are always present as part of public meetings, task force sessions, and council meetings; therefore, their inclusion in a tribally based research project is important for holistic data collection.

Third, there are several *group dynamic characteristics* of this partnership to note that were apparent from the Montag and colleagues (2017) article. For instance, there was shared leadership and influence as evidenced by data collection that was guided by local AI/AN staff. The study coordinator and locally hired AI staff were trained in the subject matter, holding focus groups and interviews, and being in charge of note taking. Local AI project staff determined the locations and times to recruit to avoid potentially disrespectful situations. Through this use of local AI staff and working closely with the community, there was an apparent cooperative development of goals and a participatory decision-making process that gave local staff and experts the space to provide their expertise into data collection.

Another important group dynamic characteristic is that data collected by this study recognized the community as a unit of identity, and input of participants was essential in developing the web-based intervention. For example, AI/AN participants had specific requests to add questions and also to include family within the intervention; all these requests were honored by the Montag team. The modification process was iterative with early recommendations incorporated into later focus group materials. The data collection also emphasized the need to build on the strength of resources within the community, such as having the intervention delivered by local AI women. Such knowledge uncovered through qualitative research means helped to incorporate the important CBPR concept of integrating local knowledge and action for the mutual benefit of all partners. According to Montag and colleagues' (2017), local community participants provided the

necessary insight into making the intervention understandable, relevant, and culturally appropriate.

In conclusion, the Montag and colleagues (2017) article highlights the importance of CBPR-based, formative research to inform future alcohol-related interventions with AI/AN communities. The data that came from using a CBPR perspective would not have occurred without the vast community input and support provided to the Montag team. Not only is CBPR an important ethical way to collect data with AI/AN communities given past research harms, it has also been cited as having higher participation rates and higher likelihood of producing lasting change, especially when working with AI/AN communities (Noe et al., 2007; Stubben, 2001). Therefore, future work on FASD prevention with AI/AN communities must incorporate concepts on CBPR in order to develop culturally appropriate and sustainable interventions.

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