

Ethical Considerations in Population Health Research With Vulnerable Communities and the Added Value of Community-Engaged Methodology

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DOI: 10.15273/hpj.v3i1.11481

Abstract

Working among vulnerable communities poses unique ethical challenges when conducting biocultural research. When communities face dire poverty and social injustice, simply observing and documenting stressors and related health outcomes may be considered exploitative by vulnerable and already overburdened residents. As biocultural researchers, our responsibility is to work toward solutions addressing differential impacts of social injustice. Here, we highlight work amongst the Comcaac, an Indigenous group native to Sonora, Mexico. Today, they experience significant resource insecurity secondary to historical marginalization and structural violence. Employing ethnographic methods (participant observation, focus groups, unstructured and semi-structured interviews), we investigated social and ecological stressors likely affecting members' health. First, we determined visible themes encompassing resource insecurity (e.g., water, food, power, medicine etc.) and struggles with poverty, racism, and associated feelings of injustice. Through deep engagement, we also discerned community members' frustrations with what they see as exploitative research – obtaining information but failing to work actively toward solutions or remain invested in participants' well-being. To begin addressing their most severe issues, we first documented substantial needs within the community, then obtained outside donors and organized a weekly food bank delivery of fresh foods. Now, these are distributed weekly by community leaders in culturally appropriate and locally embedded ways. Thereby, we were able to address an immediate need in a manner that will have continuing impact even while not actively conducting fieldwork. To have real meaning for our research communities, as biocultural researchers we must create ethically based long-term relationships to develop meaningful scholarship.

Keywords: food insecurity, water insecurity, ethnography, stress

Working among vulnerable communities poses unique ethical challenges when conducting population health research. When communities face dire poverty and social injustice, simply observing and documenting

stressors and related health outcomes may be considered exploitative by vulnerable and already overburdened residents. In this commentary, we posit that our responsibility in research goes beyond documentation and

includes working toward solutions addressing differential impacts of social injustice. Here, we highlight work among the Comcáac, an Indigenous group native to Sonora, Mexico. Formerly a widespread semi-nomadic society, today Comcáac experience significant resource insecurity resulting from historical marginalization and structural violence. The Comcáac historically subsisted on and successfully managed the limited natural resources of the harsh coastal desert and sea environment, and their lifestyle, cultural traditions, and social organization are deeply entwined with their ecological knowledge and traditional environmental governance (Martínez-Tagüena & Rentería-Valencia, 2020). Yet, while the Comcáac have shown resilience and adaptability in the face of racism and environmental adversity, overall community health has worsened significantly over time. The health transition following forced sedentarization and associated insecurity has resulted in increasing prevalence of chronic diseases, including prediabetes, diabetes, and obesity, which is common in other Indigenous populations in cultural transition (Esparza-Romero et al., 2015; Monti, 2003; Ravussin et al., 1994; Robles-Ordaz et al., 2018; Villela & Palinkas, 2000).

To investigate social and ecological stressors likely affecting community members' health, we employed traditional ethnographic methods including participant observation, focus groups, and structured and unstructured interviews. While interviews and focus groups gave us many insights into environmental and health-related stressors, extensive participant observation by living and working in the community gave us deeper insights into how the process of research can be a stressor in itself. First, we determined visible themes encompassing resource insecurity (e.g., water, food, power, medicine). A community health promoter reflected on the relationship between declining health and food insecurity: "Before, there were no illnesses because we ate natural things, but now ... we have to eat many processed foods, not fruits and vegetables. We

have to travel far to find these, and they are very expensive" (translated from Spanish).

We also documented themes surrounding struggles with poverty, racism, and associated feelings of injustice. Here, a young mother remembers her birthing experience in the capital of Sonora, where most women must travel to give birth: "When I had my baby in the hospital in Hermosillo, I felt that I was treated differently for being Indigenous, and I wasn't getting the same care as the Mexican women there" (translated from Spanish).

However, after we had spent time living in the village and becoming trusted members of close-knit community social dynamics, they shared deeper reflections on the process of research conducted in the community in general. Many members described frustrations with what they see as exploitative research: obtaining information but failing to work actively toward solutions or remain invested in participants' well-being. Here, a 57-year-old Elder of the community remembers many researchers who have come to their community in the past: "Sometimes they come and take our knowledge and we get nothing in return. What is the benefit to us? How will it [the research] solve problems?" (translated from Spanish).

To mitigate the additional stressor of research among marginalized and historically exploited populations, we propose that using community-engaged methods that are solution-oriented and place participants' needs and values first is essential. Based on our ethnographic findings, we identified food and water insecurity and a lack of basic medicine as being severe, emergency-level stressors affecting the health of the community. We decided further documentation without action would be exploitative. Thus, we, in co-operation with the community and outside donors, organized a weekly delivery of fresh foods from the Banco de Alimentos de Hermosillo. Community volunteers surveyed families to determine need, while the researchers wrote to the food bank with preliminary ethnographic results and recommendations. The researchers also reached out to local businesses and connections to locate sponsors to support the

delivery to a remote area. The weekly deliveries are distributed to families in need at a gathering by local leaders. When present, the researchers also aid in distribution in a supporting role by organizing produce and packing food boxes. Additionally, in consultation with local medical staff, we collaborated with outside donors to address a shortage of basic medicine. As yet, we have not identified a temporary solution for water insecurity; however, due to recent attention by research and community activists, over the coming year the Sonoran government plans to improve potable water access.

While not a permanent solution to food insecurity among the Comcaac, preliminary ethnographic reports suggest this intervention has helped alleviate some of the severest issues in the short term. Of a convenience sample of 31 respondents surveyed, 24 (77%) said the weekly food bank delivery has significantly improved their household's food situation, with many noting that the food security of their children has greatly improved. A young mother of four children comments here: "Sometimes we don't have anything to eat, but when the food bank comes, we can save food. The kids and the whole family can eat" (translated from Spanish). Another young mother notes an increased consumption of fruits and vegetables in their family's diet: "When the food bank comes, we get fruits and vegetables. They have them sometimes in the abarrotes [corner stores] here, but we can't afford them. They're very expensive" (translated from Spanish).

We propose here that, in communities with previous traumatic experience of exploitative research, a "position of supplication," an ethnographic approach to asymmetrical power differentials between researchers and vulnerable participants (England, 1994; Pachego-Vega & Parizeau, 2018) may not be sufficient. The organization of food bank deliveries illustrates our research team's investment in community-based solutions for current problems, while residents maintain local control over this resource, as weekly distributions are organized by community leaders in culturally appropriate and locally-embedded ways. Thereby, we were

able to address an immediate need in a manner that will have continuing impact even when we are not actively conducting fieldwork. These efforts resulted in greater inclusion of our research team in local activities and improved engagement of the residents with the research process. Active involvement of the community in the food bank project helped facilitate trust and our ability to involve members in continuing research and increased our acceptance in the community. This ultimately resulted in more community interest in reciprocity and participation in ongoing population health research than anticipated. To have real meaning for our research communities, as population health researchers we must create ethically based long-term relationships to develop meaningful scholarship.

Ethics Review

This research was approved by the Ohio State University Office of Responsible Research Practices, Study ID #2021E0645.

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