



PROJECT MUSE®

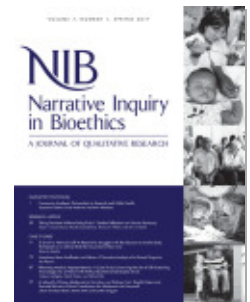
The Engaged Dissertation—Conducting Community-Based
Participatory Research with Rural Indigenous Communities as
a Graduate Student

Jana Wilbricht

Narrative Inquiry in Bioethics, Volume 7, Number 1, Spring 2017, pp. 33-36
(Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2017.0012>



➔ *For additional information about this article*

<https://muse.jhu.edu/article/664718>

or made some decisions outside the meetings and then informed the group. Now I slow down and temper my input, facilitating the process rather than directing it, knowing that they do not always have the experience of giving voice to their concerns. Before being involved in their stigma situations, I may have been silencing them, similar to those who stigmatize them. Now, I am more cognizant of giving them voice. Their fuller involvement, of course, improves the relevance and sustainability of our work. Our process also is less likely to reproduce stigma; we will not duplicate other spaces in their lives which are constrained by stigma but rather offer each other the opportunity to engage genuinely in producing change.

Acknowledgements. The author would like to acknowledge the contributions of the parents, adolescents, and service providers who participated in these projects, members of the research teams, and members of the Planning Group. Special thanks to Deborah Vazquez and Elizabeth Monk.

Funding. The projects described in this manuscript were funded in part by: the Campus Research Board and the Great Cities Institute, University of Illinois at Chicago; the Illinois Department of Public Health; the Illinois Department of Children and Family Services; and the International Association of Social Work with Groups.



The Engaged Dissertation—Conducting Community–Based Participatory Research with Rural Indigenous Communities as a Graduate Student

Jana Wilbricht

My research is equal parts academic inquiry, self-discovery, community engagement, and adventure. As a Ph.D. Candidate in Communication Studies at the University of Michigan, I study access to health information in rural,

remote communities and implications for health equity, as well as effective health message design. I am particularly interested in the role of what I call ‘emic media’ in this process. ‘Emic media’ and what we commonly refer to as community media are both locally based and community-driven. However, I see a difference in that emic media do not only present the information most interesting or relevant to a particular community, but make a conscious effort to communicate from the perspective of a cultural insider—what anthropologists call an ‘emic’ perspective—assuming a base of shared knowledge, avoiding cultural taboos, and prioritizing local indigenous norms and languages. In this way, emic media do not only serve their communities in offering a familiar voice in addition to the broader mediascape, but can function as a site of resistance to mainstream media narratives.

For my dissertation, I am engaged in community-based participatory research (CBPR) exploring the role of tribal radio stations in providing access to accurate, culturally relevant health and safety information for residents of rural American Indian and Alaska Native communities with very limited media and information infrastructures.

After working for over a year to co-design my dissertation project with my primary community partners, the general managers of two tribal radio stations, I received multiple grants, allowing me to travel to both project sites—an Indian Reservation in Northern Arizona, and a rural, mostly Indigenous community in Western Alaska—to conduct individual in-depth interviews with station employees and focus groups with listeners. I also pre-tested a survey during the focus groups which we intend to use community-wide in a future phase of the project.

There are two primary reasons why I opted to adopt a CBPR approach for my dissertation. First, tribal radio is a truly emic medium, and can only be understood to a meaningful degree with involvement from the local community, particularly those involved in its production. Second, making every effort to create equitable partnerships with the communities I work with is a matter of ethics, especially since I am an outsider to these communities. Indigenous communities in particular have long suffered

the detrimental impacts of Western colonialism in all of its forms, including discrimination and disrespect in educational and research settings. Thus, it is important to me not to engage in predatory research, but to ensure my own accountability to the communities involved in the project, treating them as the active and equal partners they are and not as mere 'sites' of research. This also includes respect for tribal sovereignty, which is why I chose to have the project reviewed by two tribal review boards representing each community involved in the project, in addition to my University's IRB. My community partners and I drafted a community partnership agreement prior to any data collection, in which we outlined each party's goals, interests, and responsibilities, in order to ensure that we are working towards a mutual goal and to hold each other accountable so that we can achieve an outcome beneficial to the communities involved.

Another aspect that was important to me, and helped me gain support from community members in terms of participation in my research is that the project addresses an urgent need already recognized as such in both communities. American Indians and Alaska Natives are disproportionately affected by health inequities and digital divides, and emic media like the local radio stations are an essential health and safety information resource, particularly in a scarce media environment. Co-designing a project addressing a specific and clearly defined need in the partnering communities furthers applicability of the research and equity of the partnership.

While I am convinced that this project is absolutely worth pursuing and that CBPR is the only suitable approach in this particular instance, I also immediately became aware of the multitude of complications I invited into my already busy graduate student life in leading this project. First, graduate students are often discouraged from engaging in CBPR, especially as principal investigators [PIs], due to time constraints and lack of control over the project, as compared to traditional survey or laboratory research. Second, neither CBPR nor fieldwork are approaches commonly used in the

Communication and Media Studies field, so I had few similar studies from my field to model my study after. Of course the remoteness of my case study locations added another dimension of difficulty to my project, as I had to plan the study remotely due to funding constraints that only allowed me to be physically present at the research site during the data collection phase, but not for participant recruitment or planning. For this, I had to rely on my community partners at each location and a project assistant in Alaska, also hired remotely. Finally, and perhaps most importantly, I am a non-Native person doing research in partnership with Indigenous communities.

One of the things I learned over time—in Native American Studies classes, my earlier research with Native communities, but especially by being in charge of my own CBPR project for the first time—is that an awareness of this outsider status and all the historical and cultural connotations it entails, are key for open, honest interactions with others, and allow for the cultural humility necessary for learning and a deeper understanding. The recognition of the limitations of my ability as an outsider to truly understand or to speak about cultural interpretations of health, for example, or any kind of spiritual understandings, is important to the success of the project. Not only does an understanding of the boundaries of outsider insight lead to more issue-focused projects that can be more helpful the community in a direct way, but it is necessary for an awareness of the ethical issues with an outsider attempting to understand, analyze, or speak about another culture or their worldview as if a full understanding and accurate representation was possible. My goal in partnering with Indigenous communities on this project was to address a need and to study a related issue, not to 'study a people.'

I was very fortunate to have the chance to work with a Native American community on research as an Undergraduate, as part of my honors thesis on digital divides affecting residents of rural Indian Reservations. As I started to focus specifically on health communication in graduate school, I became interested in moving beyond the cultural

and physical space in which most communication and media research has historically taken place, to environments with unique and much more limited information infrastructures, who are also disproportionately affected by health disparities. The unique media landscape of rural Indigenous communities in the U.S. intrigued me as a research site, but I also had the desire to pursue a research project in this area due to the urgent need. Perhaps as much a result of my personal values as of priorities of the communities in which I situate my work, I want my research to have direct impact, to be applicable to an existing issue, and to be helpful as far beyond the academy as possible.

It is my sense that in my project, the local project partners, community members who participated in focus groups, and myself as the academic researcher were able to develop a sense of working towards a shared goal. Another key advantage I had designing and implementing this project, especially in participant recruitment, was partnering with well-established and well-respected local organizations that community members had a desire to support, even if they were otherwise skeptical of academic research.

As a CBPR project, this research could not have been realized without the support of community partners, and I owe much of the project success to my community partners, who saw the value in my approach and in having an outside researcher examine an important issue in their communities from a very specific standpoint, generating analyses and a set of recommendations that can be directly helpful to their daily operations. Together, we were able to overcome the unique and significant challenges that characterize this project. Involving two distinct community partners from different cultural contexts in the same project is a challenge in itself, but in this case the three of us were also separated geographically—myself in Michigan, and my community partners in Arizona and Alaska. These circumstances, difference in time zones, and different time constraints in everyone's schedules made communication and planning difficult. This could only be resolved by allowing

ample time for the planning phase, in order not to rush or overwhelm community partners, and make sure all voices are heard and all questions answered. In my case, the entire process, from conceptualizing the study, applying for funding, remotely recruiting a research assistant and study participants, to arriving at the first project site, took about thirteen months.

The project is still ongoing, and I have already learned a lot. Engaging in CBPR, particularly while still in graduate school, takes courage, flexibility, high tolerance for uncertainty, and humility. I was prepared for the tremendous time commitment of a community-engaged project which cannot be compared to more traditional research projects in which the PI holds all power and control. I was further not only prepared for, but excited about the long-term involvement with the communities who agreed to partner with me on research, and am always willing to offer my skills wherever they can be useful. Despite numerous challenges and lack of model studies, I found the entire process to be very rewarding and feel that I learned more in terms of my research questions, but also in terms of intercultural collaboration and project management than I could have possibly learned running studies in a laboratory or designing a survey at my desk.

The ongoing relationships resulting from the project are a tremendous asset not only for my work, but for my personal development and growth. I would, however, not recommend engaging in CBPR to every graduate student. Their interests and skills need to closely relate to a community need or interest, they need to be able to invest a significant amount of time into the planning phase, have a supportive doctoral advisor, and be excited to commit to supporting their partner communities long-term and in ways that may reach beyond the confines of the project, such as—in my case—serving on a non-profit board. Local community liaisons and some level of prior knowledge and understanding of the community on the part of the researcher are also key for success.

Finally, in a CBPR project, the unexpected should be expected to happen, and flexibility is

very important during the planning stages and during fieldwork. I am aware that not all graduate schools are as supportive of doctoral students doing community-engaged work as the University of Michigan, and hope that more funding opportunities and programs will become available for doctoral students hoping to engage in CBPR for their dissertations.

For me, engaging in this project and designing my dissertation in this way is likely the most important choice I have made in graduate school, and has already had a significant impact on how I think about my identity as a researcher and as a person, as well as my future career goals. I am deeply grateful for the insights I gained about my topic of academic inquiry, the interpersonal skills I learned throughout this process, and for the new intercultural professional relationships and friendships I forged by finding the courage to take my research out of the laboratory and into the Arizona desert and the Alaskan tundra.

Acknowledgements. First and foremost, I would like to express my deepest gratitude for my community partners who continue to work with me on this project and who were willing to engage in community-based participatory research project led by a graduate student. I am further eternally grateful for the guidance and advice regarding my research overall and this project in particular that my long-term research mentor Dr. Angela A. Gonzales (Arizona State University) and my dissertation committee chair Dr. Jan van den Bulck (University of Michigan) have generously provided. I also thank all funders listed below for making this project possible.

Funding. This project was funded by the Program in Public Scholarship at the University of Michigan, the University of Michigan Library Student Engagement Program, a Rackham Graduate Student Research Grant, and the Winthrop B. Chamberlain Scholarship Fund for Graduate Student Research.

A Community-Developed, Culturally-Based Palliative Care Program for African American and White Rural Elders with a Life-Limiting Illness: A Program By The Community for the Community

Ronit Elk

African American and White caregivers in rural South Carolina who had been involved in the care of a loved one who had recently died, were asked what they found helpful or beneficial about the professional care (care provided by physicians, nurses, other hospital and hospice and nursing home staff) and what they considered ineffective or inadequate. Gaining an understanding of their perspective, through focus groups, was the first phase of this study. While this insight is important in and of itself, the more substantial purpose was to use this information to develop a culturally-based palliative care consult program for African American and White rural southern patients with a life-limiting diagnosis. Development of the program, in full collaboration with palliative care researchers and a team of African American and White community members, occurred in the next phase. Patient and family acceptance of this community-developed and culturally-based palliative care consult program was tested in the last phase.

Palliative care programs have been demonstrated to alleviate patient suffering and to enhance quality of life for patients with serious illness and their caregivers. Palliative care consults, in which a palliative care expert consults with the treating physician and makes recommendations for care, have been proven equally effective. Culture shapes how people make meaning out of illness, suffering and dying. Therefore, in palliative care, consideration of the culture of the patient and family is essential. Yet end-of-life care in the U.S. is rooted in values that represent the cultural and religious values of the white middle class. This was the first study to design a culturally based palliative care program for rural southern elders with life-limiting illness, and the first to do so with full community participation: *"A Palliative Care Program by the community for the community."*